HSC Business Services Organisation

Providing Support to Health and Social Care

Equality and Human Rights Screening Template

The BSO is required to address the 4 questions below in relation to all its policies.

What is the likely impact on equality of opportunity for those affected by this policy, for each of the Section 75 equality categories? (minor/major/none)

Are there opportunities to better promote equality of opportunity for people within the Section 75 equality categories?

To what extent is the policy likely to impact on good relations between people of a different religious belief, political opinion or racial group? (minor/major/none)

Are there opportunities to better promote good relations between people of a different religious belief, political opinion or racial group?

As part of the audit trail documentation needs to be made available for all policies and decisions examined for equality and human rights implications. The screening template is a pro forma to document consideration of each screening question.

For information (evidence, data, research etc.) on the Section 75 equality groups see the Equality Portal - Screening Resources & Evidence.

SCREENING TEMPLATE

See Guidance Notes for further information on the 'why' 'what' 'when', and 'who' in relation to screening, for background information on the relevant legislation and for help in answering the questions on this template.

(1) INFORMATION ABOUT THE POLICY OR DECISION

1.1 Title of policy or decision

My Care Record (Patient Portal)

A business case is awaiting approval by The Digital Health and Care Northern Ireland (DHCNI) to commission the regional rollout of the Patient Portal application to patients / clients living with a long term health condition. This follows the successful pilot with a group of patient living with Dementia and/or Diabetes.

A Patient Portal can be defined as:
"A secure, user friendly, web-based tool designed for patients – and their registered carers – to manage their own patient record and communicate with their healthcare providers".

1.2 Description of policy or decision

Following the completion of the pathfinder project which employed a 3 phased approach to introduce the Patient Portal (My Care Record) to a group of patients living with Dementia and / or Diabetes; a second phase of the project has been commissioned to extend the use of the portal to all specialties and subspecialties where patients are living with a long term health condition

Specific aims include:

1. To improve support and wellbeing of patients and carers of people with long term health conditions through a technology-enabled solution that builds upon existing investments in e-health and social care, in particular the Northern Ireland Electronic Care Record (NIECR).

2. To provide access to up to date personal health information anytime, anywhere with secure electronic access for those patients who register for a portal account.

3. To Increase involvement in patient's / clients own care to help improve health outcomes.

4. To improve communication between the patient / client and the care team to strengthen the patient-provider relationship.

Key Elements:
Patients will be invited via a member of their care team to register as a portal user. When they create a portal account they will be able to:

- View appointments (Hospital and Community).
- Access to a library of documents related to their diagnosis or condition.
- Share files with their care team.
- Contribute to and update patient centered goals.
- View GP mediation lists.
- View laboratory results.
- Collate a list of family and friends contact details.
- View contact details of Care Teams and Organisations collated by their care teams.
- Nominate a carer as a representative / nominee who will then share access to the patient record.

The key benefits of the patient portal include:

- Providing access to up to date personal health information anytime, anywhere with secure electronic access to shared documents, images, documents and messages;

- The portal setup will be tailored to use by multiple specialties and patients with co-morbidities;

- Increase the number of patients who will have access to the portal;

- Increasing involvement in patient’s own care to help improve outcomes by providing access to relevant and current reference information on demand;

- Appointments – view upcoming and past appointments

- Improving communication with their care team to strengthen the patient-provider relationship;

- Encouraging self-management (and family and other care providers) of their own health and others that they care for, to help keep the patient in the home and out of the hospital;

- Viewing current GP Medication lists;

- Timely electronic access to health information;

- Specific education resources;

- Ability to view downloads, add to and transmit health information, with appropriate data security safeguards.

Potential Constraints:

- **Timescales** – Phase 4 of the project was expected to run to June 2022 however this assumed a start date of April 2020 which has subsequently been delayed due to restrictions on software releases due to COVID 19.

- This version of the Portal will be replaced with the Encompass Patient Portal when it has been rolled out to the Trusts. The Encompass project rollout has also been delayed therefore there may be a requirement to continue to support the current project beyond the June 2022 end date will have to be managed.
- **Continuity and safety of service -** The Patient Portal implemented service must reflect the updates to the NIECR system in terms of information that is useful to the patient for self-management of their conditions. It must not introduce new risks e.g. from corrupted or confusing patient data.
- **Funding and affordability** – A Patient Portal Programme business case has been developed and is awaiting approval. The aim of the business case is to extend the project to a regional implementation across multiple specialties and subspecialties and secure the funding for staff, licensing and support during the project phase which will end in June 2022.
- **Information Governance -** The Patient Portal application management must guarantee the highest standards of data security, patient confidentiality and responsiveness to people’s wishes regarding the use of their records. It must comply with all relevant legislation and best practice guidelines.
- **Technical and legal** – Feedback from the patients and their carers who participated in the pathfinder pilots, discussions with suppliers and Chief Clinical Information Officers have identified issues that need to be considered, around data access and information governance. Legal issues also relate to the use and secondary use of data – e.g. consent models, secondary use legislation, will also be considered for impact on the implementation plan. If patients are unable to provide an informed consent for a relative to share access to their record consideration will be given to using Best Interest. Best Interest is a statutory principle set out in section 4 of the Mental Capacity Act. It states that 'Any act done, or a decision made, under this Act or on behalf of a person who lacks capacity must be done, or made, in his best interests'.

1.3 Main stakeholders affected (internal and external)

For example staff, actual or potential service users, other public sector organisations, voluntary and community groups, trade unions or professional organisations or private sector organisations or others

Staff

- Business Services Organisation (BSO) eHealth teams
- Health Care teams across primary and secondary care
- Clinical Network teams across primary and secondary care

Service users

- Patients living with a long term health condition
- Nominated carers of patients living with a long term health condition
- Clinical staff across all the Health and Care Trusts and GP practices that use NIECR and have access to Patient Portal functionality.
- Parents or guardians of children with a long term health condition

Voluntary and Community Groups

- Dementia NI
- Alzheimer's Society Northern Ireland
- Dementia Carers support groups
- Age NI
- Deaf Association
- Diabetes UK

Private Sector organisations

- Orion Health (System Provider)

1.4 Other policies or decisions with a bearing on this policy or decision

Making Life Better 2012–2023*;* ten-year public health strategic framework. The framework provides direction for policies and actions to improve the health and wellbeing of people in Northern Ireland

E Health and Care strategy 2016; Improving health and wealth through the use of information and communication technology

Transforming Your Care 2013

Health and Wellbeing 2026 - Delivering Together

The Northern Ireland Dementia Strategy "Improving Dementia Services in Northern Ireland 2011

Mental Capacity (NI) Act 2016

(2) CONSIDERATION OF EQUALITY AND GOOD RELATIONS ISSUES AND EVIDENCE USED

2.1 Data gathering

What information did you use to inform this equality screening? For example previous consultations, statistics, research, Equality Impact Assessments (EQIAs), complaints. Provide details of how you involved stakeholders, views of colleagues, service users, staff side or other stakeholders.

Stakeholder Consultation:

The Portal setup for each new specialty requires a consultation period with the relevant groups which usually include representation from the clinical team and patients. This setup period defines the bespoke requirements for each group and builds on the consultation work and feedback from the Dementia pathfinder programme.

- Focus groups with the Diabetes Network
- Diabetes Patient Portal steering group
- Regional Pain Management Forum
- Liaison with Endocrine specialty
- Liaison with AHP teams supporting patient living with Lymphoedema
- Focus groups with Regional Child Health project group
- Osteoporosis Teams
- Smoking Cessation Regional Group

Consultation during the pathfinder programme included

- Focus groups with Healthcare professionals and specialists in the field of Dementia;
- Liaison with the Joint Heads of the Dementia strategy and the project managers delivering the Phase one Project on Dementia, including Atlantic Philanthropies;
- Meetings with representatives of the DHSSPS, NISRA, HSCB, the Honest Broker Service, OFMDFM and BSO;
- Meetings with key IT suppliers, Age NI, Queen’s and Ulster University Computing Departments to determine their views on Health Information Technology generally; and
- Collation of wider stakeholder analysis from the Dementia Care Pathway review.

- Regional voluntary and community groups; Dementia NI, Alzheimer’s Society, Carer’s

NI, Age NI, Deaf Association, RNIB

- Survey – Lucid Talk January 2016 survey of 3,000 people across NI and their views on the use of “e-health” solutions. Survey respondents 45 years old and above.
- Conferences; Digital Government Conference - The Connected Citizen 2019 (organised by agendaNI)
- International Conference for Palliative and Dementia Care 2019 (Northern Ireland Hospice)
- Trust Dementia Navigators
- Trust Dementia / Service Improvement Leads
- Trust Carer Co-ordinators
- Trust Psychology colleagues
- Trust Dementia & Diabetes colleagues
- Trust Consultant colleagues
- GPs / HSCB / BSO / Orion Health / Atlantic Philanthropies / DoH

Data Sources

- EQUALITY IMPACT ASSESSMENT-Living well with dementia National Dementia Strategy (Prepared by the National Dementia Strategy Working Group at the Department of Health, 03 February 2009)
- Alzheimer Society publication: Equality and Inclusion policy Version: 2.0 : March 2017

Consultation approach:

Portal setup for each new specialty requires a consultation period with the relevant groups. These groups usually have clinical team, patient representation and other organisations and agencies that provide support and advice. This consultation period defines the bespoke requirements for each group and builds on the consultation work carried out for the Pathfinder programme with patients living with Dementia.

User satisfaction surveys are sent out at each stage of the project to gather feedback from Patients, Carers and Healthcare teams. The results of these surveys are circulated to the participants and other key stakeholders.

Findings from the surveys are feedback to the portal supplier to inform the supplier’s road map for development of the Patient Portal and subsequent system upgrades.

Focus groups will be held with the Healthcare teams caring for people living with long term health conditions during the regional rollout.

Consultation during the pathfinder programme included

- Liaison with the Joint Heads of the Dementia strategy and the project managers delivering the Phase one Project on Dementia, including Atlantic Philanthropies;
- Meetings with representatives of the DHSSPS, NISRA, HSC, the Honest Broker Service, OFMDFM and BSO;
- Meetings with key IT supplier, Age NI, Queen's and Ulster University Computing Departments to determine their views on Health Information Technology generally.
- Collation of wider stakeholder analysis from the Dementia Care Pathway review. "I'm still me", a multi-platform campaign which ran from September 2016 to January 2017.
- Meetings with Voluntary Services (Alzheimer's Society and Dementia NI) regional Patient and Carer groups
- Consultation with Dementia Programme implementation group whose membership includes Patient and Carer representatives.
- Collation of publications from the voluntary sector Alzheimer's Society, Age Concern and Dementia NI.

2.2 Quantitative Data

Who is affected by the policy or decision? Please provide a statistical profile. Note if policy affects both staff and service users, please provide profile for both. Also give consideration to multiple identities.

<table>
<tr><th>Category</th><th>What is the makeup of the affected group? (%) Are there any issues or problems? For example, a lower uptake that needs to be addressed or greater involvement of a particular group?</th></tr>
<tr><td>Gender</td><td>The population of Northern Ireland on Census Day 2011 [1]was 1,810,900
<table>
<tr><td>Male</td><td>887,300</td><td>49%</td></tr>
<tr><td>Female</td><td>923,500</td><td>51%</td></tr>
</table>
Health Survey Northern Ireland [2]is a Department of Health survey that runs</td></tr>
</table>

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[1] Northern Ireland Census 2022 is available at: http://www.ninis2.nisra.gov.uk/public/InteractiveMapTheme.aspx?themeNumber=136&themeName=Census%202011

every year on a continuous basis. The survey covers a range of health topics that are important to the lives of people in Northern Ireland. The latest report for 2019 examined difference in self-reported rating of health by sex

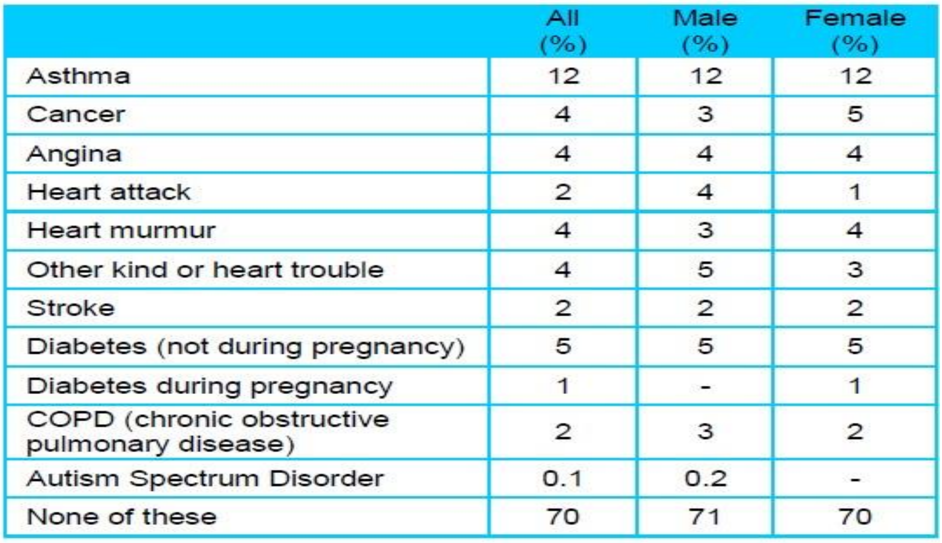
Health over the last 12 months by sex	2017/18 Males	2018/19 Males	2017/18 Females	2018/19 Females
Good	63%	65%	59%	60%
Fairly good	23%	22%	22%	22%
Not good	14%	13%	19%	18%
Total	100%	100%	100%	100%
Unweighted base	1352	1461	2003	2132

Source :Health Survey Northern Ireland 2018/19

Long Term Conditions by Gender

40% of respondents to the 18/19 Health Survey Northern Ireland reported that they have a physical or mental health condition or illness expected to last 12 months or more. Females (42%) were more likely than males (38%) to have a long-term condition.

Medical Conditions lasting more than a year by gender



	All (%)	Male (%)	Female (%)
Asthma	12	12	12
Cancer	4	3	5
Angina	4	4	4
Heart attack	2	4	1
Heart murmur	4	3	4
Other kind or heart trouble	4	5	3
Stroke	2	2	2
Diabetes (not during pregnancy)	5	5	5
Diabetes during pregnancy	1	-	1
COPD (chronic obstructive pulmonary disease)	2	3	2
Autism Spectrum Disorder	0.1	0.2	-
None of these	70	71	70

Source :Health Survey Northern Ireland 2010/11

The Patient portal pathfinder Dementia project reviewed the gender of

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[2] Health Survey Northern Ireland 2018 / 19 available at: https://www.health-ni.gov.uk/sites/default/files/publications/health/hsni-first-results-18-19_1.pdf

patients living with Dementia and found that the prevalence of Dementia by gender in the UK is reported to have a greater impact on women as the majority of carers are women. Women are 2.3 times more likely to provide care for someone with dementia for over 5 years. 20% of female carers have gone from full-time to part-time employment as a result of their caring responsibilities and 17% felt penalised at work.

Source: Women and Dementia: A Marginalised Majority by Alzheimer's Research UK[3]

In the second phase of the pathfinder project a group of 379 patients living with Diabetes or Dementia had been invited to use the portal.

	Invites sent	**Accounts created**
Male	52%	48%
Female	48%	52%

Source: My Care Record – activity statistics October 2020

Transgender

The Gender Identity Research and Education Society [4](GIRES) estimate the number of gender nonconforming employees and service users, based on the information that GIRES assembled for the Home Office (2011) and subsequently updated (2014):

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

The numbers who have sought treatment seems likely to continue growing at 20% per annum or even faster. Few younger people present for treatment despite the fact that most gender variant adults report experiencing the condition from a very early age. Yet, presentation for treatment among young people is growing even more rapidly (50% p.a.). Organisations should assume that there may be nearly equal numbers of people transitioning from male to female (trans women) and from female to male (trans men).

Applying GIRES figures to NI population (using NISRA mid-year population estimates for June 2018) N=1,881,600:

- 18,816 people who do not identify with gender assigned to them at birth
- 470 likely to have sought medical care
- 282 likely to have undergone transition.

Age	General population

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[3] Alzheimer's Research UK *: Women and Dementia: A Marginalised Majority*, Cambridge.

[4] Gender Identity Research and Education Society available at: https://www.gires.org.uk/ .

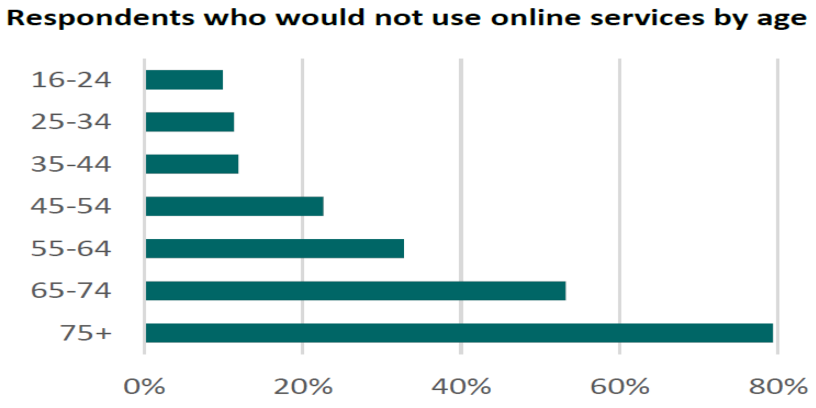
(Census Data, 2011)

Children (under 16)	379,300	21%
Working age (16-64)	1,043,600	65%
65-84	233,997	13%
85+	31,765	1.7%

NISRA Estimated and projected population by age, mid-2016 to mid-2041 show that in 2016, 20.8% of the NI Population was aged 0-15 years, and this is projected to decrease 18.2% in 2041. The proportion of adults aged 16-64 in 2016 was 63.2% of the whole population, set to decrease to 57.2 by 2041. However, the proportion of people aged 65 years and over is projected to rise from 16.0% in 2016 to 24.5% in 2041, overtaking the numbers of children

The Health survey NI 2019 reported that prevalence of long- term conditions increased with age with 15% of those aged 16-24 compared with 71% of those aged 75 and over

Age may also be a significant determining factor on attitudes to the use of online services for health care.



Source :Health Survey Northern Ireland 2018/19

At the end of October 2020 - 379 people living with diabetes or dementia had been invited to create a portal account with an age range between 18 and 87. 262 of those receiving invites went on to create an account and use the portal the youngest was 17 and oldest was 81

Patient Portal invites between Jan – Oct 2020	**Age Range**

<table>
<tr>
<td></td>
<td>
<table>
<tr><th></th><th>0 -17</th><th>18 -45</th><th>46 - 65</th><th>66 - 100</th><th>Grand Total</th></tr>
<tr><td>ACTIVE</td><td></td><td>14</td><td>3</td><td>2</td><td>19</td></tr>
<tr><td>EXPIRED</td><td>7</td><td>64</td><td>25</td><td>2</td><td>98</td></tr>
<tr><td>REGISTERED</td><td>4</td><td>179</td><td>68</td><td>11</td><td>262</td></tr>
<tr><td>Grand Total</td><td>11</td><td>257</td><td>96</td><td>15</td><td>379</td></tr>
</table>
Source: My Care Record – activity statistics October 2020
</td>
</tr>
<tr>
<td>Religion</td>
<td>NI Population

41.6% of population from a Catholic background
40.8% of population from Protestant and other Christian background
17.6% of population from other religions, no religion or religion not stated (2011 Census data)</td>
</tr>
<tr>
<td>Political Opinion</td>
<td>General population

“Generally speaking, do you consider yourself as a unionist, a nationalist or neither?” (Northern Ireland Life and Times, 2018[5])

Unionist 26%; Nationalist 21%; Neither 50%; Other 1%; Don’t know 2%.</td>
</tr>
<tr>
<td>Marital Status</td>
<td>NI Population - All usual residents aged 16 and over 1,431,540

Percentage of all usual residents aged 16 and over who are:
<table>
<tr><td>Single

(never married or never registered a same-sex civil partnership)</td><td>36.14</td></tr>
<tr><td>Married</td><td>47.56</td></tr>
<tr><td>In a registered same-sex civil partnership</td><td>0.09</td></tr>
<tr><td>Separated (but still legally married or still legally in a same-sex civil partnership)</td><td>3.98</td></tr>
<tr><td>Divorced or formerly in a same-sex civil partnership which is now legally dissolved</td><td>5.45</td></tr>
<tr><td>Widowed or surviving partner from a same-sex civil partnership</td><td>6.78</td></tr>
</table>
</td>
</tr>
</table>

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[5] ARK. Northern Ireland Life and Times Survey, 2020. ARK www.ark.ac.uk/nilt, June 2020. Accessed 04 December 2020.

Dependent Status	Population data: **Official statistics from the Health Survey NI (2017/18) suggest that in Northern Ireland:** • 13% have caring responsibilities • Approx. 70% receive no monetary reward for giving this care • 48% received help from other family members, but 38% received no support from others. • More females (14%) than males (10%) had caring responsibilities. • Of those aged 35-44 years 17% had caring responsibilities; as did 19% of those aged 45 -54 years; 17% of 55-64 year olds and 14% of those aged 65 – 74 years. **Parents with dependent children** 238,094 households (33.9% of all NI households) have responsibility for dependent children (Census 2011) **NI Lone parent families** = 115,959, with 123,745 dependent children. Statistics also reveal a gender disparity in relation to single parent families - of the 115, 959 lone parents, 16, 691 are males and 99,268 are female. (Census 2011)
Disability	**Health Survey NI (2017/18 – published 2019)** • 43% longstanding illness (32% limiting and 11% non-limiting illness) • Females (44%) were more likely than males (40%) to have a long-term condition. • Prevalence also increased with age with 22% of those aged 16-24 reporting a long-term condition compared with 70% of those aged 75 and over. • Four-fifths of respondents (81%) had contact with the Health and Social Care System in Northern Ireland • Of these, 84% were either very satisfied or satisfied with their experience • A fifth (21%) reported high levels of anxiety, while 45% reported very low levels Census data reveals that of the NI population: • Deafness or partial hearing loss – **5.14% (93, 078)** • Blindness or partial sight loss – **1.7% (30, 785)** • Communication Difficulty – **1.65% (29, 879)** • Mobility or Dexterity Difficulty – **11.44% (207, 163)** • A learning, intellectual, social or behavioural difficulty - **2.22% (40, 201)** • An emotional, psychological or mental health condition - **5.83% (105, 573)** • Long – term pain or discomfort – **10.10% (182, 897)** • Shortness of breath or difficulty breathing – **8.72% (157, 907)**

	• Frequent confusion or memory loss – **1.97% (35, 674)** • A chronic illness (such as cancer, HIV, diabetes, heart disease or epilepsy. – **6.55% (118, 612)** • Other condition – **5.22% (94, 527)** • No Condition – **68.57% (1, 241, 709)** The Dementia strategy for NI [6]estimates, that around 60,000 people will be living with dementia by 2050.
Ethnicity	Although data for the numbers of people from different ethnicities living in Northern Ireland is limited, Northern Ireland Pooled Household Survey [7](NIPHS) tables, published 2017 show that**:** **2013/14:** Ethnicity White 98.2% (1,399,000); All other Ethnicities 1.6% (23,000) **2014/15:** Ethnicity White 98.2% (1,409,000); All other Ethnicities 1.8% (26,000) Statistics from the HSC Interpreting Service showed a large rise in requests for interpreters from 1,850 in 2004-2005 to 10, 6541 requests in 2016-2017. The most popularly requested languages are described below: 1. Polish 31220 2. Lithuanian 15866 3. Romanian 8975 4. Portuguese 8323 5. Arabic 6203 6. Slovak 5356 7. Tetum 5319 8. Chinese - Mandarin 5103 9. Bulgarian 3421 10. Hungarian 3387 11. Chinese - Cantonese 2858 12. Russian 2541 13. Latvian 2042 14. Somali 1151 15. Czech 855 16. Chinese - Hakka 748 17. Spanish 589 18. Farsi 515 19. Bengali 369 20. Urdu 297

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[6] HSC & NI Executive (March 2018) *Regional Dementia Care Pathway*, Cambridge: Seamus McErlean.

[7] Northern Ireland Statistics and Research Agency (2017) *Northern Ireland Pooled Household Survey (NIPHS) Tables,* Available at: *https://www.nisra.gov.uk/publications/northern-ireland-pooled-household-survey-niphs-tables* (Accessed: 04 December 2020).

	Hate crime incidents and offences with a racial motive increased substantially, with racially motivated crimes having overtaken sectarian motivated hate crimes for the first time in 2017/18. Figures from the Public Prosecution Service (PPS)[8] show that of the cases involving hate crime, 38.5% were on the basis of race.
Sexual Orientation	There are no accurate statistics on sexual orientation in the community as a whole, it is however estimated that between 5% and 10% of the population would identify as lesbian, gay or bisexual. A report published by the Rainbow Project (O'Hara, 2013)[9], based on research conducted with more than 500 individuals found that the respondents reported common experiences of invisibility, homophobia/transphobia, and a range of violence from threats to physical violence, whether direct or indirect. As a result of their actual or perceived sexual orientation and/or gender identity: - 65.8% had been verbally assaulted at least once; - 43.3% had been threatened with physical violence at least once; - 33% had been threatened to be 'outed' at least once; - 34.7% had experienced discrimination in accessing goods, facilities or services at least once.

2.3 Qualitative Data –What are the different needs, experiences and priorities of each of the categories in relation to this policy or decision and what equality issues emerge from this? Note if policy affects both staff and service users, please discuss issues for both. Also give consideration to multiple identities (such as single parents for example).

Category	***Needs and Experiences***
Gender	By October 2020 the number of users on the portal had increased from 18 at the end of phase 1 to 262 at the end of phase 2 of these users 48% were male and 52% female. Gender differences in Health are often cited in research and the latest Statistics published from the Health Survey NI 2019 indicate that females (42%) were more likely than males (38%) to have a long-term condition. Certain health and wellbeing issues are more commonly associated with one gender i.e. dementia, depression and

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[8] Public Prosecution Service & NISRA (2017 / 18) *Statistical Bulletin : Cases Involving Hate Crime 2017/18*, Belfast.
[9] The Rainbow Project (2013) *Through Our Minds*, Belfast: Malachai O'Hara.

	arthritis are more common in women, while men are more prone to lung cancer, cardiovascular disease and suicide (Broom, 2012[10]). While other research reports that in industrialized societies men die earlier than women but women have poorer health than men. (Macintyre et al 1996)[11] There are a lot of research and articles available on the impact for females either living with long-term conditions or who care for a relative with the disease but there does not appear to be any data re how the same diagnosis affects males. Anecdotally males are believed to be less likely to join in or engage with group activities however the project team did not find this in either the Dementia or Diabetes support groups they attended. Males were well represented in all the groups we attended.
Age	The UK already has a larger proportion of people over 65 than the EU average, and as the number of older people rises steeply, the need for carers will continue to increase. The number of older people over 65 has increased by 16% since 1999 and will show a similar increase from the current figures of 255,000 by 2015. This will include a rise of 29% in the number of people over 85years. Research by Age Concern and the Alzheimer's society [12]in 2020 suggests that older people with long term health conditions have been some of the hardest hit by the Covid pandemic. The disruption to their daily lives and the need to shield appears to be having an adverse effect on their long term health conditions with many struggling to manage their conditions with worsening symptoms and reduced ability to complete daily activities. As a consequence of the pandemic the majority of health care related appointments have moved from face to face to virtual appointments either by phone or videoconferencing which necessitates the use of technologies which may be new to the older age groups. During phase 2 of the pathfinder project and as a result of COVID 19 changes to the delivery of healthcare services the original limits on numbers for diabetes patients was lifted to facilitate communication between the patient and the health care teams. This has proven to be very successful and the project is now being rolled out to all the Regional Diabetes teams. While recruiting for the phase 1 pilot the project team noted that the older age group were less likely to use technology and many had no access to email which is a prerequisite of using the portal. Age also appears to be a significant determining factor on willingness or ability to use online health services. Age concern published a Digital Inclusion Evidence Review 2018 [13]which found that while "the trend over the last decade has been for increasing internet use among the older population, a substantial group – including the majority of those age 75 and over – are not online". They

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[10] Broom D (2012) Gender and health. In: Germov J (ed) *Second Opinion: An Introduction to Health Sociology.* Melbourne: Oxford University Press.

[11] Macintyre et al (1996) *Gender differences in health: are things really as simple as they seem?* , Available at: *https://pubmed.ncbi.nlm.nih.gov/8643986/#affiliation-1* (Accessed: 04 December 2020).

[12] Alzheimer's Society (September 2020) *Worst hit : dementia during coronavirus* , London.

[13] Age UK (November 2018) *Digital Inclusion Evidence Review 2018*, London: Susan Davidson.

	recommend that Digital inclusion providers need to find ways to engage older people through activities that interest them. Training needs to be personalised and flexible and delivered at the older person's pace with ongoing support. It should be noted that age alone was not the only determining factor of ability/willingness to use the healthcare online systems. Where someone lives has a significant impact on online activity with rural areas and areas of high deprivation often having poorer access to online services One in four respondents (28%) to the Health Survey NI 2019 said they would not use any of the online services. Of these, over two-fifths (44%) said they would prefer direct contact with their health care provider while 36% said that they did not have the required technical ability / know-how to use such methods addressing the inability or reluctance to use online services in the older age groups must be addressed so as not to disadvantage older people. The percentage of people living with long-term conditions increases with age and the reluctance/ inability for this age group to use online healthcare systems means the Patient Portal project team will need to tailor and address the specific training needs and support provided to this group of users.
Religion	Data did not suggest any particular issues or needs with regards to religion. The project is targeting a regional audience with cross community engagements to recruit patients which have been designed to negate any bias towards those with different political opinions.
Political Opinion	Data did not suggest any particular issues or needs with regards to political opinion. As above the regional nature and cross community engagement steps taken to recruit patients are designed to negate any bias towards those with different political opinions.
Disability	According to Disability Discrimination Act 1995 the[14], a person is said to be disabled if he has a mental or physical impairment that is long-term and has a substantial negative impact on his ability to carry out his normal daily tasks. Disabled people have less possibility to live in internet provided homes than their non-disabled counterparts. From 2012 records, 61% of the disabled population live in homes where there is internet compared to 86% of non-disabled persons (Compiling the statistics of disabled people living in the UK Disability Information and advice line) Dementia is the most feared condition for people over the age of 55, more than any other major life-threatening disease, including cancer, stroke, heart disease and diabetes many people appear to struggle post diagnosis facing the stigma and overcoming the shock and trauma of the diagnosis; whilst recruiting for the phase 1 pilot the project team noted that immediately post diagnosis individuals were less likely participate in the program as it took a period of time to accept their diagnosis. This may not be true for all conditions as the portal offers a library tailored to their diagnosis many of

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See https://www.nidirect.gov.uk/articles/protection-against-disability-discrimination (Accessed 29 December 2020)

	the respondents to the Phase 2 user surveys found that having access to the library meant they could dip in and out of the documents provided as and when they needed them and they used them to reinforce the information provided at the time of diagnosis. Patients (and their carers) who are partially sighted may have difficulties in accessing the portal. It is the intention of the project to embed text to speech software on the site which may partially resolve this issue although it should be noted that the software will not be able to translate the clinical documents Patients with Learning difficulties may have additional needs in using the technology to access the portal or information materials provided in the libraries. Patients with certain diagnosis for example Parkinson's or dexterity issues may be unable to use the technology and therefore unable to access the portal themselves. For all patients with disabilities if they have the ability to provide an informed consent they may wish to nominate a family member or carer to use the portal on their behalf.
Marital Status	It may be more difficult for single people to access services as no spouse or partner to push them for treatment / diagnosis. The project team noted that during recruitment that the married couples who enrolled where more likely to follow through with registering than those who lived alone and were relying on other family members to assist them with the technology.
Sexual Orientation	Research has demonstrated that LGB people report poorer experiences when accessing health and social care, are likely to delay access to healthcare based on previous negative experiences and fear of negative attitudes of health workers specifically in relation to their sexual orientation, and may have poorer health outcomes than their heterosexual peers.[15] The negative impacts of experiences of discrimination and marginalisation, both direct and indirect, on LGBQ+ individuals and groups are also well established.
Ethnicity	In order to gain access to Patient Portal all users require a HCN usually obtained via your GP; migrants may find it more difficult to register with a

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[15] See: Elliot, M. et al. (2015). Sexual Minorities in England Have Poorer Health and Worse Health Care Experiences: A National Survey, *Journal of General Internal Medicine*, 30 (1): 9-16; Light, B. et al. (2011). *Lesbian, Gay & Bisexual Women in the North West: A Multi-Method Study of Cervical Screening Attitudes, Experiences and Uptake*. The Lesbian & Gay Foundation and University of Salford.

	GP consequently inhibiting their ability to access Patient Portal. Language barriers may be faced through the Patient Portal package as English is the current format; documentation within Patient Portal is only available in the written language. Consequently these language barriers may impact on the information needs of some ethnic minorities. However, individuals using the HSC services have access to translation services, including the Telephone Translation services, such as The Big Word. Evidence has also highlighted that some ethnic minority cultures prefer to deal with health care professionals of the same sex as themselves; as this cannot be guaranteed due to workforce constraints it will impact some ethnic minorities.
Dependent Status	Those with caring or childcare responsibilities may find it more difficult to access the Portal as they don't have the time. This may include those living in rural or disadvantaged areas and dependants with more than one person to care for. Patients with chronic conditions may have more **specific requirements**, for example: • Care needs to begin early and may evolve rapidly; • Short intervals of care, often requiring constant monitoring and coordination; • Compared to more acute conditions, there is a need for more personal care, more hours of care and more supervision, higher carer strain and carers likely to give up or cut back on work to care; and • Care is life-long once it commences. With the burden of care often focused on informal carers, the issue of carer strain identified above is a particular issue, but as is carer readiness and carer competence to undertake such an intensive, stressful and life changing role. As part of the Carer's Week Campaign in Scotland, a survey of carers of older people (not just those with dementia) was undertaken to explore the impact that caring has on people's lives. The survey found that: • 77% of carers are not prepared for all aspects of caring; • 83% of carers are not aware of the support available; and • 35% of carers had received wrong advice about the support available. Clearly, this indicates a need to ensure that carers are educated, confident in their roles and that the impact of the caring role on the carer is monitored and mitigated where possible – the mitigation focus is the key focus of the

	- It is estimated that one in four care-givers suffer from depression; - Informal care-givers have a higher mortality risk compared to the general population.

2.4 Making Changes

Based on the equality issues you identified in 2.2 and 2.3, what changes did you make or do you intend to make in relation to the policy or decision in order to promote equality of opportunity?

In developing the policy or decision what did you do or change to address the equality issues you identified?	***What do you intend to do in future to address the equality issues you identified?***
Gender: Transgender All HSC staff are required to complete the Making a difference training which deals with issues to do with Transgender (reference in next section)	Evaluate the gender breakdown of patients and their representatives at each phase of the project. Encourage females attending the voluntary groups to register for a patient portal account. Provide additional training and support for females with a caring role at a time and place that suits them.
Age The percentage of people living with long-term conditions increases with age and the reluctance/ inability for this age group to use online healthcare systems means the Patient Portal project team will need to tailor and address the specific training needs and support provided to this group of users.	Promote the use of the Portal regionally across NI. The nature of the disease often dictates the age of the patient groups i.e. Dementia mostly over 65 years of age. Type 1 Diabetes mostly below 30 Provide additional training support to those older patients who want to use the Patient Portal application but are not IT literate. User manual added as a link on the Portal under the help menu. Simple bite size guides added as a link on Portal which show how to perform activities on the portal i.e. register for an account.

Religion	The project team engage with the voluntary sector Patient and Carer groups within all communities, promoting the portal regionally within NI across all areas using local groups on all sides of the community
Political Opinion	Promote the portal regionally within NI across all areas using local groups on all sides of the community
Marital Status	Raise awareness among clinical staff inviting patients to use the portal to consider Marital status when selecting patients and provide additional support and training as required.
Dependent Status	Inform patients and carers that the use of the portal should be used to complement existing information about their relatives care Patient privacy issues and competence to provide an informed consent by their relative is a limiting factor for enrolling patient representatives Training is provided at a time and place convenient to the carer to fit in with demands in their schedules Training provided in various formats i.e. video, face-to-face, user manuals and contact details for advice will be provided
Disability	The Portal is currently a web app but future plans include making it more mobile friendly and enabling fingerprint recognition for login. There is no audio function available at the moment, but this has been added to the Portal enhancement list. Audio format could help alleviate some issues for those who have sight issues or learning disabilities Dragon Speak will be embedded on the Patient Portal to aid partially sighted users Computer accessibility options such as instructions to zoom screen size are included in the user guide

	Patients currently have fewer face-to-face appointments (result of Covid restrictions) functionality is extended to include use of virtual clinics within the portal Post diagnoses – follow up clinic after time to digest diagnoses. All healthcare staff to attend mandatory Disability Awareness training
Ethnicity	Use Big Word translation service for instant translation Patients may request same sex interpreter or health professional if possible – information can be added within Shared Files until a patient space ‘to note their personal information’ becomes available An enhancement request has been raised with the supplier to provide page where patients may add detail preferences for example same sex health care provider English is the only language available although there are translation apps now available which could be used to translate the clinical documents into the preferred language
Sexual Orientation	As mentioned previously in Gender Section: All HSC staff are required to complete the Making a difference training which deals with issues surrounding sexual orientation
Evaluations	Engagement with steering groups for each specialty to define requirement and a post go live user survey. Project evaluation reports to be sent to participants

2.5 Good Relations

What changes to the policy or decision – if any – or what additional measures would you suggest to ensure that it promotes good relations? (refer to guidance notes for guidance on impact)

Group	***Impact***	***Suggestions***
Religion	N/A	
Political Opinion	N/A	
Ethnicity	N/A	

(3) SHOULD THE POLICY OR DECISION BE SUBJECT TO A FULL EQUALITY IMPACT ASSESSMENT?

A full equality impact assessment (EQIA) is usually confined to those policies or decisions considered to have major implications for equality of opportunity

How would you categorise the impacts of this decision or policy? (refer to guidance notes for guidance on impact)

Please tick:

Major impact	
Minor impact	✓
No further impact	

Do you consider that this policy or decision needs to be subjected to a full equality impact assessment?

Please tick:

Yes	
No	✓

Please give reasons for your decisions.

Although the project will be expanded to include further cohorts of patients living with a long-term health condition the equality impact issues remain similar to the assessment carried out for the original project with the patients living with Dementia. It is not felt that a full EQIA will highlight any additional information relating to the needs and experiences of the equality groups already covered in this screening document.

(4) CONSIDERATION OF DISABILITY DUTIES

4.1 In what ways does the policy or decision encourage disabled people to participate in public life and what else could you do to do so?

How does the policy or decision currently encourage disabled people to participate in public life?	*What else could you do to encourage disabled people to participate in public life?*
Disabled people continue to play a role in developing the service. We have liaised with the following groups: Regional voluntary and community groups; Dementia NI, Alzheimer's Society, Carer's NI, Age NI, Deaf Association, RNIB Survey – Lucid Talk January 2016 survey of 3,000 people across NI and their views on the use of "e-health" solutions. Survey respondents 45 years old and above. Conferences; Digital Government Conference, Inaugural Conference of Palliative Dementia Care Patient representatives within the Diabetes Network group Other patient representatives will be recruited for each new group of users added to the portal during the rollout phase	Disabled people continue to play a role in developing the service. Engagement with steering groups for each specialty to define requirement and a post go live user survey. Project evaluation reports to be sent to participants Future design decisions will be based on feedback from patients and carers. Patient groups will be included in the membership of the disease specific implementation groups during the roll out across the region.

4.2 In what ways does the policy or decision promote positive attitudes towards disabled people and what else could you do to do so?

How does the policy or decision currently promote positive attitudes towards disabled people?	*What else could you do to promote positive attitudes towards disabled people?*
N/A	Clear and concise information to user. Promote use of the portal to maintain

	independence by providing healthcare information which allows them to contribute to their own health and wellbeing.

(5) CONSIDERATION OF HUMAN RIGHTS

5.1 Does the policy or decision affect anyone's Human Rights? Complete for each of the articles

ARTICLE	Yes/No
Article 2 – Right to life	No
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment	No
Article 4 – Right to freedom from slavery, servitude & forced or compulsory labour	No
Article 5 – Right to liberty & security of person	No
Article 6 – Right to a fair & public trial within a reasonable time	No
Article 7 – Right to freedom from retrospective criminal law & no punishment without law	No
Article 8 – Right to respect for private & family life, home and correspondence.	Yes
Article 9 – Right to freedom of thought, conscience & religion	No
Article 10 – Right to freedom of expression	No
Article 11 – Right to freedom of assembly & association	No
Article 12 – Right to marry & found a family	No
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights	No
1st protocol Article 1 – Right to a peaceful enjoyment of possessions & protection of property	No
1st protocol Article 2 – Right of access to education	No

If you have answered no to all of the above please move on to ***Question 6*** *on monitoring*

5.2 If you have answered yes to any of the Articles in 5.1, does the policy or decision interfere with any of these rights? If so, what is the interference and who does it impact upon?

List the Article Number	Interfered with? Yes/No	What is the interference and who does it impact upon?	Does this raise legal issues?* Yes/No
8 Patients who cannot provide an informed consent to share their record with a family member or carer Children competency Guardian access to child record		Secure and accessible – by the right people, to the right level of detail. Identification of approach to authentication (layering, permissions, device generic etc.) to ensure those individuals involved in the care of a person who is unable to provide an informed consent to share their record with a family member or carer (e.g. person, their family, care team, care home etc.) are given appropriate access. Patient is able to remove access from a person they have nominated to share their record at any time.	

** It is important to speak to your line manager on this and if necessary seek legal opinion to clarify this*

5.3 Outline any actions which could be taken to promote or raise awareness of human rights or to ensure compliance with the legislation in relation to the policy or decision.

N/A

(6) MONITORING

6.1 What data will you collect in the future in order to monitor the effect of the policy or decision on any of the categories (for equality of opportunity and good relations, disability duties and human rights)?

Equality & Good Relations	Disability Duties	Human Rights
Section 75 groups – collecting information on gender, age etc. trying to collate information from the LB GTQ community. Add evaluation comment Engagement with patients will be incorporated into each new service in the form of steering group membership, focus groups and post project user satisfaction surveys. Patient feedback will be added to the enhancement list for portal development to ensure that specific needs are met when designing key features within the Patient Portal Ongoing monitoring of activity during the project to highlight groups where additional training or engagement with the project team may be required.	Improving attitudes towards people. Collect and review data from people involved in during the regional rollout to all specialties where patients are living with long-term health related conditions.	N/A

Approved Lead Officer: Anne Mulgrew

Position: Senior Project Manager BSO
Contact Details anne.mulgrew@hscni.net

Date: 03/12/2020

Policy/Decision Screened by: Anne Mulgrew

Please note that having completed the screening you are required by statute to publish the completed screening template, as per your organisation's equality scheme. If a consultee, including the Equality Commission, raises a concern about a screening decision based on supporting evidence, you will need to review the screening decision.

Please forward completed template to:
Equality.Unit@hscni.net

Any request for the document in another format or language will be considered. Please contact the Equality Unit:

Equality Unit/ BSO /James House/ 2-4 Cromac Avenue/ Belfast/ BT7 2JA

Tel: 028 9536 3961