HIV Testing in Urban Indian Hospitals: a Study of Policy-Practice Relationships in the Formal Medical Sector

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By

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Abstract

HIV testing is an example of the separation between public health policy guidelines and practices of medical providers in urban Indian hospitals. An action-centred policy framework and interpretivist analytical approach was adopted to investigate problems of policy-practice gaps and identify strategies to resolve them. I conducted depth interviews with 61 respondents representing different groups of involved actors, including medical practitioners from public and private hospitals in five Indian cities, administrators, public health officials, regulators, educators, representatives of civil society organizations and international agencies, and with key informants. Respondents' perspectives on their participation in implementing the policies and on interactive processes between different groups were explored. There was a concentration on four aspects of HIV testing – selectivity in testing, pre-surgical testing, informed consent, and confidentiality.

I found that the actions of medical practitioners and other actors, and their respective interactions with each other, frequently diverged from expected norms of policy implementation. Explanations for divergences in actions included ambiguities around roles, conflicting value-orientations and practical considerations such as workplace relationships and systemic inadequacies. The nature of existing interrelationships between groups of actors was often inconsistent with a 'rational' top-down process of implementation. Irregularities in conveying meanings of policies also contributed to problems in their implementation.

Different groups of actors are observed to inhabit discrete 'systems of meaning' and be guided by differing senses of purpose in their actions. This raises questions of the sufficiency and appropriateness, in isolation, of conventional prescriptions of strengthening regulations towards aligning implementers' practices with policymakers' intentions. In India's complex health policy ecosystem, the need for greater attention to the quality of interactive processes is identified. A renewed understanding of 'rationality' in the implementation of public health policies, based on good communicative practices and inclusion of different forms of knowledge, is suggested as a standard for change.

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List of Abbreviations

AIDS: Acquired Immune Deficiency Syndrome

ANC: Antenatal care / clinic

ART: Anti-retroviral Therapy

ARTC: Anti-retroviral Therapy Centre

ARV: Anti-retroviral (drug)

CBHI: Central Bureau of Health Intelligence (of the Government of India)

CH: Charitable Hospital

CME: Continuing Medical Education

CMO: Chief Medical Officer

CPA / COPRA: Consumer Protection Act

DHS: Directorate of Health Services

DMER: Directorate of Medical Education and Research

DOTS: Directly Observed Therapy Short-course chemotherapy (for tuberculosis)

ELISA: Enzyme-linked Immunosorbent Assay (diagnostic test for HIV)

GOI: Government of India

GH: Government Hospital

HAART: Highly Active Anti-retroviral Therapy

HBV: Hepatitis B Virus

HCV: Hepatitis C Virus

HIV: Human Immunodeficiency Virus

HOD: Head of Department

ICMR: Indian Council of Medical Research

ICO: Infection Control Officer

ICTC: Integrated Counselling and Testing Centre

IMA: Indian Medical Association

LSHTM: London School of Hygiene and Tropical Medicine

MCI: Medical Council of India

MOHFW: Ministry of Health and Family Welfare (of the Government of India)

MS: Medical Superintendent

NABH: National Accreditation Board for Hospitals

NABL: National Accreditation Board for Laboratories

NACO: National AIDS Control Organization

NACP (or HIV/AIDS programme, the programme): National AIDS Control Programme of India

NARI: National AIDS Research Institute

NCMH: National Commission for Macroeconomics and Health

NGO: Non-governmental Organization

NICD: National Institute of Communicable Diseases

NIHFW: National Institute of Health and Family Welfare

OI: Opportunistic Infections

OPD: Out-patient Department

PCP: Pneumocystis carinii pneumonia

PEP: Post-exposure prophylaxis (against HIV infection)

PH: Private Hospital

PITC: Provider Initiated Testing and Counselling

PLHA: People Living with HIV/AIDS

PNH: Private Nursing Home

PPTCT: Prevention of Parent to Child Transmission (of HIV infection)

SACS: State AIDS Control Society

SMC: State Medical Council

STI / STD: Sexually Transmitted Infection / Disease

TB: Tuberculosis

UN: United Nations

UNAIDS: Joint United Nations Programme on HIV/AIDS

UP: Universal Precautions

VCT: Voluntary Counselling and Testing

VCTC: Voluntary Counselling and Testing Centre

WHO: World Health Organization

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Chapter 1. Introduction: the Policy-Practice Gap in HIV Testing

1.1 HIV/AIDS IN INDIA

The HIV/AIDS epidemic in India is heterogeneous, in terms of the demographic subgroups and the regions it has affected, and the modes of transmission. The southern and north-eastern states report the majority of HIV infections and AIDS cases, and there is considerable variation between different states. Heterosexual transmission is known to be the commonest mode of transmission of infection nationwide. In the North-Eastern states, shared needles are the commonest route of transmission (NACO 2006).[1] Like some other diseases, and especially because it is linked to sex, HIV is often stigmatised, and the secrecy around knowledge of HIV status have made it difficult to control, and to estimate the extent of the epidemic (Bharat 2001). Since the discovery of the first case of HIV infection in 1986, the number of HIV infection has risen to a count of millions of individuals (MOHFW 2005b). The most recent formal estimate of prevalence of infection in the country was between 2 million and 3.1 million (NACO 2007d). Although this amounts to a relatively low prevalence of less than 1%, it is still the second largest absolute burden of any country after South Africa. More than 60,000 full-blown AIDS cases were reported nationwide, in the most recent official estimates (Solomon et al. 2004).

HIV testing is a critical aspect of HIV/AIDS care. Testing is often the first point of contact and entry into formal systems of health care for People Living with HIV/AIDS (PLHA). The processes around diagnosis, including prior preparation of the patient, the manner of disclosure, and advice imparted, potentially have a role in determining patients' further help-seeking behaviour, safe sex practices, access to care, continuity and adherence to treatment (Moss et al. 1996; Sastry et al. 2004).

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[1] National prevalence figures are collated from data of 1122 surveillance sites conducting unlinked anonymous testing on "high risk" (STI clinic attendees, intravenous drug users, and men who have sex with men) and "low risk" (ante-natal clinic attendees) groups (NACO 2006).

1.2 GUIDANCE ON HIV TESTING FOR MEDICAL PROVIDERS

Issues around HIV testing are ethically complex and it is widely recognized that practitioners require guidance on how to address different aspects of the process. A prototypical process for diagnostic HIV testing involves the following steps (NACO 2004):

- Informed consent for the test is obtained from the patient and pre-test counselling is undertaken.

- If the patient gives consent for the test, venous blood is extracted and the serological tests for diagnosis are conducted. Three reactive ELISA / Rapid / Simple tests with different antigens / principles are required to establish a positive HIV test result.[2]

- The test results are disclosed to the patient, maintaining full confidentiality.

- Post-test counselling is undertaken. Proper follow up for management is arranged.

There are clearly stated national policies published by the National AIDS Control Organization (NACO) to guide the behaviour of medical care providers, and assist them in making the appropriate decisions. The aspects of these guiding policies which apply specifically to the behaviour of medical practitioners, i.e. doctors who advise the tests, can be broadly summarised under four themes: *selectivity* in deciding to advise the test, proscription of *mandatory testing* as a pre-condition for providing a service, specific written *informed consent* for a HIV test, and strict *confidentiality* of the HIV test result. NACO's policy guidelines are intended to be applicable in all private and public healthcare institutions involved in overseeing and conducting HIV tests.

1.2.1 Selectivity in testing

The National Guidelines for HIV testing (NACO 2003a) advise the 'highest specificity' in HIV testing. The guidelines do not identify specific criteria for deciding to test; however these are touched upon in NACO's guidelines for Voluntary Counselling and Testing Centres (VCTC) (NACO 2004) state that: 'a health care provider may... recommend a test based on a patient's behavioural history and/or clinical findings such as STDs or opportunistic infections'. However the same document emphasizes 'the importance of the client's free will and conscious decision to get tested'. The National AIDS Prevention and Control Policy document (NACO 2003b) offers the following guidance: 'The question which must be asked before a testing procedure is

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[2] These tests involve detection of serological markers by ELISA technique. ELISA results are available within a few hours, and it is the favoured test for use in most Indian laboratories, although Rapid and Simple serological tests – which give results within minutes and do not require special equipment or trained staff – are also widely used (NACO 2004).

undertaken is how this result will be used for the benefit of individual or of the community; if there is a policy and means to support the group under testing following the test result...' There is no indication of routine testing being advised for any group of individuals.

1.2.2 Proscription of 'mandatory' testing

Mandatory testing is a term commonly used to describe the practice of HIV testing as a pre-condition for receiving a service or being granted a privilege. NACO's stance is to categorically oppose mandatory HIV testing on any individual. According to the National AIDS Control Policy statement, '...considerable thought has been given to this issue. The government feels that there is no public health justification for mandatory testing. (On the contrary) such an approach could be counter-productive as it may scare away a large number of suspected cases from getting detected and treated.' (NACO 2003b)

1.2.3 Specific informed consent

NACO's Guidelines for VCT Centres (NACO 2004) define consent as being 'a deliberate and autonomous permission given by a client to a health care provider to proceed with the proposed HIV test procedure'. National policies clearly support specific informed consent for HIV testing. The National AIDS Control Policy states that: 'in the case of diagnosis of clinically suspected cases, the testing will be done... with informed consent of the individual' (NACO 2003b), and according to national HIV Testing Guidelines, the 'testing procedure must offer pre and post test counselling to the client and involve explicit consent' (NACO 2003a). Essential elements of the consent process are listed in the Guidelines for VCT Centres as follows: 'This permission is based on an adequate understanding of the advantages, risks, potential consequences and implications of an HIV test result, which could be both positive and negative' (ibid). It is recommended that discussions around these subjects be held in a counselling process prior to obtaining informed consent. Further, the guidelines state that 'this permission is entirely the choice of the client and can never be implied or presumed' and 'informed consent to HIV testing should be obtained from the client in writing, on a standardized consent form, prior to proceeding for HIV testing' (ibid.). In summary, the policy stance is that consent is meant to be fully *informed* - given after receiving adequate information; *specific* and *explicit*, not implied; and *written*, not merely verbal.

1.2.4   Confidentiality

The national Guidelines for HIV Testing stress on the importance of the strictest confidentiality: '...even health care workers who are not directly involved in care of the patient should not be told about the result' (NACO 2003a). Disclosure of HIV status to the spouse or partner is however encouraged, with the consent of the client.

1.3   DIVERGENT PRACTICES IN URBAN HOSPITALS

Numerous studies and informal reports have indicated that NACO's policy guidelines are frequently not followed by doctors who advise HIV tests, both in government and in private institutions in India. Insisting on HIV tests before hospital admission or surgery, denial of care (either of specific services or complete denial) based on test results, breaches of confidentiality and testing patients without their permission are common and widely acknowledged infractions of doctors in India.[3]

In a review of discrimination and stigma around HIV/AIDS in India conducted in urban private and public hospitals, Bharat reported multiple instances of testing without proper consent, routine "mandatory" testing of pregnant women and patients before surgery (Bharat 2001). Patients interviewed in this qualitative review reported that HIV tests were frequently used by hospitals to screen patients for eligibility to receive care, and those who tested positive would be turned away or denied care. Test results were widely accessible to uninvolved healthcare staff and disclosure was often made to family members and spouses without the patients' consent.

Furthermore, since the formal publication and promulgation of the national policy in 2003, a number of studies have shown a continuing trend of such transgressions in HIV testing (Kurien et al. 2007, Mahendra et al. 2006, MAAS-CHRD 2006, Sheikh et al. 2005b, Grover et al. 2003). In a multi-centre study of 2200 healthcare professionals in the private and public hospitals and health centres, Kurien et al (2007) found that 65% of practitioners were aware of the presence of national policy guidelines for HIV testing and 38% reported having read them. Only 14% of respondents were aware that screening for HIV before surgery was not recommended in the national policies (49% believed that it was recommended and the remaining 37% did not know), 67% reported that

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[3] Authors Paul (2005) Agarwal (2002), Abraham (2002), Thomas (1998), Pandya (1996) in separate commentaries corroborate this point.

they screened patients for HIV before elective surgery, and 92% felt that universal pre-surgical HIV screening was a desirable policy. As many as 18% of doctors reported having refused care to HIV infected individuals. Identification and labelling of HIV positive individuals in care was common (47%), 19% of doctors *never* informed their patients before getting them tested for HIV, and only 30% reported obtaining written consent for the test regularly.

Mahendra et al. (2006) in a study of urban Indian government and private hospitals reported that 79% of doctors supported the use of HIV tests on patients before surgery (to allow surgical staff to take greater precautions), and 66% supported mandatory testing of pregnant women. Sixty-seven percent of doctors did not regularly take consent from their patients before a HIV test. Several instances of breaches of confidentiality were reported in which doctors informed health workers not directly involved in caring for the patients, without the explicit consent of patients. Fifty-eight percent of doctors in the baseline survey reported that they never asked patients' consent for disclosure of their test result to a family member.

A study on access to HIV care conducted by the MAAS group among PLHA in Andhra Pradesh, Orissa and Maharashtra states revealed that 27% of PLHA were not asked for consent before they were tested for HIV in private and public facilities (MAAS-CHRD 2006). Fifty-two percent of respondents reported that doctors had informed other individuals (usually family and immediate kin) of their HIV positive status.

Sheikh et al. (2005b), from their study of private sector practitioners in clinics in Pune city, Western India observed that private practitioners (PPs) prescribed HIV tests in large numbers and often indiscriminately. Forty percent of the PPs reported that they routinely required a HIV test result before conducting invasive procedures. Of the private laboratories surveyed, 39% reported that they disclosed test results to individuals other than patients.

Widespread mandatory pre-admission testing and public labelling of hospital beds of HIV positive patients were also reported by Grover et al. (2003). Rao (2004), Nandakumar (2005) and Maya (2006) have separately reported on widespread pre-surgical HIV screening, denial of care and prenatal HIV testing without consent in government and private hospitals.

1.4 RESEARCH PROBLEM AND AIMS

Research problem

The separation between national policies and practices of medical practitioners in hospitals in the respect of institutional HIV testing is a clearly established phenomenon in India. In spite of the public promulgation of formal national policy guidelines, there is a continuing trend of inconsistency on the part of doctors in both government and private institutions, in adopting and applying nationally prescribed guidelines.

Aims of research

This research was undertaken with the aims of *understanding the nature of policy-practice gaps in HIV testing in urban Indian hospitals* and *identifying opportunities to bridge these gaps*. A policy analysis approach was applied and field-based research undertaken towards addressing these aims.

1.5 PLAN OF THE THESIS

In this opening chapter I have introduced the research problem of policy-practice gaps in HIV testing in urban Indian hospitals and the aims of the study. In Chapter 2, I set the context for an exploration of the problem by 1) presenting an overview of the formal medical sector and health systems in India, emphasising the organizations and structures involved in implementation processes, and 2) reviewing the existing literature on policy-practice gaps in public health in India, focusing on the explanations for gaps suggested by different researchers and commentators, and their engagement with strategic questions.

Chapter 3 is a review of theories and frameworks of policy analysis and the policy-action relationship. In Chapter 4 on Methodology I start by introducing the 'action-centred' policy analysis framework that is used to conceptualise the research problem in this study, and outlining the research questions. The data-collection process involving interviews with medical practitioners and other policy actors, the interpretivist approach of analysing the data from interviews, and methods for organizing and presenting the data are elaborated. I conclude the

chapter with reflections on research quality, methodological limitations and ethical considerations.

Chapters 5, 6 and 7 present data from participants' accounts of their experiences of participation in the implementation of HIV testing policies and interactions with other groups of actors. Chapters 5 and 6 focus on medical practitioners' accounts and Chapter 7 on accounts of actors *other* than medical practitioners. In Chapter 8 I synthesize major observations from the previous three "results" chapters, and present the key diagnostic findings of the study explaining the policy-practice gaps.

In chapter 9, I discuss the findings in the context of the literature on public health policy in India, and identify the contributions of the thesis to an understanding of health policy implementation in developing countries. I then discuss strategic opportunities for change towards bridging policy-practice gaps, and conclude with recommendations for planners and reflections on future directions in the implementation of public health policies.

Chapter 2. Background and Review of Literature

This chapter focuses on key areas of knowledge which form the context for the research problem. In the first section I have profiled urban Indian hospitals and medical professionals, existing structures of policy implementation in health in India, and relevant legal frameworks supporting implementation. The second section (2.2) reviews the literature on the problem of policy-practice gaps in public health in India, in general.[4]

2.1   BACKGROUND

2.1.1   Medical practitioners and hospitals in urban India

The government of India officially recognizes medical qualifications for five systems of medicine including allopathy (western biomedicine), three indigenous systems (Ayurveda, Siddha, and Unani) and Homeopathy (Department of AYUSH 2006). Hence the term "formal" could actually have wider application to include medical providers from these specialities. However for the purposes of this study, only recognised practitioners in the allopathic system and hospitals which employ allopathic doctors have been considered. The doctors[5] who staff hospitals which constitute the "formal" allopathic medical sector hold at least the basic M.B.B.S. degree, and in some instances diplomas or degrees of postgraduate specialization. Their professional qualifications and right to practice medicine are conferred by the Medical Council of India (MCI).

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[4] For the literature review, internet database searches were undertaken on Google Scholar, PubMed, and catalogues of major libraries including the British Library and the libraries of the London School of Economics and University College London, using keywords "India" in conjunction with "health policy" with the Boolean operator AND, and then separately with "India" AND "medical providers". The resulting index of books and articles from both searches was examined, and relevant articles sourced, and used to develop this review. A systematic review of the tables of contents of a relevant list of peer-reviewed journals was conducted to supplement this index. Additionally relevant chapters in books, non-indexed journal articles, project reports of different academic and public health organizations, and news reports, were identified through further internet searches, and through cross-references from the articles already sourced.

[5] The terms "medical practitioners" and "doctors" are used interchangeably throughout the text of the thesis to refer to doctors trained in the allopathic system of medicine, unless specified otherwise.

According to the Central Bureau of Health Intelligence, there were 696,747 qualified allopathic doctors registered with medical councils in India in 2007 (CBHI 2007). Allopathic doctors are disproportionately located more in cities and developed areas than in rural areas. Significantly more of them work in private (75-80%) than in public (20-25%) facilities (MOHFW 2005a; Peters et al. 2002). Apart from any institutional systems of accountability, allopathic doctors are officially subject to disciplinary procedures of their respective state Medical Councils in case of negligent behaviour or violation of the Council's Code of Ethics (MCI 2002).

Medical institutions in cities in India are diverse. *Government hospitals* in cities cater to large numbers of people from all sections of society, but particularly the poor, including populations from urban slums, neighbouring villages, and even from distant states. They are frequently overcrowded, with a high rate of bed occupancy, and overflowing out-patient departments (Gupta and Mitra 2002, Gawande 2003, Sahni 2002). They are funded largely by governmental income from taxes, and offer either free or highly subsidized health care (MOHFW 2005a). Government hospitals in cities include the following types (from Gupta and Sood 2005, MCI 2008):

- Teaching institutions which are governed (usually) by State Directorates of Medical Education and Research (DMER), universities, or by specific central social insurance schemes for government employees such as the Central Government Health Scheme (CGHS).

- Some specialist or research-oriented hospitals, which are governed by a University, or centrally by the Directorate General of Health Services.

- Municipal Hospitals run by municipalities.

- District hospitals under the charge of district Chief Medical Officers (CMO).

A typical teaching hospital contains outpatient departments, in-patient wards with 500-1500 beds, different speciality departments, emergency care units and operating theatre facilities (Gupta and Sood 2005), staffed by allopathic doctors among other staff, and is under the executive management of a Dean or Medical Superintendent. Non-teaching hospitals usually have fewer beds and may have fewer sub-speciality departments, but are otherwise similar in their administrative structure.

Private hospitals can be found in a wider variety of organizational arrangements. Establishments run by individuals or household businesses are the most common type accounting for 82% of all private institutions and 62% of those in urban areas. The remaining 38% of urban private institutions which employ staff, range from small nursing homes with 1-20 beds, to large multi-

speciality hospitals run by private trusts or corporate houses. The type of executive management within these hospitals varies considerably (MOHFW 2005a).

Non-profit healthcare institutions account for 1.3% of the total health care enterprises in India, and similarly vary in organizational structure, from small clinics to large hospitals (MOHFW 2005a). Charitable hospitals offer either free or low-cost treatment, although their fee structures are usually not under any form of regulatory control (ibid.). Management of non-profit hospitals varies from faith-based organizations to non-profit trusts and societies. A number of charitable hospitals are involved in HIV/AIDS treatment and care in India (MAAS-CHRD 2006).

In Indian cities, by a number of accounts, linked HIV tests[6] are frequently conducted in institutional (hospital or clinic) settings at the behest of medical practitioners (Shinde et al. 2007, Kurien et al. 2007, Solomon 2006). Testing facilities for laboratory diagnosis of HIV are widely available in private and government hospitals in Indian cities. Many government hospitals offer HIV testing services either in separate departments of microbiology or pathology, or through Voluntary Counselling and Testing Centres (VCTC) or Integrated Counselling and Testing Centres (ICTC) which have been instituted in their premises (NACO 2007e).[7] HIV testing facilities are widely available in private diagnostic laboratories, and a number of anti-retroviral drug formulations are available in the private market. It is likely that a growing number of private hospitals are involved in advising HIV tests and treating patients with HIV/AIDS (Sheikh et al. 2005a, Sheikh et al. 2005b).

Utilization and costs of hospital care

Urban hospitals are important sites of health care delivery. According to the report of the National Commission for Macroeconomics and Health, in the year 2000 there were 15,888 hospitals in India with a total of 719,861 beds. A majority of all hospitals (68%) are private; but 63% of all hospital beds are found in government hospitals. There are nine times as many hospital beds in cities, per capita, as in rural areas (MOHFW 2005a, CBHI 2007).

A World Bank study showed that 82% of outpatient visits occur in the private sector, and this dominance of the private sector in outpatient care is similar across income groups. The volume (incidence) of hospitalization is shared almost equally by private and public hospitals, but is

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[6] "Linked testing" is testing in which patients are made aware of the outcome of the test, as opposed to unlinked testing for purposes such as surveillance.
[7] This is linked to the availability of free anti-retroviral therapy in the same hospitals

skewed across income groups with public hospitals accounting for 61% of hospitalization among the poorer quintiles, and only 33% among the richest quintile (Mahal et al. 2001).

The average expenditure for treatment of an illness episode in different facilities was compared, in a study by the Institute of Economic Growth (IEG) in Delhi (Gupta and Dasgupta 2000). Private hospitals were three times as costly as a government hospital, and care in charitable hospitals was the most economical.

Type of Care Provision	Average Health Expenses (Rs.)[8]
Private Hospitals	2892
Government Hospitals	809
Charitable Hospitals	275

Table 2.1 Average Total Expenditure for Illness Episode by Type of Provider[9]

Government hospitals usually offer free consultation, investigations and treatment. However sometimes drugs, equipment and investigations are not available, and have to be purchased in the market at patients' expense. Other associated costs for a patient such as transportation, can also be high. The clientele of private hospitals is usually skewed towards more affluent sections, although costs of care in private hospitals also vary considerably. Poor people in cities often visit private practitioners initially and for lesser complaints, but can seldom afford hospitalization in private hospitals (Gupta and Dasgupta 2000). Health insurance coverage is very low in India, and to a large extent expenditure for hospital care is out-of-pocket (MOHFW 2005a; Uplekar et al 2001).

2.1.2   Systems for health policy implementation

The health policy environment in India is complex and populated by a diverse range of public and private actors. India's parliamentary democracy has a federal structure and areas of operation are divided between the Union and 28 States. In the Constitution, the subjects "Public Health" and "Hospitals" are assigned to State government, although some related areas such as "Medical

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[8] One US dollar is approximately Rs. 47
[9] From Gupta and Dasgupta (2000)

Education" are included in the concurrent list (GOI 2005b). However in operational terms, bodies at Central and State levels both tend to be involved in the administration of health systems.

At the national level the Department of Health of the Ministry of Health and Family Welfare is the primary authority, and is supported in technical matters by the Directorate General of Health Services (DGHS). Numerous *national programmes* of health, including the National AIDS Control Programme (NACP), and *regulatory bodies* such as the Medical Council of India (MCI) are also nominally subordinated to the Department of Health, although they enjoy different degrees of autonomy in their operations. Other national level public health institutions of relevance include technical agencies such as the National Institute of Communicable Diseases (NICD), under the parentage of the DGHS; the National AIDS Research Institute (NARI), and its parent body the Indian Council of Medical Research (ICMR), and the National Institute of Health and Family Welfare (NIHFW) (MOHFW 2005a, Gupta and Sood 2005).
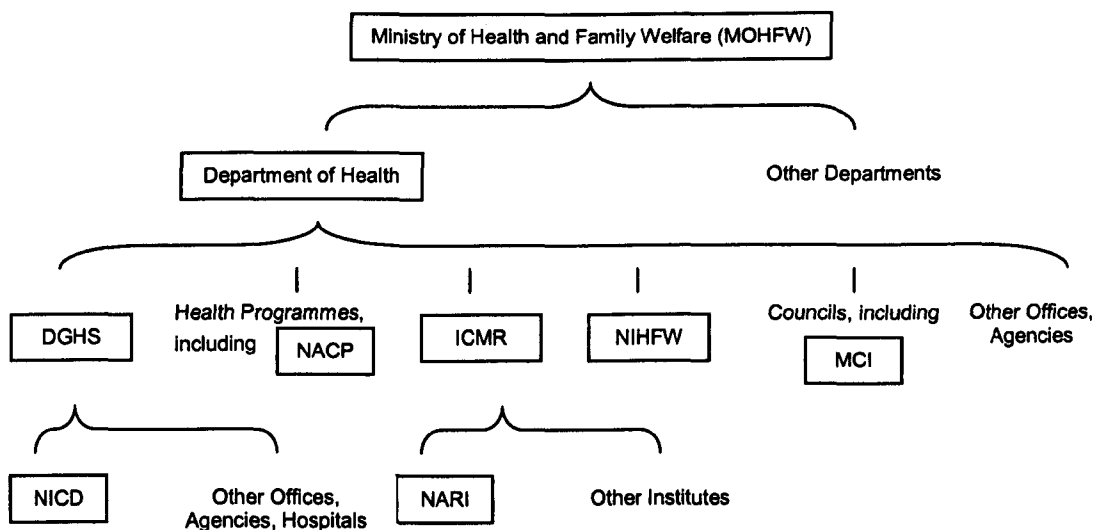
Figure 2.1 Departments under the Ministry of Health and Family Welfare[10]

Typically, policy guidelines for the care and control of diseases, such as the HIV testing policy are published and promulgated by National Programmes of Health. Several such Programmes exist under the aegis of the Ministry of Health and Family Welfare, including for tuberculosis, reproductive and child health, malaria, leprosy, and HIV/AIDS. The *National HIV/AIDS prevention and Control Programme (NACP)*, launched in its third phase in 2006, is coordinated by a nodal body - the National AIDS Control Organization (NACO) at the national level, and by

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[10] Adapted from MOHFW (2005a, p106) and Gupta and Sood (2005)

State AIDS Control Societies (SACS) at state level. The programme is involved in setting up and administering Voluntary Counselling and Testing Centres (VCTC) and Anti-retroviral Therapy Centres (ARTC) in government hospitals, and is the official source of national policies and guidelines for various aspects of HIV care including for HIV testing.

At a central level, NACO collaborates with various bilateral and multilateral partners in administering the HIV/AIDS programme, including United Nations technical agencies, the Global Fund for AIDS TB and Malaria (GFATM), overseas development departments of the American, British and German governments, the World Bank (which is the major donor partner for the NACP) and independent international philanthropic agencies such as the Bill and Melinda Gates Foundation and the William Clinton Foundation (NACO 2007b).

At State Level, the Department of Health and Family Welfare oversees two *Directorates – of Health Services (DHS)*, and of *Medical Education and Research (DMER)*. The DHS runs numerous hospitals, implements certain state and national health programmes and is responsible for tasks like registration of private medical establishments. Many government teaching (tertiary) hospitals are under the jurisdiction of the DMER, whereas secondary level hospitals usually fall under district level administrations (Gupta and Sood 2005). *State Medical Councils* are quasi-governmental bodies which are charged with regulation of medical practices, including registration of physicians and maintenance of a Code of Ethics.

Until the past decade, the system of *medical education* in India was dominated by government-run medical colleges, and the majority of doctors practicing in India as of now have had their formative education in government colleges. In 2000 there were 61 private and 115 government colleges, in 1990: 41 and 102 respectively, and in 1980 only 14 private colleges in five states, compared to 96 government colleges spread across the country (MCI 2008, Mahal and Mohanan 2006). However, in recent years, the number of recognized private medical colleges has increased (see Table 2.2 for numbers of government and private medical colleges). Seventeen out of the 35 States and Union Territories in the country have private medical colleges in 2008 (MCI 2008).

Continuing Medical Education (CME): A few states have initiated rules for re-registration of medical degrees, based on credits obtained from CME. However these lack legal backing and have not been stringently implemented (De Sarkar and Kumar 2004). Voluntary agencies, medical colleges and Medical Councils are other actors involved in conducting CME and in-service training programmes, with funding support variously from government and international organizations (ibid.). Pharmaceutical companies in India are a thriving industry, and other than supplying drugs and materials, they are also active in supporting training programmes and CME

for doctors. Representatives of pharmaceutical companies have been reported to have a major role in informing doctors of developments in medical knowledge, particularly doctors in the private sector (Greenhalgh 1987, Lal 2001, Sheikh et al. 2005a).

SECTOR	STATUS		
	Recognized / recommended for recognition	Permitted to offer under-graduate medical degree	Total
Private	83	51	134 (50%)
Government	117	17	134 (50%)
Total	200 (75%)	68 (25%)	268

Table 2.2 Private and Government Medical Colleges in India in 2008[11]

Voluntary accreditation is a relatively new area for healthcare in India. According to Nandraj et al in 1999, accreditation schemes promoted by the Indian Hospital Association and the National Institute of Health and Family Welfare (NIHFW) had met with lukewarm responses. Certification from bodies such as the Bureau of Indian Standards (BIS), and the International Standards Organization (ISO) was pursued by private hospitals to a limited extent, however are regarded not to have wide acceptance (Nandraj et al. 1999). More recent developments are the emergence of a healthcare specific accreditation agency – the National Accreditation Board for Hospitals and Healthcare Providers (NABH), an autonomous body under the umbrella of the Quality Council of India (QCI); and the increased emphasis on medical laboratories by the National Accreditation Board for Laboratories (NABL) (an office of the Government's Department of Science and Technology) (Dogra 2005).

Medical insurance is available in India through government schemes, and from public and private insurance companies. Government health insurance include employee schemes such as the Employees State Insurance Scheme (ESIS) the Central Government Health Scheme (CGHS), schemes for Railways and Defence employees, ex-servicemen and others; and voluntary insurance through public sector companies such as New India Assurance Company Limited (NIACL) and the National Insurance Corporation (NIC) (Gupta and Trivedi 2005). Private insurance companies were permitted to enter the market in 1999. Voluntary insurance was reported to be availed of by 11.2 million citizens (less than 1% of the population) in 2005, of which 10% held private insurance (MOHFW 2005a). Only an estimated 3-5% of Indians are covered under any form of health insurance (ibid.). Claims settlement by the mediation of Third

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[11] Data from MCI (2008)

Party Administrators (TPA) was introduced in 2001. However a study in 2005 revealed that their role was limited, due to low awareness on the part of policyholders, and poor acceptance by medical providers (Bhat et al. 2005).

Voluntary associations are significant actors in health policy in India. *Professional associations* such as the Indian Medical Association and its regional and local chapters have very large memberships, and are active in organizing training programmes and conferences, running scientific journals, and occasional large scale mobilization of medical care, such as for immunization drives and emergency relief (Park 2005). Other organizations such as the Rotary and Lions Clubs are also active in mobilizing physicians (particularly in the private sector) for voluntary work (Gupta and Sood 2005).

Non-governmental organizations (NGOs) play a multitude of roles in the biosphere of Indian health systems. Gupta and Sood's typology of NGOs (2005 p2.26) distinguishes organizations based on their role or purpose:

- Service providers: the "traditional" role of NGOs of offering affordable health services to the poor, particularly in underprivileged and poorly developed areas.

- Capacity building and support NGOs: offer know-how, expertise and training to medical service providers, an example being the Population Services International which is involved in social franchising of private providers in order to promote standardized STI care (Solomon et al 2004).

- Empowerment and advocacy NGOs: actively engaging in policy advocacy and social mobilization for rights-related or specific health concerns of communities.

- Umbrella or network NGOs: coordinating roles in bringing different groups together to work on common issues.

Many NGOs pursue more than one of these functions. In the first category of service provider NGOs, independent philanthropic societies, trusts and faith-based organizations have a long history in healthcare in the country. Some non-profit organizations run full-scale charitable hospitals in different parts of the country.

Private trusts and corporations which run large hospitals or chains of hospitals are now prominent actors in the healthcare world (Matthew 2006). While a majority of beds in the for-profit private sector are to be found in small practices and nursing homes, there is a relatively more rapid growth of larger hospitals in this sector.

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2.1.3   Relevant Acts and legislations

In some cities or states there are specific legislations requiring private nursing homes to comply with certain standards in order to be registered and allowed to function. These include the Bombay and Delhi Nursing Homes Registration Acts of 1949 (GOM 1949) and 1953 (GOI 1953) respectively, the West Bengal Clinical Establishments Act 1950, the Madhya Pradesh Upcharya Griha tatha Rujopchar Sambandhi Sthapnaye Adhiniyam 1973, and the Nagaland Health Care Establishments Act 1997 (Clinical Establishments Bill 2007). Typically these Acts require medical establishments to employ suitably qualified staff, to periodically register their facilities with authorities and to report the occurrence of births and deaths. Other than these, there is little by the way of mandatory regulations for health care establishments. Recently proposed amendments to these Registration Acts contain more specific criteria such as norms for utilization of space, ratio of providers to patients, and other technical criteria. The newly drafted national *Clinical Establishment (Registration and Regulation) Bill* 2007 (ibid.), which is awaiting Cabinet approval at the time of writing, recommends separate criteria for different types of establishments (Clinical Establishments Bill 2007, CEHAT 2006).

Consumer courts are an important forum for clients of health care in hospitals to exert their influence on the policy process. Litigation in civil courts has been noted to be a notoriously time-consuming and inefficient avenue of redress for many clients (Jesani et al. 1997), in which context the inclusion of for-fee medical practices under the purview of the *Consumer Protection Act* (CPA) in 1995 was a landmark step to reduce inefficiencies in obtaining justice (Bhat 1996a). This move was initiated to ease the process of litigation for consumers by reducing time and costs, and it can be expected that the increased likelihood of litigation is likely to lead to greater cognizance of, and adherence to recommended procedures and standards, on the part of practitioners. Consumer courts (forums) are organised in a hierarchical fashion, with a District Forum in each respective district, a State Commission in state capitals, and an apex National Commission at country level (NCDRC 2006). However, it is probable that the impact of this reform in influencing the quality of patient care in hospitals is yet relatively limited. A recent study showed that the proportion of cases relating to medical complaints were very few, and over 90% of cases filed in Consumer Forums took over a year to reach judgement. Most of the complaints were related to adverse outcomes of treatment, in some cases including loss of physical function and death (Misra 2000).

A recent *Supreme Court judgement* to the effect that disclosure of a patients' HIV status to their spouse did not amount to violation of confidentiality or the right to privacy, has led to increased attention on issues around partner notification and safety (Dr Tokugha Yepthomi vs. Apollo

Hospital Enterprises Ltd. 1998, Mudur 1998b, Kumar 1998). This judgement has been widely publicized and might be expected to have an impact on doctors' practices (Iyer 2002).

The *HIV/AIDS Bill* (2005) is an initiative which aims, among other things, to bring legal sanction to the implementation of HIV testing policies. The Bill widely addresses issues of discrimination against people with HIV/AIDS, of which requirements of informed consent and confidentiality in the context of hospital care is but one component. Provisions of the Bill which would bear on the implementation of HIV testing policies in hospitals are outlined in Box 2.1. The Bill is still under consideration at the time of writing, and has not attained the status of a law.

- Prohibition of discrimination related to HIV/AIDS in public and private spheres, including in healthcare facilities

- Requirement of specific free informed consent for testing, treatment and research

- Guarantee of confidentiality of HIV related information, including in healthcare settings

- Provision of *right to access* comprehensive HIV/AIDS related treatment including diagnosis

- Institution of new implementation mechanisms including:

  o HIV-specific *grievance redress* machinery in institutions, including hospitals.

  o Appointment of District Health *Ombuds* for arbitration of complaints.

  o Instituting HIV/AIDS Authorities at Central and State level with *statutory powers* for implementation of provisions of the Act

- Special court procedures to facilitate speedy and confidential judgements for HIV related complaints

Box 2.1 HIV/AIDS Bill 2005 - Pertinent Features

2.2 LITERATURE REVIEW: POLICY-PRACTICE GAPS IN PUBLIC HEALTH IN INDIA

The problem of policy-practice gaps is not unique to HIV testing. There is a significant body of public health literature which documents that doctors' practices in India do not always correspond with standard policies for care of HIV/AIDS, tuberculosis, malaria, sexually transmitted infections and diarrhoeal diseases and other major public health problems.

Singla et al. (1998) in a study of general practitioners in Delhi reported that only 12% used the recommended sputum smear investigation for the diagnosis of tuberculosis, and treatments widely diverged from the recommended DOTS regimen. Variations in tuberculosis treatment among private practitioners have also been reported by Uplekar and Shepherd (1991) and Uplekar et al (1998), among others. Mertens et al. (1998) observed that the recommended syndromic management of sexually transmitted infections was not followed by a majority of doctors in the private and public health facilities in Madras.[12] Das and Hammer (2004) used observational methods to assess medical professionals' practices in treating infant diarrhoea, pharyngitis, tuberculosis, depression and pre-eclampsia, observing significant deviations from recommended standards of practice among private and government doctors in Delhi.

Kamat (2001) observed widespread instances of presumptive treatment of malaria by private practitioners in a Mumbai suburb, and insufficient use of the peripheral blood smear investigation that is recommended for diagnosis. Chakraborty and Frick (2002) have reported shortcomings in private practitioners' treatment of acute respiratory infections in children, evaluated against a standard of WHO-recommended guidelines. Sheikh et al. (2005a) documented the use of non-recommended regimens for HIV/AIDS treatment by private practitioners in Pune city, including monotherapy with a single anti-retroviral drug, the use of non-allopathic drugs and the irregular treatment of opportunistic infections. Studies documenting divergences in HIV testing practices have already been listed in Chapter 1 (page 18).

Evidently, the separation of public health policies and practices of frontline medical providers is a widespread phenomenon and one that represents a significant area of concern in public health circles. Uniform guidelines of practice[13] are widely seen as benchmarks of the quality of care and compliance with these guidelines by frontline providers is understood as a requisite for the success of public health initiatives (Mahapatra 2003, Peters 2003, Brugha 2003, Das and Hammer 2004, Mills et al. 2002, Brugha and Zwi 1998). In the Indian context, concerns over policy-

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[12] Now known as Chennai.
[13] Other than for HIV testing and care, examples of such policies include the DOTS approach for tuberculosis involving direct observation and treatment using a short-course multi-drug regimen, the syndromic approach for the control of sexually transmitted infections, assessment and treatment guidelines including the use of oral rehydration solution (ORS) for childhood diarrhoea, syndromic management of acute respiratory infections in children, and others. There is a significant body of literature on the global context in which these policies are developed and "transferred" to national governments. Lush and colleagues (2003) report that such policies are usually based on existing clinical norms or guidelines for the care of the disease in question, but are consolidated and "marketed" as a package of interventions for the control of a particular disease, by international health organizations such as the WHO. Global public health policies are often tailored specifically towards the requirements of developing countries, and are adopted by the governments of many of these countries (Ogden et al. 2003, Cliff et al. 2004).

practice gaps have largely focused on *private* medical providers, although there is now an increasing recognition of the problem in the government sector as well.

In the following pages I review relevant studies and commentaries which seek to explain the problem of policy-practice gaps in medical care in India and the strategic directions that they suggest.

2.2.1   Providers-focused explanations

Ignorance of policy guidelines on the part of doctors is a common explanation for gaps, and one which also implicates existing systems of education, particularly continuing education. In other instances however, doctors have been shown not to comply with regulations in spite of being aware of them. In a study of private and government practitioners in Delhi, Das and Hammer (2004) noted that doctors' awareness of recommended guidelines of practice did not necessarily lead them to practice in accordance with the guidelines. While not actually canvassing doctors' perspectives on the issues, the authors suggest market-based explanations for these distinctions between knowledge and practice, inferring that private sector doctors are more liable to be unduly influenced by paying patients' demands than by approved norms of practice ("errors of commission"), whereas government doctors are liable to commit "errors of omission" since there is no economic pressure on them to perform up to standards. The authors assign a strong negative value to divergences in practice, characterizing them variously as being "depressing" and "troubling" (ibid.).

Much of the literature on health policy in India including principal texts (Duggal 2001, Peters et al. 2002, Yazbeck and Peters 2003, Gangolli et al. 2005) assumes such economic factors as the dominant influence on doctors' actions, and does not engage in other elements of providers' occupational realities around values and ideation, social and political factors and contingencies of resource constraints, or relationships with administrative and educational structures and contiguous stakeholders. Only a few studies and commentaries exist which explore medical practitioners' behaviour first-hand and/or offer more nuanced explanations for divergent practices.

Government providers

Das and Hammer (2004) paint a picture of indifference to their roles on the part of Delhi-based government doctors, based on low scores on quantitative indicators such as amount of time spent with patients, and number of investigations and drugs prescribed (which they characterize as errors of omission – see above). Baru (2005) has commented on how increasing commercialization of medicine in general and the growth of the private medical sector has impacted on attitudes of doctors in the public sector. Her study was based on personal histories of doctors who retired from serving in a prominent government hospital, and includes strong themes of supposed erosion of altruistic values among their peers in the face of the growing profile of the commercialized private sector. Even as these personal views of retired doctors may not represent factual evidence of declining values among government doctors, they convincingly illustrate a trend of *demoralization* of public sector practitioners, in the face of growing institutional and financial insecurity and loss of social prestige.

Bhat and Maheshwari's study (2005) on human resource management concerns in district health facilities in Chhattisgarh state is another example of recent empirical research involving government sector doctors. Using quantitative measures for commitment and skill, they reported that doctors had high levels of affective commitment to their profession, good team spirit, and were also highly skilled, which appears to present a different picture from that given by Das and Hammer and by Baru. The doctors' sense of commitment to their departments and institutions however was not reported to be as high as professional commitment. Das Gupta et al. (2003) in a World Bank study report strong *esprit de corps*, professional commitment and affective engagement with tasks among frontline medical providers in Karnataka state, while observing that problems in commitment were linked to low financial remuneration and job insecurities.

Also testifying to high levels of affective commitment among government doctors, Singh (2002), Gawande (2003) and others identify constraints such as heavy patient loads, resource shortages and time constraints which prevent government hospital practitioners from always adhering to recommended norms. Singh emphasizes how doctors in busy government hospitals make utilitarian decisions around maximising the number of patients they can see, at the cost of the quality of their interactions and the amount of time spent with each patient (ibid.).

Miljeteig and Norheim (2006), in a study of decision-making by government doctors in neonatal care, highlight that Indian doctors often tend to refer to a different set of values in making clinical

decisions, from the ones popularized in a Western understanding of clinical ethics.[14] Considerations of wider consequences for patients and their families guide decisions around treatment for critically ill neonates,[15] in contrast to Western doctors who focus more on individual rights and care processes, say the authors. Other contingent factors such as resource shortages (e.g. of ventilators in their study of neonatal care) are also cited as an important context for these decisions. The manner of decision-making by doctors sometimes appeared to compromise autonomy of patients (in this case patients' *parents*), but the authors emphasize that such decisions are made in the context of values which are specific to the culture, and cannot be evaluated through conventional, globally sanctioned bio-ethical frames (ibid.).

Private providers

In separate commentaries, Phadke (1994), Nandraj (1994), Jesani (1997), Yesudian (1994) and others have critiqued the excessively commercially driven practices of private medical practitioners. However even as they document instances of corruption, over-prescription and rent-seeking, these commentaries provide little by way of systematic analysis of doctors' practices and their underlying motivations. T.N. Madan's seminal work on Indian doctors' social roles, including studies on private practitioners in a north Indian city (1972), and subsequently on doctors in a prominent government tertiary care and teaching hospital (1980) also touches on issues of moral deterioration attributed as an explanation of medical behaviour. He places the problem of doctors' apparent non-interest in public health concerns in the larger context of Indian social structures. Belonging as they do largely to the aspiring middle classes, achievement of personal social goals is cited as the dominant macro-context for doctors' actions, more than identification with broader goals of social welfare (a prerequisite for following public health policy norms) (ibid. 1980).[16]

Depth studies such as those of Kamat (2001), Kielmann et al. (2005), and Datye et al. (2006), in their respective studies of private practitioners acknowledge the role of market factors in

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[14] Which are also reflected broadly in the national HIV testing policies

[15] For example, decisions around withdrawing treatment for a critically ill neonate was influenced by considerations of the lifelong burden a disabled child may place on poor parents, with implications for the welfare of the child's siblings.

[16] Madan attempts to qualify the negative tone of his observations of doctors by iterating that doctors do do "professionally competent and socially useful work" (1980 p 302), and are "a qualified and motivated category of people concerned with the alleviation of human suffering" (ibid p 299). According to him, doctors should not be scapegoated for sharing the "failings" of the larger social class that they are members of, and he does not discount the capacity of doctors to enhance their participation in social development. In the epilogue of his book, he emphasizes that his intent is not to undermine the role of the medical profession but to "ask for a fuller realization" of doctors' potential contribution to Indian society.

determining doctors' behaviour, but also account for the influence of wider social and political factors. The inferences around private doctors' practice being unduly subject to patients' expectations are supported by Kamat in his study of private practitioners' malaria treatment practices in a Mumbai suburb. The unregulated and highly competitive nature of the market is cited as a context for these divergences (Kamat 2001). Kielmann et al. (2005) conducted a series of interviews with private sector practitioners in Pune city in Western India. In the report of this study, divergences of private doctors' practices from national recommendations are explained in terms of reactions to varying market, policy and social pressures, and underlined by the challenge of keeping abreast with knowledge in a rapidly changing field (ibid.). Datye et al. (2006), reporting findings from the same study, observe that practitioners are influenced by social norms such as the close involvement of families in patient care and decisions, and moral prejudice around sexually transmitted diseases, which cause their practices in communicating with patients to diverge from policy norms.

Examples of research on the nature of private doctors' actual interactions with public health programmes are very limited. Uplekar et al. (1998), Vyas et al. (2003) and De Costa et al. (2008) have separately commented on the role of mutual distrust between private practitioners' and government health officials as a factor affecting private doctors' uptake of tuberculosis care guidelines.

It bears noting that most of the studies and commentaries on private medical providers relate to solo private practitioners or small practices - there is little substantive literature attempting to understand the practices of private doctors in hospitals, which can be expected to be guided more by organizational norms, and less directly susceptible to client agency.

Providers-focused explanations: summary

In summary, studies and commentaries seeking to explain the divergent behaviour of medical providers from norms are limited, but (apart from the convention of regarding medical practitioners as solely economically motivated individuals, assumed in most health policy texts) address a number of possible factors including ignorance of guidelines, overriding concerns of financial security in unstable markets, and contingent factors such as uncertainties of patient response and resource shortages. The role of "process" factors – such as the nature of interactions between policy implementation agencies and practitioners – on the uptake of guidelines have received very little attention. Ambiguities around financial and job security are seen to be

important contexts for government practitioners, even as professional interest and commitment have been reported to be strong. On the other hand, moral decline, poor engagement with public concerns and overriding social and commercial self-interest have also been suggested as contexts for deficiencies in practices of private doctors. In one instance, doctors' divergent *beliefs* and use of ethical frames other than those which underlie policies or which are otherwise widely recognized, has been documented.

2.2.2 Systemic explanations

There are several accounts of the roles of medical educational systems, governing and regulatory organizations, professional bodies, and to a lesser extent, of administrative structures in hospitals, in the context of the non-implementation of public policies around health care. Critically however, few of these essays contain systematic analyses or are based on empirical research. Furthermore, the perspectives of the individuals who constitute these institutions and organizations largely do not find expression in these analyses.

Governance and accountability systems

The role of health governance mechanisms has been examined in the context of divergent practices. Das Gupta et al. (2003) reported that local health authorities are often not even aware of the policies and regulations that they are expected to enforce. Resultantly they (health authorities) do not routinely assess whether regulations are being followed, the norm being to pursue such tasks only when concerns are raised by citizens or civil society organizations (ibid.). Poor awareness of relevant acts and codes of practice among private practitioners has been documented by Bhat (1996b). Bennett and Muraleedharan (1998) have also highlighted the critical area of lack of communication between departments of health and professional medical councils in coordinating regulatory activities.

Within the government sector context, Bhat and Maheshwari (2005)[17] describe interrelational gaps between health systems actors in terms of "rigidities" in management systems, which support a convention of mechanistic and centralized decision-making. Hierarchies were reported to be strong within the departments of health they studied, with limited freedom for frontline providers to communicate with peers and superiors. Assessments of performance tended to focus

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[17] In their study of district health services in Chhattisgarh state - also see previous reference.

around compliance with norms and meeting the targets of various health programmes, rather than on meeting the needs of patients; an observation that is also reported by Singh et al. (2002) in a study of TB treatment centres. The doctors in Bhat and Maheshwari's study felt that the highly centralized nature of management systems prevented them from attempting field-level innovations to improve the delivery of services (ibid.).

There is little account of the nature of interactions between government health departments and private hospitals, in the context of implementing public health policies. However, Rangan and colleagues (2004) have documented experiences of participants in *voluntary* public-private partnerships aimed at promoting private practitioners' use of government DOTS regimens for tuberculosis care. Habituated as they were to mechanized and hierarchical relationships within the government sector, working with autonomous private practitioners represented unfamiliar terrain for general health and TB programme officials. Problems in motivation of these public officials, not of the participating private practitioners, presented the major obstacle to the initiatives, and it was only the mediating role played by a NGO that allowed these partnerships to be sustained (Rangan et al. 2004). Bhat and Maheshwari (2005) have also highlighted vulnerabilities and problems in the capacity of government departments to undertake partnerships with private sector actors. The theme of mistrust between government and private providers has already been introduced (see above). In a recent paper, De Costa and colleagues (2008) suggest that this mistrust between private doctors and public functionaries is rooted in prejudicial perceptions about the other sector, which have social, moral, and economic bases. Mutual assumptions of poor competence, jealousies and value conflicts between the actors underlie difficulties in establishing partnerships, observed the authors (ibid.).

According to Nandraj (1994) and Muraleedharan and Nandraj (2003), the roles of administrators in private hospitals tend to be largely focused around encouraging doctors to maximise revenues from patients, and typically give little attention to public health concerns. There are a few well-documented instances of private hospitals taking the lead in public health programmes such as for eye health (Samandari et al. 2001) and tuberculosis care (Murthy et al. 2001), which contradict this mercenary image of private hospitals. Other than these examples however, there is little generalized knowledge on what role administrations of private and trust hospitals play in propagating public health policies, if any.

Avenues of accountability to *clients* include institutional redress and recourse to medical councils, consumer form or courts. Misra's study on consumer redress facilities in 81 hospitals (2000) found that only 33% of private hospitals and 22% of government hospitals had complaint boxes or books, and even fewer (17% private and 15% government hospitals) had guidelines for

reviewing and processing complaints. The author has also highlighted deficiencies in the process of institutional redress including unresponsive attitudes of hospital authorities, and significant delays in processing complaints (ibid). The legal machinery in India is notoriously slow and laborious, with significant costs to plaintiffs, which often act as a deterrent for clients of medical services seeking formal redress. Significant delays and obstacles in the functioning are reported even in consumer forums, which have been promoted as more expedient avenues for official redress (Misra 2000). Aggrieved clients were reported by Misra to take legal recourse only in case of serious grievous injury and financial loss (ibid.), an indication that threat of litigation may be of limited efficacy as a deterrent to divergent practices of doctors (at least in non-grievous aspects of care).

Muraleedharan and Nandraj (2003) also implicate the absence of, or lack of detail in, legal frameworks for medical care standards (nationally and in different states and municipalities), as a context for "perverse" practices in the private medical sector (p 240). The inadequacy of such relevant laws is widely attributed to political factors. Historically, there have been numerous instances of medical professional groups such as the Indian Medical Association taking advocacy positions opposing new legislations and regulations of government aimed at increasing regulatory control over private providers, with varying success (Maru 1985, Jeffery 1988, Mudur 1998a, Muraleedharan and Nandraj 2003).

The failings of Medical Councils in performing their professional regulatory functions have been the subject of extensive documentation, and are an important context for the apparent freedom with which doctors are reported to flout regulations. Several instances of corruption (Pandya and Nundy 2002, Sharma 2001) and of non-responsiveness to client complaints (Nandraj 1994, Singhi 1997, Tavaria 1997) on the part of state and national councils have been reported. Gonsalves (1997) and others have conjectured that there is a systematic subversion of the roles of medical councils away from their envisaged functions in upholding professional and ethical standards, towards the protection of doctors' interests.

Academic structures and culture

Ramachandran (2006) implicates the system of medical education in what she regards as an emerging crisis in human resources for health in India. She observed that there is a dominance of an approach in which students are trained in knowledge of the sciences but not helped to become aware of the broader roles within the health profession and society, nor given a framework within

which to develop ethical understanding and decision-making skills. Ravindran (2008) reported that medical ethics is not a separate subject in the Medical Council of India's recommended curriculum for undergraduate medical education, and that few medical colleges teach ethics routinely. Academic indifference to ethics is cited by both these authors as an important context for a declining interest in social engagement and public health concerns among medical professionals. Public health as a sub-discipline of medicine has widely been reported to have a particularly low status in teaching institutions as well as among the Indian medical community in general (Jeffery 1988, Uplekar and Rangan 1993, Dandona 2004). Dandona et al. (2004) further supports this perspective by observing that public-health related articles constitute only 3-4% of the output of medical academic research, although there is no indication of trends over time in this regard.

Failures of continued medical education (CME) and limited opportunities of academic exposure for practicing doctors have also been reported. Ramachandran (2006) highlights that continued medical education programmes in India are highly fragmented, available only sporadically to practicing medical providers, and the contents of instruction are determined by narrow interests of the agencies which finance or conduct the programmes. For example, training programmes financed by vertical programmes for disease control tend to be focused solely on these areas (ibid.). Greenhalgh (1987) and Phadke (1994) have written extensively on the dominant role of pharmaceutical companies in conveying knowledge about advances in medicine to doctors, which is problematized as a result of the vested interests of the companies, in doctors' prescribing behaviour.

In earlier accounts, Madan (1972, 1980) has commented on the lack of an academic culture and exchanges of knowledge between doctors, in the context of a highly competitive market and fears of the loss of clientele. Jeffery observed that medical professional associations (while active in protecting the political interests of doctors) have historically not played a significant part in providing opportunities for academic activity. According to him, outside of immediate workplace environments, practicing doctors are largely isolated from their colleagues in the profession (Jeffery 1988).

Systemic explanations: summary

With a few exceptions, the existing literature tends to highlight failings of the numerous institutional mechanisms involved in implementation of health care policy in India. Apathy and indifference of government departments and medical councils to their mandated regulatory

functions, problems in legal frameworks and in accountability systems, lack of regulatory mechanisms in the private sector, technical bias in medical education, and insufficient and fragmented academic opportunities for in-service doctors have all been proposed as diagnoses for policy-practice gaps. A few studies have highlighted process issues, such as the inhibiting influence of hierarchy and rigid management structures on communications within government departments, and interrelational problems in dealings between government and private actors. An important adjunctive observation is that there is a widespread lack of clarity on the nature of official mechanisms of implementation and putative roles of different offices and institutions of government in implementing regulations, which prevails even among the individuals who work within these structures.

2.2.3   Debates around policy content

There is also an area of the literature which deals with questions around the quality and appropriateness of policy guidelines – an oft-cited reason for practitioners' divergent behaviour. Universal policy guidelines for the care of different diseases have been debated, including the intermittent DOTS regiment for tuberculosis care, and guidelines for opportunistic infections and highly active anti-retroviral therapy (HAART) for the management of AIDS (John 2004). Mertens et al. (1998) has identified the need for more research to validate the utility of STI syndromic management guidelines in India. A number of authors have criticized the Indian government's policy to introduce free HAART in public hospitals. The lack of preparedness of public health systems to monitor and disburse treatments and ensure completion of treatments (Kumar 2004), and the likely emergence of drug resistance (Maniar 2006, Patel and Patel 2006) are the main concerns cited by the critics.

Porter and Ogden (1999) critiqued the DOTS strategy as applied in the Indian context, on ethical grounds. They argued that the "direct observation" component of the strategy assumed that patients were basically untrustworthy, and contained the potential for coercion and adverse impact on patient-provider relationships. The strategy was not respectful to providers and patients, they averred, and treated them primarily as means to achieve programme targets for case detection and treatment completion. Vyas et al. (2003) and Uplekar et al. (1998) have documented that doubts around the efficacy of DOTS underlie government providers' and private providers' non-utilization of the regimen.

Debates around the contents of HIV testing policies have been discussed in detail in Appendix 1.

2.2.4   Prescriptions for change

Authors writing on policy-practice gaps have traditionally focused on prescribing interventions to improve the functioning of governance mechanisms and regulatory systems. Duggal and Nandraj (1991) proposed a comprehensive legislation for medical regulation, including various parameters such as physical standards as well as quality of care. In a more recent context, Muraleedharan and Nandraj (2003) too suggested that legal reforms are an imperative, and proposed the introduction of new regulations for standards of quality, and revamping of outdated existing laws. Misra (2003) has suggested amendments in existing consumer laws to bring free government services under its purview. The introduction of greater detail in the provisions of various regulatory acts including the Consumer Protection Act, Nursing Home Acts and the Medical Council Act, towards addressing issues of quality of health care more comprehensively, has been proposed by Bhat (1996a) and by Muraleedharan and Nandraj (2003).

There is scant engagement in the health policy literature with specific proposals for reform in government health departments; which is in keeping with a general trend of inadequacy of empirical research and analysis in this area. Bhat and Maheshwari in their study of government doctors (2005) argued that the doctors' affective commitment to their work should be leveraged by giving them greater administrative duties, and argue for greater attention to fairness in human resource management, and for linking non-monetary rewards and benefits to competence in performance. Bennett and Muraleedharan (1998) have highlighted the importance of better communications between government health departments and professional councils, although they do not indicate how such communicative processes could be enabled.

Muraleedharan and Nandraj (2003) have proposed the decentralization of regulatory structures to the local level and the provision of additional funds and resources to regulatory bodies. Iyer and Jesani (1999) have also contributed to the debate on reforms in medical councils, recommending enhancing the autonomy of councils from government control[18], improving transparency in their functioning, increasing lay representation in their disciplinary committees, and decentralization and strengthening of disciplinary functions (also Nandraj 1994). Bhat (1996b) suggests that medical councils' role of regulating medical education be separated from that of regulating medical practice. Duggal (2001), Bhat (1996b) and Nandraj (1994) have separately suggested

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[18] Medical councils are constituted partially by elected members and partially by nominees from government, and they are financed largely by the government.

upgrading and standardization of continuing medical education (CME) schemes, and the linking of CME credits to renewal of medical licences.[19]

In recent years there has been an increasing interest in alternatives to state-centred approaches to regulation, a trend – according to Muraleedharan and Nandraj (2003) – motivated by concerns around failed governance, inadequate legal frameworks and government incapacity to enforce existing regulations, particularly in the private sector. In a recent article, Peters and Muraleedharan (2008) have highlighted the limitations of legal and bureaucratic approaches to regulation, arguing broadly that these approaches are tokenistic and unlikely to be successful in the context of the highly dispersed and complex nature of the health care market. They instead advocate "experimentation" with market-oriented approaches such as the promotion of accreditation as a device to improve marketability, competitive contracting out of medical services, emphasis on self-regulation and enhanced collaboration with non-state stakeholders such as consumer and civil-society organizations, medical providers' organizations and the media. They argue that Ministries of Health (state and central) would be more effective if they reoriented their roles from that of combined inspectorate and provider in health care, to a role in facilitating the participation of these non-state actors (ibid.).

Modification of the economic environments in which practitioners work is a key area of interest for economists, although (apart from Das and Hammer 2004) there is a deficiency of first-hand research on the micro-economics of health care provision in India. In an introductory chapter of a book on health policy research in South Asia published by the World Bank, Peters (2003) emphasizes the importance of better "understanding and manipulating incentives" for health service providers, and recommends the production of research exploring such mechanisms (p 28).[20] In another World Bank publication, Peters et al. (2002) make recommendations (to the Government of India) for broad reforms including the improvement of oversight, decentralization of health schemes to states, contracting out of curative services to the private sector, and emphasising the role of private health insurance (ibid., also Hammer and Jack 2001). Bhat (1996b) has also emphasized the importance of alternatives to dominant out-of-pocket modes of payment for medical services in the private sector, which are known to create perverse incentives for the medical providers.

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[19] This has now been undertaken on a provisional basis in some states.

[20] In the same mechanistic vein of conceiving policy processes, Peters enlists financing, payment mechanisms for health providers, organization (of health services and regulatory structures), regulation (including writing rules and enforcing them), and persuasion (of frontline providers to change their behaviour, involving communicative means) as the five "control knobs" for policymakers to improve the performance of a health system (2003.).

A number of voluntary approaches have also been proposed by various authors, such as accreditation, social franchising and field level partnerships between government health departments and private providers.[21] The role of independent agencies in monitoring standards of care in hospitals is suggested by Duggal (2001) in his review of health policy trends in India. Nandraj et al. (1999) have suggested the institution of voluntary accreditation systems to encourage better standards in public and private hospitals. Another model which has gained popularity in the context of influencing practices in the private sector is social franchising which has been tested in different states in India in the context of STI management and reproductive health (PSI/Avahan 2007, Gopalakrishnan 2008, Mavalankar et al. 2008).

Field-level collaborations between government health departments and private medical practitioners to promote the use of recommended treatment guidelines for tuberculosis were proposed by Uplekar and colleagues in 1998. A model of voluntary partnership, without monetary implications, was proposed for the sharing of diagnostic and treatment responsibilities between government and private clinics, supported by a documentation trail. Voluntary models such as these has since been operationalized more widely with qualified success in sustaining the partnerships and aligning private medical providers' practices with policies (Dewan et al. 2006, Ambe et al. 2005, Rangan et al. 2003)

2.2.5   Viewing the policy practice gaps: summary

The multitude of varying, sometimes conflicting, explanations of policy-practice gaps suggested by different authors reflect the difficulty in making generalized characterizations of a medical sector and health system as large and diverse as in India. There is a lack of consensus on some core areas such as the level of moral engagement of medical practitioners, the roles of government health departments and avenues for reform and strategic change. However some distinct themes are identifiable in the different approaches which have been adopted to examine the problem of policy-practice gaps.

There is a strong normative inclination in the existing literature towards adopting the perspective of (actual or hypothetical) policy planners, and the views or perspectives of health care providers and other relevant policy actors are seldom documented, leave alone used to define an understanding of health policy. The individuals and organizations that constitute these

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[21] In actuality, the practical testing and application of such alternative approaches and innovations have often preceded the publication of articles supporting them.

"subordinate" groups in policy implementation are typically *conceptualized in instrumental terms* as a means for implementing policies, not as purposive or expressive entities in their own right. There are very few accounts or analyses of the actual processes of policy implementation, of the way in which participating groups and individuals interact with each other, and the dynamics of these relationships (De Costa et al. 2008, Bhat and Maheshwari 2005).

In most analyses, the nature of the *response of actors* involved in implementation is assumed to be defined by self-interest, within fairly narrowly conscribed parameters of economic or social gain (Das and Hammer 2004, Peters 2003), and considerations such as their values, motivations and goals are seldom given attention. In general, there has been little interest in understanding policy processes from the perspective of the individual participant. While there are a few empirical studies seeking to understand medical providers' practices in sociology and anthropology (Madan 1980, Kamat 2001, Kielmann 2005), there are hardly any such studies on the other individuals and organizations that make up the rest of health systems – regulatory councils, government departments and hospital authorities. There is also little evidence of efforts to link the micro-perspectives of individual participation with a larger understanding of the functioning of institutions and health systems.

Policy prescriptions suggested by analysts are typically aimed at *aligning practices and processes with the original intentions of these policymakers* (Peters 2003, Muraleedharan and Nandraj 2003, Jesani 1999, Duggal 2001). It appears that much of the writing on which the broad presumptions about the Indian health sector are derived is inherently focused around explaining divergence in terms of *lack* (of resources, capacity, commitment and morals) and *culpability* (of systems, individuals and organizations). A dominant rationalist focus tends to ascribe a negative character to divergence and difference from norms, in the actions of the individuals and organizations designated to implement policy.

There appears to be a *distance between diagnostic and strategic interests,* as they are addressed by authors writing on the subject of implementation of public health policies in India. Typically, the authors who have conducted depth studies of medical practitioners and health systems (e.g. Madan 1980; Baru 1998 and 2005) do not accompany their diagnostic analyses of field level issues with a substantive engagement in strategizing change.[22] On the other hand, the contributions of these authors are generally not cited or utilized by the influential authors who discuss policy options (Muraleedharan and Nandraj 2003, Das and Hammer 2004, Peters 2003). Disciplinary boundaries and differences in the lenses adopted for understanding the problem may

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[22] A possible exception to this being the study on government health functionaries by Bhat and Maheshwari (2005)

underlie this distancing of interests and lack of exchange of knowledge. Variously, public health scientists, economists, sociologists, anthropologists, political scientists, ethicists and medical professionals have variously been involved in analysing the problem of policy-practice gaps.

Finally, most of these studies reviewed only touch upon specific aspects or segments of the larger problem of policy-practice gaps. There are *no examples of a holistic approach to the problem* which addresses the roles of policy-planners, frontline medical providers and the gamut of involved organizations, including non-state organizations, in the Indian context.

Rationale for undertaking this study

From my personal experiences as a doctor in an urban government hospital, and subsequently as a researcher studying the behaviour of private medical practitioners, I found these readings to be insufficient, in descriptive terms as well as *prospectively* – in not accounting for the productive or expressive capabilities of the organizations and the individuals who constitute health systems in India.[23] I undertook this research project with the intention of contributing to an empirically supported understanding of field-level processes, specifically focusing on the perspectives of medical practitioners and other health systems actors. A policy analysis framework is adopted which is comprehensive and accommodates the coexistence of multiple perspectives of different actors, and also the potential role of these actors in strategic change.

The topic of HIV testing is a good illustration of the broader problem of policy-practice gaps in public health. The separation between HIV testing policy and practice is particularly marked, and is also relatively well documented in the literature, which was helpful in defining the boundaries of the research problem. HIV/AIDS care, and in particular the response of private medical providers to national policies for HIV testing and management, have been the subjects of previous research initiatives I was involved in (Sheikh et al. 2005a, Sheikh et al. 2005b, Kielmann et al. 2005; Sheikh et al. 2006, Datye et al. 2006) and as such this thesis also represents a continuation of my interests in studying the ethics of HIV testing.

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[23] Even as the readings do deal with many critical concerns of a broader nature.

Chapter 3. Policy Analysis Frameworks

3.1 INTRODUCTION

3.1.1 The policy approach

Public policy analysis per se is not a new field of activity. As long as there have been governments and governance, policies have been scrutinized informally and formally. However, as a distinct entity, the field has seen an increase in interest in the second half of the 20th century (Hogwood and Gunn 1984). Policy approaches accommodate different disciplinary contributions in order to achieve a more complete understanding of actors and real-life policy processes. These include concepts from the political and management sciences, psychology, sociology, and economics (Walt 1994, Sabatier 1998), and in its more recent applications, from philosophy and critical theory (Fischer 2003). Further, its wide adoption in the literature of specific sectors (health policy, education policy, environment policy) also emphasises the status of policy analysis as a sub-constituent of each of those areas of study – i.e. within health studies, education studies etc. (Parsons 1995).

Analytical approaches vary based on the intended purpose of enquiry. The function of public policy analysis in its original conception was to generate specific knowledge to evaluate, support or contribute to government programmes or interventions. Such analyses "for" policy typically use targeted methods such as operational research and economic analysis to inform policy decisions (Parsons 1995). Subsequently however, research "on" policy, an approach with a more reflective orientation concerned with understanding the processes of formation and implementation of policy, has received increased attention. This approach was built on existing traditions of research into the functioning of government institutions, public administration and the role of interest groups. Hence analyses "for" policy and "of" policy collectively constitute the field of policy studies (Gordon et al. 1977, Lasswell 1970 cited in Parsons 1995).

In a contemporary sense however, distinctions of analysis *of* or *for* policy are no longer seen to be so clear. There is an increasing recognition of the diversity of roles of policy analysts in society

and the variability of processes through which research influences policy change (Parsons 1995, Yanow 2000). Ritchie and Spencer (1994) identify four types of questions that are usually asked in applied policy research - contextual, diagnostic, evaluative or strategic questions - and stressed that most research, in intent or effect, addresses more than one of these types of questions.

Another important dichotomy in the policy sciences is between positivist frameworks, which are typically deductive and seek causal explanations for phenomena; and less definitive approaches which may be exploratory or inductive, and are often broadly categorized as post-positivist or post-modern (Guba 1990, Fischer 2003). The positivist approach requires policy analysis frameworks to have the attributes of scientific theories, fulfilling such conditions as comprehensiveness, allowing empirical testing, and generating falsifiable hypotheses (Sabatier 1998). In contrast, post-positivist paradigms hold that social and political realities cannot be fully understood or explained through deductive lines of reasoning. Furthermore social knowledge is multidimensional and subject to human interpretation, and hence not always provable or "falsifiable" in a scientific sense (Parsons 1995). Inductive methodologies which are linked to post-positivist approaches focus on multi-dimensional explanations of, and associations between phenomena, rather than on establishing linear causality (Ritchie and Spencer 1994).

The analysis in this study is both *of* policy and also *for* policy. The constructivist or interpretivist approaches used in the study seek to provide an understanding of the multiple perspectives of the constituent actors engaged in policy processes. This is critical in informing not just an understanding of reality (or of multiple realities), but also of the possibilities of change, since it is the actors themselves who are involved in shaping change (Yanow 2000).

3.1.2 The policy-action relationship

In the early years of the emergence of policy studies, the focus was largely on understanding the nature of policy *formation*, in which context implementation, or the link between policy and action, was "assumed to be a series of mundane decisions and interactions" and not seen to have distinct significance as a subject of study by policy scientists (Van Meter and Van Horn, 1975 p450). Implementation was widely seen as a managerial function, and not integral to the study of policy, or to the policy process.

Pressman and Wildavsky's study of implementation of a federal programme for economic development in the USA in 1973 heralded the beginnings of the new sub-discipline. Since then, the literature on implementation has burgeoned and textbooks on implementation studies have

been published, drawing on ideas from the political sciences, public administration and organizational behaviour (Grindle 1980, Barrett and Fudge 1981, Williams 1982, Younis 1990, Hill and Hupe 2002). "Implementation studies" developed as an umbrella under which academic thinking on the policy-action relationship was consolidated.

In its original conception implementation studies was conceived to address policymakers' concerns about the ineffectiveness of policies, a problem variously described as "implementation deficits" (Pressman and Wildavsky 1973) "the implementation gap" (Dunsire 1978), and "policy failure" (Hogwood and Gunn 1984). The implementation process is viewed explicitly from the perspective of policy-makers, as part of a sequence following, and separate from policy formulation (Buse et al 2005). The notions of policy accomplishment, responsibility and accountability are central to these *"top-down"* conceptualizations of the policy-action relationship (Lane 1987). "Top-down" theorists have generally been preoccupied with identifying approaches and conditions which can lead field-level practices to more closely approximate original policy intentions (Sabatier and Mazmanian 1979, Hood 1976, Hogwood and Gunn 1984).

The top-down conception of the policy-action relationship has widely been contested and an alternative movement in implementation studies has also taken root, which is often collectively bracketed as *"action-centred"* or "bottom-up" approaches. Barrett and Fudge (1981) argued that there is no reason that the perspectives of policymakers should automatically be adopted by policy analysts, since in many instances action precedes or predates policy. Policy may be a response to pressures and problems experienced on the ground, or may be developed to control or build on an existing practice or phenomenon (ibid.).[24]

Along with Barrett and Fudge (1981), Elmore (1982), Lewis and Flynn (1979), Hjern and Hull (1982) and Lipsky (1980) have made fundamental contributions to this alternative perspective. According to Lane (1987), considerations of trust, freedom of choice and learning typically underlie the normative position adopted in action-centred approaches. The two perspectives – top-down and action-centred – represent alternative ways of framing the problem of policy-practice gaps, and also reflect differing concerns and interests. Bottom-up and action-centred approaches are discussed in detail in section 3.2.1.

In summary, discourse around implementation is no longer concerned with questioning the legitimacy of the approach but with differences in addressing its specificities, including understanding the roles of different *actors*, the *contexts* that guide their actions and interactions,

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[24] This is particularly so in the case of health policy, since health care practices often precede policy formation, definitely so in a historical sense.

the nature of *processes* in the policy-action relationship (Walt and Gilson 1994), and consequently in the manner of prescriptions and recommendations for *change*. These different aspects are elaborated in the following sections, with an emphasis on the frameworks and approaches used in this study.

3.2 ACTORS IN THE POLICY-PRACTICE CONTINUUM

"Actors" is a term used to define the individuals and collectives of individuals who participate in policy processes. Policy processes are widely defined or influenced by their actions (Buse et al. 2005). Actors can be classified in terms of their membership of "groups" - metaphorical collectives of individuals or organizations delineated by structural, functional or organizational parameters (Parsons 1995). Examples include service providers, resource providers, administrators, coordinators, demand groups, etc. (Benson 1982). From a *"top-down"* perspective which emphasizes functional roles, actors each have their designated positions in implementation of policies. For example:

- Policy-planners are involved in formulating and disseminating policies.

- Street-level operatives (in this study, medical practitioners) are involved in the provision of services to recipients.

- Intermediary actors such as regulators, educators, and administrators direct or organize the actions of street level implementers through various means and instruments.

There is an implicit assumption in this perspective, espoused by many influential implementation theorists[25] (Sabatier 1998, Hogwood and Gunn 1984, Pressman and Wildavsky 1973) that decision-making is the function of policy-makers and hence decisional processes *end* with the formulation of policies by policy planners, and are then instrumentally "put into effect" by designated implementers. However there may be inconsistencies in this view of the policy process, and *action-centred* approaches offer an alternative view of actors' participation in policy implementation.

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[25] And by many health policy experts (Peters 2003, Duggal 2001)

3.2.1 Action-centred approaches

Reality may be more complex than is implied by a top-down model of a unitary central locus of decisions. According to Elmore (1982 p.20, also Lewis and Flynn 1979), the view that "policymakers control the organizational, political and technological processes that affect implementation"[26] is a fallacy which is often not borne out by experience, observation and research. Groups who are designated as implementers continually reinterpret, modify and change policies in the process of implementing them (Barrett and Fudge 1981, Lipsky 1980). Further, groups and organizations involved in implementation are often autonomous or semi-autonomous, and not in direct hierarchical relationships with those making policy (Barrett and Fudge 1981). This makes it necessary, in exploring policy-practice gaps, to consider distinctly the decision-making processes and capabilities of all involved actors, not just those of designated policy planners.

Core characteristics of action-centred approaches in studying the policy-action relationship are:

- They emphasise *action as the focal point of study*, rather than policy, focusing on "observing what actually happens or gets done, and seeking to understand how and why" (Barrett and Fudge 1981 p.12)

- They view communication in policy as bi-directional, emphasising the *interactive nature of relationships between actors* in the implementation process.

- They are often oriented on the *perspectives of actors involved in policy implementation*, other than policy-makers. They may explicitly address the view from the "bottom" i.e. that of street level implementers

The "groups" metaphor is useful in action-centred research. Yanow (2000) indicates that membership of a group is not just linked to common instrumental functions, but to individuals' use of similar cognitive mechanisms, language, and forms of expression and action. Group processes of working together reinforce these similar ways of seeing and acting.[27] However, it is also important to understand that groups are not fixed or exclusive, but represent fluid and overlapping categories. The implementation process can be seen in terms of interactions between different groups.[28]

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[26] Also known as the "noble lie" of conventional public administration and policy analysis (Williams 1982)
[27] Hence Yanow uses the term "communities of meaning" to describe groups.
[28] Discussed further in section 3.3.1

Focus on service providers

While the perspectives of all actors in the implementation continuum are given importance in the action-centred perspective, actions at street-level have been proposed as a suitable point for initiating research enquiry into implementation processes (Williams 1982). Elmore (1982, p21) proposed a research orientation which starts "not with a statement of intent, but a statement of the specific behaviour at the lowest level of the implementation process" and works upwards through the different layers of the organizational hierarchy. This "backward mapping" approach[29] potentially accounts for a more comprehensive range of explanations for policy-practice gaps than a narrow search for reasons for the non-fulfilment of intentions of policymakers (Elmore 1982).

Michael Lipsky's seminal theories of street-level bureaucracy (1971, 1980) similarly emphasized attentiveness to the actions of service providers[30], by observing that "governments may be most salient to citizens where there is frequent interaction with its representatives" (1980, p210). Lipsky reasoned that it is not the initial statements of intent by policymakers, but the altered and adjusted decisions and actions of public servants (representing a balance between upholding service values and making concessions for circumstantial factors) which are relevant for the recipients of services (1980 p.xii).[31]

There are very few examples of such approaches being adopted in the health policy literature, particularly in the context of developing countries. Walker and Gilson's (2004) investigation of the perspectives of South African primary health nurses implementing new policies for free health care, is one such example.

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[29] Backward mapping was proposed as a tool for policy analysts, and also as a prescription for policy planners. Since Elmore worked for an American government programme, in his case these two proposed functions for backward mapping may have overlapped

[30] Lipsky's theories pre-date the emergence of implementation as a distinct sub-discipline of policy studies, a widely regarded benchmark of this being the publication of Pressman and Wildavsky's book *Implementation* in 1973

[31] Lipsky observed that public servants were often subject to large case loads and inadequate resources which, in combination with uncertainties of method and unpredictability of clients made it impossible to achieve the high service ideals that they were set, and instead they adjusted by developing alternative patterns and routines (creating policy). The typical managerial (top down) prescription for such deviation and discretion on the part of implementers is increased administrative control, which however acts only to intensify the pressures on street level bureaucrats already burdened by considerable limitations and uncertainties, and has the effect of increasing their tendency to stereotype at the expense of their regard for the needs of clients (1980).

3.2.2   Understanding the individual actor's response

If, as is suggested by the action-centred framework (Figure 4.1), all actors in the implementation continuum are regarded to have decision-making capabilities, then it becomes important to understand how individual human beings involved in policy processes make decisions around action, and what guides their response.

In a typical top-down or managerial perspective, individual action is usually seen simply in terms of adherence to or deviation from institutional / organizational rules or norms (Parsons 1995). Approaches which have been adopted by economists to explain human action, such as the rational choice approach reduce actors' decisions to expressions of narrow self-interest (Ostrom 1998, Das and Hammer 2004) Political economy approaches too tend to revolve around considerations of rational choice, while acknowledging that these choices occur within political contexts (Walt 1994). Even as these approaches claim accuracy in predicting human action on a large scale (John 1998), solely self-interest based models do not offer insight into how decisional processes occur in the minds of actors, or how ideas get translated into action. They do not provide an account of individual volition, purpose, or capacity for change and learning.

More nuanced approaches have been suggested which include considerations of different forms of human cognition and expression, and of the importance of internal values, beliefs and ideational processes.

Cognition, expression and meaning

Cognition and expression are actors' forms of interactions with the outside world (Lewis and Flynn 1979). Cognitive inputs are manifold and potentially limitless, and in the context of implementation, include apperceptions of contextual and situational factors, and of the direct and indirect communications of other actors (Yanow 2000). Individual expressions of actors can take the form of their enactment of roles, within the framework of the organizational channels available to them; and also other forms of ideational and communicative expression including the conveyance of ideas which represent solutions for problems, and of the meanings ascribed to problems (Fischer 2003). But how are cognitive inputs processed by actors, and how are decisions made around how to act?

The human mind is complex and different theorists have tried to explain its workings in different ways. Theories and taxonomies of human psychology have been applied to better understand the

policy process. Human values, beliefs, needs, feelings and intellectual activity have been variously understood to be the bases of internal decisional processes. Simon's influential model of bounded rationality includes a consideration of feelings, in perceiving policy decisions as being made by a combination of intellectual reasoning and human feelings or affect. In this model, affect is regarded broadly in negative terms as a reason for departures from an intellectual-rational ideal of political action (Simon 1957, cited in Buse et al. 2005). Lasswell (1936, cited in Parsons 1995) had earlier introduced an emphasis on affective values in decision-making (although not necessarily in a negative sense), by classifying individuals on the basis of their possession of different types of political values. He divided these into two groups which he respectively called deference values – relating broadly to power, productivity and efficiency, and welfare values – relating to well-being, skill and respect. He postulated that policy decision-making by different actors was based on perpetuation and protection of their respective types of values (ibid.).

Concepts such as *"systems of meaning"* (Yanow 2000), *"frames"* (Rein and Schön 1993), or *"appreciations"* (Vickers 1965) help to understand how different actors process knowledge in the contexts of their own beliefs and interests. According to Rein and Schön (1993, p.145), frames represent different actors' ways of understanding the world. Frames are the way in which "facts, values, theories and interests are integrated" by particular actors or groups of actors to construct their realities, define problems and identify solutions for the problems. In the interpretive approach, cognitive, expressive and internal decisional processes are seen to occur within the same system of "sense-making" or interpretation by relevant policy actors (Yanow 2000). Actors interpret information through the lens of the frame or system of meanings that they function in. Collectives of actors belonging to the same groups may share systems of meaning and hence share cognitive mechanisms, engage in similar acts and use similar language to discuss policy problems (ibid.). Concepts such as meanings and appreciations are widely utilised by sociologists and anthropologists, but have seldom been applied to understand the experiences of health policy actors.

Vickers proposed a simple model to explain the individual experience of making decisions in a policy context. According to him, policy actors make an *appreciation* of a given problem, by balancing their judgements around the "facts of the problem" (reality judgements) with value judgements answering the question "what ought to be?" in order to arrive at action judgments (what to do, and how to do it?).
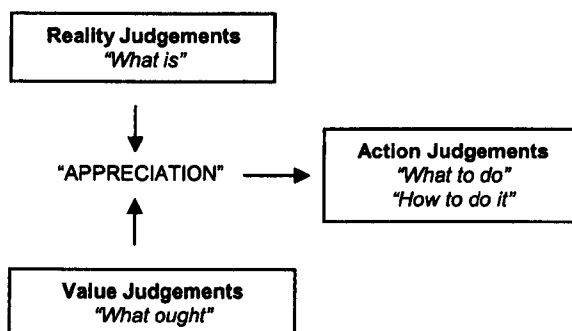
The concept of "appreciation" here is analogous to "systems of meaning" (Yanow 2000) or "frames" (Rein and Schön 1993) discussed above, defining the lenses through which policy actors define problems and pursue courses of action. Through this mental map of judgements, Vickers illustrated that policy decisions are determined by complex and specific internal processes of policy actors.[32] It provides a categorical framework on the basis of which individual actors' accounts of their experiences, and their explanations of the experiences, can be thematically organized. In proposing this model, Vickers continued the emphasis on the role of values, which he regarded as a key component of political judgment, but also included considerations of pragmatism and common-sense in decisions made by individuals. Actors may change their appreciations and their actions through the repeated exercise of judgements in the course of their work - constituting a "learning cycle" (ibid.).

Box 3.1 A Model of Individual Decision-making

3.2.3   Contexts of action

Organizational entities and structures such as hospitals, government departments, private firms, and voluntary associations are the settings for the actions of the individuals involved in implementation (Lewis and Flynn 1979). Conventionally, government apparatus such as the legislature, executive and bureaucracies were seen as neutral instruments and public policy was seen as being essentially constituted by their activities. Although these ideas have widely been

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[32] This model was originally proposed to explain decision-making by designated policy-planners. However, in a more democratic understanding of policy decision-making suggested by action-centred approaches, the model is applicable to all relevant actors.

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refined,[33] the contextual importance of organizational structures, including government bureaus, private firms and other associations in guiding action is still widely recognized. Organizations define the norms for actors to work within systems, and provide (or constrain) their channels of cognition and expression (John 1998). Workplaces such as hospitals and departmental offices routinize and reinforce patterns of action. The way in which *professions* are structured allows them to exert a strong normative influence on actors' behaviour, particularly relevant in the context of medical providers (Freidson 1986). However the relationship between norms and structures and the actions of those involved in implementation is seldom linear or predictable and, given the diversity of organizations involved in implementation processes, does not lend itself to generalized theories.

Ambiguities around contextual influences

Sources of policy are often multiple, which is a cause of ambiguity for implementers. Implementers' actions are rarely based exclusively around the fulfilment of unitary policy objectives. In implementation, say Lewis and Flynn (1979, p 125), there are "frequent disagreements about policy goals and objectives; vagueness and ambiguity about policies and uncertainty about their operationalization in practice; (and) inconsistency between powers available and existing problems". The theme of ambiguity is developed by Hjern and Porter (1981), who make the salient observation that multiple organizations are involved in the implementation of programmes, and organizations participate in several programmes. The requirements of different programmes, and of the involved organizations, are not necessarily well-coordinated or mutually commensurate. Implementers hence often face dilemmas between serving the goals and objectives of a particular programme – the "programme rationale", or of the organization they work in – the "organizational rationale". [34]

How then does action take place in the context of such ambiguities? According to Lewis and Flynn (1979), considerations of feasibility in given circumstances, and adjustments and compromises between two or more competing sets of priorities and policy areas, are often truer guides of action than the formal constitutions of organizations. Dynamics of power, social

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[33] The neutral perspective on state institutions has widely been challenged in the political sciences, with the growing recognition that their purposes and functions are often unclear, and that they may themselves be vehicles for the exertion of social power and expressions of hidden interests (John 1998).

[34] "Organization rationale" is a synthesis of values and goals adapted from those of the programmes within the organization and perceptions of the niche that the organization fills in its environment. It is embedded within organizations and usually followed and endorsed by administrators.

relations, conflicting interests and value systems in interactions between different groups all may be important in shaping action (Barrett and Fudge 1981).

Other perspectives include those of economists who typically conceive contexts for action in terms of market factors, in which organizational arrangements and structural and environmental factors are interpreted in terms of their economic value, and opportunities or threats to maximization of self-interest for the relevant actors (Das and Hammer 2004, Peters 2003). Sociologists have identified how health care organizations may function as social systems, or within social contexts (Nichter 1996, Madan 1980).

Need for empirical exploration

Much of the literature on the policy-action relationship in health presumes the dominant influence of particular set of contextual factors - administrative, economic or social. In truth, all these formulations represent different ways of contextualizing action, but none in isolation captures the multidimensional reality of the worlds which policy actors inhabit. While acknowledging that there are various understandings of contextual influences, Hjern and Hull (1982) warn against presuming the ways in which the influences shape action, suggesting that these equations are unique to different policy milieux, and best understood through empirical research, from the perspectives of the relevant actors. This inductive view is mirrored in the interpretivist policy analysis approach (used in this study)[35], which seeks to understand different participant actors' meanings of policy problems and processes, without predetermination of contextual factors (Yanow 2000).

3.3   POLICY-ACTION PROCESS

Early approaches influenced by public administration (Pressman and Wildavsky 1973, Van Meter and Van Horn 1975) conceived policy implementation in a classically "top-down fashion", as a series of instrumental tasks designed towards putting policy into effect. The alternative to a purely instrumental view, and one that corresponds to the action-centred view of implementation used in this study, is an *interactive perspective* in which the continuum from policy to practice can be visualised as a series of interactions or communications between the promulgators of

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[35] See Chapter 4 (4.4.1)

policies, the groups and organizations involved in an intermediary role, and street level implementers of policies (Barrett and Fudge 1981, Yanow 2000).

3.3.1 Interactive processes

Barrett and Fudge (1981), in their book "Policy and Action", were among the first to emphasise the *bi-directional nature* of associations in the context of implementation. In this interactive perspective, the authors emphasised that a range of issues can be highlighted including power, dependence, interests and motivations, which guide behaviour and interactions. Discourse theories, and in particular the interpretive policy analysis approach proposed by Yanow (2000) further develop the theme of the interactive approach, by regarding policy processes as being essentially communicative, and crucially including the place of *ideas* and *meanings*, as well as of power and interests in defining interactive processes. It is apparent that decisions in policy are primarily enacted through communicative means, involving the use of linguistic and symbolic devices. Many acts overtly involve the transfer of ideas - for instance policy guidelines are essentially a set of ideas which are conveyed to doctors, and doctors' enactment of the guidelines too involves communication with patients. However, even the most instrumental of processes[36] can be viewed in communicative terms, in terms of how they are carried out and what they represent to stakeholders (Yanow 2000).

Hjern and Hull point out that actual relationships and associations between individuals in different organizations may not conform to formally expected norms of group functions, and emphasize the importance of understanding the nature of "living" (as opposed to "written" or formally expected) processes of interaction (Hjern and Hull 1982). These living processes of interactions between groups of actors have a functional or instrumental dimension, and also a less definable ideational dimension (Fischer 2003, also Yanow 2000).

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[36] Such as infrastructural changes, or the institution of documentation systems, in examples given by Yanow (2000)

3.3.2 Functional and ideational dimensions of interaction

Functional dimension

The functional dimension of interactions refers to the enactment of approaches and devices for the instrumentation of policies, guided by the written rules and norms of organizations. The use of these devices depends on the type of policy being implemented, and the preferred methods and intents of executives in putting the policy into effect. John (1998) classifies policy implementation instruments as being legal, financial, organizational or personal. Legal instruments include laws and statutes; financial instruments link role performance to remuneration; organizational instruments are exertions of bureaucratic power; and personal instruments include various forms of persuasion including education. The literature on health policy implementation in India has focused variously on financial (Peters 2003, Muraleedharan and Nandraj 2003), instructional and organizational instruments (Grimshaw et al. 2001 McColl et al. 2000, Uplekar et al. 1998, Mertens et al. 1998), although in some instances legal (statutory) changes have been made or suggested to add weight to policies guiding medical practice (Bhat 1996, Grover et al. 2001).[37]

In an interactive framework, all instrumental processes can be seen as acts of interaction or communication between the groups (authorities or executives) who enact the laws and regulations or make educational, organizational or financial arrangements, and the groups (functionaries or implementers) responding to these official arrangements.

Ideational dimension

The movement of ideas has increasingly received recognition as an important element of policy processes in general, and the policy-action relationship is no exception. Discursive theories of policy state that political action per se can be characterised in terms of the movement of ideas, or in other words, that ideas represent the substance of policy (Fischer and Forester 1993). Policy statements such as those for HIV testing are an example of ideas which represent solutions for problems. Other such *ideas for policy* too may circulate in the policy environment (March and Olsen 1989), and their success in filtering through to the consciousness of formulators of policy depends on a number of factors. Other than the persuasiveness of the ideas themselves, power relations between groups of actors, "entrepreneurial" efforts to promote particular ideas and

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[37] See Chapter 2 for details.

propitious political and socio-economic conditions are factors which influence the uptake of new ideas (Hall 1997, Kingdon 1984).

The other type of ideational interaction which is of significance in the policy-action relationship is of the mutual conveyance of "meanings". As discussed earlier (3.2.2), different policy actors have different ways of perceiving and interpreting issues and problems, and interactions between members of different groups necessarily involve communication *across* systems of meaning.[38] Policy controversies often persist as a result of different ways of framing realities and problems (Rein and Schön 1993). In a policy milieu, actors variously choose to convey their respective meanings to each other (or not), and particular systems of meaning may dominate popular consciousness at the expense of others (Yanow 2000).

3.4   STRATEGIZING CHANGE

Conceptions of *rationality* in human action underlie most frameworks seeking to explain policy processes and are particularly relevant in the context of making prescriptions for change. Herbert Simon advocated how organizations should function, by maximising rationality in decision-making by means of a systematic step-wise process consisting of intelligence, design and choice (Simon 1957, cited in Parsons 1995). This represents a dominant strand of thought in policy studies (including health policy), in which scientific and objective rationality is seen as an ideal standard to be achieved, and the actual behaviour of individuals perceived as a divergence from that ideal (Parsons 1995).[39] In these approaches, a problem-solving approach is usually implicit, in seeking how implementation processes can more closely approximate a rational end-point, and prescriptions typically tend towards increasing or maintaining control over processes and individuals and minimizing deviation from initial goals as stated in policies.[40,41]

According to Yanow (2000) it is the *rhetorical power* of such ends-oriented approaches which apply scientific principles to social science contexts to produce objective solutions for policy

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[38] See previous explanation of the concepts of frames, systems of meaning and appreciations on page 53

[39] According to Miller (1984, also Parsons 1995) this is evidenced by the pre-dominance of solution-oriented approaches and techniques in the field, such as cost-benefit analysis, economic forecasting and determination of social indicators.

[40] For instance Pressman and Wildavsky (1973) attributed policy failure to the erosion of the original intents of policy in each successive step of implementation, and emphasised streamlining systems to enhance cohesiveness

[41] Such approaches have also dominated in prescriptions around health policy in India - see Chapter 2 (2.2.4)

problems, which has led them to dominate the field of policy studies, in spite of a narrow view of rationality that they represent.

Process-oriented view of change

Alternative perspectives of positive change do exist which focus on improving processes rather than on developing solutions, and are not necessarily recent in their articulation. The importance of better communication and deliberation between policy actors has been emphasised in the work of seminal policy theorists Lindblom, Lasswell and Vickers. Charles Lindblom (1959) was of the belief that the need for agreement and consensus was not replaceable by rational analytical techniques in making policy decisions, especially complex ones. Lasswell proposed the use of "decision-seminars" as a participatory and deliberative technique for policy development with an emphasis on personal development and learning (Laswell 1971, cited in Parsons 1995). Vickers (1965) too believed that mechanistic rational models of human regulation needed to be adapted to take individual and social considerations into account. He emphasised the importance of adjustment, adaptation and learning - over goal-seeking - as movers of human action in politics. In more contemporary contexts, the importance of communicative practices in policy-planning has been explored and developed by theorists such as Healey (1993) and Fischer (2003).

In the health policy context, there is an increasing interest in elements such as trust and respect, in the context of patient-provider relations as well as relations between health workers and employers (Gilson et al. 2005, Green 2004). A process-orientation is implicit in this literature, which emphasises the importance of recognizing the relational nature of health systems (Gilson 2003). Porter and colleagues (1999) have argued for a shift in the approach to policy for infectious diseases towards more attention to process, and to an appreciation of how health systems actually function in the context of socio-economic realities. They contend that existing public health programmes for disease control need to be re-examined in terms of the roles they play in communities, and not just in terms of the targets they are focused on achieving.

In summary, solution-oriented and process-oriented perspectives are complementary in their view of the policy process, and suggest different and often conflicting prescriptions for change. In the concluding chapter of this thesis, I discuss strategies and recommendations for change focused on improving the quality of interactive processes in implementation.

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3.5 CHAPTER SUMMARY

The field of policy analysis provides a consolidated way of looking at the policy-practice relationship as a whole. However different theories and frameworks of the policy-practice relationship differ in their conceptualizations of:

- the manner of participation of different *actors* and the contexts of their actions

- the nature of policy-action *processes*

- ways of strategizing *change*

In this study, an action-centred framework (Barrett and Fudge 1981) is used to conceptualize the policy-practice continuum and investigate the gaps. Within this broad framework, other concepts and theories from the policy literature too find application and help to understand the complexity of the problem (Hjern and Hull 1982, Elmore 1982, Yanow 2000, Ritchie and Spencer 1994, Vickers 1965, Hjern and Porter 1981, Healey 1993). The conceptual framework, research questions and methodology are elaborated in the following chapter.

Chapter 4. Methodology

4.1   RESEARCH ORIENTATION

4.1.1   Conceptual framework

In this study, the relationship between HIV testing policy and practice is conceptualized as an *action-centred framework* focused on understanding "what actually happens or gets done", and how and why (Barrett and Fudge 1981). In this framework, actors involved in implementation are seen to have decision-making capabilities and power to take action and effect change, and are linked together through interactive processes (Figure 4.1).
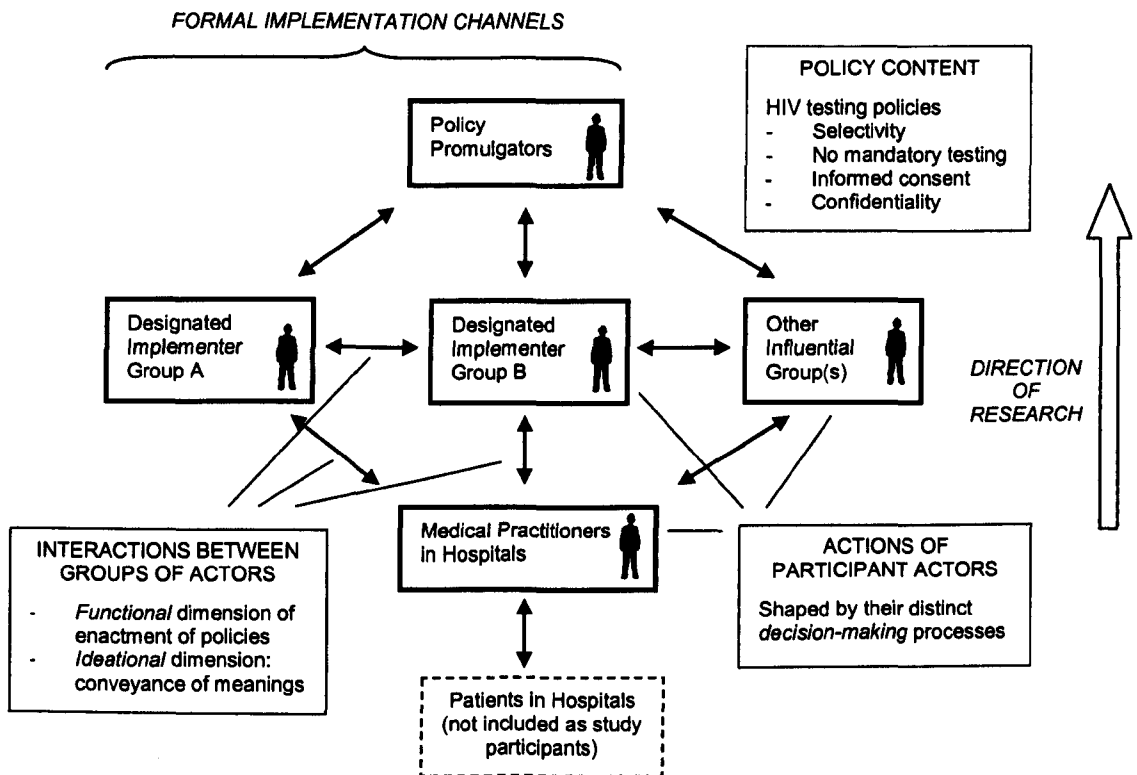
Figure 4.1 Policy-Practice Continuum as a Web of Decision-makers

Participant Actors

Actors involved in implementation of policies are differentiated into groups broadly based on the designated functions of the organizations to which they belong (John 1998):

- Policy-planners and promulgators

- Street level implementers – the medical practitioners

- Groups which are formally designated to have roles in implementation such as hospital administrators, the HIV/AIDS programme, and professional regulatory bodies

- Groups which do not have designated roles in implementation, but are otherwise influential, such as civil society organizations, international organizations and professional associations

These *actors' participation* in policy implementation is understood to be shaped by their respective internal decision-making processes. The manner and contexts in which these decisions are made are explored through the process of empirical research, and not presumed (Hjern and Hull 1982).

Interactive Processes

The links between different groups are conceived as *interactive or communicative processes* (Barrett and Fudge 1981, Yanow 2000). Interactive processes are bi-directional and have functional and ideational dimensions, corresponding respectively to the enactment of roles in policy implementation, and to the mutual communication and conveyance of ideas and meanings.

Inferring from the conceptual map (Figure 4.1), gaps between policies and practices may result from divergences or irregularities in either of two sets of phenomena: the nature of *actors' participation in policy implementation*, and the *interactive processes*. The research questions for the study are focused on understanding these two core aspects of the policy-practice continuum.

4.1.2 Research questions

Research Question 1   *How do medical practitioners in hospitals in India respond to national policies around selectivity in HIV testing, mandatory testing, informed consent and confidentiality, in practice? Why do they respond as they do? What are the factors which determine their behaviour?*
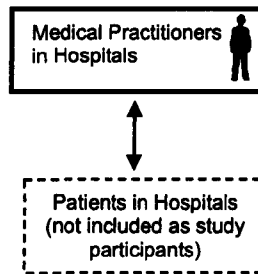
Figure 4.2 Orienting Point – Action at the Level of Service Delivery

Actions at the level of service delivery are taken as the orienting point for the research, and the research process proceeds "upwards" from this initial point, drawing from *bottom-up* principles (Elmore 1982, Hjern and Hull 1982). The first research question is based on understanding medical practitioners' responses to national HIV testing policy guidelines in the real life contexts of their practices.[42]

Research Question 2   *What is the nature of the different arrangements through which national HIV testing policies are expected to be implemented in urban government and private hospitals?*

There is insufficient information in the public domain about the designated roles of different organs of government and other influential organizations in ensuring the implementation of public health policies in hospitals, and of how they are expected to interact with each other. This second question is focused on establishing the details of these putative arrangements, providing a context for understanding the actual performance of roles by these actors, and their interrelationships.

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[42] See Chapter 1 (1.2) for NACO's policies.

<u>Research Question 3</u>   *Who are the various policy actors involved in the implementation of HIV testing policies?   What are the different policy actors' roles in implementing HIV testing policies?*

FORMAL IMPLEMENTATION CHANNELS

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                        ┌──────────────┐
                        │ Policy       │
                        │ Promulgators │
                        └──────────────┘

┌──────────────┐      ┌──────────────┐      ┌──────────────┐
│ Designated   │      │ Designated   │      │ Other        │
│ Implementer  │      │ Implementer  │      │ Influential  │
│ Group A      │      │ Group B      │      │ Group(s)     │
└──────────────┘      └──────────────┘      └──────────────┘
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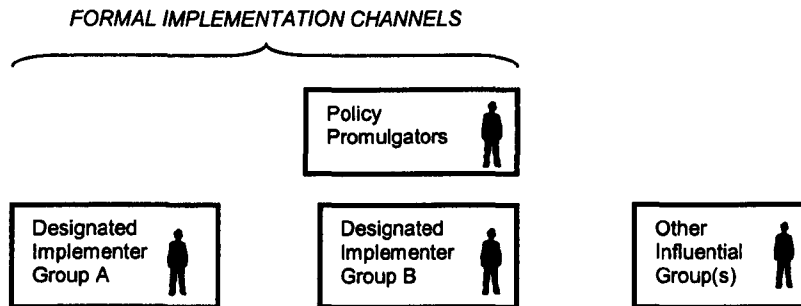
Figure 4.3 Groups Formally and Informally Involved in Implementation

Apart from the groups who are involved in the formal arrangements of implementation, other actors too may be directly or indirectly involved in the implementation process.   Furthermore, groups who are formally designated as implementers may not enact their roles as they are officially required to do.   This question is focused on establishing the identities of the different groups formally and informally involved in implementation, and understanding their *actual roles* (as opposed to their putative roles) in the implementation process (Hjern and Hull 1982).

<u>Research Question 4</u>   *How do practitioners and other policy actors interact with each other in the process of implementing HIV testing policies?*

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                        ┌──────────────┐
                        │ Policy       │
                        │ Promulgators │
                        └──────────────┘

┌──────────────┐      ┌──────────────┐      ┌──────────────┐
│ Designated   │      │ Designated   │      │ Other        │
│ Implementer  │ <──> │ Implementer  │ <──> │ Influential  │
│ Group A      │      │ Group B      │      │ Group(s)     │
└──────────────┘      └──────────────┘      └──────────────┘

                        ┌──────────────────┐
                        │ Medical Practitioners │
                        │ in Hospitals     │
                        └──────────────────┘
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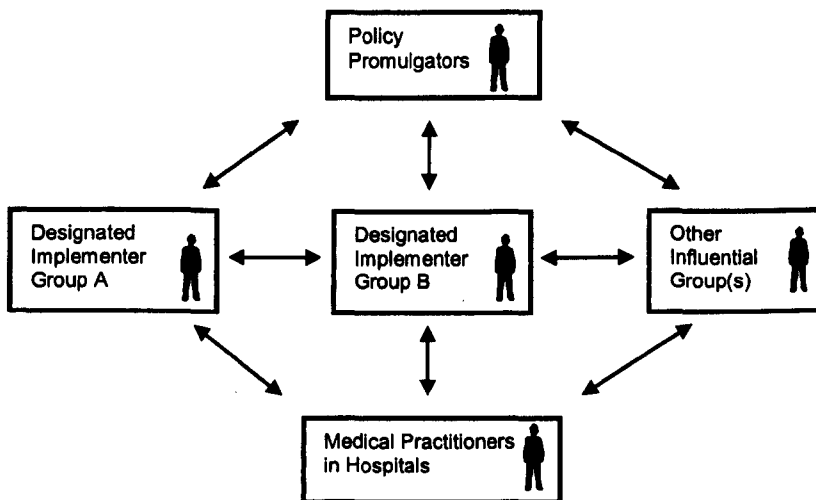
Figure 4.4 Interactions between Groups

Understanding functional and ideational interactions between different groups of actors participating in implementation processes forms the basis of this fourth question.

<u>Research Question 5</u>   *How can medical providers and other policy actors contribute to reconciling the gaps between policy and practice?*

The final question focuses on the capabilities of, and opportunities for different groups of actors to contribute to a process of bridging policy-practice gaps.

4.1.3   Methodology overview

In exploring the policy-practice relationship in this study, the *interpretivist approach* of policy analysis is adopted, in which events and phenomena are viewed through the lens of the apperceptions and interpretations of participant actors (Yanow 2000). Action-centred implementation theorists have emphasised the importance of establishing participating "individuals' definitions of a policy system" (Lewis and Flynn 1979), and of "policy problems as defined and addressed by relevant actors" (Hjern and Hull 1982). The interpretivist approach is derived from constructivist epistemologies in social research which aim to "include multiple voices and views in their rendering of lived experience" (Charmaz 2000 p525). The intent is not to establish a singular objective reality of the policy-practice relationship, but understand the multiple realities of the different groups of actors who participate in the system.

Social science research methods are used to investigate the problem. Starting with medical practitioners and moving up through the echelons of the health system, different actors' views around their participation in implementation processes, and interrelationships with other groups are obtained through depth interviews, and analysed in order to understand and explain policy processes. Interpretivism requires the analyst to be immersed in the beliefs of participants to try and understand their real purposes and motivations for actions, and convey these to the reader (Yanow 2000). The approach is elaborated in section 4.4.1.

Table 4.1 is a tabulation of research questions against the methods used to address the respective question and the chapter or section in which relevant findings are presented.

Research question	Methods used[43]	Relevant chapter/section
1	Depth interviews with *medical practitioners*, thematic analysis[44]	Chapter 5 and 8 (section 8.1)
2	Review of policy documentation, interviews with *policy actors other than medical practitioners*	Chapter 7 (section 7.1)
3	Depth interviews with *policy actors other than medical practitioners*, thematic analysis	Chapter 7 and 8 (section 8.2)
4	Depth interviews with *all actors*, thematic analysis	Chapter 6, 7 and 8 (sections 8.3, 8.4)
5	Depth interviews with *all actors*, thematic analysis	Chapter 9

Table 4.1 Research Questions, Methods and Corresponding Chapters

Different themes emerged as data from respondents' narratives were generated and processed in the qualitative research process. Some models and theories which had not been applied pre-emptively were found to be pertinent in organizing or understanding some of these emergent themes,[45] complementing the framework which was initially used to structure the research process. This process of a combined inductive and deductive approach towards developing a unified thematic framework is based on principles of the *"framework" approach* for applied policy analysis (Ritchie and Spencer 1994), and is described in detail in section 4.4.2. A thematic framework was developed on the basis of which the data from depth interviews were analysed.[46] Details of selection of study subjects, organization of data collection and analysis are elaborated in the following sections.

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[43] In addition to the methods cited, key informants' opinions and contextual insights were utilized in the text where relevant, to provide contextual information.

[44] See thematic analysis framework on page 80.

[45] These included Vickers' heuristic of value, reality and action judgements to characterize the internal process of decision-making by individuals in policy (1965); and the distinction of organizational and programme rationales (Hjern and Porter 1981) to interpret individuals' ambivalence between different affiliations. In prescribing change, a lens of communicative rationality was applied (Healey 1993). The applications of these different frameworks are highlighted in the relevant parts of the thesis.

[46] The thematic framework is presented later in this chapter on page 80.

4.2 DEFINING THE FIELD AND SELECTING SUBJECTS

4.2.1   Delineating the groups

The identification and delineation of different groups was initially determined by common taxonomies found in Indian health policy texts (Gupta and Sood 2005, Park 2005), and from discussions with key informants. These classes were based broadly on the putative functions of different organizations or offices (Benson 1982). As the interviews proceeded, respondents identified organizations who were potentially involved in implementation processes, which were then included in the classification of groups. This reflects an iterative empirical approach for identifying relevant actors (Hjern and Hull 1982). The eventual listing of involved groups of public and private actors is presented below.

1. Medical Practitioners[47]
   a. Government sector
   b. Private for-profit sector
   c. Voluntary sector
2. Institutional (Hospital) Authorities[48]
   a. Government sector
   b. Private for-profit sector
   c. Voluntary sector
3. Government General Health Authorities
4. HIV/AIDS programme Authorities[49]
5. Medical Professional Regulatory Authorities (Councils)
6. Educators
7. International Organizations
   a. United Nations technical agencies
   b. Donor agencies
8. Civil Society Actors, subdivided into two groups
   a. Those engaged primarily in legal and policy advocacy
   b. Those engaged primarily in field level activities
9. Medical Professional Associations
10. Accreditation Agencies

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[47] Also referred to interchangeably as "doctors" or "medical providers"
[48] Also referred to as "hospital administrators"
[49] HIV/AIDS programme authorities are sometimes referred to simply as "Programme authorities" or "Programme officials" in the following chapters.

There is a particular concentration on medical practitioners as a group, in this study. See Chapter 7 (7.1) for details of the putative roles of these different groups in the process of policy implementation. Representative individual actors from each group were selected and interviewed (see below). The participation of each different group of actors in implementation processes was viewed through a similar analytical lens[50], without predetermining assumptions about prevailing structures and hierarchies (Hjern and Hull 1982).

4.2.2   Hospital-based participants

Principles of maximum variation sampling (Silverman 2004) were applied in respect to identifying hospitals for the study, based on two criteria: type of hospital and geographical zone. Nine urban hospitals were selected with representation from the government, private, and charitable sectors; and located in five cities, one each from the North, West, South, East and Central Zones of the country. *Four government hospitals, three private hospitals* (including one large hospital and two private nursing homes), and *two charitable hospitals* were identified. Once the parameters of sampling had been established, the actual hospitals were selected purposively, based on suggestions from colleagues and key informants.

Individual participants from the hospitals were identified from departments likely to be associated with HIV testing and distributed across these departmental specializations, using the maximum variation principle (Silverman 2004). Apart from two counsellors, all these participants were medical professionals. Table 4.2 depicts the distribution of the participants across hospital types and specialities. This sample also included institutional authorities: participants with administrative responsibilities within the hospitals, either as superintendents, or heads of departments, but who were also medical professionals in their own right. A total of thirty-nine hospital-based respondents were interviewed, this final number being determined by adequate representation from different specialities. Of these, 12 were women and 27 were men. The least experienced of these were residents or postgraduate students, and the most senior were Professors and Heads of Department with as much as 40 years of experience.

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[50] See section 4.4

	Physicians	Surgeons	Venereologists	Gynaecologists / Obstetricians	Microbiologists	Counsellors	Total
Government Hospitals (4)	8	3	4	4	2	1	22
Private Hospitals (3)	5	3	1	-	1	1	11
Charitable Hospitals (2)	3	1	1	1	-	-	6
Total	16	7	6	5	3	2	39

Table 4.2 Hospital-based Participants by Hospital Type and Speciality

4.2.3 Participants in other settings

Participants representing different public and private organizations and government bureaus were selected for interviews. In most instances one or two individuals were interviewed per organization. Typically the participants were senior members (unless specified otherwise) with adequate experience and an awareness of the goals and objectives of their respective organization, and of its internal functioning. There were a total of 22 participants from non-hospital settings.

An indicative map of the groups with the number of respondents interviewed from each group is presented below. A comprehensive listing of all study participants including dates on which they were interviewed is presented in Annexure 1.
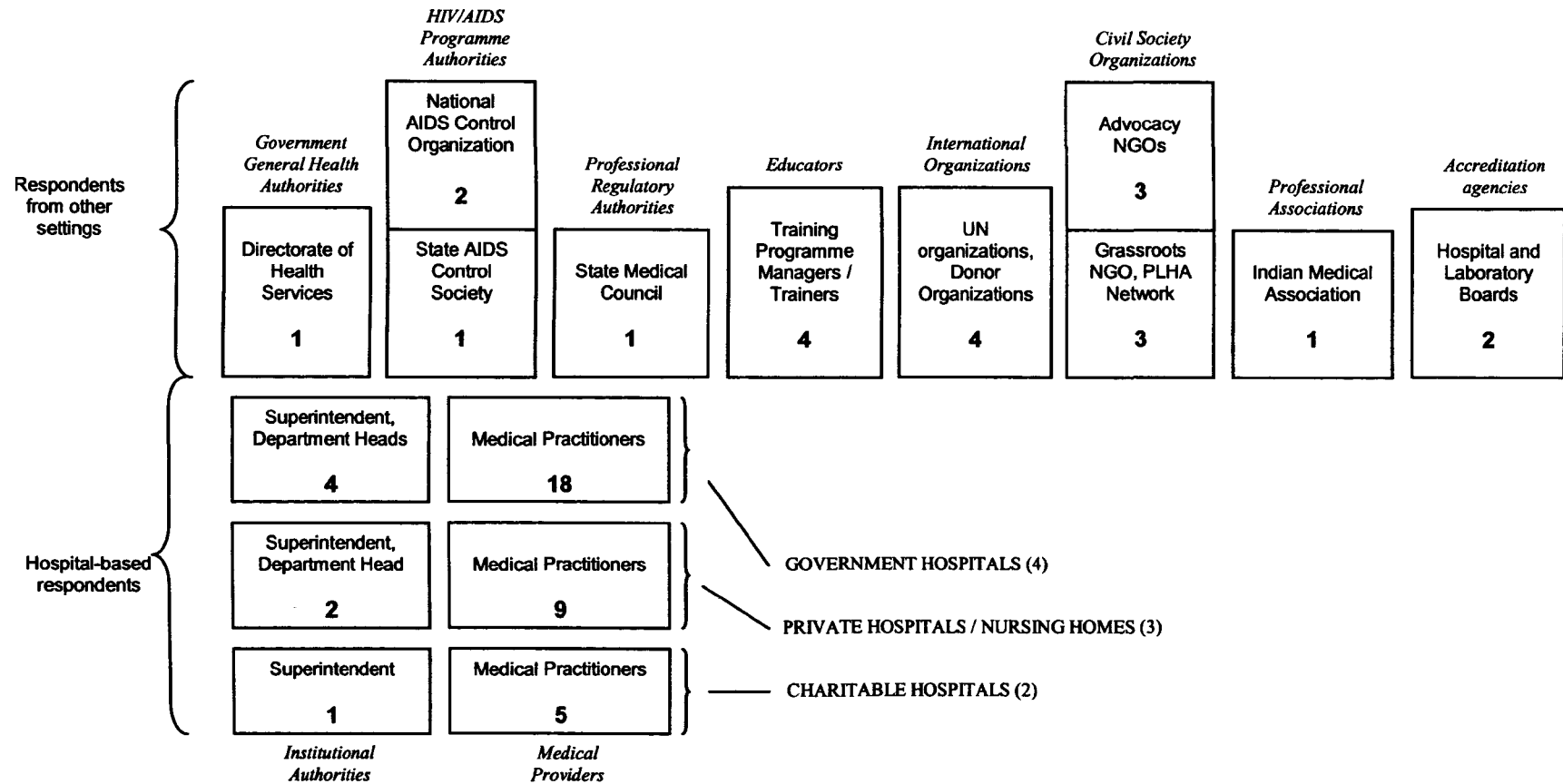
Figure 4.5 Study Participants Representing Different Groups[51]

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[51] Several precautions are taken here to protect the anonymity of respondents. For state level institutions (State Medical Council, Directorate of Health Services, SACS), the name of the state is not disclosed. The names of particular organizations are withheld, such as the donor organization, the hospitals and NGOs, either on the requests of respondents, or to prevent the identification of particular individuals. In instances where an organization's name is mentioned (with the consent of the respondent), care was taken to ensure that the descriptive label used for that respondent could apply to any of five or more individuals.

4.3   FIELDWORK AND DATA COLLECTION

The fieldwork included depth interviews with study participants, discussions with key informants and a review of policy documents, and was conducted over one year, and involved my travel to each of the five cities included in the study.

4.3.1   Depth interviews with study participants

Appointments were sought from prospective participants telephonically, by email or by personal visits to their places of work. A number of individuals who were approached declined to participate, or indicated that they did not have the time to meet. In other instances, individuals were unavailable in spite of numerous attempts to establish contact with them. In most instances replacement participants were found and the resultant gaps in the overall body of data were not significant. In one instance, a potentially significant group may have been under-represented: functionaries of the State Directorate of Health Services were unavailable in spite of numerous telephonic attempts, and visits to the Directorate. A telephonic interview with an official advisor to the Directorate was arranged toward bridging this gap.

Appointments were typically arranged in the participants' place of work. In the case of medical practitioners, all interviews were conducted within hospital premises. Within the hospitals the sites of interviews varied, and included doctors' offices, consulting rooms, duty rooms, and in one instance in the preparation room of an operation theatre. Other participants were typically interviewed in the offices which were their usual places of work. I was the sole investigator in the study, and conducted all interviews personally. A total number of *61 interviews* were conducted, including 39 with hospital-based participants, 22 with participants from other settings.

Face-to-face depth interviews (Grbich 1999, Yin 2003) with the study participants were conducted using a topic guide (see annexure for topic guides). The topic guide consisted of queries around respondents' participation in the implementation of HIV testing policies, and their interactions with other groups of policy actors. Respondents were encouraged to discuss the topics at length, and interviews were guided by probes (Britten 2000).

All interviews were preceded by the presentation of an information sheet[52], after which verbal consent was obtained. No respondent declined interview after the presentation of the information sheet. However respondents indicated varying preferences for the way in which they would be quoted, and the anonymity that their respective organizations would receive.

As an investigator, I had prior experience of the field of study, having been a student and medical practitioner in a government hospital in India. This offered the advantages of an insider's status while interviewing medical practitioners. Respondents were possibly freer to volunteer sensitive information, and saw me as a non-judgmental insider. In other settings, I frequently experienced prejudice, scepticism about the relevance of my research or the quality of my methodology, and distrust around my intentions. In all interviews, and during preliminary introductions and discussions, I attempted to identify and build on points of common experience. The aim of this was to gain the trust of the respondents so as to access "real" rather than official accounts and explanations (Fischer 2003), and also to personally achieve an appreciation of the inner motivations and impulses of the participants (Yanow 2000). Many non-hospital actors were also medically qualified, which was often an ice-breaker. As an erstwhile government employee myself, this identity was a way of establishing a connection with other public servants.

In many instances, such markers of identification could not be established beforehand, but the process of conducting the interviews often allowed mutual trust to develop. It was on rare occasions that I felt unable to achieve appreciation of a respondent's viewpoints, or the sincerity of their responses. Most respondents had strong feelings and opinions around the subjects of inquiry, which they put across with compelling arguments, often illustrated by accounts of real-life events. A number of respondents remarked on how the interview had been an unburdening and even a therapeutic process for them.

Data collection was concluded when representatives of all the groups identified as being involved in implementation processes (pre-emptively and iteratively by respondents and key informants), had been interviewed. At the point of closure of data collection, no "new" names of organizations were being identified by respondents (Yanow 2000).

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[52] Information sheet is attached in Annexure 5

4.3.2   Key informant discussions

Face-to face methods were also employed in conducting loosely structured *discussions with key informants* (Grbich 1999). Phenomena in the policy process which are publicly accessible are often best captured through key informant interviews, according to Yin (2003). Key informants were identified on the basis of their status and reputed knowledge in particular areas which were of relevance (Patton 2002), drawn from a list of academicians, experts, commentators, programme and public health officials, and civil servants. Loosely structured topic guides were developed depending on the areas of the informant's special knowledge. Interviews were conducted with an emphasis on eliciting descriptions and explanations of processes, such as influences on doctors' actions, or roles and interactions of policy actors (Yin 2003). Nine key informant interviews were conducted. A list of Key Informants is attached in Annexure 2.

All interviews were electronically recorded or comprehensive hand-notes taken, depending on the respondent's preference. The recordings were transcribed verbatim into text in the computer programme Microsoft Word and entered in the qualitative data analysis programme Atlas/Ti 4.2.

4.3.3   Contents of policy documents

The constitutions of various institutions which are officially mandated with the task of implementing policies are often not easily accessible, or even available in the public domain. Often different policy documents from the same organizations contained contradictory information on the organizations' constitutional or putative roles.

Relevant details of the constitutions of various groups were obtained from records and reports of the Ministry of Health and Family Welfare; and from perusal of the official internet websites of government and private agencies. Visits to the offices of these institutions in the course of conducting the research study also allowed me to access some relevant official information which was not available widely. In the course of conducting the interviews, wherever possible, I collected relevant documentation which was germane to the topics being discussed. Documents included policy statements, reports of organizations or hospitals, circulars and minutes of meetings. The content of these materials was also sometimes useful in clarifying the context for respondents' accounts, and in guiding the discussions.

4.4   DATA ANALYSIS

Data from interviews with study participants was analysed from an interpretivist perspective (Yanow 2000), which seeks to understand policy processes from the perspectives of the participant actors. Data from Key Informant interviews and from policy documents was thematically categorised on the basis of content, and not subjected to analysis. Data from policy documents too were taken at face value, and extracts were used to prepare section 7.1.

4.4.1   Reading the data: the interpretivist approach

Interpretivist policy analysis methodology offers an integrated way of understanding the nature of the policy-action relationship, in considering all processes to be essentially communicative (between individual actors or groups of actors), and contingent on their respective apperceptions and interpretations (Yanow 2003). Interpretivism is built on an understanding of the coexistence of multiple realities of different policy actors.[53] Exchanges between policy actors are essentially viewed as communicative, either in verbal or symbolic terms. All actors in a policy situation, says Yanow, "interpret issue data as they seek to make sense of the policy".

The aim for the analyst is to achieve an appreciation of the rationales within which policy actors think and act, by immersing him/herself in the values and beliefs of the respondents. The emphasis is not so much on describing policy processes, as on elaborating the meanings actors attach to those processes (Yanow 2000).[54] Interpretive analysis is done by focusing on actors' expressions of real reasons and motives for actions, "as opposed to those officially offered" (Fischer 2003 pp.141-142). In accessing the apperceptions and interpretations of actors through depth qualitative methods, interpretive approaches may account for the role of various factors including beliefs, assessments of realities, values, self-interest and dominatory power in shaping

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[53] Interpretivism is linked to relativist conceptions of the social construction of reality, but such ontological presumptions are not given pre-eminent importance. In Yanow's terms "the interpretive approach is less an argument contesting the nature of reality, than one about the *human possibilities* of knowing the world around us, and the character of that knowledge" (Yanow 2000, p7). This knowledge can then be used to understand opportunities for change on the part of different actors.

[54] Yanow (2000) identifies three roles of the interpretive policy analyst:
- Clarifying the varying interpretations of policy meanings made by different groups
- Understanding the various elements through which these meanings are communicated
- Ensuring that underrepresented groups are enabled to make their interpretations heard

The role of the interpretive analyst may involve generating new ideas, synthesizing opposing arguments and reframing debates; and is hence different from the traditional role of a policy analyst of advising designated policy decision-makers on making choices between available options (Yanow 2000, pp18-19).

actions and interactions. The knowledge of actors' motivations and systems of understanding derived from interpretivist research can be used also to understand their capabilities for change.[55]

The data from transcripts of participants' interviews was read through such an interpretivist lens. Themes that had emerged during the interviews were refreshed, and numerous new themes and interpretations came to light. In instances where I had difficulties in achieving an appreciation of respondents' viewpoints in the course of the interviews, re-reading their transcripts and relating this to the experience of the interview was an important step in achieving an appreciation of their interests and motives.

4.4.2   Organizing the data

For organizing the textual data from transcripts of interviews, the "framework" approach for applied policy analysis, combining inductive and deductive approaches was used (Ritchie and Spencer 1994).[56] In policy analysis, an entirely generative approach is not appropriate (Pope et al. 2000), and in this case there are fairly narrow criteria defining the boundaries of the research. "Framework" allows the researcher to retain focus on the core areas of interest, without sacrificing the depth of inductive or grounded approaches.[57] The following sections elaborate the steps I followed in analysing the data, on the lines of the "framework" approach.

Developing the thematic framework

Following an intensive process of familiarizations with the data, a thematic framework or index was developed, corresponding with the second step of the framework approach (Ritchie and

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[55] A communications-based approach is not simply a way of describing and explaining processes, but is also attuned to addressing strategic or prescriptive questions.   The conscious use of debate in policy-planning has been regarded as having a potentially liberating influence on the policy process (Fischer and Forester 1993).   Healey (1993) argues that policy planning can and should be a "communicative enterprise", wrought through deliberative and respectful debate and argument between stakeholders (also Lasswell cited in Parsons 1995 p 445). Fischer (2003), developing the ideas of the philosopher Habermas, assert the positive and productive aspects of "communicative" power, in organizing action through discourse (also Dryzek 1987). For further discussion and application of these concepts, see Chapter 9 (9.2).
[56] The approach was developed by the UK's National Centre for Social Research.
[57] The steps in analysis recommended in the "framework" approach are:
-    Familiarization with raw data
-    Identifying a thematic framework, based on pre-determined objectives, and field level issues
-    Indexing – by applying the thematic framework systematically to the data.
-    Charting – rearranging the data into distilled summaries of views and experiences.
-    Mapping and interpretation – using the charts to locate concepts, phenomena, typologies, and associations between themes.

Spencer 1994). Three layers or levels of thematic codes were developed and applied to the data: a priori themes determined by the topic guide, emergent issues arising from interviewees' responses and analytical themes based on prominent patterning of emergent themes.

At the broadest level, all transcripts were indexed into two overlapping coding categories or super-codes, corresponding with the core areas of enquiry.

- Category A: Relating to their own participation in implementation of policies
- Category B: Relating to interactive processes between groups

Level 1 or surface themes (see Box 4.1 below): this level of codes corresponded to the *a priori* themes raised in the topic guides[58], and hence differed slightly between different groups corresponding with the variations in the topic guide. For instance, medical practitioners were asked specifically about implementing different aspects of the HIV testing policies, and other actors were asked for a general description of their involvement.

Category A: Participation in policy implementation
  Subcategory: general account of involvement (all respondents except medical practitioners)
    1.1   Organization's expected role in implementing policies
    1.2   Description / account of actual experience
  Subcategory: account of experience for each aspect of policy (only medical practitioners)
    1.3   Selectivity in testing
    1.4   Mandatory testing
    1.5   Informed consent
    1.6   Confidentiality
Category B: Interactive processes between groups
  Subcategory: Description of interactions with respective groups
    1.7   Institutional Administrators
    1.8   Government and Legislature
    1.9   HIV/AIDS programme
    1.10 Professional Regulatory Authorities
    1.11 Educational and Academic Platforms
    1.12 International Organizations
    1.13 Civil Society Organizations
    1.14 Professional Associations
    1.15 Accreditation Agencies
    1.16 Others

Box 4.1 Level 1 (*A Priori*) Index of Codes

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[58] Topic guides are presented in Annexures 3 and 4

The second layer of analysis dealt with *emerging themes* from the respondents' accounts. Emerging themes were broadly divided along the lines of their perceptions and actions around implementing policies. Both conscious (overtly stated) and unconscious expressions of respondents' perceptions were noted (Silverman 2001). Under Category A (roles in implementing policies) emerging themes were classified into subcategories based on respondents' reports of their *actions* in the process of implementing policies, and their *explanations for these actions*. Likewise, data under category B was categorized in terms of respondents' *experiences* of interactions with other groups and their *explanations* for the nature of these interactions. Respondents' *opinions and feelings* about the relevant aspect of policy implementation or about interactions with the other groups were also classified (see Table 4.3).

In developing the *analytical theme* categories, respondents' explanations for actions, and the meanings they attached to processes were given particular importance, in keeping with the aims of the interpretivist approach (Yanow 2000). Vickers' formulations (1965) of the appreciative dimensions of the individual response: *reality judgements, value judgements* and *action judgements* were useful in classifying respondents' explanations of their actions, particularly in the case of medical practitioners (see discussion of Vickers' model, page 55). Other important themes that emerged were ambivalences around *roles and "rationales"* as a guide to action (see discussion on page 56, particularly Hjern and Porter (1981)). *Functional* and *ideational* dimensions were subcategories used to classify codes relating to interactions and relationships between actor groups, drawing from Yanow (2000) and Fischer (2003) (see page 59). *Communicative intent* and *effort*[59] were analytical themes used to evaluate the "rationality" of policy processes and suggest strategic change, drawing from Healey (1993).

Table 4.3 summarises the thematic subcategories used for organizing the data from participant interviews.

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[59] These themes are discussed in detail in Chapter 9, and criteria of communicative rationality are outlined in section 9.2.1

	Category A: Participation in Implementation of Policies	Category B: Interactive Processes between Groups
A priori themes	Organization's *expected* role in implementing policies (all except medical practitioners) General description of actual experience (all except medical practitioners) Experience of implementing each aspect of HIV testing policy (only medical practitioners)	General description of interrelationships with other groups
Emergent themes	Account of actions in implementing policies (or not) Explanations for actions Related opinions and feelings	Experience of interactions with other groups Explanations for the experiences Related opinions and feelings
Analytical themes	Role perceptions and rationales Judgements of reality (what is) Value orientations (what ought) Action judgements (what to do, how to do it)	Functional dimension Ideational dimension Communicative intent and effort

Table 4.3 Thematic Framework for Participant Interviews

Indexing and charting

The thematic framework, once developed was applied systematically to the data (Ritchie and Spencer 1994). First, a priori codes were attached to the relevant segments of text, using the computer programme Atlas Ti. These coded chunks of data were then retrieved and copied into separate files (Microsoft Word documents). A separate file folder was created for each group, containing several of these documents, corresponding to each *a priori* theme. Hence ten *file folders* were created corresponding to the ten groups in the study, each with between three and fourteen *documents* containing data of their accounts of their participation in implementing policies and on interrelationships with other groups.

The second layer of the index was then applied to each of these documents separately, and the textual data from each group was organized into *matrices or charts* with the columns representing the emergent theme categories (actions or experiences / explanations for actions / opinions and affect), and the rows representing different respondents. These matrices were used as the templates for writing up the findings, as in Chapters 5, 6 and 7. A section of one such matrix - from the accounts of three medical practitioners on the topic of mandatory testing policies -is presented as an illustrative example as Table 4.4.

Matrices of emergent themes enabled intra-case and cross-case comparisons, which helped in the development of analytical themes. Once the analytical code categories were determined, they were similarly applied to each initial document and chunks of text corresponding to the analytical themes were retrieved, and written up as a report (analytical themes are found mainly in Chapter 8). In some instance diagrams and tabulations were used to illustrate particular findings.

Respondent	Actions	Explanations for actions	Opinion and affect	Notes for analytical themes
# 19 *Gynaecologist*	Do not do it "Even a Gynae surgical patient that we operate we do not get their HIV test done as a routine screening"	Obedience to government policy "as far the government set-ups are concerned we are all bound by the governments directions, which we receive, and for us there is no policy of routine screening for all patients"	Agree with policy generally "nothing should be compulsory"	Routine screening described as a policy: "we don't have any policy of routine screening for HIV in any of our population either Obs or Gynae."
# 29 *Surgeon*	Do it sometimes "when we have clinical suspicious situations, we do it but it is not a routine"	Compliance "I think the Government of India regulation wants that the person has to be counselled for HIV even before he is informed, and screening for HIV is not allowed." Co-worker factors "whenever we had to do surgery on one such or even the contemplation of surgery, it produces a lot of reaction ... and the theater staff they all feel as if it is an invitation to death or something and they really resist any such effort." "nobody is ready to make way for them (HIV+ patients)"	Disagree with policy "By and large I think most people would like to know if somebody is HIV positive..." Public health logic "by not screening them ... I am sure that we are losing out quite a bit (on diagnosing HIV)" Emotive importance "it is a big issue for us!"	Fear of HIV among surgeons and OT staff Adapting to ensure continuance of core functions: "I can take a view that if something is not done then we will not do this case, but at the end of the day it is the patient who is not getting any care so that is not the situation which is acceptable at the end of the day." Clinical logic –maximizing knowledge of condition: "By and large I think most people would like to know if somebody is HIV positive..."
# 24 *Microbiologist*	Do it sometimes (under pressure from clinicians) "We are actually not supposed to do pre-operative HIV	Pressure from clinicians to do mandatory testing "We are actually not supposed to do pre-operative HIV checking ...but we do get requests again and again and again. ..."	Disagree with policy "I think they are justified." (in testing) Discretion:	Secrecy culture around mandatory testing: "This is something people try to keep hush-hush. I don't know why we are not openly discussing this issue"

			"You shouldn't test everybody" but "let the doctor decide when it is required"	Adapting to accommodate clinicians:
checking ...but we do get requests again and again and again. ... so we tick them under the schedule of referred client."				"We are actually not supposed to do pre-operative HIV checking ...but we do get requests again and again and again. ...
			"We should assess if the person is high-risk"	
				Subversion of rules:
			Against HIV exceptionalism:	"...so we tick them under the schedule of referred client."
			"When you can order a syphilis serology, then why can't they order a HIV?"	
			Beneficence assumption:	
			"It is for the patient's benefit after all! We are not doing to protect ourselves. All the time, it has been projected as though if we get the HIV testing done,	
			its not for the benefit of the patient, but it is to protect us. That is not the issue!"	

Table 4.4 Section of a Matrix of Emergent Themes[60]

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[60] From government medical practitioners' narratives on mandatory testing

Transcripts of discussions with Key Informants were coded on the basis of the content of their accounts into three categories: Indian medical providers' behaviour, perceptions and influences; roles of various groups in implementing policies; and nature of associations between different groups. Coded segments were retrieved and organized by category.

4.4.3   Interpreting and presenting the findings

There are many ways in which interpretations can be made from the data, according to Ritchie and Spencer, which are guided by the research questions and by the themes and associations which have emerged from the data.[61]   The interpretive process is not mechanistic but requires intuition and imagination on the part of the analyst (Ritchie and Spencer 1994).   The four succeeding Chapters 5, 6, 7 and 8 are oriented around presenting the findings from the analysis of participants' accounts.[62]   Chapters are divided on the lines of the group that the participants belong to, and on the thematic layer or level of analysis.

Chapters 5 and 6 are constructed in terms of narratives of medical practitioners interviewed, organized on the basis of Level 1 themes and emergent themes.   Chapter 7 outlines the putative roles (the written constitutions) of different groups[63] (hence addressing the focus of research question 2)[64], and then traces accounts of participants representing each of the other groups.   In these three chapters, quotations are liberally used in the presentation of the respondents' accounts, especially those of medical practitioners (Roe 1994, Yanow 2000).   Verbatim narratives, as were obtained by recording and faithfully transcribing the interviews, are useful in interpretive analysis because they convey first hand, actors' words and phrases in the interpretation of policies and processes.   These three chapters (5, 6 and 7) are focused largely on the "how" and "what" aspects of the research questions, particularly questions 1, 3 and 4; "How do medical practitioners in hospitals in India respond to national policies", "What are the different policy actors' roles in implementing HIV testing policies?" and "How do practitioners and different policy actors interact with each other?".   *Ranges and natures of phenomena* (actors' experiences of their participation in implementation, and their interactions) are presented, the aim being to describe

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[61] Examples of interpretations defined by Ritchie and Spencer include: identifying concepts as defined by respondents, mapping the range and nature of phenomena, creating typologies, finding associations, providing explanations and developing strategies (Ritchie and Spencer 1994).
[62] Serial numbers of respective respondents (in parentheses) are attached to their quotations and in instances where they are cited in the text.   *Annexure 1 contains a full serialised listing of respondents with dates and venues of interviews, for reference.*
[63] Drawing on data from the contents of policy documents
[64] Research questions in Chapter 4 (page 65)

and illustrate the "living" processes of implementation, from the perspectives of the actors themselves (Hjern and Hull 1982).

Chapter 8 synthesizes the analytical themes, and the resultant discussions are structured on the lines of the subcategories of analytical themes (see Table 4.3). In this chapter the emphasis is on "why" questions – *demonstrating associations* and *providing explanations* for the behaviour of different groups, and for the nature of communicative processes. The *development of strategies* toward the convergence of policies and practices (corresponding to research question 5) are discussed in Chapter 9.

4.5   QUALITY, LIMITATIONS AND ETHICAL CONSIDERATIONS

Credibility, system and fair dealing

In the constructivist approach, according to Fischer, it is presumed that the world is constituted of multiple realities of different actors, and hence "validity" in the sense of an objective assessment of the truth, is not of paramount relevance. Instead, *credibility* or trustworthiness, defined as "the compatibility of the constructed realities that exist in the minds of respondents, with those that are attributed to them" may be a more relevant standard (Fischer 2003 p.154). Such credibility can be assessed by determining whether the descriptions developed through the research inquiry "ring true". According to Erlandson et al., a credible inquiry is "...typically imprecise in defining boundaries and specific relationships... but rich in providing depth of meaning and richness of understanding" (Erlandson et al. 1993 p.30). It is desirable for this assessment to be made by individuals from the setting where the research was conducted. I presented preliminary hypotheses and findings to key informants, and to study participants in the course of collecting data, for their opinions on the credibility of the accounts. Adjustments to the lines of interpretation were made iteratively in the course of the study, based on their feedback.

Reflexivity is sensitivity to of the role of the researcher and the research process in influencing the way the data is collected or interpreted (Mays and Pope 2000). Previous sections contain details about my role in the research process, and my personal antecedents and motivations in undertaking the research. Annexure 1 contains a full timeline of the interviews as they were undertaken.

The framework approach for analysis allows the investigator to explicitly demonstrate that the research process was *systematic* (Ritchie and Spencer 1994), which is an important criterion for assuring reliability (Mays and Pope 2000). The stepwise process of developing a thematic framework, applying it and interpreting the results has been presented in previous sections. In that the entire study, including data collection and analysis, was undertaken by a single researcher, a high degree of uniformity and internal validity in the collection and interpretation of the research can be assumed.

"Fair dealing" is the process of ensuring that the views of particular groups are not presented as the sole truth about a situation (Dingwall 1992). The inclusive nature of the research design and the range of actors who are interviewed ensure that a multiplicity of perspectives is represented, even as the views of particular actors, specifically medical practitioners, are represented more than others.

Limitations of the methodology

The study adopts a lens of looking at policy processes through the perspectives of individual actors. The research is substantively based on individual accounts, and objective criteria such as the transfer of funds and management structures are not examined independently but are of relevance only as contexts for the narratives of the participants. This focus could be said to be biased towards seeking *micro-level and individualized explanations*, and relatively neglecting broader structural factors and contexts.

Organizations have complex and multiple roles in the larger policy environment, and often may not fit perfectly within the delineation of groups that has been used. It is also recognized that these individuals *may not be "perfect" representatives* of their respective organizations, although efforts were made to select respondents who had positions of authority, and significant experience and knowledge of organizational objectives and functions. Furthermore, participants often had affiliations to more than one organizational entity – for example the HIV/AIDS programme and the hospital they work in – and were subject to the logics and rationales of these different affiliations.[65] These themes are addressed in depth as part of the analysis, particularly in Chapter 8 (8.1.2).

Medical professionals formed the main core of the study, and it is likely that the themes around *other actors' perspectives are not equally well developed* and supported. Also, the perspectives

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[65] See related discussion on page 56

of patients are not explored. Patients and PLHA rights groups are represented among the civil society organizations however, and their perspectives may be seen to have some reflection in those of patients.

Whereas *urban hospitals,* the focus of this study, are a very important context for health service delivery in India, there are other segments of the health sector which may have different dynamics of policy-action relationships. There are also considerable *regional differences* in India, culturally and in terms of the HIV epidemiology. These regional differences are not explored, primarily because the geographical reasons where hospitals are located are not identified, for purposes of confidentiality of respondents. Crucially the north-east region of India, where there is high HIV prevalence in some states, and the characteristics of the HIV epidemic are distinct from other areas, is not represented.

The process of organizing and analyzing the data, including developing and applying the thematic framework reflect a more *messy and uncertain* reality than is apparent in the preceding sections of this chapter. Analysis did not proceed in a straightforward and time-bound fashion, and modifications and adaptations were made in the thematic framework, based on fresh insight and information gained in the process of the research. Incorporating this "messiness" in the write-up would, however, have entailed losing clarity in describing what are complex processes in any case.

Ethics review

Local institutional ethics review was conducted with the help of the collaborating institution, the Sexual Health Resource Centre, New Delhi. A panel of local experts and stakeholder representatives formed the review committee. The committee reviewed and passed the research proposal. The LSHTM ethics review committee also deliberated on and passed the proposal. The official form of clearance from the LSHTM, and the text of the email from the local committee are attached in Annexure 6.

Interviews were conducted and (in some instances) recorded following verbal consent. A standardized information sheet (approved by local and LSHTM ethics review committees) were presented to respondents before obtaining verbal consent. The information sheet is attached in the Annexure 5. Respondents were specifically advised to inform the interviewer if they wished any part of their exchanges not to be quoted.

In keeping with LSHTM committee recommendations, considerable care had to be taken to mask details of certain characteristics or affiliations of individuals and institutions which may have allowed them to be identified. Instances of these precautions have been footnoted throughout the text of the thesis. On occasion, these measures may have detracted from the quality of the inferences that could be made about a particular actors' role or relationship with other actors.

Transcripts of interviews and recordings were accessible only to me. The anonymity of respondents and institutions was protected by not revealing the names of individuals, hospitals, and cities. In some instances when organizations are cited by name, it was with the prior approval of the respondent. In quoting individuals, it was ensured that there could never be less than five people who matched a particular identifier (e.g. "senior scientist in a national research institute" or "junior surgeon in a government hospital"). Prior approval was obtained from respondents about the personal and institutional identifiers to be used while quoting them.

Chapter 5. Medical Practitioners' Accounts: Implementing Policy Guidelines

This chapter is based on the accounts of medical practitioners from the nine hospitals in the study, around their actions in advising HIV tests to clients and patients, focused specifically on implementing NACO's policies for HIV testing. Data from key informant interviews was also used to provide contextual information. In keeping with recommendations of the LSHTM ethics committee, care has been taken to exclude details about interviewees which may have allowed them to be identified.

5.1 HOSPITAL SETTINGS

General facilities and admission procedures at the hospitals

The four government hospitals, two charitable hospitals and one private hospital are all multi-speciality multi-department institutions, with outpatient departments (OPD), emergency services and ante-natal care (ANC) departments. The two private nursing homes saw outpatients and also admitted some patients for indoor care. One of the nursing homes also had a surgical department with operating theatres and post-operative facilities.

In the government and charitable hospitals, newly arriving out-patients were required to queue at a registration counter where they received OPD cards, and were directed to the appropriate department, where they then awaited their turn to meet a doctor. Following consultation and assessment, patients were either treated on an out-patient basis or admitted to in-patient wards. Returning outpatients were required to produce their OPD cards, upon which they were admitted directly to the appropriate departmental waiting rooms. Ante-natal clinics were run in a similar fashion to the OPDs. The emergency ward in the Government Hospital and Charitable Hospital was typically fronted by a casualty desk where patients were screened and directed to the appropriate emergency room – medical, surgical, orthopaedic etc.

The private hospital and the two private nursing homes were all fronted by a reception, which issued appointments to clients to meet the consultants, based on their consulting hours.

HIV related facilities and programmes

Doctors in all the hospitals were actively diagnosing and treating HIV positive patients, for HIV related illnesses as well as for unrelated illnesses and health needs. All four government hospitals and one of the charitable hospitals ran Voluntary Counselling and Testing Centres (VCTC), staffed by counsellors. The private hospital had HIV counsellors on staff. All four government hospitals, both charitable hospitals and the private hospital had diagnostic science departments with laboratories with the facilities to conduct HIV tests by the ELISA method. The two private nursing homes did not have laboratory facilities in-house to diagnose HIV. All the government hospitals had free or subsidised anti-retroviral therapy (ART) programmes, with the drugs being prescribed and dispensed at the respective hospitals. One charitable hospital had facilities to arrange low cost ART for poor patients. Three of the four Government hospitals and one Charitable hospital also had operational Prevention of Parent to Child Transmission (PPTCT) programmes, with counsellors, either instituted as regular programmes or running on a pilot basis.

	Outpatient / Inpatient	HIV Treatment and Care	HIV Testing Lab In-House	VCTC / Counsellor
Government Hospital 1	Both	Yes	Yes	VCTC
Government Hospital 2	Both	Yes	Yes	VCTC
Government Hospital 3	Both	Yes	Yes	VCTC
Government Hospital 4	Both	Yes	Yes	VCTC
Charitable Hospital 1	Both	Yes	Yes	VCTC
Charitable Hospital 2	Both	Yes	Yes	No
Private hospital 1	Both	Yes	Yes	Counsellor
Private nursing home 1	Both	Yes	No	No
Private nursing home 2	Both	Yes	No	No

Table 5.1 Services and Facilities in the Nine Hospitals[66]

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[66] Further details of facilities available are not revealed to protect confidentiality of the hospitals

Profile of clientele

All the government hospitals are general hospitals and cater to a large clientele with a variety of illnesses and health needs. The clientele come from different parts of the cities in which the hospitals are located, and also from outlying areas in the home state and neighbouring states.[67] Patients travel long distances, sometimes for days from their homes, and wait in long queues before they can be admitted to see the doctor.

> [For a patient] to get seen [by a doctor] is a big thing, because it takes time. You know, to get your [registration] paper made, and hang on
>
> Junior venereologist, government hospital (27)

The two charitable hospitals and the private hospital were also general hospitals, and similarly received a clientele from a wide geographical area across more than one state. The two nursing homes reported having a predominantly local clientele.[68] Government hospitals were either free or charged a small registration fee. A large proportion of patients accessing government hospitals are from the lower socio-economic strata[69], while a minority were reported as being from "the middle or upper middle classes".[70] According to one internist from a government hospital,[71] many of their patients were illiterate, particularly those from rural areas and women. Both charitable hospitals also provided low cost care, and received a similar clientele from the poorer and middle socio-economic classes. The private for-profit hospital and nursing homes received a relatively more affluent "middle-class to upper middle-class" clientele.[72]

5.2   SELECTIVITY IN TESTING

NACO policies require practitioners to exercise specificity in selecting patients for diagnostic testing.[73] The statement contains an implicit note of caution and opposes indiscriminate testing. The decision to go for a HIV test, in a clinical setting, and the final act of performing the HIV test

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[67] Several respondents (02, 14, 41)
[68] Respondent 67: physician, private nursing home
[69] Several respondents (14, 21, 23)
[70] Respondent 27: junior trainee venereologist, government hospital
[71] Respondent 13: senior physician and HIV specialist, government hospital
[72] Respondent 67: physician, private nursing home
[73] See Chapter 1 (1.2.1) for the wording of the NACO policy

usually involves the participation of both the practitioner and the patient. In the following section, we look at the practitioners' part in these decisions.[74]

5.2.1 Different aims of testing in a clinical setting[75]

Clinical case management

Counsellors in government hospital VCTCs reported that numbers of clients who were internally referred by hospital doctors with the aim of making a clinical diagnosis exceeded those who voluntarily accessed the VCTCs.[76] Clinical management of HIV & AIDS had steadily grown as an area of interest for clinicians, receiving a significant boost in parts of the government sector where ART is available, and increasing numbers of patients were being actively treated for HIV/AIDS and HIV related illnesses.[77]

Doctors in all the hospitals were involved in clinical management of patients with HIV/AIDS. Broadly speaking, the bulk of clinical management was shared between departments of internal medicine and venereology, while gynaecologists and obstetricians were involved mainly in diagnosing patients and referring them on to the other two departments for management. Doctors in seven of the nine hospitals were involved in prescribing HAART. In one private nursing home and one charitable hospital where ART was not widely used, patients were managed for opportunistic infections and incident illnesses.[78] In some of the bigger hospitals, government, charitable and private, ART-based care has become an established practice, and teams of physicians are involved in HIV care for in-patients and outpatients.[79]

> We are seeing many more cases, and certainly my and my unit's involvement has been because of physically looking after lots of patients and understanding the need, and feeling in some way part of it...
>
> Physician, 15 years experience, charitable hospital (65)

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[74] Since the precise criteria for specificity are not spelt out, it cannot be determined categorically whether policy is being followed or not. Practitioners' approaches to selecting clients / patients for HIV testing can however be subjectively assessed.

[75] Testing for public health surveillance or scientific research are not included since they are not traditionally aims of a routine doctor-client interaction.

[76] Respondent 42: counsellor, government hospital voluntary testing and counselling centre

[77] Respondent 30: senior physician, government hospital

[78] Respondent 36: Senior physician, charitable hospital

[79] Several respondents (13, 15, 38)

Unanimously, the physicians felt that HIV testing was a vital step and knowledge of HIV status was an essential element in clinical management of the patient.

> It helps you in making the medical diagnosis... there is a huge difference between somebody is breathless with HIV, or without HIV – the diagnosis differs greatly.
>
> Venereologist, 7 years experience, government hospital (14)

> A patient comes normally I suspect garden-variety pneumonia. In HIV there is a good chance this may be PCP.[80] I can't test for PC – you know what it's like, the microbiology department have other things to do. Unless I test for HIV, how will I know how to treat him?
>
> Senior physician, government hospital (33)

Even in contexts where medical treatment was not always available or follow up could not be ensured, respondents noted other benefits of HIV testing for the patient and the community, including counselling, partner protection and opportunities for behaviour change.[81]

> If I am not able him to give the care then at least I can refer for the better care. Even the smallest possible effort in India can help the person.
>
> Venereologist, 7 years experience, government hospital (14)

Safer maternity and prevention of transmission

Women attending Ante-natal clinics in government hospitals were routinely tested for HIV, usually following group pre-test counselling. If they were found to be HIV positive, they would generally be offered individual post-test counselling, and advice on prevention of transmission, breastfeeding, contraception. They are offered ante-natal prophylaxis in late pregnancy. They would also be referred to another department (either Medicine or Venereology) for assessment and management, including ART if they met requisite clinical criteria.[82,83]

Practitioners' self-interest

Another aim of HIV testing, and one which goes against policy recommendations is self-interest, to enable the doctor to take steps to avoid acquiring the infection from the patient. This rationale

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[80] Pneumocystis carinii pneumonia, an opportunistic infection found in PLHA but rare in non-HIV patients.
[81] Several respondents (13, 14, 17, 36)
[82] Respondent 20: Junior gynaecologist, government hospital
[83] Respondent 22: Gynaecologist, 8 years experience, government hospital

for testing is found in the common practice of pre-surgical HIV screening of patients. This topic will be discussed in greater detail in the following section on mandatory testing.[84]

5.2.2 Criteria for selecting patients for testing

The table below lists criteria commonly cited by doctors in selecting patients for HIV testing.

Major	Minor
- Tested for HIV before - HIV in spouse, parent - History of septic abortion - STIs - Recurrent Herpes - Reactive arthritis - Non-response to treatment with antibiotics	- History of high risk behaviour - Tuberculosis - Fever of unknown origin - Chronic diarrhoea - Weight loss - Cough and pneumonias - Candidiasis - Skin manifestations

Table 5.2 Criteria for Identifying Patients for HIV Testing

Tuberculosis and STIs were the most commonly cited clinical risk factors.[85,86] Many HIV positive patients who came to hospitals for treatment had already been tested for HIV elsewhere (a phenomenon which is discussed in detail in Appendix 2 of the thesis), and this would commonly be grounds enough for repeating and confirming the test result, according to one government venereologist '...if he comes (from a private practitioner) with one ELISA test – I am not going to take that as positive, I am going to repeat him for the HIV test for sure.'[87]

In government and charitable hospitals, patients were reported to come at late stages, with a spectrum of OIs found in advanced HIV infection. Testing spouses and children of HIV positive patients was seen as a way of detecting patients earlier in the progression of the disease.[88]

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[84] According to one respondent (08), private hospitals also used HIV testing as a money-making opportunity by charging excessively for tests although this was not widely supported, since the costs of HIV testing are quite low and profit margins likely to be small compared to other investigations commonly advised in the private medical sector.

[85] Respondent 27: Junior trainee venereologist, government hospital

[86] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital

[87] Respondent 14: Venereologist and HIV specialist, 7 years experience, government hospital

[88] Several respondents (13, 20, 37)

> Normally the infections which are suspected are opportunistic infections like TB, MDR TB and all those typical infection, like candidiasis. You know in India most of the patients come at a very late stage. ... most patients are stage three or four disease - they walk in late. And very often we get a very low CD4 count. The ones which are picked up earlier are the spouses. There may be children.
>
> Senior physician and HIV specialist, government hospital (37)

Physicians reported that it was often difficult to elicit histories of risk-taking, and they sometimes resorted to indirect queries around sexual history. Combinations of different risk factors were usually implicated in suspicion of HIV – see Table 5.2.[89] Most physicians in all the hospitals used either one or more suspicion criteria and exercised their individual clinical judgment in selecting candidates for testing.

In some cases, however, algorithms were used to identify patients, or patients were tested universally. In one government hospital, and a charitable hospital the doctors reported that all patients with STDs were sent for HIV tests.[90] Another government hospital doctor reported that 'scoring systems' were used to support a decision to test. These approaches were based on shared clinical experience according to the respondent.

> ...it is something that has evolved in the unit, and it is not just me. All the people in my unit think that way. Their eyes are tuned because we have been doing this for many years now. And they have seen as a reference, our seniors and consultants doing that.
>
> Venereologist, 7 years experience, government hospital (14)

In the case of ante-natal HIV testing, obstetricians in a government hospital reported that they aimed to offer counselling and testing to all pregnant women, but were sometimes unable to do so because of a shortage of counselling staff and testing kits to cope with the large numbers of ANC attendees.[91,92]

5.2.3   Growing knowledge and awareness around HIV

Compared to the present day, in the 1980s and 1990s HIV medicine was still a new and poorly understood science. In the absence of a definitive treatment for HIV, confidence and interest around HIV management was reported to be at low ebb. Discrimination and denial of treatment

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[89] Several respondents (14, 16, 24, 67)
[90] Several respondents (18, 23, 27, 28)
[91] Respondent 20: Junior gynaecologist, government hospital
[92] Respondent 21: Senior gynaecologist and head of department, government hospital

around HIV were prevalent, even in the more well appointed urban hospitals, according to some respondents.[93,94]

Acquiring skills and confidence

Doctors said that they had grown in confidence over time, thanks to greater clinical experience, training and investments by their institutions in improving and upscaling HIV care.

> We have come to a point that every senior faculty and junior teachers, residents and postgraduate students... they are all engaged in HIV and STD care. So it has become a team effort.
>
> Senior physician and HIV specialist, government hospital (13)

A key element of greater clinical confidence around HIV was the impulse to identify more patients with HIV. Making a diagnosis of HIV was felt to be an important new skill by physicians and venereologists, and widening of the 'index of suspicion' diagnose more patients with HIV was seen as a sign of scientific progress.[95] Opportunities to enhance their skills and learn about HIV were not available to all doctors however. According to respondents from the private nursing homes, in-service training courses were usually available only to government employees and opportunities for private sector doctors were limited.[96] In the large private hospital, interest in HIV care was not widespread and was limited to a few motivated consultants.[97]

Heightened awareness of personal risk

As the epidemic spread and more people were detected with HIV, doctors also acquired a heightened consciousness of the risk of acquiring HIV in a clinical encounter. According to a number of respondents this was one reason for a rise in HIV tests advised by doctors.[98] HIV testing is commonly used as a screening test before patients are admitted for treatment or invasive

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[93] Respondent 65: Physician, 15 years experience, charitable hospital
[94] Respondent 67: Physician, private nursing home
[95] Several respondents (02, 13, 14, 67)
[96] Respondent 67: Physician, private nursing home and trainee in intensive HIV educational programme
[97] Respondent 41: Venereologist, 15 years experience, private hospital
[98] Several respondents (08, 21, 23, 24, 67)

procedures (see Chapter 1). For some doctors however, awareness about HIV was equated with little more than knowledge of their own vulnerability, and the need to screen their patients.[99,100]

> [speaking of colleagues] ...some of them do not know too many things about HIV/AIDS so they are not thinking about that kind of vulnerability. ...to some extent they are using the precautions, not in the form of universal precautions, but general precautions. They are advising the tests before surgery.
>
> <div align="right">Physician, private nursing home (67)</div>

The phenomenon of mandatory screening before surgery is discussed in detail in section 5.3.

5.2.4 Zeal for clinical investigation

Once doctors acquired a certain degree of confidence around HIV management, their regular impulses of advising diagnostic tests freely tended to assert themselves. The impulse to make a diagnosis is part of a clinician's role identity, and the idea of consciously not advising a diagnostic test, or reducing the number of tests advised, was difficult to comprehend for some respondents.[101,102]

> [If we don't test] then we will not come to know where we stand! And unless and until we know where we stand, we cannot take all the measures.
>
> <div align="right">Microbiologist, 13 years experience, Private hospital (39)</div>

The enthusiasm for HIV testing however was not just driven by altruism. Doctors expressed feelings of accomplishment in diagnosing HIV[103,104] were indicative of a growing interest in the science of HIV medicine, as described before. The keenness in advising HIV tests was also described as characteristic of an inclination of doctors towards all things technological.

> Common precautions like say hand-washes between the patients, very few doctors would do it but when it comes into ordering ELISA test or a sophisticated immunological test or a high tech test for TB they would not hesitate in ordering.
>
> <div align="right">Senior physician, charitable hospital (36)</div>

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[99] Respondent 08: Senior physician, private nursing home
[100] Respondent 67: Physician, private nursing home
[101] Respondent 14: Venereologist and HIV specialist, 7 years experience, government hospital
[102] Respondent 37: Senior physician and HIV specialist, government hospital
[103] Respondent 14: Venereologist and HIV specialist, 7 years experience, government hospital
[104] Respondent 67: Physician, private nursing home

In some instance this zeal for investigation may have been excessive and exceeded the utility of the test as a tool for management, and subordinated the rights and interests of patients.

> You also still have senior persons in the faculty when they get a suspected [HIV] sero-positive, or maybe a sero-positive, and the entire interview is diverted towards it as though Sherlock Holmes is trying to find out how you got the infection!
>
> Physician and HIV specialist, government hospital (16)

5.2.5 The "HAART" effect

Doctors from the government and charitable hospitals reported a shift in their attitudes towards HIV and HIV testing, after free or low cost anti-retroviral therapy became more freely available in the government sector since 2004. In the 1980s and 1990s, ART was available in the private market but was expensive. Treatment choices for HIV/AIDS were limited in the charitable and voluntary sectors with a mainly low-income clientele. In the absence of effective low-cost treatment specifically for HIV, and what were perceived as limited opportunities to improve patients' lives, levels of motivation to manage HIV were low. In some quarters, there was a feeling that it was not essential, and even possibly damaging for some patients to advise a HIV test, given the highly stigmatized nature of the disease.

> ARV access was very poor at the time [the 1990s], it was mainly a private sector affair, and the cost of the drugs was very high.
>
> Senior physician and HIV specialist, government hospital (13)

> [The mindset was that] you are going to treat the OIs anyhow… when he gets TB you will treat him… By testing [for HIV], you were creating stigma around the disease which was worse than the disease itself. So we were going with a very conservative stance of testing. There was a reluctance [to test].
>
> Physician, 15 years experience, charitable hospital (65)

Impact of low-cost HAART on HIV testing

In recent years conservatism around HIV testing has diminished, and tests are freely prescribed in the awareness that HAART is widely available at a low cost. Doctors now tend to value the opportunity to treat the patient. This physician from a charitable hospital said he tried to communicate this optimism to his patients.

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> Earlier I was reluctant to discuss this with a patient, I would not tell a patient, I would ask for risk factors for HIV, but I would never say that OK, you do an HIV test because TB is an indication. Today I am telling patients that TB can be associated with HIV, if we can diagnose HIV then you can live longer.
>
> Physician, 15 years experience, charitable hospital (65)

In the era of HAART, doctors' notions around the untreatability of HIV have faded, and even in hospitals where HAART was not available, more HIV tests were being conducted, with a view to other benefits to the patient and community at large.[105]

5.2.6   Role ambivalence in government hospitals

Government hospitals as institutions have a dual role in fulfilling certain public health roles, and also providing curative services. Sometimes these institutional roles overlapped and conflicted, and the practitioners experienced that ambivalence.

In the early years of the HIV epidemic, the thrust of the National AIDS Control Programme was on the prevention of HIV infections, and on setting up systems for surveillance to estimate the extent of the epidemic. Government hospitals were often centrally involved in these public health activities with HIV sero-surveillance centres being set up, but, given the small number of patients with HIV infection at the time, the staff were not experienced in curative care for PLHA.[106] However, over time, growing numbers of patients with HIV related illnesses seeking care increased and hospital staff had to adapt to an additional care-providing role. One respondent reported how the nomenclature for the HIV testing centre in the hospital changed to reflect these changing roles of the hospital.

> Our testing centres changed their names from sero-surveillance centres to HIV testing centres. And one day, when I was attending a meeting everybody was talking about VCT. And I asked "*yeh kya hai*, VCT?" [what is this VCT?] and they got very annoyed with me. You have been testing for the last so many years, you don't know what is VCT? It is Voluntary Counselling and Testing. So it became VCT. Then later somebody said that, no, it is VCCT, Voluntary Confidential Counselling and Testing ... the names changed, but the thing remains the same.
>
> Senior microbiologist, government hospital (66)

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[105] Several respondents (13, 14, 36)
[106] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital

In clinical departments, practitioners continued to feel the pressure of enacting two different roles, that of the public health functionary and the clinician, both with essentially different sets of aims and goals. Sometimes, the doctors appeared to confuse the contrasting aims of public health and clinical medicine, when it came to selecting patients for HIV testing.[107]

> My argument for (routine) testing is very simple – I think we are not aware about our numbers and this would help to make us aware of numbers.
>
> Senior gynaecologist, government hospital (21)

In the confusion around which role to adopt, doctors tended to opt for an indiscriminate approach aimed at detecting more patients, than a more specific approach as recommended by national policies.[108,109]

5.2.7 Selectivity in testing: summary

HIV tests are advised freely and prolifically across all sectors, not always in fulfilment of the criteria laid down in the national policies. Broadly, doctors' reasons for testing more patients predominated over reasons for selecting fewer clients for testing (see Figure 5.1and Figure 5.2).

The NACO policy requires doctors to consider the question of the usefulness of conducting the test for the community and for the patient and whether there is a continued source of support (see page 16). In spite of the increased availability of HAART, these messages may still be important in the context of deficits in health systems' capacity for providing uninterrupted treatment (Grover 2006, Sheikh 2004). However the consideration of withholding the test appeared to be largely inimical to doctors' sense of identity and purpose, and to their conception of learning and skill development.

Amid the upsurge in HIV testing, the policy may have a partial role in deterring indiscriminate testing, in the public and voluntary hospitals, through the medium of internal checks and controls instituted for ensuring counselling and consent. However, even when official procedures prevented government surgeons from performing "mandatory tests", they frequently bypassed the procedures by referring their patients to private diagnostic laboratories for testing.

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[107] Several respondents (19, 21, 23)
[108] Respondent 22: Gynaecologist, 8 years experience, government hospital
[109] Respondent 23: Venereologist, 10 years experience, government hospital
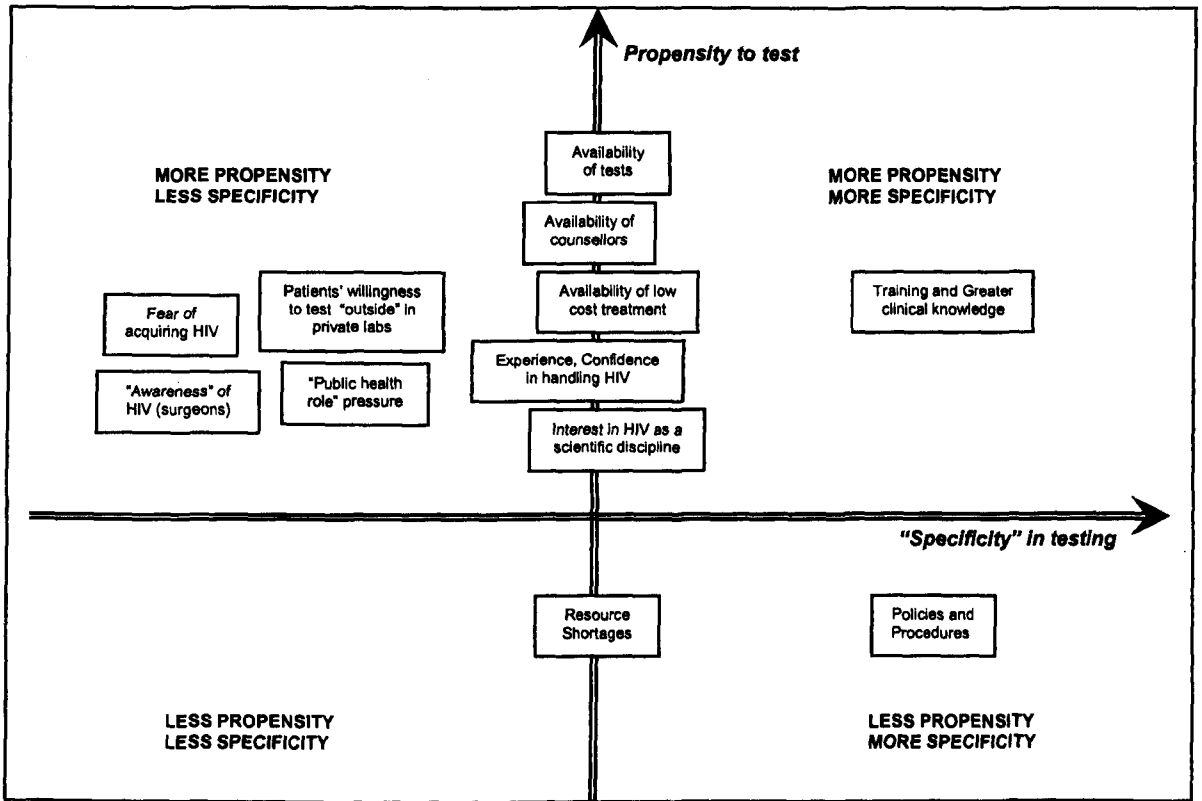
Figure 5.1 Factors Influencing Selectivity in HIV Testing (Government and Charitable Hospital Practitioners)
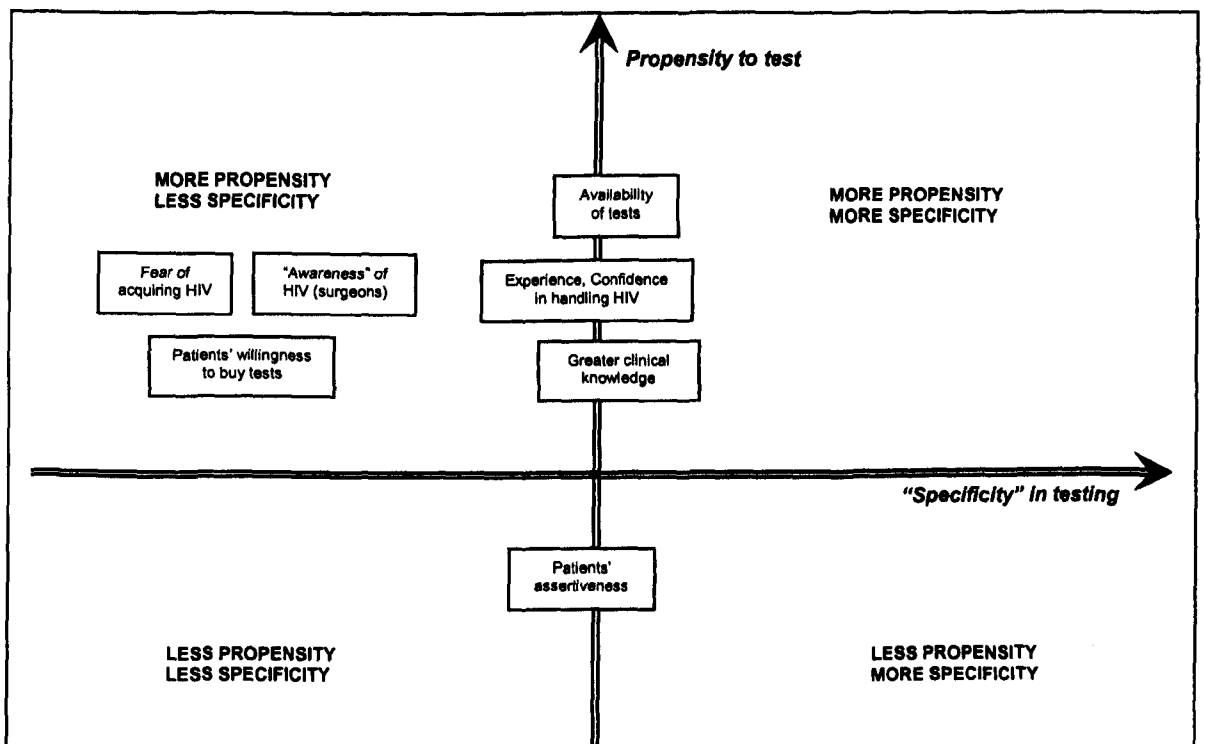
Figure 5.2 Factors Influencing Selectivity in HIV Testing (Private Hospital Practitioners)

5.3   PRE-SURGICAL (MANDATORY) HIV TESTING

This section details doctors' perspectives on the widespread practice of requisition of HIV tests before undertaking surgery on patients, the most conspicuous form of mandatory testing in health care settings.[110]

While the national HIV testing policy prohibits the practice of mandatory testing,[111] there are however different possible interpretations of what constitutes mandatory testing. Literally, the word mandatory is defined as "obligatory" or "compulsory"[112], and semantically speaking, it means no more than that the test is compulsory for the client or patient. However its connotations and associations in real-life settings extend beyond the literal meaning of the word. The national policy itself describes it as testing without 'explicit' consent of the patients (NACO 2005). Frequently also, there is an implication that undergoing the test is a precondition, either for accessing a service or undergoing some procedure. Key features of mandatory testing in health care settings are listed in Box 5.1.

- Non-voluntary, often coercive or under coercive circumstances
- Often indiscriminate, in that there may be no indication for suspicion of HIV in the person being tested
- Often a *condition* to determine subsequent availability, quality or type of care

Box 5.1 Characteristics of Mandatory Testing in Healthcare Settings

Among the community of medical practitioners under study, the term "mandatory testing" was generally synonymous with pre-surgical HIV screening. The terms "mandatory testing" and "pre-surgical screening" for HIV are used interchangeably in the text. Pre-surgical HIV testing is often conducted as a condition for surgery to take place, and the main purpose of conducting the test is not to initiate treatment or to advise the patient, but to provide reassurance of knowledge of the patients HIV status to the surgeons.

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[110] The term "mandatory testing" has wider connotations extending to pre-employment and pre-marital HIV testing, testing of immigrants, and mass testing to detect HIV in specific populations. In clinical facilities (the setting for this study) the term was invoked mainly in the context of (i) screening patients as a condition for admission to a facility or a reason for expulsion (ii) screening patients before surgery and invasive procedures.

[111] See Chapter 1 (1.2.4) for the wording of the NACO policy

[112] Dictionary.com Unabridged (v 1.1). Retrieved October 24, 2008, from Dictionary.com website: http://dictionary.reference.com/browse/mandatory

5.3.1   Process of pre-surgical screening

Basis for selection of patients

As discussed in the previous section, selection of patients for pre-surgical screening was often unmethodical or indiscriminate, given that surgeons are rarely interested in or well informed about HIV and its related risk factors.[113,114] Decisions to test were often made ad hoc by a surgical team or individual surgeons.[115,116] Personal prejudices of surgeons may have played a part: 'in surgeries, mandatory testing is very biased... you look at a guy and feel that something is wrong, you test him', said a government physician.[117] Selection of patients for pre-surgical testing in private and government hospitals was often a discretionary decision of individual doctors, and in government hospitals it was marked by secrecy.[118,119] In private nursing homes, specificities of the doctor-patient relationship were likely to influence pre-surgical screening. A physician from a private nursing home observed, 'the patient can ask "why are you doing this test?"... but if the doctor has 15 or 20 years experience, whatever he or she is writing, the patient is accepting'.[120]

In other instances, there was a more organized basis for mandatory testing. In one charitable hospital, universal pre-surgical HIV screening was endorsed by hospital policies (contrary to national policy guidelines) and practiced before all major surgeries. In the private hospital too, universal pre-surgical testing was (unofficial) hospital policy. In government hospitals where mandatory testing was not permitted officially, some heads of surgical units took it upon themselves to sanction the use of pre-surgical HIV screening in their units.[121]

Performing the test

In the *charitable* hospital and *private* hospital where pre-surgical screening was normal, these tests were performed in-house in the hospitals' respective departments of diagnostics.

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[113] Respondent 16: Physician and HIV specialist, government hospital
[114] Respondent 67: Physician, private nursing home
[115] Respondent 29: Senior surgeon, government hospital
[116] Respondent 32: Junior surgeon, government hospital
[117] Respondent 37: Senior physician and administrator, government hospital
[118] Respondent 19: Gynaecologist, 15 years of experience, government hospital
[119] Respondent 24: Senior microbiologist, government hospital
[120] Respondent 67: Physician, private nursing home and trainee in intensive HIV educational programme
[121] Respondent 31: Senior surgeon, government hospital

Reportedly, patients were informed that they were to be tested, but pre-test counselling was not provided.[122,123]

In *government hospitals*, the introduction of compulsory procedures such as the use of consent forms reportedly acted as a partial check on unofficial practices of pre-surgical testing: 'you have to take consent, it is a big *jhanjhat* [hassle]' said a junior venereologist.[124] In an attempt to sidestep consent procedures, clinicians in government hospitals sometimes pressured their colleagues in the diagnostic departments to conduct the tests unofficially without taking consent and undergoing due procedures for a HIV test.[125] In these instances, 'people are not sent for testing, samples are sent', reported a public health specialist.[126] Hospital microbiologists sometimes bent the rules to accommodate HIV testing of pre-surgical patients by their surgeon colleagues.

> Every patient from [a particular surgical department] used to come along with a requisition for HIV test. I thought - they don't need this. But they [the patients] would say "the doctors are saying that if there is no test, there will be no operation"... [The head of a surgical department] is my classmate from college. So I thought of a way. [I told him] ...don't record HIV test in the requisition. Just give me a call, and I will do the test, and you can do your operation. I am guilty of doing this process for many years.[127]
>
> Senior microbiologist, government hospital (66)

In other instances, doctors referred their patients to private diagnostic laboratories located near the hospitals, for testing (see Appendix 2, page 322 for a description of this common practice of 'outside testing'), whereupon patients would be expected to return with the test results. In either case patients were not asked to consent to the test. Sometimes patients may have been told that undergoing the test was obligatory before surgery, even if it was not made clear if a HIV negative test result was required for surgery to continue.

> We don't tell them what we are testing. We say get these four tests done. Haemoglobin, blood sugar, blood urea and this... [HIV]
>
> Senior surgeon, government hospital (31)

In the case of *private nursing homes*, patients were sent to private diagnostic labs *to be tested*, which, generally speaking, did not have facilities for counselling.

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[122] Respondent 17: Physician and administrator, charitable hospital
[123] Respondent 34: Senior surgeon, private hospital
[124] Respondent 27: Junior venereologist, government hospital.
[125] See Appendix 2 (A2.2) for a description of recommended procedures around a HIV test.
[126] Respondent 48: Public health specialist, consultant to UN technical agency
[127] Several particulars, including name of hospital, department and precise designations are withheld to prevent identification

Outcome of a HIV positive test on surgery

What happened after a test varied greatly in different circumstances. Reportedly, pre-surgical screening resulted, at worst, in HIV positive patients being denied care or otherwise discriminated as a result of their HIV status, or at best, in surgeons' simply adopting greater safety precautions while operating on a HIV positive patient, without actively compromising on the type or quality of the intervention.

Often, in cases where the decision to test was secretive or discretionary, further action was also determined by individual discretion. In some instances, there was flat-out refusal, and in other instances reluctance or poor preparedness on the part of surgeons to operate. 'In the middle of the night there is less chance of operating if the patient is HIV positive. They will be hesitant and more likely to put them on conservative management', reported an HIV specialist.[128] There was also reported resistance on the part of other surgical staff to participate in surgery on known HIV positive patients. By other accounts surgeons *were* reported to be operating on PLHA, but with the use of greater personal protection and precautions.[129]

In the charitable hospital which officially permitted pre-surgical screening, there was also an accompanying provision that all those diagnosed with HIV would be operated on, or cared for. 'The policy is that there will not be discrimination on the basis of positive or negative or indeterminate test...' said a charitable hospital administrator.[130] Respondents from the private hospital reported that surgery on HIV positive patients was common, and that doctors took additional precautions to protect themselves from infection.[131,132]

5.3.2   Risk and self-protection

Notions of risk

Most surgeons had a heightened awareness of the risks of acquiring HIV from an infected patient in surgery. The perils of conducting surgery on HIV positive patients and the likelihood of being injured by infected surgical instruments were highlighted by a number of respondents, as also

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[128] Respondent 16: Physician and HIV specialist, government hospital
[129] Several respondents (20, 21, 32, 66)
[130] Respondent 17: Physician and administrator, charitable hospital
[131] Respondent 35: Physician, 12 years experience, private hospital
[132] Respondent 40: Counsellor, private hospital

were the dangers for supporting staff. Needle-stick injuries were reported to be very frequent in government hospitals.

> Sometimes, you will find that the tissue is not holding, we will press a finger on to it, here it is bleeding immediately, we will stop it with a finger and put a needle in the same place...
>
> Senior surgeon, government hospital (31)

> [Sometimes] a staff nurse gets an injury today, and ART is started tomorrow. In between, again she gets an injury... In our hospital setup, it is quite common.
>
> Infection control officer, government hospital (68)

According to this officer, the incidence of occupational "needle-stick" injuries was very high, and a recent study had reported extremely high prevalence of hepatitis B infection among surgeons in the hospital, (which is more easily transmissible than HIV). The fear of acquiring HIV is considerable among surgeons, and emotionally charged, even as official figures of occupational transmission belie the notion of great risk.[133],[134]

> It is more of a psychosocial issue, it is not a scientific issue for the surgeons... that [the risk of acquiring HIV from a] needle-stick injury is 0.1% really doesn't mean anything. The point is that I can be that "0.1% guy". If it is me, then it is 100% for me.
>
> Physician and HIV specialist, government hospital (16)

> Save ourselves! The patient comes later... There is a saying in Hindi *"bhookhe pet na hoye bhajan gopala"* [I can't express my devotion to God, with an empty stomach].[135] If we are hungry, if we are sick, if we are down, then how we will serve?
>
> Senior surgeon, government hospital (31)

Fear appeared to have a far-reaching impact on the psyche of surgeons, and led them to focus on risk avoidance and self protection. Ways of doing this included conducting pre-surgical mandatory tests and/or taking greater precautions during surgery. In some instances however, the fear of HIV even led surgeons to delay surgery or refuse to operate on HIV positive patients. An administrator expressed consternation over this rejection by surgeons of their primary professional role: 'he is a surgeon, he wants to operate, he has come to the hospital to operate, so why is he refusing?'.[136]

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[133] Respondent 26: Senior surgeon and administrator, private hospital
[134] Respondent 67: Physician, private nursing home
[135] The metaphor is of a bard who sings devotional songs (*bhajans*).
[136] Respondent 37: Senior physician and administrator, government hospital

In the case of one charitable and one private hospital, it was pressure from surgeons that had led to the creation of hospital policies endorsing pre-surgical screening. In one of these instances, reports of a health worker being infected with HIV from a patient precipitated a concerted push for protection of practitioners' rights. The "package" of interventions and provisions for practitioners that was introduced in these two hospitals included mandatory pre-surgical HIV screening, universal precautions in surgery, assurance of post-exposure prophylaxis, and treatment with HAART in case of infection.[137,138]

Awareness equals fear

For surgeons, the relationship between knowledge about HIV/AIDS and their response to it was a complex one. Surgeons had little scientific interest in HIV and were not generally motivated to learn about developments in HIV medicine. Their standards of knowledge about all aspects of HIV/AIDS were variable, and when awareness about HIV did manifest, it was synonymous with awareness of the risk of acquiring HIV from patients.

HIV and the fear of HIV, was not necessarily a prominent theme in surgeons' professional lives. The response to HIV among surgeons in some hospitals, especially in areas which were known to have low HIV prevalence, was limited. HIV did not feature in these surgeons' compass of attention.[139] For some, anxieties around HIV were present but latent and not acted upon. Reportedly government surgeons may have regularly operated on HIV positive patients without knowing or ascertaining their status beforehand.[140]

In this context of initial inattention to the likelihood of HIV, reactions were extreme whenever the status of a HIV positive patient was somehow made known to the surgeons or operation theatre staff. Surgeons' anxieties and lack of preparedness surfaced when met with referrals from a physician known to be dealing with HIV positive patients. Surgeries were delayed or denied to patients, or clients were refused admission to nursing homes and hospitals, reported the physician.

> ... the surgeons generally operate on individuals without bothering about the HIV status. But once they come to know that this individual is HIV positive, suppose they get a referral from me, then the story begins.
>
> Senior physician and HIV specialist, government hospital (13)

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[137] Respondent 17: Physician and administrator, charitable hospital
[138] Respondent 25: Senior surgeon, private hospital
[139] Respondent 67: Physician, private nursing home
[140] Respondent 29: Senior surgeon, government hospital

In other hospitals however, a greater consciousness had evolved among the surgeons about the presence of HIV and the risks to themselves.

> We have been seeing the cases of HIV for very long … They would come to us and whether we found them HIV positive or not, we would treat them. But then awareness came... and we wanted to take precautions.
>
> Medical superintendent, private hospital (38)

According to respondents, in parts of the private sector the response of doctors has shifted from a general disinterest to a more HIV-cognizant attitude accompanied by rhetoric around being aware and "taking precautions". Mandatory testing was one of the "precautions" which were taken, the others being the use of protective equipment and specific procedures while performing surgery and handling the patient.[141],[142]

The use of routinized pre-surgical testing in the private sector (followed by the use of greater protective precautions for HIV positive patients) was seen by some as a manifestation of a greater awareness and acknowledgement of HIV, an improvement on the previous state of affairs, of denial and active exclusion of HIV positive patients.[143],[144] For some it signified a greater preparedness, necessary for the establishment of a comfort level on the part of practitioners to deal with HIV. In its most benign form, pre-surgical testing was accompanied by policies requiring surgeons to undertake surgery on HIV positive patients irrespective of the outcome of the test (see section 5.3.1). In other instances however, mandatory testing may have still been used as an instrument to discriminate against HIV positive patients and deny them care.

In some government hospitals too, "awareness" had spread and most government surgeons stated that they would prefer to know the HIV status of their patients. However the government's policies carry more weight in government hospitals[145], and pre-surgical testing remained a secretive, if widespread, practice in these hospitals.

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[141] Respondent 67: Physician, private nursing home
[142] Perceptions about "Universal Precautions" are discussed in the following section
[143] Respondent 37: Senior physician and administrator, government hospital
[144] Respondent 67: Physician, private nursing home
[145] Officially, government surgeons are required to accept HIV positive patients, not to screen patient before surgery and to treat every surgery as potentially being on a HIV positive patient, by adopting universal precautions.

Understanding "universal precautions"

The question, "Why don't practitioners use standard precautions for all surgeries, and thus offset their need to know the HIV status of the patient?" has many answers, related varyingly to the availability and costs of protective equipment, practitioners' lack of trust in the equipment when available, and uncertainty around what constitutes standard or universal precautions (UP).

Government surgeons said that they were asked to use universal precautions, but that this was not always feasible, when protective equipment was not available. They unanimously held the opinion that arrangements for equipment were inadequate, and cited this as a explanation for choosing to screen their patients to eliminate HIV infection.[146,147] Contrarily however, the occupational health administrator in the same government hospital reported that there was actually an adequate supply of protective equipment, and cited attitudinal problems among surgeons in accessing these facilities.[148] It was apparent that surgeons' and administrators' ideas of equipment to be used in surgery on HIV positive (or potentially HIV positive) patients did not match. Surgeons' expectations of adequate precautions extended to more sophisticated and expensive protective equipment than proposed by government policies.[149] Their focus of attention generally tended to be on the equipment involved ('visors', 'gumboots', 'special gowns') rather than on safer procedures and practices.[150,151]

Given their heightened expectations – focused around expensive equipment – of what constituted adequate precautions, surgeons paradoxically felt that the expense of procuring them was not justified in resource-strapped government hospitals with lower-income clientele.

> We are not averse to treating these [HIV positive] people, whether conservatively or surgically. But the thing is - are we in a position to justify that we get what we deserve... in terms of precautions and barriers etc.
>
> Senior surgeon, government hospital (29)

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[146] Respondent 31: Senior surgeon, government hospital
[147] Respondent 32: Junior surgeon, government hospital
[148] Respondent 68: Infection control officer, government hospital
[149] Government guidelines for prevention and care of occupational exposure include a list of universal work precautions and algorithms for post-exposure prophylaxis. The work precautions include instructions on hand-washing, disposal of sharps and body substances, reporting of injuries and the use of protective gear including gloves for low-risk exposures and additionally gowns, aprons, masks and eyewear for medium to high risk exposures including surgical procedures and vaginal delivery.
[150] Respondent 29: Senior surgeon, government hospital
[151] Respondent 32: Junior surgeon, government hospital

> Universal precaution will be a good thing, and we eventually have to follow it, but... where you don't even have proper medicines, are you going to take the investment of universal precautions?
>
> Senior surgeon, government hospital (31)

In this context, mandatory pre-surgical screening was seen by government surgeons as a virtue, as a low-cost alternative to procuring expensive protective equipment. On the other hand, in the private sector, protective equipment was usually purchased at the expense of the patients. Respondents from the private nursing homes indicated that patients' inability or unwillingness to pay for expensive equipment was a prohibiting factor that prevented the use of UP: 'in the private sector, we have to think about cost to the patient' said one respondent.[152] Again here, mandatory testing (also at patients' expense) was seen to be a cheaper alternative. In the private hospital, the practice of mandatory screening was supported by the argument that greater precautions were taken only when patients were HIV positive, thus keeping costs down for a majority of patients.[153]

According to a HIV specialist in a government hospital, surgeons were misled in the belief that highly sophisticated equipment was required to practice universal precautions. He blamed a general 'mindset of deprivation' as the reason for surgeons' stubbornness over this issue.

> Universal Precautions sounds very hi-fi [sophisticated] like its only applicable for a New York hospital, but if you go through the details, you can apply it in any district hospital of India... We don't feel we are big resourceful people working in a huge medical college... we feel we are a deprived lot – "we don't have this and we don't have that, so how will I work?"
>
> Physician and HIV specialist, government hospital (16)

It was also widely reported that surgeons were poorly informed about Universal Precautions and unwilling to change their habitual practices.[154,155] An underlying disinterest in low-tech interventions and inertia around changing simple practices was typified by surgeons' behaviour in this regard.[156] An administrator reported that even after needle-stick injuries, practitioners were reluctant to be tested and access post-exposure prophylaxis. Taking precautions against risk was seen by them as an unwanted chore and even as an active distraction from clinical tasks.[157]

The core theme that emerges is that doctors are uncertain and under-confident about what precautions they have to take to protect themselves. It was felt that training and exposure to

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[152] Respondent 67: Physician, private nursing home
[153] Respondent 26: Senior surgeon and administrator, private hospital
[154] Respondent 16: Physician and HIV specialist, government hospital
[155] Respondent 67: Physician, private nursing home
[156] Respondent 36: Senior physician, charitable hospital
[157] Respondent 68: Infection control officer, government hospital

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issues around HIV, and above all demonstration of UP by peers was required in order to instil confidence.[158]

5.3.3   Pre-surgical testing and professional values

The practice of mandatory screening was often defended by respondents. Usually this extended simply to "justification" of the practice – as a concession to surgeons to alleviate their anxieties, and as a low-cost and convenient alternative to uniformly using special protective gear in surgery. However, further exploration revealed that some practitioners held values which led them to regard mandatory pre-surgical screening as a positively meritable or desirable practice.

Often pre-surgical screening was characterized as a "policy", whereas government policies were simply "recommendations".[159] HIV screening was regarded as a valid option, and even as a good habit for surgeons to adopt. Government doctors envied their counterparts in the private sector who did not face procedural constraints (such as informed consent) placed on them by their hospitals, and had relatively greater freedom to screen their patients.[160]

Pre-surgical testing was often conflated with the use of other precautions for hygiene and safety and its practice was seen as a sign of thoroughness and professionalism.[161] In one private hospital, it was included as part of an in-service training curriculum for doctors:

> Now we are not doing [HIV screening] routinely for all pre-operative patients... but I think that we should do it. I am interested and I tell my residents to do the HIV test. One thing [benefit] is that we will be more careful with these patients. Also, we can prevent hospital infections – like we know that this is a positive patient so [it helps in] the disposal of waste.
>
> Gynaecologist, 8 years experience, government hospital (22)

> This was a part of high-risk virus training for Hepatitis B, C and HIV. Any patient who is going to the OT, they are screened for these things irrespective of suspicion.
>
> Physician, 12 years experience, private hospital (35)

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[158] Respondent 29: Senior surgeon, government hospital
[159] Respondent 19: Gynaecologist, 15 years of experience, government hospital
[160] Respondent 32: Junior surgeon, government hospital
[161] According to one HIV specialist, doctors' conception of precautions being for the purpose of self-protection was a distortion of the original professional ethic, which required precautions to be taken primarily to avoid the spread of infection from one patient to another (via the surgeon), and only secondarily to protect the surgeon from infection (08).

In other instances, arguments around the rights of practitioners and professional solidarity were invoked to support the practice of mandatory screening.[162]

> It was felt by the profession that the doctors have every right to be protected as well. Otherwise, who will protect us?
>
> Senior surgeon, private hospital (34)

While respondents generally agreed that the screening was primarily conducted for the benefit of the practitioners, some insisted that there could be only advantages for patients and for public health in pre-surgical HIV screening. Respondents cited the absence of contestation by patients, and argued that screening was a valid approach to detect the disease, an opportunity for patients to enter into the ambit of medical care, and a step in preventing further spread of the infection. In the eyes of some, a diagnostic procedure such as HIV testing was innately beneficent and they could not comprehend the idea that such a procedure could potentially contain hazards rather than benefits for patients.[163]

Hence in summary, some perceived professional values (or distortions of the same) conflicted with the HIV testing policies.

5.3.4   Primacy of the surgical act

A generalized finding around mandatory screening is that surgeons were primarily focused on the task of performing surgery, and rarely prepared to deal with the eventuality of a patients being HIV positive and the exigencies of HIV care. Surgeons perceived their work to be of a particularly critical and demanding nature, justifying unique requirements and close-to-ideal working conditions.

> Surgery is a different field... This is not a physician's group, that are hands-off. They will be happy with universal precautions. For us, who are playing in pools of urine, pool of faeces, pool of blood, inside the body cavities of the patient, our situation is different... This microbiology doctor and the surgeon, is there no difference? Administrators, all these people: different pedestal; and surgeons who are actively handling: different pedestal. Their requirement is different.
>
> Senior surgeon, government hospital (31)

Mandatory testing for some was one of many necessary steps in preparing for the surgery, and regulations preventing mandatory testing were regarded by surgeons as obstacles in the way of

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[162] Several respondents (17, 34, 26)
[163] Several respondents (24, 29, 40)

performing their defining role. According to surgeons, patients usually shared this approach of focusing on the surgery, and were not concerned with what were perceived as the niceties of consent and counselling for a HIV test (see section 5.3.6)

> The patient is only interested in their own illness. They are sick patients, and it's difficult for them to go to the VCTC, which is full of patients. To go and to get a time [appointment], for them it's a waste of time. They say, our main aim is surgery, not HIV testing. [In terms of] the testing, whatever you require, we will do.
>
> Junior surgeon, government hospital (32)

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1. *Pre-surgical testing is done to facilitate the successful completion of surgery.* In the surgical departments, the energies of those involved were ostensibly wholly directed towards the act of surgery. In such a context, pre-surgical HIV testing in these settings was one of many "supporting" investigations conducted in order for surgery to proceed.

2. *Pre-surgical testing is usually done to eliminate, not diagnose HIV.* The normal sequence of events was for a HIV negative diagnosis to be established so as to proceed with surgery. The eventuality of a HIV positive test result is a deviation from this norm for which surgeons are not always well prepared (dashed lines in the figure). Surgeons had little interest in the science of HIV medicine, and a diagnosis of HIV would not normally influence the type of surgical management.
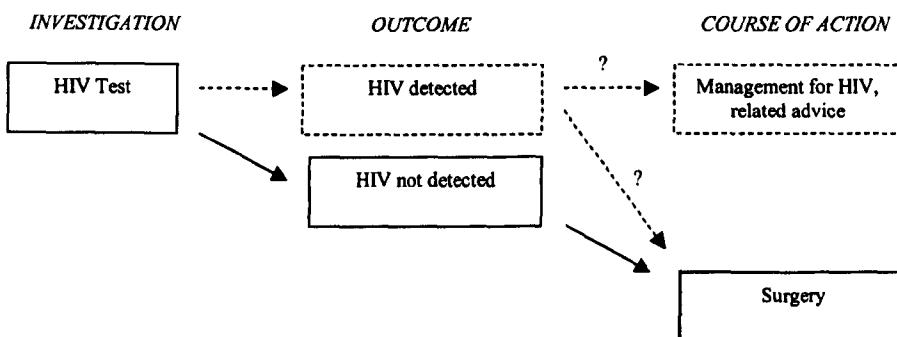
When a patient was found to be HIV positive, the issue was "foregrounded" to the extent that surgeons inevitably responded actively to protect themselves, either by the use of more protective equipment or by reportedly delaying or denying surgery to HIV positive patients. Hence while pre-surgical HIV screening did not usually influence *how* the patient is to be managed clinically, it may have influenced *whether* or not patients received timely and appropriate surgical management.

Box 5.2 Purposes and Outcomes of Pre-surgical HIV screening

5.3.5   Working in teams

In these highly tuned and regimented environments, all actions were geared to the successful completion of the actual act of surgery. Different actors took the stage each with their designated roles in a sphere of activity insulated from external disturbances. The role of support staff in the operation theatre (OT) was felt to be critical to the progress of the surgery, and the needs of other team members were often taken into account in decisions by surgeons.

> The surgeon has right to order a test if he thinks there is a large team – lot of trainee physicians and trainee nurses and there are lot of sharps handled, so he wants to take extra precautions."
>
> Administrator, charitable hospital (17)

A number of surgeons from all sectors spoke of fear and resistance on the part of their support staff to participating in surgery on HIV positive patients.

> The noise started coming from the OT [staff], you are bringing in HIV, you are bringing in HBsAg[164]. You are bringing in all these people, what the hell...
>
> Senior surgeon, private hospital (34)

> The theatre staff they all feel as if it is an invitation to death or something and they really resist any such effort.
>
> Senior surgeon, government hospital (29)

Close knit loyalties and affiliations characterize the formation of OT teams. Co-worker protection was an imperative according to one government surgeon, citing this as a reason for mandatory screening.

> My view is that suppose you are with me, should I protect you or not?... and when I can't do that, then every one should be screened, and we must do it.
>
> Senior surgeon, government hospital (31)

In another instance, a private surgeon narrated how he refused to avail of protective vaccinations unless his staff received them too. In this context of close and interdependent OT teams, surgeons were particularly resistant to being influenced to change their practices.[165]

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[164] Hepatitis B
[165] Respondent 24: Senior microbiologist, government hospital

5.3.6 Patients' responses to pre-surgical screening

According to many respondents (17, 67, 34), clients in general were accepting and cooperative in their practice of mandatory pre-surgical screening and, as a surgeon remarked 'most people take it in their stride'.[166] However it was rarely specified if the option to refuse to be tested was available to patients. With the exceptional case of one charitable hospital, it was also not specified to patients whether the performance of the operation was conditional on the patients' taking the test, or on any particular outcome of the test. It is likely that the patients were at the receiving end of considerable tacit and situational pressures to undertake the test. One physician pointed out that even eminent and influential persons were screened for HIV when admitted to a private speciality clinic, and did not object to it.[167]

In the view of a counsellor in a private hospital, patients did harbour fears and apprehensions around being tested, but seldom acted upon them

> They [patients] may have queries. That, "Doctor Saab why are you getting it done? What is this test?" But they do not refuse. *Dar to sabke man me hai* [everyone has apprehensions], that if the doctor has said, then may be [I could be HIV positive]? ... but nobody goes to the extent of refusing.
>
> Counsellor, private hospital (40)

Some doctors said that they expected patients to understand doctors positions, and make concessions for their (doctors') benefit, given the purportedly exceptional circumstances of HIV risk.[168]

5.3.7 Surgeons isolated

While mutual loyalties were strong within surgical teams and shared notions of risk and self protection characterized the response to HIV, the same was not always true of interactions between surgeons and other departments and specialities, especially within the large multi-speciality hospitals. In a number of hospitals, there were conflicts and divergences between surgeons and non-surgeons over the issue of mandatory screening.[169]

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[166] Respondent 34: Senior surgeon, private hospital
[167] Respondent 37: Senior physician, HIV specialist and administrator, government hospital
[168] Several respondents
[169] Several respondents (16, 37, 17)

> Right now, we are actually leading to positions of no-win between the people who are saying that consent is really crucial and the people who are saying that the rights of the care-giver are far more important.
>
> Administrator, charitable hospital (17)

Administrators and physicians on their part were ambivalent about the issue of mandatory testing. As fellow-doctors, they empathised with the surgeons' predicament. On the other hand, some of them (who were engaged in developing HIV services in their hospitals) were concerned with the profile of HIV care in their institutions, which they felt would be tarnished by the knowledge that pre-surgical screening was practiced. Others disagreed with mandatory screening in principle. In government hospitals, administrators were also bound by policies which did not permit mandatory testing. However generally speaking, the issue of non-performance of surgery on HIV positive persons predominated over that of pre-surgical HIV screening. In the context of such occurrences, mandatory screening was felt to be a "soft" issue, for which administrators generally adopted the route of persuasion and not of enforcement.[170,171]

Nevertheless, in the light of the ambivalent stance of administrators and their non-surgical peers over this issue, some surgeons expressed feelings of isolation and lack of support. They believed mandatory testing to be an essential step toward ensuring their personal safety and even survival, and felt that unilateral action to continue screening was justified on their part. In government hospitals mandatory testing was not openly admitted to, and it sometimes took on the character of an underground practice. 'This is something that people are trying to keep hush-hush', said one microbiologist from a government hospital.[172]

5.3.8   The impact of institutional policy

Many of the themes around surgeons' response to the issue of mandatory testing resonated across both public and private sectors. These included their perceptions of risk of acquiring HIV, desires for more protective gear, close bonds with their respective OT teams, and preoccupation with the act of surgery over other facets of practice. However clearer distinctions emerged between the responses of surgeons, based on the stance taken by the respective hospital administrations around mandatory testing. (See Table 5.3)

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[170] Respondent 17: Physician and administrator, charitable hospital
[171] Respondent 35: Physician, 12 years experience, private hospital
[172] Respondent 24: Senior microbiologist, government hospital

In government hospitals where mandatory testing was officially banned, surgeons continued to conduct screening tests, if to a lesser degree than in some private hospitals. However, since these tests were conducted "unofficially", the outcomes of the test were similarly unofficial, and management decisions following a HIV positive test result were usually made secretively and on a discretionary basis by the surgeons. These variably involved either the use of greater protective equipment in surgery or, in instances, delays and refusals of surgery.[173,174,175]

In contrast, in the charitable hospital where mandatory screening was official policy and practiced openly and universally, processes following a HIV positive diagnosis were also more transparent. According to administrators surgeries were regularly performed on such patients with greater protective equipment, and in the instance of the charitable hospital channels for continued medical management of HIV were also well established.[176]

Thirdly, in institutions with no specific policies (one charitable hospital and private nursing homes), there were no checks either on mandatory HIV testing or on subsequent management of patients. Decisions to screen were made independently by the surgeons, and HIV positive outcomes reportedly led to delays and refusals of surgery, and in covert biases towards conservative (as opposed to invasive surgical) management.[177]

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[173] Respondent 16: Physician and HIV specialist, government hospital
[174] Respondent 32: Junior surgeon, government hospital
[175] Respondent 37: Senior physician and administrator, government hospital
[176] Respondent 17: Physician and administrator, charitable hospital
[177] Respondent 36: Senior physician, charitable hospital

	DECISION TO SCREEN	PROCESS OF SCREENING	SURGERY ON HIV+ PATIENTS
1. Hospitals with policy AGAINST mandatory testing (all government hospitals)	Pre-surgical screening: Independent, sometimes secretive decision against hospital policy	In-house unofficially, no counselling OR Sent out to private labs, no counselling	Discretionary decision: Surgery with greater protection OR Delays, refusals
2. Hospitals with formal HIV policy PERMITTING pre-surgical testing (one charitable hospital)	Universal pre-surgical screening, supported by institutional policy	In-house, signed consent, no counselling	Ostensibly, regular surgery with greater protection
3. Hospitals with NO SPECIFIC POLICY on pre-surgical testing (one charitable hospital, private nursing homes)	Pre-surgical screening: Usually independent decision	In-house, no consent or counselling OR In private diagnostic labs, no counselling	Delays, refusals, preference for conservative management

Table 5.3 HIV Screening and Outcomes in Hospitals with Different Policies

In conclusion, while the presence of institutional policies permitting screening may have led to screening in greater numbers, post-diagnosis procedures were also more regularised in these hospitals. In environments where the practice was prohibited but widely practiced, the initial occurrence of mandatory testing was less prolific, but there may have been a greater risk of unaccountable outcomes for patients following a positive diagnosis.

5.3.9   Pre-surgical HIV testing: summary

Across the board, most of the surgeon respondents favoured mandatory testing and opposed the national policies in this regard. A majority of surgeon respondents interviewed said that they *practiced* pre-surgical HIV testing, either universally on all their patients or on a discretionary basis on patients who they suspected were more likely to have the infection. Two private hospitals (one for-profit and one charitable) had policies permitting mandatory pre-surgical testing, and universal HIV screening was carried out by surgeons.

Explanations

Among those who did not practice pre-surgical screening or practiced it to a limited extent, usually those in the government sector, obedience to government (and institutional) policies was

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cited as the main reason for the same.[178,179] In some other instances, surgeons may not have been sufficiently apprehensive about HIV or motivated to conduct screening tests. When probed, almost all surgeons expressed a fear of contracting HIV and a desire to conduct mandatory tests, but in some cases these anxieties may have been latent, or not considered sufficient to act on. In contrast, a number of explanatory or mitigating factors were cited in surgeons' practice of mandatory pre-surgical testing. (Table 5.4)

For mandatory screening	Against mandatory screening
- Growing fears of HIV and notions of risk - Poor confidence and awareness around HIV/AIDS - Lack of trust and confusion around protective equipment - Simplicity and low cost of HIV testing - Centrality of act of surgery in surgeons' role performance - Professional ideals of thoroughness, utilitarian ideals - Co-worker fears and pressures - Total compliance on the part of patients - Administrative support for pre-surgical screening (in two hospitals: private and charitable)	- Government policy against mandatory testing (government hospitals) - Low awareness of HIV and associated risks - Latency of anxieties around HIV

Table 5.4 Surgeons' Reasons For and Against Mandatory Screening

The principal reason for conducting pre-surgical mandatory tests was the doctors' fear of acquiring HIV and notions of the risks of surgical procedures. There was a considerable emotional element to the surgeons' fears of contracting HIV, and frequently these notions were not driven by scientific understanding of the risks of transmission.

Surgeons as a rule did not display great scientific interest in the field of HIV, other than the cognizance of personal risk. Knowledge and "awareness" of HIV tended to be equated with little more than awareness of the risk of acquiring HIV. In some contexts, mandatory testing was a sign of a more "HIV-cognizant" culture or attitude among surgeons, and hence associated with better preparedness for dealing with HIV positive patients. However in other contexts, especially those associated with arbitrary or secretive practices of mandatory testing, there was poorer

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[178] Respondent 19: Gynaecologist, 15 years of experience, government hospital
[179] Respondent 28: Senior venereologist, government hospital

preparedness for HIV positive test results, which led to surgeries being delayed or denied to HIV positive patients.

In certain contexts such as in government hospitals and smaller private sector outfits, problems with the (high) costs and (poor) availability of protective equipment were cited as justifications for mandatory testing. Surgeons generally distrusted the capacity of basic protective equipment to guard them from HIV infection, and in government hospitals, there were disagreements between surgeons and administrators as to the type of equipment required to protect against HIV. Surgeons mistrust and lack of confidence around Universal Precautions (UP) was also linked to lack of knowledge on the subject, and to a general preference for the reassurance of material barriers, as opposed to changes in procedure and adoption of preventative practices. To a large extent, surgeons considered the performance of technical clinical tasks (in general), and the act of surgery (in particular) to be their predominant role, as opposed to procedural and precautionary tasks such as taking consent from patients, and adopting safer surgical practices.

Surgeons also regarded the field of surgery to be uniquely different and occupying a special status, and felt that its critical nature justified the fulfilment of special demands and requirements. The need to know the HIV status of their patients was one such demand made by surgeons in order for surgery to proceed. Faced with the calamitous threat of non-performance of surgery - the immediate and main concern of all involved, surgeons, patients and administrators – the ethical hazards of mandatory testing were considered to be of less significance and the practice was seldom actively opposed. In some contexts, the practice of pre-surgical screening was aggrandized and held up as a sign of greater professionalism and thoroughness among surgeon peers. Additionally, in a stance at odds with the tone of the national policy, many doctors also believed that HIV screening was innately beneficial for patients and the community, and served utilitarian goals of detection of more HIV infections.

As much as surgeons, other surgical staff too feared acquiring HIV from patients, and voiced these fears openly. With large teams working in tandem in the operation theatres, surgeons were at pains to ensure that the demands of all staff were met, in order for surgeries to proceed. Mandatory HIV screening was often conducted on the basis of collective pressure from surgical staff. While *patients* may have had apprehensions about being tested for HIV, these were seldom voiced. The environment around surgery was not conducive for such assertiveness on the part of patients. Also, given the critical nature of the intervention and the collective focus on the performance of surgery, patients were not encouraged to regard the HIV test as more than a minor detail.

Discussion

National policies against mandatory testing may have little impact on practices in the private and charitable hospitals. Screening was often conducted unchecked and in large numbers by surgeons in these institutions, in some instances leading to adverse outcomes for patients detected with HIV.

In government hospitals the situation was more complex. Some surgeons did follow the policies and conduct regular surgeries without screening their patients, but this compliance was marked by continuing unease and apprehensions on their part over the perceived risks of acquiring HIV. In other instances surgeons disobeyed the policies and conducted HIV screening tests. In such cases there were reported impediments to the completion of surgeries and proper medical follow-up for patients diagnosed with HIV.

The requirements of ensuring ethical HIV testing are clearly vital, especially in the private sector, where mandatory tests are conducted widely and indiscriminately. However it is apparent that other health care processes and outcomes are interconnected with HIV screening – surgery, continued care for HIV – which are vitally important to the actors, and it becomes important to balance the quality needs of all these aspects. This involves addressing shared goals of all actors involved, patients, medical practitioners and administrators. Sense of personal security, harmony and efficiency of procedures remain particularly important concerns given the critical and exacting nature of surgery.

5.4   INFORMED CONSENT

The NACO's policies and guidelines require that specific written informed consent should be obtained when testing for identification of HIV positive individuals.[180]   In reality however, practices of doctors in this regard vary from obviously coercive HIV testing to fully informed consent before a HIV test. Doctors' experiences of implementation of the consent procedure, and their perspectives on the processes of obtaining informed consent from patients are discussed in this section.   Chiefly, informed consent in the context of HIV testing for clinical diagnosis is discussed here. Specific themes around (lack of) informed consent in the context of pre-surgical HIV screening have been dealt with in the previous section on pre-surgical testing.

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[180] See Chapter 1 (1.2.4) for the wording of the NACO policy

5.4.1   Institutional procedures

Different hospitals had different procedures and policies around informed consent. A number of service providers were involved in the process and varyingly, counsellors, treating doctors and microbiologists were responsible for providing pre-test information, obtaining consent and managing consent forms.

In the *government hospitals*, there were formal procedures instituted for obtaining written informed consent. Informed consent was to be obtained by the doctors who advised the HIV test or coupled with pre-test counselling in a counselling centre / VCTC. A standardized consent form was in use which patients were required to sign after receiving relevant information. Obstetricians, venereologists and physicians more closely involved or interested in HIV care reported that they followed these formal procedures.[181,182]

In one of the *charitable hospitals*, there was a VCTC which had a policy of obtaining oral consent before HIV testing for clinical diagnosis. However in the case of HIV screening before surgery, patients were informed but not asked to consent to the test.[183] In the other charitable hospital, there were no formalities of obtaining written consent for a diagnostic HIV test.[184]

The *private hospital* however, had implemented the use of a consent form for HIV testing: 'We have got a requisition form on one side, the back of the form has consent', said an administrator.[185] Respondents from private nursing homes reported that consent was rarely taken for a HIV test.[186]

To a great extent patients reportedly gave permission for HIV testing when asked, whether for diagnostic purposes, as part of ante-natal investigations or before surgery. Patients' responses to mandatory pre-surgical screening are further detailed in the previous section (page 115). Refusal of consent to be tested, by a patient, was a rare occurrence across all sectors of care, especially in government hospitals. In the charitable and private hospitals too, refusals were very infrequent.[187] 'Out of thousands of pre-test counselling in three years, we had 2 such cases [of refusal]' said a government hospital counsellor.[188]

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[181] Respondent 12: Senior physician, government hospital
[182] Respondent 20: Junior gynaecologist, government hospital
[183] Respondent 17: Physician and administrator, charitable hospital
[184] Respondent 36: Senior physician, charitable hospital
[185] Respondent 38: Medical superintendent (and physician), private hospital
[186] Respondent 67: Physician, private nursing home and trainee in intensive HIV educational programme
[187] Respondent 13: Senior physician and HIV specialist, government hospital
[188] Respondent 42: Counsellor, government hospital VCTC

	GOVERNMENT HOSPITALS	CHARITABLE HOSPITALS	PRIVATE HOSPITAL	PRIVATE NURSING HOMES
Diagnostic / Pre-natal HIV Testing	Written Informed Consent	Oral Informed Consent	Written Informed Consent	No procedures
Pre-surgical HIV Screening	NA[189]	Patients informed, no consent	Written Informed Consent	No procedures

Table 5.5 Institutional Procedures for Informed Consent

5.4.2 Adherence to policy

Only seven of the 33 doctors interviewed, mainly surgeons from both private and public hospitals, said outright that they did not take specific consent before advising HIV tests[190] (this aspect is also discussed in more detail in the previous section on pre-surgical testing). Many of the other respondents reported that they 'normally' took consent, often citing the binding influence of their respective hospital policies.[191,192,193] However it was revealed that consent procedures were often not followed wholly or in the manner prescribed, and sometimes principles of free informed consent were not adhered to.

In government hospitals, formal written consent was sometimes not obtained by physicians, as in the case of indoor patients.[194] In the private hospital too, the consent form was not always used by doctors, nor were patients always fully informed about the test, especially in the context of pre-surgical HIV testing.[195] When consent *was* taken, there were often overtones of coercion or suggestion involved in obtaining patients' signatures on consent forms, in both private and government hospitals. Patients' consent was often presumed, and attitudes of practitioners were not favourable for patients to give "deliberate and autonomous permission", as recommended by policy (NACO 2005). This was especially so in instances of pre-surgical HIV screening where HIV testing was initiated specifically for the (perceived) benefit of practitioners. As one government doctor seemed to imply, consent was seen as a formality to get out of the way, before pursuing core tasks of testing the patient for HIV as a routine.

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[189] Not applicable: pre-surgical HIV screening was officially not permitted in government hospitals
[190] Several respondents (29, 30, 31, 32, 37, 26, 34)
[191] Respondent 22: Gynaecologist, government hospital
[192] Respondent 23: Venereologist, government hospital
[193] Respondent 39: Microbiologist, Private hospital
[194] Respondent 30: Senior physician, government hospital
[195] Respondent 38: Medical superintendent, private hospital

> All the patients who come with the sexually transmitted diseases, their
> consent is taken and pre-test counselling is done, then we do the test for
> each and every patient who walks into the STD clinic.
>
> Senior venereologist, government hospital (28)

Even where formal protocols for written consent were in place, the process of signing consent

forms may not always have been conducive for patients to make considered choices.

> All that [consent forms and protocol] is there. See, in the government
> setup, patients are not choosers; they do whatever you tell them to do.
> They don't have any choice.
>
> Infection control officer, government hospital (68)

In the private hospital, patients were required to 'agree to be tested' before surgery, rather than

consent to it, in the words of a counsellor.[196] In other instances there were deficiencies in the

information provided to patients before taking consent. Especially in the case of pre-surgical HIV

screening, patients were unlikely to be adequately informed about the test.[197] One counsellor

reported the problems of imparting information about a test which was not essentially performed

for the patients' benefit (also see Box 5.2).

> There is nothing that you have to say. What do we tell them, that we are
> doing this for the doctor's safety? They will say "let the doctor test for
> it! Why should I test for it?"
>
> Counsellor, private hospital (40)

On rare occasions when patients refused to be tested, this was sometimes viewed with suspicion

by doctors. Refusal of HIV tests was a cause of suspicion for this private sector surgeon, who

characterized such individuals as not being 'genuine' in their intents.

> One or two people who have already known it [their HIV status] from
> somewhere else, and they try to pull a fast one. They try to sneak in.
> Otherwise if somebody is a genuine recipient, or a genuine donor, or a
> genuine patient for dialysis, all of them quite happily accept it [being
> tested for HIV]
>
> Senior surgeon, private hospital (34)

In government hospitals too, refusal of consent was often regarded as an unwanted problem[198] and

in some instances doctors were of the opinion they should go ahead with the test even if the

patient did not consent.[199]

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[196] Respondent 40: Counsellor, private hospital
[197] Respondent 37: Senior physician, HIV specialist and administrator, government hospital
[198] Respondent 28: Senior venereologist, government hospital
[199] Respondent 22: Gynaecologist, 8 years experience, government hospital

In summary, with the exception of surgeons, most doctors were in the habit of obtaining specific informed consent from their patients for HIV tests, yet there appeared to be gaps in enacting consent, in both private and public sector hospitals.

- Not taking consent

- Taking oral consent where written consent is the policy

- "Coerced consent" – pressurizing or obligating patients to give consent

- Not conveying complete and comprehensible information

- Not honouring patients' decisions to refuse consent

Box 5.3 Common Types of Deviations from Consent Policy

5.4.3   Rationale for HIV-specific consent

Doctors differed in their understanding of the reasons or rationales behind taking specific informed consent for a HIV test. While a few cited specific reasons related to the necessity of preparing a patient for a HIV diagnosis, equal knowledge sharing with patients and ensuring non-discrimination, others expressed their uncertainty over the possible rationales for specific consent. Yet others believed that there were insufficient reasons to justify specific consent for HIV testing.

Some respondents cited reasons in favour of specific informed consent related to the need for information and preparedness of the patient, given the psychological blow of a HIV test result and the long term health and social implications of the diagnosis.[200,201] HIV specialists and doctors engaged specifically in HIV care were more likely to cite these explanations, and in general to offer contentions in support of specific informed consent.

Another reason cited for specific informed consent was the need for knowledge and assurance (for patients) of the beneficence of the practitioners' motives for conducting the test. This was considered to be necessary in the light of the stigma surrounding HIV test results within healthcare environments, and the frequent utilisation of HIV test results by doctors to discriminate

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[200] Respondent 13: Senior physician and HIV specialist, government hospital
[201] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital

against patients.[202,203] Conversely, some doctors resented the implicit suggestion contained within the consent procedure, that their ability to treat patients without discrimination was suspect.[204]

A number of doctors (mainly non-HIV specialists) were uncertain around the rationale of taking specific informed consent for a HIV test. Some of them openly expressed their perplexity.

> I asked people [colleagues]: "Why do you have to do this? Why do you have to take written informed consent before doing a test?" And they all agreed with me – they said yes, there is no reason for it. But its there.
>
> Senior physician, government hospital (33)

A majority of the doctors felt that there was *no adequate basis or rationale* for obtaining specific informed consent for HIV testing, or that opposing factors outweighed the utility of the procedure. These perceptions are discussed in detail in the following sections.

5.4.4   A sign of "exceptionalism"

The requirement of specific informed consent before a HIV test was widely seen as an example of HIV favouritism or "exceptionalism", i.e. the institution of special procedures and conditions in the care of HIV which were not universally applied for other conditions or investigations. Respondents' opinions differed over whether these special procedures and conditions, such as informed consent and pre- and post-test counselling, and the emphasis on confidentiality, were warranted.

For and against "exceptionalism"

Many doctors questioned the requirement of specific informed consent for a HIV test, and the implicit exceptional treatment of HIV involved.[205,206]

> Why is it that I see a person who has HIV, I tell the person how is it transmitted, what is the treatment, what is the prognosis, what are the precautions around it, you tell me, for which other diseases will you do all this? And other diseases... the biological consequences may be even more severe. Why is it that you can keep a patient with cancer and not

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[202] Respondent 32: Junior surgeon, government hospital
[203] Respondent 36: Senior physician, charitable hospital
[204] Respondent 65: Physician, 15 years experience, charitable hospital
[205] Respondent 21: Senior gynaecologist and head of department, government hospital
[206] Respondent 24: Senior microbiologist, government hospital

> tell them the diagnosis, because the family doesn't want them to know the diagnosis? TB has stigma too, but we don't take [consent].
>
> Physician, 15 years experience, charitable hospital (65)

In some instances doctors appreciated that general patient consent was necessary, but felt that patients' assent for individual diagnostic tests did not require repeated confirmation and could be inferred from their signing of admission papers on entry to the hospital.[207] Exceptionalism was criticized by some doctors as a cause of compartmentalization of the disease, which was seen to increase, not-diminish stigma. A charitable hospital consultant felt that by enforcing specific informed consent was 'creating certain notions around a disease which can actually, in a way, make it feel different'.[208] Another physician felt that it 'created a mystery around HIV/AIDS'[209], and a gynaecologist regarded it as a symptom of the excessive 'hype' around HIV.[210]

In government hospitals, the emphasis on HIV/AIDS was often seen as a divergence from the ethos of government service. In the context of overburdened clinics and pressing priorities of providing basic medical care to a largely impoverished clientele, the diversion of time and resources to "soft" interventions such as consent and counselling was often felt to be misplaced.

> You say we should do counselling! This is very funny... For counselling, we need a man, a patient, a sofa and a cup of tea, and a room. And there in the emergency, you have three patients on one bed, one is alive, one is dying and one is dead. I am not against counselling. What I am saying is, the ground realities are entirely different.
>
> Senior surgeon, government hospital (31)

Notably, doctors who were specializing in HIV medicine or who had had a greater involvement in issues around HIV care were more supportive of the need for special procedures around HIV testing. To a large extent these respondents ascribed the value of specific informed consent for HIV testing to addressing concerns of HIV patients beyond the immediate bounds of the clinical encounter. These explanations ranged widely, from mitigation of the psychological trauma of HIV diagnosis, to the seriousness of a long-term prognosis and lack of a cure, and the impact on patients' familial, social and occupational lives.[211,212] In contrast, other doctors' critiques of specific informed consent tended to be focused around concerns located within the immediate

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[207] Respondent 17: Physician and administrator, charitable hospital
[208] Respondent 65: Physician, 15 years experience, charitable hospital
[209] Respondent 33: Senior physician, government hospital
[210] Respondent 21: Senior gynaecologist and head of department, government hospital
[211] Respondent 13: Senior physician and HIV specialist, government hospital
[212] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital

context of the clinical encounter. (This is discussed in further detail in the following section 5.4.5)

A small number of the doctors interviewed (mainly venereologists and some physicians), in private and public hospitals were focused on HIV care more than on other aspects of their sub-discipline. The emergence of such specialist "HIV practitioners", some but not all of whom also had the formal training in HIV medicine, represented a larger trend in India, according to respondents and key informants.

> Right now there is a great hope in HIV... you have a
> proliferation of people who are very committed and who want
> to do it, of providing only HIV care... If you are in the HIV
> business then people say that you are on a bandwagon,
> because there is money there or fame.
>
> Physician, charitable hospital (65)

HIV practitioners tended to favour special procedures for HIV such as informed consent. Becoming an HIV practitioner or specialist represented not simply an addition to their clinical repertoire, but also an awakening to concepts beyond the narrow concerns of clinical science, including ethical, human rights and public health issues.[213][214]

Box 5.4 Becoming a "HIV Practitioner"

Ambivalent opinions

The divergence of opinion over this issue was not simply between different individuals, but it also appeared to divide doctors internally. For many of them, the essential dichotomy around this topic was between supporting taking informed consent as a *progressive measure* on the one hand, and *opposing the bias in favour of HIV* to the disadvantage of other patients, on the other hand. Many respondents appeared to introspect and cite contrasting arguments when questioned by the interviewer around the value of specific informed consent.

> HBV, HCV are also equally life-threatening. HBV is far more likely to
> spread as a result of needle stick, than HIV. We generally do not take
> informed consent for every other investigation, then why for HIV? If we
> are not taking consent for syphilis, why we are taking consent for HIV?
> The only reason is because HIV has long term implications, and
> somebody might be discriminating against the patient. So it is to prevent
> those things. VDRL does not have such long term implications.
>
> Junior surgeon, government hospital (32)

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[213] Respondent 09: Junior physician, private nursing home
[214] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital

One physician welcomed the greater attention around HIV that policies such as those for specific informed consent represented, even while questioning the practical utility of always obtaining formal consent for the HIV test.[215] A physician from a charitable hospital pondered on some of the dilemmas around the special treatment of HIV.

> At this moment in time, at this historical juncture, there may be use for it [exceptionalism]... But one also has to see further than that... If you look at it in the long run, its like, why do we have informed consent for HIV and not for anything else? Why have care homes for HIV?... All these moves, in a way make that disease seem different. It is separate; it is not well integrated into other health services. What kind of sustainability does it have?
>
> Physician, 15 years experience, charitable hospital (65)

In summary, specific informed consent for HIV testing was widely seen as a sign of exceptional treatment of HIV, and doctors were divided in their opinions as to whether this was justified. Some of these opinions are detailed in Table 5.6 below.

Against Exceptionalism	For Exceptionalism
- Unfairness to other patients	- Psychological, social and public health reasons
- Compartmentalization of HIV, "stigma creation"	- Long term (extra-clinical) considerations for the patient
- Impediments in clinical care	- Consent linked to progressiveness

Table 5.6 Arguments For and Against HIV Exceptionalism

5.4.5   Consent and clinical goals

As noted before, while some doctors, notably HIV specialist or those more actively engaged in HIV care, appeared to have an enhanced consciousness of social and public health concerns, others' perspectives tended to be focused around their role and significance of their tasks within the context of the clinic. Their arguments against specific informed consent were oriented around the task of effecting the provision of clinical care efficiently and equitably.

> This business of taking informed consent from a patient before doing a HIV test... I don't know where this has come from. A patient has come to you. He is sick, he needs your help. Will you be thinking about this or about treating him?
>
> Senior physician, government hospital (33)

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[215] Respondent 17: Physician and administrator, charitable hospital

> I think it is just a question of the investigations that the doctors considers, and then orders it, that's all... it [HIV testing] is just like getting any other investigation done, an X-ray chest or anything. If you feel it is required then you will get it done. If you treat it like any other disease, then you will not have these problems.
>
> Senior gynaecologist, government hospital (21)

Priority for clinical tasks and outcomes

Frequently, the performance of clinical tasks was prioritised over procedures such as consent taking and counselling, which were often regarded as encumbrances in the course of providing care in busy hospital environments. Clinical outcomes, such as the successful treatment of incident illnesses were valued greatly by doctors, usually more than ethical procedural requirements. This was especially found to be the case for doctors working in government hospitals. As one physician indicated, 'we are keen to do the [clinical] procedure rather than look at these things'.[216] A microbiologist cited the problem of large caseloads and limited time, and felt that procedures around consent and counselling detracted from these primary tasks.

> Look at the number of patients – you have to see 200 cases in an OPD – how can you follow these rules? Counsel him, even take informed consent, explain all of HIV to him, explain the whole story, and then counsel him - it's too much! When they have no time, their primary job may be to save the patient...
>
> Senior microbiologist, government hospital (24)

Duty to test

An HIV specialist explained how a typical clinician's mindset hypothesises an 'ideal' linear sequence of events commencing with diagnosis and culminating in the departure of a well patient from the bounds of clinical care.

> As a clinician your ideal thinking is that you have your patient, you will examine and get all your clinical clues, you will send the right investigations... whatever you were suspecting the investigation will prove that you were right, and you will treat. Anything that comes in between is considered as an impediment.
>
> Physician and HIV specialist, government hospital (16)

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[216] Respondent 30: Senior physician, government hospital

This view was supported by the narratives of a number of other doctors. According to this private HIV specialist, patients expectations also corresponded with this perspective: 'when the patient comes to us, they come with the clear idea that they will be tested by us, managed by us, treated by us…'.[217] Hence diagnostic testing was seen to be an integral aspect of role performance, and a duty of the treating doctor rather than a privilege. Doctors' single-mindedness around testing and diagnosing was further heightened given the greater availability and accessibility of treatment for HIV/AIDS.[218,219] This phenomenon is also dealt with in previous sections (see pages 97, 98).

> I do understand the trauma which a patient may undergo when he comes to know that he is HIV positive, but now with the availability of very good therapy, freely available, I would rather feel that the patient's diagnosis is made, rather than keeping him in the dark about that.
>
> Senior physician, government hospital (30)

Consent procedures, as dictated by policy, are required to offer the patient an opportunity to refuse the HIV test. Although refusal was not a common occurrence, for some doctors the very idea of a patient refusing to undergo a diagnostic test represented an impediment in the performance of their roles. One physician expressed a fear that 'they [patients] will start saying "no"… If we don't know the status of the patient how will we be able to treat them?'.[220] Among government and charitable doctors in particular, there was a prevailing sensibility that doctors knew what was best for poor and illiterate patients, and that the possibility of refusal interfered with the likelihood of good care for these patients.

> Let me give you a frank opinion, if a patient has come to me with TB now finding if he is HIV positive or not is of a concern both to me and for him. We know that the response to therapy would be different in both these settings. So we tell him but many a time the patients general intellect is not enough, and the patient's physical and mental conditions may also not be fit enough [to understand the importance of taking the test]… so I will be rather sceptical about that point [the obligation of seeking consent from the patient]. And more so now when we have a proper, efficacious and comparatively safer medication.
>
> Senior physician, government hospital (30)

Hence perceptions of clinical duties sometimes extended to a belief that the diagnostic test should be conducted in some instances, even when patients did not confer formal consent.

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[217] Respondent 08: Senior physician, private nursing home
[218] Respondent 65: Physician, 15 years experience, charitable hospital
[219] Respondent 30: Senior physician, government hospital
[220] Respondent 33: Senior physician, government hospital

A logical problem

Doctors emphasised that health care was generally sought by the patient: 'A patient has come to you. He is sick, he needs your help'.[221] The idea of seeking consent *from* a patient, to provide a service sought *by* the patient and ordered expressly for their benefit appeared to be a contradiction of logic, and was a basic source of confusion for doctors.

> Why do we have to seek the permission of the patient for HIV (testing)?
> It is for the patient's benefit after all!
>
> Senior microbiologist, government hospital (24)

> When a person comes to a clinic, and you ask their permission to do something, what does it mean for that person?
>
> Physician, charitable hospital (65)
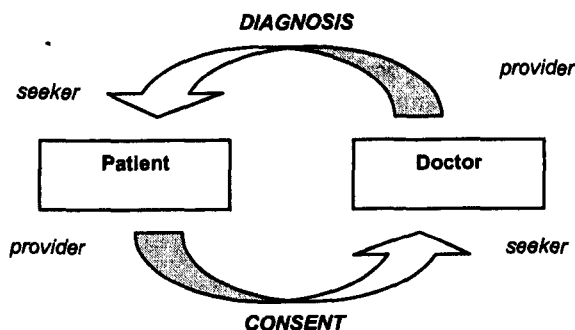
Figure 5.3 Paradox of Seeking Consent to Provide a Service

Hence doctors did not always perceive policies for consent to be beneficial or necessary for the performance of clinical tasks and the achievement of clinical goals, and in some cases they were a source of confusion or were seen as obstacles in performance of their roles.

5.4.6 Conveying information before taking consent

According to the national policies, patients should be informed about "advantages, risks, potential consequences and implications of an HIV test result, which could be both positive and negative"

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[221] Respondent 33: Senior physician, government hospital

in order to help them make a choice to consent for the HIV test (NACO 2005). This section looks at themes around imparting information and communicating with patients before testing for HIV.

Informing vs. inducing

An emergent theme around practitioners' communications with patients before taking consent was that of the dual purpose of such communication. The roles of doctors appeared to be finely balanced between convincing patients to take the test and allowing them to make their own decisions.

> In my practice, sometimes I have to explain a lot. But really, I haven't come across anybody who didn't give consent, after I gave my counselling and I made him understand the reason, what is the benefit of the test?... So if you can put this [the importance of testing] rightly into his mind, then nobody is going to refuse.
>
> Senior physician, government hospital (12)

> Some [patients] feel that it is a waste of time because they feel we have come for something else [clinical care] but something else is happening [counselling, information before consent]... sometimes they are busy and want to go back earlier... But it is job of the counsellor to understand the problem and convince them.
>
> Gynaecologist, government hospital (22)

Often, practitioners tended to be biased towards prevailing on patients to undergo testing, especially in the context of better treatment opportunities for HIV/AIDS, rather than on enabling informed but free choice (as required by policy).

Comprehension and interpretation

A common refrain of doctors when discussing the relevance of consent procedures was that patients seldom appreciated the content of the information provided, or the significance of making an informed choice around the HIV test. In most cases, this related to lack of comprehension and gaps between the language and constructs used by doctors and patients. While in government hospitals, this was linked to poor educational status of patients,[222] private doctors too reported problems of comprehension among their more affluent clientele. This was ascribed to conflicts of

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[222] Respondent 19: Gynaecologist, government hospital

'culture': principles of autonomy on which testing policies are based were said to not be appreciated by patients.[223]

For many doctors this perceived lack of comprehension was a source of frustration in wasting time over a process that was not felt to be fruitful. Imparting information was sometimes regarded as an unwelcome chore, and doctors felt that they could not ensure that the patients comprehended all the information.

> We have always taken informed consent. How much information the clients have understood is a separate issue. How do we validate or verify that? *Humne to bata diya* [We did what was required]. Now how much they have ingested, understood, we cant say that, we cant guarantee that.
>
> Senior microbiologist, government hospital (24)

Notwithstanding the perceived problems of comprehension, a number of doctors, especially those engaged in HIV care voiced their opinions in favour of imparting information and preparing patients before a HIV test. A few doctors said they attempted to work their way through the communication gaps, for which they sought the help of counsellors and patients' families.[224,225] Hence, the existence of the policy may have played a role in highlighting and remedying existing deficiencies in doctors' communications with their patients.

Scaring and offending patients?

Some doctors cited specifically negative implications of the formal consent procedure. Reportedly, the information on HIV provided during the consent procedure sometimes served to frighten patients away. Having to sign a form for consent was also believed to have unpleasant connotations for patients.

> Their concept is that if it is informed consent, it is something horrible, which must be why you are taking my consent. So they really get scared to sign on any piece of paper.
>
> Senior physician, HIV specialist, government hospital (37)

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[223] Respondent 34: Senior surgeon, private hospital
[224] Respondent 12: Senior physician, government hospital
[225] Respondent 14: Venereologist and HIV specialist, government hospital

"Drop-out" related to patients' fatigue or impatience with lengthy procedures around HIV testing was described as a common problem, especially in government hospitals, a phenomenon which is documented in detail in Appendix 2 (page 322).[226,227]

> The moment some people hear "HIV", they just vanish. They go out, they go to some other hospital...
>
> Trainee venereologist, government hospital (27)

The special emphasis on HIV was likely to offend particular patients' sensibilities and adversely affect their relationship with practitioners, according to some respondents. For private doctors, this was a particular concern given the primary importance of retaining their clientele.[228] In order to avoid these adverse outcomes, some doctors felt that greater discretion could be exercised in the matter of taking formal consent.

> I think you should try to be flexible... If we feel a patient is too anxious we can maybe just do a HIV and then see what happens. Not all patients are HIV ELISA positive, you know.
>
> Venereologist, government hospital (23)

Further themes around patients' responses to the consent process are discussed in the following section.

5.4.7   Patients' responses to informed consent procedure

This section details respondents' accounts of their patients' responses to the process of consent taking.

Consent in an asymmetric relationship

A number of doctors reported that many of their patients' attitudes were not consistent with autonomous decision-making around their own treatment. Reportedly, many patients are either not willing, or are perceived to not to be equipped to make certain choices around treatment, even when provided with information.

> We hear a lot of times when the patients come to you and you tell them about different therapeutic choices, they turn around and say "why have

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[226] Respondent 23: Venereologist, 10 years experience, government hospital
[227] Respondent 27: Junior trainee venereologist, government hospital
[228] Respondent 34: Senior surgeon, private hospital

> we come to you?" So that you can decide the best choice... it is their
> implicit trust that you will do the best work... in our country, culturally,
> people believe that when you go to a doctor they will act in their best
> interests.
>
> Physician and administrator, charitable hospital (17)

> "*Aap hi hamara bhala soch sakte hain*" [only you can decide what is
> best for us] – these are the common words you get to hear [from
> patients]. So we just sort of become their decision makers.
>
> Senior physician, government hospital (30)

One physician reported that he attempted to provide information and present choices to the patient, in spite of which decision-making processes were invariably asymmetrical, reflecting the respective social positions of the actors involved.[229] In what is a traditionally paternalistic interaction, both doctors and patients often assumed their typical roles of the instructor and the instructed, respectively. It is possible that in clinical settings, the offer of testing was not always distinguishable from an order.

Meaning of consent for patients

According to respondents, the choice to consent to a HIV test was not of uniform relevance to all patients. In some instances patients may have had other goals and requirements of their visits to the hospital which were prioritised to a greater degree. Some doctors questioned whether the procedure was of value for all their patients.

> A poor rickshaw puller with chronic liver failure... what is the point in
> telling him about choice... But then yes, if I go to a physician, I would
> like to give informed consent.
>
> Physician and administrator, charitable hospital (17)

> They [patients] take it as a part of their work-up. At times, they are not
> actually aware of what is being done. We try to explain to them, but they
> do not understand, because they just want to get their work done, the
> surgery done.
>
> Junior surgeon, government hospital (32)

A physician from a charitable hospital introspected on the significance of the consent procedure for the actors involved. He felt that there were significant gaps in the conceptualization of consent by doctors, and many patients. He questioned whether existing formal consent

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[229] Respondent 65: Physician, 15 years experience, charitable hospital

procedures were always in tune with patients' expectations while seeking health care, or if they corresponded with patients' varied and (in an Indian context) unexplored ways of according permission.

> We do it because we subscribe to it, but whether that actually reflects something that is grounded or lived... Whether it has the same significance for the patient, I am not sure... What is consent? What is the meaning of obtaining consent? They need much further exploration in the Indian context.
>
> Physician, 15 years experience, charitable hospital (65)

· Hence, according to doctors' narratives, consent for a HIV test may not have been equally relevant for, or desired by, all patients. Different patients' needs from a clinical encounter were also highly individualized, and formal standardized consent procedures did not always correspond with patients' preferred ways of according or denying permission. In some instances patients may have demonstrated dissent of HIV testing not by refusing the test, but by "dropping out" or leaving care altogether, (as detailed in Appendix 2).

5.4.8 Responsibilities and liabilities around consent

Paradoxically even while a number of respondents did not believe that the consent procedure was of much value, or opposed it altogether, yet most of them did at least nominally follow a consent procedure if their institutional policies so required.[230] There were many reasons for this divergence between opinion and actions, of which simple compliance to rules and adoption of norms was the most obvious. Other reasons may have included recognition of the opportunity to share or disperse the responsibility of diagnosing a patient with HIV.

Sharing responsibilities

HIV diagnosis was seen to contain the possibility of adverse outcomes for patients, and resultantly for treating doctors in the form of blame for those outcomes and ensuing legal implications. The significance of informed consent as a way of transferring the responsibility of diagnosis to patients did not go unnoticed by doctors.[231,232]

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[230] In the case of testing for diagnostic purposes, not pre-surgical testing.
[231] Respondent 22: Gynaecologist, 8 years experience, government hospital
[232] Respondent 27: Junior trainee venereologist, government hospital

> Without this informed consent the entire responsibility of the impact is on the testing clinician. Having been through the process of counselling, and informed consent, it is a shared responsibility. The patient has some responsibility of accepting the test result... Maybe we are trying to be overcautious... but it is always better to be like that. Whenever I speak to people [colleagues] I say there have been suicides after HIV diagnosis, and without specific informed consent, the onus is yours. So why do that?

> Physician and HIV specialist, government hospital (16)

According to a private hospital administrator too, they were in favour of formal informed consent in order for patients to assume greater responsibility, and hence encouraged doctors to follow consent procedures.[233]

There were differences of opinion as to the relative responsibilities of treating physicians and pathologists around a HIV diagnosis, with each indicating that responsibility for taking consent should be apportioned to the other group.[234,235]

Hazards of taking signed consent

As described before, patients were usually willing to sign consent even though they may not have been prepared for these responsibilities, or well aware of the implications of signing of a consent form. For these reasons, some respondents were especially critical of formalities of obtaining written informed consent.[236]

> With the NACO policy [for written informed consent], you can't prove that somebody is truly informed, you just take the signature... just ticking a checklist, whether he is being told this, told that... whatever you write, the patient will sign. Just having that kind of formality is useless.

> Senior physician, private nursing home (08)

> These things will only be written on paper, on a piece of paper they will always have informed consent, and there will be forms for the patient to sign on the dotted line. But informed consent is not always a one point thing, like I read it out "blah blah" to you and you sign it. There is a process and this process requires inherent trust between the two parties.

> Senior physician, charitable hospital (36)

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[233] Respondent 38: Medical superintendent (and physician), private hospital
[234] Respondent 14: Venereologist and HIV specialist, government hospital
[235] Respondent 39: Microbiologist, 13 years experience, Private hospital
[236] Respondent 22: Gynaecologist, 8 years experience, government hospital

In these situations, standardised written consent procedures were felt to be an inappropriate signifier of the quality of the patient-provider interaction. It was believed by some respondents that enforcing policies for consent would lead to evasive or specious practices on the part of doctors, aimed at safeguarding their own positions.

> If the bottom line is just obtaining the papers, but despite that, if the patient doesn't know anything - and there are many such examples, that is not good.
>
> Senior physician, private nursing home (08)

> If you have informed consent for everything, then the doctors will practice very safe and doctors will get away with it. They will say it is not our responsibility. Nowadays what the labs are doing, they do a dot test and give the test also in your hand. They can always say "I don't have a record. I had given it to him [the patient]" And on those tests, below that they will write: "however that is not a confirmatory test, get the Western Blot done." So they are safe.
>
> Physician and administrator, government hospital (37)

This respondent also narrated instances from private hospitals in which signatures were obtained coercively or without proper information by practitioners, for purposes other than the patients' benefit.

Hence in some instances doctors may have used written consent as a way of abdicating their responsibility for the diagnosis, and the requirement of a signature from the patient may have served only to reinforce the existing asymmetry of the patient-doctor relationship.

5.4.9   Informed consent: summary

Institutional policies and procedures regarding informed consent for a HIV test varied (see Table 5.5 on page 123). The government, private and charitable hospitals in the study all claimed to have policies either for written or oral consent in the case of testing for clinical management. The private hospital also required patients to sign informed consent in the case of pre-surgical HIV screening, while the charitable hospitals did not. The private nursing homes under study did not have any specific policies for informed consent.

In the case of testing for clinical diagnosis or for reasons of safer maternity, a majority of the doctors in all the sectors (including physicians, obstetricians and venereologists) claimed to have taken informed consent regularly in concordance with their institutional policies, yet revealed a number of inconsistencies and deficiencies in their practices (see Box 5.3). Even while consent

procedures were usually outwardly performed, in some circumstances patients may have been coerced or obligated into signing consent forms, or not provided proper or complete information before testing.

Perceptions

Opinions around the importance and relevance of consent did not vary significantly between doctors working in public or private hospitals, or those from different departments or specialities. However there were significant differences in opinion between doctors who had had special training and orientation or otherwise focused specially on HIV care, and those who did not. Some negative and positive value associations of taking informed consent are presented in Table 5.7.

Against Specific Informed Consent	For Specific Informed Consent
Superfluity - Poor comprehension of information by patients - Low demand or appreciation of consent requirement on part of patients Active hindrance in duties - Seen as scaring or offending some patients, leading to drop-out, or affecting their relationship - Delaying diagnosis: obstacle to perceived duty to expedite access to diagnosis Incomprehension of the rationale of informed consent - Paradox of taking consent for providing a desired service	Consciousness of extra-clinical concerns - Social and public health concerns - Psychological and long-term impact on patients Role in preventing stigma and discrimination in healthcare settings Informed consent as signifier of a "progressive" ethic

Table 5.7 Opinions For and Against HIV-Specific Informed Consent

Policies for specific informed consent for a HIV test were widely regarded as a sign of exceptional treatment of HIV. Whereas a number of doctors opposed such "exceptionalism" on the grounds that it unfairly favoured HIV over other conditions, and led to the "compartmentalization" of HIV as a separate entity, there was also considerable ambivalence in opinion, with several respondents suggesting that HIV warranted such special procedures.

In making day-to-day decisions, hospital doctors across all sectors tended to value the completion of clinical tasks, which value system was sometimes at odds with the requirements of specific informed consent. Informed consent, with its attendant possibility of delay or refusal of

diagnosis, was a potential impediment in doctors' role performance. Many respondents expressed consternation at the apparent paradox of "seeking permission to provide care".

Signing a consent form or giving formal consent for a HIV test was reported to be of varying significance for, and elicited different responses from patients. Frequently, patients may not have wanted to make the choice or considered it irrelevant, may have not comprehended the information, or may have been scared away or offended by the procedure. Resultantly doctors doubted the utility of taking formal consent in the case of all patients.

Explanations

Compliance to their respective institutional policies was widely cited as a reason for taking informed consent, as was the opportunity to allay the legal responsibility of making a diagnosis of HIV. These and doctors' explanations for their divergences from ideal consent policies are enlisted in Table 5.8. The varied responses and requirements of patients tended to play a role in doctors' enactment of consent. In providing information to patients before obtaining consent, doctors were driven by their "clinical role" of expediting access to treatment, and tended to induce patients to consent to the test, rather than presenting information and enabling patients' free choice, as recommended.

The low value commonly attached to taking consent and their non-comprehension of its rationale are likely causes of the general disinterest on the part of doctors in enacting the procedure. This may have led to "shortcuts" and divergences from ideal practices. The performance of clinical tasks and outcomes were often prioritised over ensuring the integrity of consent procedures.

Reasons for following consent policy	Reasons for not following consent policy
- Institutional requirement - Opportunity to relinquish responsibility	- Variability of patient response and comprehension - Perceptions of low value of consent procedure - Incomprehension of rationale of consent-taking - "Clinical role" pressure and greater priority for clinical tasks - Mitigation of personal risk (surgeons)[237]

Table 5.8 Reasons for Following / Not Following Consent Policy

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[237] Addressed in the previous section

Discussion

Informed consent policy is an example of the reforms wrought through the emergence of a HIV care movement in the country, perceived by some as a force for progress and emancipation. For many doctors it acted as a reminder of the need for ethical standards in providing care, and it had a role in raising consciousness about longer term concerns of HIV positive patients, and broader social and public health implications. The widespread policies for informed consent may have partially checked indiscriminate and "mandatory" testing, and played a role in improving the quality of provider-patient communications, and patients' preparedness for a HIV diagnosis, as expected.

However in its practical application in busy hospital environments, the value of consent for HIV testing was sometimes not apparent to the actors involved, and many doctors perceived consent for HIV testing to be disconnected from ground realities. Even while a majority of doctors reported that they followed consent policy at least nominally; improvement of the quality of that consent process becomes a key concern. Successful implementation of informed consent policy is hampered by conflicts between the roles that doctors are expected to enact: of providing efficient clinical care as well as ensuring ethical standards. Also, the imposition of standardized policy presents a fundamental problem when its utility and rationale are not apparent to doctors, the implementers of the policy.

The benefits of written consent for practitioners as a safeguard against litigation – rather than for patients – did not escape the practitioners' attention, an observation which has also been made by Kalantri (2000) and by Shenoy (2002). Reportedly also, formal informed consent procedures (entailing the demonstration of autonomy and explicit sharing of responsibilities) may not have been in line with all patients' priorities and needs. Generation of knowledge on the unexplored area of patients' responses to consent procedures could assist in the adaptation of policies. Further, the push for wider enforcement of standards in HIV testing needs to be balanced by an appreciation of the unique nature of each provider-patient interaction, and the role of discretion on the part of practitioners in sustaining care processes and relationships.

5.5   CONFIDENTIALITY

NACO's policies for HIV testing call for adherence to a code of confidentiality around patients' HIV status or test results, requiring that health care workers who are not directly involved in care of the patient should not be told about the result.[238]   Certain concessions are made for the involvement of patients' spouses for their protection, and patients' families with the consent of the patient.   Doctors' practices around confidentiality and their perspectives on the policy are examined in the following pages.

5.5.1   Adherence to policy

A number of respondents said that they held the principles of confidentiality in high regard and claimed to follow the policy faithfully.   In the government sector especially, doctors said they took special measures in case of patients with HIV to ensure confidentiality.   In some instances institutional procedures were specifically oriented toward maintaining confidentiality.[239]   However, closer enquiry revealed a number of instances in which doctors could not or did not adhere to the policies entirely.   Breaches of confidentiality ensued through deliberate or unintended disclosure of patients' test results to another individual or individuals without the patients' consent.

Knowledge of patients' HIV status available to:

- Health workers not immediately involved in care of the patient

- Spouse, partner or family of the patient in the absence of the patients' consent or without proper counselling

- Other patients, relatives and attendants present in the hospital

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Box 5.5   Types of Breaches of Confidentiality Policy

The parties commonly mentioned as gaining knowledge of patients' HIV status without patients' consent (i.e. those involved in breaches of confidentiality) are enlisted in Box 5.5.   Other agencies such as employers and NGOs caring for HIV positive people were also reported to have asked

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[238] See Chapter 1 (1.2.4) for the wording of the NACO policy
[239] Several respondents (12, 16, 20, 28, 42)

doctors to disclose patients' HIV status, which requests were generally rejected according to the respondents.[240,241,242]

5.5.2   Concepts of confidentiality

Doctors had differing conceptions of the notion of confidentiality, in the context of patients with HIV infection.

Professional norm of secrecy

For some doctors, confidentiality policies reinforced their belief in professional norms of secrecy of client information and sanctity of the doctor-patient relationship in general, not simply in case of HIV.

> I will not tell. I think it is important to have a personal bond with the patient. It is not legal but it is something between you and that person. It's nothing to do with anyone else, even if it is his wife.
>
> Venereologist, 7 years experience, government hospital (14)

Confidentiality was also seen by some as a signifier of trust between doctor and patient, and essential for retaining the patient's custom.[243,244]   Confidentiality or "professional secrecy" was widely regarded as a professional standard to strive for, even as doctors admitted that situational factors did not always allow for the high standards to be maintained.

HIV – a special case

In the case of patients with HIV, doctors' unique concerns and perceptions around HIV superimposed on their existing notions around professional secrecy giving rise to a different spectrum of opinions. On the one hand, some doctors supported the national policies in the view

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[240] Respondent 12: Senior physician, government hospital
[241] Respondent 13: Senior physician and HIV specialist, government hospital
[242] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital
[243] Respondent 22: Gynaecologist, 8 years experience, government hospital
[244] Respondent 23: Venereologist, 10 years experience, government hospital

that HIV warranted an increased emphasis on confidentiality, given the attendant problems of stigma and discrimination.[245]

Reflecting the widespread fear of acquiring HIV from patients, there was also an opposite perception that rules of confidentiality should be *relaxed*, not strengthened, in the case of patients with HIV. This feeling was especially strong in the context of health care workers' perceived right to protection from being infected. Many respondents were of the opinion that HIV positive patients have duties and responsibilities toward health workers – 'the patient should understand that he can be a risk to others', one surgeon opined[246] – and should acquiesce to disclosure of their HIV status.[247,248]

Further, a larger number of doctors opposed the special emphasis on confidentiality in HIV care, deriving from their disaffection with the "exceptional" treatment of HIV. Some respondents felt that this was a retrogressive approach which would only promote excessive secrecy and prevent "normalization" of the epidemic.

> Through this confidentiality, you are spreading the disease. Tell me, what is the formula for smallpox or polio, these days? Inform the government, inform this and inform that, so you are controlling it. If we say *"bachalo, bachalo, chupalo, chupalo"* [protect it, hide it] , then what will happen? It will keep spreading.
>
> Senior surgeon, government hospital (31)

> There are so many diseases, and when confidentiality is not maintained about any particular disease then what is so great about HIV that it has to be... the same stigma and the same things was attached to tuberculosis 50 years back and now nobody even bats an eyelid about it
>
> Senior gynaecologist, government hospital (21)

Table 5.9 summarizes some of doctors' different conceptions of the policy of confidentiality for HIV. The prominent theme of health workers' right to protection is explored further in section 5.5.3.

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[245] Respondent 12: Senior physician, government hospital
[246] Respondent 32: Junior surgeon, government hospital
[247] Respondent 31: Senior surgeon, government hospital
[248] Respondent 42: Counsellor, government hospital VCTC

	General	**HIV-specific**
Favouring Confidentiality	Congruent with medical professional norms of secrecy	Correctly emphasised in light of HIV stigma and discrimination
Against Confidentiality	Convenience of involving family members in patient care	Obstacle in actualization of practitioners' right to safety Liable to reinforce stigma and secrecy around the disease

Table 5.9 Practitioners' Opinions For and Against Confidentiality Policy

5.5.3 Health workers' knowledge of patients' status

Disclosure of patients' HIV status to health workers not directly involved in the care of the patient was categorically proscribed in government policy. Respondents variously either followed policy closely or chose to involve more healthcare staff in knowledge of patients' HIV status; and correspondingly advanced explanations for their practices.

On the part of more "HIV-aware" consultants, there were avowals that the text of policy was followed strictly, and that references to HIV status of the patient were carefully shielded from those not directly involved in patient care.[249] The distinction of who was directly involved in patient care, and hence authorized to know patients' HIV status or not, was however open to variable and discretionary interpretation.

> The sister [nurse] would know, the doctor would know, all those handling the patient would know. It is essential for them to know...
>
> Medical superintendent, private hospital (38)

> I will just disclose a report to my juniors, only to people who are concerned with the care. The sweeper has to dispose off the body fluids, and that is an issue. The intern has to take a sample - that is an issue. And I have to operate.
>
> Junior surgeon, government hospital (32)

In a number of other instances, doctors opposed outright the policy of shielding HIV test results from any healthcare staff, including 'guards and sweepers' and paramedical staff.[250,251] In the

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[249] Several respondents (17, 28, 35, 70)
[250] Respondent 31: Senior surgeon, government hospital
[251] Respondent 39: Microbiologist, 13 years experience, Private hospital

private hospital, patients' case files were marked to allow health care providers to recognize a HIV positive patient.[252]

Protecting health workers

The primary justification for allowing healthcare staff access to knowledge of patients' HIV status was the workers' need to protect themselves from potentially being infected with HIV.[253]

> Maintaining confidentiality is one issue… but at a lot of times, simple waste disposal becomes a problem. We are supposed to have segregated waste, but at times, we do not get the bags. If we look at a sweeper, taking away the waste from the hospital, you will realise how dangerous it is for him. He is carrying all that waste which has got a lot of fluids, lot of sharps, he is dripping the waste on the floor. How dangerous it is! Just because he is not aware of these things, and how dangerous it is for him.
>
> Junior surgeon, government hospital (32)

In government hospitals where there was active pressure to enforce the policies and , there was a commensurate opposition, on the part of doctors, to the policies. It was perceived as unfair for certain groups of providers to not have knowledge of patients' HIV status.[254]

> It would not be fair if I knew and I did not tell my junior doctors, or I did not tell my nurse, that will not be fair because that means I am taking the precautions and she is not…
>
> Senior gynaecologist, government hospital (21)

Hence, many doctors believed that knowledge of patients' HIV status was a right of all healthcare staff, in the likelihood of their contact with a HIV positive patient. Some doctors testified to predicaments between following policies for confidentiality and supporting their co-workers.[255]

The 'grapevine' among hospital staff

Even among doctors favouring confidentiality for HIV, many pointed out the difficulties of enforcing policies aiming to confine such knowledge, especially in the context of busy hospital environments. In government hospitals, there was an air of acceptance that knowledge of

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[252] Respondent 40: Counsellor, private hospital
[253] Respondent 20: Junior gynaecologist, government hospital
[254] Respondent 31: Senior surgeon, government hospital
[255] Respondent 20: Junior gynaecologist, government hospital

patients' HIV status was liable to be disseminated among hospital staff, to go with the tacit acknowledgement of workers' needs of self-protection.

> Strict confidentiality: this is often not possible in a government hospital. The health-care workers come to know about it. They don't make a fuss over it.
>
> Senior physician, government hospital (13)

> Initially we used to put a board behind the patients bed, but we don't do that now. But sparingly, what we noticed with the staff nurses, they still put a board for their own... They put a board there saying HIV+.
>
> Venereologist, government hospital (23)

In the private hospital however, a intra-hospital 'grapevine' about patients' HIV status was not just tolerated, but regarded as internal to the execution of HIV care in the hospital.[256,257]

> People will alert you before the message gets back to the patient. Somebody or the other, registrar or somebody, somebody will phone, "there is a positive test", or "there is some *gadbad* [problem]"... I think that the grapevine works quite well.
>
> Senior surgeon, private hospital (34)

Health workers' attitudes

Some doctors reported negative consequences of healthcare workers' awareness of patients' HIV status. One doctor told of a HIV positive patient who was a health worker in another hospital, who refused to take medication from the hospitals' ART centre, for fear that his colleagues would find out.[258] Another respondent reported that workers would create obstacles in admission of HIV positive patients: 'trolleys were withdrawn, the supplies becomes less and less...'.[259] Other respondents however reported improving attitudes and greater acceptance of HIV positive patients among healthcare staff, with increasing awareness of, and exposure to HIV.[260,261]

While some doctors acknowledged some potential harms to the patient of disclosure of HIV status to all health workers, this was countered by perceptions that knowledge of patients' HIV status was a right of all health providers, in order for self-protection. Advertisement or circulation of

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[256] Respondent 34: Senior surgeon, private hospital
[257] Respondent 38: Medical superintendent, private hospital
[258] Respondent 14: Venereologist and HIV specialist, 7 years experience, government hospital
[259] Respondent 70: Senior medical educator, coordinator of intensive training programme in HIV
[260] Respondent 20: Junior gynaecologist, government hospital
[261] Respondent 38: Medical superintendent (and physician), private hospital

patients test results among hospital staff through informal word-of-mouth routes was a practice that was often tolerated and (in the private hospital) even encouraged by doctors. The practice of labelling of patients' beds and case-sheets was also prevalent, although sometimes disparaged.

5.5.4   Involvement of the spouse or partner

The policy wording in regard of disclosure of a patients HIV status to their spouse or sexual partner contains two distinct themes. While stressing on the importance of strict confidentiality, the national policy (NACO 2005) also requires that disclosure of HIV status to a spouse or partner should be done only following proper consent and counselling of the patient.

Conflicting policy messages

The issue of informing patients' spouses and sexual partners about a patients HIV status was somewhat complex, and the messages available to practitioners were not always straightforward. While on the one hand, strict confidentiality was required, physicians were also encouraged to notify spouses / partners. Doctors had varying opinions around the issue of informing partners, with some clearly taking a stance one way or the other.

> Until and unless the patient wants, you can't discus this issue with anybody else... you tell your patient that she [his wife] is at risk, but if she is not your patient, she is somewhere else, I don't think that's right...
>
> Venereologist, 7 years experience, government hospital (14)

> Confidentiality should be absolute and complete. Except for circumstances where there is at risk an individual who is very near the patient, for example, a wife. There, confidentiality has to be breached.
>
> Senior surgeon, private hospital (25)

Others expressed their confusion and ambivalence over this issue.

> Professionally, I don't really understand what should be done. There are issue when the spouse is informed and the consequences may be drastic... Its very complicated whether the person has to be told or not? Telling is better, but also it has ramifications
>
> Senior microbiologist, government hospital (24)

> I really don't know... it is a controversial issue that if a woman doesn't want her HIV status to be disclosed to her husband, what should we do, and how should we tackle this problem.
>
> > Gynaecologist, 15 years experience, government hospital (19)

> It is truly a difficult issue. I am still struggling to cope with this issue and there is no answer.
>
> > Senior physician, charitable hospital (36)

In addition to the ambivalence around the *content* of the policy, respondents also revealed that more than one *source* of policy guidance on this aspect. Apart form NACO's policies, a Supreme Court ruling from 2002[262] was also cited which emphasised the rights of the spouse to protection over the patient's right to confidentiality.[263,264,265]

Reluctance to approach partners

The act of involving partners / spouses required an active effort on the part of the practitioners to identify partners and encourage them to attend the clinic. Some doctors were not entirely at ease with this extension of their duties beyond immediate clinical care. Said one physician[266], 'honestly speaking, we do not do it'. Additionally, the pracitioners reported practical problems in identifying and communicating with partners and spouses of patients.

> What are you going to do? Call up? Send a letter? Or call her and then discuss the test with her? Very difficult. Also, which partner are you talking about? Suppose you have got HIV from someone else? What about that partner? Here you are only talking about the spouse. What about any other partners there might be?
>
> > Venereologist, 7 years experience, government hospital (14)

Circumstances of disclosure

Among doctors who *did* involve themselves with decisions around informing spouses / partners, many reported that patient's opinions and circumstantial factors dictated their actions. Gender asymmetry was often reported as a determining factor around partner notification. Women were perceived to be more likely to face discrimination and adverse outcomes from disclosure of their

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[262] See Chapter 2 (2.1.3 Relevant Acts and legislations)
[263] Respondent 17: Physician and administrator, charitable hospital
[264] Respondent 23: Venereologist, government hospital
[265] Respondent 39: Microbiologist, private hospital
[266] Respondent 36: Senior physician, charitable hospital

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status to spouses, than men.[267,268] Frequently, doctors said they took a personalized approach to the issue of involving partners, given the differences in patients' responses.

> We encourage the patient to disclose the status to their partner. Most people have the initial anxiety and then they bring along the partner but there are still few who neglect that.
>
> Senior physician, charitable hospital (17)

> I have never had a situation where a patient has not agreed to disclose the status to the partner or family, but it might have taken 3-4 visits at a time. You may need to give them time to deal with their problem rather than saying that it is major problem and I have to do this and that.
>
> Venereologist, 18 years of experience, charitable hospital (18)

A physician from a charitable hospital described his subjective experience of making decisions around involving partners and relatives.

> So many times we make individual value judgments that may differ from case to case... At times you play God. But at times I do feel that to enjoy a long term trust and rapport with the patients, you know your patient well and they trust you, over a period of time... you know that I should tell [disclose the result] here, I shouldn't tell here. You go by your instincts, your gut feelings which are very difficult to quantify.
>
> Senior physician, charitable hospital (36)

In summary, the issues around involving spouses / partners of HIV positive patients were complicated by somewhat conflicting policy directives. Doctors perceived a confusion of roles between established clinical norms favouring absolute confidentiality, and the "HIV-specific" push for involvement of partners. Some were not comfortable with the excess effort and intricacies involved in notifying partners. Among those doctors who did engage, their actions were often determined by perceptions of patients' personal circumstances and responses.

5.5.5   Involvement of patients' families

The national policy (NACO 2005) states that: "such (HIV test) results should be given out to the person and with his consent to the members of his family... The person should also be encouraged to share this information with the family." Families were reported to be often closely involved with the care of HIV positive patients in the hospitals. Frequently relatives were

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[267] Respondent 36: Senior physician, charitable hospital
[268] Respondent 66: Senior microbiologist, government hospital

allowed to have knowledge of the patients HIV status, for a number of reasons, with or without the patients' consent. Doctors' varied approaches and perspectives on the subject are explored.

Response of family members

Family members' reactions to knowledge of patients' HIV status were variable and unpredictable. Serious adverse outcomes of disclosure of HIV-positive status to families and spouses were reportedly more common for women: 'Most common was the husband infecting the wife, the girl getting abandoned, or thrown out, back to mother's house', recounted a government microbiologist.[269]

Within hospitals, family members were seen to have considerable usefulness, in their role as attendants to administer closely to patients needs, as mediators for deliberating with doctors on the care of the patient, and in the case of government hospitals, even to perform errands such as delivering samples and picking up reports.[270,271] As such, given relatives' close involvement; it was often not easy or expedient on the part of practitioners to hide knowledge of the patients' HIV status from them.

Laissez-faire approach

Across different sectors of hospitals, a laissez-faire approach prevailed with respect to the involvement of families, with no special effort being made either to shield patients' test results from them, or to systematically inform them with the patients' cooperation. Neither government nor private hospitals ensured that test results were delivered specifically to the patients, and frequently relatives collected reports on behalf of patients.

> There is no policy, there is no system – sometimes the patient comes to collect it, sometimes the patient's relative comes to collect it – there is no clear cut guideline about the referred patients...who do we give it to.
>
> Senior microbiologist, government hospital (24)

> If you give out a report, very often the relatives receive it. There are few instances in which confidentiality is maintained. The whole family is involved.
>
> Physician, 12 years experience, private hospital (35)

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[269] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital
[270] Respondent 27: Junior trainee venereologist, government hospital
[271] Respondent 30: Senior physician, government hospital

Often, no efforts were made to separate patients from accompanying family members and spouses at the time of consultation. Relatives' involvement in disclosure of HIV test results often occurred incidentally, because they were present or seen to be useful at the time.

> Then there is the question of disclosing the result to unsuspecting patients. I think that is a matter of tact. Like the patient just we saw. Suppose there is somebody with the patient. You identify unconsciously who is the more sensible of the two. This man was a duffer. Obviously his wife was the sensible person. You play it by ear, up to a point.
>
> Senior surgeon, private hospital (34)

The involvement of family members was seldom undertaken systematically or supported by counselling. Decisions to involve families in knowledge of their HIV status were perceived to be the responsibility of the patients: 'Involving the family is up to the patient' said a government gynaecologist.[272]

Summarily - while family members were often useful in caring for patients in the hospital, their responses and reactions in the long term may not always have been favourable, especially for women patients. In what could be construed as a lax approach to confidentiality, family members' were often not actively prevented from accessing patients' reports and clinical status, and were informed of patients' HIV status (often without patients' consent) when it was seen to be expedient.

5.5.6 Confidentiality in uncontrolled environments

According to some respondents, lack of time, space and resources were important factors in not being able to achieve high standards of confidentiality, especially in government hospitals.

> When you want to have confidentiality you must have a one to one relationship with your patient... neither do we have the space nor do we have the manpower. When you have 100 patients coming to your OPD then where do you have place for one patient - one person [doctor]? The same thing goes for the ward and the labour room. We don't have the resources for it...
>
> Head, gynaecology department, government hospital (21)

A prevailing culture of "listening in" and not observing personal privacy was also reported as a contributing factor in failing to ascertain total confidentiality.

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[272] Respondent 20: Junior gynaecologist, government hospital

You see, a normal OPD is crowded.... I've noticed one interesting thing that mostly the patients who even listen to it, don't consider it to be taboo, they don't feel that "Doctor Saab is looking at a patient, so lets stand away". The other patients never shun them and that is not an issue.

Venereologist, 10 years experience, government hospital (23)

There is no respect for the individual. If I am sitting in this room and talking to you and he is sitting in the front, he is my secretary, and he is not supposed to listen to me but no, he will listen to me! That is the kind of country we are in. This is our culture.

Senior surgeon, government hospital (29)

Added to these factors, the *requirements of co-workers* and the *involvement of families and spouses in patient care* all added to the difficulties of ensuring strict confidentiality. In such a context of shifting circumstances and varying requirements of actors, doctors often responded by adjusting to the needs of the situation, rather than enforcing policies uncompromisingly.

We are trying to keep it confidential. At times I see the residents talking loudly and I tell them, don't talk loudly... at times in the rounds other patients are also there, and if we mention that she is a positive patient, they will be staring... so we say, be a bit careful about this.

Gynaecologist, 8 years experience, government hospital (22)

I think, because we know that we are not able to maintain confidentiality, so we take it loosely... and in the West they are able to maintain, so they feel that it should be done...

Senior gynaecologist, government hospital (21)

While a number of respondents were broadly in favour of its principles, "strict confidentiality" was often regarded as a target to strive toward rather than a basic standard of quality to be ensured on every occasion.

5.5.7 Confidentiality: summary

A number of doctors across all sectors said that they valued the importance of confidentiality in their dealings with patients. In some institutions, special procedures had been instituted to safeguard the confidentiality of HIV positive patients. However some doctors perceived flaws in the text of government policies, and were of the opinion that HIV status should have been available to all health workers, in order for them to avail of protection from procuring the infection.

Most doctors reported that they strived to ascertain a standard of confidentiality at most times. However there were many instances where it was reportedly difficult to prevent particular individuals from accessing knowledge of the patients' HIV status (and even expedient to permit them to do so).

As such, confidentiality and disclosure of HIV test results to third parties was an aspect in which doctors were most liable to exercise discretion. The close involvement of a number of actors – spouses, families and health workers – with individually varying roles and requirements, contributed to unique and changeable environments for each patient. Doctors were faced with plural and simultaneous concerns of expediting immediate patient care, being mindful of their long term well-being, recognizing health workers' needs, and complying with institutional and professional norms.

Explanations

Doctors' explanations for their response to confidentiality policies are listed below.

Reasons For Following Policy	Reasons For Not Following Policy
- Compliance with official norms - Maintaining professional standards of secrecy	- Health workers' right to knowledge of patient status, to enable self-protection - Logistical difficulties of hiding reports from health workers, and family - Usefulness of health worker "grapevine" in normal hospital functioning (Private hospital) - Inadequate space and resources (Government hospitals) - Expediency of involving family in patient care and hospital errands

Table 5.10 Reasons For Following / Not Following Confidentiality Policy

Discussion

Policies for strict confidentiality of HIV test results, as stated in the national policy, are in tune with, and may have reinforced, orthodox norms of professional secrecy. However phobias around acquiring HIV among the medical practitioners sometimes led them to make an exception by permitting intra-hospital dissemination of patients' HIV status. HIV testing also brings with it the

added requisites of the disclosure of HIV test results to spouses and families to prevent further spread of HIV and facilitate their involvement. Practitioners were not always mindful of, or equipped to deal with the delicacy of these decisions and their potential for adverse social outcomes for patients.

The widespread ease of access to patients' status and test results for different groups of individuals within the hospital, and the resultant likelihood of stigmatization and discrimination of patients with HIV, is a concern that bears addressing in all sectors of hospitals. At the same time, practitioners need to be better supported in making enlightened discretionary decisions around disclosure of test results to spouses and family.

Chapter 6. Medical Practitioners' Accounts: Interface with Other Groups

Medical practitioners' accounts of their interactions and relationships with different groups of policy actors are presented in this chapter, drawing on the interviews with practitioners from all nine hospitals. Data from Key Informant interviews was also used to provide contextual information.

6.1 GROUPS FORMALLY CHARGED WITH IMPLEMENTATION

6.1.1 Institutional administration

Hospital administrators

In *government hospitals*, there was little recognition by practitioners of any role of hospital administrators or superintendents in either propagating or enforcing HIV testing policies. Issues around HIV testing were sometimes characterised as being of a day-to-day nature, and not suitable for the attention of Medical Superintendents or Deans.

> The [Head of Institute] will give him maybe a piece of his mind, but then will forget this. It is not possible for the [Head] to tag behind why this guy is not doing that cholecystectomy [on a patient suspected of having HIV].
>
> Physician, 8 years experience, government hospital (16)

> This is a [matter of] day-to-day running... whether you are marking your beds or whether you are whispering about your patients, announcing it, who is to check? It may not even reach the MS [medical superintendent]
>
> Key informant

The hospital administration was not associated with a monitoring and supervision role, but more of a refereeing role for complaints and problems ('if something going wrong with HIV care',[273] 'if somebody raises an issue about pre-surgical testing'[274]), to adjudicate disputes and enforce discipline.[275] The Superintendents were also perceived in a protective role for practitioners, and were seen as a buffer from complaints and demands of patients, NGOs and pressure groups.

In the *private hospital* the hospital management was seen as being more closely involved in issues around HIV care and testing. When the administration attempted to introduce consent procedures and outlaw mandatory HIV screening, many doctors - especially surgeons - had resisted. It was apparent that the management eventually prevailed and hospital policies were modified accordingly. However, in spite of the hospital's formal adoption of policies in line with national guidelines, many doctors did not appear to be constrained by these requirements, and continued their digressive practices unhindered.[276,277]

In one *charitable hospital*, respondents related that hospital policies were created by the administration following protracted discussions between practitioners and administrators. The policies were broadly in line with national policies in promoting informed consent and confidentiality; however they differed in the key respect of permitting pre-surgical screening.

> The administration had to take a clear policy stand on the issue. But it reflected lot of tension – tensions and demands and a lot of negotiation which will never be stated in the policy.
>
> Physician, 15 years experience, charitable hospital (65)

There was a free exchange of views in this hospital between practitioners and administrators, even on contested policy issues such as pre-surgical testing. Practitioners broadly expressed their confidence in institutional policies. One physician claimed: 'It is better to have an institutional policy... because that is what people will follow. It is more relevant to you in your workplace...'.[278] Compliance with institutional policy was reported to be high.

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[273] Respondent 24: Senior microbiologist, government hospital
[274] Respondent 32: Junior surgeon, government hospital
[275] Key Informants
[276] Respondent 25: Senior surgeon, private hospital
[277] Respondent 34: Senior surgeon, private hospital
[278] Respondent 17: Physician, charitable hospital

HIV/AIDS committees and departments

Although they did not seem aware whose role it was to ensure infection control, many *government hospital* practitioners complained about shortage of protective equipment and lack of post-exposure prophylaxis (PEP).

> The question is, have they given every one these visors? Have they given enough gum boots? If the answer is no, then the hospital should be shut down. Or we should test [pre-surgical HIV screening]. They are just moralising, you ask them, these are all the things required for universal precautions, they don't have them...
>
> Senior surgeon, government hospital (31)

In some of the government hospitals, there were separate departments dedicated to infection control and safety, which were responsible for administering many HIV related policies and programmes. The authority and role of the infection control department, and in some instances even its presence, was not acknowledged by many practitioners.[279][280]

Unlike in the government hospital, in both the *private* and the *charitable hospital*, HIV committees were regarded as being closely linked to the hospital administration.

Intra-departmental authorities

Within different clinical departments of *government hospitals*, it was reported that there was some discussion but little consensus on appropriate HIV testing practices. Department heads were generally not regarded as enforcers of policies.[281] There was a particular air of secrecy and little open discussion within departments around contentious issues like mandatory testing. Said a microbiologist, 'I don't know why we are not openly discussing this issue'.[282]

Within clinical units however the story was usually one of close knit teams and compliance to the dictates of seniors or the unit Head. In surgical departments, some units actively adopted a policy around mandatory testing which was contrary to national guidelines. However the practice had only tacit and unofficial permission from Heads, which allowed them to disown responsibility in case the practices were exposed.

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[279] Respondent 31: Senior surgeon, government hospital
[280] Respondent 32: Junior surgeon, government hospital
[281] Respondent 22: Gynaecologist, 8 years experience, government hospital
[282] Respondent 24: Senior microbiologist, government hospital

> The Unit Head does decide, but generally Heads will not take matters into their own hands, because if somebody raises an issue at any time, then they will not like to expose that they have been getting investigations [pre-surgical HIV tests] done [against official policy].

> Junior surgeon, government hospital (32)

In the *private hospital*, certain surgical departments practiced pre-surgical testing, but there was no indication that this was a resulted of concerted decision-making within departments or units. Frequently, there were claims by doctors in private hospitals that all such decisions were made on an individual basis.

In the *charitable hospital*, departmental meetings and discussions within clinical teams on the subject were common, even on contentious issues. Departments and teams were seen as instrumental in propagating institutional policy, and training of junior staff on HIV care included instruction on the hospital policy. Active policy decisions however appeared to be deferred to the hospital administration.

Interface with institutional administration: summary

The institutional context is clearly an important one, however with regard to HIV testing, the participation of institutional agents in setting and implementing policy appeared to be variable.

In *government hospitals*, the central administration were not seen to be major actors in implementing HIV testing policies, regarded as having the role of overseers and adjudicators, rather than supervisors. The role of infection control departments was barely acknowledged. Intradepartmental decisions and discussions around these issues were not common, and Heads of Departments were not seen as being influential in enforcing policies. Unit Heads sometimes dictated policies around contentious issues, but did not openly acknowledge their positions.

In the *private hospital*, the administration's role in changing policies to meet national standards was resented by many doctors. However doctors often continued to practice autonomously and contrary to hospital policy. Department Heads were not cited as being influential, however strong team affiliations may have existed within surgical units.

In the *charitable hospital*, the hospital administration's role was seen as a strong central one. Hospital policies which were enacted through the mediation of department heads and units, and widely followed by the practitioners. This harmonious equation in implementation was possible as a result of the participatory nature of policy-setting, given the active involvement of

departments in hospital-level decision-making, and the fact that hospital policies had been modified to accommodate practitioners' interests.

6.1.2   Government and legislature

Perspectives of practitioners on the role of government health authorities, on relevant laws promulgated by the national government and on prospective laws around HIV/AIDS are presented.

Government health administration

Many practitioners did not necessarily interact actively with representatives of the health administration and the role of bureaucratic / administrative bodies were seldom cited specifically. They were not regarded to have any connection with specific issues such as HIV testing.[283]

However, the construction of "government", an entity regarded as being on a higher plane than institutional employers or the workspace, or the conception of being in government employ (for government doctors) was often cited as a context or an explanation for behaviour or actions. Some *government doctors* referred to being part of a chain of command under the government as part of their professional identity, regarding it as a framework for their actions: 'we are all bound by the government's directions which we receive' said one gynaecologist.[284]   For government doctors, following government policies were widely recognized as being a norm, even if the norm was not always adhered to.[285,286]   Paradoxically though, the emphasis on HIV/AIDS was often described as being foreign to, and a distorting influence on government service values. Taking an interest in activities around HIV/AIDS was sometimes regarded as superficial or meretricious.[287]

Among *private sector providers* however, there was a widespread conception that they were not accountable to the government in their practices. The government was also described as being unsupportive of their initiatives and unresponsive to their needs.

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[283] The nomenclature of government health administration here is applicable to the Department of Health under the Ministry of Health and Family Welfare at a national level; and state Departments of Health at state level. Technically, NACO and national and state medical councils are also part of the governmental health administration machinery, but they have autonomous and semi-autonomous status, and hence are dealt with separately. More details of the organization of government health machinery is presented in Chapter 2 (2.1.2) and Chapter 7 (7.1.1)

[284] Respondent 19: Gynaecologist, 15 years of experience, government hospital

[285] Respondent 23: Venereologist, 10 years experience, government hospital

[286] Respondent 29: Senior surgeon, government hospital

[287] Respondent 66 Senior microbiologist, government hospital

> The private sector has no help from the government, has no help from any religious body, has no help from any corporate. They are existing on their own, and they have to grow.
>
> Senior surgeon and administrator, private hospital (26)

> There are [training] programmes for the government sector doctors, but they don't make any effort to involve us.
>
> Physician, private nursing home (67)

In private hospitals, some doctors were aware of the government's stance on HIV testing and care, but the policies were not regarded as binding or compulsory in any way.[288,289]

In the *charitable hospitals*, the principles of government policies were generally recognized, but there was no indication that these were considered to be binding.

Consumer laws

The inclusion of medical services under the Consumer Protection Act (CPA) in 1995 meant that doctors could be prosecuted in consumer courts, purportedly faster and more convenient than civil and criminal courts. Among doctors in *government* hospitals, there was a mixed response to the spectre of litigation in consumer courts. Some expressed their apprehensions[290], while others said that they felt immune to prosecution since consumer action was only applicable for paid services, whereas their services were provided free.[291,292]

Even though the trends of clients actually taking legal action are not well known, many doctors in both sectors, but particularly in *private hospitals* had strong feelings about the threat of litigation.

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[288] Respondent 34: Senior surgeon, private hospital
[289] Respondent 38: Medical superintendent, private hospital
[290] Respondent 21: Senior gynaecologist, government hospital
[291] Respondent 23: Venereologist, 10 years experience, government hospital
[292] This is accurate but not a widely known fact among government hospital practitioners. According to Bhat (1996), the Supreme Court ruled that the CPA is applicable to *paid* medical services. Hence Government services would typically be exempt, except in instances (in some states and municipalities) where user fees are charged.

> I think the need of the hour is awareness. But with awareness, comes the problem of half knowledge. These days there are so many cases in the consumer courts. There are many of these cases against our clinic. These patients are not really aware of the issues. They don't really know what medical negligence is. They just know that one can go and file a case against doctors. They are just going to the court, and filing the case. And then the doctor has to go to the court, and *maaro chakkars* [run around].

<div align="right">Physician, private nursing home (67)</div>

HIV/AIDS Bill

While the HIV/AIDS Bill[293] did not represent an actual but only a potential policy influence, doctors' marked response to it was an indicator of their attitudes and response to legal reform for greater regulation of their practices. According to a key informant, legal reform was likely to have a partial deterrent action on practices which violated the NACO policies. Some doctors thought it was important to stay on the right side of the law, even if unwillingly so.

> Let the legislation come, and then we will see. I am a law-abiding citizen. If the legislation says that I shall not go to bed with my wife, then I shall not. There is nothing I can do... the government is supreme. They are the *Rajas*, the *Maharajas*. They want to introduce the legislation and revert that. How can you do anything about it? You cannot do anything.

<div align="right">Senior surgeon and administrator, private hospital (26)</div>

There was a widespread feeling of apprehension with relation to the Bill.[294] Legal sanction for HIV testing policies was felt to be unjust in the context of imperfect environments for complying to them, and the existence of more basic issues around lack of regulation.

> I think it would need to be opposed by doctors. You are introducing so called accountability for these things... there are so many more problems in the country where accountability should be much much more.

<div align="right">Senior gynaecologist, government hospital (21)</div>

> [Quacks] are giving out prescriptions everywhere. What is the government doing? Nothing. So when we make a law only one sincere person will be sued by somebody, and he will have to pay through his nose.

<div align="right">Senior physician, government hospital (37)</div>

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[293] See Chapter 2 (2.1.3 Relevant Acts and legislations)
[294] Several respondents (24, 41, 21)

A HIV/AIDS Law would only, it was felt, lead to subversion or defensive practices, felt one physician.[295] Others felt that it would create a 'panic situation'[296], that laboratories might hesitate from doing the tests, and physicians may be less likely to treat people with HIV/AIDS.[297] A government surgeon pointed out numerous ways of subverting the law, by taking advantage of the fact of patients' deference to doctors' orders.

> There are many answers for this. For example just like we outsource the sanitation, we will ask the patient that go and get the investigations done [from a private diagnostic laboratory outside the hospital]. We will tell them by mouth, we wont write it down. If I don't want to follow, there are so many ways of subversion. I will write it on a blank piece of paper. But if you see below, there is no signature. You tell him, get the test done, and he will get it done.
>
> Senior surgeon, government hospital (31)

Yet others felt that the law could play an educative function and provide guidance on complex ethical decisions. However this was an atypical response and, almost universally, fear and apprehension characterized doctors' responses to the idea of legal reform.

Interface with government and legislature: summary

Interactions with government health authorities were very limited in all instances. *Government doctors* were conscious of their identity as public servants, in which context government policies were seen as normative. *Private doctors* perceived no such sense of accountability and regarded government as being largely unsupportive. Consumer laws were regarded to have significant 'nuisance' value by doctors from private and government sectors. The possibility of legal reform through the submission of a HIV/AIDS Bill evoked universally strong responses, with many doctors voicing apprehensions. It was widely felt that a law regulating HIV/AIDS practices was unrealistic in the context of imperfect environments for adhering to policies, and would lead to defensive and subversive practices.

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[295] Respondent 30: Senior physician, government hospital
[296] Respondent 14: Venereologist, 7 years experience, government hospital
[297] Respondent 37: Senior physician and administrator, government hospital

6.1.3 The HIV/AIDS programme

The National AIDS Control Organization (NACO)

In the *government hospitals* NACO policies are widely acknowledged and followed, at least nominally, with some exceptions. Partially this was a result of VCTCs and ART centres (which are part of the HIV/AIDS programme[298]) being physically located in the hospitals, and being important sites for HIV testing and care provision. NACO are responsible for instituting and funding VCTCs and ART centres and, through the State AIDS Control Societies, provide equipment and salaries for their upkeep.[299,300]

The procedures instituted in the VCTCs and ART centres, such as consent forms and reporting mechanisms, and the presence of trained programme staff, act as guides on NACO's policies for doctors when performing HIV tests. In exchange, a measure of accountability was required, through means of record keeping and reporting of data to NACO: 'Every month we have to send data, how many walk-ins, how many referred, how many positive'.[301] Supervisory visits were conducted by the programme, and deficiencies and divergences were highlighted by these inspectors. Respective Department Heads were generally held accountable for these divergences by programme officials.[302,303]

Broadly NACO was seen by government practitioners as a *multi-functional agency*. Apart from being resource providers for HIV/AIDS care and propagators of norms of practice, they were also regarded as a nodal research body for HIV/AIDS (conducting surveillance).[304] Many doctors tended to view their relationships with NACO and SACS as research collaborations. Professional relationships and acquaintances with particular individuals in the HIV/AIDS programme were often cited, who may have been important in the development of these collaborative relationships.[305,306]

Doctors had a number of concerns and reservations over the content of NACO's policies or over their application, as has been discussed in the previous chapter. In some instances, the doctors had attempted to feed back these concerns to programme authorities, but perceived that they were

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[298] The distinctions between government health "programmes" and the government health administration are discussed in detail in the following chapter.
[299] Respondent 02: Senior physician, government hospital
[300] Respondent 16: Physician, 8 years experience, government hospital
[301] Respondent 24: Senior microbiologist, government hospital
[302] Respondent 02: Senior physician, government hospital
[303] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital
[304] Respondent 23: Venereologist, 10 years experience, government hospital
[305] Respondent 22: Gynaecologist, 8 years experience, government hospital
[306] Respondent 33: Senior physician, government hospital

not responsive to suggestions. One physician felt that 'NACO does not take any suggestions from us because they are guided by the US'.[307] Another government physician recounted his experience of seeking clarifications over the informed consent policies, with NACO officials.

> Why do you have to do this? Why do you have to take written informed consent before doing a test? I asked everyone in the hospital, everybody knew that there is this policy but nobody knew where it has come from. And they all agreed with me – they said yes, there is no reason for it. I visited people in NACO...Nobody could tell me where this has come from. Finally [a NACO officer] agreed – they have this, but they don't know where it has come from. He just said "its there"
>
> Senior physician, government hospital (33)

Hence NACO officials were unable to give a satisfactory explanation of the contents of their own policies, in spite of the efforts of this respondent. In other instances however, doctors did not challenge the policies and instead sought more specific or comprehensive guidance from NACO on issues around testing and care. One gynaecologist felt that there was a need for more written policies and 'clear-cut listed guidelines'.[308] A venereologist reported uncertainties around the correctness of certain day-to-day aspects of clinic functioning, and felt that more detailed guidance from NACO would be appropriate.

> When you put a patient in the ward and he is HIV positive should you label it or not? What is the policy of NACO in that? Should we write in the case sheet? Ideally you should not but if we don't there could be a chance of mishandling... NACO policies, do they clearly say that in a ward setting, should we write "HIV+" on the case sheet?
>
> Venereologist, 10 years experience, government hospital (23)

In *private hospitals*, broadly there was little recognition of NACO's authority, and it was generally regarded as another organization with which collaborations could be undertaken.[309,310] For some, NACO's role was perceived to be one of public health education, rather than of agenda and policy setting.[311] Even in some instances where there was awareness of NACO's policies against pre-surgical screening, compliance was not felt to be feasible, in the face of other pressing concerns such as physical protection from infection and the costs of universal precautions to patients.

> NACO is advising us to do tests only for diagnosis. It's not possible! These are practical things which don't change easily. They are saying that practice universal precautions, but how is that possible for everyone,

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[307] Respondent 37: Senior physician and administrator, government hospital
[308] Respondent 22: Gynaecologist, 8 years experience, government hospital
[309] Respondent 08: Senior physician, private nursing home
[310] Respondent 25: Senior surgeon, private hospital
[311] Respondent 35: Physician, 12 years experience, private hospital

> there are a lot of costs involved. As an idea, it's okay. [But] Especially in
> the private sector, we have to think about costs to the patient.
>
> Physician, private nursing home (67)

Meetings on the implementation of HIV testing policies were reported to have taken place between representatives (administrators and medical staff) of a private hospital and HIV/AIDS programme officials. These meetings failed to reach a resolution, purportedly because of a fundamental difference in perspective: programme officials regarded the discussions as an opportunity to enforce their policies, whereas the doctors viewed it as a process of negotiation towards deciding a mutually acceptable position.

> They said that there is no question of any consensus statement, because
> we are representatives of the government. We already have our own
> position on it. What position it was we never knew because they had left.
> Its so stupid. Its like many Indian government attitudes.
>
> Senior surgeon, private hospital (25)

> If I am your wife, and you're my husband, there is no communication,
> what can came out of it. We had a consensus opinion about it of our own,
> without their participation.
>
> Senior surgeon and administrator, private hospital (26)

Respondents from the *charitable hospitals* did not mention any exchanges or interactions with NACO.

State AIDS Control Societies (SACS)

In *government hospitals*, State AIDS Control Societies (SACS) were viewed as conduits for NACO, being operationally responsible for providing funding and material support for VCTCs and ART centres, paying salaries, instituting procedures, and collecting reports.

> They provide us with the [HIV testing] kits. The ELISA reader is
> provided by them, CD4 counter is provided by them, the refrigerators,
> the rotators for VDRL – we get a lot of support from them. The staff is
> ours... some staff is also provided by them, the counsellors, the
> technicians. We have to give our data and figures to SACS they send it
> on to NACO.
>
> Senior microbiologist, government hospital (24)

There was a measure of accountability of hospital departments to the SACS in the areas in which support was received from them. Beyond this, although they were more proximate to the hospitals than NACO, the SACS appeared to have little role in monitoring the HIV testing

practices of physicians in HIV testing. The role of the SACS was seen – by doctors – as that of an external donor, facilitator and collaborator (even as for counsellors and technicians [312] they were immediate employers).

Doctors from *private and charitable hospitals* revealed little, if any intercourse with the SACS.

Interface with HIV/AIDS programme: summary

NACO and the SACS were responsible for setting up and supporting HIV-related work in hospitals, and within the ambit of VCTCs and ARTCs the programme may have had an influence on field-level activities. Outside of these activities, the HIV/AIDS programme agencies were seen as potential research partners and collaborators. In instances when doctors challenged the rationales of NACO's policies, their response was felt to be unsatisfactory, and they were widely regarded to be unresponsive to feedback on contentious issues. In some instances a need for more detailed guidance from NACO on correct ethical practices in HIV care was expressed by doctors.

The jurisdiction of HIV programme authorities was not recognized in *private hospitals*, and their attempts to impose their norms on the hospitals were widely opposed.

6.1.4   Professional regulators

Medical councils found little mention as being influential among doctors in any sector of hospitals. Frequently, councils' roles were discussed in the context of regulating medical education, but not medical practices. A number of doctors and key informants were of the opinion that medical councils did have the power to influence doctors' practices, but took little initiative in that regard. One surgeon from a private hospital felt that 'if the State Medical Councils say, the doctors will follow (policies)'.[313] Medical councils had the nominal power to revoke licences, but due to their inaction, had 'rendered themselves toothless', according to a key informant.[314]

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[312] These staff were employed on a contractual basis, and several operational problems were reported in the timely disbursement of their salaries.
[313] Respondent 25: Senior surgeon, private hospital
[314] Respondent 45: Key Informant

6.2   EDUCATIONAL AND ACADEMIC PLATFORMS

Formative education

Undergraduate medical education and work cultures in teaching institutions were cited as formative influences on the behaviour of doctors. Areas such as interpersonal communication, and ethics which are important in the context of HIV testing were considered non-technical and were traditionally given less importance.[315]

> When did we as students ever get trained, or train students in interpersonal communication and skills?... Most of the people have been trained in the government set-ups and in the government set-ups nobody ever had the time. And the inclination was also possibly poor. Anybody who is more sensitive possibly feels a little more.... anybody who does it spontaneously, does it on their own, otherwise they don't do it. They have never been made to think about it that way.
>
> Senior gynaecologist, head of department, government hospital (21)

A key informant was of the view that teaching institutions promoted the concept of a 'sanitary inspector' approach to public health problems, particularly communicable diseases, focused on active case finding and a utilitarian ethic: 'Locate the carriers, isolate them, cure them'.[316] According to him, this shaped attitudes among many medical providers, particularly doctors in government hospitals.

In-service training

Government doctors were exposed to formal training programmes to a limited extent within their own institutions. These workshops were conducted either by the government or by technical agencies partnering the government, such as the WHO. Respondents from government hospitals had mixed feelings about these programmes, expressing scepticism about the imposition of alien "western concepts", but also a keenness to learn new concepts and skill-sets such as counselling and interpersonal communication.[317,318]

Among *private sector doctors*, perspectives vis-à-vis continuing education were quite different. Doctors from the private nursing homes rued the lack of opportunities to update their knowledge on emerging areas such as HIV/AIDS. In this context, doctors highlighted the importance of

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[315] Several respondents (21, 67, 39)
[316] Respondent 48: Senior consultant to UN technical agency
[317] Respondent 37: Senior physician, HIV specialist and administrator, government hospital
[318] Respondent 67: Physician, private nursing home

personal initiative in identifying opportunities to expand their knowledge and identify training opportunities.

> There are many programmes which are available to government persons [doctors], but for the private [doctors], there are not many options... There is no effort to involve us. I have been looking for a training opportunity in HIV for the past year.
>
> <div align="right">Physician, private nursing home (67)</div>

> There are no regulations which allow me to learn about HIV. The major flaw in our medical profession is that there are no regulations for post-training. ... so whatever doctors are learning, they are learning on their own.
>
> <div align="right">Senior physician, private nursing home (08)</div>

The few HIV training programmes that were available to doctors in the private sector were run by a variety of different agencies. Typically, such programmes were collaborations between a funding partner - such as a major international donor, and a technical partner – a medical association or a teaching institute or university. Experiences of training programmes - particularly of the intensive, practically-oriented type – were almost uniformly positive for practitioners. Respondents spoke of experiences of professional growth, transformation of preconceptions, and of the value of such programmes in creating career avenues and openings for future collaborations.

> I was keen to know more about HIV. I wanted a career option, which I could take further, and which not a lot of other people were doing... Then I joined this programme [an intensive training course on HIV medicine] I have done a M.D before, but we never did anything like this, how to plan and programme... The main thing is, that we have learnt to implement things, not just receive knowledge. Now I am very keen to develop the services in our hospital.
>
> <div align="right">Physician, private nursing home (67)</div>

However good quality training courses focusing on HIV/AIDS issues may have had limited reach, and many in the private sector remained unexposed to newer concepts in HIV care. According to the same respondent, '...not a lot of people (colleagues) know what is VCT... Those who are working in the field know about it. Those who are not, don't'. Technical training and CME programmes were available to some extent for doctors in private *hospitals*, but were said to give little attention to HIV/AIDS related issues and may even, as in one programme in which pre-

surgical screening was recommended, have included instructions which were contradictory to national policies.[319]

Apart from the residual influences of formative medical education, and references to the West for guidance (see section 6.3), what were the sites of development of professional culture for these doctors? From respondent's accounts, there were few indications of the influence of shared professional cultures or norms of work in the medical fraternity, or of organized discourse on a cross-institutional scale, on their practices. Key informants felt that the sites for exchange of knowledge and ideas - journals and fora such as medical associations were deficient in discourse on serious academic subjects.[320] Particularly, discourse on ethics and rights was felt to be lacking. According to one informant, in the absence of widespread discourse or exchange across the medical fraternity, individual workplace cultures often tended to have a dominant impact on practices.[321]

Doctors (or departments) in government hospitals sometimes undertook collaborative research and educational projects in conjunction with peers in other institutions and with national and international donors such as the SACS and NACO, and WHO and UNAIDS. In many instances collaborations with international agencies were linked to the provision of aid and materials through the mediation of the HIV/AIDS programme.[322] These collaborations contributed to doctors' academic environment.

Box 6.1 Limited Opportunities of Academic Exchange

Educational and academic platforms: summary

Most doctors from *all sectors* had been trained in government medical colleges and the culture of those institutions, characterized by the focus on clinical tasks and neglect of areas such as interpersonal skills training, was said to have a lasting influence on practice cultures. The conflation of clinical service delivery roles with public health roles (maximising case detection) – a culture among government doctors - may also have been ingrained in medical educational institutions.

Training programmes were relatively easily available to *doctors in government hospitals*, and were important avenues for the transfer of policies and ideas. The doctors' acceptance of these programmes was mixed. Since their undergraduate or postgraduate medical education,

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[319] Respondent 35: Physician, 12 years experience, private hospital
[320] Respondents 05, and 52: Key informants
[321] Respondent 45: Key informant
[322] Respondent 02: Senior physician, government hospital

opportunities for discourse outside the workplace sphere were few and far between, particularly for doctors in the private sector. *Private doctors* found it difficult to access training on areas around HIV/AIDS since these were usually initiated by development agencies and tended to preferentially admit government doctors. However their experiences of such programmes were positive in terms of professional development.

For practitioners working in environments deprived of avenues and cultures of serious discourse, the benefits of professional interactions ran deeper than the matter of adherence to policies. For many practitioners, establishing contact with peers and people in related disciplines, through training programmes, research projects and collaborations represented unprecedented opportunities for self-actualization and professional growth. The HIV/AIDS movement in particular may have exposed a number of doctors to ideas and concepts which were not otherwise given importance in their formative education.

6.3   OTHER KEY INTERACTIONS

6.3.1   International organizations

Technical guidelines published by such agencies as the World Health Organization or the Centers for Disease Control, Atlanta, were sometimes followed by doctors in *government and private hospitals*. While these were regarded as being markers of high technical standards, there was no indication that they were considered to be binding.[323]   Organizations like the WHO had little direct contact with doctors, other than through sporadic collaborative projects and training programmes.

Another important point of reference for doctors in government and private hospitals was the concept of the "West", as a place of training, the point of origin of normative ideas and principles, or of technical guidance. Many doctors compared their conception of practices in the West with those in their own workplaces.[324,325]   Some respondents had received training in Western countries on aspects of HIV/AIDS care, which they applied to guide their practices in India

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[323] Respondent 67: Physician, private nursing home
[324] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital
[325] Respondent 30: Senior physician, government hospital

> I went to [a USA based technical institute[326]]. I was there for a month, there was an elective. There was a course on diagnosis. Under that, they taught that you can't forcefully impose mandatory testing. It will be violation of human rights.
>
> Infection control officer, government hospital (68)

> Some of us had gone abroad and got trained in all these things, so we were convinced that all these things we were talking about: universal precautions, improved cleanliness and hygiene etc.
>
> Medical superintendent, private hospital (38)

Often the HIV testing policies were categorized as being of 'Western' origin,[327,328] and international organizations, and civil society organizations were regarded as conveyors of these ideas. Opinions on the application, in practice, of the "Western ideas" that HIV counselling and consent represented, was divided. Some respondents pointed out how the policies did not necessarily translate well in local settings.

> Once some people [international experts] had come to check the counselling centre. "Is there an AC[329], toys for the children, cold water to drink, did the counsellor wish you when you entered?". [laughing] It is hilarious. Conceptually, it is a wonderful idea. In a society where they have come to an advanced stage, they are well-to-do, resourceful, it might be OK. But in our set up, the technicians are overloaded with the work.
>
> Senior microbiologist, government hospital (66)

Others were of the opinion that exposure to these concepts was beneficial, and could be adapted for local application. The West appeared to have a conflicted position in the collective psyche of doctors. On the one hand, exposure to training in Western countries represented opportunities for exposure to new ideas, and Western-derived ethical frameworks provided a useful framework within which to articulate their own practical dilemmas. At the same time, there was considerable resentment and frustration at the prospect of following "imported" ideas and policies.

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[326] Name of institute not revealed to protect identity of respondent.
[327] Respondent 37: Senior physician and administrator, government hospital
[328] Respondent 66: Senior microbiologist, government hospital
[329] Air-conditioner

6.3.2   Civil society organizations

Activist NGOs

In *government hospitals*, as described before, patients tended to be docile and generally accepting of doctors advice or edicts, and correspondingly doctors approaches tended to be directive. However there were some reports that patients were increasingly active in asserting their rights in the context of interactions with providers. This was especially so in the context of HIV/AIDS movements with their focus on human rights. The emergence of People Living with HIV/AIDS (PLHA) support networks and groups may also have helped in engendering this newfound assertiveness. Some doctors felt that this assertiveness was a sign of exceptional importance to HIV over other diseases.

> I used to do counselling with Leprosy patients in 1970s. Leprosy patients were grateful, that you are doing their tests, the Lepromin test. But the HIV patient is God. On their own basis, or NGOs basis, they demand. There is nothing wrong with it. Let me give you analogy of a dog and a cat. The dog says that my master is my God, he looks after me, and he gives me food, generally affectionate and devoted. The cat on the other hand says: I am God. There were some cases when HIV patients would pick fights with me. Sometimes, my crude thoughts used to say "you brought the disease here, and you became God?" But on the face of it, I never lost my temper.
>
> Senior microbiologist, government hospital (66)

NGOs and community based organizations sometimes played a role in speaking for the rights of PLHA in healthcare settings. Fear and distrust marked doctors responses to the interventions of these civil society organizations. It was suggested variously that these actors (which included human rights advocates, philanthropic and religious groups, social workers and legal activists) were unsympathetic to doctors perspectives, influenced by alien concepts, or publicity-hungry.

> Sometimes these people I meet in meetings, I feel they have no experience in HIV, they talk as though they have been sent by God, and they are the last word. Some of these people, especially from NGOs, they can be very critical. It is so easy to criticise the system, but try to be in it, change it, in whatever way you can.
>
> Senior microbiologist, government hospital (66)

> So when patients are not objecting [to mandatory testing] then why are [a NGO[330]] making a big deal out of it, maybe under the pressure of USA or some international agencies.
>
> Senior physician, and administrator, government hospital (37)

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[330] Name withheld for confidentiality

> Whenever I used to go to meetings with [Mr. A[331]], I used to have acute panic! I used to feel that these are the people who are doing some good for the society by coming out with legislations, and awareness etc. But I also have an innate feeling that these people are in it for the limelight. I am scared of them, frankly.
>
> Senior microbiologist, government hospital (66)

Pressures from PLHA groups and NGOs may have made doctors more aware of issues around HIV testing, and even had an impact on their practices. NGOs were reported to have acted through various means to correct doctors' practices. They had publicized instances of policy infringements in the media, and influenced politicians and bureaucrats to take cognizance of these shortcomings. They also had representation in various committees and consultations of the government health services and the HIV/AIDS programme. Some practitioners mentioned that hospital administrators played a buffering role, typically protecting them from the ire of activists.

In *private hospitals* however, the activist interventions of NGOs had little impact, and were viewed by practitioners as little more than an opportunity to update their knowledge.[332] Respondents from *charitable hospitals* did not recount any interactions with activist groups.

Care provider NGOs

Many grassroots NGOs assisted doctors in *government and charitable hospitals* in caring for patients. The relationship with them is collaborative, although not typically formal.[333] Doctors widely encouraged the efforts of NGOs to take on responsibilities of patient care that they were incapable or unprepared to handle.[334] Being involved in this supportive capacity enabled NGOs to also have an influence on doctors' practices.

> Because the NGOs are involved, NGOs are ensuring compliance. So, they may be a bad thing for the government set up, but they are the right thing for the society, because they look after the other side [non-technical aspects of care of HIV/AIDS patients].
>
> Senior microbiologist, government hospital (66)

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[331] Name withheld for confidentiality
[332] Respondent 40: Counsellor, private hospital
[333] In some instances NGOs formally collaborated with government hospitals by offering staff or services. But usually, these associations were at an informal level.
[334] Several respondents (02, 28, 32, 70)

Reformer NGOs

In one instance, a project was initiated as a partnership between a local and a international NGO to reform doctors' practices, with an interventional objective to develop and implement hospital HIV policies. The response from doctors was lukewarm, and the programme was not sustained.

> When they made the presentation, HODs were not present, barring 3 or 4 people. So if so few HODs were there, you can imagine what must have been the seriousness of the [response to] presentation, the project.
>
> Infection control officer, government hospital (68)

In the private hospital too, attempts to reform practices around HIV care, on the part of international agencies and NGOs did not meet with a positive response from the doctors.

Interface with civil society organizations: summary

Doctors in government hospitals faced a limited amount of pressure to change their practices, from increasingly aware and assertive HIV positive patients, backed by NGO supporters and PLHA networks. The influence of NGOs was perceived to be fairly strong, given their access to the press and policy decision-makers. Grassroots NGOs provided support to doctors, particularly in government and charitable hospitals, in caring for their patients, and were a source of exposure to non-clinical aspects of HIV care. Doctors in all hospital sectors were generally resistant to attempts of civil society collaborators to actively reform their practices.

6.3.3   Professional associations

Medical associations had apparently little influence on HIV testing practices of physicians either in the private or public sectors. 'The associations have very little involvement or work on HIV' said one physician from a government hospital.[335] Associations were widely regarded as representing the interests of private practitioners. The little involvement that associations had in respect to HIV/AIDS care was to conduct occasional sensitization programmes.[336,337]

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[335] Respondent 02: Senior physician, government hospital
[336] Respondent 69: Senior official, medical association
[337] At the time of conducting this study, the Indian Medical Association were about to initiate a collaboration with the William Clinton Foundation to conduct HIV sensitization programmes for a large number of private practitioners across the country.

6.3.4   Quality assurance and accreditation bodies

Schemes and programmes for ensuring technical standards and quality included governmental schemes such as the External Quality Assurance Scheme (EQAS) for laboratories and accreditation by National Accreditation Boards, and schemes of independent standards agencies such as the ISO. *Government hospitals* were active participants in the EQAS scheme, which however only addressed the technical quality of tests, and did not account for human aspects and procedures around the test such as counselling and consent-taking.

The *private hospital* had received accreditation from an international body, which required it to comply with national guidelines for HIV testing. Consent procedures had been formally instituted as a result of this requirement.

6.4   CHAPTER SUMMARY

Interfaces with implementation systems differed for practitioners from different types of hospitals – government, private and charitable, as a result of the presence of different contiguous policy structures and actors.

Government hospital practitioners

Government doctors were widely influenced by their identities as government servants, in which context they regarded adherence to HIV testing policies propagated by a government department (NACO) as being normative. Some of NACO's policies were institutionalized through the presence of VCTCs in hospitals and a regularized informed consent procedure. Hence the policies were synonymous with organizational rules or norms in these respects, and breaching policies involved breaching organizational (hospital) norms, since diverging from the policies would entail not using these routinized mechanisms, or subverting them.

However paradoxically there was also a widespread perception that HIV policies did not represent organizational goals, and were imposed by influences from outside the hospital. Non-institutional actors appeared to be as instrumental in enforcing policies as *institutional mechanisms* such as departmental and hospital management. Officially, *local representatives of the programme*

supervised HIV policy implementation in hospital departments, and unofficially, *activist NGOs* may have played an active part in monitoring doctors' compliance to policies.

Given the deficiencies of formative medical education in addressing areas around ethics and interpersonal communication, collaborative projects with international organizations, with the HIV/AIDS programme, and with peers in other institutions represented *opportunities for exchange of knowledge* on relevant topics. Informal associations with local NGOs may have helped in orienting doctors towards a broader understanding of HIV/AIDS care.

The *threat of legal action*, while not representing an active concern, was a latent source of worry for doctors. The doctors did not appear to be widely concerned with formal channels such as institutional disciplinary procedures or medical council regulation.

Private hospital practitioners

Private hospital practitioners widely regarded themselves as *independent* agents when it came to practices around HIV testing. The hospital administration's attempts to introduce a policy on the lines of national policy were initially opposed, and the policies when introduced were only partially followed. Influences cited as being conducive to implementation of HIV testing policies included training in Western countries and the requirements of accreditation agencies.

Other than this however, doctors did not appear to have significant avenues for academic discourse on HIV/AIDS, or exposure to ethical issues and concerns. Hospital training in the large private hospital tended to be oriented around specific technical skills. The *government was perceived to be unsupportive* in regard to offering training opportunities to private doctors. Medical associations were seen to be involved mainly in protecting private doctors' political and financial interests, not in academic development.

There was a largely *latent perception of threat* from the likelihood of a law for HIV/AIDS, and from consumer litigation. There was little recognition of the role of government, HIV/AIDS programme authorities, medical councils or civil society organizations in policy implementation.

Charitable hospital practitioners

In contrast with the government and the private hospitals, the hospital administration in one charitable hospital had taken a particularly active stance in formulating and propagating *hospital policies* around HIV testing. The influence of this policy was regarded to be pervasive: its implementation involved the cooperation of departmental heads and there was widespread compliance, attributed to the participatory process through which it was formulated. The hospital policy diverged from government policy in allowing pre-surgical screening.

Apparently there was an active *culture of discourse on ethical issues* and HIV/AIDS within the hospitals. However there was little interaction and few avenues for academic exchange with other organizations in the public or private sectors, other than with local care provision NGOs, and occasionally through collaborations with international organizations and universities. The practitioners largely sympathized with the government's position built on principles of public service and welfare, however did not consider themselves directly accountable to government departments, such as NACO. There was little indication of a role of medical councils, nor a perceived threat of the law.

Chapter 7. Other Policy Actors: Roles and Interrelationships

The first section (7.1) of this chapter outlines the putative roles of different groups of policy actors (other than medical practitioners), in implementing policies. The remainder of the chapter (sections 7.2 - 7.10) elaborates these actors' accounts of their (and their respective organizations') actual participation in implementation processes and interactions with other groups of actors, drawing from depth interviews.[338] Data from key informant interviews add relevant contextual knowledge. In line with recommendations of the LSHTM ethics committee, particular care was taken to exclude details about interviewees which may have allowed them to be identified.

7.1 PUTATIVE ROLES OF DIFFERENT GROUPS

The putative or "expected" roles of different policy actor groups are presented in this section. Hospital authorities and members of various government institutions and bureaus are the groups formally charged with roles in policy implementation. A number of other agencies and groups are potentially influential in the process of implementation of policy guidelines, even if they are not formally instrumental in ensuring implementation, and their "expected" roles too are described. The information presented in this section was derived mainly from documentation obtained from site visits and from the respective official websites of the different organizations (for details of data collection methods, see sections 4.3.3, on page 75). Contextual information on putative organizational roles was also obtained from discussions with key informants and interviews with the respective policy actors.

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[338] See Chapter 4 for details of selection of study participants and data collection methods.

7.1.1 Groups formally charged with implementation

Hospital authorities

Within different hospitals, it is likely there are different styles of management and accountability. The administrative structure in terms of departments and units represents a system of accountability, in that Heads of departments/units are answerable for the services provided by doctors in their department/unit. Superintendents are the ultimate authority and hence also ultimately responsible for staff behaviour. Cadre-based accountability is often practiced in which appointed chief staff of nurses, paramedical and non-medical workers supervise their respective subordinates. Particular departments may have specific areas of authority, for instance a department of infection control may be required to ensure that all staff in the hospital adhere to norms for waste disposal, hygiene, safety and personal protection.

Formal mechanisms for accountability include continuous supervision and monitoring of task performance, periodic inspections and reviews, maintenance and audit of medical records, arbitration and disciplinary procedures, and redress of complaints and grievances.[339] Some government and private hospitals have grievance cells and public relations offices, to address patients' concerns with the quality of care.[340]

Governmental authorities

Departments of Health Services (DHS) and of Medical Education and Research (DMER) at the Centre and in the respective States are entrusted with the implementation of relevant laws and regulations. The standards cited in these Acts and regulations are typically broad, and do not address specific areas such as the actual quality of care provision, or adherence to policies by practitioners. There is little information in the public domain about accountability mechanisms between government health administration and (government or private) hospitals, or within hospitals. Government hospitals, in the position of being financed by health departments, are officially under their direct scrutiny. Typically, government health officers' functions in government hospitals involve periodic inspections of facilities, focusing on physical and technical

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[339] Several respondents: physicians and administrators in government hospitals.

[340] In a survey of healthcare facilities in Andhra Pradesh 96% of public sector hospitals and 84% of private hospitals reported that they kept medical records (Mahapatra 2003). Misra's study on consumer redress facilities in 81 hospitals found that 33% of private hospitals and 22% of government hospitals had complaint boxes or books, although fewer than these (17% private and 15% government hospitals) had guidelines for reviewing and processing complaints (Misra 2000).

standards and documentation.[341] Officially, many accountability functions, such as the handling of grievances and complaints are decentralized to the level of the respective hospital authorities (GNCTD 2007).[342]

HIV/AIDS programme organizations

The National AIDS Control Organization is the government's nodal agency for HIV/AIDS control. NACO's stated objectives are to "bring about HIV prevention" and "provide treatment to people living with HIV/AIDS" (NACO 2007f). According to the official website of the organization, it was constituted in 1992 with the purpose of implementing and steering a nationwide programme for HIV/AIDS control - the National AIDS Control Programme. (NACO 2007a).
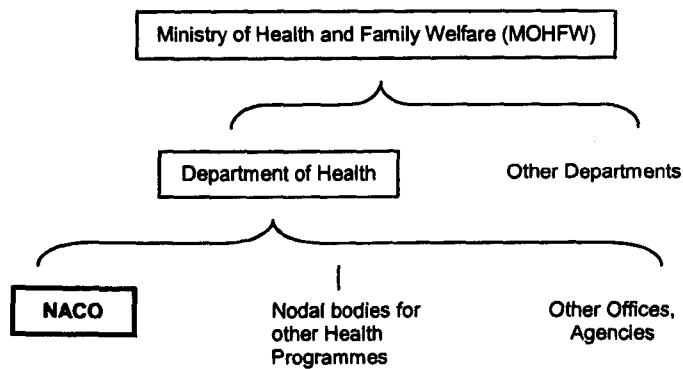
Figure 7.1 NACO's Official Position in the MOHFW[343]

Some of NACO's core activities include HIV surveillance and research, infrastructure development for blood banks, STI clinics, VCTCs and ART Centres, and conducting Targeted Interventions (TIs) for high-risk groups focusing on behaviour change communication (undertaken with the help of NGOs). In the context of HIV/AIDS care in hospitals, NACO's role

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[341] Several respondents: physicians and administrators in government hospitals.

[342] The website of the directorate of health services of the State of Delhi outlines the following procedure for complaints and grievances: "If patients have any complaint/grievance, they should approach:
For (Government) Hospitals – The Medical Superintendent of the concerned hospital.
For Private Hospitals & Nursing Homes – Medical Superintendent of Nursing Home conducts a preliminary enquiry. If allegation substantiated in preliminary enquiry, a report is sent to conduct for necessary action (sic)." (GNCTD 2007)

[343] Adapted from Gupta and Sood (2005)

appeared to be mainly focused around setting up VCTCs and ARTCs in government hospitals,[344] and supplying human resources and materials towards running them. There is also mention of advocacy for sensitization of healthcare providers and prevention of discrimination in healthcare settings among other settings, in the national AIDS prevention and control policy of 2003. NACO also publishes and promulgates policies and guidelines for various aspects of HIV care and control. Relevant sections of the guidelines for HIV testing are paraphrased in Chapter 1 (1.2). Programme documents do not specify the adoption (by NACO) of any regulatory role, although in the national policy (NACO 2003b) there is advice to State Governments to "adopt legislative and other measures to ensure that private hospitals and nursing homes conform to the national policy and guidelines relating to HIV testing."

NACO is supported financially in its activities by a number of donor agencies (see Table 7.1). The World Bank and bilateral agencies are the major donors, and there is also a significant outlay from the Government of India toward the NACP.

	Donor Agency	Funds Earmarked (In Millions of Rupees)
1	World Bank	9590
2	DFID	4874
3	USAID	2306
4	Government of India	1960
5	Global Fund	1227
6	CIDA	378
7	AusAID	247
8	UNDP	65
	Total	20647

Table 7.1 Funding of the National AIDS Control Programme Phase-II (1999-2006)[345]

NACO is headed by a Director General who is drawn from the bureaucratic cadre – the Indian Administrative Services (IAS). There is an extensive organizational structure with an Additional Project Director, a Director of Finance, and seven Joint Director positions with such portfolios as Basic Services, Treatment Care and Support Monitoring and Evaluation and Administration and Procurement. In addition, there are numerous subordinate positions. Functionaries are appointed

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[344] At the time of writing, the majority of VCTCs were instituted in medical colleges and teaching hospitals (NACO 2007e).
[345] From NACO (2007j)

to various positions based on their qualifications and technical expertise (Gupta and Sood 2005 p.111; NACO 2007k).

The operations of the National AIDS Control Programme are partially decentralised, in most instances to State level, and in some instances to District level. The State AIDS Prevention and Control Societies (SACS) are set up as autonomous registered societies with "functional independence to upscale and innovate", but are also mandated to implement all aspects of the HIV/AIDS programme at State level. Each SACS has a governing body headed by the State minister or chief secretary, and constituted of representatives of stakeholders including other government departments, NGOs, PLHA networks and private sector (NACO 2007i).

The SACS receive funds from NACO and have partial discretion to utilize these toward supporting NGOs for programme activities, and for equipment and contingencies (Gupta and Sood 2005 p 6.31). In matters of dealing with hospitals including administering VCTCs and ART Centres, they can be said to represent operational arms of the National AIDS Control Programme.

The SACS are headed by a Project Director who is usually from the administrative civil service cadre, at par with the Director General of NACO. The recommended organizational structure for SACS includes six Joint Director positions and 15 Assistant Directors in charge of different aspects of the programme, including for Integrated Counselling and Testing Centres (ICTC) and for ART (Gupta and Sood 2005 p.111, NACO 2007g).

Professional regulators

The Medical Council of India (MCI) and state medical councils are the only agencies with a unequivocal mandate of regulating the behaviour of allopathic medical practitioners in India. The MCI is the body which officially confers allopathic doctors with the right to practice medicine, once they have graduated. The MCI was formulated in 1934 on a model of professional "self-regulation", along the lines of the General Medical Council of Great Britain. Near the time of independence in 1947, the Bhore Committee report of the Government of India recommended the continuation and strengthening of this model. However subsequent national-level deliberations led to certain modifications in the rules, notably those relating to the constitution of the Councils (Iyer and Jesani 1999 p.5). Membership and leadership of Councils is partially decided democratically through election, ensuring representative participation from different states, and there is also a minority presence of nominated members and government representatives (GOI

1956). A recent Bill has suggested further modification in composition of the MCI, and greater control by, and accountability to the central government, but is yet to be passed (GOI 2005a).

The Councils are intended to function autonomously and have quasi-judicial disciplinary powers. They are financially supported through funds from the Government of India. The Medical Council of India (MCI) was originally constituted with the responsibility of maintaining uniform standards of medical education and to secure international recognition of Indian medical degrees (Madan 1980 p.21). The Indian Medical Council Act of 1956 formally expanded the scope of duties by charging the MCI with the responsibility of regulating standards of medical education, the professional conduct of medical providers, and maintaining an Indian Medical Register of physicians. Minor amendments were made to the Act in 1993 and 2001, which did not alter the MCI's core mandate. A notable addendum to the 1956 Act was the enunciation of Code of Ethics Regulations in 2002, which outlined in detail: a Code of Medical Ethics, duties and responsibilities of physicians, definitions of unethical acts and misconduct, and guidelines for punitive action (MCI 2002).[346] The National Health Policy of 2002 reiterates some points from the original Act of 1956, and advises that: "a contemporary code of medical ethics should be notified and rigorously implemented by the Medical Council of India" (GOI 2002).

However, the official website of the MCI does not cite the implementation of the code of ethics or regulation of professional conduct among its functions. The "Functions and Objectives" column includes only recognition and de-recognition of medical colleges and individual medical qualifications, inspection of medical educational institutions, registration of degrees, and maintenance of the Register (MCI 2006).

From a perusal of the official web-pages of some *state* medical councils however, it is apparent that the task of regulating professional conduct *is* recognized as a core function. For instance, the self-professed functions of the Delhi Medical Council include, among others:

- Prescription of a Code of Ethics (along the lines of the MCI Regulations)

- Receipt and processing of complaints against misconduct or negligence by a medical practitioner, and related disciplinary actions

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[346] The Code of Ethics Regulations do not explicitly refer to informed consent for diagnostic tests or confidentiality of medical conditions. However they do stress aspects such as the maintenance of secrecy and delicacy in dealings with patients (section 2.2 of the regulations), and the paramount importance of benefit to the patients in every consultation (section 3.2). Other relevant sections of the Regulations include "No physician shall arbitrarily refuse treatment to a patient (such as might be linked with the practice of mandatory testing)" (section 2.1.1) and "They should co-operate with the authorities in the administration of sanitary/public health laws and regulations." (section 5.1) (MCI 2002).

Disciplinary actions include reprimanding the practitioners, and suspension or deletion of registration (DMC 2008). Role delineations of many other State Councils are similar. In some instances State Acts have been promulgated which detail the role of the respective Medical Council (DMC 2008, GMC 2006).

7.1.2   Other influential groups

International organizations

The number of international organizations involved in various aspects of health in India are too numerous to enlist. In its capacity as a global centre of technical excellence, the World Health Organization (WHO) has a prominent role in policy *formation* – in guiding the formulation of national policy guidelines in many aspects of public health, including HIV testing. The WHO has a supporting role in the implementation of national policies. According to the vision statement of the WHO's office in India, the organization's main role is in providing technical expertise to partners in national, state and local governments, civil society and other partners (WHO India 2008). Relevant focus areas in which the WHO aims to provide technical support are:

- Providing leadership in "setting norms and standards" and "developing health systems to ensure equity in health"
- "Mobilizing, developing and optimally utilizing human and financial resources"

The mandate of the Joint United Nations Programme on HIV/AIDS (UNAIDS) is to coordinate the response to HIV/AIDS and provide a platform for advocacy. Working with its co-sponsors, and with NACO, the SACS, civil society organizations and academia, UNAIDS aims to promote strengthened leadership at all levels, enhanced human resources, a stronger evidence base for policy, a focus on rights, and sustainability of existing programmes (UNAIDS 2008).

The World Bank is an important actor in health policy in India, providing funding support to numerous government projects and programmes in various areas. The Bank is the leading donor partner of the National AIDS Control Organization and the programme (See Table 7.1). Although it does not officially play a direct role in implementing the policies of NACO, its close associations with NACO and the government, and its involvement with health systems across the country through other programmes makes it a potentially influential actor (World Bank 2008).

Other important bilateral organizations are the United States Agency for International Development (USAID), the UK Department for International Development (DfID) and the Canadian International Development Association (CIDA), who are important donors and contributors to the National AIDS Control Programme (See Table 7.1). The Indian offices of USAID and DfID also support many independent research, training and capacity building projects in hospitals and NGOs. A prominent philanthropic organization is the Bill and Melinda Gates Foundation which supports an independent HIV prevention initiative *Avahan*, working closely with the Government of India and with NACO (BMGF 2008). Some agencies whose work has addressed the issue of HIV care in the hospital sector include the William J Clinton Foundation, the Population Council and Population Services International (PSI). The Clinton Foundation was involved in a countrywide HIV sensitization and training programme for private practitioners in collaboration with the Indian Medical Association (WJCF 2008). The Population Council has conducted intervention-cum-research programmes in government and private hospitals with the aim of reducing stigma and discrimination (Mahendra et al. 2006). PSI undertakes social franchising programmes among private practitioners to promote evidence-based STI care (PSI 2008).

Civil society organizations

Apart form the important involvement of non-governmental organizations as care providers in their own right, numerous agencies are also involved in activities which impinge on the implementation process. Various groups are involved in promoting civil and human rights and the rights of clients and consumers of medical care. Others are specifically engaged in activism around HIV/AIDS. There are several networks of People Living with HIV/AIDS (PLHA) in India. A prominent network is the Indian Network for People living with HIV/AIDS (INP+) (Ratnathicam 2001). INP+'s mission statement and objectives are oriented mainly towards community based support and mobilization of PLHA, and broad goals of preventing transmission. "protection of human rights" and "improved access to quality services" are two strategic objectives which are relevant in the context of hospital based HIV testing. PLHA networks have had a role in taking up concerns of discrimination or unresponsiveness in healthcare settings with authorities, and through public channels such as the media and internet fora (INP+ 2008., AIDS-INDIA 2008).

Consumer rights agencies play a supportive role in educating clients about their rights and advising them on legal matters, and some have also taken on policy advocacy roles at national

level. Two prominent non-governmental consumer agencies are the Association for Consumer Action on Safety and Health (ACASH) and the Voluntary Organization in the Interest of Consumer Education (VOICE). A prominent group of legal activists, the Lawyers Collective HIV/AIDS Unit have been active in advocating legal reforms around HIV/AIDS, and were responsible for drafting the HIV/AIDS Bill (2005) for consideration by Parliament (Bhardwaj and Divan 2005). The Bill has not yet been passed as of the time of writing in June 2008 (see details on page 31).

Medical associations

Medical Associations are voluntary professional organizations of medical professionals, which enjoy a large membership and a popular following among the community of Indian doctors. Being voluntary bodies, medical associations do not typically have a clear or uniform mandate of implementing national policies. While there are numerous associations in India, some catering to doctors from different systems of medicine, the most prominent association for allopathic doctors is the Indian Medical Association (IMA) with a national membership of more than 130,000 and over 1600 regional and local chapters (Jeffery 1988 p176-178, IMA-MW 2008). The IMA's stated objectives are as follows (IMA 2008):

- Promotion and advancement of medical and all related sciences

- Improving public health and medical education in India

- Maintaining the honour and dignity of the medical profession

The IMA publishes an internationally indexed journal, the Journal of the Indian Medical Association (JIMA), and is involved in some research programmes, in advocacy activities and in certain relief and public health programmes. The IMA is also active in conducting sensitization programmes and seminars, mainly aimed at doctors in the private sector (Park 2005 p.702). A major recent initiative is the undertaking by the IMA to train private practitioners nationwide in issues around HIV care, in collaboration with the William Clinton Foundation (WJCF 2008).

Accreditation agencies[347]

The National Accreditation Board for Hospitals and Healthcare Providers (NABH), a constituent board of the Quality Council of India, is an autonomous body set up to establish and operate a system of voluntary accreditation for hospitals. The basic guideline for accreditation is a set of standards for hospital quality, the elements of "quality" including such topics as Care of Patient, Patient Rights and Education, Human Resource Management and Information Management Systems each with numerous objective criteria which would be relevant in the context of following policies for HIV testing.[348] The accreditation process as outlined by the NABH is a multi-step process in which the hospital is advised on the improvement of various parameters. The NABH is supported financially by various donors from industry and government, and through user fees. Since its institution in 2004-05, 69 hospitals countrywide have applied for accreditation, and 14 are presently accredited (QCI 2008). The National Accreditation Board for Testing and Calibration Laboratories (NABL) is an autonomous body under the aegis of Department of Science & Technology, Government of India, which offers voluntary accreditation to different types of laboratories including medical diagnostic laboratories. NABL standards are primarily oriented around technical quality. However their criteria for accrediting for medical laboratories include compliance with any existing national policy guidelines (NABL 2008).

Few hospitals have formal accreditation in India. Accreditation has recently come to greater prominence in the health arena and is still regarded widely as an alternative rather than a mainstream approach.

Figure 7.2 summarizes the putative roles of different groups and organizations in implementing public health policies such as for HIV testing.

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[347] Since accreditation boards are autonomous agencies, they have been discussed here, rather than under formal channels of implementation.

[348] Relevant criteria in the NABH booklet include: PRE.1. *The organization protects patient and family rights during care*, PRE.2. *The patient and family are involved in decision-making processes*, PRE.3. *A documented process for obtaining patient consent*, COP.1. *Uniform care of patients is guided by the applicable laws and regulations*, HRM.7, *A grievance handling mechanism exists in the organization* (NABH 2005).
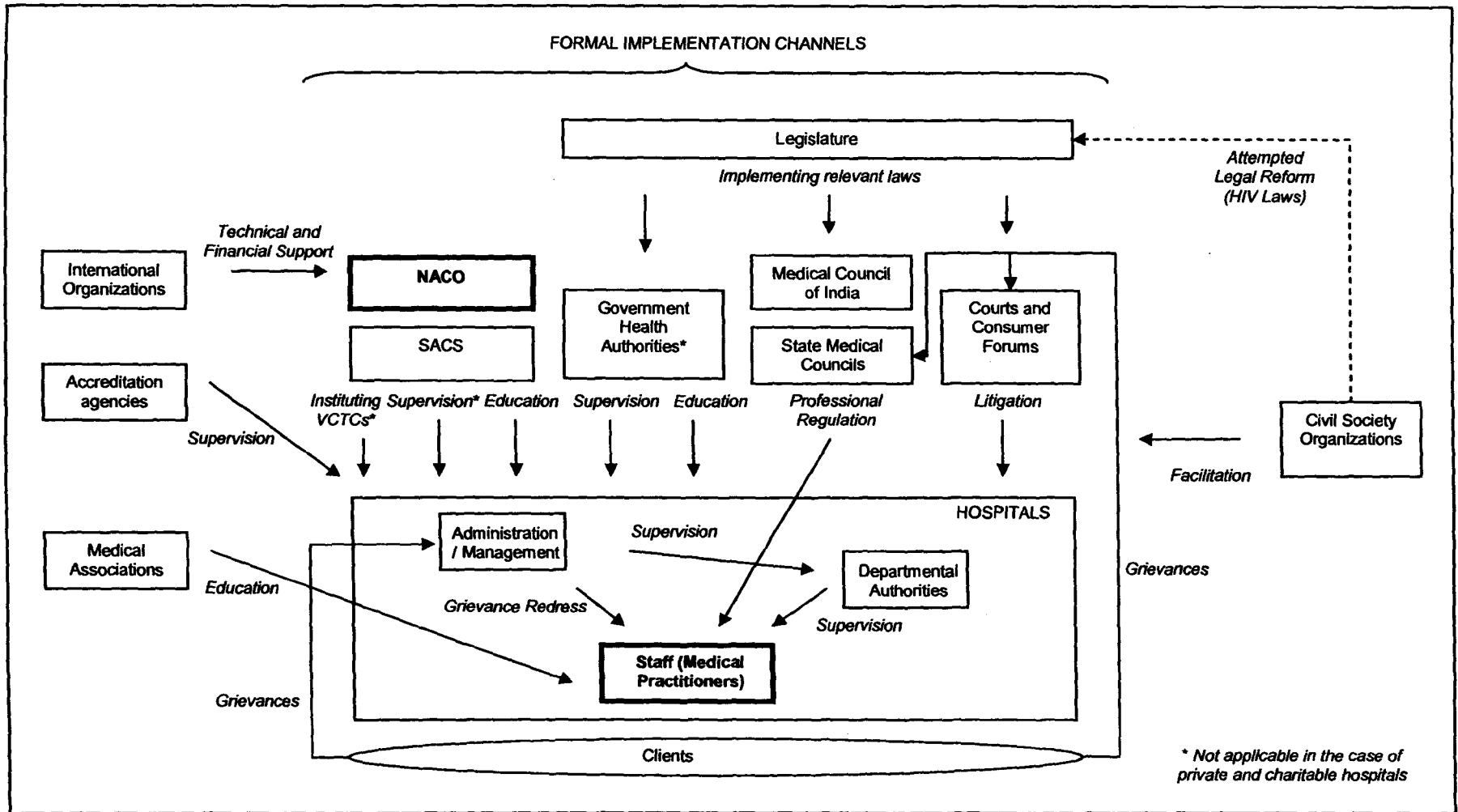
Figure 7.2 Putative Roles of Various Groups in Implementing the Policies

7.2 VIEWS OF HOSPITAL AUTHORITIES

Each hospital was organized into administrative levels represented by officers such as Medical Superintendents or Deans; Department heads; and Unit or team heads. Many of the larger hospitals had specially appointed HIV nodal officers or teams to address HIV-specific administrative issues. This section is based on the views of these hospital authorities.

7.2.1 Government hospital Heads of Department (HOD)

The two sets of institutional actors who were closely engaged with issues around HIV testing in government hospitals were Heads of Departments (HOD), and Infection Control Officers (ICO). This section is based on interviews with a representative selection of Heads of clinical departments. Respondents frequently remarked that the quality of care in their departments was contingent on availability of time and human and material resources, which were insufficient to cope with the overwhelming burden of patients. In this environment of insufficiency, team leaders and HODs claimed that optimal allocation of time and resources was a perpetual preoccupation for them.

> Some [patients] may need more time while some may not. You can give more attention to the few who really require it... this dilemma between quantity and quality, it is a permanent question, a permanent problem. We may be not looking at it with that perspective, but we do need to.
>
> Head of gynaecology department, government hospital (21)

Heads of clinical departments are medical practitioners in their own right, and broadly shared the value orientations and role perceptions of the other doctors. Their role identities were typically focused around clinical care, departmental coordination and teaching duties, and other tasks including HIV policy implementation were often seen as secondary to these core responsibilities.[349]

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[349] Respondent 12: Head of medical department, government hospital

Relationships with practitioners

When queried closely, there was little indication of HODs exercising any actual role in enforcing HIV testing policies among their colleagues and subordinates. At most, there were reports of informal discussions within the department about the appropriateness of particular practices or policies.[350] It was evident that in practice HODs often encouraged or supported practitioner discretion rather than uniform compliance to policy.[351,352] Apart from their natural leanings favouring autonomous decision-making by doctors, HODs also cited solidarity with staff (in matters of protection from HIV infection) as explanations for lack of involvement in enforcing policies.

> There are senior doctors, junior doctors, nursing staff and everybody would like to know about the patients' status and probably it would not be fair if I knew and I did not tell my junior doctors, or I did not tell my nurse, because that means I am taking the precautions and she is not.
>
> Head of gynaecology department, government hospital (21)

HODs' relations with their colleagues were often delicate. One Head mentioned reporting their own staff to authorities rather than taking corrective action to control discriminatory practices.

> They [colleagues] used to send this report with a red stamp, for which I had to fight and fight and tell them, in fact I used to tell NACO, because why should I fight with my professors unnecessarily. So I have written to NACO that this is what is happening and there itself there is discrimination.
>
> Head of medical department, government hospital (37)

Relationship with HIV/AIDS programme authorities

For HODs, the HIV/AIDS programme's authority appeared to stem largely from its role as resource providers to their departments. When specifically questioned, most Heads of Department (HOD) admitted that they were supposed to implement NACO policies, but only in the context of tasks associated with the HIV/AIDS programme. Implementing policies was seen as a reciprocal act in exchange for receiving resources (drugs, reagents, some staff) from the programme.[353,354]

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[350] Several respondents (21, 23, 27)
[351] Respondent 02: Head of medical department, government hospital
[352] Respondent 21: Head of gynaecology department, government hospital
[353] Respondent 02: Head of medical department, government hospital

To account for use of funds and technical support from the programme, HODs were required to furnish data to the SACS using a regular reporting format. One HOD said that they were often busy with the submission of reports and fulfilment of formalities. Tasks of HIV/AIDS-related documentation were reported to be exacting and subject to greater scrutiny by authorities.

> We are accountable to NACO, in that we have to give them all the information... how many walk-ins, how many referred, how many positive etc. We have give our data and figures to SACS, they send it on to NACO.

> There is lot of accountability for this. If a sputum sample is not cultured nobody will hold me responsible, but if something goes wrong with the HIV care, the kind of hype there is, the higher authorities and everybody seems to give a lot of importance to HIV, so if you go wrong in something with HIV...

> Head of microbiology department, government hospital (24)

Departments were sometimes inspected by HIV/AIDS programme officials. One department head recounted two separate visits coordinated or undertaken by the HIV/AIDS programme. Sometimes the inspectors had international connections ('foreign experts'[355], 'expert from NACO, trained abroad).[356] While these international experts observed digressions from recommended standards, there was reported to have been a certain amount of complicity between other (local) programme officials and department Heads to conceal these deficits, and 'present a good face' of the programme.

> I told [the HIV/AIDS programme officials] that if you are sending somebody, you should let me know one day in advance or at least give me two hours time. Of course, [the programme officials] would only show them the suitable boys... we would have to present a very good face.

> Past head of microbiology department, government hospital (66)

Other interactions

As discussed earlier, *hospital administrators* (superintendents) were not reported to play a proactive role in implementing HIV testing policies, but were regarded by the doctors (including by HODs) more as referees for complicated issues, and as buffers against external criticism. Apart from their relationships with their staff, hospital administrators and the HIV/AIDS programme, some HODs reported influential interactions with *peers from other institutions*,

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[354] Respondent 24: Head of microbiology department, government hospital
[355] Respondent 02: Head of medical department, government hospital
[356] Respondent 66: Erstwhile head of microbiology department, government hospital

usually in the context of organizing training and research programmes around HIV/AIDS.[357] Notably, interactions with government health departments, state medical councils, and hospital infection control departments (all of which are officially mandated to regulate practices) were rarely cited in the context of implementing policy. Interactions with *government health departments* were cited only in the context of broad administrative and financial matters such as audits, infrastructure development and procurement of instruments.[358] The role of institutional *infection control officers* was barely acknowledged by some HODs, when probed.[359,360] See Figure 7.3 for a construction of Heads of Departments' web of relationships in the context of policy implementation.
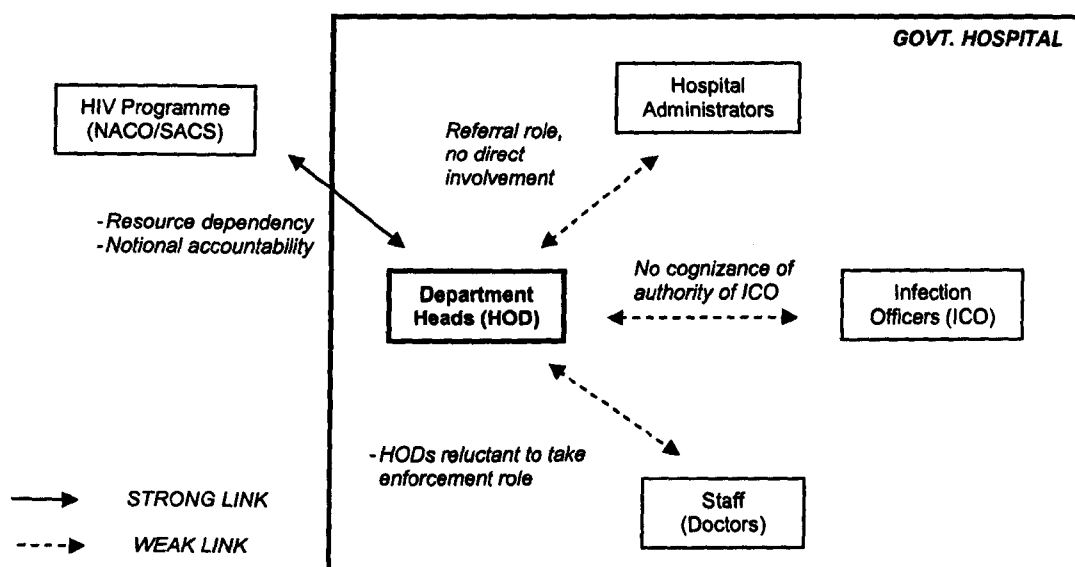
Figure 7.3 HODs' Interactions in the Context of Implementing Policies

Summary: Government hospital Heads of Department

- HODs were obliged to the HIV/AIDS programme for the support they received in material and human resource terms. In exchange, HODs *complied with programme formalities* such as maintaining documentation and reporting back to the HIV/AIDS programme

- HODs were not equally active in taking steps to actually change HIV testing behaviour among their staff of practitioners. *Complicity* between HODs and some HIV/AIDS

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[357] Respondent 33: Head of medical department, government hospital
[358] Respondent 66: Erstwhile head of microbiology department, government hospital
[359] Respondent 31: Senior surgeon, government hospital
[360] Respondent 66: Erstwhile head of microbiology department, government hospital

programme officials to hide field-level problems and maintain 'a good face' may have reduced the efficacy of supervision by the HIV/AIDS programme.

- Broadly the performance of their roles was *skewed toward interactions with authorities*, not with subordinates; and they appeared to *emphasise paperwork*, over the communicative aspects of implementation.

- HODs reported minimal interactions with other policy actors, save with collaborators in other institutions.

7.2.2   Government hospital Infection Control Officer (ICO)

As noted before, some of the government hospitals had independent departments dedicated to infection control and safety, which were also mandated with the responsibility of administering some related policies and programmes. The prescribed roles of these departments included ensuring that policies around HIV care were followed, and providing personal protection to practitioners and equipment for waste management.[361] An Infection Control Officer from one government hospital was interviewed.

The ICO reiterated what was evident in interviews with government doctors: that policies were often not followed "in spirit" even though all supporting paperwork and procedures were in place. For the officer, his relatively junior position and the non-clinical nature of his work prevented him from exercising authority over doctors. The officer expressed frustration at the dismissive attitudes of doctors, particularly of surgeons, and the obstacles this posed for him in executing his prescribed duties.

> It is very difficult to make people understand. Specially the medical community… if you don't belong to that community, it is impossible. If you go to a professor, [they say] *kal ka bachcha* [you spring chicken], where have you come from? You have come to me, will you tell me what to do?
>
> The surgeons are the most *badmash* [scoundrels]. Sorry to use that word, but they think they are the bosses. They try to dictate. They never asked reasonably: "we want this, we want that." Instead, *halla macha denge* [they will raise a ruckus]: "We don't have this, we don't have that."
>
> Infection control officer, government hospital (68)

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[361] Respondent 68: Infection control officer, government hospital

Hospital administrators were also reported to be unsupportive in these endeavours of the ICO. According to the ICO, administrators may not have been cognizant of the need to budget for non-material aspects of running an infection control programme (such as educational and promotional interventions), and not have prioritised these aspects in their mix of tasks, an observation that was also shared by key informants.[362] The ICO contended that public health and preventive tasks were generally regarded as peripheral and unimportant in hospitals. In this discouraging environment, the officer felt inhibited in initiating interactions with staff and undertaking innovative activities, and instead tended to focus more on his routine and clerical tasks.

> All these things are not on the priority list of administrators. They are all thankless jobs. Nobody will be given credit... there is no culture of this. Here, public health people are not well recognised... you do whatever you like, but the main question is, the person should be given recognition by the people who are around.
>
> Infection control officer, government hospital (68)

The officer reported that there was no significant interaction of the department with the HIV/AIDS programme, or with the SACS-instituted VCTC and treatment centre in the hospital.

In *summary*:

- The Infection Control Officer reported *gaps between his prescribed and actual role* in policy implementation.

- Answerability to hospital administrators tended to be focused around management of materials, and not around improving communications with practitioners.

- Practitioners generally *rejected the authority* of the ICO, and the officer did not find it viable to pursue an agenda of behaviour change or reform.

- The ICO was *isolated* and felt *disempowered* due to his weak relationships with both administrators and practitioners.

7.2.3   Private hospital administrators

In contrast to government hospitals, administrators[363] in the private hospital were closely involved in issues around HIV testing. The administrators were active in instituting and supporting a HIV nodal group in the hospital, which created policies and instituted procedures such as consent

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[362] Key Informant 6
[363] Precise designations are not revealed, to protect anonymity.

forms for HIV testing, arrangements for post-exposure prophylaxis and universal precautions, and pre-test and post-test counselling. This section is based on interviews with administrators and members of the HIV nodal group in the private hospital.

Relationship with practitioners

The introduction of HIV testing policies in the hospital was opposed by the hospital doctors, particularly the surgeons, but eventually the administrators prevailed and the policies were introduced.[364]

> The senior consultants were up in arms and they said that: "what about us? We would like to find out what is the [HIV] status [of surgical patients]. Since then a lot of water has flown under the bridge... Finally everybody agreed [to introduce policies prohibiting pre-surgical screening]. I mean, we bade them to agree.
>
> Medical superintendent, private hospital (38)

While these written policies did exist, along the lines of national guidelines[365], there was considerable leniency in the way they were practically implemented. It appeared that the administration and the hospital HIV committee preferred to take an approach of persuasion rather than enforcement, and often made accommodations towards the demands of practitioners, for the sake of smooth day-to-day functioning.

> We thought, let us start with consent, and we keep putting the pressure, gradually. Once consent forms come into line, then we will put some pressure for pre-test counselling. So, slowly it will be streamlined.
>
> Member, HIV committee, private hospital (40)

Ensuring convenience for doctors' and staff in the context of day-to-day operations was an important priority for hospital administrators.

Relationship with government and the HIV/AIDS programme

It appeared that the adoption of HIV testing policies for the hospital was prompted in part by pressures from the HIV/AIDS programme, requiring the hospital to be more accountable in terms of HIV care.[366,367] These interactions with the HIV/AIDS programme were reported to have been

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[364] This is corroborated separately by doctors and administrators
[365] Not made available to me
[366] Respondent 35: Physician, 12 years experience, private hospital

fractious, and the hospital administrators generally held a poor opinion of programme officials and of the role of government authorities in guiding HIV/AIDS care. Some critical remarks directed at the HIV/AIDS programme authorities by the respondents included: 'typically stupid... like Indian government attitudes'[368] and 'a lost organization'[369]. Respondents also repeatedly emphasized that they were not accountable to government. However, in spite of their absence of regard for government authorities, the administration did choose to adopt their HIV policies in the hospital. The reasons cited for this were twofold.

Firstly, this was a gesture aimed at enhancing the reputation of the hospital, and secondly the administrators foresaw the value of adopting procedures such as consent, and their utility as a protective measure against litigation. The administrators identified themselves strongly in the role of institution-builders, and stressed on the value of an adaptive and open-ended style of hospital management, with the eventual goal of 'growth of the hospital'.

> We should have the ability to evolve and adopt whatever is new. If we
> have too rigid structures, too many sanctions, then nothing happens.
>
> <div align="right">Medical superintendent, private hospital (38)</div>

According to respondents this style of management was encouraged and enabled by the presence of strong leadership at the level of the board of trustees of the hospital.

Summary: Private hospital administrators

- Administrators of the private hospital were actively involved in issues around HIV testing.

- In spite of their *oppositional relationship with government officials*, government policies were nominally adopted by the hospital

- The actual enforcement of the policies among their staff of medical practitioners was pursued by administrators largely *as per convenience*, and not seen as an imperative.

- Hospital administrators' participation in processes of implementation of HIV testing policies were characterised by negotiation and adaptation to the positions of other stakeholders (government programme, staff, clients), and overall were seen as secondary to the *larger goal of institution-building*.

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[367] Respondent 38: Medical superintendent, private hospital
[368] Respondent 25: Senior surgeon, private hospital
[369] Respondent 38: Medical superintendent, private hospital

7.3   VIEWS OF GOVERNMENT HEALTH AUTHORITIES

Officials of the Directorate of Health Services (DHS) were not available for interview, in spite of repeated attempts to organize appointments. A telephonic interview was eventually organized with one official. He indicated that the involvement of the Directorate in monitoring medical provider behaviour was limited, and they were not specifically engaged with micro-level issues such as the quality of HIV testing, corroborating the similar observations of government hospital staff[370] and key informants.[371] Recent activities of the directorate had included monitoring and introducing legislations for broad-based quality criteria such as facility registration and ensuring qualified staff.[372]

7.4   VIEWS OF HIV/AIDS PROGRAMME AUTHORITIES

This section is based on interviews with officials from the National AIDS Control Organization and from a State AIDS Control Society.[373]

7.4.1   National AIDS Control Organization (NACO) officials

The two senior NACO officials interviewed were both of the view that in practice the HIV/AIDS programme was primarily focused on developing and expanding existing services, rather than regulating them (also supported by the SACS official – see following section). Information gathering, by way of data on numbers of HIV positive patients and their response to ART, was another important activity of programme officials at a national level.

Role ambivalence

Even as NACO's formal stance was to support the strengthening of regulations for HIV testing by legal means[374], the officials' attitude towards changing medical provider behaviour was focused

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[370] Respondent 66: Senior microbiologist and erstwhile head of department, government hospital
[371] Key informants 6 and 9
[372] Respondent 56: Official, state directorate of health services
[373] The state is not identified for purposes of anonymity.

around supportive interventions, such as educational programmes and improvement of universal precautions and post-exposure prophylaxis in government hospitals. One of them also opposed the institution of laws around HIV testing, in contradiction of NACO's official stance.

> This [infringement of policies by doctors] is being addressed basically through the mechanism of education... My opinion is that we have a lacuna in that we have not been able to take the message to our doctors. So if we educate and try to train them, I think that will have some impact.
>
> Frankly speaking if you put some kind of regulatory mechanism, at least in India I think, that approach may not serve the purpose... I think because it is a democratic state, you know. If we keep insisting on an HIV law, every hospital should have this, should have that, then people will come out with their own ways...
>
> <div align="right">Senior official, NACO (55)</div>

This respondent expressed disagreement with some of his organization's policies and approaches. Being a physician himself, there were strong overtones of empathy in his discussions of doctors' positions, around such issues as personal safety and routine testing of clinically suspected patients.

> Their doubts are absolutely valid, and whatever practices they are doing, they have a reason, it is not unnecessary. Either we [should] convince them or we [should] modify the policy.
>
> <div align="right">Senior official, NACO (55)</div>

Although the NACO official himself claimed to have an insight into practitioners' perspectives, he felt unable to highlight them in official circles, because of the unwillingness of practitioners themselves to communicate these divergent perspectives in formal fora.

> You know these people [practitioners] don't come out in front and say these things. They come to meetings but they don't say. Otherwise if you talk to 100 doctors, 80 will say that way. But if this can be documented properly, it will be good food for thought.
>
> <div align="right">Senior official, NACO (55)</div>

The other official also indicated the difficulties of regulation of practices in the private sector, and detailed NACO's strategies for working with private medical providers, which included partnership with the William Clinton Foundation to sensitize private practitioners around HIV care, and the promotion of voluntary accreditation initiatives.[375]

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[374] NACO's policies advise governments to adopt "legislative and other measures" to ensure conformity to testing policy. The HIV/AIDS Bill 2005 which would bring about legal sanction for HIV testing policies around consent and confidentiality enjoys the official support of NACO. See Chapters 1 and 2 for details.

[375] Respondent 04: Senior official, NACO

Relationship with WHO

In spite of holding a fairly important position in the hierarchy of the NACO, one official appeared to regard certain policies as evolving through means beyond his control or influence. The World Health Organization and other international agencies were cited as an influential source of guidance in respect to policies for HIV testing.

> I think provider initiated testing should be encouraged, and I think WHO is also promoting this idea. But somehow it is not getting into practice.
>
> Senior official, NACO (55)

> Yes, quite a few of them [policy guidelines] are imported. Well, they are not directly implanted. We borrowed a lot of policies... our PEP guidelines are from CDC guidelines ... because we never had guidelines, so we had to take from somewhere. Quite a few of our treatment training programmes are from WHO.
>
> Senior official, NACO (04)

The lack of leadership and capacity at national level to determine unified policies for the whole country as an explanation for the adoption of international policies, was also offered by other respondents including a key informant.[376]

Summary: NACO officials

-   The officials felt that the primary role of the programme was to *prioritise the expansion and development of the HIV/AIDS programme.* Their practical approach *favoured supportive and educational interventions over regulatory functions*, in interactions with medical providers.

-   There were indications that the organization's *policies were adopted from international agencies*, and *poorly informed by the experiences of field-level practitioners.* An official remarked on the reluctance of practitioners to highlight their own concerns in formal fora. It was not apparent that active efforts were made to solicit these perspectives.

-   In spite of holding prominent decision-making posts, the officials appeared to *lack ownership of the policies*, and agency in determining the policies promulgated by their own organization (NACO).

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[376] Key informant 4

7.4.2   State AIDS Control Society (SACS) official

Role ambivalence

The senior SACS official who was interviewed was ambivalent about the actual role of the organization in implementing national policies. Initially the respondent indicated that the SACS was 'into [implementing] all the policy and programmes, different components of the National AIDS Control Programme'.[377]   Subsequently in the interview, reflecting on his practical experience, he admitted that 'we are more of an advocacy agency than an implementation agency'. The respondent placed a high value on the role of the SACS as a resource provider, and felt that it was not feasible or desirable to combine this with a policing role.

> People may not take it that sportingly if we are trying to be some one
> who is enforcing, and trying to police them. We would prefer it to be as it
> is, more of advocacy than enforcement.
>
> Senior official, SACS (46)

The organization's role in training medical providers in different aspects of HIV care was particularly emphasized. The official denied that there were widespread infringements of HIV testing policies in government hospitals, and insisted that the existence of consent forms in public hospitals and procedures instituted in the VCTCs and ART centre were sufficient to ensure compliance to NACO policies to a great degree.

Relationship with government hospital providers

The SACS official said that there were certain problems in programme implementation at the level of hospitals, since many of the designated implementers of the HIV/AIDS programme in hospitals (department Heads, ARTC in-charges, VCTC in-charges) were regular employees of the State Health Department, and not of the SACS (see Figure 7.4).

> Though we have designated VCTC and ART in-charges[378] [in hospitals],
> they don't get any salary for that. This is extra responsibility for no extra
> remuneration. These people are employees of State Government, of the
> health department, they are doctors. So they have other duties to perform.
> If you have extra responsibilities or extra burden, you tend to neglect
> some aspects. If he is managing 100 outpatients, and gets additional
> charge of VCTC, or ART, it will be difficult for him. The importance

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[377] Respondent 46: Senior official, State AIDS Control Society (SACS)
[378] These were typically doctors (often Heads of Department) from a relevant clinical speciality department such as Internal Medicine or Venereology.

that this [the HIV/AIDS] programme should carry is not reflected in the implementation.

<div align="right">Senior official, SACS (46)</div>

Other than the regular hospital staff, there were also some programme workers (including administrative staff, counsellors and technicians) who were hired on a contractual basis by the SACS. The SACS official explained that these short-term programme staff faced difficulties in integrating unfamiliar emphases such as HIV-specific informed consent, in hospital environments in which there were established cultures focused mainly around clinical task performance. See Figure 7.4 for a representation of this web of relationships between the HIV/AIDS programme structure and government general health services, as seen by the SACS official.
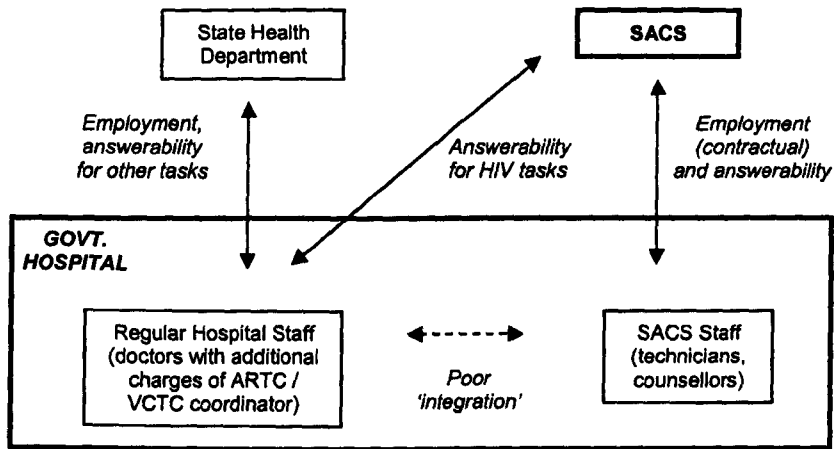
Figure 7.4 Health Department and HIV/AIDS Programme – Parallel Structures

Relationship with state health departments

According to the SACS official, they (the SACS) received no financial assistance from State Government, and that SACS were part of an autonomous administrative structure parallel to that of the State government's health and hospital administration. A key informant reported how there were frequent frictions and tensions between these two parallel structures, as a result of the HIV programme being relatively better endowed financially than the general health systems.[379] In some states however, higher functionaries of the SACS were also senior officials of the State health administration, which allowed them to exercise their authority over hospital staff. In these

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[379] Key Informant 6

instances, said the SACS official, 'the integration is happening at the top most level...and the work gets ...more by force, than by motivation'.[380]

Relationship with private sector providers

When asked about the private medical sector, the official explained that the enormity of the task of regulating private providers' practices was beyond the means of the SACS. The official assumed a conciliatory approach to their infringement of NACO policies.

> We can't control them. It is only a part of advocacy, a part of motivation... I understand that some of private doctors do test patients without consent before surgery... [But] it has not come to us through any source which has a strong base... written complaints have not come.
>
> Senior official, SACS (46)

The SACS' involvement with private medical providers was very limited overall, and the official confirmed the claims of private doctors that most of their training programmes were aimed only at government doctors (see Chapter 6).

Relationship with NACO

In spite of its autonomous status as a registered society, the SACS official interviewed clearly perceived the SACS as an operational arm of the National AIDS Control Organization or Programme.

> All these activities we do are NACO exercises... We have many partners, but as far as donor partner is concern, we have a single donor. All the money is coming from NACO.
>
> Senior official, SACS (46)

The official focused strongly on the SACS' function of helping to expand NACP services and frequently cited statistics of numbers of patients who had been counselled and tested, or received care under the programme, as signs of the success of the programme.

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[380] Respondent 46: Senior official, SACS

Summary: SACS official

- The SACS official generally prioritised the aspect of *expansion and development* of the HIV/AIDS programme, over concerns of regulating the practices of medical providers.

- The official appeared to perceive *ambivalence around multiple roles*: as resource providers, advocacy campaigners, and policy implementers. He felt that in practice, their role as *advocates and resource providers* was incompatible with, and took precedence over their role as implementers of policies, a contradiction of the SACS' written constitution.

- In operational terms, the official perceived significant obstacles in the implementation of policies in hospitals. The programme functioned as a *parallel administrative structure* distinct from the general health services and as such, *lacked true authority* over government hospital practitioners.

- Further, there were frictions between the SACS and state health administration, and programme staff experienced *problems in the integration* of HIV-specific objectives into the regular functioning of government hospitals.

- The SACS official completely abdicated *responsibility for policy implementation in the private sector*, claiming that it was beyond their means.

- In spite of their autonomous status as registered societies, the SACS were perceived universally as operational arms of NACO.

7.5   VIEWS OF A PROFESSIONAL REGULATOR

Interviews with an officer from a State Medical Council (SMC)[381] form the basis of this section.

Regulatory role

The SMC officer described the Council as being 'an autonomous body under the State Government' with 'quasi-judicial functions', and having the primary role of regulating the standards of medical practice of allopathic doctors in the State. When asked about the nature of the council's regulatory role, the officer focused his responses mainly on the Council's efforts in

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[381] Name of state not divulged to protect identity of respondent.

promoting continuing medical education (CME) for doctors in government and private institutions, and on recent efforts to link re-registration of doctors to a system of CME credits. The *disciplinary* functions of the Medical Council, which have a prominent position in the written constitution of the Council, were not mentioned by the respondent initially. However when probed, the respondent elaborated on the disciplinary role of the Council and the constitution of the disciplinary committee as follows:

> We have got a disciplinary committee, I forgot to mention, and we also maintain a code of ethics, maintenance of ethical practices. Disciplinary committee has a chairperson who is a senior medical practitioner; there is a member who is a reputed person. As of now, [a prominent journalist] [382] is a member, but has not turned up for any meeting. There is one legal person, a practising lawyer, and one MLA. But none of them turn up.
>
> Senior official, State Medical Council (58)

Asked about the procedures of the disciplinary committee, the respondent said that the process was initiated on receipt of complaints, which could be from an aggrieved individual (typically), or from the government or another agency. The arbitration procedure consisted of preliminary screening of the complaint, followed by a hearing with both parties present. After this, the disciplinary committee held consultations and passed judgment. The officer said that the number of complaints lodged had increased in recent years. When asked about their role in the implementation of HIV testing policies, the official indicated that violation of government policies could putatively be a matter of arbitration for the Council.

> In all these issues [HIV testing, counselling, consent], there are definite rules, conventions, and procedures of the government. So everybody has to follow that. If they do not follow, they [the government] take a course of action. They also intimate us so that we can take action against them. Any violation of any rules and regulations is also taken as medical negligence and we take action on that.
>
> Senior official, State Medical Council (58)

There was no instance however of government or any other party lodging a complaint with councils on the basis of non-adherence of practitioners to HIV testing policies. In fact the officer related that, in total, punitive measures had been taken against no more than 'three or four doctors' who had been found guilty on charges of medical negligence in the past year. These measures included reprimands, and suspension of the right to practice for between three and six months.

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[382] Name withheld for confidentiality

Additional roles

The officer also mentioned some additional roles and functions of the SMC, which revolved around protecting the rights of doctors and maintaining the sanctity of the profession.[383]

> Whenever there is a need, we provide them with protection. We take up their issues with the concerned authorities, within the ambit of existing rules and norms
>
> [Investigator: How would such a case come to your notice?]
>
> The doctor informs us. Or we may take *suo motu* action if we come to know about some oddity.
>
> <div align="right">Senior official, State Medical Council (58)</div>

In one instance the Council had played an proactive role in petitioning the government against wrongful legal action taken on a doctor. Another important focus area, according to the respondent was the eradication of quackery, for which the Council had instituted special procedures and committees for investigation.

In contradiction of the organization's primary official role of regulation of practices, the respondent explicitly indicated his disinclination toward the use of force to change practices of doctors. Deficiencies in medical care were discussed in sympathetic terms, as lack of awareness on the part of practitioners, to which an approach of patience and forbearance was advocated.

> All these things will take a little time. People have to be informed about it. In the course of time, everybody will be doing it [following policies]. We cannot do everything by *danda* [the stick]. We have seen for the last 56 years since independence, how many ill effects there have been by [the use of] *danda*.
>
> <div align="right">Senior official, State Medical Council (58)</div>

When queried about the violation of NACO policies around mandatory pre-surgical testing , the official was disinclined to believe that such violations took place in government hospitals.

Relationships with other groups

Medical associations had some representation in the SMC, with elected posts in the Council being reserved for members of the local chapter of the Indian Medical Association. The disciplinary

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[383] These functions were not mentioned in the official webpage of the SMC at the time of the interview, nor were they part of the constitution of SMCs as indicated in the MCI webpage. When asked about this, the respondent said that they were recent additions to the constitution.

committee too had representation from the Medical Association. Reportedly, representatives of the Association were important and active participants in Council proceedings. They may have had a dominant role in the Council, particularly in the context of other committee members often being absent.

The officer indicated that the SMC had few practical interactions with the Medical Council of India, except to contribute to the national register of doctors, maintained centrally. The roles of the State and National level councils were reportedly complementary, the two levels being in charge of regulating standards of medical practices, and of medical education respectively. There was no indication of any substantive interaction with government health departments.

Summary: Professional regulator

- The SMC official appeared to be *less focused on the core tasks of the organization of regulating medical practice*, and more on routine documentation and educational initiatives.

- It was evident that the council *did not play a proactive role in preventing or identifying instances of misconduct*, and were reliant on aggrieved clients or other agencies for initiating complaints. As such, their practical role in matters such as implementation of HIV testing policies may have been limited.

- The council was apparently *dominated by interests from the medical profession* and representatives from voluntary Medical Associations were prominent members of Council committees.

- A high value was placed on actions undertaken by the council toward *protecting and promoting the interests of medical professionals*, including campaigns against quackery. On the other hand, the value of regulation of doctors' practices was underplayed by the officer.

7.6 VIEWS OF CME EDUCATORS

A number of programmes for HIV/AIDS training for in-service doctors exist in India. These are diverse and can be categorised on criteria such as their duration, which sector of doctors they are

available to, whether they are voluntary or part of a compulsory requirement, or the type of training imparted.[384] A typology of training programmes is presented in Box 7.1.

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-   Aimed at government doctors or private doctors or both

-   Short-term (days or weeks) or longer duration (months)

-   Voluntary or mandatory

-   With or without practical component

-   One-off or repeated exposures
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Box 7.1 Types of Training Programmes

Training initiatives are financially supported and administered by different government and non-governmental agencies, including some by international NGOs and bilateral agencies. The actual training may be conducted by hired trainers or by dedicated staff. Trainers are often drawn from medical colleges or institutes where they hold regular teaching or research positions.

The section is divided into two parts, the first part (7.6.1) looks at sensitization programmes and workshops, which were of a short duration (a few days or weeks). The second subsection (7.6.2) focuses on longer term training programmes with an inbuilt practical component. Educators and administrators from four different training programmes were interviewed.

7.6.1   Managers and trainers: short-term sensitization programmes

Educators from two different types of short term educational programmes were interviewed. The first was a mandatory refresher workshop for government doctors, and the second was a sensitization programme for private sector doctors, coordinated by an international NGO.

A government educator recounted that many of the participants in these refresher workshops were not very interested in learning about HIV, and were present only because it was a compulsory requirement of their government jobs.

> Just because there is an order from the government these people come
> here but they are not interested. Some circular goes to different medical
> colleges, the professor of medicine, professor of paediatrics, doctor blah

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[384] Several key informants

> blah should go and attend this. They are reluctant. Nobody has taken
> their consent: are you willing to work in HIV?
>
> Senior physician and trainer, government hospital (37)

The other example of short term training programmes, a HIV sensitization initiative for private practitioners utilised a standard curriculum of instruction which had been developed with a specific focus on NACO guidelines for HIV testing and management. The programme was being carried out on a countrywide scale with the help of local chapters of a medical association, had official support from the HIV/AIDS programme, and the Medical Council of India, and financial assistance from major international bilateral agencies.

Administrators and educators employed by the programme themselves expressed reservations about its effectiveness in changing the behaviour of private medical providers.[385,386] According to one of the educators interviewed from the programme, the training programmes was unlikely to lead to significant attitudinal and behaviour change, since it was not linked to an active programme of skill development. She also expressed doubts about the response of doctors to the instructional approach adopted in the programme.

> If someone comes to you, as a doctor, and tells you "do it like this" or
> "do it like that", how would you react? But these people [colleagues]
> seem quite optimistic that it will create some change.
>
> Senior educator and consultant to training
> programme for private physicians (50)

However, the educators asserted that the main expectation from the programme was simply to sensitize doctors to new concepts. A key informant also endorsed the utility of such short term training initiatives, in creating awareness of policies and issues where there was none.

> These medical doctors, through a process of attrition, they lose what they
> have learnt during their medical college years. The value is in making
> them aware of what is going on.
>
> Key informant 6

Some characteristics of such programmes and their potential impact on practices, according to respondents, are listed in Table 7.2.

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[385] Respondent 44: Manager, short term HIV training programme for private physicians
[386] Respondent 50: Senior consultant to HIV training programme for private physicians

Duration and frequency	Short term (days), single exposure
Style of training	Instructional
Focus of Content	Policies, general information
Desired outputs	Knowledge of, adherence to policies
Cost per capita	Low
Alignment of behaviour with policies (non-contentious aspects)	Variable
Alignment of behaviour with policies (contentious aspects)	Poor

Table 7.2 Characteristics of Short-Term Sensitization Programmes

In summary:

- The trainers and administrators were not universally satisfied with the quality of interactions with their trainees in short term programmes. However they recognized the utility of short term training in effectively *sensitizing practitioners to newer concepts*, which included national policies.

- In the instance of the HIV/AIDS programme for private doctors, the educators were *sceptical about the effectiveness* of their programme's instructional approach, and did not expect it to have an immediate impact on aligning practitioners' practices with policies.

- The programme for private physicians was *well supported by donors,* which was attributed by respondents to political support, and to the low per capita cost of such initiatives.

7.6.2   Managers and trainers: intensive training programmes

The two longer term HIV training programmes for mid-career doctors were located in (respectively, one government and one private) medical colleges, and conducted by their teaching faculty. Both were available to doctors working in any sector, following a competitive entrance process, and included a practical training component and repeated contacts over a year-long period. The programmes were popular and regularly oversubscribed. Respondents from both programmes stressed the importance of repeated educational inputs in engendering change in practices. The effectiveness of practical exposure and sensitization to new concepts through practical work, in changing attitudes and behaviour, was also emphasized.

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> The need of the hour is not just education but continuous education. Exposure and sensitisation leads to a gradual change in practices... the more number of cases you see, the more your attitude changes.
>
> Senior educator and training coordinator (70)

One respondent described how students readily adopted concepts such as consent and confidentiality in their practice, but not when these conflicted with their own wishes to undertake pre-surgical HIV screening.

> You have surgeons who want to advocate pre-operative testing. I don't think that all the education and all the discussion really facilitated addressing that stalemate. Different people are using the inputs of the course in various ways.
>
> Medical educator, 20 years experience (15)

The focus of the programme however was not specifically on adherence to policies, but on the capacity development of practitioners at a broader level. In fact, one objective of the training was to help students to develop their own workplace policies and standard operating procedures.[387]

Training programmes of long duration and with a practical component are very expensive, and may or may not have brought about changes in behaviour as expected. Often such interventions encouraged independent thought and led to practitioners making autonomous decisions which may have been at odds with national policy guidelines. The benefits of such programmes lay deeper - in creating exposure to new concepts and career paths, and engendering peer intercourse and collaborations.

> Training will bring about a change; you are sowing seeds for change. That is all that will happen. If I say that I can change it within a year, you will not find any significant change. But to some of the people who are a little involved in their practices, it may make a difference. There will be some who are enlightened to see the logic and rationale of training. And many will not.
>
> Key Informant 6

> It is like nurturing a baby. I will not say these are students but they are like future collaborators. It is a real experience... you know everyday we start with looking forward to what is going to happen next. It is a very pleasant experience.
>
> Senior educator and training coordinator (70)

Box 7.2 'Sowing Seeds': Immeasurable Gains of Intensive Training

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[387] Respondent 70: Senior medical educator, coordinator of intensive training programme in HIV

For the educators, the training programme also represented an opportunity to 'network' with peers, students and trainers hired from other institutions. Arrangements were worked out to share resources for training across institutions, and the local SACS was also involved in providing technical expertise.[388] Some characteristics of intensive training programmes and their potential impact on practices, according to respondents are listed in Table 7.3

Duration and frequency	Long term (months), multiple exposure
Style of training	Educational
Focus of Content	Skills, concepts
Desired outputs	Clinical skills, knowledge, cognizance of ethical principles, capacity for decision-making, other
Cost per capita	High
Alignment of behaviour with policies (non-contentious aspects)	Good
Alignment of behaviour with policies (contentious aspects)	Variable

Table 7.3 Characteristics of Intensive Training Programmes

The idea of supporting such intensive training programmes with their high per capita costs and indefinable outputs may not have been attractive to funding agencies with a short-term vision for change. In spite of the popularity of the programmes, respondents indicated that the withdrawal of donors was threatening their continuation.

In summary:

- The educators saw their programmes as a channel for communicating knowledge and ideas and imparting *skills and concepts*. Practical exposure and experience of working with HIV positive patients was felt to be particularly important, and was linked to attitudinal changes.

- It was widely acknowledged that the education *did not necessarily result in the alignment of practices with national policies*, especially when the content of instruction conflicted with other interests and priorities.

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[388] Respondent 70: Senior medical educator, coordinator of intensive training programme in HIV

- Intensive training presented opportunities for *personal development* for trainers and trainees alike. Participation was seen by educators as an opportunity for innovation, and a platform for engendering *professional relationships* across institutions.

- The "output" of intensive training was a small numbers of trainees at a very high cost which may have explained the *reduced interest of donors* in these programmes.

7.7 VIEWS OF INTERNATIONAL ACTORS

7.7.1 Office-bearers: United Nations agencies

United Nations (UN) agencies, the WHO and UNAIDS are authors of global guidelines which are often a basis for national policies and as such have a potential role in shaping how policies are implemented. Both organizations have country offices in India, and interviews were held with a representative selection of officials from these offices.

Role in implementation

Neither organization was officially responsible for policy implementation. The UNAIDS secretariat, as 'the joint voice of the UN'[389] on HIV/AIDS issues, was charged with coordination between different agencies and for advocacy. The WHO office's putative role was to provide technical support to the government. According to one respondent from the WHO office, theirs was not officially an advocacy role, but practically involved 'a lot of lobbying and advocacy'[390] around their core areas of technical contribution.[391]

The primary mode of involvement of UNAIDS and WHO in field level processes was in helping central and state governments develop and promote programmes for training and capacity development, and for accreditation. At an organizational level, there were limited practical means available to them to play a role in enforcing compliance to policies.

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[389] Respondent 03: Mid-level official, United Nations technical agency
[390] Respondent 47: Officer in UN technical agency, 7 years in the UN, recently deputed to India
[391] These areas of technical support reportedly included surveillance and an initiative to decentralize HIV treatment, care and prevention, known as the IMAI (Integrated Management of Adult Illnesses) initiative.

Value orientations

Nevertheless, the respondents tended to place a high value on compliance and on streamlining the practices of doctors to meet national standards. When asked about their organizations' position on implementing policies, officials generally felt that it was important to enforce uniform standards in regard to issues such as consent and confidentiality, which they considered to be universal principles.

According to most of the respondents, doctors' explanations for infringements of HIV testing policies had little foundation. They clearly valued the principles of universalism that were enshrined in the WHO/UNAIDS policies. Their arguments were generally predicated on a strong conception of the importance of personal autonomy in medical care interactions.

> Not just for HIV, but for all other health problems, there should be confidentiality; there should be systems of counselling, or informing the patient. Even that is not happening here. Why? I am sure you have seen, in the West, people really make sure that you are the one who decides. The doctor is not the one who decides. He tells you these are the options available for you, you decide what you want.
>
> Officer in UN technical agency, recently deputed to India (47)

One respondent regarded the policies for voluntary testing and specific informed consent as a signifier of future directions for health systems in India, stating that 'we are a little bit ahead, but this will be a path-finder for other systems as well'.[392] He drew on examples from Western health systems to envision a future in which patients in India would exercise greater autonomy. 'Eventually in India, people will demand that you treat me with decency, that you treat me with respect', he felt. The advantages of adopting consent procedures were explained by some respondents in terms of the legal protection they gave to both parties involved, patients and doctors.

Linking global and national policy

Shortly before the interviews took place, a joint WHO/UNAIDS global policy statement had been published promoting routine offer of HIV testing by practitioners in healthcare interactions, in recognition of the need to scale up HIV testing – an approach termed "provider-initiated testing

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[392] Respondent 03: Mid-level official, United Nations technical agency

and counselling" (PITC) (WHO/UNAIDS 2006).[393] One of the officials described the problems of communicating the recent policy changes to HIV/AIDS programme and government officials.

> This whole policy statement caused a lot of confusion, because instead of "routine offer" it became "routine testing". There is a very delicate line you have to draw, and people easily tend to say "oh yeah, WHO says routine testing, we should just test every one". For people to understand the difference between routine testing and routine offer is going to be very difficult.
>
> Officer in UN technical agency (47)

The official emphasised that he had some concerns about the new approach and hence had not "pushed it" in discussions with NACO officials. The official HIV testing policy in India retained its focus around the VCT approach and the central role of VCT centres.

Summary: UN agency officials

- The officials from UN agencies did not perceive a significant role for their organizations in enforcing policies at field level, being more focused on their supportive role to governments. Nevertheless, they did tend to place a *strong emphasis on standardization of practices* and compliance to global guidelines (developed by their organizations).

- The officials significantly valued *principles of universalism* in medical care, giving particular importance to *personal autonomy*. Greater expression of autonomy on the part of patients was seen as a future ideal of Indian health systems.

- The officials also experienced *difficulties in communicating the principles* of HIV testing policies to HIV/AIDS programme officers and government departments.

7.7.2   Donor agency official

I interviewed a representative from the country office of an international donor agency, one of the major financers of the National AIDS Control Programme (see Table 1.3). According to the respondent, the organization had no specific role in implementation or field level processes. They were involved mainly at the level of financing the Government of India, and activities revolved around deciding budgetary allocations. From a financer's perspective, fund utilization by supported projects was cited as an important yardstick of successful implementation.

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[393] Also see Appendix 1 (A1.5 Recent shifts in policy)

The official indicated that her major struggle in making financial decisions was to identify core problems, given the multiple perspectives of different stakeholders in a complex field such as HIV/AIDS. Referring to the act of reaching policy decisions on the basis of stakeholder consultations, the respondent felt that 'it was an amazing challenge to extract a common outcome'.

> Where everyone wants to be touchy-feely, and "this is all about people" and things like that, we have to define fairly narrowly what we are going to do, and how we are going to do it.
>
> HIV/AIDS department in-charge, major donor agency (54)

The respondent felt that non-state actors such as civil society organizations had a particularly strident voice, which she regarded to be a distraction for the HIV/AIDS programme from pursuing their core public health functions. She reiterated the 'need to define things tightly in sectors like ours' (i.e. the health or HIV/AIDS sector).

In summary

- As financers of the National AIDS Control Programme, the donor agency official was mainly concerned with issues such as *fund utilization*, which was regarded as evidence of programme implementation.

- The respondent placed a high value on the importance of a *streamlined approach to implementation*, especially in the context of diverse voices and perspectives that populated the HIV/AIDS world.

7.8 VIEWS OF CIVIL SOCIETY ACTORS

7.8.1 Consumer rights advocates

According to a representative of a consumer rights organization, the focus of activity for the organization was threefold: on improving formal modes of redress for consumers of medical services, better clarification of standards of medical care, and greater consumer awareness of their rights. These approaches all have potential, if indirect relevance for the implementation of existing polices, such as for HIV testing. The consumer advocate emphasised the value of the

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Consumer Protection Act[394] in adding legitimacy to the consumer movement. He felt that the Act had been a 'good weapon' and over the past two decades, had been effective in engendering awareness and making medical professionals 'conscious towards their roles and responsibilities'.[395] The organization's contemporary approach, said the respondent, was to shift the focus away from litigation and more towards voluntary and internal regulatory mechanisms such as accreditation.

Over the past two decades, the medical fraternity have had mixed reactions to the consumer rights movement. The respondent narrated events from 1995, when medical associations protested a Supreme Court order sanctioning the inclusion of medical services in the Consumer Protection Act (CPA) (see section 2.1.3). 'They went on the street, they demonstrated', he reported. However he felt that in the past few years, the associations' antagonism to inclusion under the CPA, and to the consumer movement in general, had decreased considerably.

Recognizing the expediency of involving medical interests, rather than antagonising them, the organization had admitted them as partners in new initiatives for accreditation of medical facilities. According to the respondent, 'we wanted to make sure that if (the medical associations) have to say something, talk about it right now, before we move further.'

In summary,

- The consumer advocacy group had a potential role in influencing processes of policy implementation, by *raising consumer awareness* of their rights, and by their role in facilitating legal redress.

- In recent years however, they appeared to favour *communication and collaboration with powerful medical interests*, in contrast to the former emphasis on legal avenues to challenge their dominance.

7.8.2   Legal rights activists

A sub-sample of respondents from a prominent groups of legal activists, engaged in drafting new laws against HIV/AIDS related discrimination, were interviewed. Policy advocacy and litigation were two prominent areas of work in HIV/AIDS for this NGO, according to one respondent. *Litigation* relating to violation of HIV testing policy was improbable, said a respondent from the

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[394] See Chapter 2 (2.1.3)
[395] Respondent 53: Head, consumer rights organization

organization. Patients may have got upset or angry at instances such as mandatory testing, but they would consider formal action only if there was a 'bigger repercussion', such as loss of employment.[396] She reported one instance when a patient was tested without consent and approached the organization's legal unit with the grievance. The problem was resolved by a phone call discussion with hospital authorities.

One of the organization's major *advocacy* initiatives involved preparing a Bill for Parliament aimed at protecting the human rights of people with HIV/AIDS. The Bill had been prepared following consultations with numerous stakeholder groups. At the time of the interview, it was undergoing revisions by National AIDS Control Programme authorities. The Bill addressed many areas which coincided with national HIV testing policies, including requirements of informed consent, confidentiality, etc. One of the respondents reported that doctors widely opposed the Bill on various grounds, but largely dismissed the arguments posed by doctors as invalid.[397]

In response to the suggestion that the Bill (if passed) would promote unnecessary litigation, respondents played down this possibility, given the difficulties involved for complainants.

> Its very difficult to get to the court, you need a good lawyer, money, resources... three years is a long time. That's how long it takes to file motions, get evidence, deposition, hearing, final case disposal...
>
> Junior member, legal rights group with focus on HIV/AIDS (51)

Instead they emphasised the role of the law as a deterrent to discriminatory practices. The Bill also contains provisions for strengthening grievance redress mechanisms at hospitals and at district level, and the respondent emphasised the importance of these non-litigious mechanisms in addressing deficits in the quality of care: 'we would rather have these informal mechanisms, and we are trying to convey this to the health care providers.'[398]

In summary,

- Legal rights activists pictured their involvement in policy implementation mainly as *facilitators of legal reforms* for HIV/AIDS care, for which they had nominal support from NACO.

- Paradoxically even though they supported the creation of new and powerful laws, respondents played down the importance of litigation as a means to regulate doctors' practices. Instead

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[396] Respondent 51: Junior member, legal rights group with focus on HIV/AIDS
[397] Respondent 49: Senior member, legal rights group with focus on HIV/AIDS
[398] Respondent 49: Senior member, legal rights group with focus on HIV/AIDS

they emphasised stronger institutional mechanisms, and saw the *role of law mainly in terms of enhancing awareness* of problems and deterring discriminatory practices.

- Their *relationship with the medical fraternity was vexed* over conflicts around the content of the Bill.

7.8.3   NGO advocacy project

I interviewed representatives of a NGO partnership who had been involved in an intervention project to reduce stigma and discrimination against PLHA in urban hospitals. The project was a partnership between an international and a local NGO.

Role and motivations

One respondent spoke about how she and her colleagues were motivated to initiate the project by the knowledge of discriminatory practices in hospitals emerging from research studies throughout the country.

> How long can you just keep documenting [discriminatory practices], we
> know this exists, but isn't there a way to do something about it?
>
> Member of NGO with focus on HIV/AIDS (64)

The aim of this project was to change and standardise practices, and their interventions largely supported the implementation of NACO's HIV testing policies, focused as they were on issues such as consent and confidentiality and ensuring an ethical process of advising HIV tests. Activities conducted as part of the project included an evaluation of discriminatory practices, training workshops and helping hospital authorities develop standard institutional guidelines and operating procedures.

Interactions with hospital administrators

For the NGO workers, the process of engaging decision-makers in the hospitals in this process was a long and painstaking one, involving numerous meetings and seminars, over a period of more than a year. Endorsements from official bodies such as the SACS or NACO were often required to gain access to both government and private hospitals. A number of hospitals were approached and some refused to participate in the project.

In some instances the NGOs had to actively make concessions in their stance in order to be accepted by hospital authorities. For instance, in a private hospital the guidelines had to be modified to allow for compulsory pre-surgical HIV testing and routine testing of pregnant women.

Interactions with medical practitioners

Introducing a project on stigma and discrimination to doctors, who are often counted among perpetrators of discriminatory practices, required a high level of diplomacy on the part of the NGO workers. To make the interactions more palatable to doctors, they tended to assume sympathetic positions to doctors' perspectives on personal safety, and framed issues in terms of scientific rationales.

> Doctors are accepting of scientific rationales. When we take the approach of infection control, universal precautions, and not necessarily point at stigma and discrimination which is the other side of the same coin, I think that helps you in getting entry into hospitals, and health care professionals are much more open in to talking to you.
>
> Senior member of NGO with focus on HIV/AIDS (62)

> "We are not just talking about protecting patients, but also about protecting you, because you are the ones who will eventually protect the patient" When you go in with that attitude, then at least you have this common ground.
>
> Member of NGO with focus on HIV/AIDS (64)

The outcome of the intervention was that attitudinal and behavioural changes were observed in a few aspects of medical practice, in the post-intervention assessment. However to a large extent, the project failed to meet its initial objectives of standardizing practices across different departments and hospitals. The NGO workers were largely phlegmatic about these failures, and tended to focus on the achievements of the project, in sensitizing practitioners to human rights concepts.

Viewing day-to-day hospital processes first-hand gave the NGO workers new insights and transformed some of their preconceptions on stigma and discrimination.

> When we first went in, we were like "this is absolutely stigma, this is absolutely discrimination, and they are perpetuating it and doing it...", but it changed our perspectives to go in and work with them, that maybe this isn't actually stigma or discrimination...
>
> We had this experience with patients that they would narrate to us incidents of their interactions with the health care system which were stigmatizing or discriminatory, but they didn't see it as that.
>
> <div align="right">Member of NGO with focus on HIV/AIDS (64)</div>

The respondents emphasised their own experience of learning from their interactions with healthcare staff in the hospitals, including appreciation of the difficult working conditions in government hospitals, a greater understanding of doctors' apprehensions, and recognition of doctors' good intentions in most cases.

Summary: NGO advocacy project

-   The intervention project was initiated by a NGO as a result of strong *belief in universal ethical principles*, and perceptions of responsibility to act on their principles.

-   The NGO underwent considerable *difficulties in gaining access* to hospitals for which they required official endorsement from the HIV/AIDS programme. In some instances had to compromise their positions on appropriate HIV testing policies. They had to exhibit considerable *diplomacy and empathy* towards doctors, to obtain their attention.

-   Eventually the project had a *limited impact, restricted to sensitization of doctors*, and not resulting in substantive behavioural change or in the adoption of guidelines by departments.

-   Strong *themes of learning* emerged in the accounts of the NGO respondents. First-hand experiences of hospital functioning and access to the perspectives of practitioners and patients transformed some of their preconceptions on stigma and discrimination in healthcare settings.

7.8.4   PLHA network

The head of a network of People Living with HIV/AIDS (PLHA) was interviewed for his perspectives on their role in implementation of policies.

Roles and values

The network's major activities in this context included building the capacity of PLHA to enhance their decision-making roles in clinical settings. Another important initiative for the PLHA network was the creation of a network of doctors, to facilitate care for PLHA, provide a platform for the exchange of knowledge and views and address doctors' apprehensions around caring for PLHA. According to the respondent, 'providers have their own problems around HIV/AIDS. This would give a platform for doctors to discuss it.'[399] In an early survey and pilot initiative, there had been a positive response from doctors in both private and government hospitals, and the respondent was optimistic about the success of the project. The initiatives of the organization to build the capacity of PLHA and build a network with local doctors represented a grassroots or bottom-up approach toward addressing their concerns.

> We liked that idea, that rather than trying to change the whole system, we can target individuals to change, and through that we will be able to change the system
>
> Head, PLHA network (07)

Hence a philosophy of change through individual engagement was favoured by the respondent. He did not however rule out the value of initiatives at 'a legal and policy level', although these conventional approaches had their considerable limitations, in his opinion (see below).[400]

Relationships with donors: inflated expectations

Donor agencies had also shown an overwhelming interest in some of the organizations' projects, and a consultative team had been formed for one of their projects comprised of representatives from WHO, UNAIDS, UNICEF, the National HIV/AIDS Programme, the Directorate of Health Services, the local Municipal Corporation and others. There was also reportedly interest in funding the project from the World Bank and the Global Fund. The respondent ironically remarked: 'I have been told that this is the only time that all these major groups, WHO, UNAIDS etc are together'.

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[399] Respondent 07: Head, PLHA network

[400] The respondent confirmed that the legal route for redress of problems was rarely resorted to by PLHA. Reportedly the prolonged nature and expenses of court proceedings, even in consumer forums, was a deterrent, as also were PLHA's feelings of obligation toward their doctors.

The respondent felt that PLHA groups often suffered from the inflated expectations of policy-planners, and that the trend of showcasing PLHA groups' role in effecting change at field level was not something that was always reflected in practice.

> There are pressures from abroad, global standards, pressures which have come on the government and higher organizations to show that change is being achieved [by PLHA groups], but it is a different matter whether this is being implemented properly.
>
> Head, PLHA network (07)

The respondent rued that PLHA networks in the country had not, in his opinion, succeeded in establishing united and coherent advocacy platforms.

Disenchantment with policy shifts

The respondent was also unhappy with what he perceived as the dynamics of governmental and international policy reforms around HIV testing and care.

> These policies should reach lay people and they should know what should happen, what should not happen. But there is no concept that if a certain direction has been given, it should be maintained. There is often a change in decision-makers, and this lead to greater problems.
>
> Head, PLHA network (07)

According to him, policy initiatives at the high echelons lacked momentum due to frequent changes in ideas and personnel, and were hence unable to permeate to the level of the community. He questioned the sincerity and patience of planners in sustaining efforts to provide better care.

Summary: PLHA network

- The PLHA group had a role in influencing implementation processes from a *grassroots perspective*, by sensitizing PLHA to their rights and informing them about what to expect in the course of clinical encounters. They had also made efforts to educate doctors and engender mutual understanding with them by means of a collaborative project.

- The PLHA group was at the receiving end of significant attention and *expectations of partnership from international and national agencies* and funding bodies. This was symptomatic of pressures to play a greater role in policy advocacy on PLHA groups.

- There was considerable *disenchantment with repeated policy changes* at national and international level, and the respondent was unconvinced that policy changes would lead to improved health care for PLHA.

7.9   VIEWS FROM A PROFESSIONAL ASSOCIATION

A highly placed officer of the Indian Medical Association was interviewed.

Limited role in implementation

The Indian Medical Association is a voluntary body and has no particular role in enforcing government policies, a view that was corroborated by the office-holder.

> We keep telling our doctors that "don't do it *yaar* [friend]". Still there may be some people who continue to... [practice against policy guidelines] You can't have a policy to catch hold of their necks.
>
> Senior official, medical association (69)

Much of the IMA's interests seemed to be concentrated on lobbying and advocacy to protect the economic interests of their members (most of whom work in the private sector and constitute a large proportion of India's registered doctors[401]). The officer said however that the IMA undertook a number of educational programmes, and were about to initiate a large-scale programme to sensitize private practitioners on HIV/AIDS, in collaboration with the Clinton Foundation.

Core role: popular representation

Part of IMA's *modus operandi* for protecting doctors interests, was identifying policy changes which could have an impact on their members' (usually financial) welfare, and opposing them. See Box 7.3 for major ongoing campaigns undertaken by the IMA, toward protecting their members' interests.

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[401] 15-20% according to IMA and MCI documentation

> - Contesting the reduction of autonomy of medical councils
>
> - Opposing the application of criminal codes to cases of medical negligence
>
> - Opposing aspects of Clinical Establishment Acts for the regulation of standards of medical establishments, in various states

Box 7.3 Medical Associations' Ongoing Campaigns to Protect Members' Interests

The IMA has also traditionally opposed the inclusion of medical services under the Consumer Protection Act (CPA), however this stance has softened in recent years, said the respondent, on the basis of a low incidence of Consumer Forum rulings against doctors.

> I think CPA has made us more careful and wiser. Initially we thought that it was not a good thing. But now we realize that it is OK... the rate of rulings against doctors is very low.
>
> Senior official, medical association (69)

It appeared that the IMA decision-makers' logic in opposing any efforts which would lead to greater control or regulation of medical practices in the private sector, was based around a populist agenda. The officer took great pride in the IMA's demographic strength and at one point drew parallels with their grassroots organizational presence, and that of India's two leading political parties: 'They say that there are three offices to be found in every district – Congress Committees[402], RSS[403], and IMA.'[404]

Relationships with other groups

The IMA's only active relationship was with the Clinton Foundation, to organize a sensitization programme on HIV/AIDS for private practitioners. Other than this, the official repeatedly emphasized the autonomous status of the IMA, and iterated that they had no official relationships with any arms of Government or medical councils.

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[402] Local wings of the National Congress Party
[403] Rashtriya Swayamsevak Sangh – volunteer organization with political links to the national Bharatiya Janata Party
[404] Respondent 69: Senior official, medical association

Summary: Professional association

- The IMA had a limited role in the implementation of HIV testing policies, which was linked to participation in sensitization programmes. The officer indicated that the Association had *little inclination to act to ensure that government policies were followed.*

- Furthermore, the IMA appeared to be involved in specifically *resisting attempts to increase regulatory control* over the actions of private sector doctors.

- In doing so they almost had the mindset of a political party, following a *populist agenda* in protecting the interests of their members (mainly private practitioners).

7.10 VIEWS OF ACCREDITATION OFFICIALS

Official representatives of national level accreditation agencies for hospitals and for diagnostic laboratories were interviewed.

7.10.1 Official: hospital accreditation agency

According to its official web-page, the hospital accreditation agency was 'an autonomous body supported by industry' under the auspices of a department of the central Ministry of Commerce and Industry (QCI 2008). The board was constituted of representatives of a variety of stakeholder groups including consumer bodies, industrialists, insurance regulators, educational institutions, government scientific departments and hospital administrators.

According to the official interviewed the aim of the organization was to 'improve the overall quality of the health sector', and he stressed that following proper management procedures was a basic criterion for hospitals to receive accreditation.[405] Accreditation was voluntary and available to both private and government hospitals. Accreditation followed a stepwise process with an initial self assessment by the hospital, followed by a preliminary assessment by the accreditation team, and finally a full-fledged assessment. Continued compliance was assessed through periodic monitoring visits.

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[405] Respondent 59: Senior official, accreditation agency

At the time of the interview, the agency was in nascence, and very few hospitals had yet undergone accreditation. The organization was attempting to gain acceptability among hospitals, and also establishing its position in the existing governmental machinery. This involved coordination with other ministries to avoid duplication of tasks: 'We are trying to talk to the ministries, that if their hospitals are accredited by us, then they don't need to go for inspections and visits'.

In summary,

- The role of this agency was *yet untested*. The role in implementation of testing policies would be limited to the hospitals which chose to seek voluntary accreditation.

- As a new organization in a complex policy environment, the agency had to *negotiate their position and define their role*, in the context of tasks undertaken by other organizations.

7.10.2   Official: laboratory accreditation agency

Role in policy implementation

The laboratory accreditation agency was similarly autonomous, but nominally attached to the central Ministry of Science and Technology. It dealt with accreditation for a range of different types of scientific laboratories of which medical laboratories were one type. Hence the focus of their attention was clearly on the technical quality of tests conducted, and not as such on human interactions and procedures. However, the official interviewed said that compliance to 'national laws and regulations', including NACO's policies around HIV testing was one of the requirements from medical laboratories, in order to receive accreditation.

> We have stated very clearly that all labs doing HIV testing will have to comply with NACO guidelines... Whatever we can do in implementing necessary guidelines, we do... We are insisting that any lab which has walk-in clients have to provide pre and post-test counselling, even if that sort of thing is not our main area of work.
>
> Senior official, accreditation agency (61)

Accreditation for laboratories was entirely voluntary, and available at a cost to the laboratory. The accreditation process involved initial inspection and certification followed by continuous supervision. This agency was much older than the hospital accreditation agency, and a number of medical laboratories had received certification from them throughout the country. However the

official interviewed stressed that coverage was very inadequate, in the context of the vast number of medical laboratories in the country.

> You will find only 65 accredited medical labs. To put this in prospective, I understand that there are over 3000 pathology labs in Delhi alone. So our accreditation has not even scratched the surface of testing laboratories in India. I always say, it is not one agency who can tackle this load. We are the only national accreditation body for labs. Our core staff is quite small and we have part time inspectors and officers.
>
> Senior official, accreditation agency (61)

Relationships with other groups

From the respondent's accounts, it appeared that accreditation agency functioned in an uncertain policy terrain. The organization seemed to continually struggle to define their broader role, their identity and even the legitimacy of their work. Some examples of these struggles are presented in Table 7.4.

Dealing with multiple authorities	"We are dealing with 26 states, and more Union Territories and each is going to have its own authority, its own setup... we are not dealing with one central authority, well-defined authority. Because of the number of players, each with their own rules... When it comes to accreditation of medical labs, the picture is very complex."
Defining legal basis for work	"In the state of Delhi, there is no licensing mechanism for medical labs. There is a bill, but it has not yet been passed. In Maharashtra, registration of the pathology labs comes under the Shop Act. So it is so undefined... We had to ask lawyers what we should accept as a proof of legal identity."
Defending "non-profit" identity	"Once we started charging labs, we had to fight with the Revenue department; they wanted us to pay service tax. We convinced them that accreditation is like an educational service – it gives you a degree. It's recognition like universities give. So you don't charge universities service tax, so don't charge us either."

Table 7.4 The Accreditation Agency's Struggles to Define their Role[406]

In this uncertain and shifting environment, the official stressed on the importance of learning and adaptability.

> We are educating ourselves, because we don't want to walk into grey areas where it becomes difficult for us to defend ourselves... We are learning all the time and evolving with the changes.
>
> Senior official, accreditation agency (61)

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[406] Respondent 61: Senior official, accreditation agency

Summary: Laboratory accreditation official

- The accreditation body was *promoted by various government bureaus as an alternative to conventional regulatory systems* which were widely seen to be failing. They had a *limited role in implementing* HIV testing policies, since they were confined to the small numbers of laboratories who sought voluntary accreditation. Within this small cohort however, they were active in ensuring that NACO policies were followed.

- The agency had its origins in a non-health ministry, of Science and Technology, and was *not primarily involved in serving the health sector.* The health-related functions were complicated by presence of multiple health authorities in each state with different rules and regulations.[407]

- The policy environment was complex and uncertain for the agency. There was a *lack of clarity around their official functions* and even the legal status of their work was open to challenge. In this context, organizational status and growth (and possibly even survival) appeared to be linked to their ability to adapt to prevailing demands and requirements of different government departments.

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[407] Since Health is a State subject in the federal constitutional structure.

Chapter 8. Unifying Themes

This chapter synthesizes analytical themes arising from respondents' accounts in the previous three chapters. Section 8.1 focuses on understanding doctors' actions in the context of implementing HIV testing policies, including their decision-making processes and reasons and contexts for their actions. Section 8.2 examines why other groups of actors diverge from their expected roles in policy implementation. The third and fourth sections analyse the nature of interactions between groups of actors, respectively focusing on functional and ideational interactions. The final section is a summary of the key findings of the study.

8.1   UNDERSTANDING PRACTITIONERS' ACTIONS

To start with, the spectrum of medical practitioners' actions in implementing the policies, and their internal processes of taking *decisions around action* are described (Vickers 1965), from their accounts. It is apparent that practitioners' actions in the context of implementing HIV testing policies span the full range of possible responses to recommended national policy guidelines, i.e. compliance, partial divergence, or total contravention. Reasons and contexts for practitioners' divergent actions can be classified broadly on the basis of 1) conflicting perceptions of their *roles or rationales* of practice (Hjern and Porter 1981), 2) their divergent *values and goals*, and 3) their *judgements of situational realities* and constraints (Vickers 1965),[408] and are elaborated as such in the following sections.

8.1.1   Action decisions

The range of medical practitioners' behaviour in implementing the policies, and their internal processes in taking decisions around action are described.

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[408] See Chapter 3 (3.2.2) for Vickers' model of decision-making in policy

Compliance

In many instances medical practitioners did comply with national testing policies. Some practitioners indicated that they broadly *shared the values of the HIV/AIDS programme*, and hence were led to follow the policies. The practitioners who emphasised shared values were typically individuals who had had exposure to training on HIV/AIDS or otherwise regarded themselves as HIV specialists. Belief in certain values such as non-coercion, general informed consent and patient confidentiality, part of a larger medical professional identity, were cited widely by different doctors, including non-HIV specialists.

Working in government hospitals led medical practitioners to follow government procedures, and *obedience* to this organizational rationale was often put forward as an explanation of compliance. In many instances compliance happened by default, since informed consent procedures were institutionalized in most of the larger hospitals. In several instances, doctors complied with policies in spite of their explicitly stated disagreements with, or non-comprehension of the rationales or values on which HIV testing policies were founded. Typically this was a response to pressures from the hospital authorities to comply with policy recommendations. In these cases the aim was usually to assure necessary paperwork, *without an integral engagement* with the principles of the procedure.

> We have always taken informed consent. How much information the clients have understood is a separate issue. How do we validate or verify that? *Humne to bata diya* [We did what was required]. Now how much they have ingested, understood, we can't say that, we can't guarantee that.
>
> Senior microbiologist, government hospital (24)

This theme was particularly evident around the practice of specific written informed consent for a HIV test. Written informed consent for a HIV test was seen as an inadequate signifier of the quality of the interaction. Patients could easily be coerced or pressured into signing consent, they felt, which made the process liable for misuse by providers to safeguard their own position. Doctors were widely unconvinced or unclear about the rationale of the process, yet often adhered to the formalities of the procedure.

In some instances, doctors recognized the utility of written informed consent as a legal safeguard. As a HIV specialist said: 'there have been suicides after HIV diagnosis, and without specific

informed consent, the onus is yours. So why do that?'.[409] Hence doctors may have chosen to take informed consent on the basis of *protecting their own interests*.

Flexibility

In most instances, medical practitioners' actions actually approximated a point between total compliance and total contravention of policies. For instance, practitioners sometimes treated the consent procedure as one of inducing the patient to take the test, or otherwise gave it less importance than is recommended. Others adopted a strong, even coercive approach to persuading patients into signing consent, in an effort to expedite the care process.

In the context of the likelihood of patient's dropping out, physicians reported that they tested some of their patients without undertaking a formal consent procedure: 'If a patient is too anxious, we can maybe just do a HIV and see what happens.'[410] A subjective assessment of the patient guided these decisions and the respondent stressed the *importance of discretion* in this regard. Numerous respondents indicated the importance of provider discretion, given that different patients had vastly differing needs and expectations. Judgments around involving patients' families and spouses in caring for them were felt to be particularly important. Discretion also determined doctors' decisions around involving patients' families and spouses, and their interpretation of which health care staff were adequately closely involved in patient care to be allowed to access their HIV test results.

Frequently policy violations were not the result of active decisions taken by doctors. Other patients in the consulting room often listened in on consultations, something doctors ascribed to culture as much as to overcrowding. Patients' relatives were often closely involved in care, and no steps were taken to prevent their knowledge of patients' HIV status. Co-workers' grapevines allowed them to have prior information about HIV status of patients when reports were released. A venereologist reported instances of breaches of confidentiality by nursing staff, and in another instance that patients listened into another patient's consultations. Some efforts were made to redress these problems, but at the same time reflexively, concessions or adjustments were made to the situation, in the *interests of harmony*, productivity and the continuation of the core activities of the organization. When faced with conflict, practitioners adjusted their behaviour by reorienting their positions vis-à-vis various involved actors – administrators, co-workers and

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[409] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital
[410] Respondent 23: Venereologist, 10 years experience, government hospital

patients. These pragmatic adjustments were usually immediate and reflexive responses to specific situations, and seldom the result of a deliberative process.

Varying considerations of patients, co-workers, and authorities, and situational constraints of time and resources represented the reality environment for doctors. In this context, neither strict adherence to policies nor to personally held values was always possible, and *adaptability* was often regarded as a necessity, even a virtue. For a large part, these actions of medical practitioners corresponded with Lipsky's construct of the street-level bureaucrat, well-meaning and seeking to reconcile service ideals[411] with circumstantial constraints (Lipsky 1980). The practitioners sought to extract some value from the interaction even if they were not able to entirely comply with policies. Circumstantial uncertainties may have influenced practitioners' perspectives of the significance or the meaning of policies. Said a government hospital gynaecologist: 'because we know that we are not able to maintain confidentiality, so we *take it loosely...*'[412] Particularly in government hospitals following confidentiality policies was an ideal, not necessarily a regular practice: 'these are ideals which have to be attained, not necessarily to be achieved', said one government microbiologist.[413]

Outright contravention

Policies for informed consent and confidentiality were violated in some instances. However, pre-surgical HIV testing was the commonest example of outright contravention of policies by doctors. The perception of risk around acquiring HIV infection from surgical patients was the core consideration which led doctors to consciously contravene national and (in the case of government hospitals) organizational policies. Other reality and value considerations were involved in deciding to do mandatory testing.[414] In the context of pressure from hospital authorities, government surgeons could not use the formal hospital channels to conduct mandatory tests, and instead resorted to *subversive means* such as sending their patients to nearby private laboratories to be tested, or by conspiring with hospital microbiologists to perform the

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[411] However it is to be noted that medical practitioners' own service ideals, predicated more on the lines of an organizational rationale, did not always correspond with programme rationales on which the policies were founded, as discussed earlier.

[412] Respondent 21: Senior gynaecologist and head of department, government hospital

[413] Respondent 24: Senior microbiologist, government hospital

[414] The "appreciative" mix involved in conducting mandatory tests included reality judgments around the inadequacy of protective equipment, demands of co-workers, and the compliant nature of patients; combined with values around co-workers rights and the economy of the testing procedure compared to purchasing expensive protective equipment. In some instances it was linked to a rationale of scientific thoroughness and professionalism.

tests unofficially. Hence there was an "underground" aura around pre-surgical testing in government hospitals. As noted before, the general secrecy around pre-surgical testing did not act in favour of good follow up and care, if a patient was found to be HIV positive.[415]

8.1.2   Role and rationale conflicts

Ambivalences in roles and rationales for action were a common context for providers' divergent actions.

A mix of roles

Primarily, most doctors perceived themselves in the role of *providers of clinical services*. In many instances, their conceptualization of the healers' roles was focused on the goal of the patient leaving the hospital in a well state, and not on further ramifications and repercussions around the spread of the disease or of psycho-social considerations of a stigmatised disease such as HIV.[416] In the case of surgeons their role perceptions were even more narrowly focused on the specific task of completing the surgical act successfully.[417] The clinician's role was linked closely to workplace expectations and cultures, which in turn were oriented toward a similar definition of care provision restricted to hospital boundaries. Hence doctors' identities were shaped by their *organizational roles* as much as by membership of the medical profession.

In government hospitals, doctors more specifically linked their status of employment as government servants to their performance of roles. A perception of a *public health rationale* was also projected by some practitioners as being motivational for them. Some doctor repeatedly stressed on the importance of detecting as many cases as possible. Government hospitals' traditional roles as surveillance centres may have influenced doctors to order HIV tests indiscriminately, even though contemporary policies required greater selectivity on their part.[418]

The clinical instinct to diagnose patients, especially those belonging to a scientifically "interesting" category such as HIV/AIDS may also have led to a greater propensity for advising

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[415] In one charitable hospitals and the private hospital, however, the decision to undertake mandatory testing was not discretionary. Institutional authorities had regularised pre-surgical testing and as part of the same policy had assured continued care for patients diagnosed with HIV. See Chapter 5 (5.3.8).
[416] See Chapter 5 (5.2.4 and 5.4.5)
[417] See Chapter 5 (5.3.4 Primacy of the surgical act)
[418] See Chapter 5 (5.2.6)

HIV tests.[419] Hence doctors' role identities as *scientists* also influenced their behaviour in implementing testing policies. A few doctors among the selection regarded themselves as *HIV specialists*. They perceived that they were more emancipated than other doctors, especially around their recognition of PLHA's non-clinical needs and ethical requirements such as consent and confidentiality. This segment of doctors avowedly subscribed to the human rights rationales and principles that corresponded with national HIV testing policies.

Reconciling organizational and programme rationales

One doctor from a government hospital remarked, '[In the hospital] HIV does not have more importance than others [diseases]... only as a part of the government programme.'[420] The most apparent dilemma for doctors in implementing HIV testing policies was in reconciling the organizational (i.e. hospital) rationale[421] and the HIV/AIDS 'programme rationale' (Hjern and Porter 1981). The hospitals' role as an organization in its broader environment was to ensure the provision of care, strongly determined by concerns such as efficiency in ensuring patient wellness and turnover of patients, whereas the HIV/AIDS programme mainly required doctors to be cognizant of human rights principles through the enactment of specific procedures. As translated into guidance for action on the ground, these two rationales variously converged and diverged.

8.1.3 Practice values and goals

Practitioners' values, beliefs and goal orientations often differed from recommended policies, and led them to take divergent courses of action.

Quality values

Doctors' emphasis on clinical outcomes and cure represented the value placed on *expediting clinical tasks* with efficiency and (in government hospitals) economy. The first of these tasks was diagnosis and in this context, procedures such as consent for a HIV test were sometimes seen as unwelcome obstacles. The impulse to diagnose a patient was also indicative of the high valuation

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[419] See Chapter 5 (5.2.4)

[420] Respondent 31: Senior surgeon, government hospital

[421] The organizational rationale, according to Hjern and Porter (1981), is a synthesis of the values and goals of its constituent programmes (of which the HIV programme would be one) and the niche of the organization in its environment.

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of the *scientific challenge* of the clinical procedure. Doctors fresh from training in HIV/AIDS care appeared to particularly cherish this aspect of their learning experiences. Different diagnostic tests were ordered to maximise knowledge about a patients' condition, to create a mental picture of the patient's condition: 'knowing where we stand' in order to be able to 'take all the measures' for further management.[422,423] In some instances, the inclination to investigate may have overridden concerns such as specificity in testing, and the autonomy of the patient in choosing to be tested.

In some instances pre-surgical testing was regarded as an essential part of a thorough clinical work-up for patients. It was advocated in private hospitals as part of a package of infection control interventions, and was seen as a signifier of quality in the workplace, and linked to *professional values* around hygiene and safety.[424]

Equity values

In managing patients in hospitals, doctors appeared to follow unwritten rules of *equitable allocation of time and resources* among patients. Prioritisation was done on the basis of the seriousness of patients' condition and the capabilities of the doctors and the resources to remedy it. One gynaecologist described the struggle to ensure good care for a large number of patients as 'the permanent dilemma between quantity and quality'.[425] In general hospitals with patients with a wide range of serious illnesses, the needs of patients with HIV/AIDS were often not the most imminent, and non-clinical and extra-clinical arguments in favour of HIV "exceptionalism" (specific consent, counselling etc.) did not have significant evocation for medical practitioners,[426,427] and many would have preferred to 'treat it like any other disease'.[428]

Beneficence / paternalism

Doctors generally approached problems from the position of belief in the *innate beneficence of medical interventions*, including diagnostic interventions. As one venereologist remarked, 'the

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[422] Respondent 34: Senior surgeon, private hospital
[423] Respondent 39: Microbiologist, 13 years experience, Private hospital
[424] See Chapter 5 (5.3.3 Pre-surgical testing and professional values)
[425] Respondent 21: Senior gynaecologist and head of department, government hospital
[426] Respondent 24: Senior microbiologist, government hospital
[427] Respondent 29: Senior surgeon, government hospital
[428] See Chapter 5 (5.4.4) on HIV exceptionalism

smallest possible effort in India can help a person'.[429] This belief is an important argument for doing more HIV tests, especially in the modern context of availability of HAART. The notion of informed consent for a HIV test, which is based around the possibility of a maleficent act (discrimination or stigmatization) on the part of the doctors, challenged this core belief, an many doctors had problems in comprehending this rationale. Asking for consent *from* a patient for an essential good service provided *to* them presented as a contradiction in terms. A related theme is that doctors saw *diagnosis as a duty toward patients*, and part of their embedded functions within healing institutions. In government hospitals, this was underlined by the awareness of the difficulties that poor patients underwent in accessing the free care that was available, and the conception of the duty to ensure good clinical outcomes.

Relationships between patients and medical practitioners were often fundamentally asymmetric, and patients frequently asked doctors to make their decisions for them. While this may have been contrary to the reciprocal logic of informed consent procedures which required patients and doctors to both be autonomous and mutually aware of their rights, it was seen by a number of doctors as a sign of *essential trust*, and valued greatly by them. Typifying the views of many respondents, one surgeon from a private hospital remarked: 'I think you have to be paternal in your attitude to patients...'[430] It is debatable whether the value ascribed by doctors to *paternalism* is a reality judgement (appreciation of social inequities, patients' rejection of autonomy) or a value judgement (valuing role of specialized knowledge, valuing dominance). Plausibly, it was a manifestation of doctors recognition of the positive social role of specialized knowledge ('he has come to you for help'[431]) in a society with strong asymmetries of knowledge ('many a time the patient's general intellect is not enough'[432]).[433] A number of respondents remarked on the personal validation perceived from being responsible for clients' well-being.

> They all say, well doctor if it is your child what will you do? What ever you would do for your child do the same we leave it to you. So there is a different relationship. That's one of the great things of working here [in India].
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> Senior surgeon, private hospital (25)

In the words of a physician from a government hospital: 'tomorrow my client and his well-being depends on me and it is a great feeling'.[434] He expressed regret that many doctors utilized this

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[429] Respondent 14: Venereologist and HIV specialist, 7 years experience, government hospital
[430] Respondent 25: Senior surgeon, private hospital
[431] Respondent 33: Senior physician, government hospital
[432] Respondent 30: Senior physician, government hospital
[433] This is an example of overlaps between reality and value judgements that were often apparent.
[434] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital

privileged position for self-aggrandizement. Beyond the egoistic gratification gained from the dominance of the paternalist position, there appeared to be a more complex value orientation. Patients' attitudes allowed doctors to serve unilaterally, to effect cure and relief to the suffering without contestation of the essential benevolence of their actions, and unadulterated by the doubt and confusions that underlie a reciprocal relationship. This privileged and possibly illusory *position of unconditional giving* was highly prized by them.

Rights of medical practitioners

Lastly, a key value consideration upheld by doctors was that of teamwork and *solidarity between co-workers*. The rights of all health workers to optimal protection from infection were invoked in defence of practices of mandatory testing. Fairness in allowing all health workers access to patients' HIV status was a consideration which contradicted confidentiality policies.

8.1.4   Judgements of 'reality'

Practitioners' assessments of situational factors and constraints or "reality judgements" (Vickers 1965), including shortages of time and resources and relationships with different workplace actors, emerged as important contexts of divergent practices.

Resource lack and deprivation

An important "reality" for doctors was the *risk of infection* by a HIV positive person through the medium of needle stick injuries or in the course of surgical procedures. Although the likelihood of their being infected in scientific terms was very low, the fear of infection was considerable among most doctors, and particularly surgeons, and motivated indiscriminate HIV testing by doctors, especially pre-operatively by surgeons. The perception that routine protective equipment available to prevent cross-infection was inadequate also led surgeons to pre-emptively test their patients for HIV. In some hospitals, there were actual shortages of gloves and protective equipment. However, in other instances, administrators claimed that protective facilities were adequate, and further that surgeons were widely misguided in assuming that advanced protective equipment was required to protect themselves, whereas in actuality simple practical measures could be taken to prevent infection. They (administrators) described this as a symptom of a *sense*

of deprivation that prevailed among doctors, comparing their conditions against an imagined ideal of standards of facilities in Western countries.

Apart from a shortage of resources, doctors described their constraints in terms of lack of time and manpower and of excess of patients. For instance the idea of strict confidentiality in a crowded consulting room with large volumes of patients and limited hours was described as 'completely impractical', by one gynaecologist in a government hospital.[435] In other instances, shortages of counselling staff were reported to limit the number of patients who could be offered tests.[436] Given a low staff to patient ratio, relatives of patients were usually co-opted to perform various basic tasks of care provision, in the context of which confidentiality of patients' HIV status was highly improbable. In this environment of constraints and contingencies, a gynaecologist underlined the vulnerability of doctors to appraisal against unreachable standards: 'first these unrealistic polices are made, then you will criticize the doctors that they are not measuring up to the standards they are supposed to be following.'[437]

Relationships with patients

Patients' actions and attitudes were key reality considerations for doctors. The attitudes of patients in government and private hospitals were widely reported to be inconsistent with autonomous decision-making. There were reports of *patients not appreciating the consent procedure*, and deep-rooted problems of comprehension of the information imparted around HIV testing, particularly in the case of poor, illiterate patients attending government hospitals.[438] Reportedly patients often approached the clinical encounter trusting the doctor to make the best decisions for them, and hence asking for written consent represented a rejection of that expectation.[439]

Further, patients' expectations were said to be usually oriented around receiving care for their complaints. In this context, formal procedures for consent and counselling were seen as time consuming diversions, especially when they required going to a separate room or department. In government hospitals there were fears that patients would abscond when asked to consent and be counselled prior to a HIV test. In the private sector, often, introducing procedures such as specific consent and counselling around the HIV test was seen to be potentially offensive to patients, and

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[435] Respondent 21: Senior gynaecologist and head of department, government hospital
[436] Respondent 20: Junior gynaecologist, government hospital
[437] Respondent 21: Senior gynaecologist and head of department, government hospital
[438] See Chapter 5 (5.4.6) for details on practitioners' problems in conveying information to patients.
[439] See Chapter 5 (5.4.7)

hence antithetical to the aim of retaining patient custom. *Retaining patients' custom* was a key consideration of doctors in both private and public sectors.

Relationships with co-workers

In some instances, staff who worked in operation theatres with surgeons clearly expressed their objections to participating in surgery on HIV positive patients. Supporting staff are vitally important in the successful undertaking of surgical procedures, and their perspectives were given considerable importance by surgeons.[440]

Concerns around the risk of HIV infection through needle-stick injuries for nurses, paramedical staff and hygiene workers were voiced by doctors in all sectors of hospitals. Health workers widely felt that they needed to know which patients were HIV positive, and resorted to informal 'grapevines' and devices such as labelling of case files or beds. Such practices were widely tolerated by doctors with a sympathetic perspective of the needs of their co-workers.

8.1.5   Understanding practitioners' actions: summary

Policies were typically "taken loosely" or flexibly by doctors, who followed logics of discretion, maintenance of harmony and adaptation to the needs of situations and of other stakeholders, addressing value considerations where possible. Outright contravention was seen in some instances, particularly in the context of pre-surgical HIV screening, and was marked by a sense of secrecy. In a number of instances doctors did comply with policies, motivated by shared values with the HIV/AIDS programme, or by a sense of obedience to institutional or governmental norms. In some instances, practitioners complied with policies in spite of not comprehending, or disagreeing with the principles on which they were based.

A mix of role perceptions, value orientations and pragmatic 'reality' considerations which conflicted with compliance to the policies underlay practitioners' divergent practices (see Figure 8.1). Themes around reality judgements and value orientations often resonated similarly among public, charitable and private sector doctors.

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[440] See Chapter 5 (5.3.5)

Role / rationale ambivalences	Conflict between roles: - Clinical service provider - Scientist - Government servant (G) - Public health worker Conflict between organizational rationale and programme rationale
Reality judgements conflicting with compliance to policy	Risk of infection Context of lack and deprivation (G, C) Patient actions and attitudes Co-worker needs
Value orientations conflicting with compliance to policy	Clinical efficiency Economy (G, C) Scientific challenge of diagnosis Equitable treatment of patients in the hospital (G, C) Professional thoroughness (pre-surgical screening) (P) Essential beneficence of medical encounter Duty to diagnose (G, C) Trust and paternalism Rights of medical providers

Action Judgements

Flexibility / discretion
Contravention
Superficial compliance

Figure 8.1 Explaining Medical Practitioners' Divergent Actions[441]

8.2 UNDERSTANDING ROLES OF OTHER ACTORS

Like medical practitioners, the actions of many other actors too diverged from their expected roles in policy implementation processes (see detailed accounts in Chapter 7). Analytical themes derived from the accounts of these other actors (administrators, regulators, private sector actors, international actors and independent groups) of their actions in the context of policy implementation and their explanations for these actions, are presented in this section. Like with medical practitioners, their explanations can broadly be understood in terms of role perceptions, reality judgements and value judgements (Hjern and Porter 1981 Vickers 1965)

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[441] (G) refers to government hospital practitioners, (C) to charitable hospital practitioners and (P) to private hospital practitioners

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8.2.1 HIV/AIDS programme and public functionaries: a double role

For a number of public servants, including institutional functionaries in government hospitals, HIV/AIDS programme officials, and the State Medical Council officer, there appeared to be significant *discrepancies between their expected and actual roles* in implementing policies. Typically, in practice, public servants relatively neglected their tasks towards ensuring the implementation of policies. Programme officials disavowed their regulatory functions, instead focusing on supportive interventions and institution-building activities. Hospital functionaries typically did not enforce policies among hospital staff. Medical councils adopted a passive role in enforcing disciplinary standards, tending to focus on continued education and efforts to protect the interests of medical professionals. Government general health departments are occupied with the management of broader structural and financial issues, and do not concern themselves with regulating medical providers' behaviour.

However, in official terms, symbolic acts signifying the completion of regulatory tasks were often adhered to. Public officers often concentrated their energies on the fulfilment of formal and documentary tasks, rather than on their actual roles in ensuring policies were implemented. Resultantly they tended to assume *different public and private visages* around their roles in implementation. For example, hospital functionaries maintained a façade of compliance with policies, by engaging in complicated acts of subterfuge and complicity with colleagues and supervisors from the HIV/AIDS programme, to ensure that infringements of policy did not reflect in official documentation or in inspectors' reports.[442b,443]

Public functionaries also experienced *ambivalence around core roles and rationales* for action. Hospital functionaries were often conflicted between organizational and HIV/AIDS programme rationales (Hjern and Porter 1981), programme officers' identities were divided between a entrepreneurial rationale of programme expansion involving extension of support to medical providers (preferred by them) and a policing rationale towards ensuring the quality of implementation. In the case of the Medical Council, it is likely that medical interest groups had so dominated its functioning that the functionary's *perception of core roles was subverted* toward *protecting* doctors and presumptions of the sanctity of the medical profession, rather than regulating their behaviour. Evidently, most of these Government functionaries perceived more

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[442] See Chapter 7 (7.2.1)

[443] The functionaries did not appear to be conscious of the separation of actual tasks and documentation formalities, until it was pointed out to them. One government hospital Department Head, in response to my queries around compliance to policies, said: "what you are making us accept is that there is a policy and we are not following it – that is difficult for us to do" (24).

meaning in efforts to expand the scope of their activities and support frontline medical providers, than in regulatory tasks.

Lack of conviction about the appropriateness of the policies was a common theme among government officials, even paradoxically among HIV/AIDS programme officials[444], who were ostensibly owners and promulgators of the policies. This was representative of an essential *dichotomy between their beliefs and their official behaviour*, analogous to what was observed among medical practitioners in government hospitals. Frequently also, the functionaries' departure from regulatory tasks was explained by their incapacity to perform these tasks, in the face of situational constraints. Lack of true authority over the behaviour of medical providers, particularly private providers, was a resonant theme among HIV/AIDS programme officials. Department Heads and Infection Control officers in government hospitals too perceived a lack of acceptance of their regulatory functions, by staff and administrators.

In summary, varied explanations for divergences from recommended roles emerged from the government functionaries' narratives. Like medical practitioners, public functionaries' divergences from expected roles can be understood in terms of conflicting role perceptions, reality appreciations, and value judgments (See Table 8.1). Public functionaries' actions were particularly marked by dichotomies, between actual and publicized behaviour, in the essential perception of roles and rationales, and between their feelings and their official actions.

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[444] See Chapter 7 (7.4)

	Heads of Department, Government Hospital	Infection Control Officer, Government Hospital	HIV/AIDS programme Officials	State Medical Council Official
Role orientations and preferences	Pre-eminence of role of coordinating clinical tasks		Primary role of resource provider Regulatory role perceived to be incongruent with service development ethos	Largely passive approach to regulatory role Reorientation of role around protecting more than policing medical practitioners
Reality judgements conflicting with expected roles	Delicate relationships with staff	Indifference of staff, lack of support from administrators	Lack of capacity to regulate Problems in integration of HIV/AIDS programme with general health services in hospitals	Dominance of medical interest groups in disciplinary committee, non-participation of other members Few instances of complaints against doctors
Value orientations conflicting with expected roles	Solidarity with the medical practitioners' concerns		Engagement with programme expansion, over regulation Lack of conviction of content of policies Preference for supportive-type engagement with medical providers	Preference for supportive / educational-type engagement with medical providers

Table 8.1 Explaining Public Functionaries' Divergent Actions

8.2.2 Private sector actors

Administrators of the private hospital valued their autonomy and freedom from government interference. However, they were preoccupied with an institution building role, which involved developing their scope of activities and improving the public image of the hospital. In this context, adopting governmental policies for implementation in their hospitals represented an opportunity to further the image of the hospital. In actuality however, these policies may not have been implemented rigorously.

Private hospital administrators' narratives highlighted a double role in policy implementation, similar to that of many government functionaries. When faced with pressure to adopt national HIV testing policies, these were nominally adopted on paper to appease HIV/AIDS programme authorities but were generally not enforced among staff, in practice. It is likely that there was a distinct set of policies for "internal" use, which endorsed the practice of pre-surgical testing. Hence, although private hospital administrators are not public officials, they similarly may have tended to separate public and private behaviour, in response to pressure from the state.

Box 8.1 Private Hospital Administrators' Response to State Policy

Discussions with the official from the *Medical Association* revealed the organization's self perception as representatives of private medical practitioners, and guardians of their interests. In this context, medical associations often actively opposed government's attempts to regulate the practices of private practitioners. Hence other than their engagement through educational programmes, their role in implementation of national policies may have been largely counteractive.

8.2.3 International actors

International organizations, although not formally having a role in implementation, appeared to play a role of guiding policy decisions and monitoring the implementation of policies by the national HIV/AIDS programme.

UN officials placed a strong emphasis on individual rights and values of personal autonomy, which they regarded as universal principles. They also placed considerable importance on *coherence and conformance* in the execution of policies. These value considerations combined with their intellectually dominant position over passive HIV/AIDS programme authorities contributed to their perceptions of roles as overseers of national policy formulation and implementation.

8.2.4 Independent groups: exploring niches

NGOs addressing consumer rights, human rights and PLHA rights were actively involved in the process of policy implementation. The involvement of these independent agencies in the

implementation process was typically voluntary or a result of being commissioned, and they were typically motivated by impulses for *completing tasks left unfulfilled by overburdened public institutions*. The goals of these organizations were broadly oriented around public welfare, however their respective approaches toward achieving these goals were varied and differed from those of public health institutions. NGOs were variously involved in seeking to correct the practices of medical providers, or lobbying for legal and policy reforms. Accreditation organizations are autonomous bodies which had affiliations to Government ministries, but largely operated on independent terms, by advertising their services to hospitals.

The roles of these autonomous groups in the broader policy environment were often unclear and undefined. In order to identify meaningful niches for themselves these organizations had to actively engage and negotiate with other stakeholders to define their roles better.[445] Their relationships with other public and private groups were marked by challenges to their legitimacy and status, and also by opportunities for collaboration and learning.

8.2.5   Understanding roles of other actors: summary

- The actual roles of different groups differed widely from those prescribed in their constitutions. *Government functionaries*, including programme officials and hospital administrators did not fulfil their prescribed roles in implementing policies. These divergent actions were explained on the basis of values such as the preference for developmental activities and supportive engagement with medical providers; and on reality judgements such as the lack of actual capacity to regulate, particularly in the private sector.

- The roles of *private sector actors* were complex, and their actions ranged from counteracting efforts of government to enable implementation to collaborating with the HIV/AIDS programme; depending on how their broader purposes were served.

- *International organizations* and *NGOs* played 'supporting' roles in monitoring and invigilating policy implementation, even as they are not formally mandated to do so. Their participation was broadly influenced by value considerations around coherence of policy responses to problems, and concerns over human rights, respectively.

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[445] These actors accounts are presented in detail in Chapter 7 (7.8 and 7.10)

8.3 FUNCTIONAL INTERACTIONS BETWEEN GROUPS

Analytical themes from respondents' accounts of their interactions with other groups in the context of implementing policies are synthesized here, drawing from the detailed narratives in Chapters 6 and 7.

8.3.1 Medical practitioners' interface with authorities

Hospital authorities

Medical practitioners' interrelationships with hospital authorities, including department heads and institutional administrators are the most proximate link to field level practices, in the implementation chain. In *government hospitals,* hospital and departmental-level administrators had a largely *passive role in policy implementation.* Even as the administrators appeared to have some notional authority over hospital functioning, they generally did not exercise tight control over the behaviour of their staff (practitioners) in matters such as HIV testing. In this, HODs and superintendents were influenced by their delicate relationships with the practitioners.[446] In many instances they sympathised with the practitioners' viewpoints against national policies, and doctors even perceived hospital authorities as being protectors against external criticism for not following policies. In an instance where an Infection Control Officer attempted to ensure implementation of policies, his *authority and efforts were rejected* by the doctors. Some doctors were openly indifferent to the value of administrative and coordinative tasks.

Administrative control over policy implementation in the *private hospital* was also passive and notional to a large extent, and there was little evidence of active enforcement of HIV testing policies. In the *charitable hospital,* there was a stronger influence of institutional mechanisms to ensure compliance, as a result of agreements on hospital policy between practitioners and administration. However the hospital's policies were not entirely congruent with national policies.

Other regulatory influences

Doctors, especially those in the private sector, reported feeling threatened by the possibilities of *litigation* on the basis of malpractice, in consumer and civil courts. However this threat

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[446] See Figure 7.3 on page 194

perception was largely latent, and not reflected in the numbers of doctors who are actually sued. Agencies involved in legal advocacy supported this view and felt that HIV testing was not typically regarded as an area which would lead patients to take legal action.

The threat of disciplinary action from *medical councils* was perceived to be negligible by doctors. The accounts of the medical council official too revealed minimal actual attention to disciplinary tasks. State *health departments* appeared to have no role in handling issues of such specificity (as the implementation of HIV testing policies by doctors) themselves, nor in actively ensuring that hospital administrators ensured implementation.

8.3.2   Other key interactions

HIV/AIDS programme officials and government hospital authorities

The next link in the chain of implementation - the interface between institutional functionaries (department heads of government hospitals) and HIV/AIDS programme officials was similarly complex. In spite of the presence of a clear regulatory component in their constitutional functions, the programme officials rejected this role altogether in its practical application. In practice, their relationship with hospital functionaries could be said to be broadly *lateral or collaborative*, rather than vertical. Hospital functionaries in charge of policy implementation (typically heads of clinical departments) were employees of government health services and not of the SACS, and hence there was little opportunity for the SACS to exercise the hierarchical authority which accompanies a relationship of financial dependency.[447] Contractual employees of the SACS who were placed in hospitals (such as technicians and counsellors) did not have the real authority to play a monitoring role on practitioners actions. It was also apparent that enhancing the acceptability of the programme was an important goal for the HIV/AIDS programme officials, hence their preference for supportive and educational approaches. Furthermore programme officials were usually physicians themselves and professed empathy with hospital functionaries.

Nevertheless, formalities of documentation of HIV/AIDS programme activities in hospitals were adhered to on a strict basis, and the *smokescreen of a supervisory relationship* was maintained through this process. This conscious or unconscious agreement broadly worked to protect hospitals from external criticism, or appraisal by representatives of international agencies, or even

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[447] See Figure 7.4 on page 203

HIV/AIDS programme-appointed inspectors with "international" credentials, who were not expected to have the commensurate insight or sympathy into the functioning of public systems.

Government and private sector actors

From the accounts of representatives of regulators and HIV/AIDS programme officials, it was apparent that there was a virtual abdication of particular aspects of their duties, particularly around engaging with private providers. The official from SACS commented on the difficulties of attempting to regulate private providers. On their part, private doctors tended to make a virtue of their independence from governmental control, even as they paradoxically voiced resentments over the government's lack of support, particularly academic support, and the absence of efforts to involve them in public health initiatives (see discussion in section 8.4.3).

Administrators of private hospitals and officials of medical associations – self-proclaimed representatives of the interests of private practitioners – repeatedly emphasised their autonomy from any form of government control. Meetings between HIV/AIDS programme officials and private hospital administrators were particularly fractious in one instance where the administrators resisted the programme's attempts to impose policies. The fallout of these interactions was marked by feelings of *low mutual esteem* and imputations of bad faith. The official of the medical association too had a jaundiced view of government's efforts to increase regulatory control over medical practice, which he broadly described as ploys of politicians with vested interests. The association often assumed *pre-emptively oppositional positions* to such initiatives of government. However private actors were not entirely averse to collaborations with government. Engagement with government and with programmes seen to be in the public interest had the value of conferring legitimacy on their activities or otherwise contributing to a benevolent public image.

UN organizations and HIV/AIDS programme authorities

The UN agencies' role was ostensibly to provide technical support, including inputs in determining the content of policies. Their dominance in setting standards for HIV testing was largely unquestioned by other stakeholders. In practice UN organizations actual roles appeared to extend, from the basis of their intellectual ascendancy, to the more instrumental *role of monitoring standards* in the national HIV/AIDS programme. Inspectors from international organizations were influential in identifying and highlighting gaps in the implementation of policies at hospital level.

HIV/AIDS programme officials appeared to perceive little agency on their own part in determining policies, and simply deferred to UN agencies.[448] However they (programme officials) may have partially resisted this domination in passive ways by acts of *omission and subversion*. For instance, they were cautious in their uptake of suggestions by UN officials for repeated changes in national policies, to keep up with frequent shifts in stances within the UN. The programme officials may also have colluded with hospital authorities to cover up breaches of policies in hospitals, from UN inspectors.

8.3.3   Stronger controls over implementation?

Evidently, even as HIV/AIDS programme and hospital authorities exerted a notional control over the doctors' actions in regard to policy implementation, the actual ability (and inclinations) of these authorities to exert power over doctors in correcting instances of non-compliance was limited. However, there were indications that hospital authorities were under increasing pressure from different sources to emphasize their role in implementing policies and streamline practices of their staff in accordance with national policies. These pressures reportedly came from the higher echelons of the HIV/AIDS programme and from international agencies and non-governmental organizations.

Increased administrative control over policy implementation represented a tightening of policy requirements which doctors had previously 'taken loosely'.[449] Doctors' resented the idea of greater administrative control on the basis of the injustice of being culpable for something which they felt was not within their control. Policies were ideals which they tried to 'measure up' to in the face of practical constraints, and a regulatory approach would, it was felt, emphasize the deficiencies in their practices rather than their efforts to improve.[450,451]

The accordance of *legal status to the HIV/AIDS policies* – the acme of increased regulatory control[452] – was perceived as a significant threat. On their part doctors agreed that the enactment of the Bill would partially have the effect of streamlining practices in accordance with national policy. However they also felt that it would urge many doctors to think foremost about their own interests, rather than the patient's, and even deter medical providers from undertaking to treat HIV/AIDS patients. 'You are promoting defensive medicine', said one physician from a

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[448] See Chapter 7 (7.4.1) for HIV/AIDS programme officials' account.
[449] Respondent 21: Senior gynaecologist and head of department, government hospital
[450] Respondent 21: Senior gynaecologist and head of department, government hospital
[451] Respondent 29: Senior surgeon, government hospital
[452] As postulated in the HIV/AIDS Bill 2005 – see Box 2.1

government hospital.[453] Plausibly, the emphasis on policy implementation may have had the effect of orienting medical practitioners away from a *values-based logic* of practice toward a *logic based on the perpetuation of their interests*, i.e. the legal protection gained from written consent procedures. Hence, in spite of value conflicts, medical practitioners' may have adjusted their practices toward adopting informed consent in the light of possible benefits or safeguards for themselves. Lipsky emphasizes that the street-level bureaucrat's (SLB) response to the imposition of greater administrative control is often a greater tendency to stereotype, at the expense of regard for the needs of patients (Lipsky 1980). Analogous in this study was the tendency of medical practitioners to follow the formal aspect of policy without attention to the values and meaning of the process, or in other words to *separate their actions and their beliefs*, when faced with pressure from authorities to implement policies. In the case of policies for informed consent, it appeared that the policy symbolized a transactional and autonomy-oriented logic to define the patient-provider relationship, in contrast to the beneficence-orientation that they valued in their encounters with patients. It is worth noting, as one physician pointed out, that even as the doctors' conceptions may have altered, many patients' conceptions may have remained oriented around logics of trust and paternalistic asymmetry.[454]

Stronger control over implementation of unwanted policies would also lead to *more subversive practices*, according to many respondents. A surgeon pointed out that there were numerous practical ways of subverting the law by exploiting asymmetric power equations with patients: 'We will ask the patient that go and get the investigations done (from outside). I will write it on a blank piece of paper. But if you see below, there is no signature. You tell him, get the test done, and he will get it done.'[455] Mandatory testing by such subversive means could be said to represent a distorted version of the culture of maintenance of harmony already described, in which medical practitioners tended to adjust their actions to the demands of different stakeholders to ensure uninterrupted functioning of the day-to-day business of the hospital. Since administrators represented authority figures, and good relations with co-workers were important for practitioners, the weakest or most compliant links in the chain were usually patients. The pressure to comply with policies in this instance may have *emphasised* rather than corrected this disequilibrium by encouraging "underground" mandatory testing, with patients more likely to be at the receiving end of adverse unaccounted outcomes.

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[453] Respondent 30: Senior physician, government hospital
[454] Respondent 65: Physician, 15 years experience, charitable hospital
[455] Respondent 31: Senior surgeon, government hospital

8.3.4 Functional interactions between groups: summary

- Even as the written constitutions of particular groups may have contained rules for their involvement in policy implementation, in actuality interactions between groups were shaped more by informal relationships – determined by the actors' value systems, goals and mutual power dynamics. For instance, although façades of hierarchical authority was maintained, HIV/AIDS programme authorities were reluctant to play an enforcing role with hospital authorities, and likewise hospital authorities did not insist that their staff follow policies. Governmental regulatory authorities did not feel that they had the capacity to regulate private hospitals, and hence tended to be inattentive to the aspects of their duties involving working with the private sector. In spite of no formal mandate to implement policies, a widespread perception of their intellectual dominance allowed UN agencies to play an influential role in monitoring HIV/AIDS programme performance. Hence *living relationships and equilibria between groups of actors, as much as written rules*, influenced whether (and how) policies were implemented.

- Efforts to modify "written constitutions" (Hjern and Hull 1982) to emphasise greater control over policy implementation, such as the move to introduce laws for HIV/AIDS, *do not account for the prevailing dynamics of living relationships* between different groups, according to respondents. Hence even as these measures might increase instances of policies being followed "on paper", they may also simultaneously encourage specious behaviour on the part of public functionaries and medical practitioners based on assuaging supervisors and completing formalities rather than on carrying out core tasks, including (in the case of medical practitioners) serving patients.

8.4 MOVEMENT OF IDEAS

The interactions and relationships between different groups in the process of instrumentation of tasks towards implementing policies have been discussed in the previous section. As important – although less apparent to an external observer – are ideational processes, such as the conveyance of meanings contained within the HIV testing policies and the uptake of alternative ideas.

8.4.1   Ideas contained in national policies

The contents of the national HIV testing policies were developed around ethical considerations toward safeguarding the rights of people who undergo testing. Individual rights and autonomy are particularly prominent themes underlying policies for specific informed consent and confidentiality. Ethical foundations of the different aspects of the policy are discussed in detail in Appendix 1.

Perpetuating policy ideas

The prominent role of UN organizations in originating and promoting existing HIV testing policies was apparent. In the perception of a UN official, prevailing policies were meant to be passed down from actor to actor, originating from themselves and being communicated to and adopted by the programme at national level and state level, being enforced by hospital functionaries, and being enacted by medical practitioners in hospitals.[456]

Nationwide efforts were ongoing to create a programme structure around the ideals contained within HIV testing policies, including the institution of hundreds of VCTCs. However, even as the HIV/AIDS programme perpetuated the *symbols and terminology of the policies* (Rein and Schön 1993) – slogans such as "consent" , "confidentiality" and "counselling" – the ethos of free choice and autonomy envisioned by policymakers was often reported to be deficient in VCTCs and hospitals.[457] Given programme officials' own problems of comprehension of policies, it is likely that there may have been significant gaps in the programme's ability to communicate policy ideas to implementers at street-level (see below).

Instead, *civil society organizations* may have had a prominent role in sustaining the emphasis on a rights-based policy orientation, typified by their roles in initiating legal reforms, and voluntary roles in invigilating medical providers' practices.

Although formative medical education had not equipped doctors to address some contemporary issues, in-service *HIV/AIDS training programmes* served the important purpose of increasing awareness to HIV/AIDS policies. Participation in such programmes did not always engender straightforward compliance to policies, but addressed deeper purposes of professional growth and fulfilment, and confidence in personal experience and values. Training in Western countries was often cited as being useful in endowing doctors with awareness of contemporary concepts.

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[456] Respondent 47: Officer in UN technical agency, 7 years in the UN, recently deputed to India
[457] Several respondents (12, 15, 22)

Problems in communicating the ideas

Problems in communication of policy ideas were experienced at various levels, including the highest– between UN officials and NACO. A UN official indicated that it was difficult to communicate the concept of "routine offer of testing" to programme officials, and that this was widely misunderstood to indicate an endorsement of mandatory testing.[458]

It was apparent that the value considerations underlying specific informed consent were complex and not easily comprehensible to many actors. The rights-oriented rationales on which many HIV testing policies are based were often not well understood. It was particularly remarkable that HIV/AIDS programme officials did not appreciate, and downplayed aspects of the national policies they were themselves involved in propagating. In one instance a government doctor described the inability of programme officials to explain the rationale of their own policies for informed consent. Medical practitioners' problems with appreciating the principles of national policies have already been described in detail (see section 8.1.3).

Frequent shifts and changes in policies at the highest levels may also have prevented ideas from permeating to the community and having a sustained impact, according to a PLHA activist.[459]

8.4.2   Alternative ideas

As has been discussed in the previous section, there were frequent conflicts between the requirements of HIV testing policies, and doctors' "appreciations" of situations they faced on the ground based on value and reality considerations. Some of these alternative ideas or appreciations are presented in Box 8.2, below.

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[458] Respondent 47: Officer in UN technical agency, 7 years in the UN, recently deputed to India
[459] Respondent 07: Head, PLHA network

- Value of *discretion* over standardized approaches, given the differing needs of patients

- Importance of justice in *managing patients equitably* in hospitals, as opposed to HIV exceptionalism

- Arguments in favour of *pre-surgical HIV screening,* given the risks to health workers

- Virtues of *paternalistic approaches* as being closer to many patients' expectations

- Importance of flexibility in interpretation, regarding *policies as ideals* (rather than norms) in the face of situational constraints.

Box 8.2 "Alternative" Ideas of Medical Practitioners

However, these "appreciations" or ideas of doctors were often privately contained and not widely communicated to other policy actors with whom they came in contact. In medical practitioners' interactions with other groups, these alternative ideas were dominated by the rights- and autonomy-based arguments posed by international and civil society actors. Concepts such as informed consent and strict confidentiality, which are a part of formal policies, were accorded an ideal status, and the "practical ethics" that characterized doctors' own adaptive responses were generally seen – by the practitioners themselves and by other actors – as dilutions of these high standards.

Practitioners' lack of discursive skills and confidence

For medical doctors, ethics was not really a major area of discourse, and medical knowledge for them was largely synonymous with technical and scientific knowledge. As a result of this general priority for technical aspects of medicine, they lacked the discursive skills (and also the platforms) to articulate the ethical themes on which their alternative "appreciations" were based. Linked to this linguistic incapability was the lack of confidence to imagine that personal experiences could be worthy of valuation, over enshrined universal and Western-derived principles. 'The general interpretation of the personal opinion is that you are doing something irrational', said one government physician.[460] Furthermore since particular practices such as pre-surgical testing were illegal in government hospitals, discussing it with authorities would have amounted to admission of an illicit practice.

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[460] Respondent 16: Physician and HIV specialist, 8 years experience, government hospital

Stasis of ideas

From all accounts, ideas which arose from the experiences of field-level practitioners were usually static and not transmitted beyond limited institutional or professional boundaries. Medical practitioners often did not have the confidence to openly pit their own appreciations against recommended guidelines. On occasion however, doctors claimed they did attempt to communicate these ideas to HIV/AIDS programme officials or to higher echelons.

Government doctors claimed that to a large extent these efforts were not well received.[461] Conversely, a NACO official pointed out that hospital functionaries were often reluctant to share perspectives which were divergent from national policy recommendations, when given the opportunity.[462] In the *charitable hospitals*, there was relatively freer discourse around concerns of HIV testing within the hospital, i.e. between the medical practitioners and the hospital administrators. Contested aspects were freely debated, supported by an internal culture of ethical debate; and concessions were made toward the perspectives of doctors. However the exchange of ideas was limited to the institutional boundaries, and there was little evidence of discourse with government or other groups on these issues.

In the *private hospital and nursing homes*, practitioners particularly appeared to experience a phenomenon of intellectual isolation, both within and outside their institutional spheres. There was little academic engagement with other institutions, public or private, or with civil society organizations. Discussions with the HIV/AIDS programme were unsuccessful. There was little culture of debate around HIV/AIDS related issues in private hospitals, and the emphasis of internal training tended to be very technical. Private physicians who were interested in expanding their scope of interest to include HIV care had limited opportunities.

8.4.3   Platforms for exchange of ideas

Opportunities for the exchange of knowledge and views between groups of actors and within institutional boundaries were often deficient, particularly in the case of private sector actors. Within private hospitals academic support was insufficient, and opportunities to pursue scientific and professional career interests (other than monetary interests) were rare for doctors in the private sector. Larger private hospitals provide few opportunities for academic intercourse for their medical staff, and doctors working in smaller private practices and nursing homes were

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[461] Respondent 37: Senior physician, HIV specialist and administrator, government hospital
[462] Respondent 55: Senior official, National AIDS Control Organization (NACO)

particularly isolated from meaningful peer interactions. Government doctors had relatively more opportunities for academic exposure and intercourse.

CME programmes with a public health focus presented opportunities for the exchange of ideas and rationales among practitioners, but were focused mainly on government doctors and only sparingly available to private doctors. These were often used as avenues for the promulgation of standard policies, but intensive educational programmes also encouraged medical practitioners to think independently in deciding appropriate approaches for care. Given the inadequacy of conventional medical education in aspects of ethics and interpersonal communication, it is likely that such intensive training programmes may have been important platforms for expression and interchange of ideas, and for the development of discursive skills and intellectual confidence, on the part of doctors. However, intensive educational programmes were under financial pressure, given the lack of interest from donor agencies.

Collaborative projects, such as one initiated by a NGO with the aim of reforming discriminatory practices in hospitals, also engendered free exchange and discourse between the NGO workers and hospital practitioners, and mutual exposure to each other's "appreciations" or rationales.[463]

8.4.4   Movement of ideas: summary

-   In addition to functional gaps in enforcing policies, there are also *gaps in communicating the values and principles* contained within policies. The external symbols and terminologies of HIV testing policies such as "consent" and "confidentiality" may be used to shape the structure of care delivery in hospitals, but the core principles that underlie these symbolic expressions are not equally transferred.

-   The rationales of individual rights and autonomy that find reflection in the policies were not well understood by implementers, including programme officials and medical practitioners. Such *ideational gaps had an insidious impact* on how policies are implemented. Even while medical practitioners may have complied with policies, their compliance may have been superficial, and not accompanied by integral engagement in the principles that the policies were meant to represent.

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[463] See accounts of NGO workers' experiences of interacting with doctors in Chapter 7 (7.8.3)

- *Medical practitioners' own appreciations and solutions* (for field-based problems around HIV testing, distinct from those reflected in national policies) *seldom found expression* beyond the confines of their immediate peers or hospitals.

- Educational programmes and collaborative projects represented the *limited opportunities to exchange ideas and engage in discourse* available to medical practitioners, and other groups.

8.5   KEY DIAGNOSTIC FINDINGS: SUMMARY

Gaps are identified as being located in different parts of the policy-practice continuum.

- *Medical practitioners' actions* in HIV testing widely diverge from policy recommendations. *Administrators, regulators and HIV/AIDS programme officials* do not perform many of their putative functions (particularly regulatory functions) in facilitating the implementation of public health policies which are assigned to their respective offices. *Interactions between different groups* involved in implementation frequently do not correspond with expected norms.

Diagnostic findings explaining the existence of policy-practice gaps and the contexts in which they exist, are as follows:

- *Medical practitioners'* divergent actions are explained by 1) their divergent values and rationales for action, which conflict with those suggested by compliance with the policies; and 2) the particularities of their inter-relationships with co-workers, administrators and patients, and their perceptions of situational constraints. Role ambiguities and varying orientations of purpose and values often underlie the divergences of *administrators, health programme officials and regulators* from their expected roles. Actors from international organizations and NGOs widely identify with purposes in attempting to perform some functions of government implementing agencies.

- Medical practitioners and other groups involved in policy implementation inhabit different appreciative 'frames' or *systems of meaning*, and are guided by different *senses of purpose* in their actions in the context of implementing policies. A major area of conflict in different actors' senses of purpose is between a focus on *performance* – the accomplishment of core tasks and projects, and on *conformance* – involving the regulation and limitation of activities to align with written policy (Barrett and Fudge 1981). The experiences of medical

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practitioners and government functionaries are characterized by continual *adjustment and adaptation* in order to continue performing particular core tasks in a context of circumstantial and relational uncertainties. Their experiences of implementing HIV testing policies are often marked by unexpressed *contradictions and dichotomies* between officially recommended behaviours and their own appreciations or beliefs.

- Actual interactions between different groups of actors are different from expected, and often not commensurate with a "rational" process of implementation of policies from the top down. *Living relationships and existing balances of power* often do not correspond with the enactment of putative roles in policy implementation, in spite of which facades of rational implementation are often maintained by the involved actors. The influence of these living relationships on the respective performances of actors' roles is demonstrated. There are also significant *problems in the communication of ideas and meanings* contained within policies between the groups of actors, which are a critical factor in their non-implementation. Other than the definitions and solutions of field level problems offered by international organizations, alternative ideas – notably those of medical practitioners – have limited circulation. Strengthening of administrative and regulatory control over implementation of the policies potentially increases outward compliance, but may also lead to implicit *shifts away from belief-motivated to interest-motivated actions* and more instances of subversive actions by the implementers.

Chapter 9. Conclusion

In this final chapter, I discuss this study and its findings in the context of other studies relating to policy-practice gaps in public health in India, and identify the contributions of the study to a broader understanding of the implementation of public health policies in developing countries. I then focus on strategic questions outlining approaches and opportunities for different actors to contribute in bridging policy-practice gaps. Recommendations to policy-planners are outlined, and I conclude with some reflections on future directions in the implementation of public health policies.

9.1 DISCUSSION

9.1.1 Accounting for differing meanings and perspectives

The main contribution of this thesis is in understanding health policy implementation in India from the "emic" perspectives (Charmaz 2000, Yanow 2000) of the various participant actors. In Indian and other developing country contexts, medical practitioners and other health systems actors have largely been viewed in terms of their instrumental roles in the implementation of public health policies, and there are very few examples of studies which explore their perspectives – particularly their ideational capabilities and purposive natures. Walker and Gilson's study (2004) on the perspectives of South African primary care nurses implementing a new set of policies elaborates how their interpretations of policies to be implemented are informed by their views and values. Hawkes et al. (2004) have highlighted the importance of accounting for the perspectives of stakeholders, including policy decision-makers, programme managers, service providers and recipients of services, in the context of implementing global policies for antenatal syphilis control.

In this study, Vickers' model of "appreciations", seen to be formed by a combination of judgements around values and realities,[464] proved useful in elaborating the complex of meanings which actors referred to in making decisions around action. Values-based and practical explanations were not always distinct, but sometimes overlapped dialectically in respondents' narratives – perceptions of realities often determined what actors ascribed greater value to, and conversely values shaped their perceptions of reality.[465] Hence the rationalizations or explanations for actions that were cited often took the form of an appreciation - an amalgam of philosophical and pragmatic considerations.

Medical practitioners' perspectives

The value orientations which variously influenced doctors' actions included clinical efficiency, scientific challenge, professionalism, equity, sense of duty to treat, and paternalism (see the previous chapter: 8.1.2 and Figure 8.1). Practical considerations or 'reality judgements' (Vickers 1965) included the nature of relationships with co-workers and patients and cognizance of problems of resources, time and space, large patient loads and systemic unresponsiveness. These considerations combined as appreciations or *meanings* that doctors functioned by, which differed from and sometimes conflicted with the principles contained within the policy guidelines. Miljeteig and Norheim (2006) have addressed similar themes in their study of neonatal care in an Indian government hospital, reporting that the doctors referred to ethical frames in making decisions which differed from accepted Western bio-medical ethical norms.[466] Apart from this there are no known instances in the literature of the exploration of Indian doctors' systems of values and meanings from an emic perspective.

Doctors' senses of *purpose* were shaped by a composite of interests in the performance of healing functions, in the science of medicine, and in the fulfilment of organizational and social roles.[467] As noted before, doctors tended to focus more on *performance* of core tasks – mainly clinical tasks such as ordering investigations as part of clinical management, and performing surgery – than on *conformance* with policies (Barrett and Fudge 1981).

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[464] See Chapter 3 (Box 3.1)

[465] For instance, cognizance of deep asymmetries of knowledge was linked to the value that practitioners ascribed to paternalism; knowledge that patients often 'drop out' when faced with lengthy consent and counselling procedures may have led doctors to value patient retention over the importance of taking consent.

[466] See Chapter 2 (2.2.1) for more details on Miljeteig and Norheim's observations.

[467] Additionally, issues involving overt self-interests and the protection of self-interests were usually discussed by doctors in terms of invocation of their rights – the rights to safety, and to financial and job security.

Practitioners from *government* and *charitable* hospitals cited a range of motivations for performance, identifying with roles as healers and as scientists, and also by a strong recognition of their respective hospitals' roles as sources of good quality, affordable health care in a society with high levels of poverty. Doctors in *private* hospitals were somewhat more narrowly focused on addressing their individual healing functions, and to some extent in the scientific aspect of HIV care, and unlike charitable and government hospital practitioners, did not cite broader social roles and developmental concerns as being addressed through their work. The sense of purpose exhibited in the accounts of most of the doctors (private and public) contradicts the hypotheses of some authors of a generalized moral and ethical disengagement with their work on the part of Indian doctors, typically ascribed to overriding commercial concerns (in the private sector) or indifference (in case of government practitioners) (Das and Hammer 2004, Baru 2005, Jesani 1997).

There is little other writing on the nature of purposive engagement of Indian doctors in their work. Bhat and Maheshwari have reported high levels of motivation and good "affective commitment" to their profession and organization among government doctors in Chhattisgarh state (2005). Among private practitioners, the phenomenon of lesser identification with socio-developmental roles may be understood in the context of their relative isolation, an explanation which was also advanced by Jeffery (1988) and Madan (1972, 1980). Many private practitioners, removed from meaningful exchanges with peers, with public health systems, and from most substantive interactions except with patients, tended to perceive themselves in the narrow role of care providers, and less as contributors to social goals (or as "modernizers", a term used by Madan (1980)).

Public functionaries' perspectives

Officials of governmental and quasi-governmental agencies, including some government hospital authorities, HIV/AIDS programme officials, and the State Medical Council official all tended to favour aspects of their roles which *they* perceived to be more meaningful. *Hospital authorities* were generally sympathetic with the perspectives of their subordinate staff of doctors, and favoured the efficient completion of clinical tasks over onerous responsibilities of enforcing policies. *HIV/AIDS programme officials* preferred to emphasise their roles in expanding their projects and facilities, and in training and educating medical providers, rather than in regulating practices. This preference was borne partly out of a system of values favouring development and growth more than regulation and limitation, and compounded by their lack of conviction about the content of the policies; and partly out of pragmatic considerations - the basic lack of capacity to

regulate and the difficulties of combining regulatory and emancipatory roles in their interactions with practitioners.

The *medical council* official who was interviewed revealed a similar inclination for a supportive rather than disciplinary approach toward doctors' behaviour. This perspective of the official was also reflected in a change in the official constitution of the council to include a new function of *protecting the rights* of doctors. Since quasi-judicial disciplinary functions (requiring a high level of neutrality) are central to the existence of the self-regulatory councils, this may represent a major subversion of the organization's core regulatory function. Gonsalves (1997) has commented similarly on the subversion of the roles of medical councils in India.

Summarizing, public functionaries who are charged with implementation appeared to find more meaning in supportive and developmental activities, than in regulatory functions. Like medical practitioners they appeared to value performance and accomplishment – what Barrett and Fudge call "getting things done" (1981) – over conformance. The relative neglect of their roles in enforcing and regulating standards was also linked to overriding pragmatic considerations such as the nature of relationships with practitioners and lack of basic capacity to regulate. The perspectives of Indian public health functionaries have largely not been explored in the literature.

Perspectives of other actors

Representatives of *international technical agencies* and *donors* perceived their own purposes, and those of their organizations, as standards-setters and overseers rather than as facilitators of processes of implementation. They particularly valued *conformance* with universal policies, and favoured the streamlining of systems to promote such conformance. These perspectives are a counterpoint to the performance-oriented inclinations of the government actors involved in implementing the policies (see above). Since these international organizations are often influential in determining measures of programme success (to which funding support is linked), their ways of seeing problems and solutions are critical in determining the tenor of the response of local health systems to health problems. Top-down public health policies of international organizations focused mainly on health worker conformance and achievement of targets have been criticized by several authors (Rennie and Behets 2006, Kippax 2006, Schneider and Stein 2001, Porter and Ogden 2001), on the grounds that they are often removed from local realities of health systems and needs of communities. The roles that international technical and donor organizations can play in the context of working with complex local health systems represents an important area for further exploration.

'Civil society organizations' is probably the most internally diverse of all the groups considered in this study, and is made up of several distinct 'communities of meaning' with differing values and foci of action (Yanow 2000). Ideologies of individual human rights represented an important frame of reference for the NGO workers interviewed, and respondents were variously motivated by the need to perform altruistic social functions or to correct perceived inadequacies in government health systems. Sharma and Bhatia in 1996 identified key strengths of the voluntary health movement in India in terms of its closeness to communities and their needs, and the integration of health concerns with other aspects of community development. While such 'grassroots' themes did reflect in the accounts of some of the civil society actors,[468] others were focused more exclusively on rights-based ideologies and specific topics such as HIV/AIDS, possibly representing a *narrowing focus* of interests, or a greater specialization, among civil society actors. On the other hand, the prominent role of NGOs in health policy and legal advocacy activity represents the emergence of newer roles and functions of the Indian voluntary health sector.

Administrators of the *private hospital* which was part of the study were preoccupied mainly by goals of growth and development of the hospital, including promoting its reputation as a centre of excellence. This interest in image-building influenced them to collaborate with the HIV/AIDS programme and implement national HIV testing policies in the hospital. Hence contrary to the claims of some authors (Muraleedharan and Nandraj 2003), commercial interests of private hospitals may not preclude their engagement in public health, an observation that is also the foundation of various voluntary initiatives such as social franchising (Mavalankar 2008, Gopalakrishnan 2008), accreditation initiatives (Nandraj et al. 1999) and field-level public-private partnerships (Rangan et al. 2003).

The beliefs and motivations of the *medical association* officer who was interviewed were essentially political. His perspectives mirrored the official positions of the association, and their emphasis on a populist approach to protecting the interests of private practitioners, rather than on promoting a greater level of engagement with scientific or public concerns. These empirical findings broadly support historical analyses by Maru (1985) and by Jeffery (1988) which have reflected on predominantly political, rather than developmental, roles of medical associations through Indian history.

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[468] See Chapter 7 (7.8.4)

Summary

This study contributes to the empirical knowledge on the ways of meaning (Yanow 2000) and differing senses of purpose of different actors in the health policy-practice continuum in India. An important observation is that all the actors revealed their desire for, and pursuit of, meaning in their work, even if these pursuits often took them in directions which differed from expected norms in the context of policy implementation.

Porter et al. (1999) writing on infectious disease policy have emphasised the need for greater attention to and reflection on the visions, practices and purposes of public health organizations and systems. A better appreciation and understanding of the different ways of meaning and acting of all the groups of actors involved in implementation processes (including designated policy-planners) can help in a critical engagement with their functions and purposes, and contribute to a fuller realization of their potential in promoting good health.

9.1.2 Relational themes in implementation of public health policies

The thesis also contributes to an understanding of policy implementation in terms of interactive processes between relevant groups of actors. In an international context of developing countries, there are a few studies which have explored relational themes between policy actors. Schneider and Stein (2001) have looked at implementation of HIV/AIDS policies in post-apartheid South Africa, observing breakdowns in cooperation and trust within government and between government and civil society actors, and advocating greater cognizance of existing situational constraints and possibilities for the involved actors. Gilson and colleagues (2005) have also examined relational themes in an empirical study of *trust* between actors in a South African primary care context. They hypothesise that trust in employee – health worker relations may be linked to the quality of relationships between health workers and patients. In the Indian context, this approach is poorly explored, which is surprising given the multitude of actors who are involved in different ways in health policy implementation processes, and the fundamentally relational nature of health care activity.

In this study, doctors in both the private and public sectors were observed to have complex relationships with various groups and organizations involved in implementing policies. They were generally *resistant of administrative and regulatory control* over their actions, and were often able to protect or manipulate their interests in different ways, sometimes entailing subversion or disregard of existing policies. These findings correspond broadly with perspectives

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of Bhat and Maheshwari (2005) and Das Gupta et al. (2003) on the ineffectiveness of mechanisms of governance and accountability in the Indian public health sector. However, the same level of autonomy and assertiveness of practitioners did not appear to apply in the intellectual dimension of interactions. Privately (in the course of the interviews) practitioners expressed numerous ethical and practical arguments which contradicted or conflicted with known policies (Box 8.2), but they lacked the confidence or conviction to defend or propagate these perspectives in public fora. It would not be inaccurate to say that doctors were largely *intellectually disempowered* in the context of public health and ethical discourse even though they were *politically* powerful in terms of resisting administrative and regulatory pressures. Themes of lack of intellectual engagement and opportunity for doctors in India have also been identified historically by Madan (1980) and Jeffery (1988) and more recently by Ramachandran (2006) and Ravindran (2008).

Another set of relationships that calls for better understanding, in the light of widespread concerns around the problems of regulating the Indian private sector (Nandraj 1994, Yesudian, 2001, Bhat 1996b, Muraleedharan and Nandraj 2003), is that between government and private actors. The findings from this study broadly support the observations of Vyas et al (2003) and De Costa et al. (2008), on themes of *prejudice and mistrust* between private medical providers and government actors, particularly in the case of organized interests such as medical associations who fundamentally opposed government intervention.

Private doctors have widely been characterized in the literature in terms of the excessively commercially driven (even corrupt and venal) nature of their practices (Das and Hammer 2004, Jesani et al. 1997). Some researchers have acknowledged private doctors' vulnerability to patient agency in the context of highly competitive markets (Kielmann 2005, Kamat 2001, Madan 1980). A poorly explored aspect however is their *vulnerability as a result of lack of support* from government and the public health system. Private doctors in this study rued the lack of opportunity to pursue meaningful career interests (other than monetary interests), and voiced resentments over the government's lack of support to them, particularly academic support, even as they paradoxically tended to make a virtue of their independence from governmental control. The neglect of the private sector is also apparent from the accounts of public functionaries – educators, regulators and HIV/AIDS programme officials. Jeffery, albeit in 1977, has also discussed similar themes of the isolation and vulnerability of the average Indian practitioner.[469]

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[469] Jeffery characterized this as a phenomenon of "deprofessionalization", claiming that the way the medical sector was organized in India largely did not correspond with criteria of cohesiveness and integrity that define a professionalized sphere.

Another important relationship is that between international organizations and the national HIV/AIDS programme. Relationships between international actors and national governments in the context of the "transfer" of public health policies have been examined in some detail in the existing literature. Lush et al. (2003) have documented how WHO explicitly disseminated syndromic management guidelines to national governments of lower income countries in the 1990s, a process which received the support of major international donors such as the World Bank. Many of these governments took up the guidelines in spite of the absence of local epidemiological evidence to support their utility (ibid.). Similarly Ogden and colleagues (2003) report that DOTS was aggressively marketed by WHO and the World Bank as the solution to TB control, and transferred to national and local governments globally. Making a distinction between voluntary and coercive transfers of policy, they observe that coercive transfers lead to national policies without national ownership, which can lead to deficits in implementation. Strongly convinced as they were about the efficacy of DOTS as a tool for global TB control, the proponents of DOTS policies were reported to be autocratic, sometimes linking governments' uptake of DOTS to loans and funding support (ibid.). Cliff et al. (2004) have reported how legitimacy in a global context and implications for future funding were important factors guiding the Mozambican government's decisions to adopt global policies for STI and TB control.

While these studies have looked at the perspectives of the international actors, there is still little empirical documentation of the responses of the national governments, and the processes of their uptake of the guidelines. In this study, there was a unanimous agreement among all groups of actors that the UN technical agencies – UNAIDS and WHO – were largely responsible for developing the content of the policies in question. The response of national HIV/AIDS programme officials tended to be complex, mixing passive acceptance with acts of subversion. There were apparent problems in communicating the underlying principles of the policies between international and national-level actors, and some national programme officials expressed (privately in the interviews, but not publicly) their disagreement with these principles, a finding which supports Ogden et al.'s hypothesis (2003) around *non-ownership of transferred policies* (see above).

Other notable findings included little evidence of coordination and communication between different public functionaries who shared implementation functions, supporting Bennett and Muraleedharan's assertions on the same lines (1998). State health departments and SACS reportedly tended to function as parallel administrative structures with limited overlaps (see Figure 7.4).

This study also contributes knowledge in the understanding of relationships of civil society organizations with other policy actors in the Indian context, which otherwise have found no place in the literature. It is observed that civil society advocacy groups in the field of HIV/AIDS typically had oppositional, sometimes fractious relationships with doctors, but closer associations with international technical agencies, whom they helped to propagate and promote rights-based policies. They also played a role in lobbying international donor agencies and national government for change in policies and legal frameworks. Grassroots NGOs on the other hand often worked in close collaboration with doctors in the care of patients.

9.1.3   Concept of a health policy ecosystem

The neglect, in the literature, of perspectives of participating groups of actors, and of their living interrelationships, is indicative of the dominance of a top-down conception of the policy-action relationship among analysts, centred on assumptions of the existence of a unitary decision-making entity (typically "government") that would hypothetically receive and interpret research knowledge and execute relevant policies mechanistically (Duggal 2001, Peters 2003). This conception limits the extent and nature of strategic engagement by analysts – which usually takes the form of a set of recommendations aimed at policy-planners, and is typically focused on the goal of greater streamlining and rationalization of implementation processes.[470] Furthermore, as in the Indian context, there may be significant flaws in the top-down model as a *description* of health policy implementation processes.

Firstly, it is apparent from the findings of the study that *government*, traditionally assumed as the locus of important decisions, is not one consolidated entity. There are complex vertical and horizontal balances of power, conflicts and disconnects in the relationships between the different organs in the public sector including hospitals, public health programmes, departments of health and quasi-governmental professional regulatory councils. Datye and colleagues (2005) have also reported that policy decrees on the same issues sometimes emanate simultaneously from different organs of the government and legislature, and may conflict. Secondly, apart from government, other groups such as *international agencies*,[471] particularly major donors such as the World Bank or, in public health contexts, UN technical agencies, are also identifiable as important policy decision-makers, particularly in determining policy content. The compass of actions of these

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[470] See Chapter 2 (2.2.4) for examples (in the Indian public health literature) of analysts' engagement with strategic themes.
[471] More accurately speaking - the branches of international agencies located within the country.

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bodies however is limited since they have little direct influence over the processes of implementation, and the implementing actors. Finally, discretionary decisions addressing diverse goals and functions are exercised variously by the organizations and individuals involved in implementation processes.

Due to the multiple loci of decisions and the lack of overt definition and clarity in the configuration of health systems, most evident in vertical processes requiring concerted action (such as the implementation of disease control policies), Indian health systems have often been written off as being chaotic and irrational, leading to calls for better oversight and streamlining (Peters 2003). Amid these rationality-oriented prescriptions, it is important to realise that action in health care – even collective, sustained action *does* take place, propelled as much by the discrete pursuits of the different organizations and individuals constituting health systems and their variable interconnectivities, as by attempts at streamlining (Peters and Muraleedharan 2008).

To address these varied potentialities, the public health policy-practice continuum in India may be more usefully characterized as an *ecosystem of variously interconnected and interdependent decision-makers*, than in terms of divergence from a rational top-down model. A relational perspective on policy implementation, and appreciation of the different systems of meaning and purpose of involved actors represent potentially critical areas of attention and further exploration, and also permits a wider-ranging engagement by analysts in strategic change than a top-down view.

9.2   ENVISIONING CHANGE IN A COMPLEX ECOSYSTEM

The previous analyses have shown that in the complex Indian health sector, different groups of actors inhabit differing "frames" or systems of meaning which guide their behaviour and which suggest sometimes conflicting courses of action. Particularities of interrelationships with other groups of actors (which often do not conform to a linear "rational" implementation process) and inconsistencies in the communication of ideas have an influential role in shaping the actions of those involved in implementing policies. In these uncertain and highly contingent real-life contexts that characterize the Indian health sector, how can collective action be better organized so as to further the goals of better care for HIV/AIDS in the short term and long-term? An understanding of positive change and planning based on principles of *communicative rationality* is suggested.

9.2.1 The communicative rationality approach

Drawing from formulations developed by the philosopher Jürgen Habermas and applied in the policy sciences by Healey (1993), and by Fischer (2003) among others, an approach of communicative rationality is used to identify opportunities for change.[472] Communicative rationality offers a framework for the concerted articulation of long-standing concerns around a process-orientated perspective of change, and is an alternative standard to dominant technical-rational norms.[473] This understanding of rationality is not based on natural science-derived conceptions of individualised objective reasoning and formulation of technical solutions, but on "reaching understanding between subject and subject in a social context" (Healey 1993 p.237), or what can be described as "being reasonable" in common parlance. In a world of differences, the **effort of constructing mutual understanding** – of making sense together – represents the locus of reasoning activity, according to Healey (ibid. p.240).

Communicative rationality is founded on a recognition of the existing human condition of "living together but differently", i.e. living in shared time and space and having collective concerns, but occupying different appreciative frames[474] or systems of meaning (Healey 1993 p.237). The communicative perspective emphasises positive or productive power in the hands of actors, to "organize action through consensual communication" (Fischer 2003 p.35). Key features of "rational" communication in this approach are enlisted in Box 9.1.

> - *Acknowledgement* of the possibility of legitimacy of alternative "frames"
>
> - *Effort* to bridge communicative divides by conveying ones own and listening to the other's perspectives
>
> - *Deliberation and debate* of differences in rationales for action
>
> - *Openness* of the deliberations
>
> - *Inclusion* of different participant actors in deliberations

Box 9.1 Features of a 'Rational' Communicative Approach

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[472] Since implementation has been examined in terms of being a communicative process (Yanow 2000), communicative rationality suggests itself as a framework for prescribing change. Strategizing change on the basis of a communicative rationality perspective also represents a natural progression from an interpretivist approach to diagnose gaps through actors' internal processes and appreciations, since it ascribes value to intent and effort on the part of participant actors, not to externally contingent parameters such as health outcomes.

[473] See also Chapter 3 (3.3) for a more detailed discussion of the role of 'rationality' in prescribing change

[474] See Chapter 3 (3.2.2) for discussion on frames, appreciations and meanings

Acknowledging the possibility of legitimacy of an alternative frame is a prerequisite to establishing understanding, even if that alternative frame is not immediately appreciated or understood. The challenge of communication lies in finding bridges between these different frames, in order to *act* towards addressing collective concerns (ibid.). This can be achieved through *communicative effort*, involving listening, conveying, and seeking "translative" possibilities between different frames (Forester 1993, Geertz 1983). A desirable state is the attainment of a workable level of understanding to pursue a specific task which is of common concern, even as actors should be consciously aware of areas where understanding is not (yet) attained (Healey 1993).

Healey (1993) also identifies *exteriorization* – active discussion, argumentation and debate; and *openness* in conducting such debate, as defining features of communicative rationality.[475,476] Good communicative processes are *inclusionary* and seek to offer all actors opportunity to participate (and also to learn to participate) in policy discourse (Fischer 2003).[477]

9.2.2   Applying the communications lens

A lens of communicative rationality was applied to processes of interaction between actors. The presence or absence of the communicative criteria listed in Box 9.1 were assessed and used to comment on the rationality of the processes. The purpose here is to uncover the influences that are shaping "irrational" or (in Habermas' terms) "systematically distorted" communication[478] (Fischer 2003); and to use this knowledge to identify strategic opportunities for change. First, the types of distortions in communications that were observed in this study are summarized in Box 9.2.

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[475] Exteriorization indicates that the communicative process should be explicit not implicit. Openness implies that the discursive exchange between two actors is not secretive but available to external observers.

[476] Additionally, Healey paraphrases Habermas in recommending that discursive processes should be subject to a constant process of reflexive internal critique. Habermas' original criteria to assess arguments were: comprehensibility, integrity, legitimacy and truth (Healey 1993)

[477] Proponents of communicative rationality have differing views of the place of an model of ideal communication. Fischer harkens to a conception, proposed by Habermas, of "ideal speech"– an end state of unconstrained exchange of ideas, with equal participatory opportunities for all actors (Fischer 2003 p36). According to Healey, the integrity of different systems of meaning is important, in which context communicative rationality should be focused on *translation* between different systems, and not seek a "fully inclusionary consensus" (Healey 1993, p 239-240). Nevertheless the authors are agreed that *effort* towards establishing mutual understanding is the primary focus of communicative rationality, not the existence (or otherwise) of an ideal end state.

[478] It should be noted that the appellations of "distorted" or "irrational" communications are used provisionally, in order to guide strategic concerns, and do not constitute an evaluation or appraisal of actors' performances.

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- Non-deliberation of differences of opinion

- Passive or subversive expressions of dissent

- Non-acknowledgement of the possible legitimacy of alternative perspectives

- Pre-emptive mistrust and assumptions of bad faith

- Active disrespect in mutual exchanges

- Renunciation of mandated tasks involving interactive effort

Box 9.2 Types of "Distorted" Communications between Actors in this Study

Illustrative examples are provided to highlight instances of these systematic distortions (examples 1-8), and also instances of rational communicative processes (examples 9-12):

1. An archetypically distorted or irrational process was that of *secretive mandatory pre-surgical testing* performed by surgeons in government hospitals, either by sending patients to nearby private diagnostic laboratories, or by colluding with in-house microbiologists to perform "unofficial" HIV tests. The tests were conducted secretively and official documentation (representing the avenue of communication with HIV/AIDS programme supervisors) was manipulated. Pre-surgical testing in general was an underground practice, the rationale of the process was known only to the surgeons themselves, and the issue was not widely discussed. Surgeons were able to exploit the compliant nature of patients, and there was little accountability for continued care in case they were found to be HIV positive.

2. Instances of *collusion between HIV/AIDS programme officials and Heads of Department* in government hospitals in order to conceal certain divergent practices from external inspectors[479] were similarly founded on secretiveness and the obstruction of open communication, founded on distrust of external observers.

3. Doctors seldom brought up their objections to NACO's guidelines in available fora. In many instances, their responses to ethical dilemmas and conflicts with policies in the workplace were passive. When confronted with day-to-day dilemmas around maintaining confidentiality in ward settings, doctors had a preference for *silently subverting or adapting their practices, or deferring to authorities*, rather than confronting and deliberating on these issues. The reasons for this were manifold including the lack of confidence in the value of personal appreciations weighed against globally accepted guidelines, and lack of discursive skills and platforms in general. Typically also, the emphasis on technical-clinical knowledge was such

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[479] See Chapter 7 (7.2.1) for detailed account.

that ethical and administrative concerns were not regarded as worthy of discussion. Doctors may have been further inhibited by experiences of the unresponsiveness of HIV/AIDS programme officials to suggestions.

4. A meeting between doctors from a private hospital and HIV/AIDS programme official appeared to end unsuccessfully because of non-reconciliation of the frames of action of either group of actors (the programme seeking to regulate, and the doctors seeking to collaborate).[480] The doctors' views on the process were marked by *statements of poor regard* for the programme officials, indicating the inability to appreciate the legitimacy of their (programme officials') perspectives. In spite of these instances of poor communication, eventually a collaborative relationship with the HIV/AIDS programme was established by the hospital administrators, following subsequent dialogues.

5. Certain international actors and civil society actors had a strong belief in the universality of ethical principles enshrined in the HIV testing policies, which led them to *reject the possibility of legitimacy* of alternative frames for appropriate action, such as those suggested by medical practitioners.[481]

6. HIV/AIDS programme authorities tended to adopt policies endorsed by international organizations unquestioningly, in spite of having reservations over their content. *Dissent was expressed in passive or silent ways* – by taking suggestions selectively, or by colluding in policy subversion with hospital authorities – rather than through open deliberation. Notions of the intellectual supremacy of international organizations, and the unformulated nature of alternative arguments contributed to this passivity.

7. Medical Associations' strategic frame for political action, as self appointed guardians of the interests of private practitioners, was oriented around the identification and *pre-emptive opposition* of government's efforts to regulate practices in the private sector. This considerably limited their opportunities to engage constructively or build true consensus with government.[482]

8. HIV/AIDS programme authorities and Medical Council official *renounced some interactive aspects of their roles*, citing practical difficulties and lack of capacity. The task of interacting with private sector providers to regulate their practices was considered too difficult to undertake.

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[480] See Chapter 7 (7.2.3) for detailed account.
[481] See Chapter 7 (7.7.1) for UN agency office-bearers' detailed views.
[482] See account in Chapter 7.

On the other hand in a number of instances, distinct instances of positive communicative effort were also observed, corresponding with criteria of good communicative practices (Box 9.1).

9. A physician from a government hospital spoke to various authorities in an *effort to gain an understanding* of the rationale of NACO policies for specific informed consent. In spite of many enquiries, a satisfactory explanation could not be obtained. One HIV/AIDS programme official admitted that the reason for adoption of the policy by the HIV/AIDS programme was unclear.[483]

10. In charitable hospitals, there was reported to have been active, sometimes conflict-ridden *negotiation and debate* toward developing hospital policies for HIV testing. This involved the explication of respective positions on the part of the medical practitioners and the administrators, which led to the creation of mutually acceptable hospital policies, which assured care for patients who were found to be HIV positive. These deliberations although explicit, were not open, and the perspectives of other actors, notably of PLHA groups and of the HIV/AIDS programme were not included.

11. International actors *attempted to communicate* the rationales of newer policies to HIV/AIDS programme officials, often without success. Differences in interpretation of language were explained to be the cause of this communication gap. International actors' exact articulation of terminologies was not well appreciated by programme actors, who reportedly conflated the meanings of similar-sounding terms ("routine offer" and "routine testing").

12. A NGO attempted to reform discriminatory practices in hospitals by working closely with doctors and engaging them in debates around ethics. In the process, NGO workers *learned about doctors' and patients' perspectives, recognized their validity*, and *reconsidered their own preconceptions* around stigma and discrimination. However, doctors did not reciprocate the communicative overtures of the NGO. HODs of government hospitals were reported to have absented themselves from important meetings with the NGO, rendering communicative exchange unviable.

No particular group was found to be intrinsically more "rational" than others, although particular groups' focuses around secrecy or exclusivism (surgeons in the case of mandatory testing, medical association representatives), or around the intrinsic superiority of particular viewpoints (international organization representatives, some civil society actors), tended to reduce the opportunities for rational communications.

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[483] Doctors' accounts of interactions with the HIV/AIDS programme detailed in Chapter 6.

Processes, and not actors, are rational or irrational, and the same actors engaged in rational and irrational interactions in different instances with different groups of actors. Sometimes the same interactive process was found to have rational and irrational aspects. Communicative efforts were often unidirectional in that they were exerted by one group of actors but not reciprocated by the other. Communicative efforts were sometimes fractious and conflict-ridden, and did not necessarily lead to mutually satisfactory outcomes in the short term. However they represented a step towards achieving mutual understanding for a joint course of action.

9.2.3   Identifying bridging opportunities

The conceptual basis of communicative rationality provides broad guidance for policy actors to orient their actions around a systematized logic (see criteria in Box 9.1). The core message is that actors should be mindful of *how* they communicate with other actors as much as *what* they communicate, and that they should find ways of orienting these communications to maximise the likelihood of establishing mutual understanding.

In some instances in which actors were strongly influenced by fixed value systems or by political concerns to protect their interests, the possibility of appreciating an alternative system of meaning was inimical. Such positions as those occupied by international and civil society actors (see example 5: page 274), and medical associations (example 7: page 274), appeared intractable.

However, Healey informs us that apparently *fixed interests and preferences can be altered* through articulation and sharing - the communicative process itself holds the potential of reformulation of actors' appreciations (1993). Communicative exchange promotes reflection about individual and organizational action and purpose (Fischer 2003). What appear to be two irreconcilable positions may be bridged through persistence of communicative effort. In example 12 (page 275), a representative of a NGO explained how the effort undertaken by observing doctors practices and interacting with them in their habitats led to an re-examination of strong preconceptions around stigma and discrimination. In example 4 (page 274) apparently irreconcilable differences between the HIV/AIDS programme officials' and private hospital doctors' frames were overcome and collaboration was established. In this instance, private hospital administrators eventually recognized that there were other benefits of associating with the HIV/AIDS programme, and overcame the initial resistance of their staff of medical professionals to interference by the programme. Hence *opening communicative channels*, even (or especially)

in the apparent absence of common ground is a vital step in moving towards mutual understanding.

Respectful overtures are critical in ensuring the possibility of a constructive response from other actors. *Curtailing overt disrespect*, such as that evidenced by private doctors' expressions of poor regard towards the HIV/AIDS programme (see example 4: page 274), and in other instances between an Infection Control Officer (ICO) and surgeons in a government hospital[484], would be an important step in moving toward addressing common concerns.

Doctors' blind deference to directives of HIV/AIDS programme officials (see example 3: page 273), and similarly HIV/AIDS programme officials' unquestioning acceptance of UN policies (example 6: page 274), represents conscious or unconscious forsaking of the responsibility to make "official" decisions. From doctors accounts it is clear that they often made complex ethical decisions, but did not 'see it that way'[485] i.e. they did not regard the ethical issues they dealt with daily as potential subjects of discourse. Undertaking *deliberative discursive practices* on relevant topics emerges as an opportunity for doctors to learn the language of discourse and present their workplace dilemmas within a communicable framework. The physician in example 9 (page 275) was an exception to the norm of silent deference. In spite of considerable efforts to communicate with HIV/AIDS programme authorities he was not successful in achieving his aims.

This example highlighted that inter-discursive communication (i.e. the conveyance of meaning across different perceptual frames) is often very difficult, as is evidenced in example 11 (page 275) which highlights the problems in communicating policy messages at the highest echelons. Here it is important to understand here that the non-distinction between "routine offer" and "routine testing" may not have represented intellectual deficiency on the part of programme officials, but their occupation of a different frame for action, in which the wording of policy was not a matter of prime significance. HIV/AIDS programme officials may hence have adopted the terminology of policy, but since there was little engagement in the actual meaning of the policymakers' frames, the words were easily confused. This illustration is indicative of the difficulties of establishing understanding, which sometimes caused actors to abdicate particular communicative functions altogether – see example 8 (page 274). It is vital in such instances to emphasize the criticality of *effort of communication* toward achieving workable, context-specific understanding, even in the face of systemic problems or wider ideological divides[486], since the

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[484] See Chapter 7 (7.2.2) for ICO's accounts of interactions with doctors.
[485] Respondent 21: Senior gynaecologist and head of department, government hospital
[486] A conceptual transcendence is required in order to achieve fuller understanding of another actors' frame, which according to Geertz (1983) is rarely achieved. It is not required that each actor attempts such conceptual transcendence. It is only necessary to seek "the opening of windows to what it means to see

process of communication contains its own potentialities for idea generation and facilitation of consensual action. In the words of an officer of the state health department: 'our responsibilities will not go away by saying that there is too much work to be done'.[487]

Openness in communicative processes has a potentially demystifying impact (Healey 1993). Existing subterranean dynamics are brought to light as participants are required to make explicit their arguments and motivations. Oppressive or exploitative processes can be checked, and alternative avenues of action can be created through consultation. In the charitable hospital for example, it was demonstrated that communicative effort and struggle between hospital administrators and surgeons eventually materialised in a consensus which reduced the likelihood of exploitation of patients, and also alleviated the anxieties of surgeons (see example 10 above: page 275). Contrarily, un-deliberated concerns of government hospital surgeons were linked with underground exploitative cultures of mandatory testing (see example 1: page 273).

9.2.4   Recommendations to government planners and donors

Communicative rationality does not necessarily contain a specific "blueprint" for action, yet it may in particular contexts be used to plan and strategise (Fischer 2003). Where opportunities for communication are absent, it provides a practical basis for the creation of new discursive structures. Where existing structures are deficient or are constrained by conventions and norms which do not support open deliberation, they can be reoriented to enhance their communicative potential. Existing communicative platforms may be strengthened and built on. Government planners and donors can play a specific role in building the capacity of under-involved groups for deliberating on relevant subjects, and encouraging more equitable intellectual participation of different groups in policy-relevant discourse. In order for this, it is necessary for planners to accept broader conceptions of *success* of public health programmes, incorporating long-term goals of learning, emancipation and development of intellectual capital, not just short-term targets predicated on mechanistic conformance on the part of constituent actors (Connelly and Emmel 2003, Porter and Ogden 2001).

In the previous chapter I have outlined how the implementation of existing policies was constrained by problems in communicating their underlying rationales and principles (see page 255). The increase in administrative control through legislative and regulatory means is typically

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things differently" (Healey 1993 p 240), not the attainment of "complete" consensus or conversion (of self or other) to a singular viewpoint.
[487] Respondent 56: Official, state directorate of health services

proposed as a solution for divergent practices, but it is evident that this is of limited value, and can even be detrimental to patients' interests unless accompanied by concurrent educational and capacity-building interventions for medical practitioners around HIV/AIDS care.[488]

Educational programmes oriented around transferring existing knowledge on HIV/AIDS, including information on policies and ethics have the value of injecting new ideas into the existing appreciative mix of doctors beliefs' and perceptions. However, such instructional approaches have their limitations in bridging policy practice gaps, since they are not centred on many of the concerns that medical practitioners face in their practices. Since they are supported and perpetuated by existing institutional structures, they have the potential of domination, in "crowding out" these less well-articulated but equally valid appreciations, yet at points where the instructions conflict with practitioners' interests, in practice they are often ignored or subverted.[489]

Hence it is also vital for health systems to take account of, and process knowledge which evolves from the experiences and values of field-level actors. This requires the institution of channels for *listening* to field-level actors, for ideas to feed "upwards", for the HIV/AIDS programme and policymakers to learn from the perspectives of implementers, and adapt policies accordingly. Doctors' appreciations, like other forms of local knowledge are often not well structured or articulated (Yanow 2000), and often do not conform to widely recognizable "frames" (such as the individual rights and autonomy frames around which HIV testing policies are founded). In the first place, an approach toward inclusion of local knowledge requires a conceptual *widening of the scope of what constitutes valid knowledge* as a basis for planning action. Healey, paraphrasing Habermas, suggests that this includes such knowledge forms as practical sense, lived experiences and accumulated moral and cultural knowledge (Healey 1993).

How could different types and forms of knowledge be sourced, in practice? The creation of inclusive fora for the discussion of policy problems is suggested, which would enable exchanges between different groups who engage collectively in the project of policy implementation yet have potentially different perspectives. Hypothetically, the aims of such fora or meetings would be to invite representatives of various groups[490] to explicate their positions and appreciations around a particular policy problem, and to attempt to establish mutual understanding of each others' respective positions around the problem (following the principles of rational

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[488] See Chapter 8 (8.3.3)

[489] See Chapter 7 (7.6.2)

[490] Such as medical practitioners, administrators, Programme officials, involved government bureaus, international organizations, professional associations, and civil society organizations.

communication - see Box 9.1).[491] In addition to deliberatively *including* new forms of knowledge and perspectives from groups who do not normally contribute to policy discourse, such fora would have the added potential of *generating* new ideas for action.[492]

It is also vital to develop the deficient discursive skills of groups such as field-level medical practitioners, to help them to articulate their perspectives and enable their inclusion in policy discourses. The experience of students and teachers in intensive long term training programmes with practical exposure revealed that these programmes were not simply instructional but were transformative: in enabling access to new knowledge systems, ethical frameworks and career and collaborative opportunities, and liberating in helping the students (medical practitioners) to better articulate, and to learn to value their own appreciations.[493] The prioritization (by donors and government) of support to intensive or depth-oriented educational and academic opportunities which engender and promote new forms of discourse among medical practitioners is hence suggested. It was notable that in spite of the various benefits to all participants, such existing intensive training programmes faced financial difficulties due to their high cost per student trained, which was not attractive to donor agencies.

A number of voluntary collaborations and programmes for care provision exist in India, which involve field-level partnerships between (variously) government departments, private medical providers and NGOs (Murthy et al. 2001, Gopalakrishnan 2008, Rangan et al. 2003, PSI/Avahan 2007).[494] From a communicative perspective, such programmes have significant benefits, over and above the goals of improving programme outcomes, in facilitating intellectual exchange between relevant actor groups, and exposure to alternative ideas and perspectives in immediate practical contexts. Support for such programmes can enable critical learning processes for the actors, and contribute to a better understanding of avenues of collective action.

In summary, government and policy planners can make clear contributions towards ensuring wider participation of all actors in discourse on policy-relevant themes, and in improving the capacity of these actors, particularly medical practitioners to engage in such discourse. Specific measures which can be taken include:

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[491] The aims of such meetings should *not* be to establish what constitutes a "right" or "wrong" approach, and even if consensual solutions for problems are arrived upon, it should be understood that they are changeable through further deliberation, or in different contexts.

[492] According to Healey, discursive interaction between and within different groups generates new knowledge. A communicative approach to knowledge production maintains that "knowledge is not merely a pre-formulated store of systematized understandings, but is created anew through exchanging perceptions and understandings" (Healey 1993, p 241).

[493] See Box 7.2

[494] See Chapter 2 (2.2.4) for detailed examples.

- *Balancing increased regulatory measures with commensurate efforts* to convey the principles of existing policies to medical practitioners, through training programmes.

- *Support for intensive and participatory educational and academic programmes* which help to develop the discursive capabilities of medical practitioners.

- In order to facilitate the transfer of knowledge and the creation of understanding across different "frames" or systems of meaning: the *institution of participatory fora for the deliberation of policy questions,* accommodating a wide range of forms of knowledge including pragmatic and field-level considerations.

- Further support to and encouragement of *partnerships and programmes for care provision which are centred on human interaction* and exchange between different stakeholders is also proposed.

9.3   TOWARD 'REGIMES OF RESPECT'?

Communicative practice in implementation

How can systems for the implementation of policies for HIV/AIDS (in public health policies in general), involving a mix of actors with differing perspectives, be oriented so as to permit alternative beliefs and purposes and allow them to find expression, yet ensuring that essential tasks are performed cohesively and policy objectives are accomplished? Quoting one of the participants of the study, 'what is needed is the creation of regimes of respect'.[495] To move towards such regimes or cultures, it is not necessary for existing systems and hierarchies to be dismantled, or for policy content to change (unless appropriate), but for the interactions between different groups of actors to be oriented more towards good communicative practices – involving acknowledging the possible legitimacy of other actors' views, listening to these views, and conveying their own (Healey 1993).[496]

In a regime of respect, it is envisioned that the perspectives of all actors are acknowledged. While doctors' values are important, so are those of policy planners who would seek to see systems

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[495] Respondent 54: HIV/AIDS department head, major donor agency
[496] The term "communication" has often been used euphemistically to refer to a one-way mechanism of *persuasion* of frontline providers to comply with approved norms (Peters 2002). Healey (1993) emphasizes however that *listening* to, and accounting for alternative perspectives is an equally critical component of communicative practice.

being more efficient in accomplishing what is planned, and of civil society actors who wish to see the cessation of discriminatory practices. Each actor brings a different set of ideas and meanings to the milieu, which potentially represents the collective values and interests of the societies they belong to (Lasswell 1936 cited in Parsons 1995).

Critically, the different groups who are engaged in the collective enterprise of working towards the care and control of HIV/AIDS (or another health problem or disease) must necessarily find ways of conveying their perspectives to each other. Policy planners have the responsibility of conveying the rationales of their policies to groups who are designated to implement them. If implementers (medical practitioners, administrators, programme functionaries) seek to diverge from their designated roles on the basis of alternative rationales or ideas that they possess, they have the responsibility of communicating these rationales to policy planners openly, through deliberation and debate (and also the right of being heard). It has been observed that divergences contain innovative potential, and that deliberative processes can generate new ideas for policy. Also, the openness of deliberations has the virtue of making actors' concerns, needs and interests transparent, and hence has the potential of curtailing the abuse of existing asymmetries of power.

Hence respectful relationships are a template on which perspectives can converge and eventually be shared, but also a framework for the permission of divergence and innovation. Only in an environment of mutual respect between authorities and functionaries, can concerns of accomplishment and accountability be addressed concurrently with "bottom-up" values of trust, choice and learning (Lane 1987).

Re-imagining convergence

Members of some groups, notably medical practitioners and programme officials appeared to lack the confidence in the value of their own appreciative abilities, when weighed against globally recognized policies. This was the basis of dichotomies in their experience of implementing the policies, acting privately on the basis of their own beliefs and judgements of reality, but maintaining facades of policy compliance. These internal ambiguities and dichotomies were also observed in the accounts of other implementers (hospital administrators, HIV/AIDS programme officials, regulators) when faced with conflicting messages from policies and from their lived experiences. Wider participation in collaborative and discursive activities can help these actors to enhance their capabilities towards engaging in deliberations with other groups, and encourage

them to acknowledge the intellectual value of their own appreciations. Recommendations around the role of planners in improving such opportunities have been discussed (section 9.2.4).

Street-level implementers are a key link that systems and programmes have with the recipients of services, and hence it is particularly important not to allow their perspectives to be neglected (Lipsky 1980). In health policy, accounting for the values of care providers is particularly critical because the central act itself is predicated on an affective value orientation that pre-dates health policies, health systems, hospitals, and most social structures as we know them today - insight into the suffering of fellow beings and the impulse to resolve it. This human impulse has historically been institutionalised as the profession of medical practice, and health providers placed within structures such as hospitals and public health systems which *should* enable the impulse to be expressed optimally. However observations from this study and of other authors indicate that such supporting structures and institutions sometimes take directions which repudiate this lineage of values (Freidson 1986, Illich 2000, Jesani et al. 1997). Hence it becomes necessary to re-emphasise the role of core values of empathy and succour (Batmanabane 2008), and sustain these emphases as a constant reminder of the purposes of health systems.

In health policy implementation, this emphasis can be made by *re-imagining the core concern of convergence* not simply as the outward similitude of policy guidelines and the actions of frontline providers, but in terms of the possibility of the confluence of policies, actions of the individuals implementing policies *and* their values. It is desirable that the actors involved in the implementation of policies should have the opportunity to practice what they believe in, openly and without resort to subterfuge.

In conclusion, it is not a system which has attained external convergence between written policies and outward practices, but one which contains the possibilities of internal convergence (of beliefs and actions) for participant actors, possibilities predicated on their uptake of responsibilities, and sustained respectful communicative exertion, that presents itself as a future ideal. The precise parameters of such future systems cannot be presumed or predicted, since they will be defined and redefined by the actions and deliberations of the involved actors themselves. The emphases on respect and deliberative communication offer a foundation to address *present* concerns by reorienting policy action in a way that is "future seeking but not future-defining" (Healey 1993, p 247). An important challenge that lies ahead is of enfranchising voices which are not included in policy discourse – to bring to light the perspectives of silent participants in the policy process and to help them develop their own capacities to deliberate appropriate courses of action on the basis of their values and lived experiences.

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Annexures

ANNEXURE 1. INTERVIEW TIMELINE

SN	Date	Interview Venue[497]	Respondent[498]
1	August 18, 2005	Key informant's workplace	Key informant 1
2	August 23, 2005	Respondents' consulting room in hospital	Senior physician, government hospital
3	August 30, 2005	Offices of the UN agency	Mid-level official, United Nations technical agency
4	August 30, 2005	NACO offices	Senior official, National AIDS Control Organization (NACO)
5	September 8, 2005	Key informant's workplace	Key informant 2
6	September 10, 2005	Key informant's workplace	Key informant 3
7	September 10, 2005	Office of the PLHA network	Head, PLHA network
8	September 11, 2005	Respondents' consulting room in hospital	Senior physician, private nursing home
9	September 11, 2005	Hospital outpatient department	Junior physician, private nursing home
10	September 16, 2005	Respondent's consulting room	Surgeon, 10 years experience, charitable hospital
11	September 24, 2005	Key informant's workplace	Key informant 4
12	October 13, 2005	Teacher training centre	Senior physician, government hospital
13	October 13, 2005	Respondent's consulting room in hospital	Senior physician and HIV specialist, government hospital
14	October 14, 2005	Teacher training centre	Venereologist and HIV specialist, 7 years experience, government hospital
15	October 16, 2005	Teacher training centre	Medical educator and practitioner, 20 years experience
16	October 16, 2005	Respondent's consulting room in hospital	Physician and HIV specialist, 8 years experience, government hospital
17	October 18, 2005	Office in administrative block in hospital	Physician and administrator, charitable hospital
18	October 19, 2005	Respondent's consulting room	Venereologist, 18 years of experience, charitable hospital
19	November 16, 2005	Respondent's consulting room	Gynaecologist, 15 years of experience, government hospital
20	November 16, 2005	Gynaecology ward in respondent's hospital	Junior gynaecologist, government hospital
21	November 16, 2005	Respondent's consulting room	Senior gynaecologist and head of department, government hospital
22	November 16, 2005	Respondent's consulting room	Gynaecologist, 8 years experience, government hospital
23	December 3, 2005	Teacher training centre	Venereologist, 10 years experience, government hospital
24	December 6, 2005	Coffee shop in hospital	Senior microbiologist, government hospital
25	December 11, 2005	Respondent's consulting room	Senior surgeon, private hospital

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[497] Interviews took place in 5 cities. However the city names are not revealed, to protect respondent confidentiality.

[498] See next annexure for details about key informants.

26	December 11, 2005	Office in administrative block in hospital	Senior surgeon and administrator, private hospital
27	December 16, 2005	Doctors' common room in hospital	Junior trainee venereologist, government hospital
28	December 16, 2005	Respondent's consulting room	Senior venereologist, government hospital
29	December 16, 2005	Respondent's consulting room	Senior surgeon, government hospital
30	December 17, 2005	Respondent's consulting room	Senior physician, government hospital
31	December 17, 2005	Respondent's consulting room	Senior surgeon, government hospital
32	December 17, 2005	Preparation room of operation theatre	Junior surgeon, government hospital
33	December 23, 2005	Respondent's consulting room	Senior physician, government hospital
34	December 24, 2005	Respondent's consulting room	Senior surgeon, private hospital
35	December 24, 2005	Respondent's consulting room	Physician, 12 years experience, private hospital
36	December 26, 2005	Respondent's hotel room during a conference	Senior physician, charitable hospital
37	December 28, 2005	Respondent's consulting room	Senior physician, HIV specialist and administrator, government hospital
38	January 12, 2006	Office of the superintendent in the hospital	Medical superintendent (and physician), private hospital
39	January 12, 2006	Microbiology laboratory	Microbiologist, 13 years experience, Private hospital
40	January 12, 2006	Counselling centre	Counsellor, private hospital
41	January 14, 2006	Respondent's consulting room	Venereologist, 15 years experience, private hospital
42	January 14, 2006	VCTC attached to hospital	Counsellor, government voluntary testing and counselling centre (VCTC)
43	January 28, 2006	My residence	Key informant 5
44	February 3, 2006	Offices of the donors supporting the educational programme	Manager, short term HIV training programme for private physicians
45	February 3, 2006	Key informant's workplace	Key informant 6
46	February 6, 2006	Office of the SACS	Senior official, State AIDS Control Society (SACS)
47	February 8, 2006	Offices of the UN agency	Officer in UN technical agency, 7 years in the UN, recently deputed to India
48	February 15, 2006	Offices of the UN agency	Senior consultant to UN technical agency
49	February 16, 2006	Offices of the legal rights advocacy group	Senior member, legal rights group with focus on HIV/AIDS
50	February 20, 2006	Offices of the donors supporting the programme	Senior medical educator and consultant to HIV training programme for private physicians
51	February 20, 2006	Offices of the legal rights advocacy group	Junior member, legal rights group with focus on HIV/AIDS
52	February 23, 2006	Key informant's workplace	Key informant 7
53	March 1, 2006	Office of the consumer rights organization	Head, consumer rights organization
54	March 2, 2006	Office of the donor agency	HIV/AIDS department head, major donor agency
55	March 3, 2006	NACO offices	Senior official, National AIDS Control Organization (NACO)
56	April 17, 2006	Telephonic interview	Official, state directorate of health services
57	April 17, 2006	Key informant's workplace	Key informant 8
58	April 17, 2006	Office of the State Medical Council	Senior official, State Medical Council
59	April 19, 2006	Office of the accreditation agency	Senior official, accreditation agency
60	April 20, 2006	Key informant's workplace	Key informant 9
61	April 25, 2006	Office of the accreditation agency	Senior official, accreditation agency

62	April 26, 2006	Office of the NGO	Senior member of NGO with focus on HIV/AIDS
63	April 26, 2006	Respondent's consulting room	Gynaecologist, 10 years experience, charitable hospital
64	May 4, 2006	Office of the donors supporting the NGO project	Member of NGO with focus on HIV/AIDS
65	May 4, 2006	Respondent's consulting room	Junior physician, charitable hospital
66	May 6, 2006	Coffee shop in hospital	Senior microbiologist and erstwhile head of department, government hospital
67	May 19, 2006	Residence of the respondent, neighbouring the nursing home	Physician, private nursing home and trainee in intensive HIV educational programme
68	May 26, 2006	Office of the infection control officer in the hospital	Infection control officer, government hospital
69	June 20, 2006	Medical association offices	Senior official, medical association
70	June 21, 2006	Education department of hospital	Senior medical educator, coordinator of intensive training programme in HIV

ANNEXURE 2. LIST OF KEY INFORMANTS

Key informant 1	Senior public health manager with experience in government and voluntary sectors
Key informant 2	Medical ethicist and civil rights activist
Key informant 3	Senior scientist in government HIV/AIDS research institute
Key informant 4	Head of major international donor agency with more than 20 years of experience of projects in India
Key informant 5	Medical ethicist specialising in issues around regulation
Key informant 6	Senior public health educator and programme manager in the public sector
Key informant 7	Senior academician with major interest in medical providers and institutions in India
Key informant 8	Senior scientist in government communicable diseases research institute
Key informant 9	Senior health economist with experience in HIV/AIDS issues

ANNEXURE 3. TOPIC GUIDE FOR MEDICAL PRACTITIONERS

Name: Sex:

Designation and Department:

Hospital:

Years of experience: Other relevant details:

1. Clinical duties and responsibilities in the clinic / hospital
2. Position in the clinic hospital – role, supervisors, subordinates.
3. Experience of HIV/AIDS management
4. Experience of HIV testing
5. Specific issues / concerns in HIV testing?
6. Institutional norms, or policies for HIV testing, if any
7. Experiences of implementing policy guidelines in practice
   - Selectivity in testing
   - Informed Consent
   - Mandatory testing
   - Confidentiality
8. Relevance of policies for HIV testing
9. Experiences of interface with the following, with respect to implementation of HIV testing policies
   - Institutional Administrators
   - Government and Legislature
   - HIV/AIDS programme
   - Educational and Academic Platforms
   - International Organizations
   - Civil Society Organizations
   - Professional Associations
   - Accreditation Agencies

Field Notes and Observations:

ANNEXURE 4. TOPIC GUIDE FOR OTHER ACTORS

Name: Sex:

Designation:

Organization:

Years of experience: Other relevant details:

1. Duties and responsibilities within organization
2. Work of organization in HIV/AIDS and / or public health
3. Expected role of organization in implementation of policies
4. Experiences of implementation of policies, in practice
5. Relevance of the policies
6. Experiences of interface with the following, with respect to implementation of HIV testing policies
   - Medical Practitioners
   - Hospital Administrators
   - Government and Legislature
   - HIV/AIDS programme
   - Educational and Academic Platforms
   - International Organizations
   - Civil Society Organizations
   - Professional Associations
   - Accreditation Agencies

Field Notes and Observations:

ANNEXURE 5. INFORMATION SHEET FOR RESPONDENTS

This sheet was presented to respondents and read out verbatim, prior to obtaining verbal consent for interviews.

INFORMATION SHEET

HIV Testing in Urban Indian Hospitals: a Study of Policy-Practice Relationships in the Formal Medical Sector

HIV/AIDS is an important public health problem in India, and HIV testing is an important aspect of HIV care. There are guidelines for testing, around subjects such as mandatory testing, informed consent, re-confirmation of results, counselling, confidentiality and assuring follow-up. For various reasons, these guidelines have been contested by some physicians.

We need to create policies for HIV testing which are appropriate, and also practical to implement. For this we need to know more about the circumstances of doctors and patients in HIV testing, and also understand the perspective of policy-makers and administrators. In this research study, I am trying to understand more about:
- Experiences of doctors around HIV-testing
- Existing means of implementing HIV testing policies
- The roles of different agencies in implementing the policies

I will ask you some questions to start the discussion. Please answer frankly and freely. You are also free not to answer any questions if you wish. In the course of the interview, please feel free to indicate if you do not wish a particular statement or statements to be quoted. The interview is entirely confidential. Only the principal researcher will have access to the transcripts of the interview, which will be password-protected.

The information you provide will be used only for research purposes. You will not be identifiable in any processed versions of the research such as theses, and research papers. For example, if something you have said is cited, the quote will be attributed to: "Dr XY, senior/junior doctor working in a public/private hospital"

If you would like more information about the study, please feel free to contact me. Contact details are given below.

Thank you for your help.

This research project has been approved by review committees of the Sexual Health Resource Centre (SHRC), Delhi, and the London School of Hygiene and Tropical Medicine (LSHTM).

Contact details:

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Email: kabirsheikh@hotmail.com, Telephone: 9810953885

ANNEXURE 6. ETHICAL CLEARANCE

Text of email from chair of the local ethics committee instituted by the Sexual Health Resource Centre, New Delhi:

The ethics committee recommends that:

-   A draft consent letter covering the required ethical issues should be prepared and approved by all the committee members. The researcher should give an undertaking that this letter would be read **verbatim** to each respondent and also the meaning of the contents would be explained to each of the respondent before canvassing the questionnaire. With this undertaking the researcher may take verbal consent of all the respondents.
-   The names of hospitals/ respondents should be strictly kept in confidence and nowhere in the research findings, that should be reflected. Names of hospitals etc could be given with letters like A,B, or C hospital.
-   The draft findings should be shared with the respondents' groups and with other stakeholders for feedback. The researcher is expected to take the feedback seriously in terms of fair representation of the respondents' views and for reconsidering his interpretation of the data. But divergent views are in no way binding on him.

The ethics committee grants unconditional clearance to this research proposal.

LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE

ETHICS COMMITTEE

APPROVAL FORM
Application number: 2073

Name of Principal Investigator   **Kabir Sheikh**

Department   **Infectious and Tropical Diseases**

Head of Department   **Professor Hazel Dockrell**

Title   **Implementation of HIV diagnostic testing policy in India: a study of policy-practice links in the urban formal medical sector.**

Approval of this study is granted by the Committee.

Chair
Professor Tom Meade   *T.W. Meade*

Date   ......22 July 2005   ....

Approval is dependent on local ethical approval having been received.

Any subsequent changes to the consent form must be re-submitted to the Committee.

Appendices

APPENDIX 1. DEBATES AROUND HIV TESTING POLICY

In this appendix, ongoing ethical debates around the different aspects of HIV testing policy are elaborated, with a focus on the Indian context. A literature search was undertaken on internet database PubMed and Google Scholar, using keywords "informed consent", "routine testing", "mandatory testing" and "confidentiality" respectively, using the operator AND in conjunction with "HIV". For India-specific articles, the search was repeated with an additional keyword "India". Underpinnings of the national policy approach on the different aspects of HIV testing are described, and some key debates and variations of views on these topics are summarized in the following sub-sections.

A1.1 Selectivity in testing

The selectivity or specificity exercised in deciding which patients should be tested is an aspect which has been the subject of much debate. All national level policy and programme documents advocate caution on the part of health care providers in advising the test, and stress on the client's role in the decision to be tested.[499]

The themes of selectivity and caution in the national policies derive partly from the conception that knowledge of HIV status could not always be linked to a constructive outcome in terms of continued healthcare for the patient. In 1993, in the early years of the concerted response to HIV/AIDS, Lal and colleagues, officials of the National AIDS Control Organization wrote in a special issue of the Journal of the Indian Medical Association (JIMA) that 'It is better to avoid testing unless a rational utilization of the test result is envisaged. HIV testing procedure must be supported by... means and skills for intervention, and otherwise not done' (Lal et al. 1993).

The overtones of caution in HIV testing are also linked to philosophies underlying the Voluntary Counselling and Testing (VCT) approach and its origins in civil rights movements which originated in the USA and UK in the 1980s, as a resistance to draconian and discriminatory policies of HIV testing and widespread occurrences of HIV-linked stigmatization and

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[499] See Chapter 1 (1.2.5) for recent policy developments.

discrimination in health care settings (Danziger 1996, Gostin 2006). Voluntary Counselling and Testing was based on the right of individuals to seek and gain knowledge of their own HIV status, and the role of the medical provider in this process was relatively de-emphasized. VCT was legitimized worldwide as part of global policy for HIV/AIDS, and adopted as national policy by many governments including India (Lo et al. 2006, Coovadia 2000). Special institutions (VCT Centres) were instituted, where clients would be assured of a supportive and stigma-free environment. Although VCT Centres were conceived as community-based institutions, in India they are frequently physically located within hospitals, which paradoxically leads to their being used mainly as HIV diagnostic centres for provider-advised referrals (NACO 2007e).

The recommendations may also have been aimed at deterring indiscriminate testing by medical providers for reasons not intended exclusively for the benefit of patients, e.g. to deny them admission, refer them to other providers or avoid performing invasive procedures on them.

The message of high selectivity in advising HIV tests on the grounds of inability to assure continued management is increasingly being seen as outdated. Treatment quality has improved vastly in the past decade and ART has become more accessible and affordable in many parts of the world. According to advocates of the expansion of HIV testing, stigma around HIV testing has decreased, and the benefits of treatment opportunities available to patients after testing positive outweigh the problems of stigma and discrimination (Steen et al. 2007). It is perceived by some commentators that special procedures and centres for HIV testing (signifying what some regard as "HIV exceptionalism" (Bayer 1991)) actually tend to foster a destructive secrecy, and increase rather than reduce stigmatization (De Cock et al 2002).

Globally, opinions have been voiced in favour of encouraging medical providers to advise more HIV tests. As part of efforts to expand access to HIV testing, influential commentators called for the promotion of "offer of routine testing" to all patients, particularly in populations with high-level epidemics. Prevention of the spread of the disease was an important factor cited in favour of expanding the scope of HIV testing (De Cock et al 2002, Bayer and Fairchild 2006). Of late, "routine offer of testing" has become part of the vocabulary of WHO's policies for HIV testing (see below A1.5), and has been adopted as a comprehensive national policy by the Government of the USA (Branson et al 2006). These approaches are often regarded as being at odds with erstwhile "rights-based" philosophies, and have been criticized for their potential of impinging on clients' liberties and reducing their (clients') roles in accessing HIV testing (Kippax 2006, Rennie and Behets 2006).

In the Indian context, a government programme has been instituted to provide free ART across the country (NACO 2007l). However Grover points out that the government had not met its targets of distributing first-line ARV drugs, and less than a tenth of the people in need of ART in India have access to affordable treatment, hence it can hardly be argued that the context of accessibility has changed significantly for a large portion of the population (Grover 2006). Furthermore, simple initiation of ART does not equal access to treatment; there are numerous obstacles to access including discontinuities in medical care and human resource shortages (Sheikh 2004, Solomon et al 2006). Incidences of stigmatizing and discriminatory practices in healthcare settings persist (see section 1.3 for details).

In an operational sense however, the prospect of advocating caution in HIV testing to medical practitioners in India would seem incongruous to many, given a strong culture of use of laboratory investigations to support clinical decisions and a thriving market of available diagnostic technologies (Vazirani 2007). As described earlier in section 1.3, routine and in some cases indiscriminate HIV testing is common in many government and private hospitals. Tests are also often conducted for reasons other than of aiding in the treatment of patients, an aspect which is discussed in detail in the following section on "Mandatory Testing".

A1.2 Mandatory testing

Well known instances of institutionalized mandatory testing include HIV testing as part of immigration policy, before joining employment, particularly in the armed services, and before marriage as mandated by some states in India (Asthana 1996, Jayaraman 1998, Grover et al. 2000, Tandon 2002). In most cases, the mandatory test is not conducted with the purpose of benefiting the person being tested, but for the requirements of the individual or group who order the test, although in some instances the person being tested may subsequently receive care if they test positive (Agarwal 2002). In hospital settings, mandatory testing usually refers to patients being required to submit to a test before they are admitted to a facility, or before an invasive procedure or surgery is performed.[500] The result of the test or refusal to be tested may influence the availability, quality or cost of care provided to the patient [501] (Pandya 1997a, Abraham 2002, Rao et al. 2004, Kurien et al. 2007). Considerations of individual rights are cited as the basis for NACO's stance of opposing mandatory testing in any form (NACO 2003a).

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[500] This type of "mandatory testing" is not identical to simple absence of consent, since the patients may knowingly agree to being tested. Hence there may be informed – if not free – consent in cases of mandatory testing.
[501] Typically costs of extra protective equipment for surgeons may be borne by HIV positive patients, or those who refuse testing.

Doctors' arguments in favour of mandatory testing before surgery tend to focus on their perception of high risks of transmission of HIV infection from patients to operating surgeons. In this context, surgeons' right to safety and protection from infection is often cited as the reason for pre-surgical HIV screening (Meadows et al 1995, Danziger et al. 1996, Orji and Ogunniyi 2001). According to some doctors, mandatory testing spares the need to use enhanced protection against HIV in all surgical procedures, which in turn significantly reduces expenses for themselves and for patients (Viswanathan 2002, Kurien et al 2007). Another argument in support of mandatory testing is that knowledge about HIV status aids in continued medical management of patients (Viswanathan 2002; Dutta 2003).

There are some question marks over the validity of these arguments. While the frequency of injury to surgeons intra-operatively are relatively high, the documented risk of transmission of HIV infection is reported to be very low, and it is likely that surgeons apprehensions in this regard are overstated (Mathiharan 2002, Narain et al 1993). Doctors in India are also reported to be poorly informed about measures of risk prevention including universal precautions and post-exposure prophylaxis (PEP) (Kurien et al 2007, Chogle et al 2002). The possibility of a patient being in the "window period" when HIV infection cannot be detected through routine tests, diminishes the value of pre-surgical testing as an effective infection control technique (Pandya 1997a). Furthermore, according to a study by Lawrence et al (1993), there is apparently no significant benefit in terms of costs, of adopting routine pre-surgical HIV testing over using universal precautions.

A1.3 Specific informed consent

The rationale of NACO's requirement of specific informed consent for HIV testing is based on principles of individual rights and autonomy of choice for people, which the programme regards as being inseparable from long-term public health goals (NACO 2003a).

According to Kalantri – himself a physician – writing about other doctors' perspectives on consent in the Indian Journal of Medical Ethics - many doctors oppose the idea of taking consent from patients, and regard it as an onerous formality. Their arguments against consent procedures tended to be framed around logics of paternalism - taking decisions in clinical settings was seen as a responsibility, and something which patients often expected of them (Kalantri 2000). Consent procedures, predicated as they are on autonomy and doctor-patient equality, were regarded as theoretic and superfluous by Kalantri's doctors, in the context of the essential inequality of

relationships between patients and doctors (ibid). It is also reported however, that these doctors did little to discourage this relational imbalance, which the author (Kalantri) regards as a sign of doctors' desire for dominance.

Consent procedures and formats for written consent have sometimes been criticized on the grounds of being too complicated or technical, or for not serving their intended purpose of providing optimal information for patients to make decisions. It is well known that a majority of patients attending free government and charitable hospitals are poor and underprivileged, and illiteracy can be high as reported among attendees of a HIV testing centre in a government hospital in West Bengal (Joardar et al 2006). Sastry et al. maintain that the length and technicalities of standard consent procedures can be intimidating and lack meaning for individuals who live in societies where literacy and awareness of rights is low. Based on an intervention among pregnant women attending ante-natal clinics in Maharashtra, India, they relate the success of innovations in the consent process (such as the use of visual aids) in increasing clients' comprehension (Sastry et al. 2004).

Even in developed country contexts, standard informed consent forms have sometimes not been perceived to be helpful, by patients. A common perception among patients at an English hospital was that consent forms are primarily meant for the legal protection of hospitals, or for the transfer of power and control to doctors (Akkad et al 2006). In India, good acceptance of written consent procedures by doctors has been linked to its perceived value as a safeguard against litigation (Shenoy 2002, Kalantri 2000).

Some commentators and physicians object to the specific requirement of consent for a HIV test. According to Mathan, the decision by a patient to seek help at a health care facility "implies his or her consent to undergo the necessary diagnostic tests as ordered by, and at the best clinical judgement of the healthcare worker" (Mathan 1993). Other diagnostic tests usually do not require specific consent of the patient, and in this context HIV "exceptionalism" was the target of criticism from doctors (Dutta 2003). This view is rebutted by civil rights activists who point out that the HIV test is still more liable than others to be misused by practitioners and be linked to discrimination and adverse outcomes for patients (Rennie and Behets 2006). According to Grover, principles of consent are not strongly rooted in practice in Indian health care settings, and rescinding written consent policies could be seen by practitioners as encouragement to conduct mandatory tests (Grover 2006).

Advocates of elimination of written consent feel that it is a burdensome procedure which can impede the expansion of access to HIV tests (Bayer and Fairchild 2006). Of late, global policies

have moved away from written consent requirements in the context of HIV testing in healthcare settings (see below A1.5)

A1.4 Confidentiality

Confidentiality is widely regarded as a cornerstone of public health strategies for HIV/AIDS, deriving from core ethical principles of autonomy and privacy and from concerns of discrimination against individuals with HIV (Abraham et al 2000). National and global HIV policies both have consistently emphasised the importance of confidentiality (UNAIDS/WHO 2004, WHO 2007). Opposition to strong emphasis on confidentiality has come from commentators on the grounds that it fosters a general environment of secrecy which eventually prevents the normalization of HIV as a health problem (De Cock et al 2002). There is also criticism that the pedantic application of confidentiality norms poses an impediment to equally essential information-gathering functions of health systems, such as surveillance (Verity and Nicoll 2002).

In India, debates around confidentiality in clinical settings have centred around two areas: the extent to which a patients HIV status should be advertised to health workers, and the involvement of families. The prominent labelling of patients' case-papers or beds in hospitals to indicate their HIV positive status is commonplace in many Indian hospitals. Pandya reports that the explanation offered by doctors is that all healthcare staff need this information so that "they can take necessary precautions (to protect themselves from infection)" (Agarwal 2002, Pandya 1997a). It is likely however that knowledge of a patient's HIV status is often a cause of insensitive and discriminatory behaviour of care providers, and that it may often be available to individuals other than the care providers themselves (Pandya 1997b, Pandya 1997c).

Involving families in disclosure of diagnostic test results is reported to be common practice in many healthcare settings in India. Families are reported to be important sources of social and financial support, and of continued care to HIV positive patients (Ratnathicam 2001; MAAS-CHRD 2003). Conversely there are instances of families being instrumental in the persecution and abandonment of people diagnosed with HIV, notably of women more than men (Bharat and Aggleton 1999).

	National Policy stance (2003)	Areas of Debate
Selectivity in Testing	Caution and discrimination in prescribing test	Enhanced availability of ART obviates need for caution? Other opportunities for care, prevention of spread Strong prevailing culture of, and markets for diagnostic testing
Mandatory Testing	Forbids use of test as precondition for service Test only for patients' benefit	Health workers right to protection Effectiveness as infection control technique Cost effectiveness vs. universal precautions
Specific Informed Consent	Autonomy paramount, consent to be specific, informed, written	Paternalism valued by doctors and some patients? Procedure regarded as mechanical and ineffectual, problems of comprehension for some clients Regarded as helpful for doctors, not patients Objections to HIV specificity, exceptionalism
Confidentiality	Strict confidentiality in clinic settings Partner and family involvement with patient consent	Rights of, and convenience for health care workers Conflicted role of families

Table A.1 National Policies for HIV Testing and Related Debates

A1.5 Recent shifts in policy

In the recent past (after the fieldwork for this study was completed), certain changes in the official positions of national and global policymakers have taken place. Some of these revisions are outlined here.

The World Health Organization has introduced separate policies for what is termed "Provider-Initiated" Testing and Counselling (PITC), while retaining its strong focus on Voluntary Testing and Counselling (VTC) initiatives. The PITC policy model is aimed at diagnostic testing in healthcare settings and recommends an "opt-out" approach, in which medical providers are encouraged to offer the HIV test to patients on a routine basis[502] and the patient has the opportunity of granting or withdrawing consent (WHO 2007). Depending on local conditions, it

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[502] In WHO's guidelines for provider-initiated testing, medical providers are advised to offer the test routinely to all patients with clinical presentation suggestive of HIV infection, and in regions with generalized HIV epidemics, to *all* patients irrespective of presentation (WHO 2007).

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is recommended that pre-test information, not counselling be provided to a group or individual, and consent be obtained privately but verbally.

The previous emphasis on specificity and caution around advising a HIV test is absent in NACO's new Guidelines for HIV Testing. In the 3rd phase of the National AIDS Control Programme, the appellation of Voluntary Counselling and Testing Centres in official documentation has been changed to Integrated Testing and Counselling Centres, in recognition of their dual role as hospital-based diagnostic centres for provider-initiated referrals and testing centres for individuals independently seeking knowledge of their HIV status. In other respects, national policy documents on HIV Testing are marked by contradictions. The Guidelines for HIV Testing make no mention of "opt-out" approaches and do not advocate routine testing in any context. The Guidelines reiterate the emphasis on specific written informed consent for a test. Paradoxically, the Operational Guidelines for ICTCs (published within 4 months of the Testing Guidelines) are inconsistent with Testing Guidelines in this regard, and do *not* indicate requirement of written consent from provider-referred patients. Routine offer of test to patients with signs of HIV and ante-natal clinic attendees, with the option to "opt out" is recommended in the Operational Guidelines (NACO 2007c, NACO 2007h).

APPENDIX 2. CLIENTS' MOVEMENTS AROUND HIV TESTING

This section is based on respondents' accounts about their clients' experiences and their movements outside and within the hospital while accessing HIV diagnosis.

A2.1 Movements before diagnosis

Approach to HIV diagnosis

Counsellors in government and private hospitals reported that there was a growing trend of walk-in clients, who come to the Hospital VCTC with the primary aim of getting tested for HIV.[503] With rising awareness about HIV, people were reportedly increasingly coming forward specifically to seek confirmation of their status.   However, patients have had differing motivations in seeking care, of which the desire for HIV diagnosis may not always have predominated. One physician described a typical scenario of a HIV related consultation:

> The usual thing that happens, a sick man comes to our clinic, with a woman, his wife standing next to him, and a baby in her lap. My concern is always: am I dealing with one patient or three? ... Often, when I asked the asymptomatic wife: what about you? And they say: this is my report. Then I ask: you know what is wrong? She doesn't understand the implications of being HIV infected. Her concerns are basically for her husband. He is sick, if he dies, she is going to probably be kicked out of his family. In-laws often turn violent, if the husband dies. So these big social issues are there.
>
> Senior physician and HIV specialist, government hospital (13)

The woman's relative lack of concern around her own HIV status, combined with the presence of potentially three patients in a single consultation reflect some of the complexities of health care interactions in these settings. This physician felt that some of these issues challenged the boundaries of his role as a care-giver, and sought help from other sources.

> Being a physician, of course it's not within my realm, my capacity to deal with these things. That's why I always try to network with PLHA support groups, or CBOs or NGOs who are supporting PLHA
>
> Senior physician and HIV specialist, government hospital (13)

---

[503] Respondent 42: Counsellor, government hospital VCTC

According to a number of doctors, among the patients who consulted them for the first time, illness episodes were usually the precipitating event which led patients to seek care in hospitals, more than simple awareness of HIV status. Reports of patients often coming in advanced, symptomatic stages of the disease supported this view.[504,505] Some patients even considered the procedures around HIV testing to be a distraction from their immediate needs of receiving treatment for a problem.

> There is always fear of drop out... If he feels that ... he will not get treated for what he has come for, instead he is just being tested for HIV, then he may not come back.
>
> Counsellor, government hospital VCTC (42)

Reportedly, patients' often had feelings of secrecy and denial around their HIV status. Respondents said that many patients were not keen to divulge or confirm their status, and actively resisted the idea of HIV testing.[506]

Previous testing and referral

Other than the hospitals, respondents' accounts revealed that there are two other types of facilities typically involved in patients accessing HIV diagnosis – primary care providers (most often private practitioners) and private diagnostic laboratories.
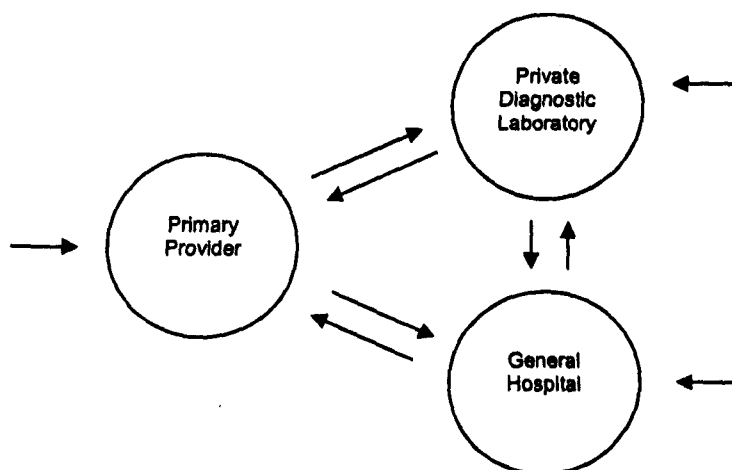

Figure A.1 Clients' Movements in Seeking HIV Diagnosis

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[504] Respondent 23: Venereologist, 10 years experience, government hospital
[505] Respondent 41: Venereologist, 15 years experience, private hospital
[506] Several respondents (23, 34, 40)

Patients frequently access different practitioners and get tested in different laboratories, before (and after) they consult doctors in the larger general hospitals. Typically patients would have been tested at a private laboratory or laboratories, at the behest of a private practitioner. According to a number of practitioners from each type of hospital, many of their HIV positive patients had already been tested elsewhere, at the time of coming to the hospitals.[507] '70 to 80% of patients come to us with already HIV positive reports' said one private physician.[508]

The availability of better care for HIV related illnesses, and more specifically the availability of ART were cited as reasons why primary level providers and private practitioners refer patients to general hospitals.[509,510] However, it is not possible to say definitively that patients' movements between providers are always results of directed referrals from medical providers. Formal referrals may not always be made and patients may not always be supported to understand the procedure of referral, or be made to perceive a sense of continuity in moving from one medical provider to another. In some instances the "referral" may be a form of shunting out a patient - denying care when it is discovered that they are HIV positive.[511,512] According to some practitioners, many patients exercised their own choices in accessing different providers: 'They go on repeating the testing from other private clinics and laboratories' said one government venereologist.[513]

In summary, many patients have visited other facilities before, seeking HIV diagnosis and care, but some patients may also access the hospitals as first points of care.

A2.2 Movements during diagnosis

Following consultation with a doctor in the hospital, a decision may be made to conduct a HIV test. Even after such a decision is made, a number of steps present themselves before a HIV diagnosis is completed.

1. Decision to test

2. Consent and pre-test counselling

3. Sampling and testing

---

[507] Several respondents (09, 13, 14, 16, 17, 18, 19, 21, 27, 28, 30, 37, 40)
[508] Respondent 09: Junior physician, private nursing home
[509] Respondent 14: Venereologist 7 years experience, government hospital
[510] Respondent 28: Senior venereologist, government hospital
[511] Respondent 09: Junior physician, private nursing home
[512] Respondent 23: Venereologist, 10 years experience, government hospital
[513] Respondent 14: Venereologist, 7 years experience, government hospital

4. Disclosure of results and post-test counselling

5. Referral for further advice and management

To undertake these different steps, patients are referred to different sites or locations either within the hospital complex or, in the case of nursing homes without testing facilities, to private diagnostic laboratories nearby. In hospitals with testing laboratories and VCTCs or appointed counsellors (4 government, one charitable and one private hospital), there are three official sites or locations involved where the patient undergoes the processes of HIV diagnosis: the consulting clinic of the doctor, a counselling centre or VCTC and a testing laboratory.
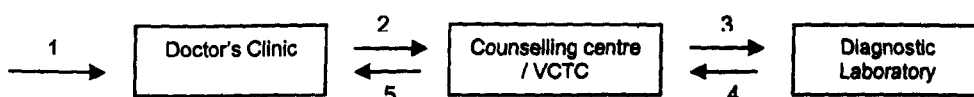

Figure A.2 Expected Movements of Patients in Hospital

According to respondents, sometimes each of these steps was enacted in a regular order. There were also considerable variations in the movements of patients, either as a result of personal practices of the doctors, or systemic or institutional factors, or due to patients' actions.[514] The commonest types of irregularity involved omission of the "counselling" step in one manner or other. Pre-test counselling was not offered in some contexts, especially in the case of pre-surgical HIV screening, and in nursing homes and hospitals without counselling facilities, doctors did not always counsel their patients or enable access to counsellors. Doctors in government hospitals often sent their patients outside the hospital to private laboratories to be tested, again commonly in the context of pre-surgical screening. On a number of occasions, patients "dropped out" at different stages of the cycle of diagnosis. The phenomena of "outside testing" and drop-out are described further in this section (page 322 and 322 respectively). More details of irregularities and omissions around counselling will be discussed in later sections on enacting policies.

Movement between clinical departments

Patient movement between different clinical departments in a hospital was found to be common, even before a decision to test for HIV is made. Three departments in the hospitals are mainly involved in HIV diagnosis and care – Medicine, Venereology & Dermatology and Obstetrics &

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[514] Several respondents (02, 12, 13 , 16, 17, 18, 19, 23, 24, 28, 30, 40)

Gynaecology.   Interdepartmental referrals are common in the government hospitals, and suspicion of HIV in one department often leads to diagnosis in another. Doctors in several of the hospitals had made attempts to integrate HIV care to some degree, from linking interested consultants to form cross-departmental HIV teams, to designating special HIV/AIDS clinics with their own timings and multi-speciality staff. Even after entering into the hospital system, in the larger hospitals patients may have had to visit several different rooms and departments to fully access HIV diagnosis, including variously located clinical departments, counselling centres, sample collection rooms and laboratories.

The role of VCTCs

VCTCs in hospitals play a dual role of counselling and testing truly voluntary or "walk-in" clients as they are sometimes referred to, and providing the same services to patients who are referred to them by doctors, following consultation. After testing and post-test counselling they are expected to refer HIV+ patients back to the doctor's clinics for further management. VCTCs hence occupy an intermediate position between the clinics and testing laboratories.

According to counsellors working in government hospital VCTCs, they receive considerably more "referred" patients than "walk-in" clients. Some respondents felt that VCTCs in hospitals tended to assume the role of glorified diagnostic centres, which did not reflect their popular characterization as voluntary community-based facilities.[515] They expressed some doubts about the "voluntary" nomenclature, and about the supposed under-utilisation of VCTCs.

> There is nothing voluntary about it… in VCTCs… they don't have more than 2-3 patients in a day, and of those most of the patients are from the hospitals, and directed by the doctors.
>
> Senior physician, government hospital (37)

> Voluntary *kahan hai ji*? [how is it voluntary, sir?] Here all the patients come from the hospital.
>
> Senior microbiologist, government hospital (66)

However, counsellors did report growing numbers of voluntary patients accessing VCTCs, and it is possible that doctors may not have been well informed about these trends.[516]

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[515] Respondent 20: Junior gynaecologist, government hospital
[516] Respondent 42: Counsellor, government hospital VCTC

'Outside testing'

'Outside testing' or the practice (in government hospitals) of sending patients to private laboratories to be tested was used by some government doctors as a convenient alternative to the multi-step procedure of testing within the hospitals. Results of in-house testing were not always available on the same day, and there were issues of overcrowding, short opening hours and charges of 'official lethargy' which the doctors felt impeded prompt delivery of test results, considered essential for patient management.[517] Private laboratories were often seen to be a more efficient alternative, easily accessible, open for long hours and prompt in returning the results, at a cost to the patient.

Doctors may have also resorted to outside testing when faced with obstacles to ordering pre-surgical tests in-house, since this was not officially sanctioned by the hospital. In hospitals where norms against pre-surgical mandatory screening were in place, there were tensions between surgeons, who advised these tests and diagnosticians, who were reluctant to bend the rules to perform the tests.[518,519,520] According to some respondents, pre-surgical patients are often willing to forgo the lengthy government hospital procedures and pay for private tests.

Drop-out

Clients / patients may drop out at any point of the cycle of HIV diagnosis, a phenomenon commonly reported in government hospitals, and also to an extent in the private hospital. At the first instance of consultation, the very suggestion of HIV from a treating physician may cause a patient to leave:

> Say, if you have a "shady" history from a male who has a genital ulcer, and you tell him this, this, and we are going to do HIV, and go and talk to those people. The moment some people hear "HIV", they just vanish. They go out; they go to some other hospital.
>
> <div align="right">Junior venereologist, government hospital (27)</div>

Patients also drop out after pre-test counselling sessions, an occurrence so common that much of counsellors' energies and attentions are directed towards persuading patients to remain within the system.

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[517] Several respondents (27, 31, 32, 42)
[518] Respondent 24: Senior microbiologist, government hospital
[519] Respondent 31: Senior surgeon, government hospital
[520] Respondent 66: Senior microbiologist, government hospital

Sometimes it happens that two or three patients are taken together. We have to make sure that while we are talking to one, the other does not get up and leave, because some how or the other he became ready for HIV test, but if he feels anything, he may think "forget it, let me go".

Counsellor, government hospital VCTC (42)

A counsellor ascribed frequent dropout to the nuisance of multiple inter-department transfers, procedural delays and lack of attention to their primary complaint.[521] Even after results are made known to the patients, they often drop out, seek second opinions or continue to "shop" for alternative diagnoses or treatment. Mistrust and fear of revelation of HIV status or sexual indiscretions, common themes in this deeply stigmatized disease, were also cited as grounds for patients' wariness around HIV testing. [522,523,524]
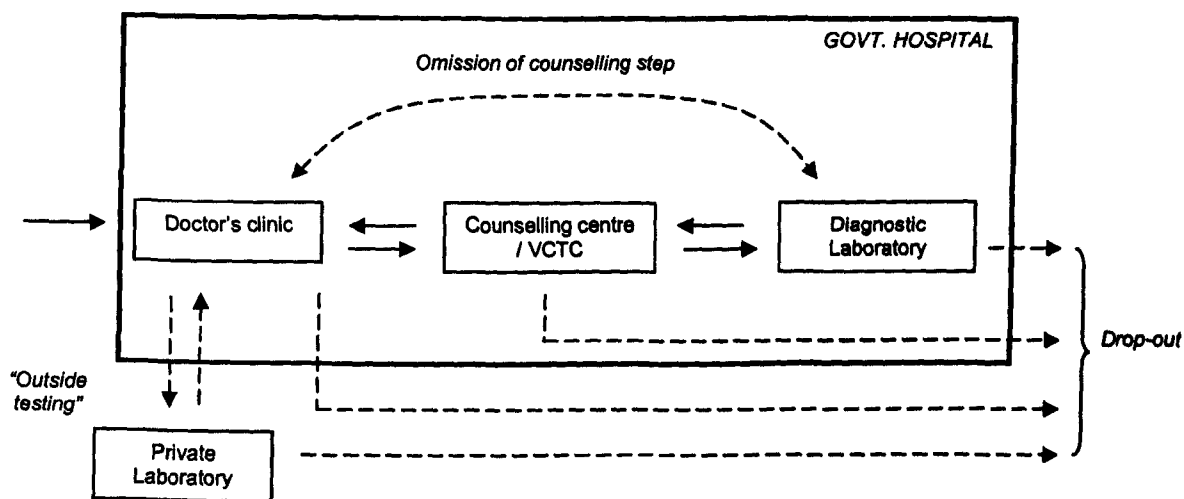

Figure A.3 Patients' Actual Movements during HIV Testing[525]

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[521] Respondent 42: Counsellor, government hospital VCTC
[522] Respondent 13: Senior physician and HIV specialist, government hospital
[523] Respondent 23: Venereologist, 10 years experience, government hospital
[524] Respondent 40: Counsellor, private hospital
[525] Dashed lines indicate divergences from expected movements