HSC Health and Social Care Board

Equality, Good Relations and Human Rights
SCREENING

The Health and Social Care Board is required to consider the likely equality implications of any policies or decisions. In particular it is asked to consider:

1) 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 or none)

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

3) 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 or none)

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

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.

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 and Human Rights Information Bank on the BSO website: http://www.hscbusiness.hscni.net/services/1798.htm

Health and Social Care Board

Equality, Good Relations and Human Rights
SCREENING TEMPLATE

(1) INFORMATION ABOUT THE POLICY OR DECISION

1.1 Title of policy or decision

Relationships, Sexuality and Dementia - Operational Guidance

1.2 Description of policy or decision

- **what is it trying to achieve? (aims and objectives)**

Dementia is an overall term used to describe a wide range of symptoms associated with the deterioration of functions including memory, thinking, behaviour and the ability to perform everyday activities.

Symptoms differ from person to person but can affect orientation, perception, understanding, memory, decision making, ability to learn, communication and judgement.

There are many types of dementia including Alzheimer's Disease, Vascular Dementia, Frontotemporal Dementia and Dementia with Lewy Bodies. Dementia can happen to anybody but is more common after the age of 65.

The aim of the Guidance is to:

- Ensure the rights of people with a dementia and their partners are upheld so that they can engage in personal and sexual relationships, if they so wish.
- Provide information about personal and sexual relationships for staff working with people with a dementia, their partners, carers and families.
- Offer practical guidelines to staff.
- Promote best practice within dementia care services.
- Support people with a dementia, their partners, carers and families to deal with and talk about sexual matters in a safe and supportive context.
- Support the maintenance of relationships or the development of new relationships as appropriate.
- Ensure that the privacy of the person with a dementia and their partner is

respected.

- Provide information, education and support to people with a dementia, their carers, partners and families as appropriate.
- Promote a consistent and considered approach.
- Safeguard people with a dementia, their partners, carers, families and others from risk of harm or exploitation.

- **how will this be achieved? (key elements)**

This Guidance is being developed to support staff to deliver a more person-centred service to people with a dementia, their partners, carers and families. It is important therefore that staff feel confident to address the issue of relationships and sexuality in a supportive and timely manner.

Helping people come to terms with the changes that dementia can bring about in behaviour, understanding and sensitivity, sexual activity and moods, means that the conversation needs to begin at time of diagnosis and continue throughout the dementia journey.

These aims will be achieved through staff induction programmes, training and supervision.

- **what are the key constraints? (for example financial, legislative or other)**

Although funding has been tentatively agreed, the actual amount required or available to support staff training and to embed this Guidance in practice has not yet been established.

A challenge will also be in finding trainers who are suitably qualified and competent to design and deliver training to staff. The authors of the Guidance have had initial discussions with one Consultant who currently provides training in this area and who would be willing to offer this knowledge / support to Trusts in the interim period until firmer arrangements are established.

The Guidance must be regularly updated (this will be confirmed / agreed when Trusts sign-off on the document). Regular updating will ensure that account is taken of new practice or requirements e.g. Mental Capacity Legislation

There may be some constraints resulting from staff / public attitudes however, this can be overcome through induction, training and supervision (staff) and public awareness campaigns / information (public)

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

This Guide has been developed at the request of and primarily for the benefit of staff working within HSC Trusts however, it's impact is much wider as reflected in the number of key stakeholders who contributed to its development including:

- HSCB / PHA staff
- HSCT staff (various disciplines and programmes of care)
- Independent sector staff
- Academics
- Dementia Specialists who have written / lectured in this area
- Community and Voluntary Sector
- Representatives of minority or marginalised groups
- Trade Unions / Professional Bodies
- Regulators (RQIA / NISCC)
- Legal Services
- People with a dementia
- Carers of people with a dementia

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

- **what are they?**
- **who owns them?**

The following Policies / Procedures and Statutes have guided the development of this Guidance:

Improving Dementia Services in NI - A Regional Strategy (2011): which seeks to improve the services and support arrangements currently available to people with a dementia, their carers, partners and families

Human Rights Act 1998: in particular Article 8 which includes the right to respect for privacy, Article 10 which relates to freedom of expression and Article 12 in respect of rights to marry and have a family.

Disability Discrimination Act (1995) (amended 2005): which works alongside the Human Rights Act for the purpose of ensuring that persons with disabilities are valued and treated as equal citizens. The amendment of the Act in 2005,

places a duty on public authorities to promote disability equality.

Section 75 of the Northern Ireland Act 1998: which places a duty on public bodies to promote equality of opportunity amongst nine equality categories. It is important to recognise an individual's potential membership of any of the categories, and that these may overlap.

UN Convention on the Rights of Persons with Disabilities: which seeks to eliminate discrimination relating to marriage, family and personal relations.

Mental Capacity Act 2016: this legislation, which partially came into effect on 2nd December 2019 (in relation to Deprivation of Liberty Standards - DoLs) provides a single legislative framework to deal with all persons aged 16 and over on the basis of their capacity to make a decision in relation to their care, treatment and personal welfare. The key principle behind the act is to support personal autonomy and self-determination, creating a legal requirement to support a person to exercise their capacity where they can. It also sets out in statute that it must be established that a person lacks capacity before a decision can be taken on their behalf, and that a lack of capacity cannot be assumed due to the person's underlying condition. If it is established that a person lacks capacity to make a specific decision at a particular time, the Act puts in place a new, alternative decision-making regime that provides important additional safeguards for the person who lacks capacity. When commenced, the Act will also require all those acting in a professional capacity, for remuneration, in relation to the care, treatment or personal welfare of a person over 16 who lacks capacity to have due regard to the associated Mental Capacity Act (NI) Code of Practice (2016) and (2019) which relates to (i) Deprivation of Liberty Safeguards and (ii) Research, Money and Valuables

Mental Health (Northern Ireland) Order 1986: provides a framework for the care, treatment and protection of all persons with a mental disorder and establishes systems through which the statutory rights of individuals and their relatives are protected and the duties, responsibilities and powers of professionals regulated.

NB: All staff need to be aware of the Mental Capacity Act (NI) 2016 which partially came into effect on 2nd December 2019 in relation to Deprivation of Liberty Safeguards (DoLs). Staff need to be aware of the current Common Law position and the Mental Health (Northern Ireland) Order 1986.

NB: As part of the review procedures for this Guidance, Trusts will have regard to the status of the Mental Capacity Act (NI) 2016 and amend the Guidance accordingly (see Section 1.9 below). All staff should be advised

of the amendments and their duties under any change to the legal position.

Safeguarding Policy, Guidance and Legislation:

The Safeguarding Vulnerable Groups (NI) Order as amended by the Protection of Freedoms Act (2012): outlines the safeguarding requirements when organisations are recruiting staff and volunteers to certain positions which involve contact with adults at risk. The Order makes it an offence for employers to knowingly recruit barred individuals into 'regulated activity' with adults. Organisations must also refer to the Disclosure and Barring Service (DBS) any individual who has harmed, or poses a risk of harm to adults, and who has been permanently removed (or would have been had they not left the organisation) from regulated activity.

Adult Safeguarding: Regional and Local Partnership Arrangements (2010): provides regional guidance on the establishment of new adult safeguarding arrangements.
http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/Adult-Safeguarding-in-Northern-Ireland-Regional-and-Local-Partnership-Arrangements-March-2010.pdf

Adult Safeguarding in Northern Ireland: Prevention and Protection in Partnership (2015): jointly developed by the Department of Health and Department of Justice the regional policy sets out how the Northern Ireland Executive intends adult safeguarding to be taken forward across all Government Departments, their agencies, and in partnership with voluntary, community, independent and faith organisations.

Safeguarding Vulnerable Adults: Regional Adult Protection Policy and Procedural Guidance (2015):

(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.

This Guidance has been developed with the co-operation of staff from the five Health and Social Care Trusts (Dementia Services), staff from Trust's Learning Disability Services who developed a similar Guidance (HSCB / PHA / HSC Trusts March 2016), DoH (Capacity Legislation and guidance), Trust Leads for Safeguarding, Academics, Legal Services, RQIA, NISCC, HCPC, RCN and the voluntary sector (Dementia NI and Alzheimer's Society) whose staff consulted with people with a dementia, their partners, carers and families.

In the development of this Guidance, the authors consulted widely with various stakeholders specifically, agencies / bodies representing:

- People with a dementia
- Carers of people living with a dementia
- Community and Voluntary Sector including – Alzheimer's Society, Dementia NI, Age NI, Carers NI, Rainbow, Sail NI, Action on Elder Abuse – however, it should be noted that although these groups were invited to contribute to the development of the Guide, not all availed of that opportunity.

This Screening Template was completed with reference to the following data sources:

- Northern Ireland Health and Social Care Workforce Census March 2019
- Census 2011
- 2017/18 NI Health Survey
- Domiciliary Care Services for Adults in NI (2018) Information Analysis Directorate
- NISRA Statistical Bulletin (2018) Estimates of the population aged 85 and over Northern Ireland.
- Northern Ireland Pooled Household Survey (NIPHS) tables, published 2017.
- FPA Disability and Sexuality policy (2017).
- Talking about sex, sexuality and relationships: Guidance and Standards. (2016) The Open University.
- 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.
- Dementia Action Alliance (undated) Meeting the Challenges of Dementia in Prisons: Roundtable Discussion Briefing Paper
- Prisons and Probation Ombudsman Independent Investigations (July 2016) Dementia. Learning Lessons Bulletin. Fatal Incidents Investigations.

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- SCIE (2018) Black and Minority Ethnic (BME) Communities and Dementia
- 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.
- Staff data collected from HRPTS

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.

It is estimated that at present in Northern Ireland there are 25,000 people living with dementia with numbers of people with dementia rising around 60,000 by 2051. Reliable and accurate data about people with a dementia, their carers and dependents is difficult to obtain. The Delivering Social Change Phase 2 Dementia Project which focuses on e-health, data analytics and research and which is due to complete in March 2020, should make a significant contribution to our knowledge in this area

Category	***What is the makeup of the affected group? (%) Are there any issue or problems? For example, a lower uptake that needs to be addressed or greater involvement of a particular group?***
Gender	**Service users** Northern Ireland's population was estimated to be 1.88 million people. Just over half of the population (50.8 per cent) were female, with 955,400 females compared to 926,200 males (49.2 per cent). This Guidance is pertinent to both males and females however, since life expectancy is marginally higher for females and the risk of acquiring a dementia increases with age, it is possible that there may be more females living with a dementia than males. However, this may change - while women accounted for two thirds (66.2 per cent) of those aged 85 and over in mid-2017, the population increase among males over the decade from mid-2007 has been noticeably higher than that among females (52.6 per cent and 24.8 per cent respectively). Transgender

	The Gender Identity Research and Education Society (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% 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. **Staff** The workforce within health and social care is predominantly female, particularly among staff who provide personal care. The majority of the HSC workforce were female (79%). Of these female staff, 54% were employed full-time. Males represented 21% of all HSC staff employed. Of these male staff, a large majority (85%) were employed full-time.
Age	**Service users** The risk of acquiring a dementia increases with age making it more likely that the out-workings of this Guidance could impact more on older people. • Approximately 1 in 6 (16.4%) people in Northern Ireland are aged 65 years and over (308,200). • The population aged 85 and over increased by 1.5 per cent (from 37,200 to 37,700) between mid-2017 and mid-2018, representing 2.0 per cent of the population. • Also, it is projected that from mid-2028 onwards the older population (people aged 65 and over) will be larger than the number of children (i.e. people aged 0 to 15 years). However, an increasing number of people under 65 years are being diagnosed with a dementia. There are estimated to be at least 42,000 younger people with dementia in the UK: more than 5% of all those with dementia. In NI, the number of people under the age of 65 with a dementia is estimated to be 1,500. The demographic within prisons has changed i.e.:

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- Prisoners over 60 make up the fastest growing segment of the prison population (increase of 125% between 2004 and 2014)
- Prisoners over 50 make up the second fastest growing segment of the prison population (increase of 104% between 2004 and 2014)

These figures apply to UK but are equally applicable to NI particularly in the context of life in a post-conflict society

- Prisoners (50+) health deterioration 15 years before non-prison population
- Risk factors up to 15 times greater than general population
- Dementia diagnosis among prisoners is very low however, based on the medical evidence outlined above, it is quite plausible that the prevalence of dementia among prisoners is higher than the general population
- Dementia care in prisons is an area that requires more development but is being considered by the regional Dementia Strategy Leads

Staff
39% of all HSC Staff were under the age of 40, while 29% were aged between 40 and 49 and 32% were aged 50 and over.

</td></tr>
<tr><td>Religion</td><td>

Service users
There is no data collected on the religious breakdown of service users. Census data reveals that the NI population currently identify as:

- Catholic 40.76% (738, 108)
- Presbyterian Church in Ireland 19.06% (345, 150)
- Church of Ireland 13.74% (248, 813)
- Methodist Church in Ireland 3% (54, 326)
- Other Christian(including Christian related) 5.76% (104, 308)
- Other religions 0.82% (14, 849)
- No religion 10.11% (183, 078)
- Did not state religion 6.75% (122, 233) (Census 2011)

Staff
42% of HSC staff identify as Protestant, 44% identify as Catholic, 3% as other religions and 11% identified as having no religion.

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<tr><td>Political Opinion</td><td>Service users
There is no data collected on the breakdown of political opinion for service users. However, population level data from the NI Life and Times Survey (2018) suggests that in Northern Ireland, people identify as:
Unionist 26%;
Nationalist 21%;
Neither 50%;
Other 1%;
Don’t know 2%.
Staff
The majority of HSC staff did not state their political opinion (72%). Given the level of missing information, the population level data in the previous paragraph should be used.</td></tr>
<tr><td>Marital Status</td><td>Service users
There is no data collected on the marital status of service users. Population figures from the most recent census show that of the NI population:
47.56% (680, 840) of those aged 16 or over were married
36.14% (517, 359) were single
9.43% (134, 994) were either divorced, separated or formerly in a same – sex partnership
6.78% (97, 058) were either widowed or a surviving partner
However, given that dementia is more common amongst older people, there are likely to be a higher proportion of people with a dementia who are widowed or widowers than the general population.

Staff
50% married/ civil partnership; 35% were single; 14.75% other or unknown.</td></tr>
<tr><td>Dependent Status</td><td>Service users
The NI Census figures shows that 11.81% (213, 863) of the population provide unpaid care to family members, friends, neighbours or others because of long-term physical or mental ill – health/disabilities or problems related to old age.
3.11% (56, 318) provided 50 hours care or more.</td></tr>
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	• 33.86% (238, 129) of households contained dependent children. • 40.29% (283, 350) contained a least one person with a long – term health problem or a disability. A recent Health Survey in Northern Ireland found that 13% of the NI population have caring responsibilities. While 48% received help from others, 38% got no support from others. **Staff** Given that there are wide gaps in staff information relating to dependants, population data should be used. Given that most carers are female, suggests that the proportion of those with caring responsibilities in the HSC workforce will be higher than the population average.
Disability	**Service users** There are no overall figures available on the disability status of service users. However, in the last census, 21% (374, 668) of the population regard themselves as having a disability or long – term health problem, which has an impact on their day to day activities. This included: • 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)** Evidence shows that people with a Learning Disability (Down Syndrome) are likely to develop a dementia at a much younger age than the general population. There are an estimated 1,500

	people under the age of 65 living with a dementia in NI however, the numbers of people within this group who have a Learning Disability are not know. Research, recently commissioned under the Delivering Social Change Phase 2 Dementia Project, will address this issue and should significantly improve our knowledge of this group of people. Figures from the 2017/18 NI Health Survey show that of the NI population: • 43% longstanding illness (32% limiting and 11% non-limiting illness) • Males: limiting longstanding illness 29%; non-limiting longstanding illness 11% • Females: limiting longstanding illness 34%; non-limiting longstanding illness 11% • Prevalence of disability increases with age. Limiting longstanding illness increases from 17% among young adults aged 25 -34 years to 56% among those who are 75 plus years. **Staff** Data on staff disability contains a lot of missing information; therefore the statistics in the above paragraph should be used.
Ethnicity	**Service users** Ethnicity of service users is not captured. Although the last census (2011) provides information on the ethnic breakdown of the NI population, it is important to note that patterns have changed over the last number of years. More recent data from the Northern Ireland Pooled Household Survey (NIPHS) showed that in 2014/15: • Ethnicity White 98.2% (1,409,000); • All other Ethnicities 1.8% (26,000). Statistics supplied by the NI Regional HSC Interpreting Service showed a large rise in requests for interpreters from 1,850 in 2004-2005 to 130,025 requests in 2018-2019. The most popularly requested languages are described below: 1. Polish 30948 2. Arabic 16690 3. Lithuanian 16512 4. Romanian 12789

	5. Portuguese 8361 6. Bulgarian 7557 7. Tetum 6604 8. Slovak 6152 9. Chinese - Mandarin 5120 10. Chinese - Cantonese 3388 The Social Care Institute for Excellence (SCIE, 2018) reports that there are 25,000 older people from BME communities living with dementia in UK however, no data is available for NI. Research shows that • African-Caribbean and South Asian - vascular risk (hypertension) • Newer immigrants - may have less experience of dementia as they tend to be younger • Older communities (Irish / Jewish) demographically older and may therefore be more at risk • Chinese community refers to 'lost intelligence disease' and report fears of isolation • There may be a stigma around dementia in some cultures, it may be regarded as 'punishment for past misdemeanours' or might 'damage marriage prospects for a young relative' • Some ethnic communities may delay in seeking help from mainstream services and only seek help, information and support when their situation has reached crisis point • There may be communication barriers • Because of a perceived or actual cultural bias in assessment tests and diagnosis - these may be of limited value to some BME communities • In NI, there has traditionally been a difficulty for members of the travelling community in engaging with mainstream services. Efforts to date by the regional Dementia Strategy Leads to engage with this group have proved difficult **Staff** Staff data is line with the general population statistics, with approximately 2% of Trust staff identifying as belonging to an ethnic minority group.
Sexual Orientation	**Service users** There are no statistics on sexual orientation of service users, and

	there are no reliable statistics relating to the proportions of LGB people in Northern Ireland. However, it is estimated that between 7% and 10% of the general population will identify as LGB. **Staff** Much of staff information relating to sexual orientation is missing, so it can be assumed that the patterns reflected in the general population will apply to HSC staff also – between 7% and 10% who identify as LGB.

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.

Category	***Needs and Experiences***
Gender	It is theoretically possible that some staff may find overt sexually explicit behaviour more challenging to deal with if the person exhibiting that behaviour is either male or female (gender stereotypes e.g. the belief that it is less acceptable for a woman to be overtly sexual / have multiple partners whereas it is more acceptable for a man to be so) however, these issues are addressed in the Guidance through Case Studies (scenarios) that include learning / discussion points. The guidance also advises staff to report these concerns / address these issues through staff training and supervision. A programme of training to support the implementation of this Guide is being developed. A person with a dementia may feel more comfortable discussing issues to do with sexuality and relationships with someone of the same gender as themselves. The Guidance also addresses lesbian, gay and transgender issues both from the perspective of the person living with a dementia and its impact on their understanding of who they are and also from the perspective of staff who may find these issues morally, socially or personally challenging or difficult to

	understand. Some people who identify as transgender may or may not have completed the physical transition process but express their identity through their style of dress. If an individual has not had gender reassignment surgery, and is receiving personal care, HSC staff may become aware of the person's gender identity even if they haven't chosen to disclose it. This can make the individual uncomfortable if they feel intimate care or physical examination "outs" their biological sex. Another issue faced by people with dementia who have changed gender (or are in the process of doing so) may be that they do not remember that they have been through this process. A transgender person might forget that they have, or have not, started the process of changing gender (gender reassignment). This can be distressing and confusing.
Age	The risk of acquiring a dementia increase with age however, dementia is not a normal part of aging and younger people (under the age of 65 years) can also acquire a dementia. People with a learning disability (particularly Down Syndrome) are more likely to acquire the condition at an earlier age than the rest of the population. People with a history of alcohol and / or drug abuse are also at an increased risk of acquiring a dementia at an earlier age. There may be issues for younger people diagnosed with a dementia e.g. younger women using contraception. The Guide stresses the importance of good health care including sexual health and the responsibility of professional staff for ensuring that people with a dementia have access to these services as appropriate and necessary
Religion	Some people may be reticent to discuss 'intimate personal' issues for various reasons (which may be influenced by their own personal value / belief system). Staff may find the subject of sexuality and relationships difficult to address (again for personal / value based reasons).

Political Opinion	Neither the political opinion of staff or service users is regarded as raising any additional needs with regards to the Relationships and Sexuality Guidance.
Marital Status	People with a dementia may forget that they are married and regard another person as their spouse when they are not, they may want to engage in a sexual relationship with that individual. This can be a painful experience for the actual spouse and family members. The person with the dementia may make advances to this ‘other’ person and may have those advances rejected which may be confusing for them. People with a dementia who are not married may find it less socially acceptable to engage in sexual relationships. These are complex and emotive issues which are addressed within the guidance. The Guide is intended to apply to anyone in any relationship however that relationship may be defined or regarded socially or legally
Dependent Status	It is acknowledged that persons with a dementia may be more dependent on others in relation to activities of daily living. This dependence may raise issues in relation to the delivery of personal care and the potential risks of abuse for either the person with the dementia or their carer, regardless of wither or not that carer is a formal (paid) or informal carer (usually family). The Guidance covers safeguarding policies and procedures and lone working policies. Arrangements will be put in place to provide support / training to staff and informal carers
Disability	Dementia over time, impacts on the physical and cognitive capacity of the individual with a dementia which in turn may affect the nature and quality of their relationships with their partner(s). This is addressed within the Guidance. People with a learning disability (particularly Down Syndrome) are at an increased risk of acquiring a dementia. So too are people with a history of drug and / or alcohol abuse

	There is evidence to suggest that people with a disability face additional difficulties in obtaining fulfilling and healthy sexual relationships due to stigma Moreover, some people with disabilities may be dependent on their families, HSC staff or other carers in order to have relationships or engage in sexual activity. Some people (depending on the type of disability) may need support in practicalities of sexual health (e.g. checking themselves for STI's and accessing and safely using contraception / condoms. All of these issues are addressed in the Guidance and will be examined more fully in the training that will follow the approval of this Guidance.
Ethnicity	Some ethnic groups have a negative attitude to dementia, regard it as a stigma and keep it hidden (do not seek help). This issue will be highlighted in training programmes for staff and awareness programmes for the public and HSC staff working within dementia care will be expected to pick up and address these issues. Certain ethnic groups may have particular preferences for an HSC worker the same gender as themselves. There may also be communication difficulties which will require to be addressed through the publication of materials translated into different languages or need to have an interpreter present. Some ethnic groups may have a particularly conservative attitude towards relationships and sexuality, which may make implementation of the guidance more difficult for family/ carers of the person with dementia.
Sexual Orientation	The negative impacts of experiences of discrimination and marginalisation, both direct and indirect, on LGB individuals and groups are also well established. Research has documented that LGB people are more likely to report having a longstanding psychological or emotional problem than heterosexual counterparts.

	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 have poorer health outcomes than their heterosexual peers. Most types of dementia cause people to experience memory problems. LGB people may be affected by these in different ways e.g. if an LGB person has told some people about their sexual orientation but not others, the person may forget who they've shared this with. They may think they have told some people when they haven't, which might be distressing for the person, and for those supporting them.

2.4 Multiple Identities

Are there any potential impacts of the policy or decision on people with multiple identities? For example; disabled minority ethnic people; disabled women; young Protestant men; and young lesbians, gay and bisexual people.

The Guidance starts from the premise that everyone has the right to live fulfilled and meaningful lives, free from abuse or exploitation and that this includes the right of people with a dementia to express their sexuality in a safe and non-judgemental way.

To support learning and provide practical support to staff, this Guidance includes a number of case studies (stories), all of which have been adapted from research and other literary sources (original sources are referenced in the text) or from case examples which staff themselves have been involved in.

These case studies (learning tools) have been developed to reflect various identities although it must be acknowledged that as the dementia progresses and cognitive function declines, the person becomes increasingly vulnerable to other illnesses, infections, health problems and are at risk in terms of personal safety / exploitation and abuse

Dementia can affect anyone regardless of gender, ethnicity or class.

There may be a gender issue insofar as life expectancy for women is higher than for men. There is a higher number of women living with a dementia.

Different ethnic minorities may be prone to particular types of dementia

Following a diagnosis life expectancy will vary according to the type of dementia and complications resulting from it, and the stage at which the person is diagnosed.

2.5 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: Gender issues (including specific issues for transgender service users and patients) are dealt with in detail within the Guidance. Trusts will be required to review and update the Guidance at regular intervals (every 3 years or more frequently if necessary). This should help to address emerging issues or situations that were not considered in the development of this Guide. Given that some patients may feel more comfortable discussing issues to do with sexuality/relationships with someone of the same gender as themselves, this will try to be accommodated where possible, given that the majority of the HSC workforce is female (see Section 2.2 of the template)	Work still needs to be undertaken to develop and roll out a programme of training for staff however, funding to support this programme has been tentatively agreed and a programme will be developed in collaboration with HSC providers, academics, trainers, independent and voluntary sectors, people with a dementia and their carers. In addition to this training programme, other sources of help are available through: • Regional Dementia Learning and Development Framework • http://www.hscboard.hscni.net/our-work/social-care-and-children/dementia/learning-development-framework • Information Guides • https://www.publichealth.hscni.n

Age: Dementia is not a normal part of aging but increased age does bring increased risk. This is addressed within the Guidance and the various training / information guides that have been published to date and available on the websites listed opposite. Marital status: Individuals who are not in legally binding relationships (e.g. marriage) may find there is more resistance to entering into another sexual relationship. However, the guidance will be very clear in that it will apply to anyone in any relationship however that relationship may be defined or regarded socially or legally. Religion: Some staff / carers may find this a difficult issue to deal with based on their own personal belief system. This will be addressed through induction, training and supervision (staff) and awareness raising and support (carers) Ethnicity: Some ethnic groups have a negative attitude to dementia, regard it as a stigma and keep it hidden (do not seek help). This issue will be highlighted in training programmes for staff and awareness programmes for the public and HSC staff working within dementia care will be expected to pick up and address these issues. Some ethnic groups may also have	et/publications?keys=dementia • https://www.publichealth.hscni.net/publications?keys=delirium • Apps - available from NISCC and shortly to be available in a regional Dementia Apps Library • Information about dementia and how to access services is available on the NI Direct website • www.NIDirect.gov.uk/dementia There are still groups that are hard to reach however, the appointment of new Dementia Service Improvement Leads in each of the HSC Trusts have, as part of their job description / role, the requirement that they engage with these groups and provide support, advice and guidance as necessary / appropriate.

communication issues, and may need materials translated into different languages, or need an interpreter present. The HSCB and HSC Trusts have access to the HSC Translation Service, as well as a real-time telephony translation service, The Big Word. Sexual orientation: The Guide recognises sexual differences / preferences / orientation and addresses these issues both in the main text and in the Case Studies which are intended to be used for staff induction, training, supervision and reflection. (See Section 6 of the Guidance specifically and more generally elsewhere within the Guide)	

2.6 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	X
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	X

Please give reasons for your decisions.

This Guide will improve the knowledge, skills and understanding of staff working in dementia care which in turn has the potential to significantly enhance the quality of life and experience of people with a dementia and their partners, carers and families with regard to relationships, sexuality and dementia.

The Guide will safeguard and enhance the rights of people with a dementia, their partners, carers and families.

The evidence suggests that staff need this support and that currently, people with dementia and their partners may be left unsupported because of staff uncertainty (lack of knowledge / skills) of how to deal with this very personal / sensitive issue particularly in a society where issues of sexuality are contentious, stigmatised or taboo.

The Guidance offers a Human Rights based, person-centred approach to this challenging issue and therefore enhances equality of opportunity to this client group.

(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?*
In developing this Guide, the authors consulted with people with a dementia and their carers through links with Alzheimer's Society and Dementia NI. Trusts will be required to review / update this Guidance on a regular basis and will be expected to include people with a dementia and their carers in that process	The Regional Dementia Strategy Implementation Leads have engaged with people with a dementia and their carers throughout the entire process and require other agencies / individuals to do likewise in relation to any work in this area. Trust Dementia Leads, Service Improvement Leads and Navigators have, as part of their job description to demonstrate active, meaningful engagement with this client group and significant stakeholders

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?*
The Guidance positively impacts on the quality of life and experience of people with a dementia by recognising their right to live fulfilled lives in a supported and non-judgemental way. The Guide will support staff to provide a compassionate, safe and person-centred service to these individuals and their partners, carers and families. The rights of people with a dementia and their partners to continue to live a sexually active and fulfilled life style has received little attention either publically or in training courses.	The Guide will advance the debate / discussion on rights of people with a dementia and their partners, carers and families. As it is rolled out / implemented, knowledge will be increased and hopefully stigma, prejudice and negativity will be reduced.

Research into the sexual behaviour of older people generally and people with a dementia (or other illnesses) has until relatively recently been a much neglected area. Reasons for this apparent lack of interest may be due to the discomfort felt in discussing intimate personal difficulties (including those with dementia, their partners and professionals) and societal bias which values youth, beauty and productiveness. As a result, the level of knowledge that care staff have about this subject and their ability / confidence to support individuals is limited and they are increasingly finding themselves in situations where they feel ill equipped to respond. The onset of progressive cognitive decline does not necessarily indicate an end to sexual need however, the changes brought about by dementia can lead to social, emotional and behavioural challenges including ethical, consensual and safeguarding issues. These issues need to be addressed if people with dementia and their partners are to be enabled to experience emotionally fulfilled and safe lives. Our sexuality and the expression of that sexuality is an integral part of our daily living experience. We all need to feel loved and this is no less true for people with a dementia. The feeling of being loved and being able to express sexuality in a safe and rewarding way contributes to an individual's overall	

sense of self-worth and well-being. Developing or maintaining a sexual relationship can be an enriching experience and it is important to remember that a person with a dementia has the same rights and needs as anyone else.	

(5) CONSIDERATION OF HUMAN RIGHTS

5.1 Are Human Rights relevant? 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	Yes
Article 11 – Right to freedom of assembly & association	No
Article 12 – Right to marry & found a family	Yes

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 onto to 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 have a potential positive impact or does it potentially interfere with anyone's Human Rights?

List the Article Number	Positive impact or potential interference?	How?	Does this raise any legal issues?* Yes/No
No 8	Positive	By safeguarding protecting the right of the individual and his / her partner to continue to life enjoy a sexually fulfilled live-style	There may be issues in relation to safeguarding however, these are addressed within the Guide
No 10	Positive	Guide provides a basis by which people with a dementia and their partners are enabled to express their sexuality (need and preferences)	There may be issues in relation to safeguarding however, these are addressed within the Guide
No 12	Positive	The majority of people with a	There may be issues regarding marriage

		dementia may be married or in a relationship (long or short-term) and while there would undoubtedly be issues relating to capacity when it came to making decisions about getting married or having a family, these would be addressed through safeguarding and capacity legislation	or having a family, these would be addressed through safeguarding and capacity legislation

Staff are advised throughout the Guide that they should seek help from their Line Manager and / or obtain legal advice if they uncertain about a particular practice, situation, policy or procedure.

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.

A training programme will have to be developed although some funding has been tentatively agreed to support this development however, Appendix 4 of the Guide provides suggestions as to what would be included within this training programme.

SUGGESTED TOPICS FOR INCLUSION IN A STAFF TRAINING PROGRAMME

Training programmes should be developed in line with the thematic and tiered approach set out within the Regional Dementia Learning and Development Framework which is available at www.hscboard.hscni.net/our-work/social-care-and-children/dementia/learning-development-framework/

NB: The list below is not exhaustive and should be adapted or amended to meet the requirements of staff and the service

- Understanding Dementia: The Ageing Process and Types of Dementia
- Communicating with a Person with a Dementia
- Person-Centred and Relationship-Centred Dementia Care
- Understanding and Managing Dis-inhibited Behaviours
- Values, Rights and Principles in Care
- Promoting Physical, Psychological and Social Well-Being in Dementia Care
- Sexual Health and HIV Awareness, including infection control
- Legal and Ethical Considerations in Dementia Care
- Consent and Capacity including Legislation and Codes of Practice
- Equality, Cultural Diversity and Inclusion in Dementia care
- Working in Partnership with Families and Carers
- Protection of Adults at Risk of Harm or in Need of Protection
- Involvement in Decision Making
- Learning Disability and Dementia
- Trust Procedures and Protocols
- Confidentiality
- Involving Partners, Carers and Families
- Medication and the Use of Non-Pharmacological Interventions
- Gender, Sexual Identity and Orientation

Appendix 4 of the Guide and Section 2.5 above provide details of other training resources that are available.

(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
This Guide will, in the first instance, be shared with senior management within all 5 HSC Trusts and Trusts will be asked to approve and implement the Guidance. Funding has been tentatively agreed to cover the cost of roll-out, training and any publicity that may be required. Trusts are asked to review the Guidance every 3 years or more frequently as necessary e.g. in response to any requirements of the Mental Capacity Act NI (2016) and within that review process to have regard to: • Best practice based on research evidence • Legislation, policies and procedures, Departmental directives • Equality and Good Relations • Disability duties • Human Rights Trusts and Training providers would also be	As part of the review by Trusts, data can be collected on the number and type of different disability groups involved in the review and any suggestions that are made.	Data on the number of incidences where service users felt that their Human Rights were infringed upon, or where HSC staff felt that there was a breach of Human Rights, will be maintained and analysed and reported on as part of the process of reviewing the Guidance

asked to collect equality data on those who have been trained. Staff should also collect and analyse data on when they have used the Guidance e.g. equality groups involved i.e. male / female / transgender, age, ethnic minority, disability, sexual orientation etc and whether any specific issues / problems arose for any person with a dementia, their partners, carers and families within any of the Section 75 categories when the Guidance is implemented		

Approved Lead Officer: Seamus McErlean

Position: Social Care Commissioning Lead, HSCB

Policy/Decision Screened by: Seamus McErlean

Signed:

Date: 6th December 2019

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

Template produced November 2011
If you require this document in an alternative format (such as large print, Braille, disk, audio file, audio cassette, Easy Read or in minority languages to meet the needs of those not fluent in English) please contact the Equality Unit:

2 Franklin Street; Belfast; BT2 8DQ; email: Equality.Unit@hscni.net; phone: 028 95363961 (for Text Relay prefix with 18001); fax: 028 9023 2304