

## COHORT PROFILE

# Cohort Profile: Africa Centre Demographic Information System (ACDIS) and population-based HIV survey

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### How did the study come about?

The health and demography of the South African population has been undergoing substantial changes as a result of the rapidly progressing HIV epidemic. Researchers at the University of KwaZulu-Natal and the South African Medical Research Council established The Africa Centre for Health and Population Studies in 1997 funded by a large core grant from The Wellcome Trust, UK. Given the urgent need for high quality longitudinal data with which to monitor these changes, and with which to evaluate interventions to mitigate impact, a demographic surveillance system (DSS) was established in a rural South African population facing a rapid and severe HIV epidemic.<sup>1</sup> The DSS, referred to as the Africa Centre Demographic Information System (ACDIS), started in 2000. In 2003, population-based HIV testing (also funded by the Wellcome Trust, UK) was started in ACDIS through annual surveys. In this article, we seek to describe the most salient features of ACDIS and the population-based HIV cohort and briefly present some of the most important results to date.

### What does the study cover?

ACDIS was established to 'describe the demographic, social and health impact of the HIV epidemic in a population going through the health transition' and to monitor the impact of intervention strategies on the epidemic.<sup>1</sup> South Africa's political and economic history has resulted in highly mobile urban and rural populations, coupled with complex, fluid households.<sup>2</sup> In order to successfully monitor the epidemic, it was necessary to collect longitudinal demographic data (e.g. mortality, fertility, migration) on the population and to mirror this complex social reality within the design of the demographic information system. To this end, three primary subjects are observed longitudinally in ACDIS: physical structures (e.g. homesteads, clinics and schools), households and individuals. The information about these subjects, and all related information, is stored in a single MS-SQL Server database, in a truly longitudinal way—i.e. not as a series of cross-sections. For a comprehensive description of ACDIS and rationale for its design see Hosegood *et al.*<sup>2</sup>

### Where is the study area?

The surveillance area (Figure 1) selected is located near the market town of Mtubatuba in the Umkanyakude district of KwaZulu-Natal. The area is 438 km<sup>2</sup> in size and includes a population of approximately 85 000 people who are members of approximately 11 000 households. The population is almost exclusively Zulu-speaking. The area is typical of many rural areas of South Africa in that while predominantly rural, it contains an urban township and informal peri-urban settlements. The area is

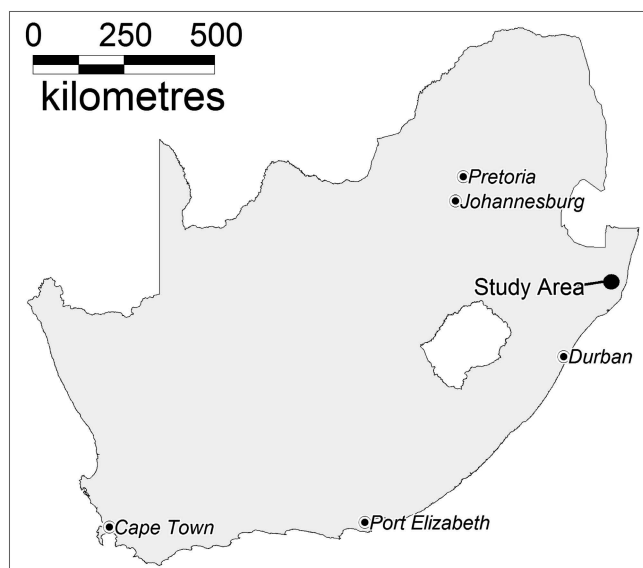
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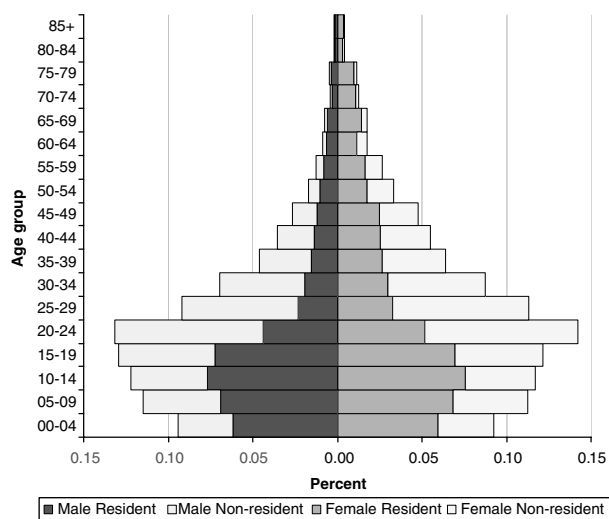
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characterized by large variations in population densities (20–3000 people/km<sup>2</sup>). In the rural areas, homesteads are scattered rather than grouped. Most households are multi-generational and range with an



**Figure 1** Location of the study area in South Africa



**Figure 2** Age and sex profile of the surveillance population by residency, 30th June 2006 ( $n = 56,791$  residents;  $n = 29,164$  non-residents)

average size of 7.9 (SD = 4.7) members. Despite being a predominantly rural area, the principle source of income for most households is waged employment and state pensions rather than agriculture. In 2006, approximately 77% of households in the surveillance area had access to piped water and toilet facilities.

## Who is in the sample?

To fulfil the eligibility criteria for the ACDIS cohort, individuals must be a member of a household within the surveillance area but not necessarily resident within it. Crucially, this means that ACDIS collects information on resident and non-resident members of households (Figure 2) and makes a distinction between membership (self-defined on the basis of links to other household members) and residency (residing at a physical structure within the surveillance area at a particular point in time). Individuals can be members of more than one household at any point in time (e.g. polygamously married men whose wives maintain separate households). As of June 2006, there were 85 855 people under surveillance of whom 33% were not resident within the surveillance area. Obtaining information on non-resident members is vital for a number of reasons. Most importantly, understanding patterns of HIV transmission within rural areas requires knowledge about patterns of circulation and about sexual contacts between residents and their non-resident partners.<sup>2</sup>

Nested within the ACDIS cohort is the population-based HIV cohort.<sup>3</sup> Between 2003 and 2006 (three rounds of data collection), all women aged 15–49 years and men aged 15–54 years resident in the surveillance area were eligible for HIV testing. However, starting in 2007, eligibility was extended to cover all residents aged  $\geq 15$  years of age. In addition to the resident sample, a 12.5% stratified sample of non-residents ('migrants') is also included in each round of data collection. These non-resident study participants are sampled randomly into equally sized strata by sex and frequency of their presence pattern within the surveillance area (e.g. returns at month end). The total numbers of eligible residents and non-residents during the first three survey rounds are shown (Table 1).

**Table 1** Eligibility and uptake of the population-based HIV testing

	Residents			Non-residents		
	Eligible	Contacted (%)	Consented (%) <sup>a</sup>	Eligible	Contacted (%)	Consented (%) <sup>a</sup>
Round 1 (2003–2004) <sup>†</sup>	25 901	19 867 (77%)	11 551 (58%)	1952	916 (47%)	551 (60%)
Round 2 (2005)	22 357	21 936 (98%)	8909 (41%)	2145	1468 (75%)	605 (41%)
Round 3 (2006)	23 338	21 387 (92%)	8136 (38%)	1581	989 (63%)	410 (41%)

<sup>a</sup>Calculated as a percentage of number of participants contacted.

<sup>†</sup>Taken from Welz *et al.* 2007.<sup>3</sup>

## What has been measured?

ACDIS has two separate cycles of data collection—household and individual. During the household data collection cycle, a set of questionnaires are routinely

**Table 2** Data collected at each routine household visit, 2000 and ongoing

Subject	Types of information
Homestead	Latitude, longitude Owner Number of households
Household	Formation and dissolution Household head
Individuals	Individual details: inc. date of birth, sex, parents Household membership(s)
Household members	Update household list: members who join, leave or die Residency status: inc. pattern of return visits Marital and partnership status Relationship to household head
Births	Pregnancy outcomes: abortions, still and live births. Delivery environment: inc. assistance, place Birthweight, APGAR
Deaths	Location and care provision at time of death Open description of circumstances
Migrations	Details of place of origin or destination Type of migration, e.g. household or individual migration
Child health	On first birthday: vaccination history

The forms used to collect this data are available at <http://www.africacentre.ac.za/Default.aspx?tabid=69> Refer to forms, BSR, BSU, HHR, HHU, IDR.

administered every 6 months (Table 2) to a key informant in each household. These questionnaires record key attributes and events regarding physical structures, households and individuals and their relationship to each other. Additional modules are administered occasionally (Table 3) and provide further descriptive variables for the subjects over time and are intended to extend and enhance the core dataset for specific research purposes. The HIV serosurvey (Table 4) comprises part of the individual data collection cycle (undertaken annually) and requires an interview with the eligible individual in person because of the sensitivity of the questions. Ethical approval for all data collected within the cohorts was obtained from the University of KwaZulu-Natal's Ethics Committee. For a complete list of the most recent questionnaires visit <http://www.africacentre.ac.za/Default.aspx?tabid=69>

## How are the data collected?

Before embarking on any data collection activity, all research initiatives at the Africa Centre are first discussed with a Community Advisory Board (CAB) for comment and feedback. The CAB consists of approximately 25 members chosen by the community and also provides a forum to discuss the results of specific studies and how best to disseminate these to the community.

**Table 3** Data collected occasionally during routine household visits, 2000–2007

Topic	Types of information	Frequency	Eligibility criteria
Household socio-economic data	Household infra-structure: inc. water, sanitation, electricity Economic status: inc. household expenditure, asset ownership	Annual 2001, 2003/2004/2005/2006	Household is resident in DSA on date of visit
Individual socio-economic data	Education Employment	Annual 2001, 2003/2004/2005/2006	Individual is a member of a resident household on date of visit
Child grants	Receipt of government grants for children	2002	All households resident in DSA on date of visit

The forms used to collect this data are available at <http://www.africacentre.ac.za/Default.aspx?tabid=69> Refer to forms, HSEI,II,III,IV and CGR.

**Table 4** Data collected at each individual survey visit, 2000-ongoing

Topic	Types of information	Frequency	Eligibility criteria
HIV status	HIV status Reason for refusing test	Annual 2003/2004, 2005/2006/2007	2003–2006: women 15–49 years, men 15–54 years 2007 women and men 15 years and older
Sexual behaviour	Pregnancy history (women only) Contraceptive use Sexual activity Attitudes to condom use	Annual 2003/2004, 2005/2006/2007	2000–2003: women 15–49 years only. 2003–2006: women 15–49 years, men 15–54 years 2007 women and men 15 years and older
Biomeasures	Blood pressure Height and weight	2003/2004 only	2003/2004: women 15–49 years, men 15–54 years

The forms used to collect this data are available at <http://www.africacentre.ac.za/Default.aspx?tabid=69> Refer to forms, HIV and biomeasures (BMF) and sexual behaviour (WHL, MGH, WGH, MGH-E, WGH-E).

Since its inception, ACDIS has developed and maintained geographical information systems (GIS) capacity that allows the spatial analysis of any of the variables collected. All homesteads and facilities in the study area have been mapped by fieldworkers using differential global positioning systems (to an accuracy of <2 m) and the homesteads database is continuously updated as new homesteads are built as part of the ongoing surveillance programme.<sup>4</sup> To operationalize fieldwork, the demographic surveillance area is divided into workload-equivalent areas using a GIS-based methodology.<sup>5</sup> A detailed description of ACDIS data collection procedures and research methodologies is contained elsewhere.<sup>6</sup>

During the household data collection cycle, households are visited every 6 months by fieldworkers and information supplied by a single key informant. For data collected as part of the HIV sero-survey, teams of two trained fieldworkers visit each eligible individual in his or her household on an annual basis. If a subject is absent, the field workers make up to four repeat visits to the same household. If a subject no longer lives in the household, the field worker hands the case to a specially trained tracking team that attempts to find the individual in his or her new residence which may be as far as Johannesburg or Durban. After written informed consent, field workers collect blood by finger prick and prepare dried blood spots for HIV testing according to the Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO) *Guidelines for Using HIV Testing Technologies in Surveillance*.<sup>7</sup> HIV status is determined by antibody testing with a broad-based HIV-1/HIV-2 ELISA (Vironostika® HIV-1 Microelisa System (Biomérieux, Durham, NC, USA) followed by a confirmatory ELISA (Wellcozyme HIV 1+2 GACELISA; Murex Diagnostics Benelux B.V., Breukelen, The Netherlands).

HIV test results can be obtained confidentially in a number of counselling centres which have been set up for that purpose in the survey area. A linked, anonymous voluntary HIV testing system with pre- and post-result counselling using confidential personal pin numbers and handheld computers for result communication has been established.

## What are participation rates like?

The ACDIS and HIV cohorts are dynamic open cohorts with individuals continually leaving and entering each cohort. Participation rates for household data collection within ACDIS are >99%. For the HIV survey, the contact rates for residents and non-residents improved in the second round compared with Round 1 (Table 1). However, the consent rate to test for HIV decreased from approximately 60% in 2003–2004 to 40% in 2005 and 2006 and raises concerns about selection bias. We are addressing these issues both operationally and analytically.

Operationally, the HIV surveillance is implementing a range of activities to increase consent rates, such as rapid testing and home-based delivery of test results. Analytically, Africa Centre researchers are using information about demographic, socio-economic and behavioural characteristics that are available both for those individuals who do consent to an HIV test as well as for those who do not consent, in order to diagnose and adjust for selection effects.<sup>8,9</sup> This information is used to characterize differences across observable variables between consenters and non-consenters, to take into account selection effects when it seems reasonable to assume that missingness is at random [e.g. through multiple imputations (MIs)<sup>10</sup>] and when random missingness cannot be assumed (e.g. through Heckman-type selection models<sup>11</sup>). We are able to use the latter approach because the detailed operational information available to researchers includes a number of variables that are relevant and likely valid exclusion restrictions in selection models.<sup>12</sup>

## What has it found?

ACDIS data have been extensively used to provide empirical evidence about the demographic and social impact of the HIV epidemic in a severely affected population. HIV/AIDS has considerably increased mortality rates in the study population and significantly reduced life expectancy at birth. By 2000, the probability of dying between the ages 16 and 60 years was estimated at 58% for women and 75% for men.<sup>13</sup> However, a recent study has suggested that the upward trend in mortality rates is being reversed by the ART programme which has contributed significantly to an increase in life expectancy.<sup>14</sup> Studies using the verbal autopsies show that the leading cause of death is AIDS, followed by non-communicable diseases. In 2000, AIDS caused 73 and 61% of the female and male deaths, respectively among the 15–44 age groups. Among males, deaths from injuries were high.<sup>13</sup>

Studies of fertility in the surveillance area show marked declines during the late 1990s (TFR 4.4) and early 2000s but have recently stalled at around three births per woman.<sup>11,15</sup> Unlike in other countries, the stall is correlated neither with levels of education, nor contraceptive use. We find no evidence of a strong substitution of contraceptive methods. The impact of HIV on these changes in the level and pattern of fertility is not yet clear. Early findings suggest that HIV prevalence is subsidiary to the main determinants of fertility (socio-economic, social and demographic). In contrast to overall fertility decline, fertility among adolescents has remained largely stable over the last decade.<sup>16</sup>

Studies using ACDIS data to investigate the socio-demographic impacts of HIV have considered a wide range of outcomes including orphanhood, household

composition and dissolution, migration, education and grant uptake. In rural South Africa, a large proportion of children live apart from their mothers and fathers due to labour migration, child migration related to care giving and schooling, parental separation and divorce and orphanhood.<sup>17,18</sup> HIV makes this phenomenon more pronounced through its impact on parental survival. Between 2000 and 2005 there was a doubling of orphanhood, which is also related to the high AIDS-related mortality. There was an increase from 9 to 12% ( $n=3499$ ), from 3 to 6% ( $n=1656$ ) and from 1 to 4% ( $n=1031$ ) in paternal, maternal and double orphans, respectively.<sup>19,20</sup> Adverse consequences for children experiencing parental death have been shown in their education achievement, access to welfare support and increased mobility.<sup>21–23</sup>

In terms of the impact on households, contrary to a widely anticipated consequence of the epidemic, there is a little evidence from ACDIS that high adult mortality has resulted in a substantial increase in extreme household forms such as child-headed or skipped-generation households.<sup>20,23</sup> Rather, HIV- and AIDS-affected households experience negative consequences in relation to their survival and ability to migrate,<sup>24</sup> economic resources,<sup>21,22</sup> isolation and conflict and ability to respond to subsequent deaths or financial shocks.<sup>24,25</sup>

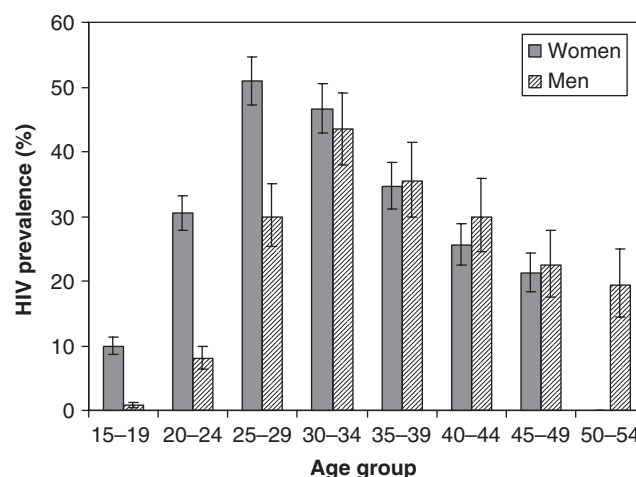
Data from the Household Socio-Economic Surveys have been used to measure the economic well being of households in the DSA. The socio-economic indicators show improvement between 2001 and 2006 (Table 5). The area has experienced a marked increase in the provision of electricity, water and sanitation in the past 5 years. Access to toilet facilities (primarily through access to improved pit latrines) increased from 61 to 77% of households over this period. Households reporting piped water almost doubled—from 43 to 78%, and electricity increased from 50 to 62% of households.

The population-based HIV survey is the first of its kind in South Africa to investigate the prevalence of HIV in a rural area among residents and non-residents. It shows some of the highest population-based infection rates ever documented worldwide (Figure 3). Prevalence peaked at 51% (95% CI 47–55%) among women aged 25–29 and 44% (95% CI 38–49%) in men aged 30–34.<sup>3</sup> Non-resident men are nearly twice as likely (adjusted OR=1.8) to be infected in comparison with their resident counterparts; whilst the corresponding ratio for women is 1.5.<sup>3</sup> The disease is far from uniform geographically. Informal settlements located near the National Road have the highest prevalence (>35%); whilst the more inaccessible rural areas are characterized by the lowest prevalence (<10%).<sup>26</sup>

The overall incidence of HIV infection in the HIV cohort is 3.2/100 person years (95% CI 2.8–3.8) and the highest incidence occurred in the age group 25–29 for both men (8.7/100 PY, 95% CI 4.8–15.8) and

**Table 5** Household socio-economic (HSE) data collected between 2001 and 2006

	HSE1	HSE2	HSE3	HSE4
Collection dates	2001	2003/4	2005	2006
Number of households	10 826	10 806	9736	9140
<i>Government services: Fraction of households with:</i>				
Electricity	0.5	0.54	0.59	0.62
Piped water	0.43	0.55	0.67	0.78
Toilet	0.61	0.75	0.75	0.77



**Figure 3** HIV sero-prevalence by age and sex (95% CI) among residents (2003–2004).<sup>3</sup>

women (8.0/100 PY, 95% CI 4.9–13.0).<sup>9</sup> Assuming that infection rates remain constant over a person's lifetime and in the absence of competing risk of death, by age 35, the cumulative risk of becoming HIV positive is 64% for women and 68% for men. The cumulative incidence is 74% by age 49 for women and 78% by age 54 for men.<sup>9</sup>

For a complete list of ACDIS publications see: <http://www.africacentre.ac.za/Default.aspx?tabid=66>

## What are the main strength and weaknesses?

The use of ACDIS as a comprehensive sampling frame for the HIV cohort eliminates many of the problems commonly affecting surveys e.g. errors with household listing and selection and allows a quantification of the effects of non-participation on HIV prevalence estimates. All data collected by the HIV survey can be linked anonymously to other demographic, socio- and household-economic and health and behavioural data collected by the demographic information system. Nevertheless, as noted previously, consent rates for

HIV testing are comparatively low and 10 variables associated with HIV status were also associated with non-participation.<sup>3</sup> However, the additional socio-demographic information from ACDIS on each individual allows us to adjust for selection effects in HIV prevalence and incidence estimation. For example, we find that taking into account selection on observable variables (using MIs) significantly increases overall incidence estimates in all age–sex groups. HIV incidence was 2.08 and 2.22 times higher than the non-imputed rate in women and men, respectively. The absolute increase in incidence was largest in age groups above 29 years of age. Whilst the highest incidence in women occurred in the age group 25–29 both without and with MI, in men MI shifted the highest HIV incidence from the age group 25–29 to the age group 30–34.<sup>9</sup> In contrast, initial results using MI suggest that overall HIV prevalence estimates do not change substantially when selection on observables is taken into account (but further analyses are ongoing).<sup>8</sup> These results underline both the importance and the potential of adjusting for selection effects in the statistical analyses.

The longitudinal design and collection of data for both resident and non-resident members and relationships to households is a key strength of the cohorts. Understanding of the population is enhanced by data about household dynamics, population mobility, inter- and intra-household relationships and social networks. Using a different set of eligibility criteria for individual enumeration than standard census definitions provides an opportunity to examine the coverage and the representation in the census of the full set of individuals who are integrally part of the population.<sup>2</sup> To our knowledge, no other HIV survey has been able to track non-resident members of rural households to their migration destinations. Extension of the eligibility criteria for the HIV survey into the older age groups (>50 years) from 2007 is a further strength and will generate important knowledge on the impact of the HIV epidemic in these neglected age groups.

It has become widely acknowledged that processes that go beyond the individual are responsible for the rapid spread of HIV in Africa.<sup>27</sup> Another key strength of the cohorts is the production of detailed comprehensive information at different levels: the community, the household and the individual. Few, if any, sites in Africa have this degree of depth or breadth of information. This allows hierarchical statistical approaches to investigate multi-level determinants of outcomes such as HIV infection. A further strength lies in the opportunity to quickly evaluate the impact of the ART programme on demographic indicators collected in ACDIS. The Africa Centre partners with the Department of Health in the PEPFAR-funded ART programme in the government hospital and 14 peripheral primary health care clinics in the surrounding area.<sup>14</sup>

In future, the cohorts will be of vital importance for assessment of interventions for African populations. The ART programme, expanding rapidly in Africa and other developing countries, is the largest public health programme ever contemplated on the continent, but the evidence-base from Africa is severely limited. The cohorts provide a unique platform to monitor and comprehensively evaluate the effects of ART delivery at both a population and individual level.

## Can I get hold of the data? Where can I find out more?

ACDIS data are easily and widely accessible, through a suite of datasets and accompanying documentation posted on the Africa Centre website ([www.africacentre.ac.za](http://www.africacentre.ac.za)). Dataset documentation includes the definition of variables and the questionnaires which were used for data collection. Use of ACDIS data is however on the basis of a collaborative principle. Collaborators sign a Data Use Agreement to be able to utilize ACDIS data and all analyses are conducted in collaboration with members of the Africa Centre. In addition, each data use request must be accompanied with an Analysis Plan. The Analysis Plan and the Data Use Agreement are submitted to the Director and are discussed and approved internally, through the surveillance scientific meeting.

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**Conflict of interest:** None declared.

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