



Northern Ireland
**Diabetic Eye
Screening**
Programme

Equality Impact Assessment on the Service Delivery Options for the Northern Ireland Diabetic Eye Screening Programme

7th November 2018

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1.0 Introduction

An Equality Impact Assessment (EQIA) is a method used to analyse a policy or change to existing practice which may have an impact on Section 75 equality groups (defined under Section 75 of the Northern Ireland Act 1998). These groups are; gender, age, religious belief, political opinion, marital status, dependency, disability, ethnicity and sexual orientation. The aim of an EQIA is to establish the differential impact of a policy on these groups and to consider potential measures which could reduce any negative impacts. It also seeks to identify opportunities to better promote equality and good relations.

This EQIA is published following a three month pre-consultation period and alongside the full public consultation on the potential service delivery models for the Northern Ireland Diabetic Eye Screening Programme.

The pre-consultation document and questionnaire can be found at <http://www.publichealth.hscni.net/modernising-diabetic-eye-screening-programme>

2.0 Background

2.1 The NI Diabetic Eye Screening Programme

Diabetic eye disease is one of the leading causes of blindness and visual impairment, in people of working age, in the UK¹. It is also a major cause of blindness in older people. It is a complication of diabetes, which causes damage to the tiny blood vessels (capillaries) that nourish the retina (the tissues in the back of the eye that react to light). Diabetic eye disease, if left untreated, can lead to sight loss which can have a devastating effect on individuals and their families. By promptly identifying and treating the disease, these effects can be reduced or avoided completely.

During the early stages of diabetic eye disease there may be no symptoms. However, vision will be affected as the disease advances. Research shows that if retinopathy is identified early, for example through screening, and treated

¹ RNIB, <https://www.rnib.org.uk/who-we-are-knowledge-and-research-hub-research-reports-prevention-sight-loss/dr-prevalence>

appropriately, blindness can be prevented in the majority of those at risk. The UK National Screening Committee (NSC) advises that:

- screening for diabetic eye disease should be offered annually to all eligible people (age 12 and over) with diabetes; and
- the screening test should consist of digital retinal photography within an organised screening programme.

The Northern Ireland Diabetic Eye Screening Programme (NIDESP) aims to reduce visual morbidity caused by diabetic eye disease by facilitating early diagnosis and treatment of sight-threatening retinal disease through population screening.

Screening is performed using a special digital camera that can take photographs of the back of the eyes. These photographs are reviewed by a specialist and anyone who is identified as requiring further assessment or treatment is referred to the hospital eye service (HES).

Those who have a normal screening test should (ideally) be screened every 12 months i.e. the screening interval should be 12 months. The achievable standard for the programme is that 98% of eligible people with diabetes should be offered an appointment for routine digital screening occurring 6 weeks before or after their due date (i.e. after 12 months +/- 6 weeks).

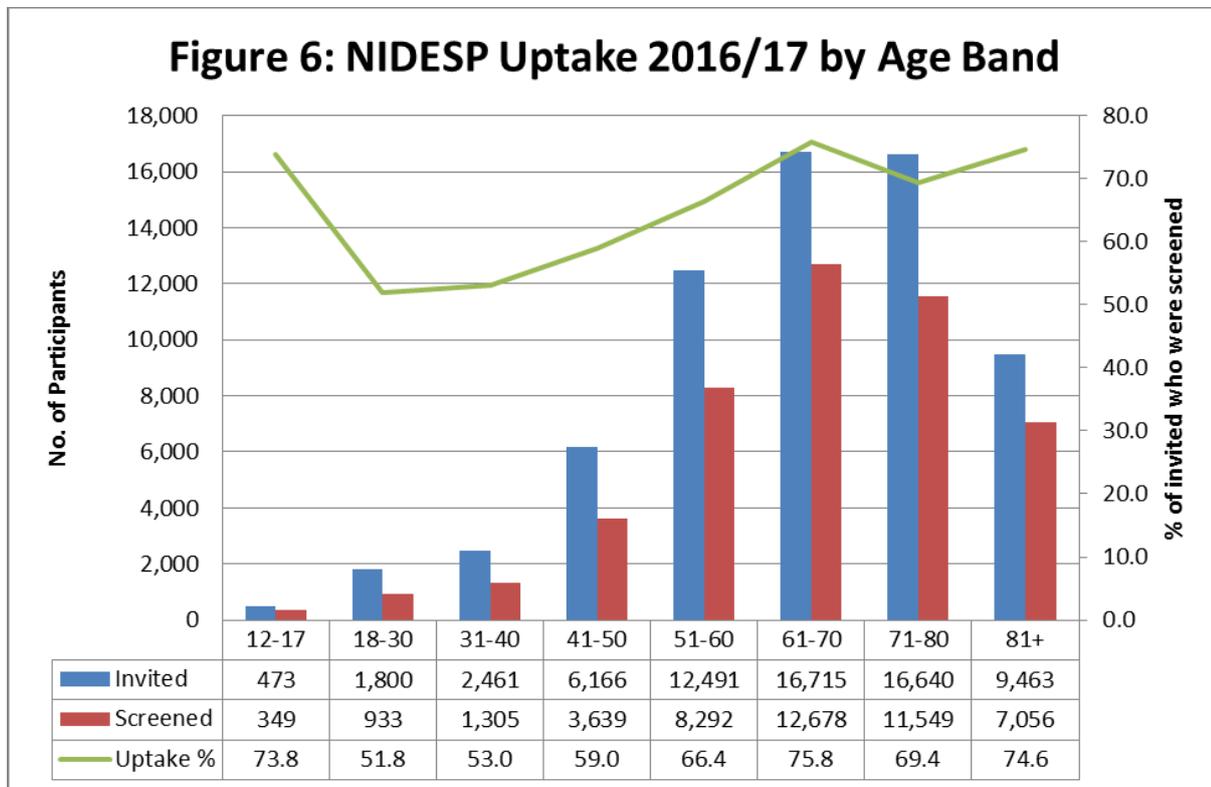
In other parts of the UK diabetic eye screening also includes testing visual acuity (an eye examination that checks how well you can see different sized letters on a chart). For logistical reasons this has not yet been possible in the NIDESP.

The programme is delivered by the Belfast HSC Trust and in 2016/17 there were over 91,000 people over the age of 12 with diabetes registered with the programme². This is a significant increase from the approximately 50,000 at the start of the programme and the eligible population is expected to increase as the number of people with diabetes continues to rise (currently by 5% per year). By 2020/21 it is expected that 108,000 people a year will be eligible for diabetic eye screening³.

² Northern Ireland Diabetic Eye Screening Programme, Programme Performance Report 2016/17, OptoMize

³ Based on 5% year on year increase of current eligible population

In 2016/17 66,271 people were invited for routine digital screening and of these 45,845 attended, Figure 1 below shows the numbers invited that attended by age band in 2016/17.



2.2 Current Model of Delivery

The current model of delivery for screening is a mixed model: fixed in the Western HSC Trust (WHST) area and mobile everywhere else. In the WHST area diabetic eye screening is provided by community optometrists at 6 fixed HSC sites. This service has historically been able to maintain a screening interval of 12 months. Although some patients may have to travel a bit further for screening, the uptake (the percentage of people invited for screening who attend) is comparable to the uptake in the rest of Northern Ireland. Advantages include patient choice on when to attend, the consistent screening interval, increased screening efficiency and availability of suitable accommodation, with the cameras on site. The fixed site model in the western area is currently working satisfactorily and would only be considered for change if two of the long list of options were chosen (see ‘Consultation on the way the NIDESP is provided’ for further details).

Throughout the rest of NI a mobile screening service is provided at individual GP practices. Screener graders employed by the Belfast HSC Trust travel to all GP practices in the Belfast, Northern, Southern and South Eastern trust areas on a rotational basis visiting each practice as close to annually as possible. They transport the digital camera to the practice by van and establish a screening clinic in a room provided by the practice. Around 280 sites are visited. The amount of time that the screening service is available at each practice depends on the number of people in that practice who are eligible to be invited. This service is convenient for many patients, and surveys of patients and GPs conducted by the PHA in 2015/16 reported high satisfaction rates. This model provides an opportunity to integrate diabetic eye screening with other diabetic care services; although this only happens in a minority of GP practices.

2.3 The Need for Change

The current mobile model of delivering clinics in individual GP practices has been coming under increasing pressure, due to the growth in the number of people eligible for screening and a number of factors impacting on quality and operational issues.

- Reflecting trends worldwide, the number of people living with diabetes continues to grow each year in Northern Ireland, and has almost doubled in the last decade
- Maintaining the screening interval at 12 months is posing another key operational challenge. In 2016/17 the average screening interval for the 262 practices (out of 337 eligible practices in total 77.8%) that were screened was 13 months, however this does not take account of the remaining 75 practices whose eligible patients were not screened in 2016/17. 337 GP practices in Northern Ireland (77.8%) who had their eligible diabetic participants screened. The screening interval can be affected by both practice and/or programme related factors including:

Figure 2: Factors Affecting Screening Interval

Practice related factors	Programme related factors
<p>Practices are required to provide a room in their premises for a set number of days during a specific period of time. As the size of the eligible screening population increases rooms are required for longer. This also impacts upon other work in the practice.</p>	<p>Screeener graders operate as lone workers, causing issues with staff satisfaction and retention. Clinics are vulnerable to cancellation if a screener grader is unavailable.</p>
<p>In other parts of the UK diabetic eye screening also includes testing visual acuity (an eye examination that checks how clearly you can see different sized letters on a chart). For logistical reasons this has not been possible in the NIDESP as rooms provided are usually unsuitable for testing visual acuity. Visual acuity testing can be helpful when making a decision about whether to refer someone to the hospital eye services.</p>	<p>Screening efficiency is sub-optimal as screener graders need to travel to multiple sites and set up the cameras each time they go to a different venue. These cameras are bulky items, which are transported in a container bigger than most fridges. There is also continuous wear and tear on the equipment due to the need to move them from practice to practice.</p>
	<p>People are invited by practice, not individually. This makes it more difficult to ensure each individual is invited at the correct time and people can only be screened in their own GP practice. Those who can't attend during the time screening is being provided at their practice have to travel to Belfast to what are called "mop up" clinics.</p>

In reviewing the model of service delivery, there are other significant factors to be taken into consideration:

- There is considerable pressure on primary care services and the General Practice Committee of the British Medical Association has indicated that individual practices will not be able to continue to provide accommodation to support diabetic eye screening into the future.
- In November 2015 the National Screening Committee recommended that for people with diabetes at low risk of sight loss, the interval between screening tests should be changed from 12 months to two years. Whilst this would reduce the numbers being screened each year by around a third, it will require a service that can guarantee an individual screening interval of 12 month (higher risk) or 24 months (lower risk), as opposed to one based on attempting to provide screening within each practice every 12 months. It would be vital to ensure that 24 months did not increase. While the numbers being screened would initially reduce they would increase to the original level again in 8 or 9 years due to the year on year increase in the number of people with diabetes⁴.

2.4 The Modernisation Programme

In 2014 the NIDESP underwent a review by the Regulation and Quality Improvement Authority (RQIA). This review resulted in a number of recommendations for improvement, and subsequently a modernisation programme was established. Phase 2b of this modernisation programme is to review the delivery model used to provide the service.

2.5 The Process to Date

The need for change and the advantages and disadvantages of the different options were examined at a regional stakeholder workshop in 2016.

In September 2017 a pre-consultation paper was produced, giving an overview of each of the model options, their advantages and disadvantages and the proposed objectives for carrying out an options appraisal. An accompanying questionnaire was also produced with questions seeking feedback on the suggested options and objectives but also on potential impacts on section 75 groups and rural communities. Staff from the PHA DESP team attended multiple events, meetings, conferences providing an overview of the pre-consultation exercise, seeking participation, and engaging with stakeholders. The pre-consultation document and questionnaire were available on the PHA website, as well as being circulated to users at screening and HES (Hospital Eye Services) clinics and via Diabetes UK NI. A

⁴ Investment Proposal Template for the Introduction of Surveillance Clinics, 2018, PHA/BHSCT

full list of the engagement events can be found within the appendices of the consultation paper.

Pre-Consultation Summary

The pre-consultation was held between 1st October and 31st December 2017. Respondents were asked to complete ten questions and given an opportunity at each to add comments.

Within the 12 week consultation period 39 responses were received from a range of stakeholders including:

- **14** from an optometry background
- **12** members of the public
- **7** screening service/HSC trust based staff
- **6** from primary care

Clear themes emerged from the responses around the advantages and disadvantages of some of the models, and their potential impacts. A majority of responses to the questionnaire stated that the current service delivery model needs to change, whilst there were a number of service users who were happy with the current service. Many of the comments focused on concerns over the potential accessibility of fixed sites, i.e. increased travel time, cost and the availability of public transport and parking. The needs of older screening populations, in rural areas, with limited mobility or with physical/sensory disabilities were highlighted. Proposed solutions to these concerns included transport and its availability and the use of interpreters. Within the responses from high street optometry practices and organisations the convenience of premises was highlighted.

Equality and Rurality

There was overlap between the responses to the equality and rurality questions, with a majority of answers focusing on the potential impacts on older people and those who were house bound/had restricted mobility. The primary concerns were that with a fixed model there would be an increased need for travel/longer travel distances, and that sites chosen would have adequate access to public transport. It was highlighted that those living with diabetes would be more likely to have restricted/limited mobility and that consideration should be given to their needs in deciding any potential screening sites.

The feedback highlighted that revision of the options appraisal and accompanying costings paper was needed and that the descriptions and costs of some models needed further clarity. A further summary of key themes by respondent group can be found in the consultation document, available at

<http://pha.site/DESPconsultation>

A shortlisting exercise was carried out by the Project Team in May 2018, the results of this were presented to the Project Board in June 2018. The Board considered the shortlisting results and also examined each option in terms of their ability to address the drivers for change. It was proposed that the consultation seek feedback on 3 options;

Option 2a – Regional Fixed Site Service (Preferred Option)

This model would provide the service at HSC locations e.g. local hospitals, community hospitals, health and wellbeing centres, and suitable GP practices. It would provide screening clinics at an estimated minimum of 4 fixed HSC sites in each of the Belfast, Northern, Southern and South Eastern HSC Trust areas. The screening test would still be provided by the same screener graders that deliver the service in the current model. Whenever required, and possible, they would work in pairs for support, making it less likely that a screening clinic would be cancelled if a screener grader was unavailable. The current model in the Western Trust area would be maintained.

Option 2b - Regional Fixed Primary Care Sites

This model would provide the service at a selected number of suitable GP practices, identified in collaboration with LMCs. It would be provided at a minimum of 4 fixed HSC sites in each of the Belfast, Northern, Southern and South Eastern HSC Trust areas. As with option 2a, would still be provided by the same screener graders that deliver the service in the current model. Also whenever required, and possible, they would work in pairs for support, making it less likely that a screening clinic would be cancelled if a screener grader was unavailable. The current model in the Western Trust area would be maintained.

Option 5 – High Street Optometry Service

In this model screening, photography only, would be carried out in an estimated 60 community optometry practices throughout Northern Ireland. Laptops (or PCs) would be provided to each practice and all screening participants would continue to be appointed and managed on the OptoMize system. The photography, and visual acuity, would be provided by high street optometry staff, not the current screener graders. All grading, further examination, surveillance appointments and onward referral to Hospital Eye Services would be carried out by the screening team employed by Belfast HSC Trust. A number of the screener graders would be retained to provide the primary grading function of their role and continue where appropriate to carry out surveillance clinics.

3.0 Impacts on People and Scope of Equality Impact Assessment

There are many groups who will be affected by a potential change to the service delivery model, however the 2 main groupings are the eligible screening population, their families and carers, and those working within the screening programme.

Other stakeholder groups include:

- Other HSC Trusts (staff working in potential fixed sites, e.g. Health and Wellbeing Centres)
- General Practitioners/Primary Care staff
- Public Health Agency
- Health & Social Care Board
- Voluntary and charitable organisations, including RNIB, Diabetes UK (NI) and Guide Dogs for the Blind NI
- Optometrists within Northern Ireland

This EQIA will look at the impact of the two broad model types, i.e. fixed site and high street optometry, on the groups listed above and specifically on each of the section 75 groupings and how these may differ from the current service provision.

3.1 Overview of Implications of Fixed Site Models

The key impact of a move to fixed sites on service users and their carers/families would be that the number of sites providing screening would decrease and those currently attending screening at their GP practice may have to travel further. However the provision of fixed sites would allow invitation by individual, therefore participants would no longer be restricted to attending their own GP practice; they could choose a location and date more convenient for them, e.g. a site nearer their work or school. Within the fixed site models, service users would continue to be seen by the same screening team, i.e. the screener graders.

Screening staff would have their working patterns changed with a move away from a peripatetic service; this could have positive or negative impacts depending upon individual circumstances. It would allow screening schedules to be planned significantly more in advance, resulting in a more stable and consistent working pattern. There would also be less manual handling, as the cameras could remain in the same location. However the fixed sites may result in increased and less convenient travel needs.

3.2 Overview of Implications of High Street Optometry

Invitations would be based upon the individual rather than GP practice therefore participants would be able to choose the most convenient location and time for them. However the number of locations would be reduced from around 280 GP practices (and 6 fixed sites) in the current model to 60 high street optometry practices. Service users would no longer be screened by the screener graders, this would be carried out by a small number of optometrists within each of the approved high street practices.

In terms of staff, few screener graders would be required to provide the grading, surveillance etc. Those that remain would have a different role and working pattern. They would be providing the surveillance at a reduced number of sites, primarily HSC hospitals and wellbeing centres. Grading, arbitration, audit etc would be provided from the central screening offices in Belfast.

The high street option would also impact on those in the western area as this would be a regional option, i.e. screening would no longer be provided at the 6 fixed sites currently used. Therefore both users and staff would be impacted by the change in locations and working patterns discussed above. However for users in the west

there may be improved availability of screening locations, dependent upon interest of local optometrists in providing the screening service. There would no longer be a need for the current optometry service in the western area, screening would be provided by high street practices and as per the rest of Northern Ireland the grading, surveillance and referral would be carried out by the screening offices in Belfast.

It should be noted at this point that it is not clear how many optometry practices in Northern Ireland would seek to provide the screening service nor yet how many of these practices would meet a suitable specification.

4.0 Data Collection

In line with the Equality Commission (NI) Guide to the Statutory Duties and EQIA Guidelines, data was drawn from a number of sources to inform this EQIA.

To examine the impact on those most likely to be affected by changes in the DESP data was reviewed in relation to:

- Service users who participate in the diabetic eye screening programme and their families/carers
- Staff groups delivering or supporting the delivery of diabetic eye screening programme. The programme is delivered by a multidisciplinary team consisting of administration, management, screener grader, optometry and medical ophthalmology staff.

In preparing the draft EQIA, the findings from a range of data and research sources were taken into account.

Quantitative data (statistics) were considered including.

- *Activity data provided by BHSCT and PHA DESP team*; including numbers invited and attended for screening, data on the screening interval for GP practices in NI, and uptake figures by age band
- *Primary Care Data (2015/16) from the Clinical Informatics Team, HSCB*; this includes data on comorbidities for those with diabetes and other long term conditions
- *The Northern Ireland Statistics and Research Agency*; mid-year population estimates

- *The Northern Ireland Neighbourhood Information Service (NINIS), NISRA*
- *The Electoral Office for Northern Ireland*
- *Diabetes UK Key Stats*; this includes data on those living with diabetes throughout the UK
- *Public Health England Diabetes Prevalence Model*;
- *Staffing data for BHSCT DESP screening team*; anonymised breakdown of screening staff within BHSCT by Section 75 grouping, provided by the Belfast HSC Trust HR department. It should be noted that data was provided for those staff whose primary job is recorded as being within the NIDESP and is therefore not complete.

Qualitative data which can provide insights into perceptions held by those who are likely to be most affected by the change in programme delivery including:

- *Responses to the 'Pre-Consultation on the Way the Northern Ireland Diabetic Eye Screening Programme is Provided'*. These included questionnaire responses from service users, screening staff, high street optometrists and primary care staff. Discussion at engagement events were also taken into consideration, for example discussion at Local Commissioning Groups. The pre-consultation document and accompanying response questionnaire was widely distributed; to users attending screening/HES clinics, workstreams of the Diabetes Network, user representatives within Diabetes UK (NI) and was published on the PHA website. Representatives from the Public Health Agency involved in NIDESP also attended multiple stakeholder events and presented on the purpose of the pre-consultation and the aims of the modernisation project. Presentations were given, for example, to the Primary Care Diabetes Society, each of the five Local Commissioning Groups, the Optometrists NI board, and the Northern Ireland General Practitioner Committee.
- *Feedback from stakeholder engagement events.*
- Further research papers, published reports etc were used to provide further data for the key findings sections, details of these can be found in the reference section at the end of this document.

5.0 Key Findings

Given the wide age range criteria for diabetic eye screening, the eligible population is potentially very diverse, i.e. all those aged 12 and over living with diabetes with light perception in at least one eye. Therefore it can be assumed that their needs, and influences on attendance will be equally diverse.

The key findings for each of the Section 75 groups are set out below

Gender

Recent data on the number of people living with diabetes in Northern Ireland (2015/16) showed that of the 86,613 diagnosed with diabetes, 49,301 (57%) were male and 37,312 (43%) were female⁵. Compared to the gender distribution of the overall population of Northern Ireland (estimated at 1.862 million⁶ in 2016 with 49.2% male and 50.9% female), there is a slightly higher percentage of males affected by diabetes than females.

Accurate data on the number of people identifying as transgender or non-binary in Northern Ireland is not available. GIRES⁷ 2014 estimate the number of gender nonconforming employees and service users:

- gender variant to some degree (1%)
- have sought some medical care (0.025%)
- having already undergone transition (0.015%)

Data on the number of transgender people who are eligible or attend for diabetic screening is not available.

Applying GIRES figures to the NI population of n=1,862,100 (2016 mid-year estimates) would suggest the following:

- 18,621 people who do not identify with gender assigned to them at birth
- 466 likely to have sought medical care
- 279 likely to have undergone transition

⁵ Primary Care Data Extract 2015/16, Clinical Informatics Team, Health and Social Care Board

⁶ NISRA, 2016 mid-year population estimates, June 2017, <https://www.nisra.gov.uk/publications/2016-mid-year-population-estimates-northern-ireland>

⁷ Gender Identity and Research Education Society

Whilst the offer of screening for diabetic eye screening is not gender specific there may be issues gender related which may affect a participant's ability or desire to take up the offer of screening.

For those who identify as transgender or non-binary, or those in the process of transitioning, a change to their familiar screening site may result in anxiety/stress due to new surroundings, e.g. the same support network that would be in GP practice would no longer be there. There may also be concern that new locations might lead through 'hostile' neighbourhoods. This issue may be somewhat heightened in a commercial environment in comparison to local health care venues which the individual may already be familiar with. However some transgender or non-binary people may value being able to choose a different service provider.

Data relating to the gender of the current team delivering the screening programme in the Trust suggests that the workforce is 66% female and 34% male⁸. A change to fixed sites may cause additional travel time and costs for screening staff; this may adversely affect those in part-time work, who are more likely to be female. This group may also be affected by a change in working patterns, e.g. longer days, clinics outside normal working hours. The current screening workforce.

Age

Published figures (2015/16) on the age distribution of all those diagnosed with diabetes suggest that less than 3% (2,332) are aged under 25. However 53.3% (46,191) are aged 65 and over⁵.

Type 2 diabetes is more likely to affect older people and Type 1 usually starts below the age of 40. Diabetes UK estimates that for all those living with diabetes 10% have Type 1, the remaining 90% have Type 2⁹.

Those aged 20-64 make up 45% of the eligible population⁵ therefore it would be key to ensure those of working age are not disproportionately affected by a change to the service delivery model, i.e. choice of location which could be closer to work, clinics outside normal working/school hours. This is particularly important when

⁸ Section 75 Staffing Profile for NIDESP, Belfast HSC Trust

⁹ Diabetes UK, 'Facts and Stats' 2016,

https://www.diabetes.org.uk/Documents/Position%20statements/DiabetesUK_Facts_Stats_Oct16.pdf

considering the lower uptake in those aged 18 to 30 of 51.8% (see Figure 1, section 2.1). Young adults can be less likely to engage with diabetes services¹⁰, this is reflected in the uptake rates for diabetic eye screening. A potential barrier to attendance can be a lack of flexibility of appointment, e.g. closer to school/university or work, appointment times that can work around other time commitments e.g. part time work.

There is also a considerable proportion of those living with diabetes over the age of 80 (14.3%, 12,386). Therefore consideration should be given to ensuring the accessibility of sites and the availability of suitable transport.

This was echoed in the pre-consultation responses with concern raised regarding the older screening population, particularly in rural areas, and those with limited mobility or with physical/sensory disabilities.

Both the fixed site and high street optometry models are likely to involve increased travel for both users and staff. This is likely to disproportionately affect those in younger age groups, who don't yet own a car, and older age groups, who may no longer have access to one. According to the Northern Ireland Department of Infrastructure's Travel Survey 2014/16¹¹ 59% of those aged 17-29 years and 71% of those aged 60 or over hold a full drivers licence, compared to 84% of those aged 30-59.

Religion

Data regarding the religious backgrounds of those living with diabetes in Northern Ireland is not available.

However the religious background of the population of Northern Ireland, according to the 2011 census is as follows:

40.8% Protestant, 41.6% Catholic, 10.1% no religion, 0.8% other, 6.8% not stated.

Whilst there is no data to suggest a difference in incidence of diabetes based on

¹⁰ Transition: Diabetes UK position on the transition of a young person from Paediatric Care into Adult Care, February 2017

¹¹ <https://www.infrastructure-ni.gov.uk/publications/travel-survey-northern-ireland-tsn-urban-rural-report-2014-2016>

religious beliefs, the availability of neutral screening venues should be considered to help prevent potential barriers to acceptability and accessibility. This should be considered particularly within fixed site options.

Section 75 data on the religious beliefs of screening staff within NIDESP is not complete, with 55% recorded as 'not known' however data on community background shows 52% are of a Protestant background and 41% Roman Catholic.

Political Opinion

Data relating to the political opinion of those living with diabetes in Northern Ireland is not available. However the Electoral Commission's data on the first-preference votes per party in the Northern Ireland Assembly Elections 2017 can provide a recent guide to political preferences in Northern Ireland as a whole.

Table 1: First preference votes per party in Northern Ireland Assembly Elections 2017 (Source: Electoral Office NI, 2017)

Political party	Vote
Democratic Unionist Party	225,413
Sinn Fein	224,245
Social Democratic and Labour Party	95,958
Ulster Unionist Party	103,314
Alliance	72,717
Other	81,668

There is no data to suggest a difference of incidence in diabetes related to political opinion.

A review of literature regarding equality and human rights and access to health and social care in Northern Ireland, conducted by the Department of Health and Social Services and Public Safety NI in 2005, concluded that it is difficult to know how statutory health and social services perform as regards political opinion. This is partly because of a lack of research. In general those attending screening may have needs related to their political beliefs in terms of location of screening clinics and access routes.

Marital Status

There is no data available on marital status in those living with diabetes in Northern Ireland, however the 2011 Census showed that :

- 47.6% (680,840) of those aged 16 and over were married
- 36.1% (517,359) were single
- 0.1% (1,288) were registered in same-sex civil partnerships
- 9.4% (134,994) were either divorced, separated or formerly in a same-sex partnership
- 6.8% (97,058) were either widowed or a surviving partner

Whilst there is no specific data available, given contributory lifestyle factors some groups may be assumed to be more likely to be overrepresented amongst those with diabetes, e.g. separated, widowed or divorced people. With regards uptake there has been some suggestion that those who are married are more likely to actively engage with healthcare providers.¹²

Dependent Status

Whilst there is no specific data relating to those living with diabetes in Northern Ireland and dependent status, the 2011 Census highlighted that 12% per cent of the population (213,980) provided unpaid help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health/disabilities, or problems related to old age. Around a quarter (26%) of those did so for 50 or more hours a week, a total of 56,000 people¹³.

Given their older age profile, it may be reasonable to assume that fewer people living with diabetes will have young dependents than in the general population as a whole. Nevertheless, it is recognised that some older people will themselves be carers, as Age UK data (2013) underlines: in the UK nearly 50,000 people aged over 85 provide unpaid care to a partner, family member or other person. In 2012, the Carers Trust estimated that around 49,000 carers in Northern Ireland were over the age of 60. Conversely, younger people with diabetes will be more likely to have caring responsibilities, including for children and/or older dependents.

Those with dependents/caring responsibilities may be affected by the removal of

¹² 'What do we know about who does and does not attend general health checks? Findings from a narrative scoping review', Dryden R. et al, BMC Public Health, Jan 2013

¹³ Northern Ireland Census 2011, CT0314NI: General Health by Provision of Unpaid Care

screening from most GP practices if they have to travel further. The additional time required may make it more difficult to fulfil their caring role. However conversely they may find the introduction of fixed sites or high street optometry advantageous, in that they will no longer be restricted to their practices, within a tight time period and within surgery opening hours.

Whilst available data for staff providing screening is incomplete with 55% unknown for caring responsibilities, it suggested that 28% did have dependents. The impact on staff of moving to fixed sites will be similar to service users in that change to their commute may impact on their ability to fulfil their caring role. However the move to fixed site should also bring a more stable and predictable working pattern.

Disability

It is estimated that between 17 – 21% of the NI population report having a disability. Twenty-one percent of the ordinarily resident population at the 2011 Census had a long term health problem or disability which limited their day to day activities.

The table below shows the percentage of people in Northern Ireland population by type of long term condition or disability, based on the Census data.

Type of long-term condition	Percentage of population with condition
Deafness or partial hearing loss	5.14
Blindness or partial sight loss	1.7
Communication Difficulty	1.65
Mobility of Dexterity Difficulty	11.44
Learning, intellectual, social or behavioural difficulty.	2.22
Emotional, psychological or mental health condition	5.83
Long – term pain or discomfort	10.10
Shortness of breath or difficulty breathing	8.72
Frequent confusion or memory loss	1.97
A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy).	6.55
Other condition	5.22

Those with diabetes are at risk of several serious complications, with 76% of those living with diabetes in 2015/16 reported as having one or more comorbidities¹⁴. These include asthma, coronary heart disease, hypertension or stroke. Those with some disabilities are also at increased risk of developing diabetes, including those with learning disabilities (estimated at twice the prevalence of general population¹⁵), depression, schizophrenia, and those who have had a stroke or heart attack.

As discussed in section 2.5, some in the pre-consultation responses expressed concern regarding the potential impact on the older population, 60% of whom at the time of the 2011 census had a long term condition or disability, compared with the average 21% of the NI population.

Given that those living with diabetes are at an increased risk of having disabilities or other long term conditions, particularly in the older screening population, it is important to consider their needs with regards to accessibility of screening appointments. It will be important to ensure that chosen sites meet a suitably designed specification. The potential within HSC fixed sites to combine diabetic eye screening appointments with other diabetes checks within the same location/site could also be considered beneficial for this group, both in terms of streamlining frequent healthcare appointments and also improving uptake for screening and/or attendance at essential diabetes health checks.

Available data relating to screening staff suggest that there are no current staff members recorded as having a disability. However the ability to ensure the accessibility of screening sites would be of potential benefit to both users and staff. Given the current peripatetic model which involves frequent travel to multiple locations, it is difficult to analyse the impact of moving to fixed sites as it will depend on many factors including an individual staff member's base/home location in comparison to their assigned fixed site. However the potential increase in predictability of working patterns and locations could be of benefit to those with a disability, where the current peripatetic service could be considered a barrier.

¹⁴ Primary Care Data Extract 2015/16, Clinical Informatics Team, Health and Social Care Board

¹⁵ <https://www.diabetes.org.uk/resources-s3/2018-02/Improving%20care%20for%20people%20with%20diabetes%20and%20a%20learning%20disability%20-%20Fact%20sheet%201.pdf>

Ethnicity

Data on the ethnic background of those attending diabetic eye screening is not available. However research suggests that people from South Asian and Black communities are two to four times more likely to develop Type 2 diabetes than those from Caucasian backgrounds¹⁶. PHE also estimate that the prevalence of diabetes is 15.2% in the S Asian and Black population compared with 8.0% in white, mixed or other ethnic groups¹⁷.

Census data on the ethnic profile of the population of NI can also inform these considerations. The 2011 Census showed that 1.8 per cent (32,400) of the usually resident population of Northern Ireland belonged to minority ethnic groups. The main minority ethnic groups were Chinese (6,300 people), Indian (6,200), Mixed (6,000) and Other Asian (5,000), each accounting for around 0.3% of the population. Irish Travellers comprised 0.1% of the population.

Accessibility and flexibility of appointment should be included when considering the model options, e.g. to allow family members/community support to also attend appointments. It should also be considered that there may be lower levels of car ownership amongst some BME people in lower income groups, therefore there would a greater importance placed on the availability of public transport.

Sexual Orientation

It is estimated that 5-7% of the population are from the gay and lesbian or bisexual community. A study by the Office of National Statistics found that in NI:

- 93.5% of the population (over 16) considered themselves to be heterosexual/straight
- 0.8 considered themselves to be gay / lesbian
- 0.2 considered themselves to be bisexual
- 0.4 other
- 4.5 responded don't know or refused to answer
- 0.5 no response

¹⁶ Diabetes UK, 'Facts and Stats' 2016,

https://www.diabetes.org.uk/Documents/Position%20statements/DiabetesUK_Facts_Stats_Oct16.pdf

¹⁷ <https://www.gov.uk/government/publications/diabetes-prevalence-estimates-for-local-populations>

Whilst there is no available data in Northern Ireland on whether the incidence of diabetes is higher amongst those in the LGBT community, it could be reasonable to assume that they are at increased risk due to the associated lifestyle factors, for example:

1. Higher rates of smoking, particularly amongst lesbian women
2. Increased issues with weight including obesity
3. Less likely to access health services, e.g. less likely to participate in cervical screening^{18, 19, 20}

These issues are often due to experiences of homophobia, marginalisation and social exclusion.

Available data on the sexual orientation of those staff who provide screening is not complete, with 48% stating that they are attracted to the opposite sex and 51% not completed. However as with users a change of site/work environment may cause some concern within the fixed site model. With regards the high street model trust employed screening staff would no longer be on the 'frontline' but based at the central screening office, which could increase concern regarding e.g. 'coming out' to colleagues, who previously they would not have seen on a day to day basis.

¹⁸ Hunt, R and Minsky A, 'Reducing health inequalities for lesbian, gay and bisexual people; evidence of healthcare needs', Stonewall, 2016

¹⁹ Rooney Eoin, 'All partied out? Substance use in Northern Ireland's Lesbian, Gay, Bisexual and Transgender Community', The Rainbow Project, Belfast, 2012

²⁰ Quiery Marie, 'Invisible Women. A review of the impact of discrimination and social exclusion on lesbian and bisexual women's health in Northern Ireland', 2007

6.0 Summary of Key Findings

In light of the factors discussed above and issues identified, the key findings are summarised below. These should be considered when choosing and planning the delivery of the future model.

Age

The eligible population for Diabetic Eye Screening is unusual amongst screening programmes in that it is so wide ranging with no upper age limit. For example there are 5,186 people living with diabetes over the age of 85²¹. This aging population is particularly important as Type 2 diabetes is more likely to be diagnosed in those aged 40 and over, and considering that the general population is also living longer. The issues around accessibility for those who are reliant on carers, family or are living in nursing homes or assisted living should be taken into consideration when deciding on suitability of models and eventual screening sites. The availability of public transport to attend screening appointments is also important particularly for those in older age groups who are less likely to have access to private transport and for those in rural settings. These were the key issues raised in responses to the pre-consultation, with many concerned about the potential impact of having to travel further to attend screening.

The NIDESP is the only screening programme to invite those aged 12 to 25 to attend for screening. Young adult age groups also have particular needs with regard to their engagement with healthcare and historically have had a low uptake within the programme.

All screening staff²² are over the age of 25, with 90% aged 25 to 54 years. Those with young dependants or caring responsibilities may be impacted by a move to fixed sites, however this impact could be positive or negative depending upon where their work and home bases are situated. It will provide more stability in terms of working patterns and allow for example scheduling of childcare.

²¹ Primary Care Data Extract 2015/16, Clinical Informatics Team, Health and Social Care Board

²² Where section 75 has been completed/recorded

Disability

It is expected that there will be higher rates of disability amongst those living with diabetes, due to increased rates of comorbidities and potential complications from diabetes. Therefore those eligible for screening could have more complex needs in terms of accessibility, flexibility of appointment (date, time and location). This should be taken into account when developing the specification for screening sites. As outlined above, pre-consultation responses expressed concern regarding the needs of those with mobility issues, sensory disabilities in respect of their ability to attend appointments and the facilities available when they do.

Available data relating to screening staff suggest that there are no staff members recorded as having a disability. However the ability to ensure the accessibility of screening sites would be of potential benefit to both users and staff and the potential increase in predictability of working patterns and locations would be of benefit to those with a disability, where the current peripatetic service could be considered a barrier.

Dependant Status

Those with dependents, caring responsibilities are likely to be affected by a move away from the current model, and their GP practice, to either fixed site or high street optometrists. If this move results in more travel time/distance to their appointment it may impact on their caring responsibilities. However the move to fixed sites and invitation by individual will allow for greater flexibility of appointment time and venue, which would allow meet other demands on their time. This impact would be similar for both users and staff with dependents or who are carers.

Gender

Unlike some of the other screening programmes, Diabetic Eye Screening is not gender specific and gender has no differential impact when conducting the screening test. However a move away from screening at a service user's local GP practice may impact more on some groups, for example, those who identify as transgender or are in the process of transitioning may experience additional anxiety or stress due to the unfamiliar surroundings and/or staff of the high street option, or the larger community setting of the fixed sites. Conversely some may prefer the relative anonymity of a new service provider.

The move to fixed sites may adversely affect part time staff who are more likely to be female, given the potential for further travel time and costs. As discussed with regards to dependent status those with caring responsibilities, who are more likely to be female, may be adversely affected by a change to working patterns.

These impacts should also be balanced against the potential improvements that will result from the introduction of a fit for purpose service delivery model. The introduction of a new sustainable model will improve the quality and safety of the service for both users, and screening staff. It will help to ensure that future service improvements will be achievable, for example, with invitations based on the individual rather than GP the programme will be able to introduce variable screening intervals. The service will be better able to meet the 12 months screening interval, helping to ensure users are seen on time. For further details on the aims of the modernisation project and the advantages and disadvantages of the model types, see the document 'Consultation on the way the Northern Ireland Diabetic Eye Screening Programme is provided' <http://pha.site/DESPconsultation>

7.0 Proposed Actions

Given the impacts discussed above, in particular on the Section 75 groups of age, disability, dependant status and gender. It is proposed the following actions to help mitigate impacts where possible:

1. The specifications to be used for choosing fixed sites, and the those used in any contracting exercise for high street optometrists would include;
 - a. Accessibility for those with mobility issues, e.g. wheelchair access to the building and the clinic room
 - b. Availability of hearing loop facilities
 - c. Easily accessible parking
 - d. Potential for evening and weekend clinics
 - e. Culturally neutral venues
 - f. Availability of public transport links
2. Whilst the identification of sites would be based on need, availability and capacity; the population profiles and travel time analysis will also be taken into consideration

3. Any service user requiring the NIHSC Interpreting Service within HSC fixed sites should be offered this service.
4. Screening staff will undertake cultural competence and diversity training as appropriate
5. The programme would seek to make information on public transport to each of the new screening sites available
6. The programme would develop an easy read leaflet for those with learning difficulties

8.0 Monitoring and Next Steps

The issues highlighted in this assessment and within the pre-consultation responses will be kept under review throughout the public consultation and subsequent project management steps. They will be actively considered when the decision on the model option is made and in the development of specifications either for fixed site selection or as part of a tendering process for high street optometry. Further feedback from stakeholder on equality issues during the public consultation will be fed into any further revision of project documentation, i.e. to inform the decision making process.

Following the 12 week public consultation period the Modernisation Project Team will make a recommendation to the Project Board on the most appropriate service delivery model. Once approved by the Project Board and signed off by the relevant bodies the decision will be implemented.

Monitoring of invitation and attendance levels, i.e. coverage and uptake, amongst demographic and equality groupings, where possible, will take place at regular intervals. The current contract for data extraction limits the number of fields extracted to those required to provide the service, for data protection purposes. Currently these include age, gender and ethnicity, however fields regarding disability or dependent status are not routinely extracted. With the introduction of the OptoMize system, the programme has also attempted to record accessibility needs on an ad hoc basis when they become aware of them. As demographic data is extracted from GP practices for the purposes of call/recall, any analysis of equality grouping will be affected by the completeness of these records at practice level.

In addition, the NIDESP plan to carry out satisfaction surveys post model implementation. However there is no current baseline data available, given that there is no current baseline measurement of satisfaction, the results of this survey would need to be taken on its own merit.

The screening programme is currently piloting clinics which combine diabetic eye screening within the same setting as other diabetes checks, this has been working particularly well in 'transition' clinics, for young adults who have moved from paediatric services to help them adjust to living with diabetes as an adult. The NIDESP is also seeking to improve links with other workstreams within the Diabetes Network, improving communication with other aspects of diabetes care, both those working in relevant health and social care setting and service users/carers.

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