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**EVALUATION OF DIABETIC RETINOPATHY SCREENING IN BRUNEI  
DARUSSALAM**

**PG HJ MD KHAIROL ASMIEE BIN PG HJ SABTU**

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**LONDON SCHOOL OF HYGIENE & TROPICAL MEDICINE**

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Research group affiliation(s): NONE.

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**NAME:** PG. HJ. MD. KHAIROL ASMIEE BIN PG. HJ. SABTU

**STUDENT ID NO:** 273781

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## **ABSTRACT**

In recognition of the increasing prevalence of diabetes in Brunei, and the expected increase in diabetic retinopathy (DR), primary health centre based DR screening was introduced in 2006 for seven health centres in the Brunei-Muara district. The Brunei National Prevention of Blindness from Diabetic Retinopathy is a policy document calling for DR screening to be made systematic at a national level. However, the effectiveness of the model in practice was not evaluated and the DR screening programme was launched without a baseline survey and situation assessment. Consequently, the responsiveness of the health system to embed a systematic approach to DR screening has faced many constraints and was slow to evolve. This study has provided evidence to support the implementation of the policy document and baseline information on the gaps and challenges within the key service provision stages for DR screening and treatment.

The overall objective of this thesis was to evaluate the DR screening model in the Brunei-Muara District. Results from this study suggest that the DR screening model in Brunei-Muara is partially systematic. The main findings showed that key processes are in place at different stages of DR screening and treatment and that sufficient resources have been allocated to detect sight threatening diabetic retinopathy (STDR) at primary health centres (PHCs) and to treat STDR at the national eye centre (NEC). This was supported by the good DR annual screening uptake rates (77%) and low DR prevalence rates (5.8%) reported in this study. However, the lack of monitoring of both the implementation processes and screening effectiveness was viewed as key limitations in the programme. This was evident through process gaps observed throughout the DR screening and treatment pathway including the identification of patients for screening at PHCs, GP to DR referral process, referral for treatment processes to NEC and disease registers that were not integrated and lacked accuracy. This was also backed by evidence that DR screening coverage rates were low (56%) across all health centres.

Based on a generic framework to analyse development of DR screening programmes used in this study, the existing screening model could be enhanced by improving

screening coverage rates, universal access to DR treatment, trained and certified workforce, implementation of a call and recall system and systematic digital photography screening system. However, further studies are required before these recommendations could be implemented.



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## LIST OF ABBREVIATIONS

<b>BNPPBD</b>	<b>Brunei National Programme for Prevention of Diabetic Blindness, A Ten-Year Strategic Plan: 2011 to 2020</b>
<b>C-E</b>	<b>Cost-effectiveness</b>
<b>DM</b>	<b>Diabetes Mellitus</b>
<b>DR</b>	<b>Diabetic Retinopathy</b>
<b>ECSDRG</b>	<b>European Conference on Screening for Diabetic Retinopathy Group</b>
<b>MOHB</b>	<b>Ministry of Health, Brunei</b>
<b>NSTDR</b>	<b>Non-Sight Threatening Diabetic Retinopathy</b>
<b>NPDR</b>	<b>Non-proliferative Diabetic Retinopathy</b>
<b>PDR</b>	<b>Proliferative Diabetic Retinopathy</b>
<b>STDR</b>	<b>Sight Threatening Diabetic Retinopathy</b>
<b>MO</b>	<b>Macular Oedema</b>
<b>WHO</b>	<b>World Health Organisation</b>

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## INTEGRATING STATEMENT

The Doctor of Public Health (DrPH) programme was an enriching four-year programme that has provided me with both knowledge and skills to understand the different issues and complexities within the public health realm and beyond. I underwent three different but interlinked learning components that were catering to equip public health leaders to make sense of the complex public health issues of in an increasingly globalised society. The DrPH programme has equipped me with a 'public health analyst's toolbox' to practice evidence informed public health policymaking. These included skills to critically assess, synthesise and communicate research evidence to inform policy making; to analyse the structure and function of health care organisations; to conduct research studies in a systematic and rigorous manner and to raise self-awareness of oneself as a change agent and of others in public health through self-directed personal and professional development. Through ongoing reflexive learning, I continue to use and refine this newly acquired 'toolbox' in my own work setting in the Ministry of Health to improve public health practice in Brunei.

The Evidence Based Public Health Practice (EBPHP) embodies the concept of 'evidence informed policy making'. In this study component, I have learnt of the merits of systematically identifying, analysing and synthesising research evidence and of equal importance, to shape it into a specific context of the policy process. The relationship between evidence and policy process is complex and different theories have been postulated (1).

The Health Policy Triangle (2) is a useful conceptual framework that I have learnt about in deciphering the complex relationship between evidence and policy making. This framework was developed on the premise that policy analysis should not be isolated in evaluating policy content alone. Proponents of this framework suggest that evidence adopted in health policies is in part driven by different policy actors having diverse interests and influence; and they are in turn influenced by the policy environment (3). Retrospectively, understanding policy processes within the complex health policy environment is vital in understanding why policies were

adopted (agenda-setting). Moreover, if applied prospectively, the framework can help in establishing factors that contribute to successful policy implementation.

A key component in understanding the health policy environment is by exploring how health organisations function and operate in delivering its public health mandate, a key policy actor. This was a key learning point in the Leadership, Management and Professional Development (LMPD). This module introduced me to different management theories that described the diverse nature of organisations and how leaders help shape the functioning of such organisations. Various management tools were also introduced in the module to understand organisations. One such tool was the McKinsey 7S framework which proposes that analysis of organisations should not be limited by just assessing structure but by breaking it down into seven different but interlinked components (4). The holistic approach of this framework is beneficial in understanding the nature of health organisations that are rarely homogenous. As a whole, public health care organisations are expected to collectively deliver a common mandate (improving health care) under a common budget system. However, individual units within the organisation are often organised to serve different purposes and therefore, place unique demands on resources. By breaking down the organisation into the different components, structure, strategy, skills, staff, styles, systems and superordinate goals, a common strategic goal of the organisation can be collectively identified and communicated across the different functional units to deliver one effective strategy.

As with the policy process, organisational mandates are determined by leaders and managers of the different units within the organisation. Therefore, gaining an understanding of the organisation culture and interactions between functional units within the organisation is required. Another tool that was offered in this module to facilitate the understanding of organisational behaviour is personal and professional development skills. The application of personality tests such as the Myers Briggs Type Indicator (MBTI) test (5) gave me the opportunity to discover my personal traits and also to promote emotional awareness of others. Although, the test has its own limitations (6), it has helped me to be more self-conscious in communicating with

colleagues. This interpersonal awareness or emotional intelligence (7) has been viewed by its proponents as an essential skill in facilitating effective communication in organisations.

The Organisational Policy Analysis (OPA) is a component of the DrPH programme, which was a three-month professional work experience, aimed at consolidating the learning of different theories introduced in the EBPHP and LMPD modules. I chose to conduct the OPA with the Health Promotion Centre, Ministry of Health (MOH), Brunei. The OPA coincided with the launching of a national health promotion policy document that provided me the opportunity to observe how the Ministry of Health negotiated with other external stakeholders to deliver its health promotion initiatives.

I chose to use the Health Policy Triangle framework to understand how NCD policies were developed at the MOH and found the application of the framework useful as a generic structure to conduct policy analysis. The framework gave me the flexibility to analyse individual components (policy content, context, process and actors) using different research tools such as semi-structured interviews and document review in the analysis and management tools (stakeholder and SWOT analysis) and to collectively assess relationships between key findings of individual components.

Analysing policy content was a huge challenge in the OPA primarily due to accessibility of documents. Interestingly, the lack of access to documents was not due to bureaucratic processes but mainly due to poor archiving of documents. Most were unavailable despite initiatives to collate them. Lack of policy documentation meant that content analysis performed in the OPA was restricted to three from a potential thirty three policy documents that were relevant to NCDs.

Stakeholder analysis was used to identify and analyse the roles, interactions and influences of different policy actors. Structured observations of different events organised as part of the launching of the National Health Promotion Blueprint gave me several opportunities to observe different interactions between different

departments within MoH, as well as with different external stakeholders such as NGOs, local university and other government ministry representatives.

The MoH's role observed in the OPA was essentially to serve as a policy mediator, negotiating interests and influence of its internal and external actors. It was observed that participation by the external agencies in health promotion activities was limited by different factors, which included political, structural (majority of policy actors adopted highly hierarchical structures contributing to prolonged decision making) and culture. Internally, organisational silos affected participation by different units within MoH in promoting NCD health promotion initiatives. In addition, the roles of key actors were unclear and there were also missed opportunities by not involving "hidden actors" relevant to NCDs.

The experience of conducting policy analysis in the OPA, built upon the theoretical knowledge acquired in the EBPHP module, reinforced my understanding for the need of reliable evidence to inform policies. This concept was further emphasised in the final component of the DrPH Programme, the DrPH Research Project.

The DrPH Research project emphasised the development of practical skills for planning and conducting research. This was achieved through an iterative process of refining research question, literature review, developing study methodology, conducting analysis and reporting of study findings that was supported by members of academia with different expertise. The concept of scientific rigour in conducting research was emphasised throughout the different stages of the research project.

The DrPH review was a process of evaluating research readiness conducted by a committee of experts prior to conducting field research. The experience of preparing the review document, presenting it in a seminar and post-seminar meeting enabled me to refine my research focus and methods. In retrospect, the constructive feedback provided by the DrPH committee led me to shift my research focus from a cost-effectiveness study to an evaluation study, providing me with more opportunities to do more fieldwork.

In the OPA, I adopted a mixed method approach comprising semi-structured interviews (SSI) and document review. Adopting a similar mixed method approach in the DrPH research allowed me to refine my research methods and improve my data collection skills. The experience of conducting SSI in the OPA gave me the confidence to further improve the way of developing topic guides and refine my interview skills. In addition, through a better understanding of grounded theory and facilitated by using NVivo software; I was able to further develop my skills in analysing qualitative data.

In summary, the DrPH programme has equipped me with the knowledge and skills in policy process, organisational management and research skills required to improve public health practice in Brunei based on in an all-encompassing concept of “evidence informed policy making”.

# 1. Introduction and literature review

## 1.1 Diabetes mellitus and diabetic retinopathy

Diabetes Mellitus (DM) is a group of heterogeneous disorders presenting with common elements of hyperglycaemia and glucose intolerance, associated with insulin deficiency, impaired effectiveness of insulin action, or both (8). DM is classified into four types (9): Type 1 DM (juvenile/insulin dependent), Type 2 DM (adult onset/ non-insulin dependent), gestational DM and other specific types.

Diabetic retinopathy (DR) is a chronic, progressive complication of diabetes mellitus that affects the microvasculature of the retina, which if left untreated can potentially result in sight loss. Both type 1 and type 2 diabetics are affected, although their progression rates differ (10). Sight loss can also occur centrally due to macular oedema (MO), which is the thickening and swelling of the macula caused by the accumulation of fluid and protein deposits on or under the macula of the eye.

### *DR disease progression: the disease pathway*

Figure 1-1 depicts the progression of DR over time viewed through funduscopy. The DR disease pathway is complex and clearly defined (Figure 1-2). The early stages of the retinopathy (non-proliferative) are non-sight threatening with minor microvascular changes and micro-aneurysms. These stages are described as non-sight threatening diabetic retinopathy (NSTDR). However, with disease progression, the walls of retinal blood vessels weaken and lead to localised bleeding (dot and blot haemorrhage) and leaking (oedema and exudates). In response to the lack of oxygen caused by the compromised blood flow in the retina tissue, new but fragile blood vessels will grow (neo-vascularisation) along the retina. At this advanced stage (proliferative), the condition is considered sight threatening and without any active treatment, DR will eventually lead to irreversible blindness from haemorrhages and retinal detachments. Sight loss can also occur at any DR stage if macular oedema is present. These stages are defined as sight threatening diabetic retinopathy (STDR). The central challenge is that retinal changes are mainly observable through funduscopy and patients often remain asymptomatic, even till late into the sight

threatening stages. This makes it pertinent for any DR screening programme to have the capability to detect DR at the earliest stages so as to prevent irreversible sight loss.

Figure 1-1 Progression of diabetic retinopathy

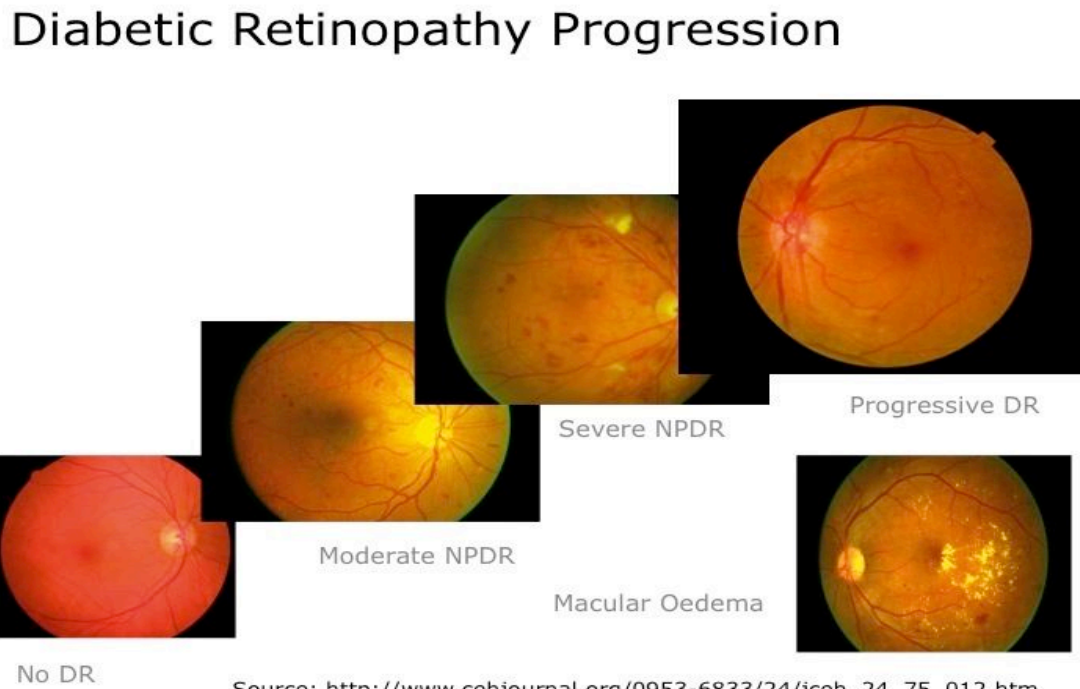
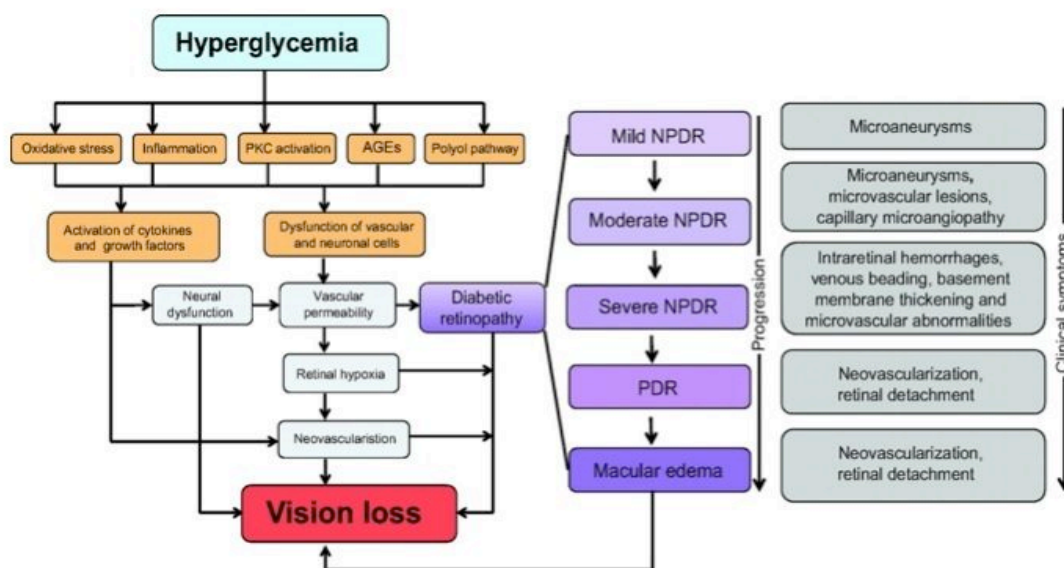


Figure 1-2 Diabetic retinopathy disease pathways

### Complexity in disease pathway



Robinson R et al. Dis. Model. Mech. 2012;5:444-456

## 1.2 Epidemiology of diabetes mellitus and diabetic retinopathy

### *Prevalence of DM and DR*

The prevalence of DM is increasing rapidly worldwide (Figure 1-3). According to recent estimates by the International Diabetes Foundation (IDF), the global prevalence of DM (20 – 79 years) is 8.3% (11). It is estimated that by 2030, 366 million people globally will be affected by the condition. In the Western Pacific Region, the adjusted prevalence of DM (20 – 79 years) is 10.1% (8). The IDF estimates that the prevalence of DM in Brunei (20 – 79 years) in 2011 was 8.58% and is expected to increase to 10.4% by 2030 (11).

The increasing prevalence of DM is closely linked to the prevalence of DR. Although DR prevalence varies in different settings, estimates suggest that 15 – 43% of people with diabetes are likely to have DR (Table 1-1). In a study that pooled individual data from several population based studies from 1980 – 2008 (12), the global DR prevalence (20 – 79 years) was estimated to be 34.6% for any DR, of which 10.2% was estimated to be sight-threatening.

### *DR and visual impairment*

DR is one of the leading causes of blindness in the working population. In a recent study, DR was estimated to contribute towards 1% of global blindness (13) (Table 1-2). However, this is likely to rise as the prevalence of DM continues to increase, ageing of the population and other causes of blindness such as cataracts are brought under control.

### *Incidence and DR risk factors*

DR incidence rates derived from the findings of the Wisconsin Epidemiologic Study of Diabetic Retinopathy (WESDR) demonstrated that the overall incidence of any DR in a 10 year interval from 1980 – 1982 to 1990 – 1992 was 74% (14). In the same study, among those diabetics with DR at baseline, 64% had severe non-proliferative retinopathy and 17% developed progressive diabetic retinopathy (PDR). These figures were 89%, 76%, and 30%, respectively among the younger-onset group



(diagnosed < 30 years); and 67%, 53%, and 10%, respectively, among the older-onset group who did not use insulin. In the 25 year follow-up of the WESDR type 1 diabetes group, the majority of patients (97%) developed DR, and of these, 42% progressed to PDR, 29% developed macular oedema (MO) and 17% had clinically significant MO (15).

Longer diabetes duration, higher haemoglobin A1c and higher blood pressure are established risk factors highlighted in several studies (16 – 23). In the Beijing Eye study, DR was also found to be higher in diabetic patients on insulin treatment compared to other treatments (diet, tablet) and was also associated with living in a rural region (24).

STDR was also associated with chronic kidney disease, cardiovascular disease and previous strokes (12), an indication of widespread microvascular pathology. Other associated factors such as obesity, hyperlipidaemia, pregnancy and ethnicity have been associated with DR, however, more population-based studies are needed to understand them (25).

In a systematic review of 28 studies, a decline in incidence rates for PDR (2.6% vs. 19.5%) and severe visual loss (3.2% vs. 9.7%) was reported at 4 years between 2 time periods (1986 – 2008 and 1975 – 1985)(26). It was suggested that the observed decline might be due to improved awareness of DR risk factors, early intervention and initiation of treatment and improved medical management of glucose, blood pressure and serum lipids. However, these studies were based on data from developed countries and the authors acknowledged that the limited number of studies used in the review significantly affected their findings.

Although these findings shows some promise in the global initiative to prevent sight loss from DR, it may not be generalizable to countries with limited responsiveness within their health systems, such as Brunei; where diabetic screening remains opportunistic and the effectiveness of glucose control and blood pressure interventions are unknown.

### *Economic cost of DR*

In 2004, a US based study estimated the economic costs of different visual disorders including diabetic retinopathy (27). Direct medical costs for diabetic retinopathy were US\$ 493 million. This was much lower compared to medical costs for cataracts (US\$ 6.8 billion), refractive error (US\$ 5.5 billion), glaucoma (US\$ 2.9 billion) and AMD (US\$ 575 million). The study also highlighted that the majority of direct medical costs were outpatient costs and in patient costs were minimal. In addition, it was also noted that the costs of diabetic retinopathy were lower among older patient groups (65 years) compared to the younger patient group (40 to 64 years). In contrast, costs of AMD and cataracts were significantly higher in the older patient group. The authors have attributed the lower outpatient costs of diabetic care coupled with a lower number of diabetic cases in the older group for these differences. These findings highlight the affordability of diabetic care compared to other eye conditions. In a study conducted in Sweden, it was suggested that healthcare costs attributed to DR could be reduced if DR progression could be prevented (28). In addition, it was shown that the average healthcare costs increase significantly with the severity of DR, further emphasizing the importance of early DR screening.

### *Prevalence of DM and DR in Brunei*

No population-based studies have been conducted to document the prevalence of DR in Brunei. However, in a Singapore-based study on a diabetic population aged 40 – 80 years of Malay ethnic origin, the majority ethnic group in Brunei (66%)(29), the prevalence of DR, MO and STDR was estimated as 35%, 5.7% and 9% respectively (25). The IDF estimated the prevalence of DM in Brunei in 2011 to be 8.6% (8). Applying these figures to the current Brunei population estimate of 400,000 (29), suggests there are an estimated 34,400 people with diabetes, of which 12,040 diabetic patients have DR, 1,960 have MO and 3,096 have STDR. As DM prevalence is expected to increase to 10.4% by 2030 (8), these projected figures will be expected to increase rapidly.

Figure 1-3 Global prevalence of diabetes (2000 and 2030)

## Diabetes epidemic

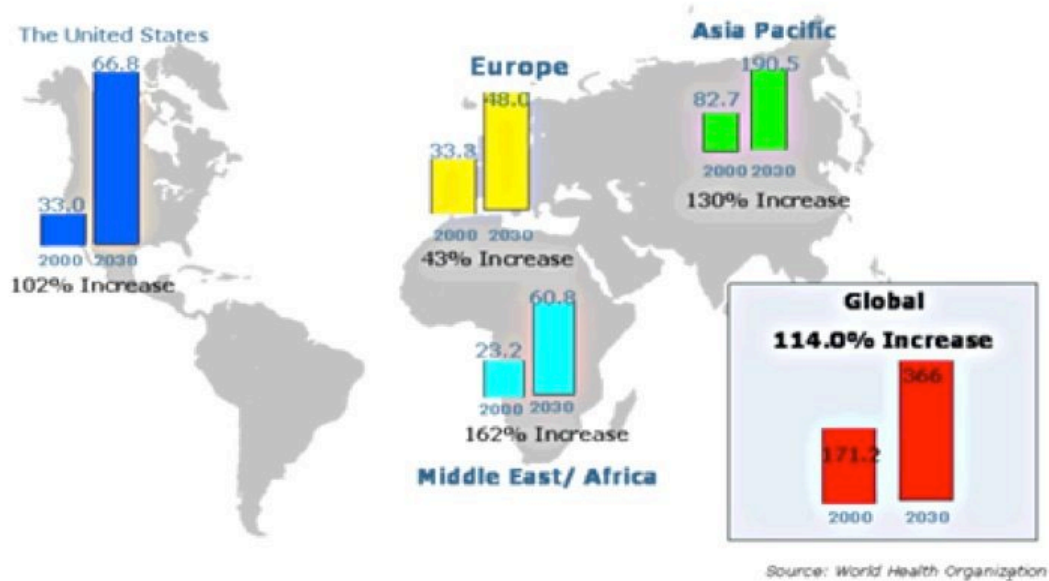


Table 1-1 DR Prevalence figures from selected population based studies

Country	Year	All DR	Ref
Australia (Blue Mountains)	1994	32.4%	(30)
China (Beijing)	2006	27.9%	(24)
China (Handan)	2006	43.1%	(31)
India (Chennai)	2005	18.0%	(32)
Singapore	2006	35.0%	(25)
United States (Beaver Dam)	1990	10.2%	(33)

**Table 1-2 Global prevalence of visual impairment (by cause)(13)**

	<i>Blindness</i>	<i>Visual Impairment (Blindness + VI)</i>
Uncorrected RE	3%	42%
Cataract	51%	33%
Glaucoma	8%	2%
DR	1% (0.39 million)	1% (2.85 million)
AMD	5%	1%
Trachoma	3%	1%
CO	4%	1%
Childhood	4%	1%
Undetermined	21%	18%

### *DR grading classification*

A standard grading classification can be used to describe the severity of the disease that is observable through funduscopy. In addition, together with recommended clinical practice guidelines, the grading classification can guide ophthalmologists to determine further management and treatment strategies of identified DR cases.

Based on a consensus amongst a range of experts, the International Clinical Diabetic Retinopathy and Diabetic Macular Oedema Disease Severity Scales (34) were developed. Table 1-3 and 1-4 depicts the five-stage disease severity scale, used in this grading system. NSTDR (low-risk to sight loss) includes a range from no DR, mild NPDR and moderate NPDR without the presence of MO. STDR (high risk to sight loss) is used as the cut-off point for referral for further treatment and includes severe NPDR, PDR and presence of MO.

Unlike previous classifications (WESDR), this simplified grading scheme was designed to accommodate retinal examinations in different settings (with basic training and availability of equipment) and it was recommended that this grading could be based on observations on dilated ophthalmoscopy.

### 1.3 DR Treatment

Success of DR treatment is ensuring that the retinopathy is detected at the right stage (through screening), followed by timely intervention. Options available for treatment of STDR (PDR and MO) include laser photocoagulation, vitrectomy, intravitreal pharmacotherapy (anti-vascular endothelial growth factor (anti-VEGF) and corticosteroids) and combination therapy for MO (intravitreal pharmacotherapy and laser photocoagulation)(35).

Laser photocoagulation is a procedure that utilises the heat from a laser to seal or obliterate abnormal, leaking blood vessels in the retina. It is effective in slowing the progression of PDR and accompanying visual loss, but the treatment usually does not restore lost vision. Pan retinal laser photocoagulation has been shown to be effective in reducing the risk of moderate to severe visual loss by 50% (36,37). Similarly, the effectiveness of focal laser photocoagulation in reducing risk of moderate visual loss amongst patients with clinically significant macular oedema has been shown (38).

Vitrectomy is a procedure that involves the surgical removal of the vitreous within the eye. Vitrectomy is recommended in the treatment of advanced STDR (including severe PDR with fibrosis, retinal detachment and also macular oedema)(35). Early vitrectomy has been shown to be effective in restoration of vision restoration amongst Type 1 diabetic patients with severe PDR (39).

Adverse effects of both laser photocoagulation and vitrectomy have been documented including visual field constriction, night blindness, acute glaucoma, retinal traction and cataract formation (35). As a result, treatment with the above mentioned procedures has been primarily focussed on reducing visual loss but not restoring it.

However, in recent years, several treatment options have been explored that have changed the way STDR is treated, in particular, the use of intravitreal anti-VEGF injections and combination therapy. The success of anti-VEGF treatment in the treatment of MO has been documented in several studies (40, 41) and it has now supplanted focal laser photocoagulation as the treatment of choice. For PDR, the

treatment of choice remains laser photocoagulation as there is not enough evidence to support the effectiveness of anti-VEGF over pan-retinal photocoagulation(42, 43).

Another emerging treatment for MO is combination therapy (anti-VEGF, corticosteroids and laser photocoagulation), driven by factors associated with intravitreal pharmacotherapy, including the burden of repeated intravitreal injections (patients and provider's perspective) and medication costs (44). There is insufficient evidence to support the effectiveness of combination therapy in addressing the above mentioned issues and more studies are needed before it can be adopted as standard clinical practice in the treatment of MO.

In view of the advances in different treatment modalities highlighted earlier, it is important to remember that DR is a systemic disease. At the non-sight threatening stages, intensive blood glucose and blood pressure control is still the most effective strategy to prevent DR progression, which has been demonstrated in several trials (23). However, findings from the Action to Control Cardiovascular Risk in Diabetes (ACCORD) trial also suggested that intensive glycaemic control appeared to have increased mortality amongst the trial participants and thus raised concerns over the management of patients with type 2 diabetes who are at higher risk of cardiovascular events (45). To address this, effective collaboration between endocrinologist/general practitioners and ophthalmologists is needed in the halting DR progression at this non-progressive stage.

**Table 1-3 Classification stages of diabetic retinopathy (DR) and its recommended management (34)**

<i>DR Severity level</i>	<i>Fundus Examination*</i>	<b>Recommended action</b>
No DR (NDR)	No anomalies	Review in 12 months at PHCs/retinal clinic
Mild non-proliferative DR (NPDR)	Only micro aneurysms	
Moderate NPDR	More micro aneurysms but less than severe NPDR	Review in 6-12 months/retinal clinic
Severe NPDR	Any of the following: >20 Intra-retinal haemorrhages in each of the 4 quadrants Venous beading in two/more quadrants Intra-retinal micro vascular abnormalities in one or more quadrants AND no signs of proliferative retinopathy	At PHCs: Refer to retinal clinic  At retinal clinic: 6-monthly review. Pan-retinal lasers if compliance to attendance is poor.
Proliferative DR (PDR)	One or both of the following: Neovascularization Vitreous haemorrhage	At PHCs: Urgent referral to retinal clinic.  At retinal clinic: Pan-retinal laser / vitrectomy indicated if vitreous haemorrhage or retinal detachment detected.

**\*Observable by dilated Ophthalmoscopy**

**Table 1-4 Classification stages of macular oedema (MO) and its recommended management (34)**

<i>MO Severity Level</i>	<i>Fundus Examination**</i>	
Absent	No retinal thickening or hard exudates in posterior pole	Review in 12 months at PHCs or retinal clinic
Present	Some retinal thickening or hard exudates in posterior pole	See below
Sub-classification if MO is present:		
Mild	Some retinal thickening or hard exudates in posterior pole but away from centre of macula	Review in 6 months at PHCs or retinal clinic
Moderate	Retinal thickening or hard exudates in posterior pole approaching centre of macula but not in the centre of macula	At PHCs: Refer to retinal clinic and refer to diabetic services for advice on management of blood sugar and blood pressure control.  At retinal clinic: Laser photocoagulation if clinically significant macular oedema detected.
Severe	Retinal thickening or hard exudates at the centre of macula	At PHCs: Refer to retinal clinic.  At retinal clinic: Laser treatment or intravitreal injections with anti-VEGF drugs.

**\*\* Observable by dilated ophthalmoscopy but hard exudates are best observed using slit lamp bio microscopy and/or stereo fundus photography.**

## 1.4 Diabetic retinopathy screening

### 1.4.1 Definition of screening and screening programme

For the purposes of this study, the UK Screening Committee definition of screening was adopted, which is ‘a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition’ (46).

Screening programme was defined in this study as ‘a system incorporating all necessary steps from identifying the eligible population through to delivering interventions and supporting individuals who suffer adverse effects’ (47). This definition was selected for this study as it captures the whole screening landscape extending from the screening pathway, grading pathway, treatment referral pathway and the organisation process to deliver the screening programme. Both definitions provide a comprehensive context for a public health programme.

#### *Systematic and opportunistic screening*

Systematic screening constitutes an organised, integrated process in which all the activities within the screening pathway are planned, coordinated, monitored and evaluated through a quality assurance framework (47). These are requirements advocated by health organisations and other professional organisations alike (48, 49).

Opportunistic screening or case finding, however, is often associated with traditional hospital based clinical examination where a condition is detected by chance as patients may often seek consultations for different reasons (47). These differences have been exemplified in a study (see Appendix 1) that compared the fundamental characteristics of systematic and opportunistic screening. Systematic screening has processes in place to invite patients for screening, screening tests selected are based on diagnostic accuracy (sensitivity and specificity) that are fit for purpose, uses



quality assurance for monitoring purposes, fixed screening intervals, specified and monitored target uptake rates and addresses patient safety (50).

#### *Phases of a DR screening programme*

For the purposes of this study, the following working definitions have been used to describe the different phases of a screening programme:

- *Screening pathway* includes all activities conducted to deliver DR screening from the identification of the at risk population (all registered diabetics at primary health centre by GPs) to diagnosis.
- *Grading pathway* directs ophthalmologists conducting DR screening (screener) to determine which DR cases should be referred for treatment or not, and also to establish when/how often to recall patients for retinal examination.
- *Clinical management protocols* guide the ophthalmologist (vitreo-retinal team, National Eye Centre) on the appropriate treatment (pan retinal/focal laser photocoagulation/vitreo-retinal surgery) of detected cases (STDR and ME) once they have been referred from the primary health centres.
- *Organisation of DR screening* refers to the allocation of resources for screening at each health institution including infrastructure, human resources, equipment and consumables.

### 1.4.2 Diabetic retinopathy screening

Regular screening of people with diabetes has the potential to significantly reduce the incidence of visual loss from DR. Diabetic retinopathy screening fulfils the necessary criteria required for a disease to be screened (51):

- It is an important growing public health problem.
- The natural history is well understood.
- It is detectable at an early stage and early treatment is more beneficial than late treatment.

Several studies have suggested the long-term benefit of screening in preventing blindness (52, 53), although no clinical trials have been conducted due to ethical challenges. Observational studies have provided some understanding of the population at risk of developing DR and how the rate of progression (DR stages) varies between type 1 and type 2 diabetes(17). DR screening programmes in Iceland have been shown to be successful in stabilising DR prevalence and reducing rates of blindness after 25 years of their implementation (54).

#### i. Systematic DR Screening

Systematic DR screening programmes are organised to be efficient enough to engage and reach all “at risk” individuals. At the same time, coverage has to be balanced with acceptability and adherence to screening within the population (46). The introduction of systematic DR screening programme requires significant start-up costs which include screening equipment, personnel, training costs, call and recall system, software for grading and quality assurance system (55). Therefore, the decision on how best to organise DR screening to meet the balance “efficacy and costs” needs to be evidence based and at the same time must be suited to the different requirements of the local health service provider, patients and society as a whole, who value the benefits of screening differently (56). In addition, to ensure all these objectives are being met and to prevent unintended consequences of poor performance standards in screening (e.g. unnecessary patient anxiety caused by

false positive results), systematic screening programmes have developed key performance indicators to monitor progress (57).

*ii. DR screening framework*

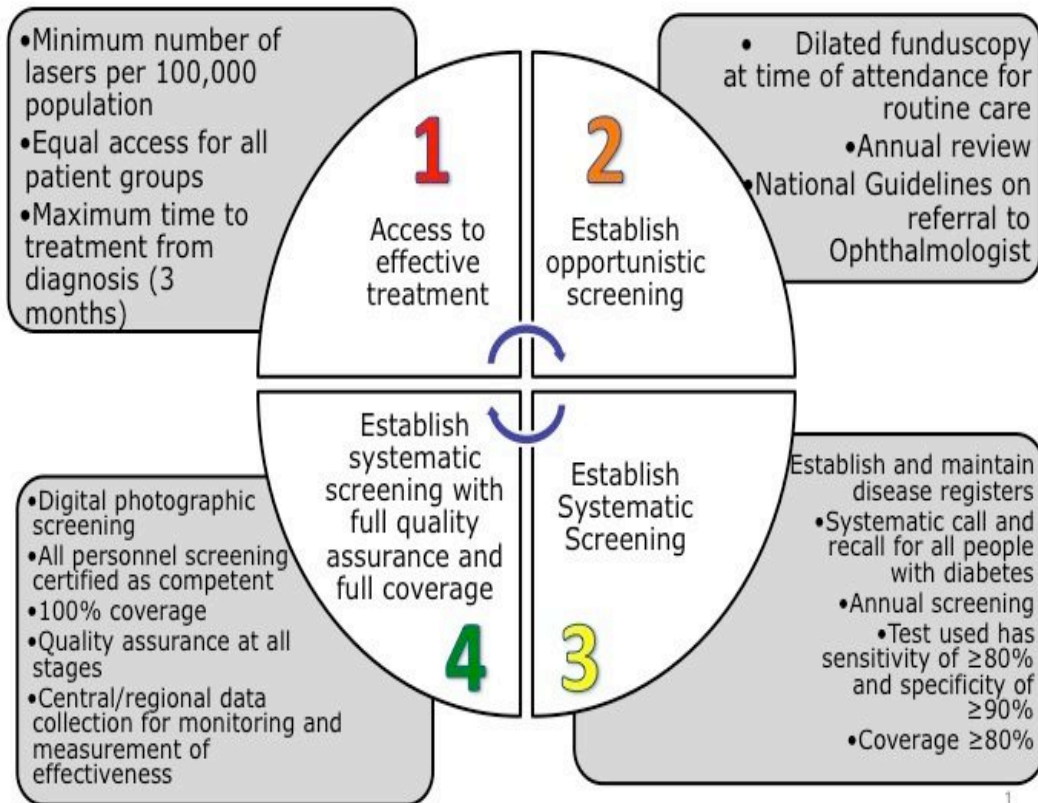
The organisation of DR screening programmes is dependent on the state of development of health systems and its financing (58), availability of human resources (59) and appropriate technology. This complex interaction is specific to each health system and there is no universal framework for DR screening programmes.

However, based on the capacity of a health system, the European Conference on Screening for Diabetic Retinopathy Group (ECSDRG) (58), represented by experts from 29 European countries, have reached a consensus on the 4 stages of development of DR screening (Figure 1-4). Each stage outlines certain targets that need to be met before a programme can move to the next step. For the purposes of this study, this framework will be known and referred to as the ECSDRG framework throughout this thesis.

Stage 1 form the basis of any screening programme, that is, to establish access to treatment facilities for DR before engaging in any screening activities. Stage 2 represents the next stage of development, which outlines the need to establish an evidence based standard of fundus examination (dilated funduscopy) and pathway that ensures early and regular annual screening, as well as a referral pathway from screening to treatment. Stage 3 outlines the basic concepts of a more structured approach to screening involving a systematic approach of identifying, inviting and informing all “at risk” patients for eye screening through an effective call and recall system and the monitoring of screening coverage in the population. It also outlines the minimum standards for the diagnostic accuracy of screening methods. Finally, stage 4 represents the characteristics of fully established systematic screening programmes that incorporate measures to monitor the quality and coverage. The DR screening developmental stages that can be adopted are directly linked with the development of the health system and all its interconnected units.

Figure 1-4 DR screening programme development stages

## Stages of DR Screening Development



Source: <http://www.drscreening2005.org.uk>

### 1.4.3 Health systems and organisation of DR screening programme

#### **Health systems and its building blocks**

The World Health Organisation (WHO) defines health systems as ‘the sum total of all the organizations, institutions and resources whose primary purpose is to improve health’ (60). The WHO further describes health systems as a framework comprising six building blocks (Figure 1-5) that represents different, but interlinked facets of a health care system that includes human resources, equipment, financing, information systems, governance/leadership and service delivery.

#### **Health systems and DR screening components:**

##### *1. Human resources*

Different cadres that need to be involved at various stages of screening include GPs and endocrinologists who diagnose and manage diabetics, primary screeners who assess the retina and refer for treatment and vitreo-retinal specialists to deliver treatment in a timely manner. This skill mix, appropriate numbers of health providers and their overall distribution has led to innovative approaches being adopted across different screening models.

Successful systematic DR screening models (e.g. Icelandic DR screening programme) have reported that effective collaboration between the different cadres is vital in ensuring the effectiveness of its screening programme (61). Moreover, in a systematic review that evaluated rates of DR progression to PDR and severe visual loss (SVL) in two different time periods, it was suggested that an increased awareness of retinopathy risk factors; earlier identification and initiation of care for patients with retinopathy; and improved medical management of glucose, blood pressure, and serum lipids as contributors to lower rates of DR progression to PDR and SVL between the two time periods (26). This will only be possible through close collaboration between different cadres at the different stages of the screening pathway.

### *Training needs*

Another important element in screening programmes is the training needs of its workforce. An Australian study (62) that described a screening model serving a rural area highlighted a positive relationship between credentialing and better quality photographs as well as timeliness of photographs sent away for reporting. Yet, there are reports of DR screening programmes conducted by individuals without formal training (63). In a review of the UK DR screening programme, it was reported that as a result of developing extensive training programmes for the workforce, a new career pathway has been created. Through this, issues such as staff turnover could be dealt with, thus, making the programme sustainable. However, it was also highlighted that the costs of developing training should be considered as an additional cost of screening (64).

**Figure 1-5 WHO health systems building blocks**



(Source: [www.emro.who.int](http://www.emro.who.int))

### *Innovations in the use of manpower in DR screening to meet demands*

In DR screening programmes, the shortage of ophthalmologists has led to innovations in the use of human resources to meet the increasing demand for DR eye screening. Table 1-5 shows the comparison of the diagnostic accuracy (sensitivity and specificity) of different health cadres in different screening models. These included optometrists, orthoptists, non-ophthalmic physicians, GPs and trained graders (66 – 69). These graders, who undergo extensive training to grade digital

retinal photographs, come from different professional backgrounds. They have been applied extensively in the UK DR screening programme to meet the demands of individual populations.

Generally, reliability of DR screening (sensitivity and specificity) was highest when examinations were performed by ophthalmic personnel compared to other non-ophthalmic health cadres. It was difficult to compare diagnostic reliability purely based on health cadres alone, as DR screening models were designed and often assessed in studies in combination with the different equipment used for screening.

## *2. Equipment and consumables*

Different types of ophthalmic equipment have been used in DR screening including direct ophthalmoscopy; indirect ophthalmoscopy, slit lamp bio-microscopy, fundus camera (polaroid) and digital fundus camera. In general, systematic DR screening programmes have adopted the use of digital fundus camera as the preferred method. It has been shown to have higher sensitivity and specificity (69) compared to direct ophthalmoscopy (70) and slit-lamp bio-microscopy (71).

UK based organisations such as the National Screening Committee and National Institute of Clinical Excellence have recommended the use of digital fundus camera for screening. Internationally, the International Agency for Prevention of Blindness, the umbrella organisation overseeing a multi-agency cooperation in prevention of blindness enlists the use of non-mydratic retinal camera as essential equipment for DR screening in developing countries (72).

However, it is widely recognised that ophthalmoscopy (direct, indirect and slit-lamp bio-microscopy) remains a prevalent method of screening for DR in less developed countries; which in part led to the birth of the much simplified international DR grading system (34). The WHO acknowledges the unique needs of each country when planning for a DR screening programmes. Several factors such as epidemiology of diabetes, number of ophthalmologists per diabetic population and the financial system need to be taken into consideration before investing in a digital photography system. It highlights decisions made are often as a 'trade-off between costs and

performance' when considering a digital fundus camera model and recommends that each country considers the availability of its resources, public expectations and the existing health systems. On a similar note, the International Council for Ophthalmology has recognised the different forms of ophthalmoscopy (direct, indirect and slit-lamp bio-microscopy) as acceptable methods for DR screening in developing countries. These considerations will be discussed further.

**Table 1-5 Comparison of diagnostic accuracy in different screening models.**

Screening models	Sensitivity / Specificity	PPV	STDR Detection rates	Digital Fundus Camera only		
				Inter-grader agreement	Rate of un-gradable images	Ref.
Family Physicians/ General Practitioners with digital fundus camera	87%/95%	33%, 94%	2.5%	N/a	39%	(73) (74)
Optometrists with slit lamp bio-microscopy	87%/91% (STDR) 75.8%/99% (STDR)	30%	N/a	N/a	N/a	(75) (76)
Optometrist with Indirect Ophthalmoscopy	N/a	60%	N/a	N/a	N/a	(74)
Optometrists with digital fundus camera	N/a	63%	6%	N/a	N/a	(74)
Orthoptists with digital fundus camera	92 - 100%/85-88%* (mild to mod. DR)	N/a	N/a	94.6, 93 & 87.6%*	13% 5%	(77) (78)
Trained DR graders with digital fundus camera.	N/a	N/a	N/a	0.6 (PDR)** 0.2 (M)**	8%	(79) (62)

\* Ranges of values based on 3 observers; \*\* Kappa values; PPV –Positive Predictive value, STDR – Sight threatening diabetic retinopathy; PDR – Proliferative Diabetic Retinopathy, M –Maculopathy.



### *Digital Fundus Camera Model: Key Considerations*

Diagnostic superiority (higher sensitivity and specificity) over other screening methods mentioned earlier, however these rates remain low for detecting CSMO. The UK NSC cites the advantage of image storage that is useful for grading, audit and health education purposes in systematic DR screening program. Furthermore, the digital fundus photography model can offer potentially better coverage through tele-ophthalmology screening in rural areas and by extending DR screening cadres by non-ophthalmologists. Such models in situations where diabetes is highly prevalent and there is a shortage in the number of ophthalmologists may be very useful.

### *Technical failure rates*

In addition, another consideration of implementing a digital fundus photography system is that patients may require re-screening at different visits if the image taken is not satisfactory. This is termed as 'technical failure (TF) rate'. The UK NSC committee has set a national standard of <5%, however studies have shown variation in TF rates between 4% (80) to 34% (81). These differences can be attributed to in part by different study populations, different types of fundus camera, and different criteria for image gradability. Technical failure is associated with patient related issues such as cataracts, small pupils, poor fixation and difficulty in positioning patients (82).

Due to the issue associated with technical failure rates, the use of ophthalmoscopy as an adjunct to DR screening has been considered, although, there is currently no consensus. One study reported that screening sensitivity improved with ophthalmoscopy (83) whilst another study did not report any improvement (84). However, this study was based on ophthalmoscopy conducted by a trained technician.

### *Graders*

Training of non-ophthalmologists as graders will be needed and this has shown to be effective (62). However, if patients are not screened by ophthalmologists, then

screening using a digital fundus camera with trained technicians may represent a missed opportunity to detect other ocular conditions, potential health education and patient-doctor rapport which may improve compliance to attend screening and also adherence to medication (85).

#### *Image quality*

Another issue of concern is compression size used for storing and remote grading. NSC guidelines (as of 2005) did not recommend compression of images (which aids storage and rapid transfer of images); issues with compression ratios if images compressed >10% become less sensitive to detection of DR compared to non-compressed format (86). In addition, countries need effective internet or satellite technology to support this.

#### *Cost*

In a review of screening and prevention of diabetic blindness, direct screening (screening by ophthalmologists using slit lamp bio microscopy) and digital photography screening (by trained photographers, graded later by ophthalmologist) was compared (87). The reviewers highlighted three different cost considerations in making the comparisons:

- i. Digital fundus photography requires more initial start-up cost
- ii. Wages of different cadres (ophthalmologists vs. cost of equipment + non-medical screeners)
- iii. Different funding scheme for screening (e.g. pay per screening reimbursement scheme may encourage direct screening by ophthalmologists)

In a UK based study (88), implementing digital photographic screening was found to be more expensive than screening using direct ophthalmoscopy by either GPs, optometrists and diabetologists. However, the study did report that the digital photography system detected 157 more cases. In an Italian study that compared three different approaches to screening and treating STDR, it was found that costs

per screening of implementing screening using fundus photography were higher than screening by ophthalmoscopy alone (89). This study also found that screening and treatment are cheaper if conducted at the same hospital.

In a health technology assessment study to determine the systematic model for implementing a comprehensive national screening programme for diabetic retinopathy in Scotland (55), the different fixed and variable costs required to carry out a systematic screening programme based on digital fundus photography was highlighted. The fixed costs included national coordination, health board coordination, screening offices, call and recall software, and image capture software. In addition, various variable costs included capital equipment, consumables, staffing, staff training and equipment maintenance. These different cost components are important to identify and measure when conducting costing studies (90).

### *3. Health care financing*

Systematic screening at a national programme level has been shown to be cost effective (C-E) (Table 1-6). In the study based on screening 5000 diabetic patients in Liverpool (88), the systematic screening (SS) model was found to be more C-E compared to the opportunistic screening (OS) model based on cost/true case detected (£209 - SS vs. £289 - OS). In a health technology assessment conducted for Scotland (55), it was reported that moving from an opportunistic screening model to a systematic screening model without mydriasis was the most cost effective option in terms of cost/QALY per new case detected compared to a move from opportunistic to a systematic model with mydriasis, or to a move from systematic screening model (with mydriasis) to a systematic screening model (with mydriasis). These studies also reported several factors that have significant influence over C-E of DR screening that are likely to vary in different geographical settings including prevalence of diabetes and DR (89, 92) costs associated with screening and treatment (56, 92, 93), utility values (56, 92) and screening compliance(56, 94).

However, despite this evidence and the increasing global prevalence of diabetes and diabetic retinopathy, there is huge variation in the way screening services are

organised in different countries. In a report of DR screening programmes in 29 European countries (58), health systems financing was suggested as an important determinant to the way DR screening is being organised. In countries that have a national health system (United Kingdom and Iceland), systematic nationwide DR screening programmes are being offered. In economically advanced countries such as Germany, Netherlands and Italy, where the health system is essentially privately funded, regional DR programmes are offered. According to the report, these programmes lack uniformity in the way DR is being classified and how screening is performed. At the other extreme of the economic scale, developing eastern European countries with weak health systems have no DR screening programmes altogether.

**Table 1-6 C-E studies comparing opportunistic with systematic DR screening using retinal photography. (§Variables influencing CE)**

Country (Ref.)	Study population	Study Type	Outcome measure	Findings	Opportunistic Screening (OS)	Systematic Screening (SS)	Variables included in sensitivity analysis (SA)
Liverpool, UK (88)	5000 diabetic patients in Liverpool	CEA	Cost/ true case detected	<b>£209 (SS)</b> £289 (OS)	Main characteristics: <ul style="list-style-type: none"> <li>• Fixed site;</li> <li>• Dilated DR examination using direct ophthalmoscopy by either</li> <li>• GPs, Optometrists and diabetologists</li> <li>• No recall system.</li> </ul>	Main characteristics: <ul style="list-style-type: none"> <li>• Mobile screening unit;</li> <li>• Dilated DR examination using 3-field non-stereoscopic retinal photography by technicians</li> <li>• Validated grading by Ophthalmologists</li> <li>• Patient recall system</li> </ul>	<ul style="list-style-type: none"> <li>• Prevalence§</li> <li>• Sensitivity and specificity§</li> <li>• Compliance§</li> </ul>
Scotland, UK (55)	Computer simulated hypothetical cohort* (US study adapted to UK population)	HTA	Cost/ QALY	<b>£7703*</b> £10,270** £28,881***			Uni-variate (SA): <ul style="list-style-type: none"> <li>• Sensitivity and specificity</li> <li>• Mydriasis and patient attendance rates</li> <li>• Cost per screen§</li> <li>• Cost of blindness§</li> <li>• Call and recall setup (without digital photography)</li> <li>• Quality of life associated with blindness§</li> <li>• Discount rate for benefits§</li> </ul>

**Cost/QALY per incident diabetic cases for: \* Moving from Opportunistic screening to systematic screening (with no mydriasis); \*\*Moving from Opportunistic screening to systematic screening (with mydriasis); \*\*\* Moving from systematic screening (with no mydriasis) to systematic screening (with mydriasis).**

#### 4. Information systems

A key feature of a systematic DR screening programme is the use of a centralised database used for identifying and inviting patients with diabetes for DR screening (disease registers with call and recall system), DR grading purposes (centralised image grading and storage), monitoring screening performance (e.g. screening coverage, timely referrals, waiting lists) and audit purposes (80, 95, 96).

One such example of information systems in DR screening programmes that have been reported in studies is the use of disease registries to estimate screening coverage. Several UK based studies have reported the importance of disease registers in estimating screening coverage (75, 77, 97 – 99). In a London-based study, it was reported that better coverage rates were attributed to the use of a locally developed GP register which was used as a source to call and recall patients to attend screening (76). In another study, the authors cited the importance of having regularly maintained registers (updating information) as well as having a call and recall system to estimate and improve screening coverage (96). The key features of a centralised disease register required to improve screening coverage were highlighted as follows (97):

- A complete and accurate list of patients updated regularly
- Linked to reimbursement (pay per screen)
- Provide feedback of attendance between ophthalmology and screening programme
- Effective call and recall software.

In diabetic care, centralised disease registers require information from multiple care providers. Therefore, close coordination between the different care providers is necessary to ensure data collection is standardised and integrated. Numerous UK based studies highlighted the importance of coordination between GPs and local screening programmes in ensuring data collected in disease registers were complete and accurate (75, 98, 99). One UK study reported incentives to encourage GPs to establish local registries under a contract system (98). In one study, the lack of

integration of a centralised register was attributed as a key challenge in improving screening coverage (76).

In the UK, there is no national disease register for diabetes (100; p.11), therefore local DR screening programmes are dependent on local GP registers and hospital data. The Scottish Clinical Information-Diabetes Collaboration has been cited as an exemplary model for a centralised disease register that incorporates data from various facets of diabetic care providers (101, 102). Similarly, the Icelandic DR screening programme was reported to have a good centralised system linking all diabetic care including DR screening data (61).

With the availability of good information systems, several studies have reported programmes venturing into the use of data to individualise screening invitations based on their risk for DR progression (103, 104). In one study, the viability of developing a model to optimise DR screening intervals for low risk DR patients using multiple logistic regression of data collected was demonstrated (102). In another study, patients undergoing routine follow up DR screening were sent invitations based each individual's risk for developing STDR, calculated using a predetermined algorithm. This mathematical algorithm utilises epidemiological data from a diabetes register of over 5,000 Danish patients for 20 years. The authors suggested that this innovation has saved health care resources by reducing the number of visits by 59% compared to fixed annual appointments (101).

##### 5. *Leadership/governance*

Health Policy is defined as 'courses of action (and inaction) that affect the set of institutions, organisations, services and funding arrangements of the health system' (103). Unambiguous evidence informed policies facilitates implementation and sets out planned activities that can be carried out by policy implementers. At the same time, policy formulation and implementation are distinct but intertwined processes (1), influenced by interests from different actors (3). Consequently, well-intentioned evidence informed policies might not achieve its intended goals. Therefore, the role

of monitoring and evaluation is critical to improve the chances of policies meeting their intended outcomes.

Systematic screening programmes are governed by a set of clinical and programme guidelines. In the UK, the National Screening Committee (NSC) sets out screening policies that govern all screening activities including DR screening (48). The NSC sets out quality assurance indicators that are reviewed periodically through a review process that includes various stakeholders. The key indicators used by the UK DR Screening programme cover multiple areas along the screening, grading and clinical management pathway including identification of screening cohort, invitation for screening, time to treatment, manpower and IT (Appendix 13). The DR review in the UK has highlighted shared challenges faced by programmes such as potential impact of organisational restructuring on meeting policy objectives; complexity of introducing new technologies to existing pathway (e.g. incorporating optical coherence tomography to detect MO); meeting expectations of the existing DR grading guidelines; meeting screening demands of increasingly heterogeneous population; meeting expectations and justifying use of existing technologies used for screening.

Opportunistic screening programmes currently lack established screening policies (58). In a review of diabetic retinopathy management guidelines (104), it was highlighted that variations exist in current DR guidelines which were mainly focused on developed country settings. The reviewers highlighted the need for a DR management policy formulation to focus on obtaining accurate epidemiologic data, ways to identify patients at risk, methods for retinal examination applicable to local context, setting up centres for photocoagulation, public health education programmes and the need to integrate DR management into a public health system.

## 6. Service Delivery

WHO defines service delivery as the way inputs are combined to allow the delivery of a series of interventions or health actions (60). DR services are preventive and curative at the different levels. At the community level, the emphasis is on assuring equity and accessibility. At the secondary and tertiary levels, management for the



treatment of DR, follow-up, counselling and supportive network between the varied providers (GP, endocrinologist, ophthalmologist, graders) are essential. Systematic DR screening programmes incorporate quality assurance as part of their core activities as a way of coordinating and ensuring that service provision meets agreed standards. The different indicators monitored by screening programmes will now be discussed.

*i. Screening coverage*

Screening coverage is defined as the proportion of the eligible population for screening that have been tested (46). Achieving high screening coverage rates are important in minimising DR progression amongst patients with diabetes in the population. Table 1-7 summarises the different studies that have reported screening coverage rates that have been dominated by the UK screening programmes. Despite the reported success of the Icelandic screening model (54), no studies on screening coverage based on this model have been found. However, centralised management of diabetes and close coordination between different diabetic care providers (diabetologists and ophthalmologists) has been documented a key feature of the Icelandic DR screening programme (61) that has enabled close monitoring of all patients with diabetes in Iceland. In addition, it is viewed that due to the differences in population demographics between the UK and Iceland, screening coverage may be a more pressing issue in the UK compared to Iceland.

Screening coverage rates of  $\geq 70\%$  of has been set by the UK National Screening Committee as the minimum standard for local screening programmes (96). In the UK, reported screening coverage rates have varied but have shown to improve over time. In 2000, screening coverage rates were 63% for a GP-led screening programme (40). In 2006, screening coverage rates as high as 93% were reported (97). These studies have highlighted the different predictors of screening coverage based on the UK experience.

### *Screening coverage and patient characteristics (age, diabetic status and socioeconomic status)*

Low screening coverage (poor attendance rates) has been associated with younger patients (<40) (99, 107), patients with type 1 (98) diabetes and patients with poor control of different diabetic risk factors (poor Hba1c and blood pressure control, smokers)(107, 108). In addition, several studies have highlighted socio-economic deprivation as a predictor of poor screening coverage (99, 107, 109). In one UK based study (105), patients living in a deprived area in Scotland have been associated with poor attendance. In another UK study (98), patients living in deprived areas of London were more likely to miss their screening appointments. In addition, this study also highlighted the importance of overall diabetic care as an important determinant of screening effectiveness.

### *Screening coverage and screening schemes*

The relationship between screening coverage and different screening models is unclear. In one UK study, GP-led screening models were linked to better coverage compared to the optometrist led-model (74). However, in another UK study, there were no differences in screening coverage reported between different screening models (no schemes versus digital camera scheme vs. optometry-led vs. mixed scheme) (96).

#### ii. *Screening uptake*

Screening uptake is defined as the proportion of patients attending screening of all those being invited (107). Various screening uptake rates based on UK DR screening have been reported in the literature from 79% (64) to 88.9% (98). In these studies, lower attendance rates were found amongst younger patients ( $\leq 40$  years), type 1 DM patients and patients living in socially deprived areas (99, 107, 111).

In a qualitative study, fear of laser treatment and guilt resulting from poor control of diabetes led to retinopathy being cited as the main deterrent for patients from attending screening (109). In another recent UK study, it was reported that GP

practices found it difficult to achieve higher uptake rates when faced with two or more of the major barriers, despite implementing strategies to improve uptake. These barriers included service related factors such as GP communication with screening services, contacting patients, integration of DR screening with other care providers, focus on the newly diagnosed diabetic patients and the perception of non-attenders. The authors also cited three additional factors which were viewed as more challenging related to the location of practices including level of deprivation; diversity of ethnicities and languages; and transport and access (110). These studies have emphasised the role of better patient education as a strategy to improve uptake (112, 114, 115).

iii. *DR treatment uptake*

Early intervention is important to prevent DR progression and sight loss amongst patients with STDR (39, 116). In developed countries, high treatment uptake rates have been reported from 85% (111) to 90.5% (50). However, treatment uptake rates in developing countries have generally been low, ranging from 45.5% (112) to 66.2% (114).

The common reason for poor treatment uptake in these studies was patients' lack of knowledge about DR (111), lack of awareness of the need for treatment and not being aware of the need to complete treatment (112). Fear of laser treatment was also highlighted as a reason for poor attendance at ophthalmic clinics for DR screening and treatment (112, 115).

iii. *Time lag between diagnosis and treatment*

Another indicator monitored by systematic screening programmes is the overall delay between the screening event and first laser treatment. The UK National NSC has stated that 95% of PDR referrals should be treated by laser within 4 weeks (100% by 6 weeks) and 95% of positively identified maculopathy referrals should be treated by 15 weeks (100% by 26 weeks) (48). In one UK study that audited compliance of DR screening programmes with the quality standards of National Diabetic

Retinopathy Screening Committee (79), found that only 26% of PDR cases detected had undergone laser treatment within 4 weeks and 30% of those with maculopathy had laser in less than 15 weeks. In another UK based National DR treatment audit (115), in 28.4% of cases referred for treatment, the overall wait for treatment from referral was more than 12 weeks.

*iv. Impact of DR screening on workload at tertiary centres*

A UK study described how attendance rates of successfully screened patients for further evaluation stabilised over the first five years of DR screening programme being implemented, suggesting the ability of the tertiary eye services to manage the case load (STDR cases) referred by the DR screening programme (116).

*v. Patient satisfaction*

Two studies assessed the satisfaction of patients with the DR screening programme. In a UK based study (74), 98% of patients reported being satisfied with the DR screening programme, irrespective of the model adopted (GP-led, optometrist with camera and optometrists with indirect ophthalmoscopy). A study in France (78) reported a higher willingness by patients to attend their next screening appointment if the examination was undertaken using a non-mydriatic camera compared to dilated funduscopy examination by ophthalmologists (99.1%). Patients also reported higher satisfaction levels when satisfaction was measured as duration of testing (96% camera vs. 82% examination) and induced visual impairment during screening due to dilation (86% camera vs. 66% examination).

*vi. Patient awareness*

In the UK study cited earlier (49), patient non-compliance was the main reason for non-attendance where 42% of patients failed to attend their follow-up appointments despite receiving screening invitation letters. In the French study (77), it was suggested that the reported high DR referral uptake rates was in part due to the introduction of the targeted DR screening programme which also included an intensive campaign to increase the level of awareness of diabetic complications and importance of regular eye examination amongst health professionals and patients.

*vii. Integrated care in diabetes management*

The risk factors (control of blood glucose and blood pressure) for DR progression and diabetes mellitus are similar. However, the management pathways of these two inter-related conditions are distinct. In one systematic review, it was suggested that cooperation between endocrinologists and ophthalmologists has contributed to the reduction of the incidence rate of DR in developed countries (26). Yet, the lack of integration of eye care services into the general health service is well recognised (117).

**Table 1-7 Studies comparing different coverage rates and predictors of attendance in the United Kingdom.**

Country, Year (Ref)	Coverage Rates
United Kingdom, 2002 (74)	<ul style="list-style-type: none"> <li>• Screening coverage rates: 63% (GP-led scheme), 24%(Optometry scheme)</li> </ul>
United Kingdom, 2004 (96)	<ul style="list-style-type: none"> <li>• Screening coverage: 63.2% (based on patients recording <math>\geq 1</math> retinal examination a year before the survey (any model),               <ul style="list-style-type: none"> <li>- Screening coverage by scheme did not differ by type of scheme</li> <li>- Screening coverage <b>highest</b> in patients treated with insulin and <b>lowest</b> in patients undergoing diet alone.</li> <li>- Screening coverage lower amongst younger patients</li> </ul> </li> </ul>
United Kingdom, 2004 (76)	<ul style="list-style-type: none"> <li>• Poor screening coverage rates reported (1.2% population over 12 months and 1.5% over 15 months)</li> </ul>
United Kingdom, 2006 (97)	<ul style="list-style-type: none"> <li>• Screening coverage (based on database system):               <ul style="list-style-type: none"> <li>o 1<sup>st</sup> year – 86%</li> <li>o 2<sup>nd</sup> Year – 93%</li> </ul> </li> <li>• Non-attendance major barrier to compliance of population based screening highlighting the importance of patient education.</li> </ul>
United Kingdom, 2006 (98)	<ul style="list-style-type: none"> <li>• Screening uptake: 88.9%</li> <li>• Attendance rates lower among young (<math>\leq 40</math> years), Type 1DM, living in deprived areas</li> <li>• Effectiveness of DR screening constrained by other factors (e.g. quality of overall diabetic care: those born outside UK (Caribbean-born) significantly more likely to develop retinopathy and importance of GPs is glycaemic and BP control.</li> </ul>
United Kingdom, 2008 (105)	<ul style="list-style-type: none"> <li>• 12% patients missed appointments; who were younger, longer diabetes duration, Poor HbA1c, BP control and smokers.</li> <li>• Social deprivation strongly associated with poor attendance (living in more deprived area)</li> <li>• Attendance at static sites better than mobile sites (travel distance between residence to screening site not affecting likelihood to attend)</li> </ul>

## 1.5 Diabetic retinopathy screening in Brunei Darussalam

### 1.5.1 Overview of Brunei Darussalam

Brunei Darussalam is situated on the northwest coast of the island of Borneo, facing the South China Sea. It has an area of 5,765 km<sup>2</sup> populated by an essentially young population (over 25% under 15 years of age) of 393,372 (2011,) growing at a rate of 1.7% (29). Gender distribution is 51.6% (males) and 48.2% (females). It has a multi-ethnic population comprising of predominantly Malays (66%) and Chinese (11%). Life expectancy at birth (2013) for males is 75.7 years and 78.4 years for females.

#### **Socio-economic status**

Brunei is an oil-based economy. The GDP per capita stands at US\$ 52,989 (2012), 66% of which comes from the crude oil and gas sector. The government provides free education and healthcare as well as subsidizing staple foods (rice, sugar and milk), housing, electricity, water and oil.

#### **Non-communicable diseases in Brunei**

Non-communicable diseases are the main cause of mortality and morbidity in Brunei. In 2012, cancers (23%), chronic heart diseases (13%), diabetes (10%) and cerebrovascular diseases (6%) contributed to half of the total deaths in Brunei and this has been the trend since 2000 (118).

### 1.5.2 Health system in Brunei

#### *Human resources in health*

The health care workforce per population in Brunei is amongst the highest in the region. However, in terms of medical doctors at least, there is continuing reliance on an expatriate health care workforce. Less than 1/3 of the doctors employed by the government and private sector are locals (118).

Amongst the challenges of employing expatriate workforce are the variation in training and no long-term retention programmes to support local leadership. This

has been identified as one of the challenges in the efforts to implement national clinical guidelines to manage diabetes (119).

### *Equipment*

The Ministry of Health, through an annual budget system provided by the Ministry of Finance, purchases all equipment and pharmaceuticals centrally. The Ministry of Health heavily regulates the use of medical and pharmaceutical products. There is currently no information on the distribution of equipment in use at the different health facilities (MoH) in Brunei Darussalam (119).

### *Health care financing*

Comprehensive health care services are provided free to all citizens. The annual health budget is allocated by the Ministry of Finance and is administered by the MOH. There has been an increase in both health budget and expenditure (Table 1-8). In 2012, the total health budget was B\$347 million (8% of the national budget); representing 1.64% of the country's GDP. In 2010, health expenditure (PPP) per capita (International \$) of Brunei was 1,503 compared to UK (3,433) and Iceland (3,230) (120).

**Table 1-8 Health care financing 2008-2011 (118)**

	<b>2008/09</b>	<b>2009/10</b>	<b>2010/11</b>
Total Health Budget (B\$ Millions)	264.4	286.8	295.4
Per Capita Health Budget (B\$)	664	706	713
Health Budget as % GDP	1.3	1.84	1.75
Total Health Expenditure (B\$ Millions)	322.1	317.4	318.7
Per Capita Health Expenditure (B\$)	809	781	769
Health Expenditure as % of GDP	1.58	2.03	1.89



### *Information system*

The Ministry of Health has implemented a stage-by-stage electronic patient management system (Bru-HIMS) since 2012. During this transition period, access to existing medical records is limited. At the time of the study, electronic records at the tertiary hospital were not linked to the electronic records at the primary health centres.

### *Governance*

Non-communicable diseases (NCDs) are a significant public health issue in Brunei (121). There have been several policies introduced by the Ministry of Health to address the prevention and control of NCDs in Brunei that has led to several initiatives at different levels of care. At the tertiary level, the National Diabetes Centre, Heart Centre and Cancer Centre have been set up. At the primary care level, health promotion policies have led to several on-going activities to promote healthy lifestyles and physical activity in the community.

However, findings from a review of NCD policies (119) suggest that implementation of policies is primarily top-down, leading to partial or little progress. The lack of co-operation between different departments in the Ministry of Health has hampered progress. Centrally, the role of the MoH has been mediating participation between departments. Internally, policy implementation has been affected by organizational (silos) and management issues (lack of resources). Externally, the MoH has recently acknowledged the need for cooperation with other agencies to combat NCDs at the national level, however, it is still too early to judge if any progress has been made.

### *Service Delivery*

The Medical and Health services are the two main departments responsible for the delivery of health care in the Ministry of Health (Table 1-9). The country is served by four government general hospitals, 16 health centres, 14 maternal and child health clinics, 8 travelling health clinics and four Flying Medical Services teams for remote areas. The strengthening of primary health care in 2000 has enabled patients with

chronic illnesses to be followed up at the primary health centres scattered throughout Brunei.

Comprehensive tertiary care, offering a wide range of medical and surgical services (28 different specialties and sub specialties), is provided at the Raja Isteri Pengiran Anak Saleha (RIPAS) Hospital, situated on a 32 acre site about 0.8 km from the capital. Due to the state funded health care private health institutions in Brunei are limited.

**Table 1-9 Organisational roles of the main departments in the Ministry of Health**

	Main Roles
Ministry of Health (Central Administration)	<ul style="list-style-type: none"> <li>• Formulation, monitoring and evaluation of health policies and strategies,</li> <li>• Development of Health Personnel</li> <li>• Management of Health Information System</li> <li>• General administration and finance</li> <li>• Health Promotion</li> </ul>
Department of Medical Services	<ul style="list-style-type: none"> <li>• Management of all hospitals</li> <li>• Nursing services</li> <li>• Laboratory services</li> <li>• Pharmaceutical services</li> <li>• Dental services</li> <li>• Renal Services</li> </ul>
Department of Health Services	<ul style="list-style-type: none"> <li>• Management of all health centres</li> <li>• Community Health Services</li> <li>• Border health (ports)</li> </ul>

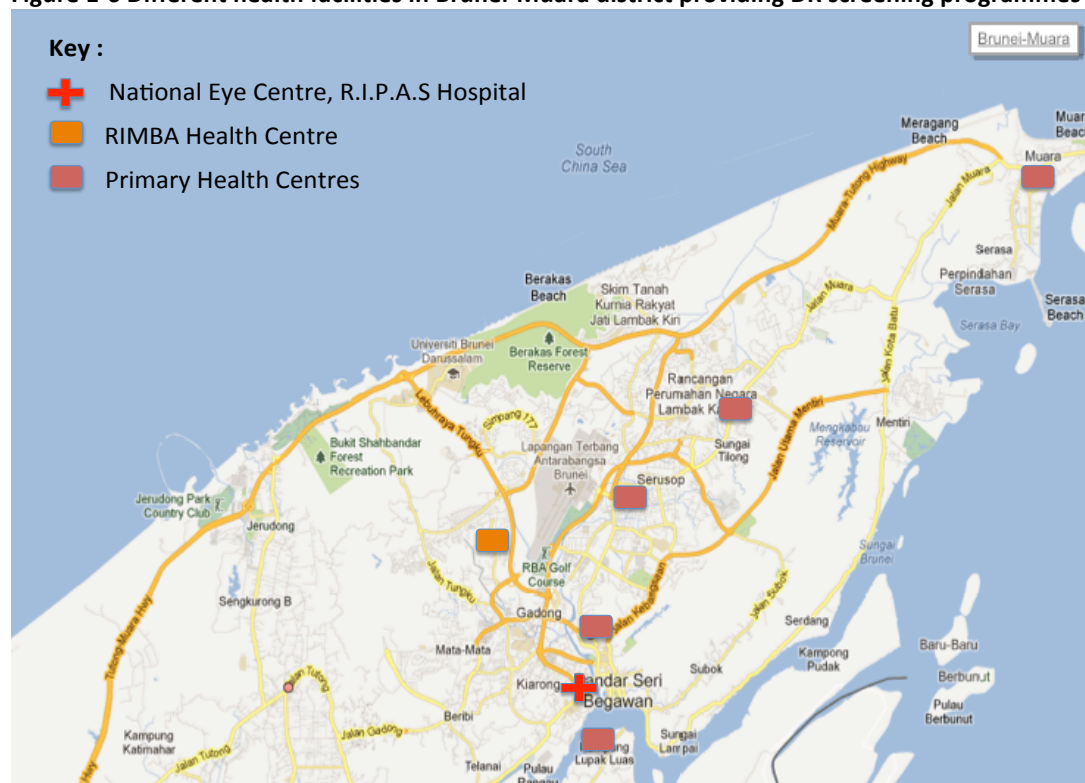
### 1.5.3 DR screening in Brunei Darussalam

In recognition of the public health importance of DR in Brunei, the Ministry of Health launched the “Brunei National Programme For Prevention of Diabetic Blindness. A Ten-Year Strategic Plan: 2011 to 2020”. The plan outlines key initiatives to strengthen the management of DR in Brunei and called for the introduction of a more systematic DR screening programme (122). However, there is limited information on how DR services are currently being provided. Therefore, it is unclear how DR screening should best be structured to meet the goals of this policy.

### Overview of the existing DR Screening programme

In 2006, a DR screening program was piloted in 7 health centres in one district (Brunei-Muara) in Brunei. Prior to this, all DR eye examination was conducted at the National Eye Centre, located in the main tertiary referral hospital (RIPAS). It was introduced in response to concerns amongst ophthalmologists regarding perceived low uptake of annual eye examinations by diabetic patients attending hospital based eye examinations. As part of the Ministry of Health's policy to decentralise primary health care in Brunei in 2000 (123), clinical management of diabetic patients shifted from hospital-based to GP-led care at primary health centres (Figure 1-6).

**Figure 1-6 Different health facilities in Brunei-Muara district providing DR screening programmes**



In the current DR screening programme, several DR screening sessions are run per week run by ophthalmologists at each of the six health centres. Diabetic patients are referred to these screening sessions by the GPs (from the same health centre) when they are first diagnosed. At screening sessions, patients undergo dilated funduscopy conducted by ophthalmologists using slit lamp bio-microscopy. Patients

with STDR are referred to the National Eye Centre for further examination and treatment.

*Perceived gaps in existing DR screening programme*

No studies have been conducted to evaluate the effectiveness of the existing DR screening programme since it was piloted in 2005. However, perceived concerns amongst ophthalmologists and programme managers about the quality of existing DR screening (lack of grading standards and standardised screening and referral pathways), screening coverage (no evaluation on attendance rates in the screenings sessions and referral rates of STDR cases has been conducted) and resource utilization (hospital-based ophthalmologists travelling to health centres to conduct screening sessions). There is an impetus within the Ministry of Health to address these concerns and develop an improved screening program. However, efforts to improve the existing programme should be supported by evidence.

## 1.6 Evaluation

### 1.6.1 Overview

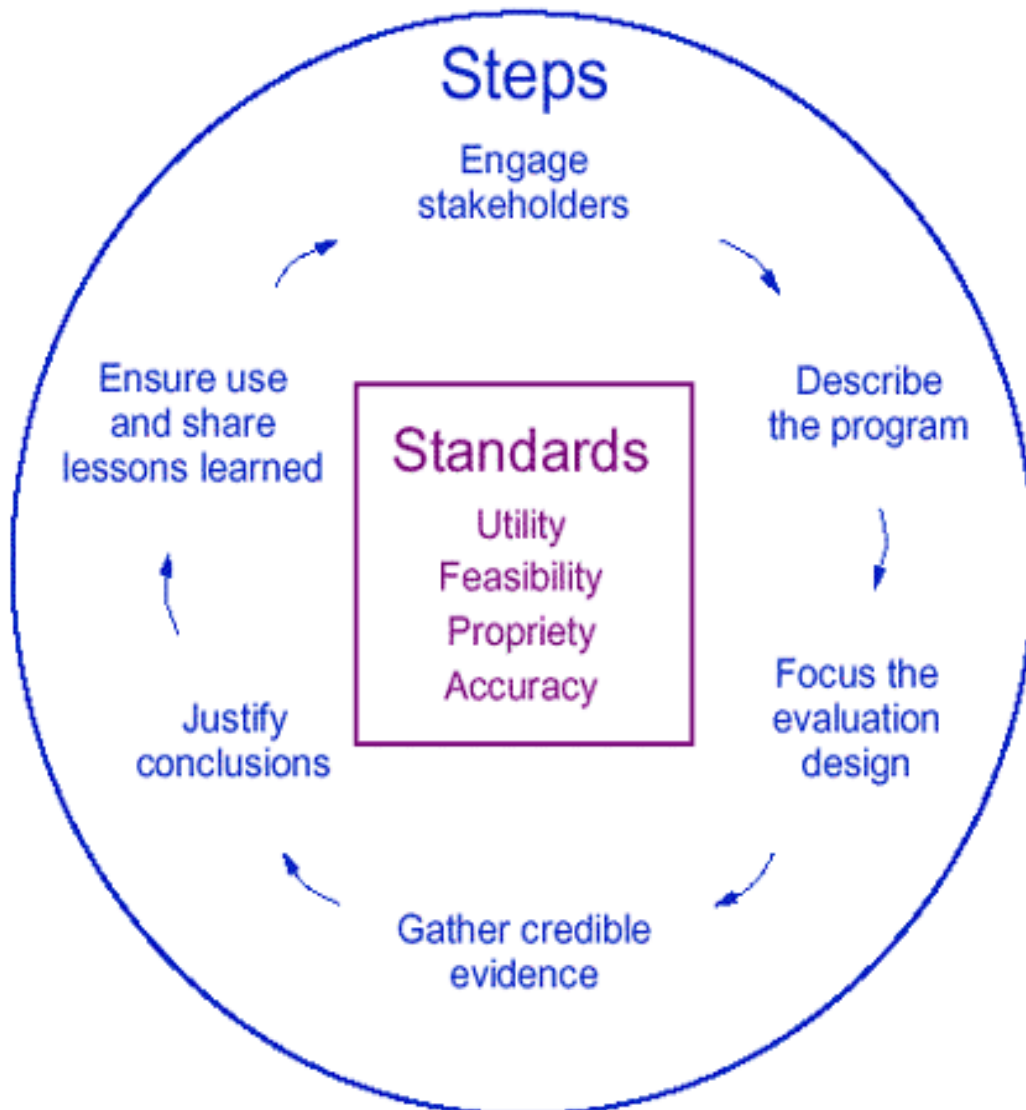
For this evaluation study, the following definitions have been adopted:

- *Evaluation* is defined as “examination of the worth, merit, or significance of an object” (124)
- A *program* is defined as “any set of organised activities supported by a set of resources to achieve a specific and intended result” (125)
- *Programme evaluation* is defined as “the systematic collection of information about the activities, characteristics, and outcomes of programs to make judgments about the program, improve program effectiveness, and/or inform decisions about future program development” (126)

#### *Framework for evaluating health programmes*

The CDC framework for programme evaluation has been adopted in this study to guide the methodological approach to evaluation (Figure 1-7). This framework outlines a cyclical process of stakeholder engagement, evaluation design, data collection, analysis and dissemination of findings guided by four set of key principles used in programme evaluation. This framework has been used to evaluate other public health programmes (127). The framework was selected due to its suitability for use in the context of this study (public health screening programme) that requires the understanding of different groups (GPs, DR screening team, Hospital based VR team) that serve different roles within the organisation but are assessed collectively using common goals (screening coverage, screening and treatment uptake).

Figure 1-7 Programme evaluation framework



Source: Centers for Disease Control and Prevention. [Framework for Program Evaluation in Public Health](#). *MMWR* 1999; 48 (No. RR-11).

### 1.6.2 Evaluation of DR screening programmes

A literature review of published studies that evaluated DR screening programme was conducted using the following search terms: diabetic retinopathy, screening, programmes and evaluation. Literature searches were run on PubMed, Medline, HEED, Cochrane Library and on several websites including WHO, National Institute for Clinical Effectiveness (NICE), UK National Screening Committee, International Association for Prevention of Blindness, European Diabetic retinopathy Group (easdec.org) and Google scholar. Only studies that focussed on evaluating population based DR screening programmes were included.

Of the 99 studies identified, only 14 studies were included for further review (Table 1-10). Most studies assessed screening coverage across different screening models (6/14), comparing screening sensitivity and specificity of different screening models (4/14). Only one study conducted a broad evaluation of their programmes.

In the study conducted in North London (74), the authors reported that all three different models of screening (GP led, optometrist-led with digital camera and optometrists-led with indirect ophthalmoscopy) met different standards set by different professional organisations in terms of screening intervals, positive predictive value, quality control and patient satisfaction. However, by the end of the 2 year pilot, screening coverage rates (proportion of patients screened out of the total number registered in to the district diabetes register) was still low at 40% and the study was not able to compare screening uptake rates (proportion of patients attending screening from the total patients invited) between the three models due to differences in the way data was collected by the different models. The authors therefore suggested that using diabetes district registers alone was not sufficient to improve screening uptake without using it as a call and recall system. In addition, the authors also suggested that based on responses from users (patients) in their study, sending one reminder to invite patients worked best for the call and recall system.

In terms of screening method, the study demonstrated that screening using indirect ophthalmoscopy alone was as effective as using a digital camera. This was in

contrast to the recommended screening guidelines outlined by the UK National Screening Committee (46).

### ***Summary***

The risk of vision loss due to DR in Brunei is likely to increase as the diabetes epidemic continues to grow. Early detection of sight threatening stages of the disease is key to preventing sight loss. Screening for DR was introduced in Brunei in 2006, but there were some concerns about the approach in terms of coverage, quality and resource use. The Ministry of Health has called for the introduction of a more systematic DR screening programme. However, it is unclear how DR screening should be structured without a detailed understanding of the processes, resources, and strengths and weakness of the existing DR screening model.

In 15 studies evaluating DR screening at the programme level, the majority were UK based. No comprehensive evaluation studies have been conducted in Brunei or elsewhere in the region. Evaluations of the UK programmes suggest that systematic DR screening results in increased screening coverage, uptake, better diagnostic accuracy supported with quality assurance initiatives and is cost-effective. However, due to differences in epidemiology, resource use and health systems, these findings may not be generalizable to the Brunei setting. There is a need to evaluate the screening programme in Brunei to understand how DR screening is currently being conducted, to identify what is working well and what is not, and finally to explore the enabling factors as well as barriers to help determine strategies towards making the existing system more systematic.



**Table 1-10 Published studies that have evaluated DR screening models included in this review**

Country, Year (Ref)	Study location	Study Objectives	Study methods	Screening model
United Kingdom, 2002 (74)	North London	To estimate screening coverage and uptake; to evaluate clinical findings of attended cases; to estimate positive predictive values of the different models across the three different models and to determine patient and providers satisfaction.	<ol style="list-style-type: none"> <li>1. 1.Database and case note review</li> <li>2. Postal questionnaire survey for patients</li> <li>3. Semi-structured interviews of KI</li> </ol>	GP-led vs. optometry (Camera) vs. optometry (indirect ophthalmoscope)
United Kingdom, 2002 (75)	St Helens and Knowsley	To compare sensitivity and specificity with National Standards	Audit against National Screening Standards	Trained optometrists using slit lamp with Volk Lens (78D) with standard reporting vs. ophthalmologists with same equipment.
Australia, 2003(62)	Kimberly Public Health Unit	To describe the screening programme and to evaluate how patients were identified for screening; to estimate the time taken for database entry and reporting of screening outcomes and time taken to call and recall patients for follow up screening.	Document review and DR screening database.	DR Screening done by credentialed aboriginal health workers and nurses using digital camera.
United Kingdom,	25 Health Authorities	To compare screening coverage	Study Questionnaire	a. 9 health authorities

2004 (96)	(HA) in England and Wales.	in different screening models.		<p>with no population based screening</p> <p>b. 6 health authorities with optometry scheme</p> <p>c. 6 health authorities with digital camera Scheme</p> <p>d. 4 health authorities with mixed scheme</p>
United Kingdom, 2004 (76)	Stockport	To determine screening sensitivity and specificity for STDR	Audit of hospital system and assessment of patients recalled for further assessment by Ophthalmologist.	DR screening by Optometrist (SL-BIO) vs. Ophthalmologists
France, 2005 (78)	North Paris,	To compare digital camera screening model against standard Ophthalmology eye examination	Study questionnaire for patient demography, clinical characteristics and patients' outcome and satisfaction	358 patients screened with non-mydratiac camera (experiment group) vs. 320 patients undergoing dilated eye fundus exam by ophthalmologist (control group)
United Kingdom, 2006 (97)	North Wales (3 local Health boards)	To compare screening coverage across different screening models; to identify barriers to meet national standards for screening coverage; to analyse hospital	Audit of central patient register	Optometry, Digital photography and hospital based examinations

		referral cases as a measure to understand population that have not been screened		
United Kingdom, 2006 (98)	South East London	To assess DR screening uptake; examine variations in attendance rates and screening outcomes	Cross-sectional study of centralised disease register 2003	Digital retinal screening programme
India, 2007 (128)	3 Districts South India	To compare screening outcomes in rural and urban settings	Survey and analysis of findings from screening camps	Binocular indirect Ophthalmoscope with 20D lens by retinal specialist
United Kingdom, 2008 (105)	Tayside Scotland	To identify factors that affect screening attendance in static and mobile DR screening models	Audit of regional diabetes population-based database, retinal screening and laser database and postcode.	Mobile Digital retinal camera at GP practice and static camera.
United Kingdom, 2009 (79)	Wakefield	To compare screening outcomes against 5 quality assurance targets	Retrospective audit of case notes	Quality assurance of screening programme digital photography by trained graders.
France, 2009 (77)	Burgundy, 72 areas with limited access to care	To assess screening outcomes of screening in rural population	Review of DR screening results	Fundus Photography by Orthoptists, interpreted by Ophthalmologist at reading centre
France, 2010 (129)	Burgundy	To assess influence of mobile DR screening model on overall annual DR screening attendance rates.	Audit of health information database	Mobile Digital Funduscopy and hospital follow up.
United	Scotland	To report yield of	Audit of clinical	Digital retinal

Kingdom, 2014 (116)		referable disease by referral reason for the first 5 years of the programme	diabetes database	screening programme
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## 1.7 Research aims and objectives

### **Aim:**

To evaluate the pilot health centre based DR screening programme in the Brunei-Muara District.

### **Objectives:**

1. To identify existing screening, grading and clinical management practices and describe the organisation of the diabetic retinopathy screening approach.
2. To estimate the DR screening coverage, the uptake of DR screening and treatment in the DR screening programme.
3. To analyse key characteristics and clinical findings of persons attending the DR screening programme.
4. To estimate the costs per person associated with the screening and treatment of DR.
5. To explore the perceived strengths and weaknesses of the DR screening programme and opportunities for enhancing the programme from the provider's perspective.

## 2. Methodology

### 2.1 Overview

Figure 2-1 and 2-2 outlines the different research methods adopted in this study. A mixed method approach was used which is defined as research designed for the collection, analysis and mixing of both quantitative and qualitative in a single study to understand an evaluation problem (130). In this study, structured questionnaires, semi-structured interviews, structured observations and quantitative analysis of diabetic retinopathy registry data, costing data, and routine (patient attendance) statistics at health centres and the National Eye Centre (NEC) in the Brunei-Muara district were conducted.

A mixed approach was selected to reflect the different needs of each objective within this evaluation study (Figure 2-2). By selecting a mixed approach, findings from different study objectives could be corroborated to achieve better validity in the findings (131). In addition, mixed methods will allow for a more comprehensive account of the findings, which would otherwise be incomplete through a qualitative and quantitative approach alone. This is achieved through the integration, linking and connection of the different methods employed, as well as in discussing the key findings (131).

Structured interviews were selected as a tool to assess any similarities or differences in the way DR screening and treatment was conducted and organised in the different health facilities included in this study. This approach was selected primarily to ensure the survey questionnaire was asked in a standardised manner to minimise interviewer related errors (131).

Semi-structured interviews (SSI) were conducted with key informants to obtain an in-depth understanding of the key strengths and challenges faced in the implementation of the DR screening programme in Brunei-Muara. This approach was chosen as it was felt that it offered better flexibility, by giving a chance for both interviewer and interviewees to clarify responses, which will contribute to better validity of findings. In addition, through probing and prompting, SSI will allow for

deeper exploration of issues, which may be viewed as ‘sensitive information’. This would otherwise be difficult to achieve through other research tools, such as focus group discussions.

Structured observations in the form of non-participant observations were conducted at the different health centres. Structured observations were not strictly guided by an observation schedule. Generally, observations of the flow of patients going through the different stages of DR screening in the clinics were recorded in a project diary. An excerpt of the project notes is presented in Appendix 11. This approach was selected to triangulate findings from structured questionnaires that have inherent weaknesses, such as the gap between stated behaviour and actual behaviour, variations in the way respondents understand key terms in a survey question, and many more (131).

### **Study setting**

The study was conducted in the Brunei-Muara district, where 70% of the Brunei population reside (33). The seven primary health centres where DR screening was introduced in 2006 are in this district (Table 2-1), as well as the National Eye Centre (NEC) where the majority of DR cases are referred and treated. No DR screening programmes currently exist in the other three districts in Brunei.

**Table 2-1 The seven health centres included in the study**

<i>Health centres in Brunei Muara district (see figure 1-6)</i>
<i>Gadong Health Centre</i>
<i>Silver Jubilee Sengkurong Health Centre</i>
<i>Bandar Seri Begawan Health Centre</i>
<i>Berakas ‘A’ Health Centre</i>
<i>Berakas ‘B’ Health Centre</i>
<i>Pengiran Anak Puteri HjH Rashidah Sa’adatul Bolkiah Health Centre</i>
<i>Muara Health Centre</i>

### **Stance of researcher**

I am the National Prevention of Blindness Coordinator for Brunei and an employee of the Ministry of Health. For the purposes of the study, I maintained an external stance to the study environment by adopting a non-participative role throughout the study. However, my role as the National Prevention of Blindness Coordinator may influence the participants' responses during interviews and observations. Efforts to minimise this effect included reassuring participants of my role as a postgraduate student and study confidentiality.

### **Consent and ethics approval**

Prior to administering the questionnaires and conducting semi-structured interviews, both written and verbal consent (Appendix 9) from key respondents were obtained. Informants were provided with an information sheet (Appendix 10) that outlined the objectives of the study, expectations of respondents and due to the nature of the study, (evaluation of health system) statements regarding study confidentiality were explicitly mentioned.

Prior to commencing the study, administrative and ethics approval from the Medical and Health Research Ethics Committee (Brunei)(Appendix 5) and the London School of Hygiene and Tropical Medicine were obtained (Appendix 6).



## 2.2 Overview of the different study methods

**Figure 2-1 Overview of the different study objectives**

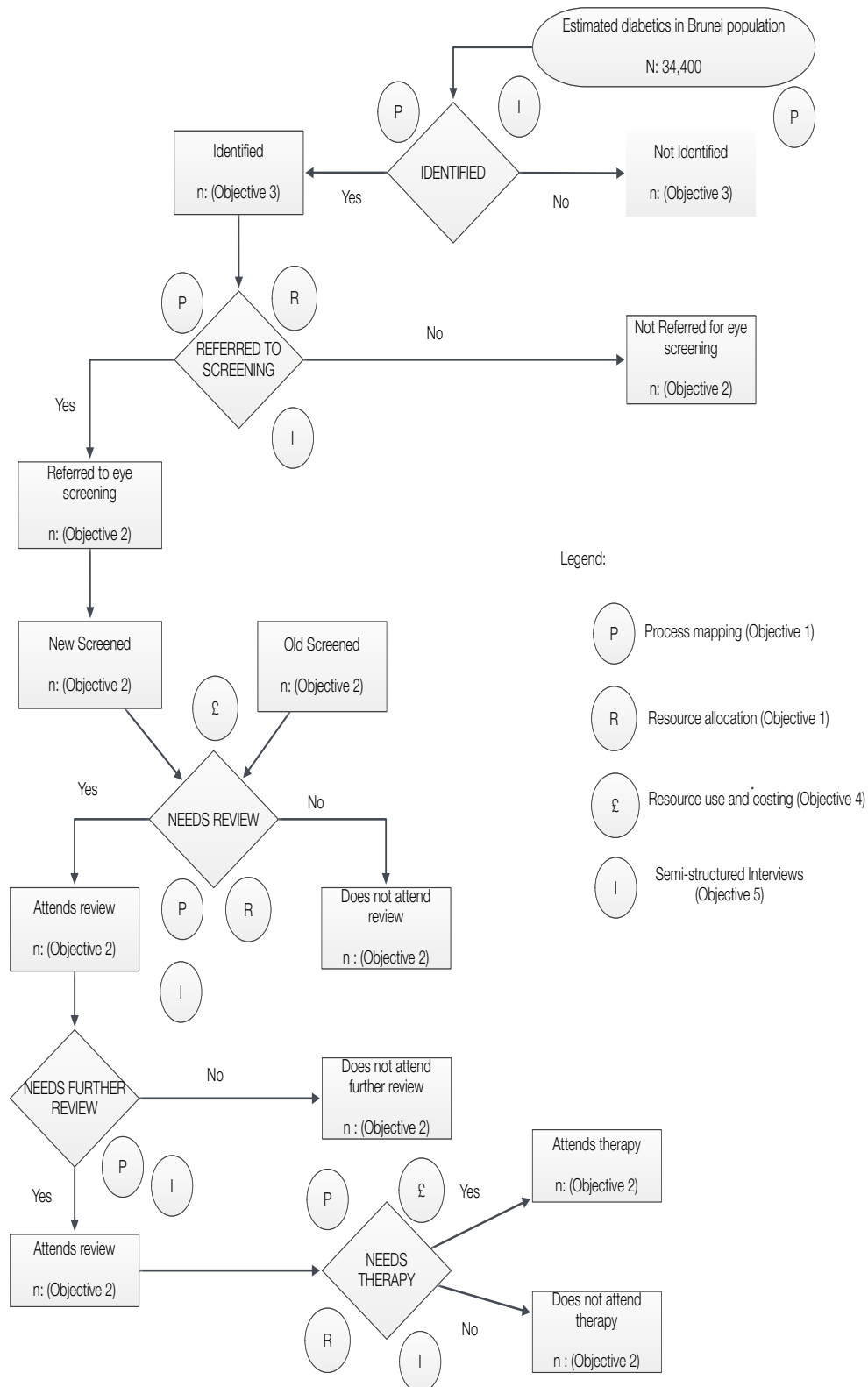
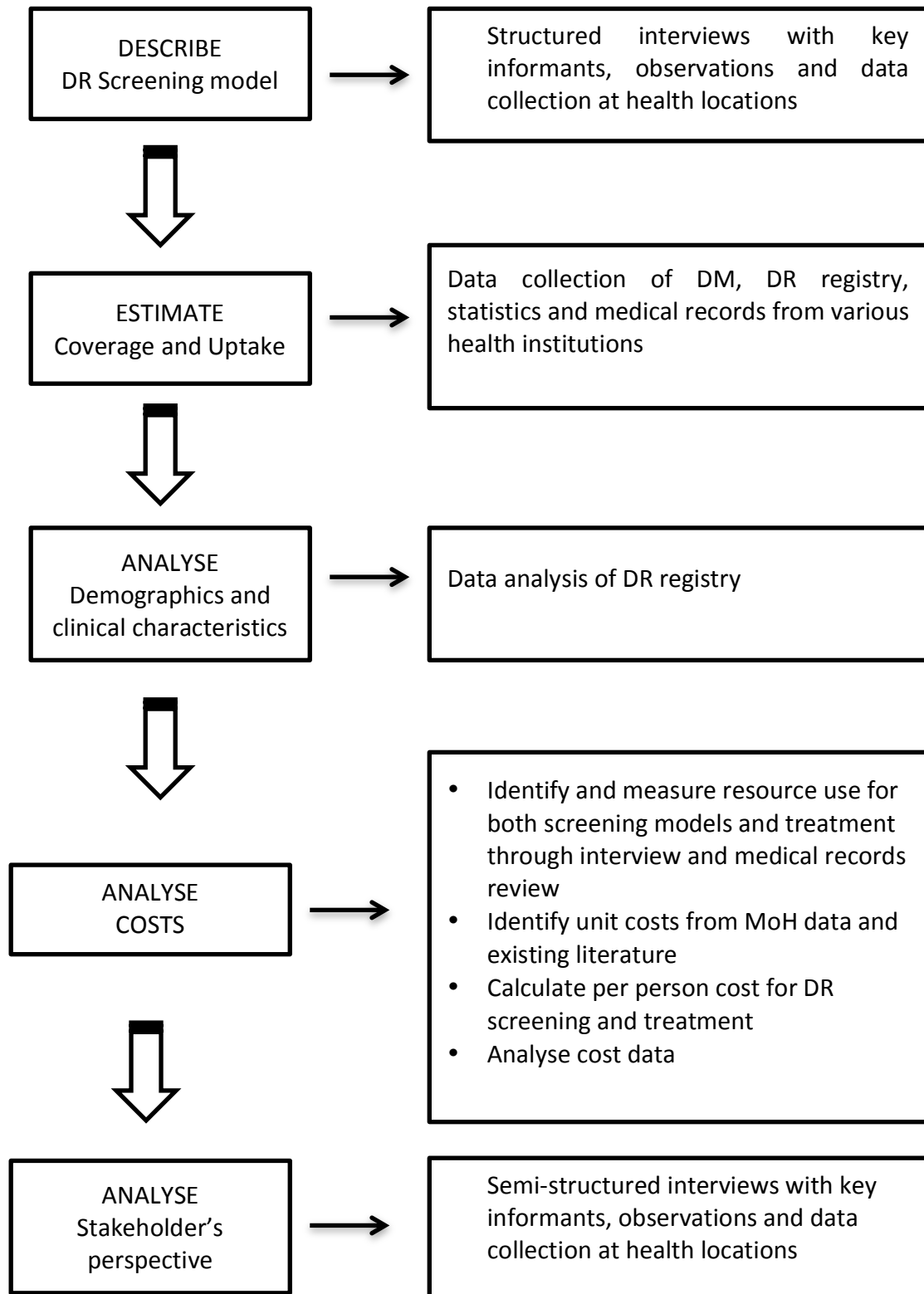


Figure 2-2 Flowchart showing different study methods by study objectives



## 2.3 Conceptual framework

### **Health systems strengthening (HSS)**

There is an increasing uptake of the health systems approach in evaluating health programmes. However, in a review of 106 evaluations in low to middle income country settings between 2009-2010, it was reported that the use of HSS as a study framework was still limited, where almost half of all evaluations focused on only one HSS building block (132). Similarly, in the context of eye care, the use of a health systems approach is almost non-existent (117).

The health systems framework will be used as an analytical framework to understand the context surrounding the delivery of DR screening and treatment in Brunei-Muara, with the six building blocks used as a framework to understand how DR screening and treatment processes apply to the different building blocks in order to identify any process gaps and limitations.

## 2.4 Study methods

2.4.1 Objective one: To identify existing screening, grading and clinical management practices and describe the organisation of the diabetic retinopathy screening approach.

### **Study methods**

Structured interviews with key informants were conducted to ascertain the key tasks/activities and the resources involved in the provision of the DR screening programme at the seven different primary health centres and in the delivery of DR treatment at the National Eye Centre.

### **Sampling**

These key informants were purposively sampled based on their involvement in the DR screening programme. This approach was chosen as the number of staff involved in DR screening is very limited. In addition, as staff members undergo rotation from one health centre and the unit of analysis is by health centre, it was appropriate to identify key personnel who understood the processes and practices at specific health centres.

Study participants included all GPs in charge at the health centre (seven GPs), all ophthalmologists who conducted screening examinations (seven ophthalmologists) and ophthalmic staff involved in the screening programme (five ophthalmic nurse/assistants) in Brunei-Muara district (Table 2-2).

Structured questionnaires were used during interviews. They were designed to understand the screening pathway, grading pathway, the clinical management of DR and the organization of DR screening services. In addition, to develop a detailed representation of DR screening and treatment processes from the perspective of three distinct groups, GPs, DR screening team and vitreo-retinal surgeons (Table 2-3), three different questionnaires (for specific groups) were piloted prior to use (Appendix 1, Appendix 2 and Appendix 3).

## **Data collection**

Structured questionnaires were administered through face-to-face interviews with key informants (Table 2-2) between October to November 2013. In addition to the structured questionnaires, structured observations were conducted at all the seven primary health centres and the National Eye Centre. Findings were recorded in a project diary kept throughout the site visits. This information was used to supplement the understanding of key activities and resources involved in the screening pathway.

## **Analysis**

Results of the structured interview questionnaires were analysed and compared with findings from structured observations to identify key processes and resources used in DR screening and treatment. The key processes were presented in a flowchart to reflect the process at each stage of screening and treatment. In addition, the key features of each process and resources used at different health centres were tabulated to contrast the findings at each health centre.

**Table 2-2 Key informants identified for structured questionnaire interviews (by cadre and role in the DR screening programme).**

	<i>Job Title (Number*)</i>	<i>Role in the screening programme</i>
1	National Programme for Prevention of Diabetic Blindness Coordinator (One)	Coordinates all DR screening activities
2	Ophthalmologists involved in screening at each health centre (Five)	Conducts eye examination in the screening programme
3	Vitreo-retinal specialist (One)	Conducts DR treatment
4	Ophthalmic nurse (In-charge National Eye Centre - One)	Supervises all ophthalmic nurses and assistants; organises resources for all DR screening activities at primary health centres and manages ophthalmic treatment activities in the NEC
5	Ophthalmic nurses and assistants involved in screening at each health centre (Four)	Conducts case history, VA assessments, dilation and manages DR screening appointments, referrals and statistics
6	General Practitioners (In-charge at each health centre - Seven)	The administrative head of all GPs at each health centre; diagnoses, manages and refers DM cases for eye screening

\* Number denotes number of personnel interviewed.

**Table 2-3 Screening pathway, grading pathway and clinical management from different stakeholder perspective.**

Screening pathway	Perspective
<ol style="list-style-type: none"> <li>1. To establish how diabetic patients are identified by GPs at each health centre.</li> <li>2. To establish how data on diabetic patients is managed (e.g., whether a list of diabetic patients is kept at the health centre and the process involved in managing the list).</li> <li>3. To assess the method and type of information conveyed to diabetic patients at primary health centres on the following key points: <ul style="list-style-type: none"> <li>• Information on DR as a consequence of DM</li> <li>• Understanding the importance for annual screening</li> <li>• Patient Information on DR screening process</li> </ul> </li> <li>4. To understand the processes involved for GPs referring diabetic patients to DR screening at each primary health centre (e.g. when are they referred, how often and by whom).</li> </ol>	GPs at health centres
<ol style="list-style-type: none"> <li>5. To understand key processes involved in DR screening of diabetic patients referred by their GPs to the health centre - from the time the patient reports for attendance on the day of screening through to when the patient leaves the health centre.</li> </ol>	DR Screening team (ophthalmologists, ophthalmic

6. To document the DR screening sessions, personnel and resources involved in conducting all processes identified in step	nurses/assistants) perspective at each health centre
Grading pathway	
<p>7. To establish details of the screening test used in diagnosing DR (who conducts the examination and how)</p> <p>8. To establish the type of DR grading system used at the health centre.</p> <p>9. To assess the present application and use of grading protocol by screeners to make decisions to refer for treatment or follow up.</p> <p>10. To understand ophthalmic management and referral procedures for patients who are identified with No DR, background DR and STDR.</p> <p>11. To understand administrative aspects of referral to the NEC and to list key resources required for further ophthalmic evaluation and management at the main hospital.</p> <p>12. To estimate how long patients have to wait for an appointment at the NEC following a positive screening test time taken to refer STDR cases</p>	DR Screening team (ophthalmologists , ophthalmic nurses/assistants) perspective at each health centre
Clinical management of cases referred to hospital.	
<p>13. To understand the process of retinal examination conducted at the NEC (method and grading scheme) to confirm the screening test results.</p> <p>14. To establish mode of treatment adopted by vitreo-retinal team in the management of STDR cases (PDR and MO).</p> <p>15. To list key processes involved in delivering the different modes of treatment identified in step 13 (e.g. type and number of treatments given to treat PDR and MO, who treatments are delivered by).</p> <p>16. To document personnel and other resources involved and estimated time taken to conduct all processes identified in step 15.</p>	Vitreoretinal team

2.4.2 Objective two: To estimate the DR screening coverage, DR screening uptake, DR referral uptake and DR treatment in the DR screening programme in the Brunei-Muara district.

**A. Screening coverage**

*i. Study Methods*

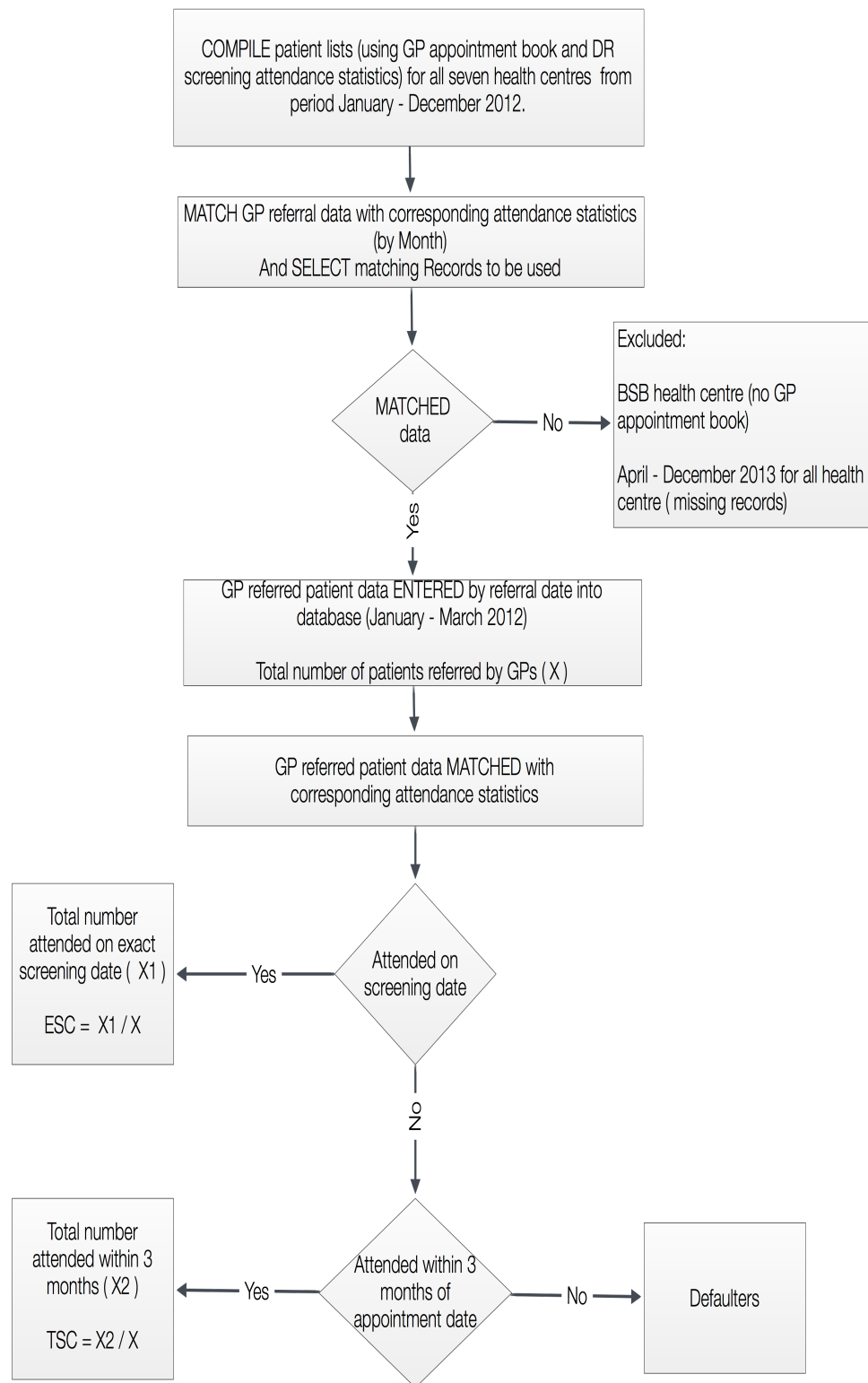
Screening coverage was defined as the proportion of diabetic patients referred by GPs for diabetic eye screening that have undergone at least one eye examination at the same health centre.

The process of estimating screening coverage is outlined in Figure 2-3. Patient lists from the respective data sources (see below) for all seven health centres from January – December 2012 were compiled and then matched for availability of records (appointment date on the referral appointment book with the corresponding data on patient attendance date statistics). Due to incomplete data (unmatched records), only records for six health centres and a time period between January – March 2012 were included. All patient data (from GP appointment book - see below) for the three month period were extracted and entered into a database. Using the patient attendance statistics for the same data period (January – March 2012), patient attendance or absence was determined (all patients attending DR screening sessions were recorded in the attendance statistics form). The same process was repeated for an extended time period (January – June 2012) to determine any patients who have attended within 3 months after the original appointment date given by the DR screening team.

Exact screening coverage (ESC) was calculated by dividing the total number of GP referred patients who attended the screening session (X1) with the total number of GP referred patients to the same health centre (X) between January – March 2012.



**Figure 2-3 Process for estimating screening coverage**



ESC - Exact screening coverage  
TSC - Total Screening Coverage

Total screening coverage (TSC) was calculated by dividing the total number of GP referred patients who attended the screening session (Y1) between January - June 2012 with the total number of GP referred patients to the same health centre (X) between January - March 2012.

*ii. Data sources*

*GP to DR screening referral appointment book*

The GP to DR screening referral appointment book is a manually kept (handwritten) appointment book used by GPs to refer diabetic patients, under their clinical care, for eye examination. Information recorded in this appointment book includes:

- Date of appointment
- Medical Record Number
- Name
- Gender
- Year of Birth
- National identification number
- Contact telephone number

*DR screening attendance form*

The DR screening attendance form records all patients that have attended DR screening sessions at any of the seven primary health centres. It is a manually handwritten form that records the following information:

- Date of appointment
- Attending eye doctor
- Health centre
- Medical record number/National Identification card number
- Year of Birth
- Race (ethnic background)
- Presenting visual acuity (right and left eye)
- Patient reported information on the following:

- o Diabetic status
- o Duration of diabetes
- o Presence/absence of hypertension
- o Presence/absence of hypercholesterolemia
- o Presence/absence of hypertension
- o Presence/absence of renal problems
- o Current smoker or not
- Latest biochemical laboratory tests for the following:
  - o Fasting blood sugar
  - o Hba1c
  - Contact telephone number
  - Intraocular pressure readings (when indicated)
  - Diagnosis
  - Duration of next review.

*iii. Time period*

The time period selected for data collection was January – December 2012 to account for seasonal variations that may occur throughout the year (e.g. public holidays) and was viewed as the most recent and best available data. From January 2013, the NEC trialled a new data collection system for DR screening as part of the introduction of a new DR grading system (REPAS Grading System), due to the interim nature of the project, access to this data was limited.

## **B. Screening uptake**

### *i. Methods*

Screening uptake was defined as the proportion of diabetic patients identified as having NSTDR at screening that have attended follow up eye examinations the following year.

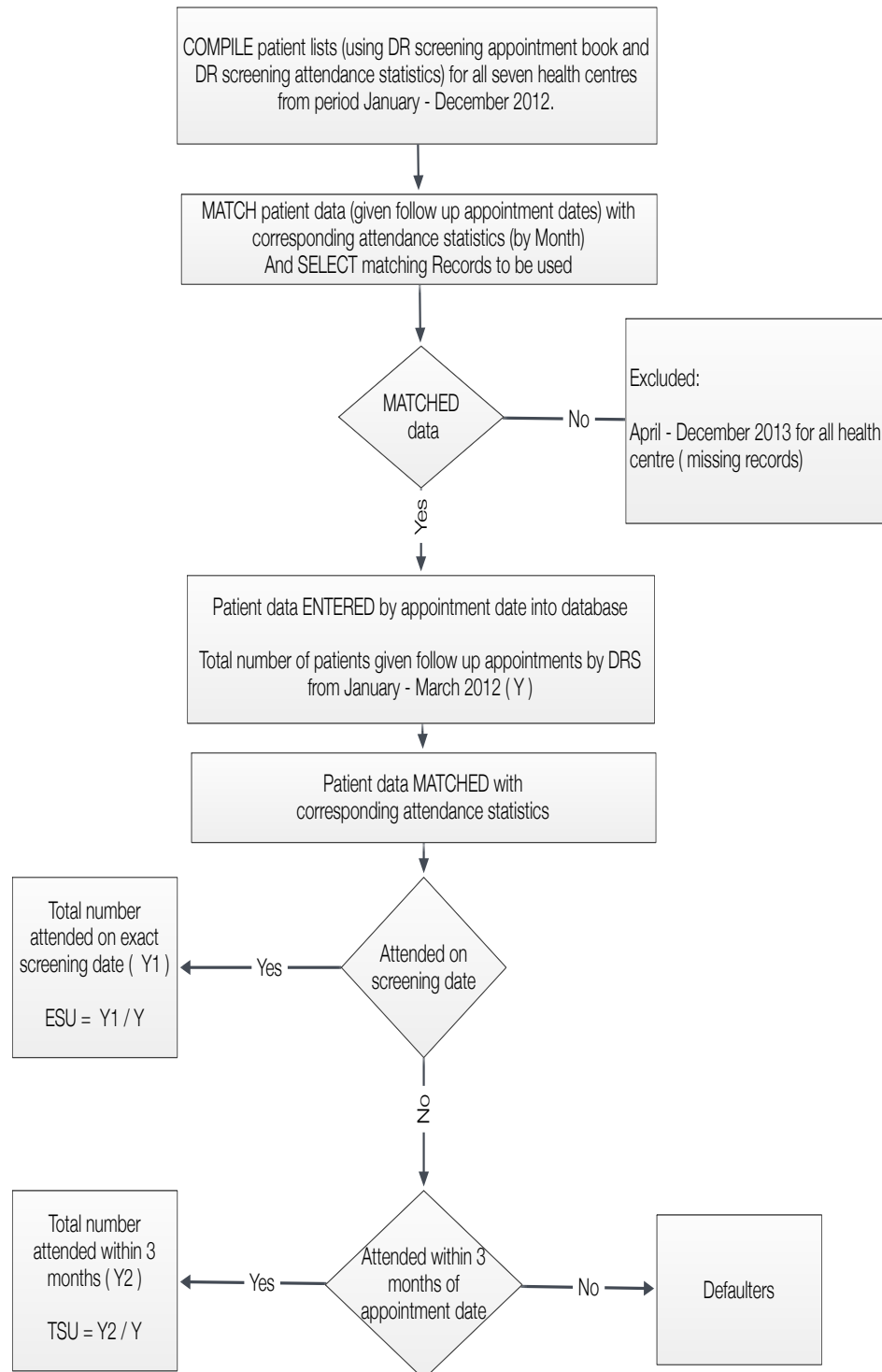
The process of estimating screening uptake is outlined in Figure 2-4. Patient lists from the respective data sources (see below) for all seven health centres from January – December 2012 were compiled and then matched for availability of records (appointment date on DR screening appointment book with the corresponding data on patient attendance date statistics). Due to incomplete data (unmatched records), only records for a time period between January – March 2012 were included. All patient data (from DR screening appointment book - see below) for the three month period were extracted and entered into a database. Using the patient attendance statistics for the same data period (January – March 2012), patient attendance or absence was determined (all patients attending DR screening sessions were recorded in the attendance statistics form). The same process was repeated for an extended time period (January – June 2012) to determine any patients who have attended within 3 months after the original appointment date given by the GPs.

ESU was calculated by dividing the total number of patients who have been given follow up appointments that have attended the screening session (Y1) with the total number of patients who have been given follow up appointments by the DRS at the same health centre (Y) between January – March 2012.

TSU was calculated by dividing the total number of patients who have been given follow up appointments that have attended the screening session (Y1) between January – June 2012 with the total number of patients who had been given follow up appointments by the DRS at the same health centre (Y) between January – March 2012.



**Figure 2-4 Process for estimating screening uptake**



ESU - Exact screening Uptake  
TSU - Total Screening Uptake

*ii. Data sources*

*DR screening appointment book*

The DR screening appointment book is a manually kept (handwritten) appointment book used by the DR screening team (ophthalmologist and ophthalmic nurse/assistants) to record all follow up eye examinations for diabetic patients that have been identified as either having no DR or NSTDR. Each respective primary health centre manages their own appointment list and is updated by ophthalmic nurses/assistants allocated to each health centre.

Information recorded the appointment book includes:

- Date of appointment
- Medical record number/National Identification card number
- Year of birth
- Contact telephone number
- Diagnosis

*DR screening attendance form (see Page 79)*

*iii. Time period*

The time period selected for data collection was January – December 2012 to account for seasonal variations that may occur throughout the year (e.g. public holidays) and was viewed as the most recent and best available data. From January 2013, the NEC trialled a new data collection system for DR screening as part of the introduction of a new DR grading system (REPAS grading system), due to the interim nature of the project, access to this data was limited.

### **C. DR referral and treatment uptake**

#### *i. Methods*

DR referral uptake was defined as the proportion of STDR cases identified by DR screening and referred to the vitreo-retinal team at NEC for further evaluation. DR treatment uptake was defined as the proportion of STDR cases identified by the vitreo-retinal team at NEC as needing treatment (laser photocoagulation) that have undergone treatment.

The process for estimating DR referral and treatment uptake is outlined in Figure 2-5. All STDR patients recorded in patient attendance statistics for all the seven health centres (January – December 2012) were compiled and patient data was entered into a database. The data were then matched with patients recorded to have undergone laser treatment at the NEC between January – July 2013.

DR referral for uptake was estimated by dividing the total number of STDR patients that were referred to NEC for further evaluation by the total number of STDR patients referred to the NEC in 2012 by the DR screening programme (Z).

DR treatment uptake was estimated by dividing the total number of STDR patients who had laser photocoagulation (Z') by the total number of STDR patients referred to the NEC in 2012 by the DR screening programme (Z).

#### *ii. Data sources (DR screening attendance form – see page 79)*

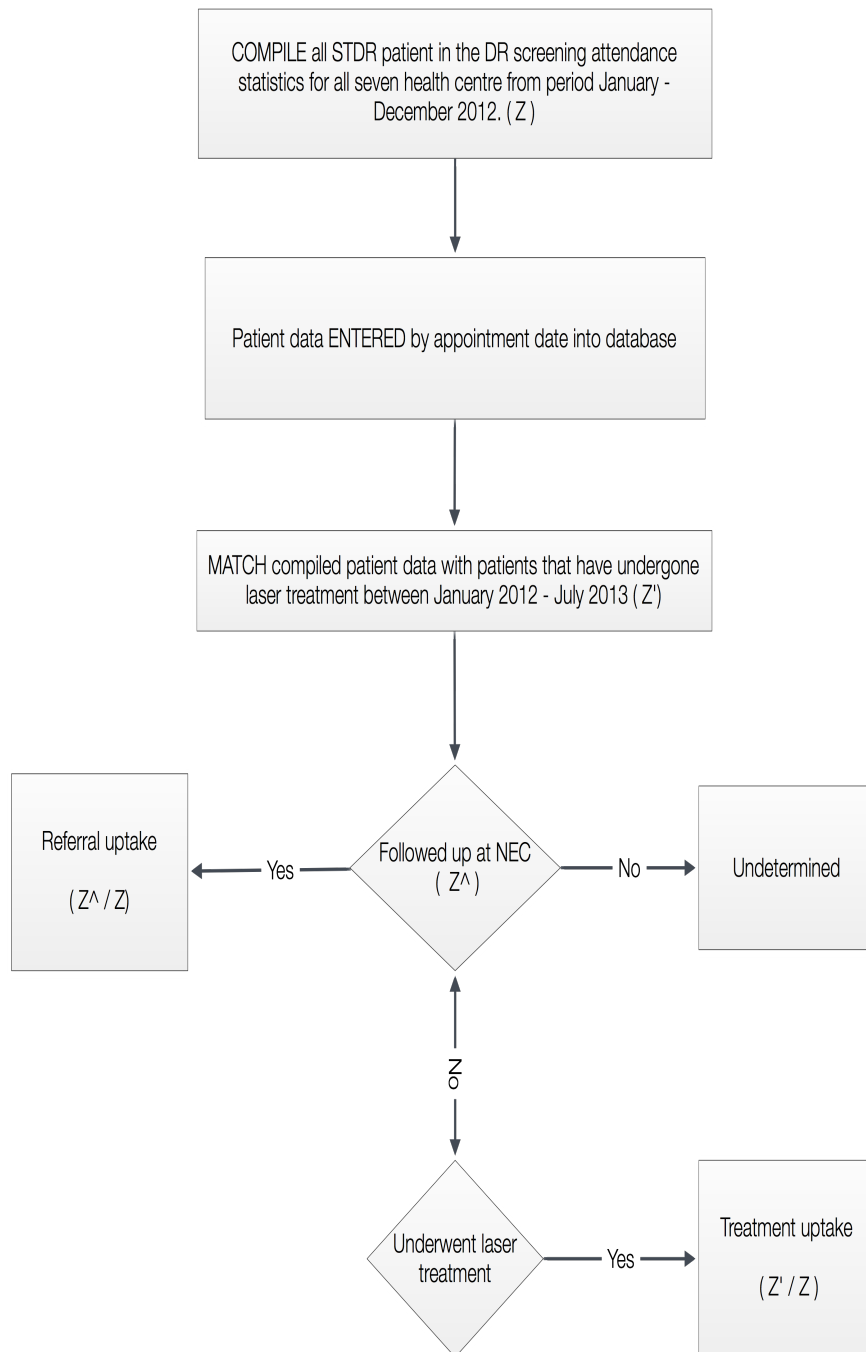
##### *Laser photocoagulation logbook (NEC)*

The laser logbook lists all laser procedures conducted in the NEC including laser photocoagulation cases. The list includes the following information:

- Patient name
- Age
- Gender
- Medical Record Number
- Diagnosis
- Details of laser procedure



**Figure 2-5 Process for estimating referral uptake and treatment uptake**



### 2.4.3 Objective three: To analyse key characteristics and clinical findings of persons attending the DR screening programme

In this study, the “worse eye” was chosen to define the retinal status based on the DR grading classification described in tables 1-3 and 1-4. STDR is defined as the presence of either neovascularization and/or vitreous haemorrhage (PDR) and/or with the presence of MO.

#### *i. Study method*

Descriptive analysis of DR registry data

DR registry data collected from 1996 – 2008 were used as source data. Information from the registry was extracted using specific queries function in Microsoft Access. Descriptive analysis of people in the DR register will be conducted to describe the following:

- Age, gender and ethnic group distribution of diabetic patients
- Proportion of diabetics that have undergone cataract surgery (cataract is often earlier in diabetics)
- Proportion of patients at each level of DR
- Proportion of patients by DM type
- Proportion of patients with hypertension
- Proportion of patients with hyperlipidaemia
- Proportion of patients with renal disease
- Mean DM duration
- Mean FBS
- Mean HbA1c duration

Measures of association (chi-square test and multivariate logistic regression) will be conducted to compare the following factors by level of DR and health centre:

- Proportion of patients with hypertension
- Proportion of patients with hyperlipidaemia
- Proportion of patients with renal disease

- Mean age
- Mean DM duration
- Mean FBS duration
- Mean HbA1c duration

Data analysis (chi-squared test and multivariate logistic regression) was conducted using STATA 10 statistical software(133).

*ii. Diabetic Retinopathy Registry (2008 – 2012)*

A DR registry was initiated in 2006 that aimed to register all patients attending the DR screening programme at the seven primary health centres in the Brunei-Muara district. Between 2008 – 2012, demographic and clinical information of 8,500 patients has been collected. Registered patients included the following:

- New DM cases referred by GPs to DR screening in each health centre
- DR cases that have been attending the annual eye examination (DR clinics) at the main eye referral centre.

The DR registry was recorded using Microsoft Access and the Brunei National Identification Card (IC) number was used as a unique identifier in the database to prevent any duplication of data entry. The demographic details collected for each registered patient are as follows:

- Age
- Gender
- Ethnicity
- National Identification Card number
- Medical Record Number
- Contact number
- Date and location of registration
- Nearest health centre (to their place of residence)

### *Clinical information*

Clinical data collected (established through clinical examination and biochemistry laboratory tests) for each registered patient are as follows:

- Monocular visual acuity (with available correction)
- DR status (dilated fundus examination using Airlie House grading system)
- Follow up treatment plan (and screening frequency)
- FBS
- Hba1c

In addition, the following self-reported clinical information for each registered patient was collected through case history:

- Type of DM
- DM duration (years)
- Presence of hypertension (Yes/No)
- Presence of hyperlipidaemia (Yes/No)
- Presence of renal disease (Yes/No)
- Current smoking status (Yes/No)

#### 2.4.4 Objective four: To estimate the costs per person associated with the screening and treatment of DR.

##### *i. Study method*

###### *Health provider costing*

A costing study was conducted from the perspective of the Ministry of Health, the main health care provider in Brunei (14). The screening cost data collection focused on one health centre (Gadong health centre), the largest and most established health centre in the Brunei-Muara district. The tertiary eye referral centre (National Eye Centre) based in the same district was the focus for costing DR treatment.

Throughout this study, the economic definition of costs (also known as opportunity cost) was adopted, whereby costs of all input resources were included, irrespective of whether it has direct financial cost implications to the program (30). All prices were collected in Brunei dollars (B\$) and prices were then converted to British Pounds Sterling on the basis of average exchange rate (2012) £1 = B\$ 1.97.

###### *Micro-costing approach*

An ingredients approach to costing was used whereby, total costs to deliver an intervention were calculated based on the total amount of resources consumed multiplied by the unit value (or price) of each resource consumed. Resources included capital items (e.g. buildings, land, equipment) and recurrent resources, staff, consumables (e.g. medications) and utilities (e.g. electricity and water).

###### **Fixed Costs**

Capital costs (equipment, buildings and land) are assets that are used over a long period of time. To account for depreciation of the assets (equipment and buildings) over time and opportunity costs, capital cost items were annualised (35) using a discount rate of 3% (36). The 3% discount rate was used in the absence of any standard recommendation for discount rates by the Ministry of Finance. Similar rates have been used in similar costing studies (5).

The annual cost method was used to annualise capital cost items. It is an accounting method that calculates the cost per year of owning and operating an asset over its entire lifespan (36).

#### *Annualised building costs*

Building costs and land costs used for DR screening and treatment were estimated using annualised rental costs for health centre (screening) and the NEC (treatment). Annualised building costs were calculated by dividing the value of the building by the annualisation factor. The annualisation factor used was 25.73 derived from a standard table (appendix 5) using a discount rate of 3% and an estimated life span of the building of 50 years.

The value of the building was estimated by multiplying the cost of building with the total floor area used for DR screening and treatment, respectively. The rate of £843 (rounded off) per m<sup>2</sup> was used as the cost of building. This is the typical rate used by the Estate department, Ministry of Health in budgeting for building outpatient clinics that take into consideration both mechanical and engineering building costs (6).

#### *Annualised equipment costs*

Equipment used for DR screening and treatment in Brunei-Muara district was identified through structured interviews and this will be described in later sections (results section: resource allocation). Prices for all ophthalmic equipment were obtained from the most recent financial data (2012) recorded by the Procurement Section, Ministry of Health.

Annualised equipment costs for DR screening (Gadong Health centre) and treatment (NEC) were calculated by dividing the value of the equipment by the annualisation factor. The annualisation factor used was **8.5302** derived from a standard table (Appendix 5) using a discount rate of 3% and an estimated life span of the equipment of 10 years. All medical equipment was assumed to have a 10 year lifespan. This assumption was used as it has been adopted in similar costing studies (91).

### **Variable Costs**

Variable costs such as staff salaries (e.g. ophthalmologists and other eye cadres); consumables (e.g. eye drops) were identified through interviews with key informants. Details of staff and estimated usage of consumables have been described in other sections (see section 3.2.5). Prices for variable costs were based on the most recently available MOH financial data (2012).

#### *Staff costs for DR screening and treatment*

Total staff costs per screening day and treatment day were calculated using the basic rate of pay formula (Equation 1). This formula, adopted from the Ministry of Manpower, Singapore's employment practices, has been used to calculate daily pay rates that accounts for wage adjustments and increments that an employee is entitled to under his/her contract of service. This method was selected due to its similarity with employment pay rate practices in the Ministry of Health, Brunei. Monthly salary used in the calculation was based on typical pay rates for ophthalmologists, ophthalmic nurses and assistants employed by the Ministry of Health, Brunei.

$$\text{Basic Rate of Pay: } \frac{12 \times \text{Monthly Salary}}{52 \times \text{Average number of days spent on screening per week}}$$

**Equation 1. Basic rate of pay formula, adapted from Ministry of Manpower, Singapore<sup>(134)</sup>**

#### *Estimated shared costs, utility, maintenance and administrative sundries costs.*

Shared overhead costs (e.g. medical records, porter services, laundry, etc.), cost of utilities (e.g. water and electricity bills), equipment maintenance costs and administrative sundries (e.g. stationery) for health centre and hospital-based activities were estimated as 10% of the total building costs. This approach was recommended by the health economist member of the DrPH thesis review committee.

### *Costs per person for DR screening and treatment*

Details on the calculation of cost per person for DR screening and DR treatment are as follows:

- *Screening costs*

Total per patient costs was calculated as the sum of screening-related per patient costs and per patient overhead costs. Screening-related costs per patient were estimated by total screening specific costs (staff, equipment and consumables) divided by the number of patients screened over a one-year period (2012) at the Gadong health centre. Overhead costs per patient were estimated by dividing total overhead costs by the same number of patients screened during the same period.

Data on quantity of resource use were estimated through interviews with key informants and based on Gadong health centre records in a 12-month period (2012). This data will be described in detail in a later section (section 3.2.5).

### *Staff costs*

Total staff costs (ophthalmologist and ophthalmic assistants) per screening day at the Gadong health centre were estimated using the basic rate of pay formula described earlier (Equation 1; see page 91). The monthly salary used in the calculation was based on typical pay rates for ophthalmologists and ophthalmic assistants employed by the Ministry of Health, Brunei(123).

### *Annualised equipment costs*

Total annualised equipment costs (visual acuity chart projector, slit lamp bio-microscope, super-field lens, indirect and direct ophthalmoscope) costs for DR screening at the Gadong health centre were estimated using the annual equipment cost formula described earlier (see Page 90). The unit prices of the equipment were based on individual equipment prices for 2012 provided by the procurement section of RIPAS hospital, Ministry of Health.



### *Consumable costs*

The main consumable item used for DR screening at RIMBA health centre was dilation eye drops (Mydriacyl). The annual cost of consumables used in DR screening was estimated by multiplying the unit cost of Mydriacyl (2012, MoH prices) by the estimated quantity of units used per month. The usage estimate was provided by the nurse-in-charge of the DR screening programme.

### *Annualised building costs*

Annualised building costs of the examination room and triage room used was calculated by dividing the value of the building cost by the annualisation factor. Other assumptions and rates used to calculate the annualised building costs have been described earlier.

- *Treatment Costs*

Total cost per patient treated was calculated by adding the total of treatment-related per patient costs with per patient overhead costs. Treatment-related costs per patient were estimated by total treatment specific costs divided by the number of patients treated (laser photocoagulation) over a one-year period (2012) at the NEC. Overhead costs per patient were estimated by dividing total overhead costs by the total number of patients treated during the same period.

For the purpose of this model, two assumptions were made:

1. Laser photocoagulation has been chosen as the mode of treatment for DR. This decision was based on the recommendations made by clinical experts suggesting that treatment outcomes for vitrectomy for advance staged DR is less clear.
2. Each patient underwent three laser photocoagulation treatments within the same year. Therefore, the number of patients treated in 2012 is multiplied by three in the above calculation. This assumption was based on findings of the structured interviews with vitreoretinal specialists at the NEC.

### *Staff costs*

The cost per treatment day for each staff was calculated using the same basic rate of pay formula (Equation 1) used to calculate cost per screening day described earlier. The monthly salary used in the calculation was based on typical pay rates for ophthalmologists and ophthalmic nurses employed by the Ministry of Health, Brunei.

### *Equipment costs*

Total annualised equipment costs (argon green laser, visual acuity chart projector, slit lamp bio-microscope, super-field lens, indirect and direct ophthalmoscope) for DR treatment at NEC were calculated using the same formula to estimate annualised equipment cost for DR screening described earlier. The unit prices of the equipment were based on individual equipment prices for 2012 provided by the procurement section, RIPAS hospital, Ministry of Health.

### *Consumable costs*

The main consumable item used for DR treatment at the NEC was dilation eye drops (Mydriacyl) and local anaesthetic eye drops (Tetracaine). The annual cost of consumables used in DR screening was estimated by multiplying the unit cost of each item (Mydriacyl and Tetracaine) by the estimated quantity of each eye drop used per year (based on total number of patients treated in 2012 at the NEC). Based on the information gathered from nurse-in-charge at the NEC, one unit of each eye drop was typically used by each individual patient. Unit prices for both eye drops were based on 2012 prices obtained from procurement section, RIPAS Hospital, Ministry of Health.

2.4.5 Objective five: To explore the perceived strengths and weaknesses of the DR screening programme and opportunities for enhancing the programme from the health provider perspective

*i. Study method*

Semi-structured interviews with key informants using an interview guide were conducted to explore the perspectives of different stakeholders on:

a) The strengths and weaknesses of the screening program including the screening pathway, grading pathway, clinical management and the organisation of the DR screening programme and;

b) Potential improvements that could be made to the programme for an enhanced systematic DR screening model.

Key informants invited to participate in this study were sampled using the snowballing technique, based on their involvement in the DR screening programme in the Brunei-Muara district and their roles in the Ministry of Health (Table 2-4).

**Table 2-4 Key Informants identified for semi-structure interviews (by cadre and role)**

	<i>Job Title (Number)</i>	<i>Role in the screening programme</i>
1	Head of Ophthalmology (One)	Administrative head for the Department of Ophthalmology in the Ministry of Health
2	Head of Community Ophthalmology (One)	Administrative head of community Ophthalmology services
3	National Programme for Prevention of Diabetic Blindness Co-ordinator (One)	Coordinates all DR screening activities
4	Ophthalmologists involved in screening at each health centre (Seven)	Conducts eye examination in the screening programme
5	Vitreo-retinal specialist (One)	Conducts DR treatment
6	Ophthalmic Nurse (In-charge of community eye services –	Supervises ophthalmic nurses and assistants and organises resources for all DR screening

	One)	activities including DR registry and statistics
7	Ophthalmic nurses and assistants involved in screening at each health centre (four	Conducts case history, VA assessments, dilation and manages DR screening appointments, referrals and statistics
8	Endocrinologist (One) from Diabetic Centre	Involved in the overall clinical management and planning of services for all Diabetics in Brunei.
9	General Practitioners (In-charge at each health centre - Five)	The administrative head of all GPs at each health centre; diagnoses, manages and refers DM cases for eye screening
10	Head of Primary Health Care Services (One)	The administrative head of all primary health care services in the Ministry of Health

### *Topic guides*

A topic guide (Appendix 4) was formulated prior to the interviews focusing on four major themes (screening pathway, grading pathway, clinical management of DR and organisation of services) that was guided by the following:

- Issues that have been raised during informal discussions with the National Programme for Prevention of Blindness coordinator
- Findings of structured interview questionnaires conducted prior to the in-depth interviews
- Key observations during site visits to DR screening programmes
- Document review of the local and international policy documents pertaining to DR screening (Brunei National Programme For Prevention Of Diabetic Blindness, Brunei Clinical Guidelines for the Management of Diabetes Mellitus and the European group for Diabetic Retinopathy Recommendations).

### *Interview process*

Semi-structured face-to-face interviews were mostly conducted in English. Two interviews were conducted in both English and Malay and were then translated into

English during transcription of voice recordings. Interviews lasted between 30 to 45 minutes and all interviews were voice recorded with consent. Six of the interviewees requested to be interviewed in pairs. All interviews were transcribed in English after full verbal and written consent was obtained from all participants.

*ii. Data analysis*

Data analysis was conducted using NVivo 10 software (135). The analysis of interview data was guided using a 4-step technique (131). These techniques were based on approaches adopted in grounded theory (136) including coding (reviewing transcripts and giving names to units that have theoretical significance)(137), theoretical saturation (continuous coding of data until it reaches a point that further reviewing codes does not produce further meaning) and constant comparative technique (a process such as memo writing that enables researcher to be able to always connect between data and concepts/categories)(136).

Briefly, the application of Bryman's 4-step technique adopted in this study is as follows:

*1. Open coding*

Interview transcripts were read in full to verify meaning before open coding was performed. Themes were identified and cases were categorised.

*2. Re-reading transcripts*

Key texts were highlighted and given codes. Each code was annotated.

*3. Coding text*

Codes were systematically reviewed and organised into themes. Any duplication of codes was deleted.

*4. Relating general theoretical ideas to text (thematic analysis)*

Interpretation of codes were added using 'memoing' technique (138)(process of providing a narrative to codes). Using the visualizations feature in NVivo 10 (135), interconnections between themes were identified.

Trustworthiness of interview data was ensured in two ways. Firstly, by explaining to key informants the aims of the study, expectations and purpose of the interview, and clarifying any doubts regarding confidentiality prior to initiating interviews. During interviews, informants were given the opportunity to seek clarification on any question being asked and similarly, through “probing and prompting” techniques, interviewees were asked to clarify any ambiguous statements that were made. Due to time constraints, this process was not repeated after interviews were transcribed. Secondly, triangulation was performed by comparing interview transcripts with what was reported in documents (e.g. DR grading practices were compared with REPAS Grading published in the BNPPBD - Appendix 8) and by comparing interview data with findings observed through structured observations.

### 3. Results

#### 3.1 Response rates for structured and semi-structured interviews.

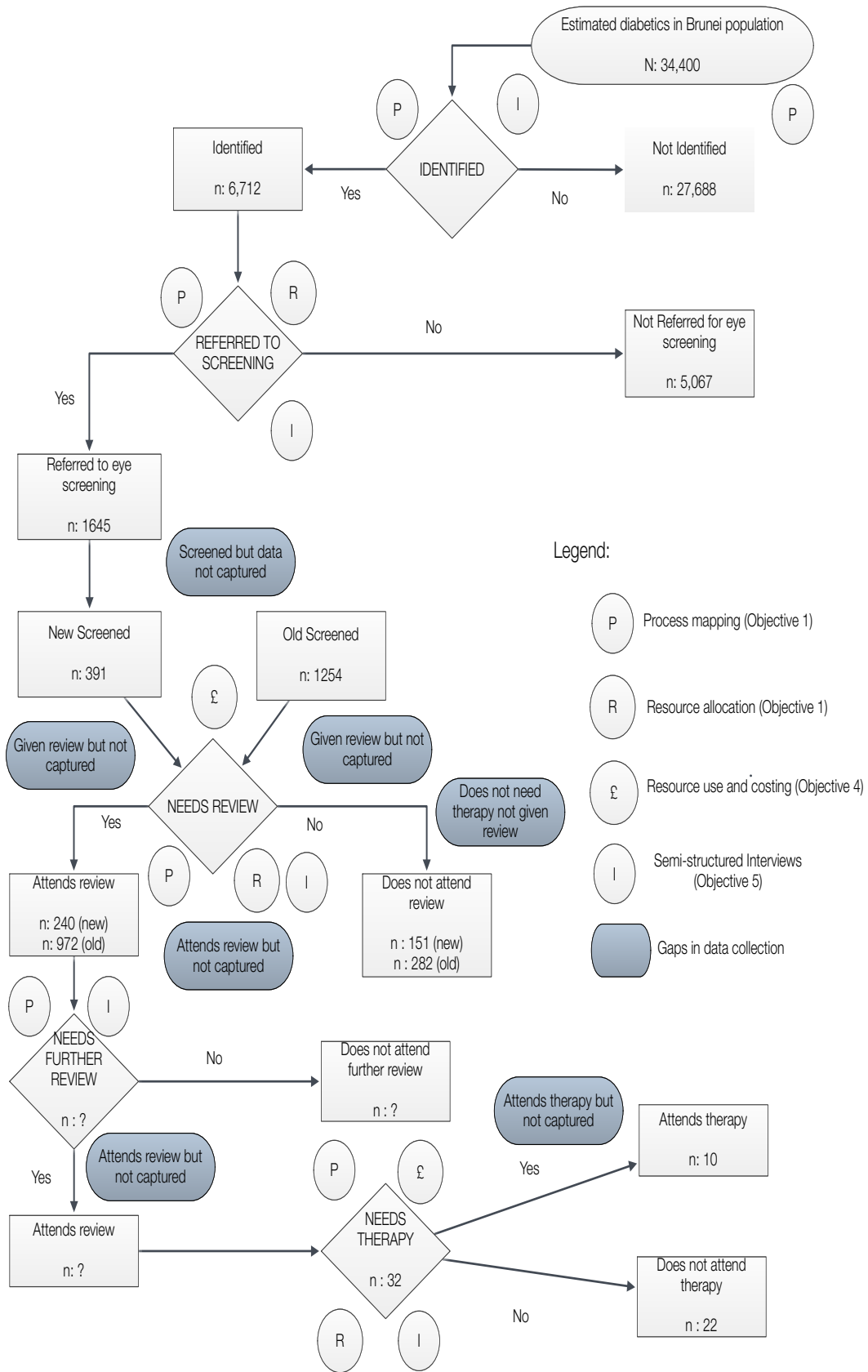
Sixteen questionnaires were administered to understand the screening, grading and clinical management of DR in the Brunei-Muara district. These were delivered through interviews with respondents representing the different health facilities where DR screening was conducted in the Brunei-Muara district. A 100% response rate was attained for both structured interviews (16 questionnaires) and semi-structured interviews (20 interviews) (Table 3-1). In addition, structured observations at all seven health centres were also conducted. Figure 3-1 provides an overview of the results of the studies and each result will be discussed in turn.

**Table 3-1 Number of study respondents and questionnaires administered by study site**

Study sites	Number of questionnaires Administered*	Respondents		
		General Practitioners	Ophthalmologists	Ophthalmic assistants
<i>Primary health centres</i>				
<i>Bandar Seri Begawan Health Centre</i>	2	1	1	1
<i>Berakas A Health Centre</i>	2	1	1	1
<i>Berakas B Health Centre</i>	2	1		
<i>Gadong Health Centre</i>	2	1	1	1
<i>Muara Health centre</i>	2	1	1	1
<i>Sengkurong Health Centre</i>	2	1	1	1
<i>Sungai Assam Health Centre</i>	2	1		
<i>TERTIARY HOSPITAL</i>				
<i>National Eye Centre</i>	2	N/A	2	N/A
<i>Total</i>	16	7	7	5

(\*One questionnaire for GPs and one questionnaire for both ophthalmologists and ophthalmic assistants interviewed together)

**Figure 3-1 Overview of results by study objectives and study gaps.**



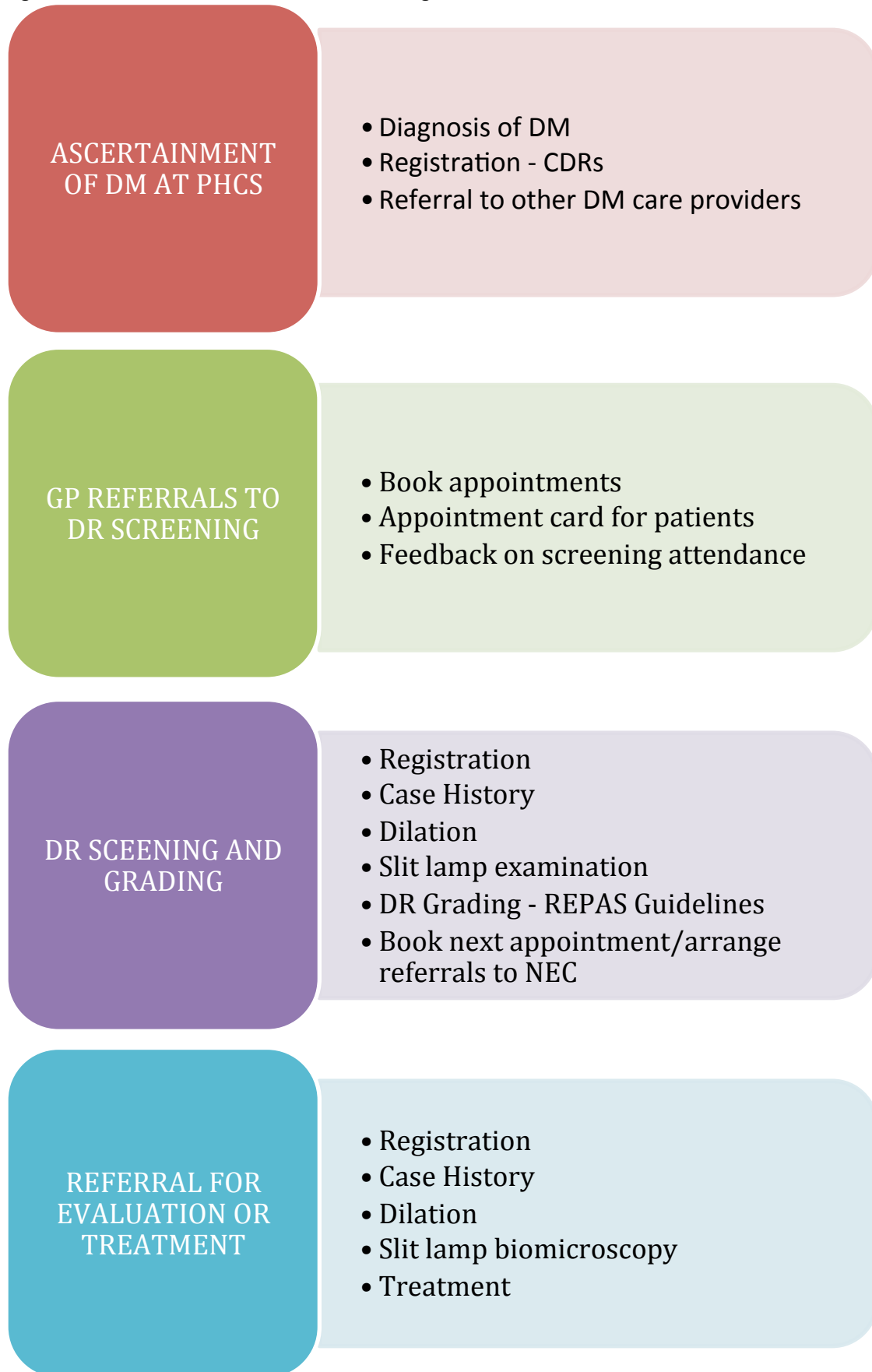


### 3.2 Existing screening, grading and clinical management practices and the organisation of the diabetic retinopathy screening

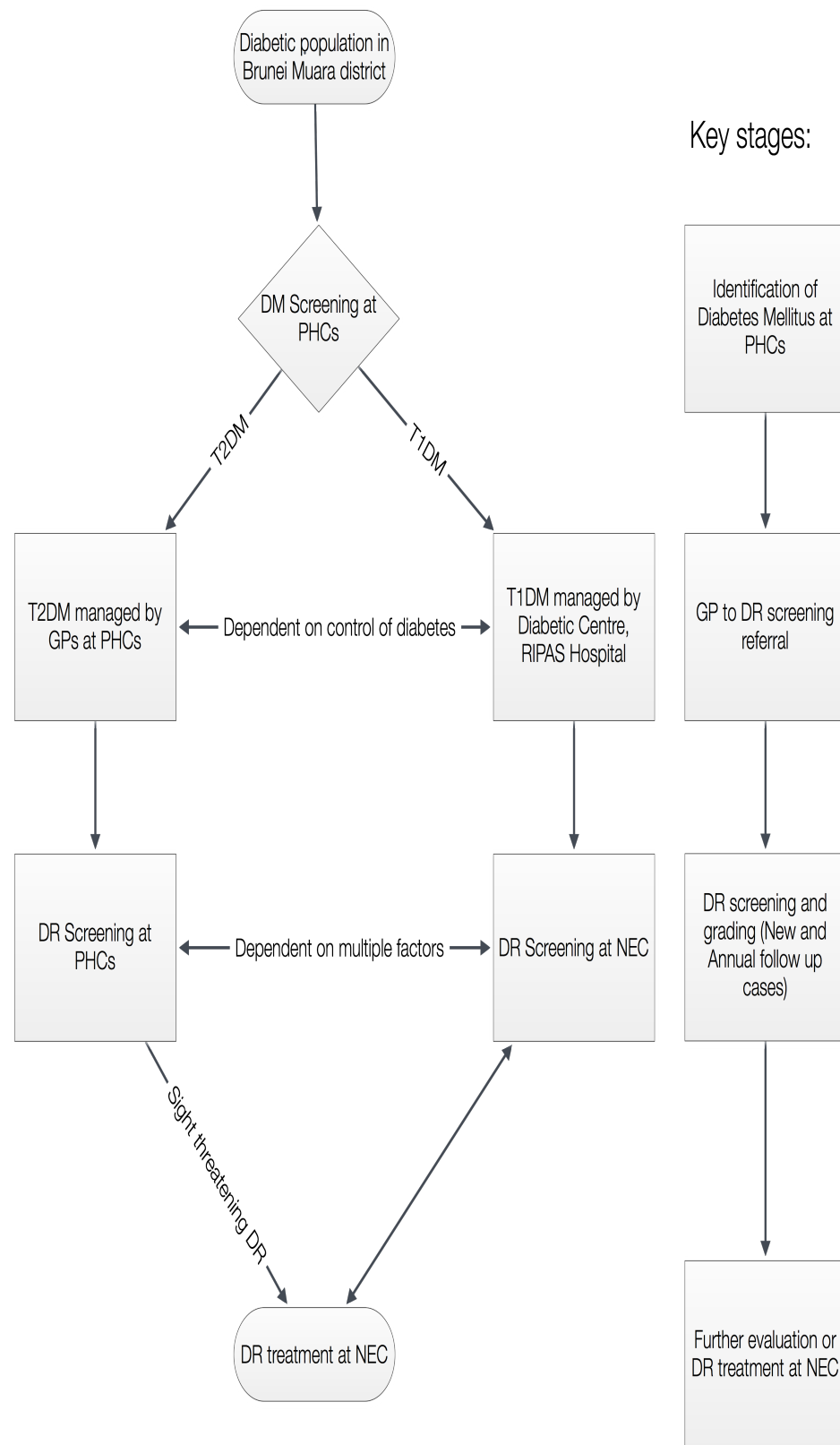
In general, responses from the structured interview questionnaires and structured observations suggest that key processes were in place (Figure 3-3) for the provision of DR screening and treatment at the primary health centres and NEC in Brunei-Muara district which can be classified into four main stages: identification of DM, GP to DR screening referral, DR screening (and grading) and further evaluation and treatment (Figure 3-2). In addition, structured observations at the NEC also revealed that DR screening was also conducted twice a week (Tuesday and Thursday) at the NEC. However, for the purposes of this study, the mapping of processes and resources was restricted to PHCs only.

These processes are presented as flowcharts (Figure 3-4 – 3-10) to depict the process flow at each stage. However, respondents (GPs) also highlighted process gaps and variations between health centres and these will be discussed in turn.

Figure 3-2 Processes for GP referral, DR screening and treatment referral



**Figure 3-3 An overview of the diabetic retinopathy screening and treatment pathway in Brunei-Muara district**



DM - Diabetes Mellitus, T1DM - Type 1 diabetes, T2DM - Type 2 diabetes, DR - Diabetic Retinopathy, PHCS - Primary Health Centres, NEC - National Eye Centre, GPs - General Practitioners

### 3.2.1 Ascertainment of patients with diabetes by GPs in the Brunei-Muara district

#### *Opportunistic diabetic screening by GPs*

Figure 3-4 provides an overview of how diabetes is detected and managed by GPs at the primary health centres. Findings from observations at PHCs (139) suggest that the key strengths of this stage were that clinical practice guidelines and chronic disease registers are in use. However, as the process of identifying patients at risk of DM was dependent on patients attending general GP clinics at PHCs, screening for diabetes mellitus at primary health centres by GPs was considered opportunistic. Any patient attending GP outpatient clinics reporting diabetic symptoms (e.g. high blood pressure) and/or patients categorised by GPs as being at risk (e.g. with reported family history of diabetes) during initial clinical examination were asked to undergo biochemical tests (e.g. blood glucose, cholesterol) to ascertain their diabetic status.

#### *Clinical practice guidelines for diabetes mellitus*

Observations at PHCS suggest that diagnosis of DM by GPs was guided by a diagnostic criteria outlined in the national clinical practice guidelines (139). In general, patients with fasting blood glucose of level > 7.0 mmol/l and HbA1c level > 6.5% were considered as diabetic. Upon diagnosis, data of newly diagnosed patients with diabetes were entered into a logbook known by GPs as the Chronic Disease Registers.

#### *Chronic disease registers (CDRs)*

In the structured interview questionnaires, all GPs (7/7) reported the use of chronic disease registers at each health centre. This finding was supported by evidence from observations made during visits to all PHCs that showed evidence that CDRs were in use and data were entered by PHC staff. However, analysis of structured interview questionnaires responses suggests that the implementation of CDR varied across the different PHCs. The characteristics of the CDRs that are in place at each health centre are summarised in Table 3-2.

*CDRs implemented at different times and lacked SOPs*

Responses of GPs in the structured questionnaire reported that CDRs were introduced at each PHC at different times. Sungai Assam health centre was the earliest health centre to implement the CDR (2002) and this was in contrast to Berakas B, which only started in 2012. Most GPs (6 out of 7) reported that there were no standard operating procedures in place to guide GPs and staff members (at PHCs) to register patients into the CDRs and how the database should be maintained. Staff members were guided by informal instructions by the GP in charge at each PHC.

*CDRs were not regularly updated despite appointment of dedicated personnel*

The majority of GPs (6 out of 7) reported having allocated dedicated personnel to manage the CDRs registers at each PHC. However, only 2 out of 7 GPs (Bandar Seri Begawan and Sg Assam) reported that they regularly updated their CDR data. However, respondents could not provide an estimate on how frequently it was done.

*CDRs used handwritten logbooks and no standardised template for data collection*

The chronic disease registers were used by GPs to register patients with chronic diseases (including patients with diabetes) attending GP clinics at each PHC. All GPs reported that information collected for CDRs was recorded using a logbook. Upon confirmation of diagnosis, patient information data (e.g. name, age, gender, patient identification number and clinical diagnosis) were recorded manually (handwritten) into logbooks. This finding was also supported by observations made at PHCs where recent entries were entered into logbooks. In addition, several initiatives were observed at some health centres (Sengkurong, Sungai Assam and Berakas A) where information from logbooks was transferred into an excel spread sheet. However, the extent to which these initiatives were implemented was very limited.

The different types of chronic diseases registered include asthma, gout, skin disorders, diabetes and hypertension. However, it was observed that the practice of data entry into logbooks varied from one GP to another and there was no standard

template in use to collect patient information and clinical diagnosis. One method was for GPs to inform a dedicated person to make an entry once a diagnosis had been made and in other cases, the medical secretary with the support of GPs, entered data by reviewing medical records.

#### *Under-registration of patients into CDRs*

Another variation reported by GPs was the lack of the completeness of the register. In the majority of cases (6 out of 7 PHCs), GPs reported under-registration of patients with diabetics in their respective CDRs. Only Berakas A reported to having registered all their patients with diabetes into the CDR.

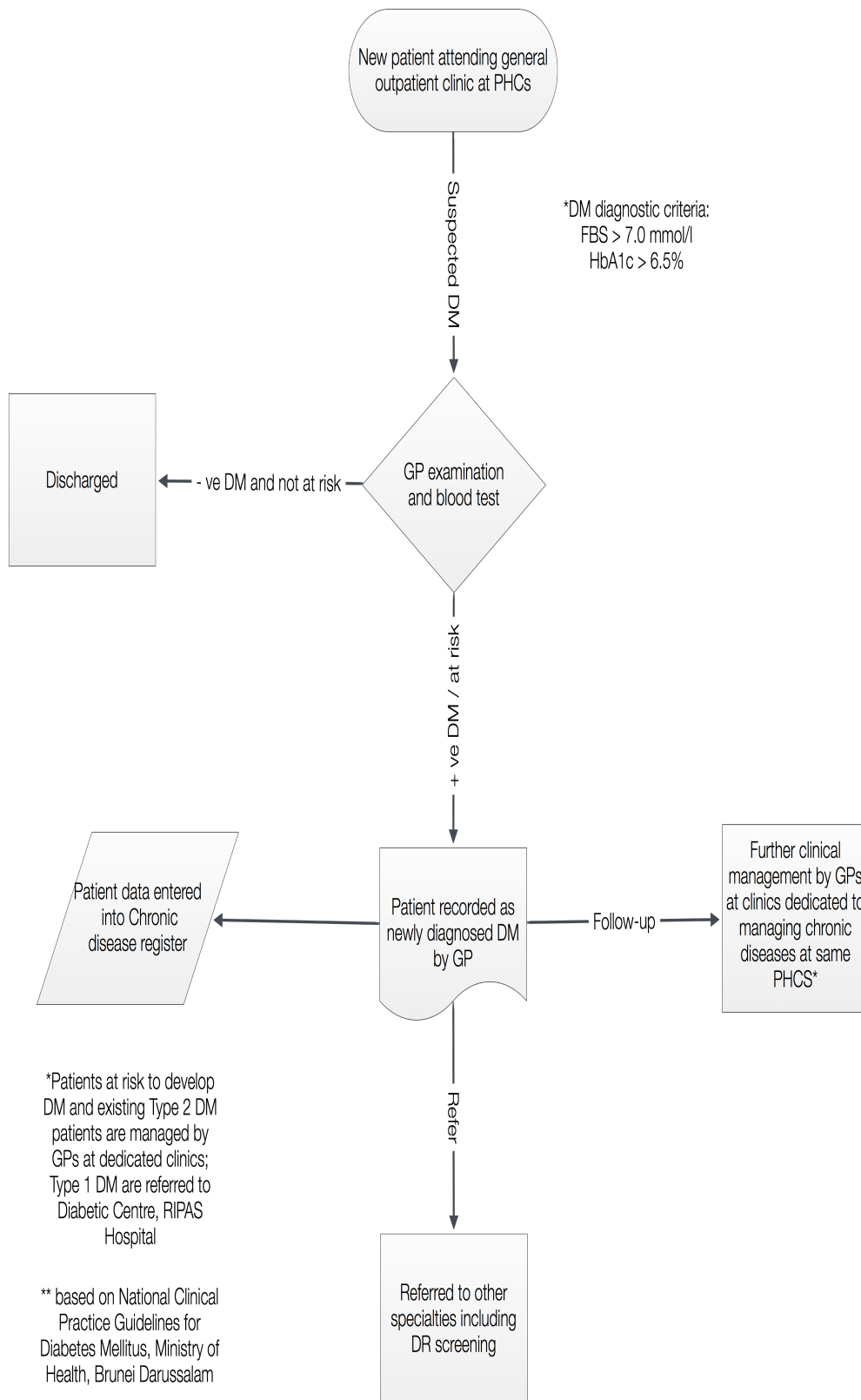
#### *CDR not used to refer patients for eye screening*

All GPs unanimously agreed that the data from the CDR were not used to refer patients with diabetes for DR screening.

The DR screening in Brunei-Muara model is dependent on GP referrals (Figure 3-3). To ensure optimal DR screening coverage at each health centre, it is essential to have an accurate register of patients with diabetes that could be offered DR screening. No specific registers for patients with diabetes were kept in any of the PHCs and the data provided by the CDR offered the best available data on the list of patients eligible for DR screening. The variations in the implementation and maintenance of CDR described earlier suggest that data collected in existing CDRs was incomplete and inaccurate.

In view of the dependence the of DR screening programme on GP referrals, these CDR related challenges were further explored through in-depth interviews and this will be discussed in section 3.6.2.

**Figure 3-4 Ascertainment of T2DM at PHCs**



**Table 3-2 Characteristics of Chronic Disease Registers by health centre**

	Bandar Seri Begawan	Berakas A	Berakas B	Gadong	Muara	Sengkurong	Sg Asam
Is there a CDR register?	Y	Y	Y	Y	Y	Y	Y
Format of register?	BOOK	BOOK	BOOK	BOOK	BOOK	BOOK	BOOK
Is there a dedicated person maintaining CDR?	Y	Y	Y	N	Y	Y	Y
When was CDR started?	NOT SURE	2005	2012	2007	2009	NOT SURE	2002
Is there a protocol in use for CDR?	N	N	N	N	N	N	Y
Is the register complete?	N	Y	N	N	N	N	N
Is it regularly updated?	Y	N	N	N	N	N	Y
CDR used for referring to DRS?	N	N	N	N	N	N	N

***Summary of ascertainment of patient with diabetes at PHCs***

- DM screening by GPs currently only opportunistic
- National Clinical Practice Guidelines were used to guide GPs to diagnose and manage DMs at PHCs
- CDR are implemented at each health centre
- Lack of standardised protocol to support implementation of CDRs for PHC staff and variations in the way patients were registered into CDRs and how CDR data was managed have contributed to CDRs being incomplete and inaccurate.
- CDRs were not used as data source to refer patients for DR screening by GPs.



### *3.2.2 Key processes in GP to DR screening referrals at other primary health centres*

Responses from the structured interview questionnaires and observations suggest that there were processes in place for GPs to refer patients with diabetes to DR screening. All GPs reported having referred their patients for DR screening at the same health centre. However, there were variations in GP to DR screening referral process observed across the different health centres and these variations are summarised in Table 3-3.

#### *GP to DR screening referral appointment system*

Most GPs (5 out of 7) reported in the questionnaire that there was a system in place for them to book referral appointments for patients with DR screening clinics at each PHC. Only, BSB and Gadong PHC reported that there was no appointment system established.

The GP to DR screening referral appointment system is outlined in Figure 3-5. Findings from structured observations at the different health centres suggest that a three step appointment booking system (identify, inform and record) was used by GPs to refer patients with diabetes (newly diagnosed and existing patients with diabetes) for DR eye screening at the different PHCs. However, there was slight variation observed for GP referral process at BSB PHC. In addition to the appointment system, subject to availability of the screening session, GPs may refer patients as “walk-ins” without the need to book an appointment with the DRS screening.

#### *Lack of GP to DR screening referral guidelines*

GP responses varied in terms of the use of guidelines to refer patients for DR screening. Only 3 out of 7 GPs (BSB, Berakas A and Sg Asam) reported having used guidelines to refer patients to DR screening. However, none of the GPs at these health centres were able to provide a copy of such guidelines, therefore, it was difficult to confirm whether the referral guidelines were in use. In addition, GPs in

the other health centres (Berakas B, Gadong, Muara and Sengkurong) reported that there were not aware of such guidelines.

#### *The lack of use of GP to DR screening referral forms*

Based on the responses to the structured questionnaire, only one GP (Muara HC) reported using referral forms to refer patients to DR screening. Most GPs (6 out of 7 PHCS), reported making written referrals using patient case notes that were shared amongst different providers within the same health centre. This finding was supported by evidence from structured observations where GP written referrals were noted when several patient case notes were reviewed.

#### *GP to DR screening appointment cards used as patient reminders*

Based on structured questionnaire responses, all GPs (7/7) reported providing patients with a reminder card showing the scheduled date and time of the screening session. This was confirmed by findings of structured observations where PHC nurses were observed giving out screening appointment cards to patients, once the appointment date and time had been agreed with the patient. However, no other forms of patient reminders (e.g. telephone reminders) were reported to be in use at any of the PHCs.

#### *Waiting lists for DR screening appointments*

The structured questionnaire responses show that most respondents (5 out of 7) did not report any waiting lists for referring patients to DR screening. However, 2 out of 7 GPs (Gadong and BSB Health centre) reported waiting lists for patients referred for DR screening. In addition, waiting lists at Gadong PHC were reported to be as long as 11 months and were only one month at Berakas A.

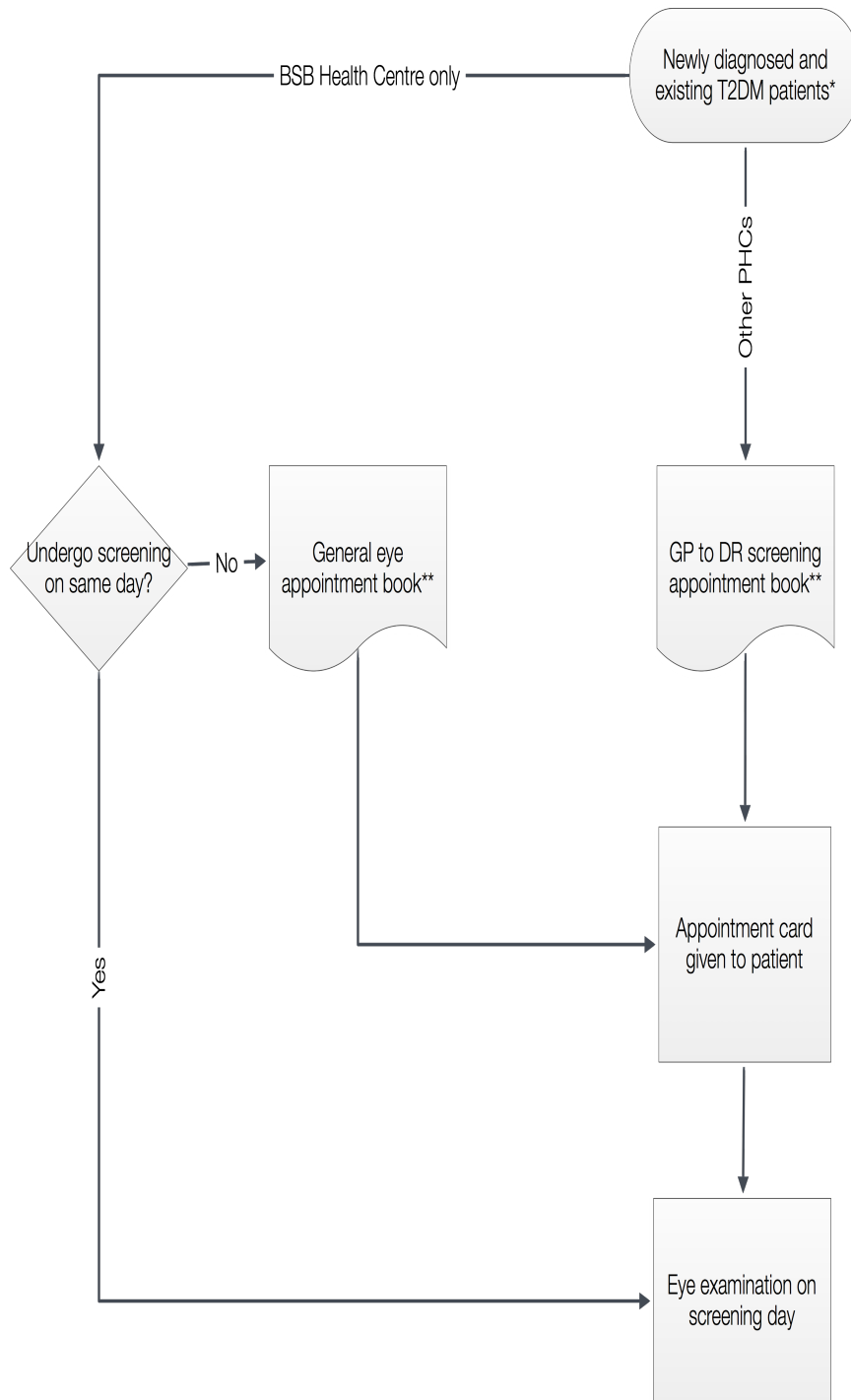
However, it was difficult to confirm these findings at Berakas A and at Gadong PHC. At both Berakas A and Gadong health centre, the GP to DR screening appointment book was reported missing by the GP in charge during the data collection period.

Therefore, it was difficult to verify the evidence of the waiting list without any data source.

*Lack of screening attendance feedback by DR screening team*

Responses from structured questionnaire showed that only 3 out of 7 GPs received feedback from the DR screening team on patients' attendance in DR screening sessions. The other GPs (4/7) reported that they did not receive any feedback. This finding was supported by structured observations where the GPs at the three health centres (Berakas B, Sengkurong and Sg Asam) reported that feedback was given to them indirectly by reviewing patient case notes that was shared by the different users in the same PHCs. However, it was also observed that due to the issue of missing case notes at certain health centres, this practice was not always possible.

**Figure 3-5 GP to DR Eye screening referral process in the different health centres**



**Key processes for booking appointments\*\***

1. IDENTIFY date and time of next available appointment
2. INFORM patient of the date of the appointment and screening procedure.
3. RECORD name, contact details, medical record number of patient in the appointment book

**Table 3-3 Key GP to diabetic eye screening referral process at different primary health centres**

	Bandar Seri Begawan	Berakas A	Berakas B	Gadong	Muara	Sengkurong	Sg Asam
Are all patients with diabetes referred for DR eye screening?	Y	Y	Y	Y	Y	Y	Y
Are patients referred for DR screening at this health centre ONLY?	Y	Y	Y	Y	Y	Y	Y
Feedback given on screening attendance?	N	N	Y	N	N	Y	Y
Is there waiting list for DR screening appointment? (Duration)	N/A*	Y (1 MONTH)	N	Y (11 months)	N	N	N
Are guidelines in use to refer patients to DR eye screening?	Y	Y	N	N	N	N	Y
Is referral form in use?	N	N	N	N	Y	N	N
Is there appointment system in place for DR screening?	N	Y	Y	N	Y	Y	Y
Are appointment cards given to patients?	Y	Y	Y	Y	Y	Y	Y
Are patients sent reminders to attend DR screening?	N	N	N	N	N	N	N

\*N/A – Not applicable; Y – Yes, N – No.

### **Summary of GP to DR screening referrals**

- Key processes were in place for GPs to refer patients with diabetes for eye screening
- Variations in GP to DR screening referral processes including direct referrals (at BSB), use of guidelines, referral forms, lack of feedback on screening attendance, only 2 health centres reported waiting lists
- Data collected affected by lack of data sources (missing appointment books).

### 3.2.3 DR screening and grading stage

Findings from the structured interview questionnaires and structured observations at the seven health centres suggest that standardised resources and processes in the DR screening and grading stage were adopted at each health centre (Figure 3-6); that includes three key processes, registration, eye examination and grading.

#### *I. Registration process*

The registration process represents one of the key strengths of the programme. Based on the structured interview responses and observations, all respondents reported the same standard process for registering patients in use at all health centres (Figure 3-7). All patients were required to pay either B\$1 (£0.51) registration fee for local residents or B\$5 (£2.54) for permanent residents and all payments were collected by a registration clerk (Table 3-4).

#### *II. Eye examination process*

A key strength of the programme is the use of standard resources to provide eye examinations at all health centres. Results obtained from the structured interview questionnaires showed that all respondents reported that a team of ophthalmologist and ophthalmic nurse/assistants conducted DR screening at each clinic. In addition, all patients underwent dilated funduscopy using slit lamp bio-microscopy and eye examinations were conducted by ophthalmologists (Table 3-5). Furthermore, it was observed that all eye examination rooms at PHCs were equipped with visual acuity charts, slit-lamp bio-microscopy and a direct ophthalmoscope.

Another key strength of the programme was the use of standardised processes for eye examination at all health centres that involved three main activities: history taking, instilling dilating drops and fundus examination (Figure 3-8). Responses from structured interview questionnaires, supported by findings from structured observations, showed that all respondents reported a similar eye examination process adopted at all health centres (Table 3-5).

In addition, all respondents stated having used the Diabetic Eye Registry forms (DER 1 and 2) as a standard guide for case history taking and recording of eye examination clinical findings. Table 3-6 shows the patient and clinical information gathered in the DER 1 and DER 2 forms (Appendix 16). However, structured observations at the health centres revealed that recording of results in DER 1 and 2 forms by ophthalmic assistants were occasionally incomplete.

### *III. DR grading process*

The DR grading process was considered another strength of the DR screening programme. Based on the findings of both the structured interview questionnaires and observations, all respondents reported that a similar grading processes (Figure 3-9) and a standard DR grading system were adopted at all health centres.

The REPAS DR grading system, developed by the Ministry of Health(122), integrates five different DR screening and treatment measures for a patient into a single DR grading scheme that includes:

- DR grading
- Macular oedema grading
- Photocoagulation (Yes/No)
- Anti-VEGF (Yes/No)
- Surgery (Yes/No)

The International Clinical Diabetic Retinopathy and Macular Oedema Disease Severity Scale (34) have been adopted by the Ministry of Health as a reference standard to grade DR and MO in the REPAS Grading System and are presented in Appendix 14.

Based on structured observations during site visits to various PHCs, it was evident that ophthalmologists used the REPAS grading system as a guide to decide further management of screened patients. Figure 3-9 outlines the key activities in the DR grading process, and based on their DR status, screened patients were either given:



1. Follow up screening appointments at the same health centre within 6 – 9 months (NSTDR cases)
2. Urgent referrals for immediate treatment to NEC (urgent STDR cases)
3. Follow up appointment for further ophthalmic evaluation within 2 – 4 months (non-urgent STDR cases).

Standardised processes in DR screening and grading stage provide the DR screening programme with a good platform towards achieving a systematic screening programme. However, several key process gaps and variations were also observed that may affect the effectiveness of the screening programme. These will now be discussed in turn.

#### *Lack of monitoring of screening outcomes*

Findings from structured interview questionnaires showed that all respondents reported that there were no measures in place to verify screening outcomes. In the existing process, for each screening session, DR screening and grading were performed by the same ophthalmologist. However, a different ophthalmologist may attend to the same patient at subsequent sessions. There were no initiatives in place to assess the consistency of grading (inter-observer variations).

Similarly, there was an observed gap for patients referred for further evaluation and treatment to NEC. In the existing system, it was difficult to determine true referrals (false positives) of screening at PHCs as there are no initiatives to monitor referrals made to the NEC. Referring ophthalmologists often referred patients to VR surgeons verbally and outcomes of eye examinations at the NEC were not monitored.

#### *Lack of feedback to GPs on screening outcomes*

Another gap observed in the DR grading process was that GPs were not informed of results of screening examinations. Only 4/7 respondents reported to have provided GPs with feedback on the results of DR eye screening examination, all of which stated that feedback was given to GPs indirectly through what was written in

patients' case notes, which were accessible to both GPs and ophthalmologists at each PHCs.

#### *Screening intervals and patient reminders for NSTDR patients*

The screening intervals for follow up screening appointments for NSTDR patients were clearly outlined in the REPAS grading system (Table 3-10) and these recommendations were observed during site visits. Patients with no DR or NSTDR were offered follow up appointments at the health centre within a period of 9 – 12 months. Appointment cards were given to all patients. However, no call and recall system was in place in any of the health centres to remind patients of their follow up appointments.

#### *Ambiguous processes and recommendations in REPAS grading system*

The process of referring STDR patients (urgent and non-urgent) was not clearly defined in the REPAS grading system. It was observed that ophthalmologists often relied on their own clinical judgements to decide whether a case was urgent when making referrals to the NEC. Referrals were dealt with on a case-to-case basis by screening ophthalmologists based on tele-consultation with the VR surgeon. In addition, there were not any clear time frames set for urgent referrals to the NEC.

Another observed gap was ambiguous recommendations in REPAS grading system (Table 3-10). For example, in the management of severe NPDR, with no CSME, pan-retinal photocoagulation was only recommended “sometimes” without further details such as frequency of laser sessions. The recommendations provided were extracted from the American Academy Ophthalmology Practice Guidelines (140). In addition, respondents also reported that no formal training was conducted on the implementation of the REPAS DR Grading system.

#### *Shared infrastructure at some health centres*

Some respondents (2/7) reported minor differences in the availability of rooms for screening. Whilst most health centres have dedicated rooms for DR screening, the rooms used for DR screening at Berakas A and Sengkurong were shared with other

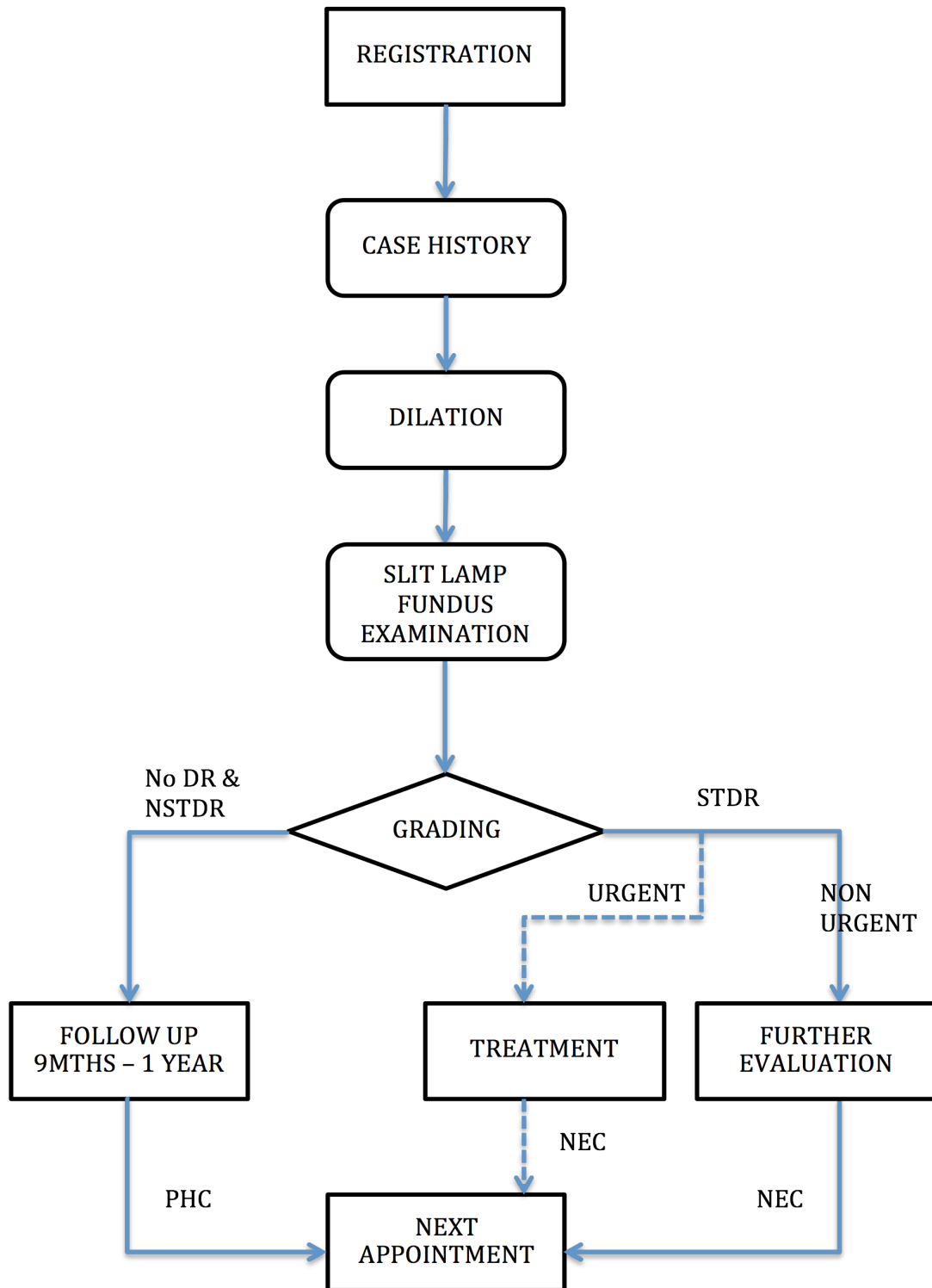
services (e.g. community dieticians and psychologists). In addition, it was also observed that there were minor differences in terms of accessibility to screening rooms between health centres. In Berakas A, the DR screening room was located on the 2<sup>nd</sup> floor of the health centre. Access to the screening rooms was by stairs only, therefore making it potentially difficult for elderly patients and wheelchair bound patients to access services. Similarly, in Berakas B, the screening room was located on the 1<sup>st</sup> floor, accessible only by stairs.

*Variations in the frequency of screening sessions and projected number of patients screened per session*

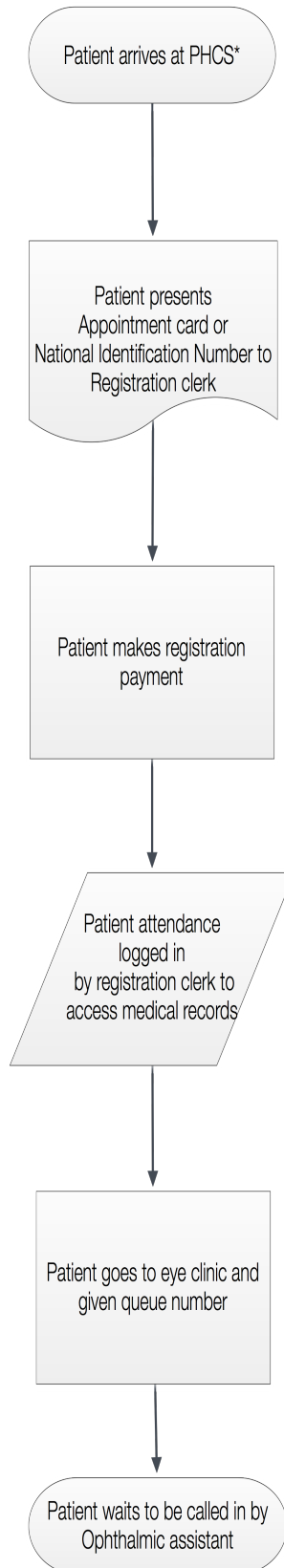
The frequency of DR screening services conducted at the different health centres and NEC was found to differ across the health centres (Table 3-8). Based on the structured interview questionnaire responses, Bandar Seri Begawan health centre offered the most DR screening sessions in a week (4 sessions). In contrast, Sungai Assam health centre provided only one screening session per week. In addition, respondents reported that each screening session could accommodate up to 15 patients per session.

As a result of the variation in screening frequency, the projected number of patients also varied (Table 3-9). Bandar Seri Begawan (BSB) health centre, which served as a satellite primary eye care centre to the NEC, can accommodate up to 60 patients in a week. In contrast, Sg Assam health centre can only accommodate up to 15 patients per week.

Figure 3-6 The DR screening and grading pathway at PHCs in Brunei-Muara district

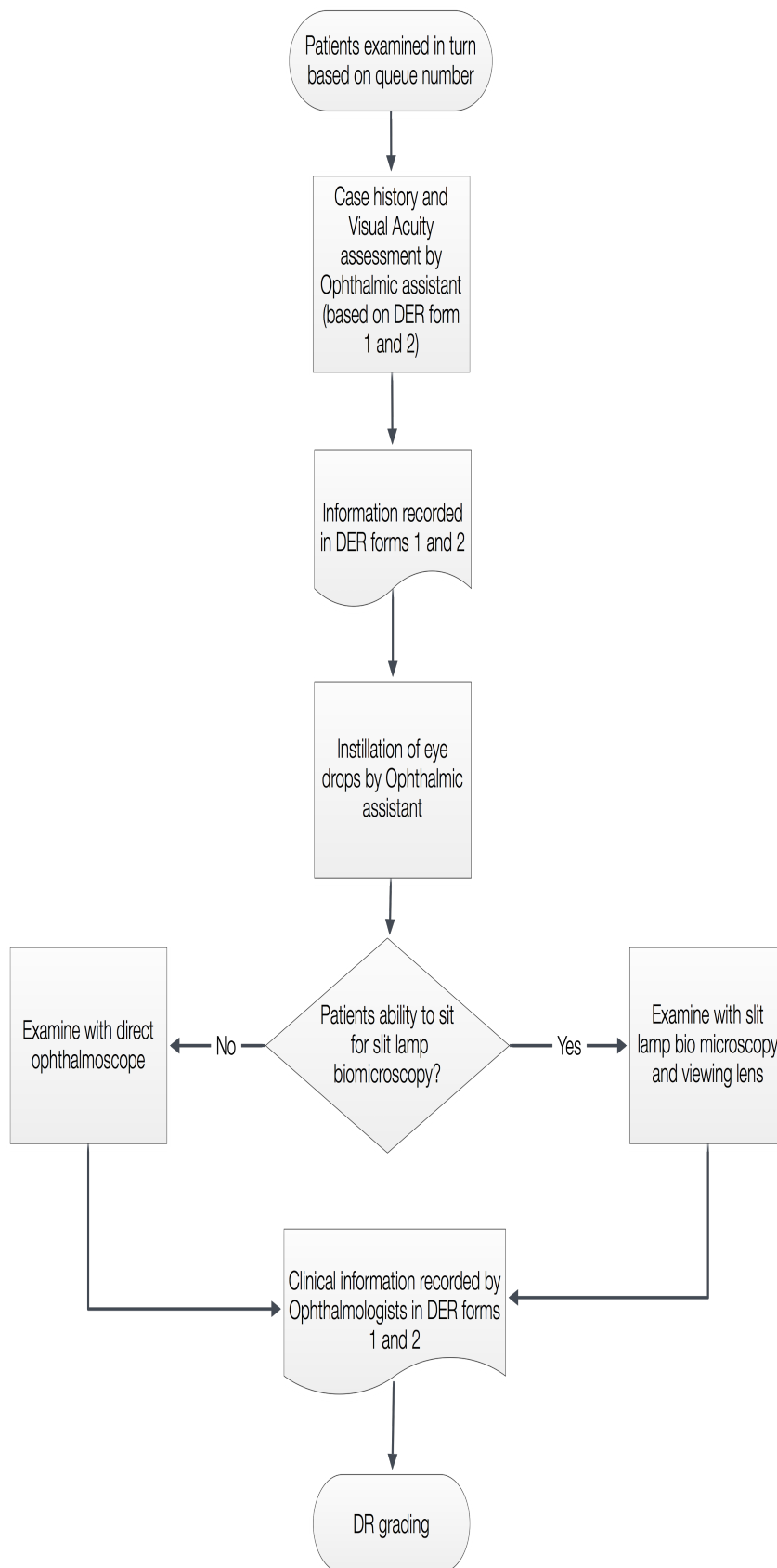


**Figure 3-7 Activities as part of registration process**

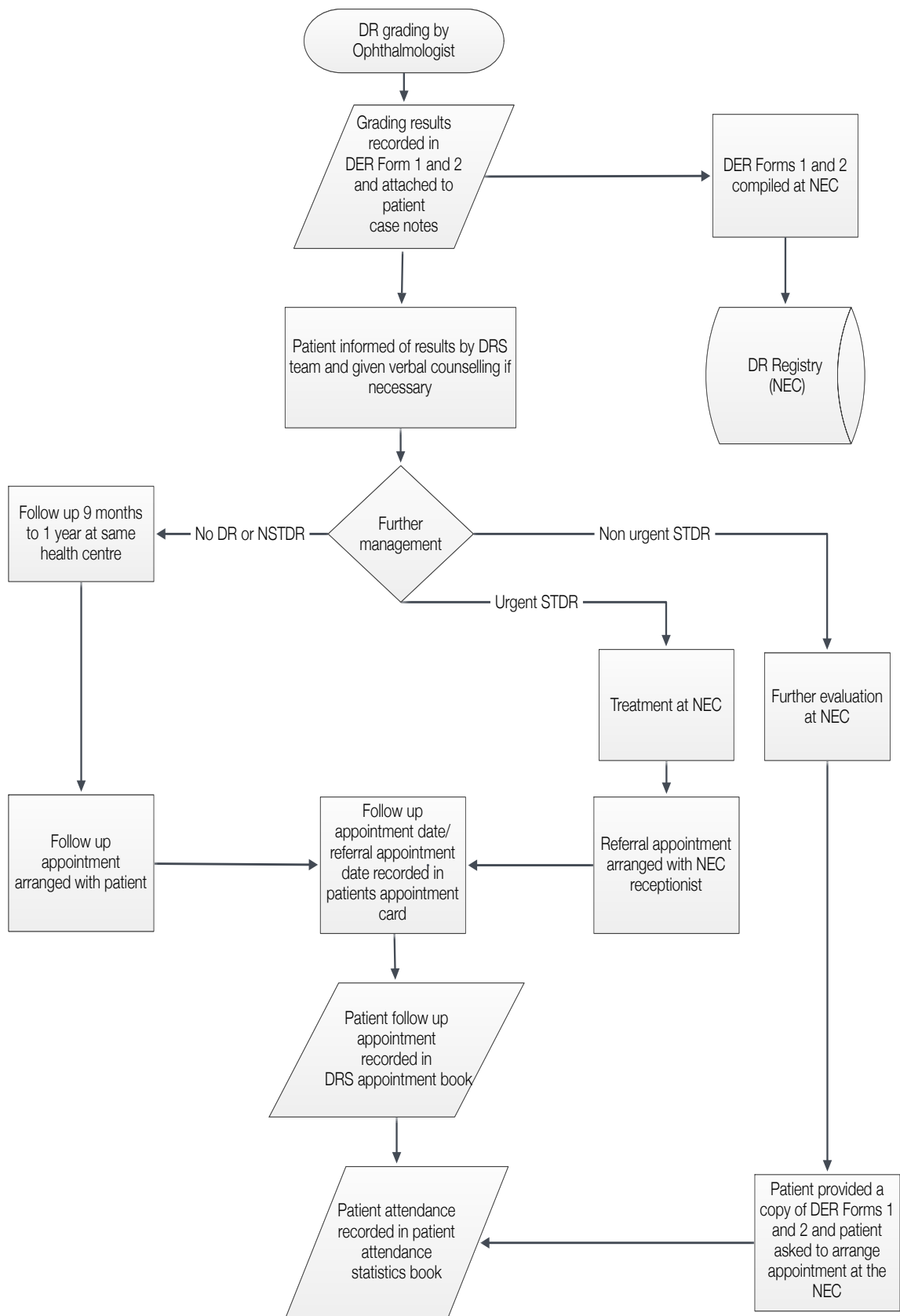


\* Except for patients at Berakas B Health Centre

**Figure 3-8 Activities in the DR examination process**



**Figure 3-9 Activities in the DR grading process**



**Table 3-4 Key features of the registration process for DR screening in all PHCs**

	All Primary health Centres
Payments for screening?	Yes
How much?	\$1 for local residents \$5 for permanent residents
Who is responsible for collecting payments?	Registration clerk

**Table 3-5 Key features in the clinical eye examination process conducted at all PHCs**

	All primary health centres
Case history taken?	Yes
Visual acuity test conducted?	Yes
Are patients dilated?	Yes
Equipment used for fundus examination?*	Slit lamp bio-microscopy (with 78D lens)
Standard form to record findings	Yes (DER 1 and DER 2 forms**)
Standard form to record patients attendance	Yes (Statistics form**)

\*Ophthalmoscopy is used when fundus is not observable on slit lamp or for patients in wheelchairs; \*\* See Appendix 1)

**Table 3-6 Key information gathered using DER forms 1 and 2.**

<i>List of information</i>	DER 1	DER 2
<b><i>Case History (Completed by Ophthalmic Assistant)</i></b>		
Name	/	/
Unique National Identification Card Number	/	/
Address (Town, district)	/	/
Date of Birth	/	/
Gender	/	/
Ethnic group	/	/
Diabetes Type	/	/
Diabetes Duration	/	/
Diabetes Treatment	/	/
Systemic co-morbidity	/	/
Risk factors (Smoking, Pregnancy)	/	/
Ocular Morbidity	/	/
Previous Eye Examination (Y/N)	/	/
<b><i>Ocular findings and management (To be completed by Ophthalmologist)</i></b>		
Uni-ocular Visual Acuity (Presenting and corrected)	/	/
Intro-ocular pressure (if necessary)	/	/
Fundus examination (REPAS)	/	/



Grading)		
Plan (e.g. routine follow up/refer for either evaluation or treatment)	/	/

**Table 3-7 Allocation of resources for DR screening at the different health centres**

Health Centre	Room	Staff	Equipment	Consumables	Stationaries
Bandar Seri Begawan	Y	One Ophthalmologist and one Ophthalmic Nurse/Assistant per session per health centre	1x Visual acuity chart	Mydriacyl (1% Tropicamide) 15ml bottle	1. Pre-printed DER Forms 1 and 2
Berakas A	N		1x Slit lamp bio-microscopy (With 78D lens)		
Berakas B	Y*			1x Direct Ophthalmoscope	2. Pre-printed Medical Record paper
Gadong	Y		1x Indirect Ophthalmoscope** (With super-field lens)		
Muara HC	Y			4. Pens	
Sengkurong	N		5. Rubber stamps		
Sg. Assam	Y			6. Staplers	
National Eye Centre	Y				

\* Screening rooms are located on 1<sup>st</sup> floor and 2<sup>nd</sup> floor respectively without lift facilities

\*\* Available at Gadong health centre and NEC only

**Table 3-8 Existing DR screening sessions at PHCs and NEC**

	Monday	Tuesday	Wednesday	Thursday	Saturday	Total sessions
Bandar Seri Begawan Health Centre	8-10 am	8-10 am	8-10 am	8-10 am	N	4
Berakas A Health Centre	8-10 am	N	N	8-10 am	N	2
Berakas B Health Centre	8-10 am	N	8-10 am	N	8-10 am	3
Gadong Health Centre	N	8-10 am	8-10 am	N	8-10 am	3
Muara HC Health Centre	N	8-10 am	N	8-10 am	N	2
Pengkalan Batu	N	N	N	8-10 am	N	1
Sengkurong Health Centre	N	8-10 am	8-10 am	N	8-10 am	3
Sg Assam Health Centre	8-10 am	N	N	N	N	1
National Eye Centre	N	All day	N	All day	N	2

N- No clinic

**Table 3-9 Projected number of patients with diabetes screened in Brunei-Muara per week**

	<i>Monday</i>	<i>Tuesday</i>	<i>Wednesday</i>	<i>Thursday</i>	<i>Saturday</i>	<i>Total</i>
Bandar Seri Begawan Health Centre	15	15	15	15	N	60
Berakas A Health Centre	15	N	N	15	N	30
Berakas B Health Centre	15	N	15	N	15	45
Gadong Health Centre	N	15	15	N	15	45
Muara HC Health Centre	N	15	N	15	N	30
Pengkalan Batu	N	N	N	15	N	15
Sengkurong Health Centre	N	15	15	N	15	45
Sg Assam Health Centre	15	N	N	N	N	15
National Eye Centre	N	40	N	40	N	80
Total	365					

*N – No clinic*

**Table 3-10 Management recommendations for patients with diabetes based on the REPAS DR grading system**

<i>Severity of Retinopathy</i>	<i>Presence of CSME</i>	<i>Follow-up (months)</i>	<i>Pan-retinal Photocoagulation</i>	<i>Fluorescein Angiography</i>	<i>Focal and/or Grid laser</i>
Normal or minimum NPDR	No	12	No	No	No
Mild to moderate NPDR	No Yes	6 – 12 2 – 4	No No	No Usually	No Usually
Severe NPDR	No Yes	2 – 4 2 – 4	Sometimes Sometimes	Rarely Usually	No Usually
Non high-risk PDR	No Yes	2 – 4 2 – 4	Sometimes Sometimes	Rarely Usually	No Usually
High Risk PDR	No Yes	2 – 4 2 – 4	Usually Usually	Rarely Usually	No Usually
Inactive/ Involved PDR	No Yes	6 – 12 2 – 4	No No	No Usually	Usually Usually

*Extracted from the Brunei National Program for the Prevention of Diabetic Blindness Guidelines*

**Summary of DR screening and grading pathway**

- Standard processes in place for eye examination and referral of screened patients, supported by standard data recording forms used to record screening outcome
- Similar resources (infrastructure, equipment and human resources) were allocated for DR screening at all health centres
- Lack of quality assurance measures such as assessing inter-observer agreement and positive predictive value
- REPAS DR grading system lacked clarity and needs SOPs
- Variation in frequency of screening sessions

### 3.2.4 Diabetic retinopathy treatment stage

Findings from the structured interview questionnaires and observations suggest that key processes are in place for further evaluation and treatment of STDR patients at the NEC (Figure 3-10). However, the findings throughout this stage were primarily based on structured interview responses. Through structured observations at the NEC, it was reported that the availability of data sources needed to evaluate DR treatment was limited either due to poor data recording or data was not collected at all. In addition, the data collection period coincided with the implementation of an electronic patient record system (Bru-HIMs), which made access to patient case notes very limited. With the best available data, key findings were analysed and will be discussed in turn.

#### *Allocation of resources for DR treatment services*

Based on structured interview questionnaire responses, the different resources (infrastructure, manpower and equipment) allocated to deliver DR evaluation and treatment session were identified and this has been summarised in Table 3-7.

In terms of manpower, laser photocoagulation treatment was provided by four ophthalmologists supported by an ophthalmic nurse (Table 3-7). This finding was confirmed through structured observations where it was noted that laser photocoagulation treatment at the NEC was performed primarily by two vitreo-retinal surgeons supported by two ophthalmologists. A full-time ophthalmic nurse was attached to one of the vitreo-retinal surgeons (VR1) to provide clinical and administrative support. However, there were no guidelines identified on how laser workload was split amongst the four ophthalmologists.

In terms of infrastructure and equipment, both respondents reported that all ophthalmologists were provided with a slit-lamp bio-microscopy, standard consumables and stationary to provide treatment. It was observed that VR 1 and 2 were given dedicated examination rooms fitted with a slit-lamp bio-microscopy with laser treatment facility and indirect ophthalmoscopes. In addition, 3 different lasers were in operation at the NEC and VR surgeons had full access to other retinal

diagnostic imaging services at the NEC, including fundus fluorescein angiography and optical coherence tomography.

In this study, it was difficult to elicit whether the resources allocated were sufficient to meet the demands of STDR patients requiring treatment. Although results of structured interview questionnaires showed that respondents reported no waiting lists for DR treatment, it was difficult to verify these findings due to poor data recording at the VR clinics. Structured observations at the NEC revealed that there were no data collected for STDR patients referred from PHCs. In addition, access to patients' records was restricted during the data collection period due to the implementation of an electronic patient information system (Bru-HIMs) and all laser sessions were recorded in a general retina clinic logbook.

#### *Frequent evaluation and treatment sessions*

Based on the findings of structured interview questionnaires and observations, it was observed that frequent sessions were allocated for STDR patients requiring evaluation and laser treatment. Both respondents reported that the evaluation and treatment sessions were available throughout the working week except for Mondays (Table 3-12). This finding was supported by observations at the NEC and by reviewing the NEC clinic rosters. However, it was also observed that there was no SOP or established protocol in use for referring of STDR patients to NEC. Referring ophthalmologists at PHCs made referrals to NEC through direct phone calls to VR surgeons at NEC.

#### *Standard protocol for DR laser treatment and good treatment uptake reported*

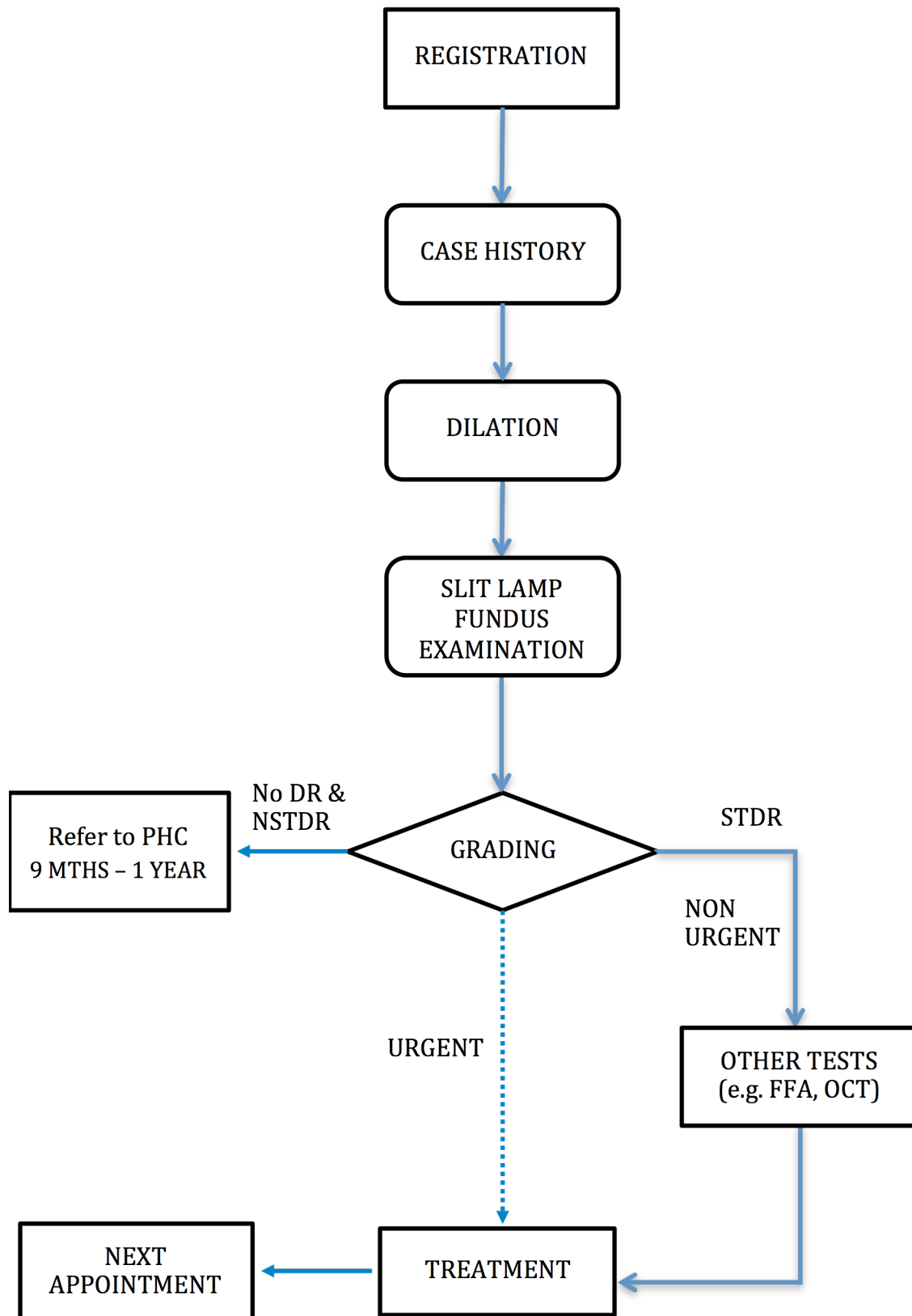
The mode of treatment (number and duration of laser sessions) reported by both vitreo-retinal surgeons on the management of STDR cases was found to be similar (Table 3-14). This finding was based on individual responses provided by each VR surgeon through the structured interview questionnaire. Questionnaires were not administered to the other two ophthalmologists as any laser procedures undertaken were determined by each VR surgeon and any procedures were performed under close supervision of the VR surgeons.

Good treatment uptake were also reported by respondents (two VR surgeons and ophthalmic nurse). Based on structured interview questionnaire responses, both respondents reported that majority of STDR patients offered laser photocoagulation do undergo the recommended treatments. Evidence from structured observations at the NEC highlights that the NEC as the only referral centre for DR treatment in Brunei. It was observed that in addition to referrals from the screening programme, STDR cases were also referred from the other three district hospitals in Brunei. However, it was difficult to establish the frequency of referrals as these were informal and data on referrals were not kept. These findings will be compared with laser treatment uptake estimated in this study, described in later (section 3.3.3).

*Lack of integration between Bru-HIMs and DR registry*

During the study period, an electronic patient management system (Bru-HIMs) was initiated. However, at the time of the study, it was observed that information recorded in the DR registry was not linked to the Bru-HIMS system and therefore patient data had to be entered twice by the ophthalmologist. In addition, it was also observed that Bru-HIMs system implemented at the NEC was not yet linked to the Bru-HIMs system at PHCs and therefore, the DR screening programme staff did not have access to any of the electronic records kept at the NEC.

Figure 3-10 Flowchart showing processes to confirm screening results and treatment for STDR cases referred to NEC



**Table 3-11 Allocated resources for DR treatment at NEC**

Health Facility	Room	Staff	Equipment	Consumables	
National Eye Centre	Yes (3 rooms)	Two VR surgeons, Two Ophthalmologist and one Ophthalmic Nurse	<ol style="list-style-type: none"> <li>1. 2x Visual acuity chart (shared)</li> <li>2. 4x Slit lamp bio-microscopy (with 78D lens)</li> <li>3. 2x Indirect Ophthalmoscope</li> <li>4. 1x Optical Coherence Tomography</li> <li>5. 1x Fundus Fluorescein Angiography system</li> <li>6. 2x Argon laser</li> <li>7. 1x Diode laser</li> </ol>	Mydriacyl (1% Tropicamide) 15ml bottle Tetracaine (Minims) Solcoseryl Eye-gel Cotton Gauze	<ol style="list-style-type: none"> <li>1. Pre-printed DER Forms 1 and 2</li> <li>2. Pre-printed Medical Record paper</li> <li>3. Pre-printed Appointment cards</li> <li>4. Pens</li> <li>5. Rubber stamps</li> </ol>

**Table 3-12 Evaluation sessions for STDR cases at NEC (by VR surgeon)**

	Monday	Tuesday	Wednesday	Thursday	Saturday
VR surgeon 1	No clinic	All day	All day	All day	
VR surgeon 2	No clinic	All day	All day	All day	

**Table 3-13 Laser photocoagulation treatment sessions for STDR cases at NEC (by VR surgeon)**

	Monday	Tuesday	Wednesday	Thursday	Saturday
VR surgeon 1	No clinic	All day	All day	All day	All day
VR surgeon 2	No clinic	No clinic	No clinic	No clinic	PM only

**Table 3-14 Laser treatment modalities by DR type**

	Number of sessions	Duration (in minutes)/session
PDR	3-4	15
SEVERE PDR	3-5	15
MO	3-5	15



**Summary of DR evaluation and treatment stage**

- Key processes in place for DR treatment
- Key strengths included a well-resourced DR treatment service, frequent DR laser sessions, no reported waiting lists
- Key challenges included poor data recording and lack of integration between electronic medical records at NEC and DR registry.

### 3.2.5 Patient Information and education

One of the most important measures to ensure optimal DR screening coverage, DR screening and treatment uptake, is to provide patients with the relevant knowledge on diabetes, management of risk factors and its relationship with DR and prevention of sight loss. By doing this, patients are encouraged to make informed choices to self-manage their diabetic risk factors, to adhere to prescribed medical treatment and to attend regular and timely eye screening. The different types of information relating to diabetes and DR screening provided to patients at different stages of DR screening and treatment pathway by GPs and ophthalmologists were explored and the results are presented in Tables 3-15 and 3-16.

#### *Information provided by GPs at PHCs (ascertainment stage and DR referral stage)*

GPs (respondents) were asked to report on whether patients were provided with any information regarding the following:

- Diabetes and eye complications
- Importance of attending regular eye examinations
- Eye procedures conducted during eye screening

Five out of seven GPs reported that patients attending their health centres were provided with information on diabetes and eye complications. Similarly, most (six) GPs reported that they informed patients about the importance of eye screening for patients with diabetes. However, only four out of seven GPs reported providing patients with information regarding the eye tests that will be conducted during DR screening. Information provided by GPs was mainly verbal. Five respondents reported providing written information to patients regarding diabetes, however, during interviews there were no copies available in the clinics. During site visits there were several diabetic nurse educators (DNEs) attached to certain health centres.

Structured observations at PHCs suggest that their roles were primarily to provide counselling to diabetic patients on a part-time basis (once a week) and that they were mainly based at the Diabetic Centre, located at RIPAS Hospital, the main

tertiary referral centre. They were also unclear on whether the counselling services that they were providing were on a temporary basis or will be developed as a standard service offered at PHCs.

*Information provided by ophthalmologists at PHCs (DR screening and grading)*

All ophthalmologists (7/7) reported in the structured questionnaires that patients with diabetes attending DR eye screening were provided with verbal information regarding diabetes and eye complications, importance of DR eye screening for diabetics and information regarding DR test procedures. However, it was observed that this was not always the case and the messages were often given through ophthalmic assistants. Messages provided by ophthalmic assistants were a direct translation of DR diagnosis and a simple statement to tell patients to control their sugar intake. Structured observations and discussions with ophthalmic assistants suggest that they had no formal training in providing health education and counselling patients.

*Information provided by ophthalmologists at the NEC (DR treatment stage)*

Both VR surgeons reported in questionnaires that patients with diabetes attending DR eye screening were provided with verbal information regarding diabetes and eye complications, importance of DR eye screening for diabetics and information regarding DR test procedures at the NEC. Based on the structured observations at NEC, it was noted that VR 1 used the retinal images as a counselling tool to encourage patients to adhere to treatment. In addition, diabetic counselling services were provided by a trained ophthalmic nurse/counsellor at NEC. However, it was also noted that counselling sessions were informal without any standard protocols. Due to the lack of a systematic approach to provide health education to patients, it was difficult to gauge the effectiveness of existing strategies on encouraging DR screening coverage, DR screening and treatment uptake.

**Table 3-15 Different types of information provided by GPs at PHCs**

	Bandar Seri Begawan	Berakas A	Berakas B	Gadong	Muara	Sengkurong	Sg Asam
Diabetes and Eye Complications	Y	Y	Y	N	N	Y	Y
Importance of DR eye screening in diabetics	Y	Y	Y	Y	N	Y	Y
Eye Examination procedures conducted in DR screening	Y	N	Y	Y	N	N	Y

**Table 3-16 Different types of information provided by ophthalmologists at PHCs**

	Bandar Seri Begawan	Berakas A	Berakas B	Gadong	Muara	Sengkurong	Sg Asam
Diabetes and Eye Complications	Y	Y	Y	Y	Y	Y	Y
Importance of DR eye screening in diabetics	Y	Y	Y	Y	Y	Y	Y
Eye Examination procedures conducted in DR screening	Y	Y	Y	Y	Y	Y	Y

**Summary of patient Information and education**

- Both GPs and ophthalmologists reported providing their patients with some information regarding diabetes and its link with eye complications, the importance of attending regular eye appointments and outlining the eye examination procedures in DR Screening
- No systematic approach by GPs or ophthalmologists to health education
- DNEs at PHCs and ophthalmic nurse educator at the NEC were under utilised and counselling services provided were informal.

### 3.3 DR screening coverage and the uptake estimates for DR screening and treatment in the DR screening programme.

#### 3.3.1 DR screening coverage

Screening coverage was defined in this study as the proportion of diabetic patients referred by GPs for diabetic eye screening that had undergone at least one eye examination at the same health centre. At each of the six health centres, screening coverage was estimated for patients given DR screening appointments by their GP between January – March 2012 that:

- 1) Attended diabetic eye screening examinations on the exact referral date (Exact screening coverage - ESC); and
- 2) Attended within the three-month period of the appointment date (Total screening coverage - TSC).

Data sources used to estimate DR screening coverage were based on GP and DR screening data for 2012 at specific health centres which has been detailed in section 2.4.2.

#### *Descriptive statistics*

In this study, 391 patients were recorded as having been referred by GPs across the six different health centres in Brunei-Muara between January – March 2012. The age and gender profiles for the GP referred patients and screening coverage estimates (ESC and TSC) for the six primary health centres in Brunei-Muara are presented in Table 3-17.

The overall mean age of the patients referred to DR screening was 51 years (SD 13). The mean age of referred patients ranged from 49 years (SD 14) at Sungai Assam health centre to 54 years (SD 13) at Muara. In general, there were more female patients referred by GPs to DR screening at all health centres. However, gender distribution varied across different health centres. For example, there were considerably more female patients referred for DR screening at Sengkurong health

centre (35:65). In contrast, Berakas A reported more males being referred (59:41). In addition, Muara health centre reported a relatively even gender distribution (51:49).

Screening coverage estimates (ESC and TSC) were generally low at all health centres (Table 3-17). There were variations observed in screening coverage estimates at individual health centres. For instance, ESC was estimated to be highest at Muara health centre (64%) and lowest at Sungai Assam health centre (51%). For TSC estimates, Muara health centre reported the highest screening coverage (66%) and Berakas A health centre reported the lowest screening coverage (57%). However, in general, when attendance to screening was extended to a three month period from the exact appoint date given to patients by their respective GPs, screening coverage estimates increased only by 5%. Except for Gadong health centre which reported a higher increase in screening coverage estimates (11%), other health centres reported either no or minimal difference in screening coverage estimates. Similar trends were observed when ESC and TSC were calculated for two selected health centres when the data period was extended for one year (January – December 2012) (Table 3-18). The similarity between ESC and TSC figures suggests that patients either attended their appointments on the given dates or not at all.

#### *Factors related to screening attendance*

The relationship between age, gender and health centre with screening attendance (TSC) was further examined (Table 3-19). At the end of the previous section, it was demonstrated that the ESC and TSC values were similar; therefore, for the purposes of this analysis only TSC values were used. In this study, female patients (68%) were more likely to attend screening compared to their male counterparts (53%) ( $p=0.002$ ). There were differences in screening attendance between the different age groups. Screening attendance was highest amongst the 50 - 59 age group (71%) and lowest amongst those aged 39 and below (47%). However, the differences were not found to be statistically significant ( $P=0.022$ ). Similarly, screening attendance was not affected by location of health centres.

**Table 3-17 Age and gender profiles and screening coverage estimates (ESC – exact screening coverage; TSC – total screening coverage) of GP referred patients to DR screening for six health centres in Brunei Muara (January – March 2012)**

Health Centre	Berakas A	Berakas B	Gadong	Muara	Sengkulong	Sungai Assam	All
<i>Age and Gender profiles for referred patients</i>							
<i>Number of patients referred</i>	46	84	64	61	81	55	391
<i>Mean age (SD)</i>	54 (12)	50 (13)	52 (11)	54 (13)	51 (13)	49 (14)	51 (13)
<i>Males (%)</i>	59	46	42	51	35	45	45
<i>Females (%)</i>	41	54	58	49	65	55	55
<i>Screening coverage</i>							
<i>Number of patients attended (ESC%)</i>	26 (57)	46 (55)	34 (53)	39 (64)	46 (57)	28 (51)	219 (56)
<i>Number of patients attended within three months of appointment date (TSC%)</i>	26 (57)	51 (61)	41 (64)	40 (66)	50 (62)	32 (58)	240 (61)

**Table 3-18 ESC and TSC estimates for Gadong and Sengkulong health centres from January – December 2012**

	Gadong health centre	Sengkulong health centre
Total number of GP referrals	346	429
Total number of patients attended (ESC %)	132 (38%)	250 (58%)
Total number of patients attended within 3-month period of appointment date (TSC %)	133 (38%)	262 (61%)
Difference	0	3%

**Table 3-19 Age, gender and screening coverage estimates (TSC – total screening coverage) of GP referred patients to DR screening for selected health centres in Brunei-Muara (January – March 2012)**

	Number of patients given appointment N	Attended appointment N (%)	Did not attend appointment N (%)	P-values
<b>Age Group (Years)</b>				
≤ 39	70	33 (47)	37 (53)	0.022
40-49	101	63 (62)	38 (38)	
50-59	114	81 (71)	33 (29)	
60-69	69	39 (57)	30 (43)	
≥ 70	37	24 (65)	13 (35)	
<b>Gender</b>				
Male	117	94 (53)	83 (47)	0.002*
Female	214	146 (68)	68 (32)	
<b>Health Centre</b>				
Berakas A	46	26 (57)	20 (43)	0.928
Berakas B	84	51 (61)	33 (39)	
Gadong	64	41 (64)	23 (36)	
Muara	61	40 (66)	21 (34)	
Sengkurong	81	50 (62)	31 (38)	
Sg. Assam	55	32 (58)	23 (42)	

\* Statistically significant (P<0.05)

### **Summary of DR screening coverage**

- Based on 3 month screening attendance data (2012), screening coverage estimates (were generally low at all health centres (ESC 56%))
- Screening coverage rates were significantly higher amongst female patients.



### 3.3.2 DR screening uptake

Screening uptake was defined in this study as the proportion of diabetic patients identified as having NSTDR at screening that have attended follow up eye examinations the following year. Screening uptake was estimated for patients examined between January – March 2011, who was given follow up appointments in January – March 2012 that:

- 1) Attended diabetic eye screening examinations on the exact follow up appointment date (Exact Screening Uptake - ESU); and
- 2) Attended within the three month period of the follow up appointment date (Total Screening Uptake – TSU).

Both screening uptake estimates (ESU and TSU) for the seven primary health centres in Brunei-Muara, based on a three month patient attendance data (January – March 2012) are presented in Table 3-20.

A total of 1254 patients with diabetes that had undergone DR screening examination in early 2011 were given follow up fundus examination appointments between January – March 2012. Of those who were given appointments, the average age was 54 (SD 11) in all health centres and mean ages across the different health centres were similar (Berakas A: 52 (SD 10); BSB: 55 (SD 12) (Table 3-20). Overall, more female patients were given appointments for screening at all health centres. However, gender distribution varied across different health centres. For example, in Muara health centre, the gender variation was the greatest (64:36, M:F). In contrast, gender distribution was least at BSB health centre (49:51, M:F).

Screening uptake estimates (ESU: 77% and TSU: 78%) were generally good at all health centres (Table 3-20). However, there were variations observed between health centres. For instance, ESC was highest at Muara health centre (ESU: 95% and TSU: 97%) and lowest at Sungai Assam health centre (ESU: 61% and TSU: 62%).

Overall, when patients' attendance to follow up screening appointments was extended to a three month period from the exact appoint date given by the DR screening team, screening uptake estimates increased by only 1%. This trend was also observed across all health centres. The similarity between ESU and TSU figures suggests that patients have either attended their appointments on the given dates or not at all.

In the following section, the effect of age, gender and health centre on TSU will be discussed and as ESU and TSU values were found to be similar, only TSU values will be used in the analysis and discussion.

#### *Factors associated with screening uptake*

Screening uptake rates (TSU) were compared by age group, gender and health centres and results are presented in Table 3-21. Screening uptake rates (TSU) varied significantly between health centres ( $p < 0.001$ ). Muara health centre (97%) reported the highest attendance whilst Sungai Assam health centre (62%) reported the lowest rates. Other health centres reported similar attendance rates. It was also noted that the total number of patients given appointments also varied across the different health centres (Table 3-21). Only 64 patients were given appointments at Muara health centre compared to 360 patients at Sengkurong health centre during the three month period.

No statistically significant difference in screening uptake rates (TSC) observed between age groups and gender.

**Table 3-20 ESU and TSU for the seven primary health centres in Brunei-Muara, based on a three month patient attendance data (January – March 2012)**

Health Centre	BSB	Berakas A	Berakas B	Gadong	Muara	Sengkurong	Sungai Assam	All
<i>Age and Gender profiles for patients given follow up appointments</i>								
<i>Number of patients</i>	111	80	284	237	64	360	112	1254
<i>Mean age (SD)</i>	55 (12)	52 (10)	56 (12)	53 (10)	53 (12)	55 (11)	55 (12)	54 (11)
<i>Males (%)</i>	49	43	40	39	36	41	37	41
<i>Females (%)</i>	51	58	60	61	64	59	63	59
<i>Screening uptake</i>								
<i>Number of patients attended (ESU%)</i>	90 (77)	65 (81)	202 (71)	190 (80)	61 (95)	288 (80)	68 (61)	964 (77)
<i>Number of patients attended within three months of appointment date (TSU%)</i>	91 (78)	66 (83)	203 (72)	191 (81)	62 (97)	290 (81)	69 (62)	972 (78)

**Table 3-21 Age, gender and screening uptake estimates (TSU – Total Screening coverage) of patients attending follow up DR screening for selected health centres in Brunei-Muara (January – March 2012)**

	Number of patients given appointment	Attended appointment N (%)	Did not attend appointment N (%)	P-values
<b>Age Group (Years)</b>				
≤ 39	120	94 (78)	26 (22)	0.823
40-49	271	208 (77)	63 (23)	
50-59	442	354 (80)	88 (20)	
60-69	293	228 (78)	65 (22)	
≥ 70	114	87 (76)	27 (24)	
<b>Gender</b>				
Male	508	338 (76)	120 (24)	0.384
Female	743	583 (79)	160 (21)	
<b>Health Centre</b>				
BSB	117	91 (78)	26 (22)	<0.001*
Berakas A	80	66 (83)	14 (17)	
Berakas B	284	203 (72)	81 (28)	
Gadong	237	191 (81)	46 (19)	
Muara	64	62 (97)	2 (3)	
Sengkurong	360	290 (81)	70 (19)	
Sg. Assam	112	69 (62)	43 (38)	

\* Statistically significant (P <0.001)

### **Summary of DR screening uptake**

- DR screening uptake rates were good at all health centres (ESU: 77% and TSU: 78%)
- Screening uptake rates were significantly higher for Muara health centre and significantly lower rates reported for Sungai Assam health centre.

#### **3.3.3 DR treatment uptake**

Treatment uptake was defined in this study as the proportion of STDR cases referred by ophthalmologists (screeners) that have undergone laser treatment. In this study, STDR cases were defined as patients diagnosed with severe NPDR and PDR cases or any DR presenting with macular oedema. There was no reported definition of STDR patients or referable cases used by the DR Screening programme. Therefore, the above definition was adopted based on recommendations by vitreo-retinal specialists interviewed in this study.

There was little information available on the STDR cases referred and treated at the NEC by the DR screening programme. Therefore, for the purposes of this study, all STDR cases recorded in patient attendance statistics for the seven health centres in 2012 (January – December 2012) were reviewed. This data was cross-referenced with all recorded laser photocoagulation treatment conducted (January 2012 – July 2013) by the main vitreo-retinal surgeon conducting laser treatment at the NEC. Using the best available data from these two data sources, the estimates for all STDR patients referred by DR screening that underwent laser photocoagulation treatment at the NEC (Treatment Uptake) were calculated.

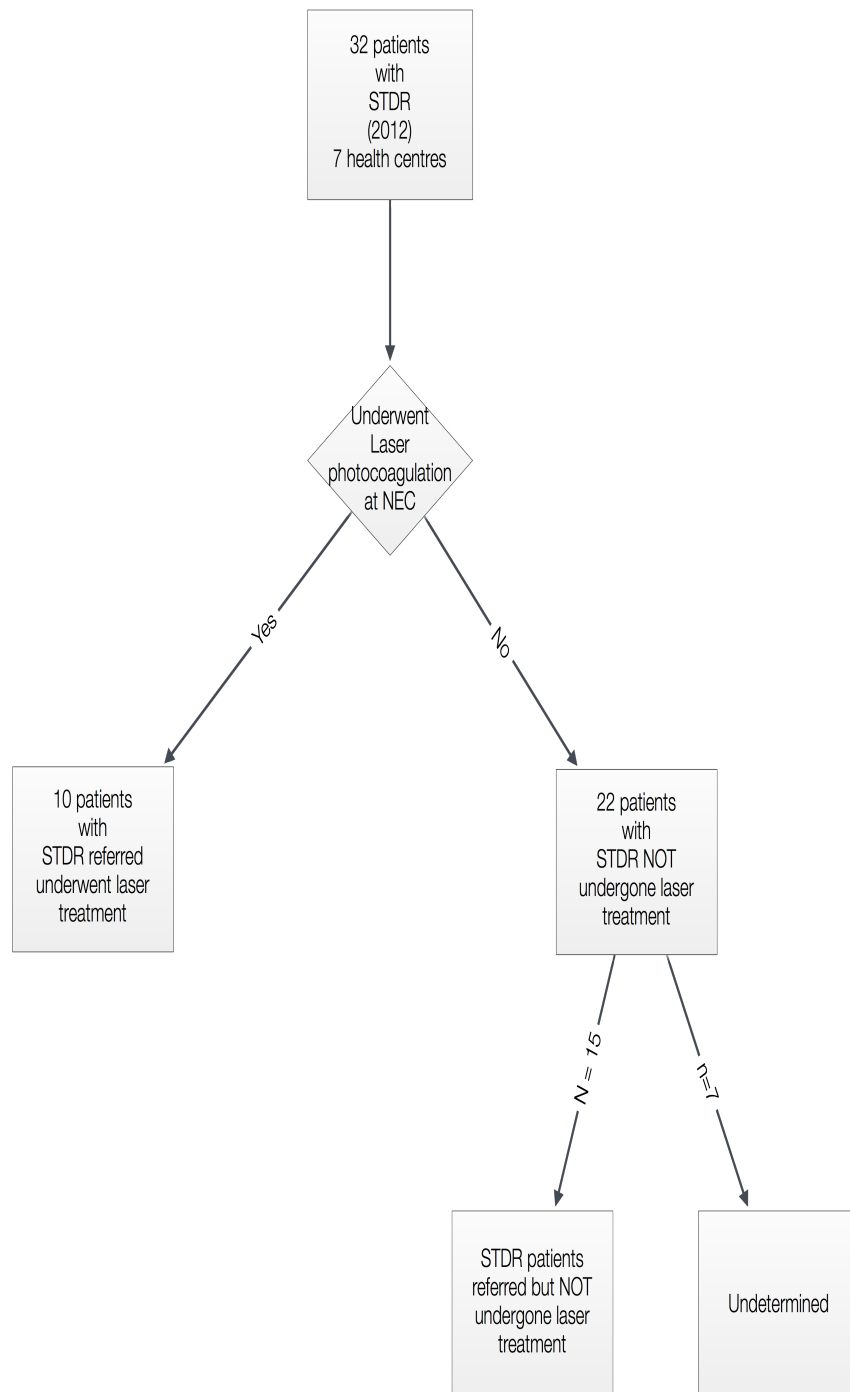
Figure 3-11 outlines the status of STDR patients referred to the NEC for treatment from the seven health centres to the NEC and the corresponding data for DR treatment uptake and age, gender profiles are summarised in Table 3-22. Between January – December 2012, a total of 32 patients from the 7 health centres were graded as STDR cases and referred to the NEC. Of the 32 patients referred, 10 (31%) patients have undergone laser treatment (DR treatment uptake) at the NEC between

January – July 2013. On average, it took 12 weeks (SD 13) for a patient with STDR referred from the health centres to undergo laser photocoagulation at the NEC. Of the remaining 22 patients that have not undergone laser photocoagulation, 15 patients were reported to be referred to the NEC but have not undergone laser treatment and the status of 7 patients were undetermined.

The profiles (age, gender and referring health centre) for patients that attended laser treatment were similar. Of the 10 patients that have undergone laser treatment at the NEC, patients were mostly males (80%) and were older (over 50s) (90%). There were more females given screening appointments and attending screening sessions compared to males (Table 3-22). It was also observed that the highest proportion of attendees for laser treatment at the NEC were referred from Berakas A (30%) and Sengkurong (30%).

Despite the reported low treatment uptake (31%), the limitation of the data sources used to derive these estimates suggests that their accuracy may be limited.

**Figure 3-11 Status of STDR patients referred by DR screening to NEC**



**Table 3-22 Age and gender profiles of STDR patients referred to NEC in 2012**

	Number of STDR patients referred	Number of STDR patients operated (%)
All	32	10 (31%)
Age <50	12	1 (10%)
Age > 50	20	9 (90%)
Male	23	8 (80%)
Female	9	2 (20%)
<i>Health Centre</i>		
BSB	4	1 (10%)
Berakas A	7	3 (30%)
Berakas B	4	1 (1%)
Muara	1	0
Sengkurong	10	3 (30%)
Sungai Assam	6	2 (20%)

***Summary of treatment uptake***

- DR treatment uptake (31%) was reported to be low
- On average, all referred STDR patients underwent their first laser treatment at the NEC within the recommended target (12 weeks).

### 3.4 Analysis of key characteristics and clinical findings of persons attending the DR screening programme

#### 3.4.1 DR registry (2008 – 2012)

The DR registry is a register of patients with diabetes attending DR screening programme in the Brunei-Muara district. The purpose of the register was to compile the list of patients that have undergone DR screening examination at the NEC and the seven health centres.

All the information recorded into the registry was based on data collected by ophthalmic assistants when patients were first registered into the system. Structured observations of the NEC suggest that this registry data was not updated and therefore, the data presented and analysed in this study will not reflect the latest information. In addition, data collection for the registry was discontinued in January 2013 as the NEC introduced a new DR registry format that was based on the REPAS DR grading. However, during the study period, data collection using the new DR registry was affected by logistical issues and therefore was not available for analysis. For this study, the registry data used was based on DR screening period from January 2008 – December 2012.

Demographic and clinical data of 6,712 patients with diabetes who attended DR screening clinics from January 2008 – December 2012 is presented in Table 3-23. The mean age of patients was 53 years (SD 11.74). The majority of patients were aged between 50 – 59 years (n = 2,400; 36%) and in contrast, patients aged 30 or below represented the least. There were more female patients (n = 4,044; 60%) registered compared to males (n = 5,668; 40%). The majority of patients registered were Malays (n = 6,129; 91%), followed by Chinese (n = 454; 7%), Indians (n = 17; 0.3%) and other ethnic groups (n = 112; 2%). The vast majority of the registry patients were type 2 DM (n = 6469; 97%).

The distribution of DR status amongst patients who were graded by ophthalmologists by mydriatic retinal examination using a slit-lamp bio-microscopy suggests a low DR prevalence amongst patients with diabetes in Brunei-Muara



attending DR screening. The majority of patients screened had no DR (n = 6,323; 94%) and only 6% (n = 373) were reported to have any form of DR. Patients with NPDR were 5% (n = 345) and 0.42% (n = 23) of patients screened had PDR. Sight threatening DR (Severe NPDR and MO) was present in 67 patients (1%). MO was present in 14 patients (0.21%). Using the International Classification of Disease 10 (ICD-10) for visual impairment based on presenting visual acuity in the better eye, visual impairment was present in 132 patients (2.27%) and 5 patients (0.06%) were classified as blind. However, the main causes of visual impairment were unknown.

#### 3.4.2 Risk factors associated with diabetic retinopathy

Table 3-24 shows the odds ratios (adjusted and unadjusted) associated with the different parameters amongst registered patients. Patients with type 2 DM had a significantly lower risk of developing DR than those with type 1 DM (unadjusted OR: 0.15; 95% CI: 0.09 – 0.25, adjusted OR: 0.43; 95% CI: 0.24 – 0.78). The odds of developing DR significantly increased with duration of diabetes. Patients having diabetes between 21 – 25 years were almost **nineteen times** (OR: 18.98; 95% CI: 6.43 – 55.94) more likely to develop DR compared to newly diagnosed DM (DM less than 1 year) and this remained significant with multivariate adjustment. The risk for developing DR is highest in patients that have been diagnosed with diabetes for 30 years or longer (Adjusted OR: 13.25; 95% CI: 1.72 – 101.98).

Patients with high FBG levels (>7.0 mmol/l) had a significantly higher risk of developing DR compared to those with lower FBG levels (OR: 1.38; 95% CI: 1.11 – 1.70), although the significance was lost after adjustment for other variables (OR: 1.05; 95% CI: 0.81 – 1.37). In contrast, patients with high HbA1c levels (> 6.5%) were consistently reported to have a significantly higher risk in developing DR compared to those with lower HbA1c levels (Unadjusted OR: 1.52; 95% CI: 1.19 – 1.93, Adjusted OR: 1.49; 95% CI: 1.18 – 2.00).

Patients with reported renal problems were found to have a significantly higher risk of developing DR compared to those without renal problems (Unadjusted OR: 6.50; 95% CI: 2.99 – 14.06, Adjusted OR: 3.34; 95% CI: 1.25 – 8.95). Smokers had a

significantly higher risk of developing DR compared to those who do not smoke (Unadjusted OR: 3.45; 95% CI: 1.67 – 7.11), but this was not significant with adjustment for other variables. In this study, both hypertension and hypercholesterolemia did not show any significant association with DR.

In this study, the sites (NEC and seven health centres) where registered patients (with and without DR) underwent eye examination were compared. The proportion of patients with DR being detected was significantly more when patients were screened at the NEC and Gadong health centre. Compared to patients being screened at Bandar Seri Begawan health centre (baseline), patients screened at the NEC were more likely to have DR (Unadjusted OR: 29.23; 95% CI: 12.93 – 66.08; Adjusted OR: 25.07, 95% CI: 11.01 – 57.05). With multivariate adjustment, an increased likelihood of having DR was also found at Gadong health centre (Adjusted OR: 4.08; 95% CI: 1.42 – 11.67).

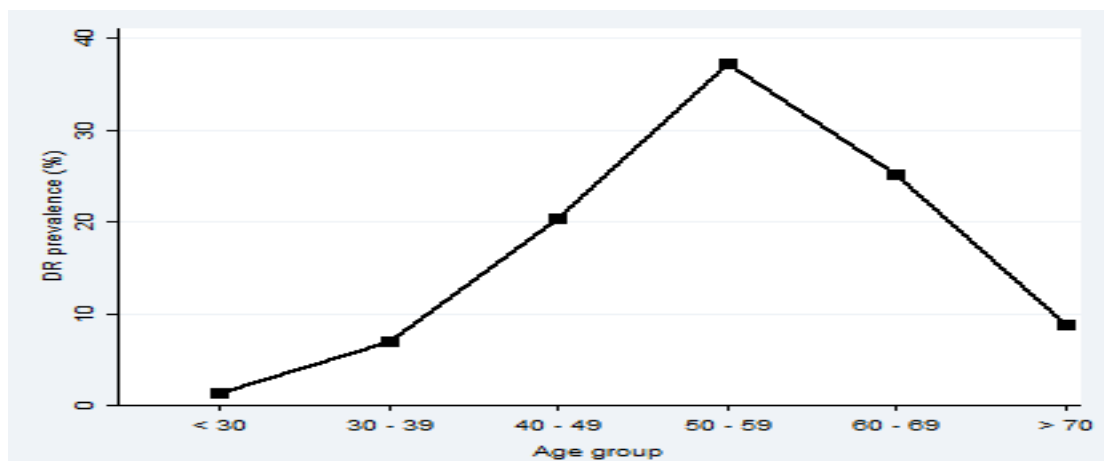


Figure 3-12 Prevalence of DR in the different patient age groups

**Table 3-23 Demographic and clinical characteristics of patients with DM (January 2008 – December 2012)**

	N	%
<i>Age Group</i>		
• < 30	166	2
• 30-39	670	10
• 40-49	1,623	24
• 50-59	2,400	36
• 60-69	1,311	20
• > 70	543	8
<i>Gender:</i>		
• Male	2668	40
• Female	4044	60
<i>Ethnic background</i>		
• Malay	6,129	91
• Chinese	454	7
• Indian	17	0.3
• Others	112	2
<i>Type of Diabetes Mellitus</i>		
• Type 1	87	1
• Type 2	6,469	96
• Undetermined	156	2
<i>DR Status*</i>		
• No DR	6,323	94
• Mild NPDR	182	3
• Moderate NPDR	134	2
• Severe NPDR	29	0.4
• PDR	28	0.4
• No Grading	15	0.2
• No View	1	0.01
<i>Presence of MO</i>		
• Yes	14	0.2
• No	6,698	99.8
<i>STDR (PDR and MO)</i>		
• No	6,629	98.8
• Yes	67	1
• Un-gradable or undetermined	16	0.2
<i>Categories of visual impairment (VA)**</i>		
0 - Mild or no visual impairment (> 6/18)	6,555	98
1 - Moderate visual impairment (6/18 - 6/60)	142	2.1
2 - Severe visual impairment <6/60 - 3/60	10	0.1
3 – Blindness (<3/60 - 1/60)	1	0.01
4 – Blindness (< 1/60 – PL)	3	0.04
5 – Blindness (NPL)	1	0.01

\*DR Status based on funduscopy findings in the worse graded according to the International Clinical Diabetic Retinopathy and Diabetic macular oedema disease severity scale<sup>(34)</sup>

\*\*Presenting distance visual acuity of better eye based on ICD-10 Classification (2006) for visual impairment.<sup>(141)</sup>

**Table 3-24 Factors associated with the presence of diabetic retinopathy**

N= 6, 696 patients registered	Number with any DR	Any DR (%)	Odds ratio (95% CI)	Adjusted Odds ratio (95% CI)
<b>Age Group (Years)</b>				
< 30	5	1	Baseline	
30-39	26	7	1.29 (0.49 – 3.41)	1.66 (0.59 – 4.70)
40-49	76	20	1.57 (0.62 – 3.93)	2.20 (0.82 – 5.89)
50-59	139	37	1.96 (0.79 – 4.85)	2.40 (0.90 – 6.41)
60-69	94	25	2.46 (0.99 - 6.14)	2.50 (0.92 – 6.76)
> 70	33	9	2.07 (0.79 – 5.39)	1.64 (0.58 – 4.70)
<b>Gender</b>				
Male	158	42	Baseline	
Female	215	58	0.89 (0.72 – 1.10)	0.90 (0.71 – 1.14)
<b>Ethnic Background</b>				
Malay	337	90	2.10 (0.66 – 6.65)	2.79 (0.65 – 12.02)
Chinese	33	9	2.82 (0.85 – 9.40)	2.43 (0.54 – 11.00)
Indian	0	0	0	0
Others	3	0.8	Baseline	
<b>Type of Diabetes Mellitus</b>				
Type 1	22	5.9	Baseline	
Type 2	321	86	0.15 (0.09 – 0.25)*	0.43 (0.24 – 0.78)*
<b>Duration of Diabetes Mellitus</b>				
Less than 1 year	5	1	Baseline	
1 – 5 years	110	30	2.96 (1.20 – 7.29)	2.87 (1.02 – 8.03)
6 – 10 years	142	38	6.48 (2.64 – 15.91)*	5.12 (1.83 – 14.38)*
11 – 15 years	41	11	7.73 (3.02 – 19.74)*	5.90 (2.02 – 17.33)*
16 – 20 years	53	14	16.34 (6.45 – 41.40)*	8.53 (2.90 – 24.98)*
21 -25 years	12	3	18.98 (6.43 – 55.94)*	7.21 (2.07 – 25.11)*
26 – 30 years	8	2	13.66 (4.30 – 43.37)*	7.36 (1.94 – 28.00)*
Over 30 years	2	0.5	11.39(2.04 – 63.50)*	13.37 (1.74 – 103)*
<b>Fasting Blood Glucose</b>				
> 7.0 mmol/l	227	61	1.38 (1.11 – 1.70)*	-
<b>HbA1c</b>				
> 6.5 %	280	75	1.52 (1.19 – 1.93)*	1.52 (1.16 – 2.00)*
<b>Hypertensive</b>	322	86	0.81 (0.60 – 1.11)	1.15 (0.80 – 1.65)
<b>Hyper-cholesterolemia</b>	285	76	0.72 (0.57 – 0.93)	1.04 (0.78 – 1.40)
<b>Smoking</b>	9	2	3.45 (1.67 – 7.11)*	1.03 (0.44 – 2.42)
<b>Renal problems</b>	9	2	6.50 (2.99 – 14.06)*	3.34 (1.25 – 9.00)*
<b>Location of screening</b>				
National Eye Centre	288	77	29.23 (12.93 – 66.08)*	25.09 (11.01 – 57.05)*
Bandar Seri Begawan	6	2	Baseline	
Berakas A	9	2	1.38 (0.54 – 3.54)	1.40 (0.55 – 3.58)
Berakas B	14	4	1.46 (0.59 – 3.63)	1.38 (0.55 – 3.45)
Gadong	17	5	3.40 (1.30 – 9.66)	4.08 (1.42 – 11.67)*
Muara	9	2	1.08 (0.41 – 2.83)	1.09 (0.41 – 2.87)
Sengkurong	22	6	1.25 (0.43 – 3.62)	1.22 (0.42 – 3.57)
Sungai Assam	8	2	1.33 (0.47 - 3.77)	1.29 (0.45 – 3.67)

\*P<0.001

**Summary of analysis of DR registry (2008 – 2012)**

- Prevalence of DR in Brunei (5.8%; 95% CI: 5.03 – 6.13) was considerably lower compared to other regional population based studies (35.0%; 95% CI: 28.2 – 43.4) (4)
- Risk factors for DR included having type 1 diabetes, longer duration of diabetes, high levels of FBG and HBA1c, smoking, presence of renal problems
- Patients were more likely to be detected with DR if screened at NEC and Gadong health centre (adjusted odds).

### 3.5 Estimated costs associated with the screening and treatment of DR in Brunei-Muara district.

In this study, the per person provider cost of DR screening at Gadong health centre and laser photocoagulation treatment at the NEC, Brunei-Muara district was calculated. The per person provider cost estimates for DR screening and treatment will now be discussed in turn.

#### 3.5.1 Annual costs of DR screening

Resource items used for DR screening at Gadong health centre (identified through interviews with key informants) have been described in detail in section 3.2.3. Direct provider costs used in this costing study are categorised as patient specific screening costs (staff, equipment, consumables) and overhead costs (building costs).

##### *Screening-related costs*

- Staff costs

Annual DR screening-related costs for different resource items (staff, consumables and equipment) at Gadong health centre are presented in Tables 3-25 – 3-28. Total annual staff costs for screening at Gadong health centre were estimated as £25,284 per year (Table 3-25). Costs were considerably higher for the ophthalmologist (£21,324 per year) compared to the ophthalmic assistant (£3,960 per year).

- *Equipment and consumable costs*

The total annualised equipment costs for DR screening at Gadong health centre based on 2012 prices was £1,318 (Table 3-26). The only reported consumable used for screening was dilation drops (Mydriacyl). Annual usage of Mydriacyl was based on an estimated 12 month usage at Gadong health Centre in 2012 on the basis of screening 1226 patients (12 x 15-ml bottles). The unit price of Mydriacyl was based on 2012 prices obtained from the procurement section, RIPAS Hospital, Ministry of Health. The annual cost of consumables used in DR screening was estimated to be £72 per year (Table 3-27).

- *Overhead costs*

Annualised building costs were estimated to be £655 (Table 3-28). These costs include rental costs for an examination room (£393) and a triage room (£262). Shared overhead costs, utility, maintenance and administrative sundries costs were estimated to be £65.

**Table 3-25 Annual costs of NEC staff involved in DR screening at Gadong health centre**

Staff	Details of activity	Units	Monthly Salary (£)	Annual Cost (£)
Ophthalmologist	Fundus examination	1	1777	21,324
Ophthalmic assistant	Administrative support	1	330	3,960
<b>Sub-total</b>				<b>25,284</b>

**Table 3-26 Annualised cost of equipment used in DR screening at Gadong health centre**

Equipment	Details	Unit cost (£)	Units	Lifespan (Years)	Annualised Cost (£)
Visual acuity Chart Projector	Used to assess visual acuity	1,208	1	10	142
Slit lamp bio-microscope	Used by Ophthalmologists to view fundus during screening	6,223	1	10	730
Super field Lens	Used by Ophthalmologists together with either slit lamp bio-microscope or indirect Ophthalmoscope to view fundus during screening	862	1	10	101
Indirect Ophthalmoscope	Used by Ophthalmologists to view fundus during screening (if fundus cannot be viewed using slit lamp)	1,670	1	10	196
Direct Ophthalmoscope	Used by Ophthalmologists to view fundus during screening (used only if fundus cannot be viewed using slit lamp or for patients on wheelchairs)	1,269	1	10	149
<b>Subtotal</b>					<b>1,318</b>

**Table 3-27 Annual cost of consumables used in Gadong health centre**

Consumables	Details of activity	Unit costs (£)	Quantity used	Annual Cost (£)
Tropicamide 1% (Mydriacyl)	Dilating eye drops	6	12 bottles	72
<b>Sub-total</b>				<b>72</b>

**Table 3-28 Cost of building space and utility costs for DR screening at Gadong health centre**

	Details	Area (per m <sup>2</sup> )	Building cost per m <sup>2</sup> (£)	Total building cost (£)	Annual building costs (£)
<i>Building costs</i>					
Examination room	Doctor examination room	12	843	10,116	393
Triage room	Visual Acuity assessments, appointments and logistics.	8	843	6,774	262
<i>Total building costs</i>			655		
<i>Shared costs, Utility (electricity and water) costs, maintenance and administrative costs</i>			65		
<b>Sub-total</b>			<b>720</b>		

**Cost per patient screened**

The total per patient costs for DR screening at Gadong health centre is presented in Table 3-29. There were 1,226 patients with DR attending screening at Gadong health centre between January – December 2012. Based on these figures, the total provider cost per patient screened was estimated at £23. The highest provider cost per patient screened was staff costs at £21 per patient and consumables (and shared costs) accounted for the lowest provider cost per patient (£0.05).



**Table 3-29 Annual costs per year and costs per patient screened for DR screening at Gadong health centre**

<b>Items</b>	<b>Cost per year (£)</b>	<b>Cost per patient (£)</b>
Staff	25,284	21
Equipment	1,318	1
Consumables	72	0.05
Building	655	0.50
Shared overhead costs, utility, maintenance and administrative sundries costs	65	0.05
<b>Totals</b>	<b>27,394</b>	<b>23</b>

### 3.5.2 Annual costs of DR treatment

#### *Treatment related costs*

- *Staff costs*

Annual DR treatment-related costs for different resource items (staff, consumables and equipment) at the NEC are presented in Tables 3-30 – 3-33. Total annual staff costs at the NEC were estimated at **£64,490** per year. This includes the annual costs for an ophthalmologist (£52,384) and an ophthalmic nurse (£12,106) (Table 3-30).

- *Equipment and consumables costs*

Total annualised equipment costs for DR treatment at the NEC were **£6,079** (Table 3-31). The most expensive equipment was the argon green laser 520 nm (£4,761), followed by the slit-lamp bio-microscope (£730), indirect ophthalmoscope (£196), direct ophthalmoscope (£149), visual acuity projectors (£142) and super field lens (£101). The two main consumables used in treatment were dilation drops (Tropicamide (Mydracyl) 1%) and local anaesthetic drops (Tetracaine Hydrochloride 1.0%). The total annual cost of these consumables was estimated to be £530 (Table 3-32).

- *Overhead costs*

The total estimated annual overhead costs (building and utility costs) were estimated to be £1,010. Annual building costs for DR treatment were estimated to be £918 per year (Table 3-33). These costs include rental costs for an examination and treatment room (£655 per year) and for a triage room (£263 per year). Utility costs were estimated to be £92 per year.

**Table 3-30 Annual staff costs for NEC staff involved in DR treatment**

Staff	Details of activity	Units	Monthly Salary (£)	Annual Costs (£)
Vitreo-retinal surgeon	Fundus examination and laser treatment	1	4,365	52,384
Ophthalmic Nurse	Clinical and Administrative support	1	1,008	12,106
<b>Sub-total</b>				<b>64,490</b>

**Table 3-31 Annualised cost of equipment used in laser photocoagulation treatment at NEC**

Equipment	Details	Unit cost (£)	Units	Lifespan (Years)	Annualised Cost (£)
Visual acuity chart projector	Used to the assessment of visual acuity	1,208	1	10	142
Slit lamp bio-microscope	Used by Ophthalmologists to view fundus during examination and treatment	6,223	1	10	730
Super-field lens	Used by Ophthalmologists together with either slit lamp bio-microscope or indirect Ophthalmoscope during fundus examination	862	1	10	101
Indirect ophthalmoscope	Used by Ophthalmologists to view fundus (if fundus cannot be viewed using slit lamp)	1,670	1	10	196
Direct ophthalmoscope	Used by Ophthalmologists to view fundus (used only if fundus cannot be viewed using slit lamp or for patients on wheelchairs)	1,269	1	10	149
Argon green laser (532 nm)	Laser machine used by Ophthalmologists in laser photocoagulation treatment for STDR cases	40,609	1	10	4,761
<b>Sub-total</b>					<b>6,079</b>

**Table 3-32 Annual cost of consumables used for laser photocoagulation treatment at NEC**

Consumables/ Medications	Details of activity	Unit costs (£)	Quantity used	Annualised Cost (£)
Tropicamide 1% (Mydrinacil) Minims	Dilating eye drops	1.10	204	224
Tetracaine 1% Minims	Local anaesthetic drops	1.50	204	306
<b>Sub-total</b>				<b>530</b>

**Table 3-33 Costs for building and utility costs for laser photocoagulation treatment rooms at NEC**

	Details	Area (per m <sup>2</sup> )	Building cost per m <sup>2</sup> (£)	Total building cost (£)	Annual building costs (£)
<i>Building costs</i>					
Examination room	Doctor examination and treatment room	20	843	16,860	655
Triage room	Visual Acuity assessments, appointments and logistics.	8	843	6,744	263
<i>Total building costs</i>			918		
Shared overhead costs, utility, maintenance and administrativ e sundries costs **			92		
<b>Sub-total</b>			<b>1,010</b>		

**Cost per patient treated**

The total per patient costs for DR per patient treated at NEC is presented in Table 3-34. There were 204 patients (612 sessions) with STDR undergoing laser photocoagulation treated at NEC between January – December 2012. Based on these figures, the total provider cost per patient treated was estimated at £114. The highest provider cost per patient treated was staff costs at £105 per patient treated

and shared overhead costs accounted for the lowest provider cost per patient treated (£0.15).

**Table 3-34 Annual costs per year and cost per patient for DR treatment at the NEC**

<i>Items</i>	<i>Cost per year (£)</i>	<i>Cost per patient (£)</i>
Staff	<b>64,490</b>	105
Equipment	<b>6,079</b>	0.9
Consumables	<b>530</b>	6
Building	<b>918</b>	2
Shared overhead costs, utility, maintenance and administrative sundries costs	<b>92</b>	0.15
<b>Totals</b>	<b>121,640</b>	<b>114</b>

### 3.6 Stakeholder's perspective of DR screening in Brunei-Muara

Twenty semi-structured face-to-face interviews with key informants (see Table 2-4, section 2.4.5) involved at various stages of the DR screening pathway were conducted between September and October 2013. The interviews sought to explore respondents' opinions on the strengths and weaknesses of the present DR screening programme and how it could be improved from the provider perspective. Several cross cutting themes emerged from the analysis of the interview transcripts and these will be discussed under two key headings:

1. Perceived value of DR screening
2. Challenges in DR screening

#### 3.6.1 Perceived value of DR screening

Respondents valued DR screening in many ways. Firstly, respondents recognised the clinical importance of DR screening and early intervention to prevent the development of DR.

*"In a way this [DR screening] will help them [patients] to reduce the severity of the complication if it is detected early; we can monitor it or do something about it" (K18, L: 48-50).*

*"So, definitely identifying the DR patients early would help managing the condition and avoiding serious complications at the early stages and it saves a lot of financial burden for the health system" (K118, L: 204-207).*

*"Especially conditions involving macular oedema early intervention with laser would definitely benefit them, even with PDR when we do early PRP (pan-retinal photocoagulation) it helps, so intervention at that [early] stage helps them to prevent further loss" (K121, L: 83-86).*

Both GPs and ophthalmologists also highlighted the comprehensive diabetic care (including DR screening by ophthalmologist) provided at health centres in Brunei. This was regarded as a unique strength of the health system.

*“Early screening and early detection and early treatment is there [available]; everything is possible when you do the screening. So, I think the patient and the overall health system benefits” (KI22; L: 77-79).*

*“It’s [the services at PHCs] like a one-stop health centre, it’s not just for screening eyes its managing the patient altogether [holistic care]” (KI6; L: 92-97).*

*“I think Brunei’s DR screening is unique in a way if you compare to other countries. It has a small population and patient to ophthalmologist ratio is quite high compared to other countries. So, we can use ophthalmologists to screen, which is almost impossible to do in other countries” (KI18, L: 149-151).*

Several themes emerged on the perceived key strengths of the screening programme are reported below as patient benefits and provider benefits.

**i. Patient benefits**

- Physical access to care

Both ophthalmologists and GPs shared the opinion that diabetic patients attending DR screening at PHCs have benefitted from the ease of physical access to these centres.

*“Accessibility, I think. Before [screening at PHCs] they just come to the hospital, as you can see it is difficult to come in and out [of the hospital compound due to traffic congestion]” (KI17, L: 136-137).*

*“I think it’s accessibility, it’s easier to park here [PHC], it’s closer to their home, they can sit here, the building is new, it’s more comfortable” (KI3, L: 115-116).*

- Comprehensiveness of services

In addition to physical access, ophthalmologists identified that the provision of DR screening sessions at the PHCs enables patients to attend both GP and ophthalmology services in one place, during the same visit. This was perceived to promote better clinical care and better health education.

*“It’s [the DR screening clinic] very close to the outpatient department where we can advise and refer if there is any [metabolic] changes, like there is uncontrolled diabetes, we can refer them to the doctor [GP] for monitoring, control, so it’s a close connection with OPD doctor, working hand in hand” (K123, L: 81-86).*

- Shorter waiting times for patients (clinical and personal benefits)

One respondent thought that patients screened at PHC have relatively shorter waiting times for examination compared to patients screened at the NEC. This brings both clinical and personal (time-saving) benefits for patients.

*“When we [Ophthalmologist] have the overall patient waiting outside for eye services [General clinics at the NEC], diabetic eye care screening patients will have to wait more [longer]. So the waiting time is a big issue now. I think it’s less of an issue at the peripheral eye clinics” (K118, L: 227-230).*

- Ophthalmologists able to spend more time per patient at PHCs

More screening sessions with fewer patients per session are held at the PHC compared to the NEC screening. This was viewed as an opportunity to provide better quality and detailed interaction between ophthalmologists and patients.

*“At NEC, patients don’t have time to ask any questions but if it’s at the health centres, doctors [ophthalmologists] can spend more time, in detail and explain [counselling]” (K111, L: 96 - 98).*

*“Here [NEC], most times when patients come, you don’t even know them [by name]. But there [PHCs] it’s like close bonding [build rapport] and lot of times we have time to call and talk to the patient, here [NEC] there is no time” (K110, L: 128 - 131).*

- Benefits of screening at the NEC is access to specialist care

Respondents suggested that a distinct advantage of being screened for DR at the NEC was that patients themselves view the NEC as being a reputable organisation compared to the relatively new eye clinics at the PHCs. In addition, respondents also highlighted that patients screened at the NEC will also have access to other specialist services located in the same tertiary hospital as the NEC.



*“So there are some patients who would like to come to RIPAS [NEC], they feel that they trust it more, its and older institute and they feel that everything is available, that is the main thing.” (KI21, L: 88-90).*

**ii. Provider benefits**

Providers considered the system to be was quicker in responding to referrals but also met the needs of cross speciality sharing of patient records for comprehensive care delivery. The PHC model was viewed to have that advantage.

- Better accessibility to DR screening appointments for GPs

GPs emphasised that one of the advantages of providing DR screening at the PHCs was that the process of GP referrals to DR screening were much better than they had previously experienced. This was because GPs had immediate access to DR screening appointment book that was kept onsite at PHC and was also in direct discussion with the ophthalmologist when making referrals. This was viewed as more efficient compared to the practice at the NEC that requires telephone arrangements for appointments.

*“ If it [screening] were to be done at NEC, we [GPs] would be calling to the NEC to book (appointment) – there will be one staff calling for every diabetic patient or what we could do is compile a list of patients and at the end of the day my staff will go to call the eye clinic” (KI3, L: 128-131).*

*“We [GPs] don’t have to go through the hassle of calling for appointments; that reduces our workload in referring patients” (KI4, L: 134-13).*

*“It’s much better now, previously it was difficult so they [patients] do skip it [appointments], then again if they miss an appointment for any cause, it is very difficult to get an appointment at NEC, when it comes to the periphery (health centres) it’s easy and flexible and we always give as early as possible” (KI22, L: 69-73).*

- Access to shared case notes

Another key benefit of providing DR screening at PHCs was access to shared patient case notes (GP and eye notes). According to GPs sharing clinical notes, which are kept at the health centre, has given them access to eye notes which were not previously available to them. This has enabled GPs to monitor the DR status of their patients.

*“We share the same notes (clinical notes), so we can see the notes as written by the eye doctor, see what their comment is and maybe they can see what we are doing as well” (K12, L: 70-74).*

*“Before we had different notes [case notes], I think that’s a positive thing about having it here [DR screening at PHC]. Another thing, they do a small (paper slip) on the patients file labelled “No DR”; so it’s easy for us [GPs] to know [DR status]” (K13, L: 140-142).*

#### **SUMMARY**

- Overall, respondents valued screening clinically and the organisation of existing services for patients with diabetes at PHCs (comprehensiveness and accessibility)
- Perceived patient benefits include: ease of physical access to diabetic care (single location, transportation, time, etc.); comprehensiveness of services (clinical care, health education), shorter patient waiting times for examination, flexibility of different screening sites and accessibility to specialist services
- Perceived provider benefits include direct GP to DR screening referrals and access to shared case notes between health professionals.

### 3.6.2 Challenges with DR screening

The perceived value of screening to providers and patients suggests that the DR screening model implemented in Brunei-Muara is generally well accepted. However, it is also apparent that some of the above mentioned benefits have not been fully achieved and the respondents highlighted several challenges. These are discussed under the following key themes:

- **Organisation of screening structure**
- **Poor Administration**
- **Lack of communication between professionals and departments**
- **Poor patient awareness and ineffective health education**

## I. Organisation of screening structure

In the earlier sections, it was described that the DR screening in Brunei-Muara is performed at both the NEC and the seven primary health centres (since 2006). Previously, all DR eye examinations were exclusively at the NEC. Analysis of interview transcripts suggests that there is a lack of linear structure in the DR screening pathway to guide both patients and providers. There are contrasting opinions amongst providers as to whether DR screening should solely be at PHCs or should screening continue to be offered at the NEC and PHCs. For example, GPs perceive that they were being discouraged by the NEC to refer patients to the NEC for DR screening. Likewise, some ophthalmologists were aware of the “referral only” policy adopted by the hospital (RIPAS) that had meant primary eye care services (including DR screening) had shifted away from the NEC. However, other ophthalmologists perceive that, in spite of these decentralisation policies, providing DR screening at NEC has its merits and should be developed instead. One respondent cited an example of this were NEC based ophthalmologists have stopped transferring the care (DR screening) of NSTDR patients to PHCs but instead had arranged for follow up eye screening to remain at the NEC. However, it is still unclear whether this lack of a linear structure is as a result of these contrasting opinions amongst respondents or if the lack of a linear structure has caused confusion amongst stakeholders. To gain a better understanding the perceived challenges that have resulted from this lack of a linear structure will be further explored.

*“We [GPs] can’t even refer [patients] to RIPAS [NEC] for diabetic eye screening, they [referred patients] will not be entertained” (KI4; L: 126-127).*

*“We have shut down here [NEC], no walk-ins and only for tertiary referrals and that’s the hospital policy and not the eye clinic policy. The whole hospital is tertiary referral, so, we send them [patients] back to the GPs” (KI17, L: 163-166).*

*“If the two-tier system [screening at both NEC and PHCs] is perfected, I see it as an ideal system, as far as I can see. Obviously currently it’s a mixed bag. The challenge is to bring the patient back for the future assessment” (KI13, L: 274-276).*

*“I remember last year, it was our practice [at NEC], after being seen by the doctor, patients were asked where they stayed and we can move you out [i.e. encourage patients to attend the next follow up screening at PHCs]. But now it’s not routine anymore [doctors stopped actively transferring patients with NSTDR to undergo screening at PHCs]” (KI19, L: 83-85).*

#### *Challenges of DR screening at NEC and PHCs*

There are perceptions of logistical issues that seem to have arisen from the availability of screening for both NEC and the PHCs, and this is impacting at a service delivery level.

- *Perceived staffing constraints on services*

The ophthalmic staff (ophthalmologist and ophthalmic assistants) involved in DR screening at PHCs are all deployed centrally from the pool of ophthalmic staff based at the NEC. Ophthalmologists highlighted their concerns that providing DR screening at both NEC and PHCs may negatively affect the running of existing ophthalmology services at the NEC due to staff shortages.

*“We are still understaffed, we send all our Medical officers out from this unit [to PHC for screening]. There are no Medical officers here except for one on-call. Because to cover the health centres, it should not be like that” (KI17; L: 147-149).*

Furthermore, a shortage of staff was felt by some respondents to result in DR screening sessions at PHCs being cancelled by the Department of Ophthalmology at the last minute. These screening session cancellations have led to patients’ frustrations that have been reported in the local media.

*“I do realise the issues of manpower where several clinics [screening sessions] had to be shut due to shortages of manpower” (KI4, L: 102-103).*

*“The issue [cancellation of screening session] was reported in the local media. This was due to a last minute change of appointment and the patient was not contactable” (KI14, L: 120-123).*

- *Loss of skills among ophthalmologists conducting screening at PHCs*

Ophthalmologists based at the NEC undergo a rotation between providing clinical services at NEC and conducting DR screening at PHCs. However, one respondent felt that some ophthalmologists were spending a disproportionate amount of time in DR screening and providing primary eye care services at PHCs compared to providing clinical services at NEC. This was perceived to put them at risk of losing their other clinical ophthalmology skills that are also required by the NEC.

*“The ophthalmologists at the health centres must do the hospital rotation [clinical ophthalmology clinics and on-calls], if not they lose their skills [other clinical ophthalmology and surgical skills]. If not [doing more primary eye care sessions [they [ophthalmologists] will be completely just doing conjunctivitis, DR and glaucoma screening” (K117, L: 233-238).*

- *Administratively difficult to monitor defaulters*

Patient defaulting their DR screening sessions was a common concern that was raised by GPs, ophthalmologists and endocrinologists. Holding screening sessions at both NEC and PHCs makes monitoring patient’s attendance difficult. There is a lack of an administrative link between the service delivery and screening activities across the system. Respondents have used the term “defaulters” to describe patients that have not attended the DR screening sessions for whatever reason.

*“We can refer them at every visit but you don’t know if they actually have been seen. You can ask the patients obviously, but I don’t know when they were seen, if they were already seen” (K17: 197-198).*

*“Majority of the patients that we are struggling to manage here [NEC] are because of [patients] defaulting appointments” (K118, L: 65-66).*

*“About the retinal screening, we do have patients that do actually still default. They [patients] say that they are being followed up at the peripheral health centres. We don’t know if they actually turn up for their appointments” (K11, L: 20-22).*

- *Data on coverage not available*

As newly diagnosed patients with diabetes are managed by GPs at PHCs, the majority of new referrals to DR screening are from GPs. Prior to implementation of the PHC DR screening model, ophthalmologists viewed that by moving from a hospital-based screening model to a PHC-based, screening coverage would increase. However, respondents indicated that due to lack of data and record keeping it is difficult to determine screening coverage.

*"When I ask them (patients) have you seen the eye doctor, some of them actually missed their eye appointment! Which is quite a few number, and so we have to re-make the appointment again for them but I cannot give you the actual statistics because we do not keep track of that" (KI2, L: 49-51).*

- *Decentralised versus one centre model*

There are two contrasting views amongst ophthalmologists on how DR screening should be structured (i.e. screening at both NEC and PHCs). Some ophthalmologists support the current decentralised system where ophthalmologists are based at primary health centres (at PHCs) and while others felt ophthalmologists should provide all DR services at one central location (at NEC alone).

*"It's [the future plan] eventually to get all the primary health centres (doubling it from now 8 – 16) with provisions of ophthalmic services. If we can do that, we are the only country in the world that is providing eye care at the primary level; a specialists in a primary health centre" (KI17, L: 207-210).*

*"My vision of treatment for DR will be one centre not multiple centres, if it's possible for the community to attend that centre where you have all facilities for DR. Let's say we have 4 or 5 Ophthalmologist for primary screening, then senior MO doing laser and then 2 or 3 retinal surgeons in one centre" (KI20; L: 149-153).*

### **Summary: Lack of linear structure for screening**

- DR screening at both NEC and PHCs is perceived to provide patient benefits including giving patients better access to specialist services and better physical access for specific patient groups (elderly).
- However, offering screening at both locations also brings challenges including staff constraints for both clinical and screening services, loss of skills of ophthalmologists working at PHC, administratively difficult to monitor defaulters and data on coverage are not available.
- Contrasting opinions on the best way to structure DR screening in the future.



## II. Poor administration

Screening has to be coordinated in order to ensure all the processes are followed through in a timely manner (referrals, record keeping, appointments) and this requires the support of an effective administration system. Analysis of interview transcripts suggests that the intended goals of the DR screening programme are affected by poor administration.

- *Manual referral system from GP to DR screening*

Currently, GP to DR Screening referral practices are based on a manual system (books). This manual appointment booking system which is based on handwritten appointments in logbooks kept at each health centre is susceptible to errors, such as incomplete entry and logbooks being misplaced. These issues have led to frustrations for both providers and patients.

*“We [eye staff] feel that appointment book system here [Bandar health Centre] is not a success and they [previous ophthalmic assistants] lost the [appointment] book, I use to photocopy the book to arrange the appointments but now it’s difficult” (K115, L: 64-67).*

*“Some patients do complain that the appointment dates were not written in their cards, so they do miss out” (K17: L: 189-190).*

- *Poor record (data) keeping*

Respondents highlighted the importance of data collection in DR screening programmes. GPs and ophthalmologists perceived several benefits of data collection in the context of disease registries. They recognised the importance of data in key areas of their work such as clinical audits, to support decision-making, monitoring attendance and for quality assurance purposes.

*“The eye registry (DR) is basically to keep an eye on those patients and to follow up the standard of eye services offered to diabetic patients all over the country to make sure it’s up to the standard we look for to prevent blindness from diabetes” (K118, L: 66 - 70).*

*“I would like to see how many did I refer, who actually or how many per cent have attended – those things are currently lacking – I’m not aware of those statistics. So it’s hard for me to know how to improve it without having the baseline information – to know what is currently going on, what is our goal then make that suggestion based on our current information. If you want to be efficient in any way, it’s important to have baseline information of the current catchment [population], attendance rate, how many patients are diabetic, that all needs to be taken into consideration for efficient use of our resources” (K12: L: 147-152).*

*“The function of this registry is to ensure that we have regular follow ups for these patients. And then to update us on statistics (how many patients with the diseases) and it helps us in audit as well” (K18, L: 21-24).*

*“It’s about decentralising, mild DR cases. In the registry, the mild cases can be kept here (at the periphery) and the centres having lasers should be mainly concentrating on those diabetics who require treatment” (K122, L: 21-24).*

However, despite this awareness, respondents raised several data collection challenges that are attributable to poor administration. Such challenges include data collection that is incomplete; the lack of a standardised template for data collection that makes it difficult to compare data across different health centres and multiple data sources kept at different health centres that are neither updated nor linked. The data collected at the various health centres are therefore considered to be inaccurate and inadequate which limits its usefulness.

*“I found it (data from the registry) useful but what he (DR Registry co-ordinator) said was some of the forms were incomplete so he emphasised that people should send the forms completed” (K10, L: 49-50).*

*“Some health centres have a template but others are doing it manually” (K14, L: 81-82).*

*"We have been doing it but whether everyone is registered at Diabetic Centre we don't know, we have separate registries" (KI1: L: 49-51).*

*"I'm sure we face this in other health clinics that once we enter them whether it's a manual or computer system we haven't found a solution to update it - to find out whether the patients have deceased or not or the patients have moved elsewhere" (KI6, L: 145-146).*

*"I think most of the time we under-register our patients because I don't think all doctors register" (KI4, L: 77-78).*

The lack of availability of useful data attributed to the poor administration of data management activities has led to health providers in making decisions that were not guided by evidence. Several respondents expressed dissatisfaction regarding this.

*"Firstly, to get as accurate background data as possible and with that to get as much information out so that we can actually plan our care in a more structured way because at the moment it's neither nor there, everything goes. Everyone has their own ideas on what to do with this or that, unless hard data come along" (KI13, L: 116-121).*

*"The issue comes from our own administration and our leaders, they create all this. What ticks me off is that they never learn from their previous mistakes ... The sad thing about this is that we still do the same things (unjustified cancellation of clinic sessions)" (KI14, L: 117-126)*

- *Breakdown or lack of feedback between providers*

Another issue raised by GPs and Ophthalmic assistants was that poor administration has led to a lack of communication between providers on important issues. GPs and ophthalmic staff reported not being informed of decisions (made by the department of ophthalmology) to cancel and change DR screening sessions at PHCs.

*"If screening sessions were cancelled I'm not sure it was informed to us – because I was not aware if it was cancelled" (KI2, L: 106-107).*

*"The constant change of clinic sessions is the main issue. We are informed in the last minute and we are not ready" (K115, L: 148-149).*

*"We [assistants] even suggested [to eye administration] that if the clinics need to be shut, please put it in writing so we can give the letter to the health centres" (K115, L: 20-126).*

- *Electronic medical records*

The Ministry of Health introduced the electronic medical records system (Bru-HIMS) at the time of this study. GPs and ophthalmologists shared their frustrations and uncertainty in the system, which they perceive has affected their existing data collection processes and has added to their existing workload.

*"At the moment, we are doing the data collection manually. With the user interface in Bru-HIMS (electronic patient management system), we cannot collect data" (K118, L: 143-144).*

*"We [GPs] are not quite sure yet. We are entering it, ICD 10, but the question is whether the system [will] have the function to extract how many patients are diabetics, etc. and to eliminate the possibility of duplication, etc." (K14, L: 86 – 89).*

*"So the problem with Bru-HIMS is that you cannot tell where the base clinic for the patient, so you can only look at where ever they live" (K18, L: 102-104).*

*"We would have to upload all the patient information on Bru-HIMS and that goes down to the doctors themselves – the doctors are left to having that task and in between seeing patients and covering other clinics with the extended hours so I do not see how we would have the time to upload all the relevant information" (K16, L: 150 – 155).*

- *Ambiguous guidelines and lack of standard operating procedures*

Another challenge attributed to poor administration highlighted by both ophthalmologists and GPs was the lack of clear guidelines on specific processes in the screening programme. Respondents expressed that better guidelines are needed

for providers to avoid confusion on patient referrals and day-to-day management of screening clinics.

*"In this health centre there is confusion between the walk in and the diabetic retinopathy screening and there are no clear guidelines" (KI3, L: 163-165).*

*"We (GPs) refer. We however don't know what is urgent/not" (KI4, L: 99).*

*"There should be a strict guideline for the doctors and staff and so everyone is following the same. I think they do have (guidelines); but clinic-to-clinic it's different; the way they do things differ and do things differently" (KI22, L: 137-140).*

*"For the referral guidelines [GP to DR screening], sometimes patients are borderline, like diabetes during pregnancy, gestational diabetes, sometimes they [GPs] refer the patients to us, and sometime we [DR screening team] miss them. So we should have a guideline for the GPs on what type of diabetes should be referred for eye screening or not" (KI16, L: 130-134).*

- *Under-resourced and ill-equipped facilities*

Ophthalmologists shared their aspirations in providing high quality diabetic retinopathy care that is comparable to regional centres of excellence.

*"What we (Department of Ophthalmology) look at now is to provide the state of art service. We compare ourselves to centres of excellence rather than to average services provided elsewhere. So, to reach that level we need to spend more, to reach Singapore level of eye care, we need to spend on equipment, infrastructure" (KI18, L: 244-248).*

However, respondents also highlighted that poor administration has affected the plans to improve DR screening services at PHCs. As a result, existing services are under resourced and ill-equipped.

*"It's not exactly where we want it yet, we still have a long way to go. We only are coming 8 health centres with half filled, half equipped clinics" (KI17, L: 144-146).*

*“Of course, the issue of space, that has been the problem from the beginning when the services move to the health centre. Now with the new projects (health centres) we always put dedicated rooms for community ophthalmologists and even orthoptists room. But with time I’m sure will have dedicated rooms in the new health centres” (KI4, L: 146-151).*

*“We always include eye equipment in the health centre budget but of course for the Ophthalmology Dept. they should look into the manpower and I don’t know for screening if you are going to train nurses, etc. I don’t know if the nurses assisting the eye doctors, their roles can be expanded” (KI4, L: 154 - 157).*

### **Summary: Poor administration**

Key challenges attributed to poor administration include manual GP to DR Screening referrals, poor record keeping, lack of communication between providers, problems with electronic medical records, ambiguous guidelines and lack of SOP and under-resourced and ill-equipped clinics.

### III. Lack of communication between professionals and departments

Respondents perceive the importance of communication between professionals and departments. One respondent highlighted the importance of teamwork in the management of diabetes, which is currently lacking. In addition, the respondent also highlighted the importance of listening to challenges faced by individuals as an effective way of problem solving challenges faced by the programme.

*"And regarding our overall concept [managing diabetes] because we (ophthalmologists) don't interact with endocrinology and we don't have group talk – nothing like that. It's [communication] good for us [ophthalmologist] but I don't know how others will benefit. It is teamwork, if that is there then more productivity will be there – that's definite" (K122, L: 80-84).*

*"There should be proper communication between the [eye] staff – that's the only way. We understand that they are also having difficulties; we have to talk to them and really understand what is happening I don't think we can solve it" (K22, L: 128 – 131).*

Respondents also viewed that the platform of communication between providers is limited. It was viewed that the constant rotation of staff at different health centres made it difficult for professionals to build rapport. As a consequence, there is perceived mistrust between providers of each other's capabilities.

*"I don't know who is in charge or looking after that patient, so through a written note just communicate with them" (K121, L: 124-125).*

*"We don't really communicate; just through the notes. No meetings, we don't" (K13, L: 255-256).*

*"There is the issue, because the primary health centres, I don't think they are effectively controlling the diabetics" (K117, L: 21-23).*

*"When you talk about screening, I am not questioning the capability of the eye clinic but I want to talk about the aftercare/provision of care; is the eye clinic ready to*

*manage the patients [once they are screened], what are the standards of care?" (K14, L: 193-196).*

**Summary: Lack of communication between professionals and departments**

- Effective communication is needed to promote a teamwork approach in diabetic care
- Better communication is needed in problem solving day-to-day challenges faced by the program staff
- Communication platform needed to build rapport between professionals.



#### **IV. Lack of health education (in diabetes and DR screening) by providers**

GPs and ophthalmic assistants highlighted the need to improve patient's awareness of diabetes and diabetic eye examination. Respondents cited that the concept of screening amongst the general population may need to be improved to encourage better participation, and they shared their particular concern about the participation of the elderly population in DR screening.

*"Most of them are just scared to find out, most of them want to see a doctor if there is a problem, because screening is reasonably new to Brunei, in the past you see a doctor for a problem but now we are trying to detect a problem before it happens. Some patients are not into that mind set yet"* (KI2, L: 126-129).

*"What is more common is that for diabetics that refuse to accept that they are diabetic. And when we look at their card, they are confirmed to be diabetic but they still refuse. They take medications every month. It may be their awareness, they say that their blood has sugar but say they are not diabetic. We encounter this more in older patients"* (KI15, L: 38-40).

*"Some (older patients) will insist to come and drive with their eyes dilated. I do find it a challenge to convince patients to come in to get their eyes checked"* (KI15, L: 183-185).

GPs and ophthalmologists were aware that patients' lack of awareness of diabetes and eye examination was attributed to their own effectiveness in promoting health education to patients. GPs specifically attributed their lack of expertise in diabetes and ophthalmology as a barrier to delivering effective health education.

*"A lot of our audit are focused on diabetes and yet it's always highlighted only how many are referred to eye or followed up at eye; so what do we do. It's always been about increasing awareness. There should be some system so that it's a fail-safe mechanism"* (KI7, L: 9 – 13).

*"I think that probably is the main challenge, we are not so good that making sure that patients understands the importance of regular follow up"* (KI13, L: 284-286).

*“Most of the time it’s me verbally speaking to the patient [counselling]. But then what I’m saying maybe wrong – that is the problem as it has been a while since I have done any eye, attached to any eye clinic [for training]. Things may have changed, updated, so that’s it” (K12, L: 138-141).*

**Summary: Lack of health education (in diabetes and DR screening) by providers**

- Patients’ levels of awareness of diabetes and importance of diabetic eye screening is poor
- Health providers are aware of the need to improve patients’ health education
- Lack of expertise is a barrier for GPs to deliver effective health education.

## 4. Discussion

### 4.1 Overview

In recognition of the increasing prevalence of diabetes in Brunei and the expected increase of diabetic retinopathy, the primary health centre based DR screening in Brunei-Muara was introduced in 2006. The Brunei National Prevention of Blindness from Diabetic Retinopathy (2012) is a policy document that called towards making DR screening systematic at a national level. However, since the inception of the programme in Brunei-Muara in 2006, no study has been conducted to evaluate the effectiveness of the model in practice. The DR screening initiative was launched without a baseline survey and situation assessment. Therefore, the responsiveness of the health system to embed a systematic approach to DR screening has been faced with many constraints and has been slow to evolve. This study provides the evidence required to support the implementation of the policy document and baseline information on the gaps and challenges within the key service provision stages for DR screening and treatment.

This discussion presents the view and suggests that DR screening in Brunei-Muara is partially systematic. To support this, the evidence of key findings and existing literature will be discussed to highlight key strengths and weaknesses of the existing model, which will be structured using the ESDRG framework. The discussions will also take into consideration the key limitations of this study.

## 4.2 DR screening in Brunei-Muara is partially systematic

Table 4-1 compares the existing DR screening model in Brunei-Muara with a fully systematic screening model based on the criteria outlined by the ECSDRG framework. Based on this framework, DR screening in the Brunei-Muara district can be described as partially systematic. Key gaps in the Brunei-Muara model include low screening coverage, lack of quality assurance, lack of data collection for monitoring, no systematic call and recall, inaccurate and incomplete disease registers, no digital photography system and no data on accessibility of screening and treatment by different population groups. Bridging these gaps will be key to shifting the existing model towards being systematic. The key strengths and weakness of the Brunei-Muara model at different stages of ECSDRG framework will now be discussed.

### 4.2.1 Access to effective treatment stage

Establishing accessible treatment facilities is an essential precursor to developing DR screening programmes (142). The Brunei-Muara model meets two out of three standards required to deliver accessible and effective treatment for DR patients in Brunei as outlined in the ECSDRG framework (Table 4-1). Evidence from this study suggests that one of the key strengths of the Brunei-Muara screening model is that a comprehensive DR treatment service is provided at the NEC.

- *Minimum number of lasers per 100,00 population*

No minimum targets have been set for the number of lasers per population in the ECSDRG framework as it was recognised that variations may occur depending on how DR treatment services were provided (100). However, the number of lasers in the Brunei-Muara model for treatment was viewed as adequate to meet the standards set by the framework as the number of lasers provided was comparable to that of systematic screening programmes. Analysis of the structured interview questionnaires and observations at the NEC (see section 2.3.4) shows that there were three operational lasers at the NEC to serve the Brunei population (0.75 lasers per 100,000 population). This figure is comparable to that of systematic screening programme such as Iceland (0.4 laser per 100,00 population). In addition, the above

analysis also revealed that existing DR treatment services provided at NEC are well resourced (manpower, equipment and infrastructure) to provide comprehensive and effective DR treatment.

- *Maximum time from diagnosis to treatment time (3 months)*

The Brunei-Muara model meets the 3 month time between diagnosis and treatment set by the ECSDRG. Analysis of quantitative data from the health centres and NEC demonstrates that in 2012, on average, it took 12 weeks for a patient with STDR referred from the health centres to undergo laser photocoagulation at the NEC. Similar figures have been reported in one UK audit conducted in 1998 where the overall wait for treatment from referral was more than 12 weeks (115).

The UK National Screening Committee (NSC) introduced a new criteria for time between diagnosis to treatment based on DR status, where 95% of PDR referrals should be treated by laser within 4 weeks (100% by 6 weeks) and 95% of positively identified maculopathy referrals should be treated by 15 weeks (100% by 26 weeks)(48). However, one study reported that local DR screening programmes have struggled to meet the targets. It was reported that only 26% of PDR cases referred for treatment underwent laser treatment within 4 weeks and 30% of those with maculopathy had laser treatment in less than 15 weeks (79). The study suggested that UK screening programmes improve their processes in identifying and prioritising referrals within ophthalmology practice and encourage better integration between the screening programme and the ophthalmology department as key strategies in meeting the criteria set by the NSC.

In this study, analysis of structured interview responses and observations conducted at PHCs and NEC suggested that key processes were in place to refer STDR patients detected through screening at PHCs, including options for urgent referrals (section 3.2.3). In addition, analysis of interview responses with VR surgeons (section 3.2.4) suggested that there were no waiting lists for DR treatment and the majority of patients referred for treatment were reported to have consented to undergo treatment.

However, in making these observations, evidence from structured observations

(section 2.3.4) suggested that the STDR referral process was still informal and lacked SOPs. This is also supported by evidence from the thematic analysis of SSI that the need for better communication (see section 3.6.2) between the DR screening team (ophthalmologists and ophthalmic nurse) and the NEC in day-to day operation of screening services, which also includes managing referrals. Addressing these challenges will be beneficial in improving diagnosis to treatment time in the Brunei-Muara model.

- *Equal access for all patient groups*

One of the key gaps in the provision of DR treatment at NEC, based on the criteria set in this framework, was that it was unclear whether DR treatment was universally accessible to all patient groups. Accessibility to treatment was not evaluated due to time and resource limitations imposed in this study. Evidence from the literature suggests several factors affecting patients compliance to treatment including accessibility (114, 115).

Evidence from this study suggests that treatment uptake at the NEC was low. Based on quantitative analysis of DR treatment data of 32 patients with STDR referred to the NEC between January – December 2012, treatment uptake rate at NEC was estimated to be 31%. This rate was considerably low compared to other rates reported in the literature where treatment rates ranged from 44.5% (China)(112) to 85% (US)(111). Factors such as awareness and also fear of laser treatment have been cited in these studies as reasons for poor compliance to treatment (112).

In this study, 22 patients did not undergo laser photocoagulation. It was difficult to follow up the status of these patients due to limited access to data following the implementation of an electronic patient database during the study period. There are no previous studies that reported barriers to DR screening uptake in Brunei. However, poor uptake rates have been reported in patients undergoing gall bladder treatment in Brunei. In the study, overall cholecystectomy rate post-ERC interventions were only 36.9% (143). Refusal to treatment included patients 'not keen' on the procedure (46.9%), patients' preference to have the procedure in another country (6.3%) and too busy with their work commitments (6.3%).

Based on these observations, it is argued that a more detailed study is needed to assess treatment uptake rates and to understand any barriers to DR treatment compliance including access of treatment by different patient groups.

#### 4.2.2 Opportunistic screening stage

An opportunistic screening model is associated with the traditional hospital based clinical examination where a condition is detected by chance as patients seek consultations for different reasons (31). In the ECSDRG framework, the opportunistic screening model emphasises the adoption of dilated funduscopy as the eye examination method, establishing pathways to ensure regular annual eye screening of patients with diabetes and to establish national guidelines for DR treatment by ophthalmologists. Evidence from this study suggests that the Brunei-Muara model fulfils all of the recommended criteria for the opportunistic screening stage (Table 4-1) and this will be discussed in turn.

- *Dilated funduscopy for patients attending routine examination*

In this study, analysis of structured interview questionnaires and observations demonstrates that all patients attending DR screening at PHCs underwent standardised examination method that included dilated funduscopy using slit-lamp bio-microscopy conducted by qualified ophthalmologists (section 3.3.3). This examination method was considered as a strength of the programme due to its superior diagnostic accuracy (high sensitivity and specificity). It has also been considered as one of the gold standards used in studies that compare diagnostic accuracy of different screening examination methods (69). In addition, it still remains the most prevalent screening examination method (34, 57).

- *Annual review of patients with diabetes*

Evidence from this study suggests that an annual review of patients with diabetes is practiced at both NEC and PHCs (section 3.2). Analysis of structured interview questionnaires and observations demonstrates that patients with NSTDR were offered follow up screening between 9 – 12 months at PHCs (section 3.2.2). This finding was also supported by observations at PHCs that demonstrated that there

was an annual screening policy for NSTDR patients outlined in the REPAS grading system (section 3.2.2). In addition, evidence from structured observations at NEC also suggests that similar practices were adopted at the NEC (section 3.2).

- *National guidelines to refer cases to ophthalmologists*

This criterion is about promoting continuity of care for patients detected with STDR requiring treatment at eye centres and avoiding the risk of blindness from DR resulting from unnecessary failures of referral systems.

Evidence from analysis of structured questionnaire interviews and observations at PHCs shows that referral guidelines for referral of STDR patients are outlined in the Brunei National Programme for the Prevention of Blindness document (Section 3.2.3). In addition, analysis of structured questionnaire interviews with ophthalmologists at PHCs (Section 3.2.3) and VR surgeons at the NEC (section 3.2.4) suggests that there were processes in place to ensure that STDR cases detected at PHCs were referred to the tertiary centre for treatment in a timely manner.

#### 4.2.3 Systematic screening stage

Systematic screening programmes are organised activities that are efficient enough to engage and reach all “at risk” population. At the same time, this coverage has to be balanced with acceptability and adherence to screening within the population (46). The ESCDRG framework outlines a systematic approach of identifying, inviting and informing all “at risk” patients for eye screening through an accurate disease register, systematic call and recall system, establishing annual screening intervals and setting minimum standards for screening coverage and diagnostic accuracy of screening methods.

Evidence from this study suggests that the Brunei-Muara model fulfils only two of the recommended criteria for systematic screening (annual screening and good diagnostic accuracy of screening tests). The strength and weaknesses of the Brunei-Muara model for each criterion will now be discussed.



### *1. Establish and maintain disease registers*

Systematic screening programmes have used disease registers to identify patients with diabetes who are eligible for screening in the population, which in turn, enables programmes to monitor screening coverage. Therefore, the accuracy of disease registers is vital to serve such purposes. This has been achieved through continuous maintenance of the database by regular updating of data that has been collected. Without comprehensive and updated diabetes registers, screening uptake and coverage cannot be monitored (57).

- *CDRs lacked standardisation*

Evidence from this study suggests that Brunei-Muara screening model only partially fulfils this criterion. Analysis of structured interview questionnaires and observations has shown that different chronic disease registers have been established at each health centre and that the majority of health centres have allocated dedicated personnel to manage each CDR (section 3.2.1). However, the analysis also revealed that implementation of the CDRs was not coordinated and was dependent on the initiative of each individual GP. As there were no CDR guidelines provided, each CDR developed at different rates resulting in variations in the way data was collected and maintained.

Evidence from analysis of structured interview questionnaires also highlighted that there was no standardised template for data collection and the majority of GPs have reported to under register their patients into the CDR (section 3.2.1). In addition, structured observations at PHCs also revealed that as each CDR was kept at individual GP offices at each PHC as manual logbooks, data collected were not shared amongst GPs. This practice may lead to duplication in the registration of patients, which may further affect the accuracy of the registers. These variations have resulted in CDRs at PHCs being incomplete and lacked accuracy. In view of this, it was not surprising that GPs have unanimously reported that CDRs have not been used as data source to refer patients for DR screening.

- *Centralised DR registry affected by poor administration and lack of integrated IT systems*

Analysis of structured interview questionnaires and observations at NEC have shown that there was a centralised diabetic retinopathy register in place at the NEC (see section 2.4) and there were processes in place to collect registry data using standardised forms (DER 1 and DER 2) from the different PHCs and NEC (section 3.2.3). However, thematic analysis of SSI suggests that poor data collection by the DR screening team (ophthalmologists and ophthalmic nurses/assistants) has hampered the quality of data collected in the DER forms (section 3.2.4). In addition, analysis of the interviews also revealed that the implementation of the electronic patient record (Bru-HIMS) that coincided with the data collection period in this study, has affected data collection. Furthermore, key informants have reported that due to the lack of integration between the electronic patient records system and DR registry system, data entry had to be performed separately into both systems (section 3.2.4).

Several studies have reported the importance of centralised registers in systematic screening programmes (75, 98, 99). In a UK based study, the importance of an integrated database was highlighted. It was reported that the use of an integrated electronic record was more sensitive compared to general practice registers in identifying diabetic subjects (94). Similarly in another UK study, the use of electronic patient records in primary care was able to detect more patients with diabetes that were not previously detected using data kept by the local DR screening (95). In the UK, the NSC has adopted quality assurance measures to ensure that disease registers are accurate and up-to-date.

## *II. Systematic call and recall for all people with diabetes*

Most of systematic screening programmes in the UK have implemented call and recall systems (144) intended to improve screening attendance rates. Analysis of structured interview questionnaires and observations at PHCs and NEC showed that there was no call and recall system implemented at any stage of DR screening or treatment in the Brunei-Muara model.

The only method of reminding patients of their screening appointments was

appointment cards. Analysis of structured interview questionnaires supported by evidence from structured observations shows that all patients were given appointment cards as a method of reminding them of their screening date. However, this practice was viewed to be ineffective as it was observed that during the registration process on the day of the appointments, several patients reported to losing their cards.

In this study, evidence from quantitative analysis of attendance data suggested that screening coverage was low (56%) across different health centres (section 3.3.1). DR screening programmes adopting centralised call and recall systems in the UK reported high screening coverage rates (75, 147, 148). It is viewed that the implementation of a systematic call and recall system will help improve screening coverage rates in Brunei-Muara model. However, this can only be achieved with centralised and accurate data. Therefore, integration of a different registry data is recommended.

### *III. Annual screening*

Early and regular attendance to DR screening sessions is important in halting DR progression. The ESCDRG framework and other UK organisations, such as National Institute of Clinical Excellence (NICE) and the NSC, recommend annual screening for patients without STDR.

Based on evidence from this study, annual screening of patients with NSTDR in Brunei-Muara is practiced. Analysis of structured interview questionnaires and structured observations at PHCs indicate that patients with NSTDR were offered follow up screening between 9 – 12 months (section 3.2.3). However, thematic analysis of SSI also highlighted that DR screening policies in Brunei-Muara could be further improved with a better screening structure. In this study, it was established that DR screening was offered at both PHCs and NEC. Although this was perceived to bring benefits to patients (e.g. better patient access to specialist services), providing screening at both PHCs and NEC posed many challenges such as staff constraints for both clinical and screening services as manpower was resourced from the same pool (NEC). It was also perceived by key informants that hospital-based ophthalmologists

who were also involved in conducting DR screening over a prolonged period might risk losing their clinical ophthalmology skills (section 3.6.2).

In this study, screening uptake rates across the different health centres in the Brunei-Muara district were good. Evidence from quantitative analysis of screening data at all health centres estimated a screening uptake rate of 77%. Of 1,254 patients with non-sight threatening DR given annual follow up review appointments in 2011, 964 (77%) patients were estimated to have attended their follow up appointments between January – March 2012 (section 3.3.2).

The UK National Screening committee sets the minimum target for screening uptake for existing cases attending follow up examination as 70% (48). All health centres, except for Sg Assam health centre (61%), have met this requirement (section 3.3.2). Several health centres (Berakas A, Muara, Gadong, Sengkurong) reported comparable and higher screening uptake rates (Muara: 95%) compared to UK based systematic screening programmes (105).

Another factor that was supportive of the evidence of good screening uptake rates amongst STDR patients in the Brunei-Muara model was the estimated low DR prevalence amongst patients attending DR screening. Based on quantitative analysis of DR registry data (2008-2012), prevalence of DR was estimated to be 5.8% (section 3.4). This prevalence is considerably low compared to regional DR prevalence estimates (35%)(147). However, in making this comparison, it is recognised that the regional estimates were based on a population study whilst the estimates in this study were based on registry data. Nonetheless, the low DR prevalence estimated in this study supports the finding that patients with NSTDR in the Brunei-Muara model were offered annual screening and attendance to these follow up screening sessions was considered at a good level.

In this study, regression analysis of attendance data demonstrated significantly variation in screening uptake between health centres ( $p < 0.001$ ; section 3.3.2). Patients at Muara health centre (97%) were more likely to attend their annual screening appointments. This was in contrast to patients attending Sg Assam health

centre, where only 62% of patients attended annual screening appointments. It was difficult to establish, from a provider's perspective, reasons for these variations to occur at these two health centres, especially when it was evident from findings in this study that DR screening and grading processes at different health centres were similar across all health centres (section 3.2.3). However, it was also observed in this study that Sg Assam health centre mainly served a water village population. Access to the health centre was primarily through water transportation, which was often affected by water tides. Evidence in the literature has recognised geographic and socioeconomic factors as important factors that influence DR screening uptake (105). These observations highlight the need for research into patient related factors that may influence screening attendance and therefore such studies are recommended to improve screening uptake.

In this study, it has been demonstrated that the Brunei-Muara model fulfils the criteria for providing annual screening to patients with NSTDR. However, it is also acknowledged that the current evidence suggests that biennial screening is sufficient and safe for patients with a low risk of developing DR (148). Biennial screening frequency is now being supported by several UK based studies (151, 152). Recent studies have also reported extending screening intervals based on individual DR risk factors as a safe and cost-effective strategy for screening low risk DR patients (103, 104). However, in the Brunei context, although data from this study reported low DR prevalence and screening uptake was good, it is viewed that without an effective information system and poor screening coverage, implementation of such strategies will be considered risky.

#### *IV. Test used has sensitivity of $\geq 80\%$ and specificity of $\geq 90\%$*

The diagnostic accuracy of a screening test is an important component of any screening programme. The ECSDRG recommends DR screening examinations use methods that have a test sensitivity of  $\geq 80\%$  and specificity of  $\geq 90\%$ . In this study, analysis of structured interview questionnaires and observations shows that the screening method adopted across the different health centres was dilated funduscopy using slit lamp bio-microscopy by trained Ophthalmologists (section

### 3.2.3).

Evidence from studies that compared sensitivity and specificity of different screening methods reported varying sensitivity (87% – 92%)(48)(50) and specificity values (91% – 99%) (41). It was difficult to directly compare the values due to different methodologies employed in these studies. However, these studies highlight that better diagnostic accuracy was achieved if the screening was performed by trained ophthalmic personnel using digital photography or slit lamp biomicroscopy but not direct ophthalmoscopy (70). Therefore based on this evidence, it is viewed that the screening method adopted in the Brunei-Muara model has sensitivity and specificity that are comparable to the set standards.

#### *v. Screening coverage $\geq$ 80%*

Good screening coverage rates ensure that patients with diabetes eligible for screening undergo diabetic eye screening examinations in a timely manner. The ESCDRG framework recommends 80% as a minimum standard for screening coverage rates.

In this study, the overall screening coverage rates were estimated to be low across all health centres. Quantitative data analysis of patient attendance data showed that only 219 of the 391 patients (56%) referred by GPs to DR screening at the six different health centres from January to March 2012 attended DR screening appointments (Section 3.3.1). Systematic screening programmes in the UK have reported much higher screening coverage rates between 89% (98) – 93% (97).

- *GP to DR screening referral process gaps*

There were small variations in screening coverage rates, with Muara Health centre (64%) reporting the highest rate and Sungai Assam (51%) reporting the lowest rate. More importantly, none of health centres included in this study achieved screening coverage higher than 70%, the minimum screening coverage criteria set by the UK NSC (151). This suggests a systemic challenge that is common to all health centres may have contributed to the low screening coverage rates.

Analysis of structured interview questionnaires and observations at PHCs have reported that although there were processes in place for GPs to refer patients for DR screening at each health centres, the processes are rudimentary, lacking guidelines, standardised referral forms and lack of data on screening attendance (see section 3.2.2). This is further supported by findings from the thematic analysis of SSI that revealed a lack of clarity in the screening structure for GP referrals (section 3.6.2). The inconsistency in the flexibility given to patients to attend DR screening either at the NEC or at primary health centres by the DR screening team, was perceived by GPs as misleading and has led to confusion amongst GPs and patients. It is therefore viewed that the GP to DRS referral process gaps reported across all health centres may have contributed to the low screening coverage and it is recommended that GPs and patients are provided with clear guidelines on this process to address this issue.

- *Effect of age and gender on screening coverage*

In this study, analysis of GP referred patients attending screening at six health centres in Brunei-Muara demonstrated that screening coverage rates were significantly lower amongst young and male patients. Female patients were more likely to attend screening appointments compared to their male counterparts (section 3.3.1). Based on quantitative data of STDR cases referred to the NEC between January – December 2012, it was also observed that STDR cases mainly comprised of males (80%)(Table 3-22; section 3.3.3). Whilst acknowledging the limitations of the data sources used to compute the STDR cases, the higher prevalence of STDR amongst males supports the importance of early detection and the need for regular screening for patients with diabetes. The lower prevalence of STDR amongst females may be the result of better compliance to screening attendance amongst females compared to males.

Similarly, low compliance to screening attendance amongst the younger population was also a cause for concern. Although, the effect of age on screening coverage was not shown to be statistically significant (Table 3-19, section 3.3.1); regression analysis of DR registry data that duration of diabetes was one of the risk factors for

developing DR (Table 41, section 3.4.2). Many studies have demonstrated diabetes duration as an established predictor of DR progression (12, 16, 149). Patients who delay or miss their screening appointments are more likely to present with late stage STDR.

Low compliance to screening attendance amongst younger and much older population groups has been documented (111, 99, 154). Similar studies also reported poor attendance amongst younger patients who also have longer diabetes duration, poor glycaemic control, poor BP control and were smokers (105), established DR risk factors (153).

A targeted programme to raise awareness amongst young patients may be needed to encourage screening attendance. Established DR eye screening programmes in the UK have reported that screening coverage can be improved (97). This has been achieved through the introduction of systematic strategies to identify, invite and inform those eligible for DR eye screening. However, before implementing such strategies, it is acknowledged that further studies will be needed to understand the barriers to screening amongst GP referred patients in Brunei-Muara and the impact of screening coverage on the diabetic population in Brunei.

#### 4.2.4 Full systematic screening stage

The criteria set out in this stage represent the current reference standard for developing DR screening programmes. Evidence from this study suggests that the Brunei-Muara model has not fulfilled any of the recommended criteria.

##### *1. Full screening coverage*

In the previous section, screening coverage in the Brunei-Muara screening model has been described in detail where it was demonstrated that screening coverage rates in the Brunei-Muara model did not meet the minimum recommended criteria for screening coverage of >80%. Based on this, it is viewed that full screening coverage will be difficult to attain in the existing Brunei-Muara model.



## *II. Quality assurance at all stages of screening*

Quality assurance ensures that standards of care provided in the screening programme do not fall below levels that may cause unintended harm to patients (57). Evidence from this study suggests that there were no policies and processes in place to assess quality standards in the Brunei-Muara model and therefore implementation of different processes throughout the screening programme were not effectively monitored.

The National Prevention of Blindness from Diabetic Retinopathy in Brunei Darussalam is a policy document outlining the implementation of DR screening programme in Brunei. However, a review of this document revealed no initiatives to implement quality assurance in the existing DR screening programme.

Analysis of structured interview questionnaire responses and observations at PHCs reveals that there were several process gaps throughout the DR screening and treatment pathway that may benefit from a quality assurance programme. In section 3.3.2, it was highlighted that despite processes in place for GPs to refer patients for DR screening, process gaps (lack of clear guidelines, lack of documentation and poor data collection) have hampered the referral process. Consequently, screening attendance (screening coverage) has been affected (section 3.3.1). Similar process gaps have been highlighted in previous sections for DR screening and grading pathway (section 3.2.3) and DR treatment pathway (section 3.2.4).

These findings have been supported by the thematic analysis of SSI that highlighted a mismatch between the stakeholder's expectations of the screening programme and what is being implemented (section 3.6). The DR screening programme was valued by stakeholders to be important clinically and provided patients with comprehensive and accessible care. However, challenges such as lack of a linear structure for screening described earlier was perceived to place manpower constraints for both clinical and screening services, the loss of skills of ophthalmologists working at PHC and made it difficult for administrators to monitor defaulters. These challenges were further compounded by organisational issues such

as poor administration and lack of communication between professionals and departments, which were also highlighted in the study (section 3.6.2).

The observed mismatch highlighted above suggests that there was intent by stakeholders to provide better screening services and improve services. However, without a structured platform monitoring of key processes, the delivery of comprehensive and accessible services was difficult. The introduction of a quality assurance programme will therefore provide such platforms for effective monitoring. In the UK, the NSC has recommended 19 different quality assurance standards (Appendix 13).

It is recommended that a pilot study be conducted to assess the feasibility of a quality assurance programme using the process gaps described in earlier sections as a base from which to develop indicators to monitor the implementation of different processes at each stage of the DR screening and treatment pathway. Such studies are needed as implementation of quality assurance programmes are costly, resource intensive, time-consuming and dependent on good information systems (57). In a more recent UK study, it was highlighted that many local screening programmes continue to struggle to meet quality standards set by the NSC (79).

### *III. All personnel screening is certified as competent*

There are currently no certification programmes for screeners in the Brunei-Muara model. However, all ophthalmologists conducting screening have undergone basic ophthalmology training. Training needs were not assessed in this study due to resource and time constraints.

However, training needs were raised by GPS during interviews. Thematic analysis of semi-structured interviews suggests that there was a lack of health education programmes recognised by both GPs and ophthalmologists (section 3.6.2). GPs have highlighted their lack of training in ophthalmology as a barrier to deliver effective health education regarding diabetic retinopathy and DR screening tests to their patients. Literature on training in DR screening programmes has focused on the training and certification of DR screeners who are non-medically trained. An

Australian study reported that screening training and credentialing was associated with better performance in grading (62). Training needs assessment, based on the screening and grading processes of the Brunei-Muara model, is needed to identify the training requirements for all screeners and graders in the existing model.

#### *IV. Central/regional data collection for monitoring and measurement of effectiveness*

Good information systems are needed to monitor and measure the effectiveness of screening programmes. This includes a centralised updated database for identifying, informing and inviting patients with diabetes requiring screening to screening events, standardised eye examination and grading data of all patients attending screening, and patient attendance data to monitor screening coverage and uptake rates.

Evidence from this study suggests that information systems are generally poor throughout the programme. Analysis of structured interview questionnaires and observations at PHCs highlighted that despite the existence of disease registers that could potentially be used as a reliable data source for identifying and inviting patients for screening, poor data management has resulted in registries being incomplete and inaccurate (section 3.2.1).

The DR registry was an attempt to centralise data collection for DR screening throughout the country. Analysis of structured interview questionnaires and observations at PHCs has also demonstrated that a standardised template for data collection for all patients undergoing screening and a standardised DR grading scheme (REPAS grading system) was adopted (section 3.2.3). However, thematic analysis of semi-structured interviews suggests that poor administration hampered the implementation of DR registry system (section 3.6.2). Key informants reported that poor data recording during screening has resulted in DER forms being incompletely filled resulting in an incomplete database.

In addition, analysis of structured interview questionnaires and observations at the NEC has also reported the introduction of an electronic medical record system that has affected data collection process for DR registry (section 3.2.4). Experiences from

UK screening programmes have associated poor information systems (availability of data, accuracy of data and linking of different database) as a key challenge in compliance to quality assurance standards (57).

- *Monitoring of STDR referrals to NEC affected by poor data management*

An aspect of the DR screening programme that may benefit from a centralised data collection is the monitoring of referrals from PHCs to the NEC. Effective referrals for further evaluation and treatment of suspected STDR cases are important in preventing sight loss through early treatment interventions. Systematic screening programmes have used quantitative measures such as referral uptake rates and rate of true referrals to monitor the effectiveness of referrals for treatment at eye centres (58, 156, 157).

In this study, the limitation of data sources was a significant constraint in assessing the effectiveness of referrals to NEC. Findings from structured interview questionnaires and structured observations suggest that key processes were in place for referrals of suspected STDR patients to the NEC for further evaluation and treatment (Figure 3-10, section 3.2.4). However, it was noted during structured observations at PHCs and the NEC that availability of data sources needed to evaluate DR treatment was limited either due to poor data recording or data was not collected at all. As a result, referral uptake rates and rate of true referrals could not be derived in this study (Figure 3-1, section 3.1).

Analysis of the available STDR referral data suggested that the majority (80%) of STDR cases were males, despite the fact that more females were screened. It is possible that there are some gender differences in terms of diabetes management i.e. that women have tendency towards better control. This is supported to some extent by the fact that more women than men attended DR screening(156,157). However it is unlikely to explain such a discrepancy in the proportion of males/females with STDR. Furthermore, the analysis of the DR registry indicated no gender differences in the prevalence of DR. Therefore, this gender difference is more likely to reflect poor data recording.

Analysis of the available STDR cases also suggested that the proportion of STDR

cases referred varied between PHCs (Table 3-22, section 3.3.3). The differences in referral rates suggest that either DR progression varies between health centres or the differences could be a result of variations in screening and referral processes between health centres. However, analysis of DR registry data did not show significant differences between health centres (Table 3-24, section 3.4.2). Furthermore, structured interviews and observations indicated that DR screening, grading and referral processes (to NEC) were similar across the different health centres (Figures 3-6 – 3-10, section 3.2.3). Therefore, the observed differences in STDR proportion across different health centres were more likely to be due to the limitations of the data used to estimate STDR cases.

It is clear that an integrated information system will benefit the DR screening programme by improving different processes and also facilitating monitoring of activities. It is therefore recommended for stakeholders in the DR screening programme to engage with Bru-HIMS administrators to address the data related issues.

#### *V. Digital photographic screening*

Digital photographic screening has been extensively used in systematic screening programmes. It has many advantages including good diagnostic accuracy (sensitivity and specificity)(158, 71), ability to store images for audit purposes and documentation (87), it is cost-effective (159), use of non-medical personnel as screeners (69) and increase screening coverage (158).

Analysis of structured interview questionnaires and observations at PHCs showed that the screening method employed at all six health centres in Brunei-Muara model was dilated funduscopy by trained ophthalmologists using slit lamp bio-microscopy (section 3.2.3). In addition, it also revealed that in the Brunei-Muara model, the same ophthalmologists performed the screening and grading, and there are no processes to verify screening outcomes in the existing screening model.

Although screening examination using slit-lamp biomicroscopy will help detect DR screening accurately, it has no capacity for storing fundus images. Without image storage, fundus examination findings recorded in the DER forms were restricted to

simple numeric codes representing the different DR status (REPAS grading system). Image capture in digital fundus photography provides ophthalmologists with the option to store images for future use (e.g. comparison of images from one visit to another) and also it allows other ophthalmologists to contribute to the grading process without having the need to reassess the patient.

Several factors need to be considered before implementing digital funduscopy system including technical failure (retinal images that cannot be viewed), training and certification (if screening is not performed by non-medical personnel) and issues pertaining to quality of stored images (59, 60, 160). Moreover, as a digital photography system requires initial capital costs (59), it is important to assess whether the implementation of such systems is cost-effective.

In this study, based on the cost analysis from the MoH's perspective, DR screening costs per patient screened per year was estimated at £23 and laser photocoagulation treatment costs £114 per patient treated per year. It was also highlighted that staff costs were the highest cost component for both DR screening and treatment. It was difficult to compare the cost estimates obtained in this study with published figures in the literature due to differences in the study methodology, differences in types of resources used for screening and the different ways resources were valued. However, in a UK based study (88) the cost of DR screening (using ophthalmoscopy) was estimated to be £289. In an Italian study that compared costs of three different screening approaches, screening costs ranged from £15 – £21 (converted from Italian Liras) per patient screened per year (89). Another UK study reported that it will cost more to replace an opportunistic screening programme (using ophthalmoscopy) with systematic screening (using fundus photography) but will result in more cases detected (88). In addition, other studies have also reported that the cost of the imaging system (55) and training costs(64) needs to be taken into consideration when implementing systematic digital fundus photography screening.

In view of this, it is recommended that a C-E study to assess the cost-effectiveness of replacing the existing DR screening model with a systematic digital fundus

photography screening model be conducted before considering the use of digital photography system in Brunei.

- Cost-effectiveness of systematic screening programme and cost of blindness

In this study, it has been estimated that it costs the MoH £23 to screen a patient for DR and £114 to treat patients with STDR based on the existing screening and treatment practices outlined in section 3.2. Enhancements such as digital photographic system, call and recall system, and training which have been identified in this thesis as potential ways to make the programme more systematic, will require additional investments from the MoH. However, the provider costs of DR screening and treatment identified in this study constitute only a part of the evidence to support such policy decisions.

Clearly, there are significant benefits from prevention of blindness – both in terms of economics and quality of life of those affected that need to be considered. Research has shown lower productivity and income among people with visual impairment compared to those without visual impairment (161,162). This is particularly relevant to DR, as the dominant cause of sight loss among those of working age in high income settings (163). Studies have reported that mean annual expenses per blind patient were nearly two times higher than a non-blind patient and time spent by caregivers to support a visually impaired person increased from 5.8 hours/week to almost 95 hours/week(164).

The global burden of disease attributed to vision disorders has increased nearly 50% in a 10 year period (1990-2010)(165). This has placed a significant economic burden on health systems. Studies have also reported global direct health costs associated to prevent blindness over a 10 year period (2011-2020) was estimated at US\$ 632 billion per year(166). Visual impairment and blindness have been associated with significant indirect costs such as productivity losses and premature mortality (164).

The cost implications highlighted earlier emphasises on the need to deliver cost-effective interventions to ensure that resources and funding for public health

programs such as prevention of blindness are equitably distributed. Studies have shown the positive impact of eye care interventions in improving the quality of life of patients (167). Systematic DR screening has been shown to be cost-effective in several high income countries other(159). Factors such as prevalence of diabetes and DR (89, 92) costs associated with screening and treatment (56, 92, 93), utility values (56, 92) and screening compliance (56, 94) have been shown to influence C-E. As these factors differ significantly from one setting to another, these study findings cannot be extrapolated to Brunei context. Therefore, it is recommended that a C-E study of DR screening to be conducted in Brunei. Such C-E studies may include a comparison of shifting DR screening from the existing DR screening model to a systematic screening model (that incorporates the enhancements identified in this study).

**Table 4-1 Gaps in the existing DR screening model in Brunei-Muara**

<i>Recommended criteria for developing DR screening programme based on development stage.</i>	<i>Full systematic screening (Reference standard)</i>	<i>Brunei-Muara Model</i>
<b>Stage 1. Access to effective treatment</b>		
1. Minimum number of lasers per 100,000 population	/	/
2. Equal access for all patient group	/	X (RG)
3. Maximum time from diagnosis to treatment time (3 months)	/	/
<b>Stage 2. Opportunistic screening</b>		
1. Dilated funduscopy at time of attendance for routine care	/	/
2. Annual review	/	/
3. National guidelines on referral to Ophthalmologists	/	/
<b>Stage 3. Establish systematic screening</b>		
1. Establish and maintain disease registers	/	P
2. Systematic call and recall for all people with diabetes	/	X (RG)
3. Annual screening	/	/
4. Test used has sensitivity of $\geq 80\%$ and specificity of $\geq 90\%$	/	P (RG)
5. Screening coverage $\geq 80\%$	/	X
<b>Stage 4. Full systematic screening</b>		
1. 100% screening coverage	/	X (RG)
2. Quality assurance at all stages of screening	/	X
3. All personnel screening certified as competent	/	X (RG)
4. Central/regional data collection for monitoring and measurement of effectiveness	/	X
5. Digital photographic screening	/	X (RG)

\* Key: / - Criteria fulfilled, X – Not fulfilled, P – Partially fulfilled, RG – Research gap.



### **Summary**

- DR screening model in Brunei-Muara is partially systematic
- Key strengths include policies, processes and resources in place for annual follow up DR screening that was evident through good screening uptake and low DR prevalence
- Key challenges included lack of quality assurance and poor data collection practices as barriers towards a systematic model
- Evidence needed to understand in screening coverage, access to treatment, training needs, implementation of a call and recall system and digital photography.

### 4.3 Study limitations

This was the first study to evaluate the DR screening programme in Brunei-Muara. A mixed method approach was adopted to allow a comprehensive assessment of the screening programme. The ESCDRG framework was used to discuss result findings and to make key policy and research recommendations. However, in making these deductions, several study limitations have been acknowledged and will now be discussed in turn.

In the mapping of processes and resources used in DR screening and treatment, structured interview questionnaires were used. In this study, the GP-in-charge at each health centre was purposively selected to participate instead of a random selection of different GPs involved at all health centres. This was to maximise the understanding of processes at each health centre. However, in doing so, it is recognised that the responses by the GP-in-charge may not be generalisable to all GPs and thus, mask any process variations at GP level.

Another potential limitation was in the use of structured observations to map processes. Prior to the DrPH, I was the National Co-ordinator for Prevention of Blindness in Brunei. It was difficult to establish whether what was observed during the study was indeed what is being done as per usual practise. However, this 'reactive effect' (131) was kept in check by triangulating findings with structured interview questionnaire responses.

In estimating the screening coverage and uptake rates, patient attendance data and statistics from each health centre records were accessed. These records were handwritten into logbooks and entries were found to be incomplete. As a result, data analysis was limited to a three month period only. It is acknowledged that this time period may not be representative of the trend for the whole year. However, to assess this effect on screening coverage, the best available data for two health centres (with comparatively more entries) were used to estimate screening coverage rates for the whole year and similar findings were obtained (section 3.3.1). However, it remains unclear whether similar trends apply to DR screening uptake estimates. Poor record keeping was also encountered for data sources used to estimate DR

treatment coverage at the NEC. In addition, access to patient medical records was difficult as the data collection period coincided with the implementation of electronic medical records. It is acknowledged that treatment uptake estimates may be significantly affected by the limited data. These data collection gaps were summarised in Figure 3-1.

In the quantitative analysis of DR registry data, several limitations were acknowledged. Firstly, the data recorded in the database (DR registry) was found to be incomplete. Attempts were made during the study period to retrieve some of the data but as most of the records reported wrong identification codes, this was not possible. Therefore, as a result several entries were excluded from the analysis. This form of selection bias was acknowledged in this study. Another potential limitation in this study was that the information in DR registry was not updated. An example of this was DR status. The DR status was graded based on fundus finding when the patient was first registered and the DR status was not updated on subsequent visits. This form of misclassification bias was also acknowledged in this study. Another potential limitation acknowledged in this study was measurement bias. For example, there is potential for under-reporting of hypertension in the registers as it was based on self-reporting by patients. It was observed during screening sessions that patients taking hypertensive medication were under the impression that that they were no longer hypertensive after being told by their GPs that their blood pressure is within normal limits with medication.

In the costing study, access and availability of several data sources was limited. As a result, proxy units of costs or assumptions were made to value costs. For example, in the absence of land and building costs of clinics used for screening, standard construction rates were used to calculate annualised rental costs. To estimate shared costs (costs for services shared by other care providers within the same clinic e.g. medical records, cleaning services, etc.), an estimation of 10% of total building costs were used. Although these practices have been implemented in other studies, it is acknowledged that it may affect the accuracy of the valuation of the costs in this study.

## 5 Conclusion and recommendations

This study has shown that the DR screening model in the Brunei-Muara district is partially systematic. Using the ESDRG framework, the key challenges to progress the existing screening model to be systematic have been identified. In addition, several policy and research recommendations have been discussed and proposed in the context of the limitations recognised in this study. The summary of the main findings and key recommendations for each study objective will now be presented.

- I. To identify existing screening, grading and clinical management practices and describe the organisation of the diabetic retinopathy screening programme

### *Main findings:*

The existing DR screening model consists of 4 main stages: ascertainment of diabetic patients at PHCs, GP to DR screening referral, DR screening and grading and DR treatment stage. Key processes and policies were in place at each stage. However, implementation of the processes was hampered by lack of standard operating procedures, poor data management and lack of systematic approach to patient education. The standardised use of resources used to deliver DR screening programmes is a key strength of the programme.

### *Recommendations:*

- Introduce quality assurance initiatives measures (e.g. assessing inter-observer agreement between graders and monitor positive predictive value) for continuous monitoring and improvement of processes.
- Mobilise diabetic and ophthalmic nurse educators to implement a systematic patient education system for diabetes and DR at PHCs and at the NEC.

- II. To estimate the DR screening coverage and the uptake of DR screening and treatment in the DR screening programme.

*Main findings:*

Screening coverage (GP to DR screening referral) was generally low across all health centres (56%) and was significantly lower amongst younger and male patients. DR screening was good (77%) across all health centres. DR treatment uptake was found to be low (31%). Nonetheless, STDR patients were found to receive timely treatment. However, these findings need to be interpreted with some caution given the poor quality of data sources used to derive estimates.

*Recommendations:*

- Incorporate screening coverage rates, screening uptake rates, treatment uptake rate and introduce referral uptake rates as key performance indicators to be reported regularly as part of the proposed quality assurance initiative
- Improve quality of data collection systems by integrating DR screening data sources into the electronic medical records and by monitoring of data collection as part of the proposed quality assurance initiative
- To conduct studies to identify patient barriers to screening at PHCs and treatment at the NEC

- III. To analyse key characteristics and clinical findings of persons attending the DR screening programme

*Main findings:*

The prevalence of DR in Brunei was considerably lower compared to other regional population based studies despite sharing similar risk factors for developing DR, such as having type 1 diabetes, longer duration of diabetes and high levels of FBG and HBA1c. However, the limitations of the DR registry

and poor data recording into the registry were acknowledged as factors that may affect the estimated prevalence.

*Recommendations:*

- Dialogue with Bru-HIMS service provider to integrate electronic medical records and DR registry
- Formal training of ophthalmic personnel on the use of DR registry and DER forms based on the REPAS grading

- IV. To estimate the costs per person associated with the screening and treatment of DR

*Main findings:*

It was estimated in this study that it costs the Ministry of Health £23 per person to screen and £114 per person to treat STDR with laser photocoagulation the Brunei-Muara district. The majority of the estimated costs were due to staff costs. However, cost data alone are insufficient for making policy about the DR programme. A C-E study is needed to determine whether a shift from the existing model to an enhanced more systematic model (identified in this study) will be cost-effective.

*Recommendations:*

- Cost effectiveness study to compare the existing DR screening model with the proposed enhanced DR screening model
- V. To explore the perceived strength and weaknesses of the DR screening programme and opportunities for enhancing the programme from the provider perspective

*Main findings:*

There is a discrepancy between stakeholders' expectations and implementation of the programme. The factors contributing to this gap include lack of linear structure for screening, poor administration, lack of communication between professionals and departments, and lack of health education (in diabetes and DR screening) by providers.

*Recommendations:*

- Dialogue between key stakeholders as a platform to address administrative issues, clarifying DR screening policy objectives and to promote communication.
- Conduct a patient satisfaction survey to understand patient's perspective of DR screening experience in Brunei-Muara district.

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