

Dementia And COVID-19 – National Action Plan To Continue To Support Recovery For People With Dementia And Their Carers

Equality Impact Assessment Record

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EQUALITY IMPACT ASSESSMENT RECORD

Title of policy/ practice/ strategy/ legislation etc.	‘Dementia And COVID-19 – National Action Plan To Continue To Support Recovery For People With Dementia And Their Carers’	
Minister	Clare Haughey – Minister for Mental Health	
Lead official	Naomi Magnus	
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Directorate: Division: Team	Directorate for Mental Health and Social Care	
Is this new policy or revision to an existing policy?	Revision to an existing policy	

Screening

Policy Aim

1. The Dementia and COVID-19 National Action Plan explains how the Scottish Government is working and plans to work with others to support people with dementia and their families to continue to get the right care, treatment support at the right time as we live with and come through the COVID-19 pandemic.

2. The plan:

- recognises the huge impact of the pandemic on people with dementia, their families and carers;
- recognises that people living with dementia and their carers often feel alone, vulnerable and anxious about COVID;
- recognises the particular worries families have about what the future holds for their loved ones with dementia;
- uses what we have learned from the experiences people with dementia and their families have told us and others to respond to their needs during the pandemic;
- sets out how we plan to help people with dementia and those that love and care for them to live well with dementia across the whole journey of the illness – and how we plan to reduce the risk of dementia;
- sets out the things we have done so far to respond to the pandemic and the things we will keep on doing
- Reinforces our shared human-rights based and person-centred approach to supporting people with dementia and their families and carers.

Who will it affect?

3. This plan aims to support people with dementia and their families to continue to get the right care, treatment and support at the right time as we live with, and come through, the COVID-19 pandemic.

4. Consensus on overall estimated dementia prevalence in Scotland is approximately 90,000 people currently living with dementia. Around two-thirds are living at home at any one time, with the remainder in residential care with a small number in hospital care settings. People with dementia account for at least 66% of the care home population in Scotland and growing.
5. Estimated annual diagnosed dementia incidence is approximately 20,000 by 2020, with roughly the same number of people dying with dementia each year. It is most common in older people but can affect people in their 40s or 50s, or even younger (Alzheimer Scotland).
6. The number of deaths from dementia including Alzheimer's disease rose by a quarter during the first wave of COVID-19 in Scotland (National Records of Scotland). Evidence has shown that dementia is also the most common underlying condition in people dying from COVID-19 in Scotland (National Records of Scotland).

What might prevent the desired outcomes being achieved?

7. The EQIA describes a number of actions that are considered necessary in helping to achieve the Scottish Government's *Dementia and COVID-19 National Action Plan*. The scope of this EQIA is to provide an equality assurance for the proposed actions.
8. In developing this EQIA the Scottish Government is mindful of the three needs of the Public Sector Equality Duty (PSED) - eliminate unlawful discrimination, harassment and victimisation, advance equality of opportunity between people who share a protected characteristic and those who do not, and foster good relations between people who share a protected characteristic and those who do not - and recognises while the measures may positively impact on one or more of the protected characteristics¹. Where any negative impacts have been identified, we have sought to mitigate/eliminate these. We are also mindful that the equality duty is not just about negating or mitigating negative impacts, as we also have a positive duty to promote equality. We have sought to do this through provisions contained in the Regulations, or by current support and guidance available.

Stage 1: Framing

Results of framing exercise

Age

9. The framing exercise brought up the need to refer to Scottish evidence regarding age or demographics, rather than evidence for the UK, as much as possible. It also addresses the need to consider evidence about self-directed support. We already know that everyone does not receive the opportunity to choose which option they might want under self-directed support. It is estimated that [nearly four out of five \(79.4%\) people were involved in choosing and controlling their support through self-directed support options \(based on circumstances where people have a choice\)](#). There are specific challenges for people under-65 with dementia around self-directed support more widely, and evidence around these challenges needs to be considered.

Disability

10. The framing exercise found that there needs to be a focus on Scottish figures regarding learning disabilities and sensory loss, deafness or blindness, and an acknowledgement where this data is not available. Colleagues recognised the need to be conscious of the language being used

¹ Section 4 of the Equality Act 2010

around people with learning disabilities and those with sensory loss, or who are Deaf, deafened, deaf-blind or blind. In order to ensure correct evidence was gathered, evidence would be sent to colleagues within the learning disabilities and assisted communication teams.

Sex/ Gender

11. There was again a focus on the need to find Scottish figures regarding the gender differences between men and women with regards to dementia diagnosis and the disproportionate impact of the pandemic on people who care for those with dementia, most of whom are women.

12. A focus on the economic impacts of women during COVID-19 was also called for, including the disproportionate impact of furlough on women. It was noted that the only aspect that might impact on pregnancy/ maternity would be NHS guidelines about working from home after 18 weeks pregnant and continuity of care, which were not judged to be significant with regards to this plan.

Sexual Orientation

13. It was discussed that older lesbian gay and bisexual (LGB) people sometimes avoid using any form of social care because of the legacy impact of discriminatory attitudes and suggested to speak more of services and service providers rather than just health workers, as the perception goes beyond health workers alone.

Gender reassignment/ Transgender

14. The need to separate out sexual orientation from transgender identity was addressed, although it was noted that discriminatory attitudes can similarly effect trans and LGB people, for example because transgender people may avoid using any form of social care because of discriminatory attitudes and therefore considering social care services as a space where discrimination may take place.

15. It was noted that evidence around transgender discrimination from a 2010 survey was out of date, as well as suggested that speaking more of services and service providers rather than just health workers.

Race or ethnicity

16. The need to be consistent in using terms such as 'BAME' and 'BME' was addressed. It was noted that evidence on Public Health Scotland's findings regarding excess mortalities from COVID-19 for BAME people should be used, although Public Health England's findings should also be referenced given the limitations impacting upon Public Health Scotland's initial findings.

17. The need to ensure sensitive and appropriate language was used was stressed, as was the extent of the evidence available; including by checking with organisations such as the Govanhill Housing Association regarding whether evidence considers Roma as part of Gypsy/ Traveller communities.

Religion and belief

18. It was noted that much of the evidence regarding religion and belief overlaps with evidence on race and ethnicity, given the cultural influences which cross these distinctive categories particularly regarding attitudes to dementia and barriers to accessing health and social care.

Other

19. The need to consider other equality categories was discussed, including socioeconomic inequality, digital exclusion and the impact of rural/ remote location during the pandemic. The need to find evidence about lockdowns and the impact of COVID-19 on people from lower socioeconomic backgrounds was stressed, for instance by comparing lockdown restrictions and rates with the Scottish indexes of multiple deprivation.

20. The impact of complete withdrawal of public transport in remote and rural areas during some phases of COVID-19 was mentioned as was the substantial cost of deliveries for those in remote and rural areas of the Highlands and in the Shetland and Orkney islands.

21. It was noted that digital exclusion issues extend beyond remote and rural areas, as there can be connectivity issues due to limitations in providers, for example. The assumption that care home staff would have access to correct computer equipment for training was also flagged as an issue. The work of the Connecting Scotland work of the Digital Health and Care Initiative in addressing digital exclusion was discussed.

Extent/Level of EQIA required

22. In undertaking this EQIA we have appraised what the potential impact the actions outlined in Dementia and COVID-19 National Action Plan are likely to be in relation to Protected Characteristics and several further equality considerations.

23. We want to ensure the Dementia and COVID-19 National Action Plan meets the needs of all service users. Our Plan is inclusive of everyone. In taking an inclusive approach, we are clear that a core principle of this work is to uphold the dignity and rights of everyone with dementia in a way that responds effectively to their needs.

24. The evidence gathering exercise outlined the necessity of conducting a full equality impact assessment on this action plan, including external engagement with stakeholders including equality groups, people with dementia and dementia carers.

25. As such, commitment 3 of the plan committed the Scottish Government to conduct a full equality impact assessment on this plan. In undertaking this impact assessment we are appraising what the potential impact the actions outlined in the plan are likely to be in relation to protected characteristics under the Equality Act and several further equality considerations, including socioeconomic inequality, rural/ remote locations and digital exclusion.

26. New regulations came into force on 23 December mandating the preparation of Island Communities Impact Assessments (ICIAs). ICIAs will ensure that the Scottish Government and public bodies consider the specific needs and interests of Island Communities when developing and updating policies, strategies and services. Although a separate ICIA has not been conducted for this Action Plan, considerations around Island Communities have been taken into account through considering the impact of these regulations upon rural/ remote communities, including but not limited to Island Communities.

27. Specifically, the EQIA considers impacts on equalities groups based on the three tests it is required to address:

- Does this policy eliminate discrimination for each of the 9 protected categories (PCs)? If not is the discrimination justifiable? Can it be mitigated?
- Does this policy advance equality of opportunity for PC groups?

- Does this policy foster good community relations between people of PC groups?

Stage 2: Data and evidence gathering, involvement and consultation

The information gathering exercises returned the following qualitative and quantitative data. Please note that these exercises did not raise any specific evidence in relation to *Pregnancy And Maternity* or *Marriage and Civil Partnership*.

Age:

Older people are more susceptible to the severe negative health effects of COVID-19. The vast majority of long-stay care home residents are over 65, and over three-quarters of social care at home clients are over 65. Over half of older unpaid carers provide 35 hours of care a week. Though dementia is primarily an illness associated with this age group, it can also develop in younger people under the age of 65. An estimated 3,200 people in Scotland have younger onset dementia. Those with younger onset dementia are more likely to have one of the rarer causes of dementia where the symptoms are less familiar to clinicians and are likely to have specific needs or face specific issues. Some of the issues highlighted by Public Health Scotland research are: being 'out of sync' with social expectation of life stages; premature retirement with implications for financial position; impact on family role and dynamics; a greater sense of social isolation and having a negative impact on self-identity and self-esteem. Those with younger onset dementia may face particular challenges around accessing, for example, Self-Directed Support or employment benefits. [Self-Directed Support is intended to ensure people's right to direct their own social care support, across all age groups and regardless of the reason that support is needed.](#) Younger carers may also face particular challenges when caring for people with dementia.

Evidence gathered and Strength/quality of evidence
<ul style="list-style-type: none"> • Older people are more likely to have underlying health conditions, making them more susceptible to the severe negative health effects of COVID-19. Nine in ten deaths involving COVID-19 in Scotland have been among those aged 65+ and two-fifths have been among those aged 85+. Older people are also more likely to live alone, less likely to have internet access and less likely to use it even if they do have it, which has potentially significant implications for their wellbeing during lockdown. They are also more likely to live in care homes or be receiving care at home, both of which have seen significant service changes during lockdown. Many older people have faced disruptions as family members are unable to visit or provide unpaid care and support. • 17% of people aged 50 to 64 provide unpaid care to a relative, friend or neighbour. This compares to 2% of under-25s, 10% of 25-49 year olds and 11% of over-65s. Over half of older carers (aged 65 and over) provide 35 hours of care a week. • The Scottish Human Rights Commission investigated the impact of The Coronavirus Act 2020, which contains several provisions in relation to social care, namely sections 16 and 17 of the Act, which amend the Social Work Scotland Act 1968, the Social Care (Self-directed Support) Scotland Act 2013 and the Carers (Scotland) Act 2016. The Commission raised concerns that older people may end up with an inappropriate or inadequate care or support package due to lack of proper assessment, or in the case of adults with incapacity, the lack of a full assessment may have further repercussions with respect to procedural safeguards. Additionally, the Commission reported that the conditions of lockdown under the Health Protection (Coronavirus) (Restrictions) (Scotland) Regulations 2020 were likely to mean that unpaid carers would have to take on a far greater responsibility for care and support at

home, but without the guarantee of an assessment or the potential for support to undertake this role.

- 91% of long stay care home residents were aged 65+ in 2017/18. 77% of Social Care at home clients were 65+ in 2017/18, meaning around one-quarter were under 65.
- Although dementia is primarily an illness associated with older people, it can also develop in younger people under the age of 65. There are an estimated 3,200 people with younger onset dementia in Scotland. There has long been recognition of the need to improve the equity and range of service provision across Scotland for people with dementia who are under the age of 65.
- Younger people may have different needs including issues around childcare, employment, age appropriate peer support and financial impact on them and their dependents. According to Public Health Scotland's report 'Dementia and Equality: Meeting the Challenges in Scotland' (2016), challenges for people with younger onset dementia and their families fall into two main areas: diagnosis and post-diagnostic support; and the impact of the diagnosis on the person and the family. There are a number of barriers to people being diagnosed. Symptoms may be misattributed to other conditions such as stress, depression, menopause, excess alcohol use and relationship difficulties.
- Younger people are more likely than older people to have one of the rarer causes of dementia where the symptoms are less familiar to clinicians. The initial pathway through diagnosis varies considerably for those aged under 65. Younger adults may be diagnosed either by psychiatrists based in older adult teams, psychiatrists based in mental health teams or through neurology departments in the acute sector.
- 'My Support, My Choice' report on SDS, highlighted that older people need better info about self-directed support.
- Public Health Scotland's (2016) report noted that research has identified the particular subjective experience of younger people with dementia and their age-specific need for emotional support and psychological intervention. Some of the issues highlighted by this research were, being 'out of sync' with social expectation of life stages; premature retirement with implications for financial position; impact on family role and dynamics; a greater sense of social isolation and having a negative impact on self-identity and self-esteem.
- Moreover, the report highlights that families of younger people with dementia also have their own specific needs: e.g. longer periods of uncertainty, dual loss of employment and income due to caring, frustration and grief, lack of peer support, and responsibility for families and young children.
- When engaged on the EQIA, members of the Scottish Dementia Working Group voiced the need for accessible transport for older people, as dementia can mean an end to driving, and the desire to continue living independently was emphasised. Concerns were expressed around young carers' knowledge and ability in terms of accessing financial help to assist them with their caring responsibilities for a loved one with dementia, if they are caring for a parent with early-onset dementia (for example). One person with younger-onset dementia noted they were dismissed from their job before a diagnosis was even confirmed and that dealing with the Department of Work & Pensions to claim the benefits they were entitled to, but which they were not fully informed about, was extremely distressing.
- Issues around two other members with younger-onset dementia being diagnosed were also highlighted during the engagement sessions: though the men live in completely different health board areas, they had the same issues, such as not being able to access their workplace pension early and polices in

place for mortgage cover around critical illness not being paid out. Other experiences were highlighted by STAND members with younger onset dementia. One person noted that there is very little support for people under the age of 65, which is why the STAND group was formed. Stigma and loss were raised as “a huge issue” which STAND are trying to educate people on. It was emphasised that, on dementia prevention, it is important that not to frame this in such a way as to blame individuals diagnosed with dementia on the basis of lifestyle choices and behaviours. Again, issues with accessing benefits for younger people with dementia was highlighted as a key concern, with the paper work being extremely complex and help to complete it unavailable.

- Likewise, STAND members stated that self-directed support was “not working for people with younger onset dementia as it should be.” The principle of SDS it is to help people to stay well and stay independent. But they reported that “this is not happening: it was felt that younger people need social support and assistance, but SDS is not being provided for this.”
- Support for a timely diagnosis was highlighted as key and The Dementia Nurse Consultant service in Fife was highlighted as a gold standard service by STAND members.
- According to Age Scotland, people with dementia/older people are not always offered all the options around self-directed support: there is a traditional focus on task and time rather than on the variety. It was noted that older people living with dementia are less likely to be aware of their diagnosis (either not having capacity to retain info, or families deciding that it is not in their best interest to be aware). Policies need to also be targeted at those who do not acknowledge, identify with or be aware of their diagnosis, therefore. Under-claiming of benefits by older people was also highlighted as endemic. Age Scotland highlighted a need to focus on the older ‘older’ age group (over 80) who often have co-morbidities and live with family members who do not consider themselves carers.

Source

[Equality and Fairer Scotland Impact Assessment: Evidence gathered for Scotland’s Route Map through and out of the Crisis](#)

[Scotland's Carers](#)

[COVID-19, Social Care and Human Rights: Impact Monitoring Report](#)

[Social Care Services in Scotland 2017](#)

[Rapid EQIA: Post-Diagnostic Support \(Edinburgh\)](#)

[‘Dementia and Equality: Meeting the Challenge in Scotland’](#)

[Spotlight on Dementia and Equality](#)

Equality Impact Assessment engagement event with SDWG and STAND members.

[My Support, My Choice - Self Directed Support Scotland | Self Directed Support Scotland \(sdsscotland.org.uk\)](#)

Equality Impact Assessment engagement event with Age Scotland.

Disability:

People with a disability or multiple disabilities and dementia face particular challenges. During the pandemic, disabled people have been potentially at increased risk of health harm from COVID-19. They have also faced particular challenges as a result of the pandemic. Many disabled people have reported that their social care support has been affected or reduced as a result of the pandemic.

People with a learning/ intellectual disability or autism have been at particular risk from COVID-19, as unfortunately reflected in [statistically higher death rates](#) of people with learning/ intellectual disabilities from COVID-19. In 2019 in Scotland, [3,466 adults with learning/intellectual disabilities lived in supported accommodation and 1,837 lived in registered adult care homes](#). Those living in care homes and residential settings, where social/physical distancing may not be able to be achieved are among those who have felt the impact of the COVID-19 most acutely. Many people with learning/ intellectual disabilities have found their social care provision reduced or changed as a result of the pandemic. Other key areas of concern include a loss of independence, social isolation, the impact on their mental health, concerns regarding medical decision-making and issues for carers and support staff of those with learning/ intellectual disabilities. [People with Down's syndrome are likely to be diagnosed with dementia significantly earlier](#), while people with learning/intellectual disabilities other than Down's syndrome also develop dementia on [average 10 years earlier than people](#) without a learning/ intellectual disability. People with a learning / intellectual disability or autism and dementia face particular challenges, including misdiagnosis.

Those who are Deaf/BSL users, deafblind, deafened, hard of hearing, blind or face sight loss and have dementia face particular challenges. 1 in 5 people aged 75+ and 1 in 2 people aged 90+ are living with sight loss or blindness. Given age is the most significant risk factor for both dementia and sensory loss, there will be a substantial number of people living with both conditions. Likewise, many people with dementia also have hearing loss or deafness. Hearing loss is also considered to be a modifiable risk factor for dementia. These groups of people face additional challenges if they have dementia, including an increased sense of disorientation and risk of social isolation. They are also at risk of misdiagnosis.

Evidence gathered and Strength/quality of evidence

- During the pandemic, disabled people have been at increased risk of health harm from COVID-19 due to difficulties implementing measures to reduce transmission, as well as potentially increased risk of severe health effects due to pre-existing health conditions. Individuals in receipt of social care may also be at greater risk of non-COVID related health harms if they have faced disruptions to formal health and social care arrangements as well as potentially losing the informal care and contact of family members. Families with disabled members are more likely to be in poverty, meaning that the impact of any reduction in income is likely to be particularly harmful.
- [The Scottish Human Rights Commission investigated the impact of The Coronavirus Act 2020, which contains several provisions in relation to social care, namely sections 16 and 17 of the Act, which amend the Social Work Scotland Act 1968, the Social Care \(Self-directed Support\) Scotland Act 2013 and the Carers \(Scotland\) Act 2016. The Commission raised concerns that disabled people may end up with an inappropriate or inadequate care or support package due to lack of proper assessment, or in the case of adults with incapacity, the lack of a full assessment may have further repercussions with respect to procedural safeguards. Additionally, the Commission reported that the conditions of lockdown under the Health Protection \(Coronavirus\) \(Restrictions\) \(Scotland\) Regulations 2020, were likely to mean that carers](#)

would have to take on a far greater responsibility for care and support at home, but without the guarantee of an assessment or the potential for support to undertake this role.

- [27% of long stay care home residents had physical disabilities and 33% of all care-home clients had physical disabilities in 2017/18](#). Many of these people will also have dementia, as 62% of long stay residents were living with dementia in 31 March 2017.
- [Supercharged: A Human Catastrophe • Glasgow Disability Alliance \(gda.scot\)](#) reported that COVID-19 had widened the inequality already faced by disabled people in Scotland. Prior to the pandemic, disabled people were 3 times more likely to live in poverty and to face food insecurity. GDA reported that policies such as not increasing disability benefits deepened inequality, as did restrictions to social care budgets and extra barriers to social security; and that disabled people already faced persistent barriers to accessing information and services, with isolation, digital exclusion and a lack of accessible information meaning many disabled people have not had the information they need to stay safe and access support during the pandemic. In addition, this research reported that prior to the pandemic, disabled people were already twice as likely to experience isolation or loneliness – which has been worsened by the removal of vital support, loss of social contact and for e.g. by rules for public spaces which have created hostility towards disabled people unable to observe them. Likewise, GDA reported that many disabled people's mental and physical health has worsened, including by disruption to access and treatments.
- [Your Say on Disability asked members whether their social care support had changed because of COVID-19 in August](#). 93% who received social care support said 'yes'. 99% responded 'no' to the question 'Is there enough support in place for carers and people receiving care during the COVID-19 pandemic?'
- [Inclusion Scotland's COVID-19 evidence survey](#) reported six key areas in which disabled people had been impacted by the pandemic, according to their research. Firstly, they reported that social care support has been stopped or reduced – almost half of responders noted that the COVID-19 pandemic has had an impact on the social care support they get, formal and informal. Secondly, that people have new or increased caring responsibilities: Around 40% of people who responded to this question were experiencing challenges with caring for children/family members since the start of the pandemic. Thirdly, that around two thirds of those responding (64%) said that the crisis has had an impact on getting the food or medicine that they need for themselves or the person they care for. They also reported that disabled people are concerned that they will lose their job (11% of respondents). Lastly, disabled respondents reported that social distancing and isolation is proving extremely challenging: disabled people with and without pre-existing mental health conditions reported finding everyday life under lock-down extremely stressful. 15% reported their mental health had worsened.

Learning/intellectual disabilities and autism

- COVID-19 has had a significant impact on people with learning/intellectual disabilities and/or autism, with Down's syndrome at particular risk. People with learning/intellectual disabilities are at higher risk of underlying health conditions, including respiratory disorders such as asthma, chronic obstructive pulmonary disease (COPD), and an increased prevalence of swallowing and eating problems which can lead to chest infections and pneumonia. [Research from the Scottish Learning Disabilities Observatory identified people with learning/intellectual disabilities were more than 3 times more likely to die from](#)

COVID-19 than people without learning/intellectual disabilities. The study also reported people with learning/intellectual disabilities were twice as likely to experience a severe outcome of COVID-19 infection. This mirrors [similar studies from Public Health England](#), which reported a mortality rate up to 6 times higher for people with learning/intellectual disabilities in England, and data from [Public Health Wales reporting a mortality rate 3 – 8 times higher](#). The pandemic has had a disproportionate impact upon people with learning/intellectual disabilities nationally. This impact suggests systemic health inequalities exist.

- Those living in care homes and residential settings, where social/physical distancing may not be able to be achieved are among those who have felt the impact of the COVID-19 most acutely. In 2019 in Scotland, [3,466 adults with learning/intellectual disabilities lived in supported accommodation and 1,837 lived in registered adult care homes](#). Given the incidence of COVID-19 in care homes, people with learning/intellectual disabilities have been disproportionately affected by COVID-19.
- People with learning/intellectual disabilities have a higher risk of developing dementia compared to the rest of the general population. Best available data for Scotland comes from a [UK-wide study which estimated that 1 in 5 people with learning/intellectual disabilities will develop dementia](#). Communication challenges, and an increased potential for sensory loss can also make diagnosis more difficult as the person with learning/intellectual disabilities may be unable to articulate what is happening to them. This can also lead to a possible risk of misdiagnosis. People First Scotland note that people with learning/intellectual disabilities face significant barriers to accessing equal healthcare which results in poorer health outcomes and lower life expectancy than the rest of society.
- Public Health Scotland's 2016 report noted that there is a significantly increased risk for people with Down's syndrome of being diagnosed with dementia at a much earlier age. [The mean age of dementia diagnosis in people with Down's syndrome is 55. People with learning/intellectual disabilities other than Down's syndrome also develop dementia on average 10 years earlier than people without a learning/ intellectual disability](#). It is predicted that 1 in 3 people with Down's syndrome over the age of 50 will develop dementia and 1 in 50 people with Down's Syndrome will develop dementia in their 30s. The prevalence of Alzheimer's type dementia in persons with Down's Syndrome exceeds that of the general population. Because more people with Down's Syndrome are living longer there is a higher prevalence: more than half of those with Down's Syndrome over 60 years old have dementia. The report also noted that there may be difficulties accessing "mainstream" dementia services for people with learning/ intellectual disabilities, as these services may not take account of their needs, and specialist services may be required.
- Scottish Commission for People with Learning Disabilities (SCLD) consulted with people with learning/intellectual disabilities and their carers between 14th April and 5th May 2020, about the impact of the pandemic on them (link in evidence below). Key areas of concern included removal of support and loss of independence; social isolation and the impact on people with learning/ intellectual disabilities' mental health; confusion and anxiety around public information; concerns regarding medical decision-making; access to school hubs and a range of issues facing family carers and support staff, such as lack of PPE.
- Autism Network Scotland's research on ageing and autism suggested several barriers facing older autistic adults, some of whom are at risk of developing

dementia. These were: Lack of access to appropriate services for older autistic adult; mental health, wellbeing and self-awareness; employment; lack of meaningful support and understanding to prepare for future; lack of knowledge, understanding and acceptance in society and professionals. Key areas of importance for autistic individuals included diagnostic and post diagnostic pathways for older adults, social isolation and the impact on physical and mental health, long term care provision and planning for older adults and support for parents and carers. Ideas around improving outcomes focused on person-centred, support with long-term planning and dedicated services; engagement, representation and consultation; social and community support and awareness understanding and training for public and practitioners.

- The SCLD have argued that one of the key impacts of the pandemic for people with learning/intellectual disabilities has been the removal of support hours at the start of the pandemic. This has had a detrimental impact on people with learning/intellectual disabilities and their carers. In the SCLD's survey, 64% of individuals said their support had changed due to the COVID-19 emergency. 58% of parents, carers and support workers said that people with learning/intellectual disabilities were not getting the support they needed during the COVID-19 emergency. Some people with learning/intellectual disabilities are facing challenges in being isolated from their friends and family. 57% of people with learning/intellectual disabilities who responded to the survey said they felt lonelier since lockdown measures were put in place. This issue appears to be particularly felt by those in residential settings who can no longer receive visits from their family.
- At the engagement event, it was noted that people with learning/intellectual disabilities can sometimes have limited access to appropriate healthcare which meets their needs, particularly due to diagnostic overshadowing - which occurs when a healthcare professional assumes that a patient's symptoms are due to their disability or coexisting mental health condition, rather than fully exploring the cause of patient's symptoms. People with learning/ intellectual disabilities and dementia may have complex co-morbidities. Diagnostic overshadowing remains a serious issue. Common differential diagnoses for individuals with Down's syndrome presenting with loss of skills are depressive illness, sensory impairments (hearing or visual), hypothyroidism, and obstructive sleep apnoea. Life changes as well as effects of medication can also mimic the symptoms of dementia. Pain recognition and pain management is often over-looked amongst people with learning/intellectual disabilities, too. People First Scotland noted that it is likely that citizens with learning/ intellectual disabilities will at times be either treated as if a diagnosis of dementia applies inappropriately, due to the lack of knowledge of health professionals regarding learning/intellectual disability, or that citizens will be sent to live in care homes where other residents are elderly when they are not. People First Scotland also stated that emergency pandemic legislation withdrew safeguards and reduced checks and balances, undermining people with learning/intellectual disabilities' human rights.
- At the engagement event it was also highlighted that older (75+) family carers of adults with learning/intellectual disabilities may have dementia.

Deafness or blindness

- There are four key pillars of deafness: deaf/BSL users, deafblind, deafened and hard of hearing. People who identify as Deaf, BSL users would have been born deaf or became deaf in early childhood and as a consequence British Sign Language (BSL) is their first language. Deaf, BSL users normally identify with a unique Deaf Culture.

- Deaf-Blindness is defined by Deaf Blind Scotland as “when one sense can no longer compensate for the other.” As the work of Deaf Scotland notes, there are various types of deaf-blindness, also termed ‘dual sensory loss’. Firstly, “Congenital”, which is a term used to describe children born with hearing loss and sight loss or who acquire these two conditions prior to language development. Secondly, “acquired”: people in this category are either born deaf and experience sight loss later; born blind and become deaf later in life; or it could apply to those who have lost their sight and hearing later in life. People who are Deafened are those who become deaf after losing hearing as an adult. Deafness here can be the result of an accident or trauma or might be a side-effect of an illness. The term ‘Hard of Hearing’ is used to describe those whose hearing loss is mild to moderate and who lose their hearing gradually over time.
- [16% of people who provide unpaid care to a relative, friend or neighbour are deaf or have partial hearing loss. 40% of people aged 50+ are living with hearing loss, deafness or are Deaf. 70% of people over the age of 70 are living with hearing loss, deafness or are Deaf.](#)
- [According to Deaf Scotland](#), there are over 31,000 deaf-blind, 700,000 hard of hearing and 350,000 deafened people in Scotland, totalling around 1 million Scots. 12,500 use British sign language. Many people with dementia also have hearing loss or deafness. Deaf Scotland’s data reports that the highest prevalence rate in Scotland can be found in Dundee City, at 11.02% and the lowest in North Ayrshire, at 5.03%. 3 out of 4 Deafblind people are in later life (so by that virtue alone more at risk of dementia).
- 1 in 5 people aged 75+ are living with sight loss or blindness. 1 in 2 people over the age of 90 is living with sight loss or blindness. Given age is the most significant risk factor for both dementia and sensory loss, there will be a substantial number of people living with both conditions. [Sight Scotland has estimated the number people living with sight loss and dementia in Scotland is around 12,500 people; other estimates are closer to 17,000.](#)
- By 2017, the Lancet Commission on Dementia, Prevention, Intervention and Care identified hearing loss as one of 9 modifiable risk factors for dementia. Later research has also confirmed that sensory loss impacted upon cognitive ability. Hearing loss is therefore now considered to be a modifiable risk factor for dementia. Deaf-Blind Scotland have argued that work needs to be done to prevent sensory loss where possible, particularly dual sensory loss, and to provide alternative communication skills as early as possible. Visual impairment is a symptom of a number of forms of dementia, as highlighted by the Life Changes Trust.
- People who are Deaf, blind or deaf-blind, or who experience deafness or hearing/sight loss and who develop dementia face additional challenges, including an increased sense of disorientation and risk of social isolation, as evidenced by Public Health Scotland’s report [‘Dementia and Equality: Meeting the Challenges in Scotland’ \(2016\)](#). The report noted that communication difficulties, and an increased potential for sensory deafness, blindness, also hinder diagnosis as the person with learning/ intellectual disabilities may be unable to articulate what is happening to them. There is also a high risk of misdiagnosis. The onset of dementia may be more difficult to detect by family and carers. Moreover, a profoundly deaf person can deteriorate rapidly due to isolation and lack of communication and stimulation, with the risk of leading to depression.
- Deaf-blind people may face misdiagnosis, due to significant communication barriers, social withdrawal (often due to the sheer mental effort of communicating) and lack of trust in health and social care practitioners. A

Deafblind person may ask the same question of a number of people, which can be mistaken for elements of paranoia.

- The engagement event involved a BSL Policy Officer, alongside Deaf Action, British Deaf Association, Deaf Scotland, Action on Hearing Loss and RNIB. These organisations felt that person-centred dementia care is not being delivered to people with sensory loss and current processes don't work for people with sensory loss. They highlighted particular challenges faced by people who are of Minority Ethnic background and are Deaf, as they may not use BSL and are less likely to access services for those who are Deaf; though groups such as the Scottish Ethnic Minority Deaf Club are working to change this.
- These groups argued that person-centred dementia care is not being delivered to people with sensory loss and that there is a need to create wider access to planning and decision-making processes and specifically refer to communication and adjustments as a matter of course in policy development and delivery. It was emphasised that most people with dementia and sensory loss/ BSL-users live at home, so language and resources in communities must be accessible. The BDA and RNIB referred to good practice guidance and toolkits they have produced.
- Major obstacles to dementia diagnosis for BSL users were highlighted by the BDA: "There is currently no dementia assessment in Scotland tailored for Deaf people who use British Sign Language (BSL) and Deaf people with dementia and their carers or family are often excluded from mainstream dementia services, care home activities and medical or professional discussions."
- The British Deaf Association noted that a Deaf person with dementia may sometimes revert to using the language they used most as a child which, in some cases, may be spoken English. Some Deaf people living with dementia may not use BSL anymore and may only rely on spoken communication.
- [Glasgow Disability Alliance research](#) has reported that food insecurity for those with sensory loss, deafness or blindness was worsened during COVID-19 by a lack of support and negative attitudes towards people with an 'invisible' disability who may not have been able to follow new restrictions around for e.g. wearing a face covering.

Data gaps identified and action taken

GAP:

There is no specific Scottish evidence on the number of people in Scotland with a learning/ intellectual disability.

Action:

Best available evidence has been used from a UK study of the number of people with learning/intellectual disabilities and the same figure applied to a Scottish context (1 in 5).

GAP:

More research is needed on multiple sensory loss and dementia. Data shows that up to 17,000 people have sight loss and dementia, but more data is needed on multiple sensory loss and dementia.

Action:

Consultation was made with Deaf-Blind Scotland to ensure a fuller picture of the experiences of people with dementia and multiple sensory loss was considered.

Source

[Equality and Fairer Scotland Impact Assessment: Evidence gathered for Scotland's Route Map through and out of the Crisis](#)

[Supercharged: A Human Catastrophe](#)

[Rights at Risk](#)

[Your Say on Disability: Weekly Poll](#)

[COVID-19, Social Care and Human Rights: Impact Monitoring Report](#)

[Social Care Services in Scotland 2017](#)

[Scottish Commission for People with Learning Disabilities. COVID-19. February 2021.](#)

[Autism Network Scotland. Exploring Ageing and Autism \[draft\]. September 2019.](#)

[COVID-19: deaths of people with learning disabilities. Public Health England. November 2020.](#)

[COVID-19-related deaths in Wales amongst People with Learning Disabilities from 1st March to 26th May 2020. Public Health Wales. September 2020.](#)

[Scottish Commission for People with Learning Disabilities. Learning Disability and Dementia – Summary of Data and Evidence. December 2020](#)

[Equality impact assessment engagement session with Enable and Scottish Commission on Learning Disability. December 2020.](#)

[The Equality and Human Rights Implications of the COVID-19 emergency for people with learning disabilities](#)

[The interface between dementia and mental health: an evidence review. London: Mental Health Foundation. 2016.](#)

['Dementia and Equality: Meeting the Challenge in Scotland'](#)

[Equality impact assessment engagement response from People First Scotland.](#)

[Equality impact assessment engagement with Sight Scotland](#)

[Equality impact assessment engagement session with BSL Policy Officer, BDA, RNIB, Action on Hearing Loss, Deaf Scotland and Deaf Action.](#)

[Deafness: Predicting the future for Scotland - The Census and beyond](#)

[The Deaf Dementia Experience in Scotland](#)

[Dementia and Sensory Challenges](#)

[Spotlight on Dementia and Equality](#)

Scotland's Carers

[Care Home Census for Adults in Scotland](#)

[Deafness and Dementia: Predicting the Future for Scotland](#)

[An Inclusive Communication Guide for Engaging with Deafblind People](#)

[Committed to Communication: 2018/19 impact report](#)

[Dementia prevention, intervention, and care](#)

[COVID-19: Deaths of people with learning disabilities.](#)

[Supercharged: A Human Catastrophe • Glasgow Disability Alliance \(gda.scot\)](#)

[Fury at 'do not resuscitate' notices given to COVID patients with learning disabilities | Coronavirus | The Guardian](#)

Sex:

Women are at greater risk of dementia due to slightly longer life expectancy at a population level. They are also more likely to be social care clients, both in long-stay care homes and at home, for the same reason. Women are also more likely to be unpaid carers than men in Scotland. Women's caring burden has increased as a result of the pandemic, with particular challenges for carers of those with dementia – many of whom are women. More women have become carers as a result of the pandemic and three-quarters of carers are having to provide more care than prior to the coronavirus outbreak. Women have also been disproportionately affected by the economic impact of the pandemic, which has compounded difficulties around caring responsibilities.

Evidence gathered and Strength/quality of evidence

- [As Public Health Scotland's \(2016\) report](#) notes, women are at greater risk of dementia, likely because they have a longer life expectancy than men. Estimated prevalence for women is higher across all age groups than for men. 17.8% of 90+ year old women had dementia in Scotland in 2015, compared to 10.2% of men this age.
- [The number of female deaths from dementia \(4,214\) was almost twice the number of male deaths \(2,207\) in 2019](#), but the gap is narrowing in percentage terms as female deaths were nearer three times the number of male deaths in 2000. [More women are social care at home clients than men \(62%\) and more women are long stay care home residents than men \(68%\)](#).
- [As of 11 June, 628,000 people had been furloughed in Scotland. In Scotland, women form the majority \(51%\) of workers put on furlough between March and August 2020](#) according to HMRC. Around 133,000 more women were furloughed than men during the first wave of coronavirus. As women are more likely to be unpaid carers, and are more likely to have been furloughed or working in sectors more negatively impacted by the pandemic, many will have been doubly impacted by the pandemic through loss of income and the increased burden on carers.
- [According to Engender](#), women's unpaid care work has been compounded by public policy and service delivery measures implemented in response to the pandemic. Work by Glasgow Disability Alliance and Inclusion Scotland has reported that social care packages have been reduced and stopped. This

undermines disabled women's rights to dignified care and has also displaced care responsibility onto female family members. [Carers Week 2020 Research Report - Carers UK](#) suggests that there are now as many as 1.1 million unpaid carers in Scotland, of which 61% are women. This is an increase of 392,000 since the start of the crisis, with 78% of carers having to provide more care than prior to the coronavirus outbreak.

- Women have been disproportionately impacted by the pandemic in Scotland. [According to Engender](#), the majority of those employed in many 'shut down' sectors have been women. Women are also over-represented in many of the sectors where median hourly pay fell below the current rate of the real living wage if employers did not bridge the 20% shortfall for furloughed staff. Women earn less than men on average and are less likely to be eligible for sick pay. Caring responsibilities may make it harder to maintain or take on employment and women are four times more likely than men to give up employment because of multiple caring responsibilities.
- ['My Support, My Choice' report on SDS](#) highlighted that women need better info about self-directed support.
- At the engagement event, Age Scotland argued that there is an intersection between age and gender, given more women have dementia, and the excess mortality rates of April – June period of 2020. They said that ongoing issues with some aspects of women's health being taken seriously and accessing their pension entitlement were also highlighted, with the intersection between lower labour market engagement and longer life expectancy action described as "a particular challenge for women."
- At the equality impact assessment engagement session, there was broad agreement that women have been disproportionately affected due to adopting a family caring role and because women generally tend to be in lower paid roles. Stakeholders, who represented carers organisations, noted an assumption that unpaid carers do not have another role, even though a significant number have another paid job. The need to look at intersectional gender roles, and the invisible voices from within some cultures, was also referenced.

Data gaps identified and action taken

GAP:

- At the time of writing, data on age, gender, value of claims and employer size were only published at a UK level and not available at a Scotland level.

Action:

- Statistics regarding the UK have been extrapolated to consider the impact of furlough on women in Scotland.

GAP:

- A key gap is the lack of reliable data that tells us how domestic and reproductive labour is being distributed between opposite sex couples, both before and since the start of lockdown in Scotland. There is also a general lack of gender-sensitive sex-disaggregated data which could provide an accurate picture of how men and women are experiencing life during the pandemic.

Action:

- I have used evidence from Engender who have been conducting [specific work](#) around the impact of COVID-19 on women in Scotland. As they note, it is important that the Scottish Government and its agencies strive to gather and analyse more information on gendered patterns within care and then bring these to bear on policymaking.

Source

['Dementia and Equality: Meeting the Challenge in Scotland'](#)

[Scotland's Carers](#)

[Gender & Unpaid Work: The impact of COVID-19 on women's caring roles](#)

[Carers Week 2020 Research Report - Carers UK](#)

Equality impact assessment engagement session with Dementia Carers Voices Project, National Dementia Carers and National Dementia Carers Action Network.

[Equality and Fairer Scotland Impact Assessment: Evidence gathered for Scotland's Route Map through and out of the Crisis](#)

[My Support, My Choice - Self Directed Support Scotland | Self Directed Support Scotland \(sdsscotland.org.uk\)](#)

[Social Care Services in Scotland 2017](#)

[Dementia and Alzheimer's deaths 2020](#)

[Coronavirus Job Retention Scheme Official Statistics](#)

[HMRC data prompts concern of 'gender furlough gap'](#)

Equality impact assessment engagement session with Age Scotland.

Gender reassignment/ Transgender

There is a lack of evidence regarding transgender people with dementia in Scotland. At the engagement event it was noted that data collection around the transgender identity of those with dementia does not occur, rendering this group invisible. Some transgender people report experiencing transphobic language and behaviour in health and social care settings, which acts as a barrier to feeling safe and confident in disclosing their identity. Widespread discrimination and poor experiences of healthcare and social care means that societal and health or social care attitudes are a very significant barrier to seeking help or accessing services for dementia. Stonewall Scotland [has reported](#) that almost two in five trans people (37%) avoid seeking healthcare for fear of discrimination from staff. For older transgender people in particular, discrimination is something that is likely to have affected many aspects of their life.

Evidence gathered and Strength/quality of evidence

- A transgender person is someone whose gender identity or expression does not fully correspond with their sex at birth. This includes but is not limited to trans men, trans women and non-binary people. Many transgender people, including those who are living permanently in their acquired gender, may keep their transgender identity private. Trans people represent less than 1% of the population.
- In Scotland in 2010, [55% of people held discriminatory attitudes towards transgender people](#), according to Scottish Government Social Research. [The SSAS 2015 updated this](#): although there was a decline from 49% in 2010, 32% of respondents still said they would be unhappy with someone in their family marrying someone who has undergone gender reassignment, and 39% would

be unhappy with someone in their family marrying someone who cross-dresses (down from 55% in 2010).

- The [EHRC's 2018 report on attitudes in Scotland](#) suggested that some minority groups that were once more hidden, such as transgender people, may now feel more confident about publicly expressing their identity. This report also noted that some transgender people experienced transphobic language and behaviour in health and social care settings.
- Public Health Scotland's report '[Dementia and Equality: Meeting the Challenges in Scotland](#)' (2016) suggested that transgender people avoid using social care because of discriminatory attitudes and the perception of social care services as a space where discrimination may take place. Many transgender people will not be out to their service providers. Widespread discrimination and poor experiences of healthcare and social care means that societal and health or social care attitudes are a very significant barrier to seeking help or accessing services for dementia. Admission to hospital or a care home can have a significant mental and physical impact on someone with dementia who is transgender, who may not be able to present as their chosen gender. Cessation of hormones can happen due to the onset of dementia for a trans person who has been through hormone therapy. This can have a significant negative mental and physical impact on someone with dementia who is transgender. For older transgender people in particular, discrimination is something that is likely to have affected many different facets of their lives, such as employment and finances, social networks, personal and family relationships, and health.
- Stonewall Scotland [has reported](#) that almost two in five trans people (37%) avoid seeking healthcare for fear of discrimination from staff. In Scotland, 22% of LGBT people would feel uncomfortable about being open about their sexual orientation or gender identity with NHS staff, and 52% of trans people said the same in relation to adult social care staff). One in four LGBT people (24%) have faced discrimination in healthcare settings and nearly three in five trans people (59%) have experienced healthcare staff having a lack of understanding of specific trans health needs.
- At the engagement event, LGBT Health and Wellbeing noted that many in LGBT groups are "invisible populations", meaning there are crucial data gaps. The Scottish Trans Alliance suggested that proactive actions are therefore needed by government and public bodies, to seek information on prevalence of dementia amongst trans people. They noted the same in relation to intersex people, or people with a variation of sex characteristics. The Scottish Trans Alliance also argued that policy is usually written on capturing 99% of the people, but equality assessments must focus on those who are traditionally invisible or ignored. A policy of 'everybody is welcome' is not sufficient – marginalised people are dehumanised and so may not feel that they are included in this 'everybody'. Explicit inclusion is needed, focusing on concrete actions of best practice actively including LGBTI people with dementia. The LGBT+ Health and Wellbeing Network noted that there is work being done in other parts of the UK on this, e.g. dementia cafes for LGBT people being run by Alzheimer's Society.

Data gaps identified and action taken

GAP:

The EHRC's 2018 report 'Is Scotland Fairer' noted that small groups including transgender people are rendered 'virtually invisible' by a lack of data. There is minimal literature around the experiences of transgender people with dementia in Scotland.

Action:

An engagement event involving the Scottish Trans Alliance and LGBT Health and Wellbeing was organised as part of consultation on the equality impact assessment.

Source

[‘Dementia and Equality: Meeting the Challenge in Scotland’](#)

[Scottish Social Attitudes 2015: attitudes to discrimination and positive action](#)

[2018 report 'Is Scotland Fairer?'](#)

[LGBT in Scotland – Health Report](#)

[Your Services, Your Say – consultation report](#)

Equality Impact Assessment event with Stonewall Scotland, Scottish Trans Alliance and LGBT Health and Wellbeing.

Sexual orientation:

Many of the same issues around prejudice and discrimination which impact upon transgender people also impact upon lesbian, gay and bisexual people. At the engagement event it was noted that there is a lack of data collection around the sexual orientation of those with dementia, which can result in the exclusion of this group. [Evidence suggests a significant proportion of the older population continue to hold homophobic views](#), and some LGB people are still experiencing homophobic or bi-phobic language and behaviour in health and social care settings. Many LGB people say they would be uncomfortable with social or healthcare providers knowing their sexual orientation. For many older LGB people, the legacy of criminalising sexual orientation for LGB people remains, and is within living memory. This acts as a barrier to help-seeking for dementia. Moreover, there are particular challenges for LGB people with dementia and their carers. For example, they may face assumptions, discrimination or a lack of acceptance, without having their individual or differential circumstances recognised.

Evidence gathered and Strength/quality of evidence

- While social attitudes towards LGBTI people are improving in Scotland, [there was still a significant proportion of the older population who held homophobic views in 2015](#): 32% of those aged 55 or over believed that sexual relations between two people of the same sex are always or mostly wrong, compared to 18% of the population as a whole.
- The [EHRC's 2018 report 'Is Scotland Fairer?'](#) notes that some LGB people are still experiencing homophobic or biphobic language and behaviour in health and social care settings. As a result of these concerns and challenges, 76% of lesbian, gay and bisexual people are not confident they would be treated with dignity and respect in a care home setting.
- [Stonewall's survey of health and social care workers reported that 72% of frontline staff have not received any training on the health needs of LGBT people, the rights of same-sex partners and parents, or the use of LGBT-inclusive language and practices](#). Similarly, 57% of frontline health and social care practitioners say they don't consider sexual orientation to be relevant to health needs. One in four LGBT people (24%) have faced discrimination in healthcare settings. Likewise, one in four LGBT people (27%) have experienced healthcare staff having a lack of understanding of specific lesbian, gay and bi health needs.

- Many LGB people will not be 'out' to their service provider. Lack of contact with outside family (including families of choice) due to COVID-19 may be particularly distressing for those with dementia who are not 'out' to staff about their sexual orientation.
- Many older LGB people may be reluctant to engage with dementia and mental health services. In Scotland, Stonewall research reported that 22% of LGBT people would feel uncomfortable about being open about their sexual orientation or gender identity with NHS staff, and 33% said the same in relation to adult social care staff.
- Older people who are LGB are more likely to: live alone, be single, or not have children, and are less likely to be in regular contact with their biological family. This means that LGB people are less likely to have a partner or family to support them as they get older, and more likely to need social services for help. Older LGB people may feel out of place in traditional dementia support groups and dementia cafes or related spaces, and they may fear that others will react negatively if they talk openly about their partner or family of choice.
- LGB carers may be caring for family of origin or 'family of choice'; be dealing with challenging birth family dynamics, assumptions around being single, having no dependents; lack of acceptance of LGB identity; find they are excluded as their relationship is not accepted by a partner's biological family; face discrimination and assumptions when using services.
- At the engagement event, Scottish Trans Alliance argued that health professionals need more awareness of the heteronormative legacy and older people coming from an "unsafe" era. In addition, it was noted that proactive signals from the workforce and targeted action are needed, as are good examples of explicit inclusion.
- At the event, LGBT Health and Wellbeing argued that lesbian, gay and bisexual (LGB) people with dementia form an "invisible population". No one collects sexual orientation or gender identity within dementia, so there is no data available about prevalence. This lack of data in turn feeds lack of action. The Scottish Trans Alliance suggested that proactive actions are therefore needed by the government and public bodies to seek information on prevalence of dementia amongst LGB people.
- Stonewall noted that Alzheimer's Society have resources on LGB people with dementia, which could be used and another reminiscence groups could be adapted to specifically include LGB people. 'Opening Doors' has started to do this through its activities in London (over 50+), but this may be difficult to mirror in Scotland given smaller demand. Moving these online during pandemic is very difficult for this population, given wider issues around older people accessing technology and people with dementia facing challenges in using this technology as they may require body language and face-to-face communication.

Data gaps identified and action taken

GAP:

There is insufficient literature around the specific experiences of lesbian, gay and bisexual people with dementia.

Action:

An engagement event involving the LGBT Health and Wellbeing and Stonewall Scotland was organised as part of the wider consultation on this equality impact assessment.

Source

[Scottish Social Attitudes 2015: attitudes to discrimination and positive action](#)

['Is Scotland Fairer?'](#)

[Lesbian, Gay and Bisexual People in Later Life](#)

[Unhealthy Attitudes: Stonewall, 2015](#)

[LGBT in Scotland – Health Report](#)

['Dementia and Equality: Meeting the Challenge in Scotland'](#)

[Spotlight on Dementia and Equality](#)

[Your Services, Your Say – consultation report](#)

Equality Impact Assessment event with Stonewall Scotland, Scottish Trans Alliance and LGBT Health and Wellbeing.

Race:

Public Health Scotland's preliminary evidence found "no signal of increased risk of COVID-19 to people from an ethnic minority in Scotland", though evidence from England and Wales has had different conclusions. 2013 evidence suggests that dementia is more common amongst minority ethnic communities. Prevalence of dementia amongst minority ethnic communities in Scotland is increasing, though the uptake of dementia care services by people from minority ethnic communities remains low. People from minority ethnic backgrounds who experience dementia are less likely to present to services and tend to make contact at a later stage of the illness. Evidence from systematic reviews of qualitative research suggests that barriers to support-seeking for dementia are knowledge, society and/or healthcare related. Language barriers may also contribute. People from minority ethnic communities with dementia, or who are unpaid carers for those with dementia, may have specific needs, which may be culturally contingent, as well as facing specific challenges, for example relating to cultural attitudes around dementia, or to stereotypes or assumptions from health and social care providers.

Evidence gathered and Strength/quality of evidence

- Public Health Scotland [has undertaken analysis](#) to investigate whether COVID-19 outcomes vary by race or ethnic group and published preliminary evidence in May, finding "no signal of increased risk of COVID-19 to people from an ethnic minority in Scotland". They continue to refine this work as additional data becomes available.
- In 2013, an [All Parliamentary Party Group report](#) found that dementia is more common amongst minority ethnic communities as a result of the prevalence of high blood pressure, diabetes, stroke and heart disease, which are all common risk factors for dementia. It is worth noting, however, that this evidence refers to the UK and that the data in question is seven-years old. The report found that families from minority ethnic communities living with dementia struggle with little or no support from the NHS or local government, as specialist services are too few and far between, and that there is an urgent need to increase awareness of dementia among minority ethnic communities. UK data also found that the black African-Caribbean population in the UK experience more prevalence of early onset dementia and have greater risk factors for vascular dementia.

- [Alzheimer Europe](#) research has shown that the number of people with dementia from minority ethnic groups is increasing, as migrant populations in Europe age and some ethnic groups have a higher risk of developing dementia. Yet the uptake of dementia care services by people from minority ethnic communities remains low.
- Public Health Scotland's report '[Dementia and Equality: Meeting the Challenges in Scotland](#)' (2016) has outlined the relationship between ethnicity/race and dementia. Dementia is often difficult to diagnose in minority ethnic communities, as most cognitive tests are developed and standardised in one ethnic group, which may not transfer appropriately to another ethnic group due to cultural, education, language and other factors.
- As Public Health Scotland's report '[Dementia and Equality: Meeting the Challenges in Scotland](#)' (2016) notes, people from minority ethnic backgrounds who experience dementia are less likely to present to services and tend to make contact at a later stage of the illness. Evidence from systematic reviews of qualitative research suggests that barriers to support-seeking for dementia are knowledge, society and/or healthcare related. Language barriers may also contribute, and may pose particular issues in [accessing self-directed support, for example](#).
- '[My Support, My Choice](#)' report on SDS highlighted that minority ethnic people need better info about self-directed support.
- This research found that, for some minority ethnic communities, dementia is not known by a specific term and knowledge and understanding of the disease is limited. Lack of understanding and awareness of dementia creates many barriers for individuals accessing timely support, often resulting in individuals receiving late diagnoses, and families trying to cope for longer without support. Evidence shows that beliefs about dementia and its causes can act as a barrier to people from minority ethnic communities seeking help in some communities. Perceptions of stigma associated with a diagnosis of dementia have also been identified as a barrier to seeking help.
- As Public Health Scotland's report '[Dementia and Equality: Meeting the Challenges in Scotland](#)' (2016) has outlined, the general practitioner is usually the first point of contact for people with dementia and their families. Even though members of the minority ethnic community access primary care in a similar way to the general population, there is a reluctance to engage with mental health services. Previous experiences of discrimination may be a factor. Many families from minority ethnic communities may resist engagement with social and health care services as they fear discrimination or they may have little confidence that services will meet their cultural, linguistic or religious needs.
- [As a report by Scottish Care outlines](#), issues faced by ethnic minority older people can also include the perceived unsuitability of sheltered housing or a care home to meet their religious and cultural needs – but difficulties arising from this in terms of adapting a home environment where families want their older parents at home, challenges for families without experience, time or resources and unsuitable care at home packages being provided. Other challenges include social isolation and loneliness in sheltered housing or a care home, particularly if language difficulties occur from a loss of or lack of spoken English; dietary needs not being met or difficulties in expressing needs and interests. The report highlights that traditional therapies centring memories or interests may be unsuitable for those of an ethnic minority with dementia, due to a language or cultural barrier and unfamiliar cultural references, particularly if they are a first-generation immigrant.

- This research has shown that language barriers may contribute to misunderstandings about the healthcare system. Older people from minority ethnic communities may have limited fluency and/or literacy in English. Interpreting services are in short supply, are inadequately advertised and often have limited funding. Potential clients may be unaware that services exist, or uncertain whether they may be able to use these services. For example, people may not know about rights and entitlements such as Self Directed Support, which can also be extremely difficult to access, and consequently is not being used sufficiently.
- [Alzheimer Scotland's further research](#) on Public Health Scotland's report noted that, when accessing services, the use of interpreters can be problematic for some older people of minority ethnic backgrounds. For example, sometimes the gender of interpreters can be important as gender roles may be very important in some minority ethnic communities. Ensuring the consistency of interpreters can therefore be key. Moreover, communities may withdraw support after a diagnosis, so the person may become more isolated, often leading to a delay in seeking a diagnosis. People become more inward looking and insular, for fear of reaction when people find out about their condition. Their research also reported that there may be cultural expectations that relatives, particularly women, should care for the older person with dementia, help-seeking may be frowned upon by other community members. Caring may be kept within the family or seen as part of the role taken on by women in the community. [Scottish data shows that 96% of people who report providing unpaid care in Scotland to a relative, friend or neighbour are from a "White Scottish/British/Irish" ethnic background](#). However, this may be as a result of underreporting by those of minority ethnic backgrounds. [For example, the carers questioned by MECOPP were surprised by their Gypsy/ Traveller Carers' project](#) – most within this group did not identify as a carer or use the term carer to describe themselves.
- In April 2018, Life Changes Trust funded (up to) 2-year projects around people living with dementia and unpaid carers in minority ethnic communities. Four projects worked in nine local authorities over Scotland, targeting Minority Ethnic. These projects were successful in raising awareness of dementia, but illuminated the racial inequality that prevails when accessing health and social care and how it can hinder the ability of families from minority ethnic communities affected by dementia to access critical support. [REACH worked in partnership with Life Changes Trust on this](#). At the engagement event, they argued that the principles of diversity enshrined in National Care Standards are neither understood nor implemented by service commissioners or providers. 12% of Glasgow's population are Black, Asian or minority ethnic but, prior to REACH being funded by Life Changes Trust, there was no dementia support tailored for the minority ethnic community. Moreover, there has been seemingly limited research on impact of dementia on the BAME community.
- Stakeholders at the engagement event highlighted that employers have an important role to play by: recognising that approaches to caring for older relatives vary and are not contingent on someone's ethnic background and supporting carers whatever their circumstances and arrangements; acknowledging gender bias in caring with women having main responsibility for caring; employing staff from minority ethnic communities to deliver inclusive services.
- The Scottish Human Rights Commission, in its evidence to the Equal Opportunities Committee in 2013, described the discrimination towards Gypsy/Travellers as "the last bastion of respectable racism". Public Health

Scotland's report 'Dementia and Equality: Meeting the Challenges in Scotland' (2016) noted that gypsy/traveller communities' experience of prejudice and fear of discrimination negatively impacts on people from these communities seeking help from services and service providers, as well as general awareness of existing services. Moreover, Scottish Government research has shown that high levels of poverty experienced by Gypsy/Travellers is linked to poor health and the lack of employment and integral to all these issues is the provision of sites across Scotland.

- [MECOPP's research](#) further indicates that a lack of recognition and understanding of Gypsy/Traveller culture often results in inadequate responses – though it should be noted this evidence is based on a project started in May 2011. Gypsy/Traveller families often reported that they felt like they were being blamed for causing their own problems, as if it was their ethnicity that was the problem, rather than an inappropriate service or lack of flexibility. For Gypsy/Travellers, community isolation was identified as an additional barrier for those who have experienced long-term misunderstanding and prejudice which has led to an increasing distancing from services, including health services. It is not uncommon for Gypsy/Travellers to travel hundreds of miles to see a known GP or trusted support worker, rather than risk rejection at a local surgery or office. [The majority of Gypsy/Traveller carers are not accessing social care services, voluntary or statutory, on a regular basis, and many had never accessed services at all. General knowledge about carers' rights/entitlements within the community is very low; most carers are not in receipt of Carer's Allowance.](#) In their dealings with service-providers and agencies, being listened to was seen as a rare occurrence. For many, caring was very much a shared responsibility. Many reported keep their identity as a hidden for fear of being treated differently by services and others mentioned the perceived inability of GPs and service providers to understand the impact of this on mental health. High levels of illiteracy impact significantly on a carer's ability to search for support. [None of the carers MECOPP worked with "were currently accessing any of the Self Directed Support options."](#) One person thought she might have heard about it in the past but when asking about it to her Social Worker, she'd been told it wouldn't be appropriate and would be too much hassle.

Data gaps identified and action taken

GAP:

Public Health Scotland has undertaken analysis to investigate whether COVID-19 outcomes vary by race or ethnic group and published preliminary evidence in May. However, the study acknowledged that "low volume and incomplete data limits the conclusion we can draw at this time." They continue to refine this work as additional data becomes available.

Action:

The disproportionate impact on people of Black and Minority Ethnic (BAME) backgrounds in other parts of the United Kingdom has been considered. A Public Health England review showed that there is an association between belonging to some ethnic groups and the likelihood of testing positive and dying with COVID-19. People of Bangladeshi ethnicity had around twice the risk of death when compared to people of White British ethnicity. People of Chinese, Indian, Pakistani, Other Asian, Caribbean and Other Black ethnicity had between 10 and 50% higher risk of death when compared to White British people. Death rates from COVID-19 were higher for Black and Asian ethnic groups when compared to White ethnic groups.

GAP:

There is no evidence which clearly outlines the number of people from minority ethnic communities living with dementia in Scotland.

Action:

Evidence is drawn from the [Life Changes Trust Report, 'Evaluation of Dementia Projects for Minority Ethnic Communities Across the UK'](#), which notes that there are more than 25,000 older people from minority ethnic communities living with dementia in the UK. Based on [APPG on dementia's 2013 report](#), Life Changes Trust predict that this number is expected to grow to nearly 50,000 by 2026 *in England and Wales*, and over 172,000 by 2051, a seven-fold increase in 30 years.

GAP:

The EHRC's 2018 report 'Is Scotland Fairer' noted that small groups such as Gypsy/ Travellers are rendered 'virtually invisible' by a lack of data. There is very little or no mention made of minority ethnic groups such as Gypsy/ traveller communities, within published literature on dementia.

Action;

Efforts have been made to consult specifically with GRT representative groups through the equality impact consultation and the involvement of Migration Scotland/ COSLA. I have referred also to MECOPP's Report on informal caring within Gypsy/ Traveller communities.

Source

[Dementia does not discriminate: The experiences of Black, Asian and minority ethnic communities.](#)

[COVID-19 Statistical Report.](#) Public Health Scotland.

[Beyond the data: Understanding the impact of COVID-19 on BAME groups](#)

[The interface between dementia and mental health: an evidence review.](#)

[Intercultural dementia care: A guide to raise awareness amongst health and social care workers](#)

[My Support, My Choice - Self Directed Support Scotland | Self Directed Support Scotland \(sdsscotland.org.uk\)](#)

[Dementia and equality briefing paper](#)

['Dementia and Equality: Meeting the Challenge in Scotland'](#)

[Spotlight on Dementia and Equality](#)

[Evaluation of Dementia Projects for Minority Ethnic Communities Across the UK.](#) Life Changes Trust, 2020.

[Equality Impact Assessment event including REACH and Colourful Heritage.](#)

[Scotland's Carers](#)

[Improving the lives of Gypsy/Travellers: 2019-2021](#)

Religion and Belief:

Religion and belief can intersect with race and ethnicity, causing similar challenges around cultural perceptions or awareness of dementia; differing approaches or stereotyping and assumptions. Faith and cultural norms can impact all aspects of dementia care in all settings. For this reason, many faith communities have developed specific resources or services to support people with dementia. For example, the Church of Scotland has a resource encouraging congregants to become more dementia-friendly and Jewish Care Scotland provides specialist support for Jewish people with dementia. There is also the Living Well project, a collaborative effort between city councils and churches, which provides a safe space for people with memories challenges to gather together and from friendships and community.

Evidence gathered and Strength/quality of evidence

- As Public Health Scotland’s report ‘[Dementia and Equality: Meeting the Challenges in Scotland](#)’ (2016) has noted, religion is closely associated with race and ethnicity with regards to community approaches to dementia: there is an interplay between cultural influences relating to religion or belief and those relating to race and ethnicity. Religion and belief impact one’s understanding of dementia, but also impact upon a person’s access to services.
- At the engagement event, Faith in Older People shared the importance of acknowledging people’s faith and cultural norms in all aspects of dementia care and in all settings. Lots of assumptions are made across services that people with dementia lose awareness of their faith and cultural touchpoints such as food, language and social behaviour. They cited faith-based services as sharing an experience of commissioners, including health and social care practitioners, challenging the need for faith based services. Religious and cultural festivals and norms have an important and positive impact for people living with dementia, connecting them to their identity and community and offering familiarity.
- Differences in community approaches to caring for older people in families were highlighted during engagement. There is more of a cultural emphasis within some communities towards keeping people at home. Experiences shared at the engagement event ranged from the increasing use of care homes within the Jewish community, to a strong commitment from the Muslim community that caring for elders at home is expected and widely accepted. However, work from Aberdeen Health and Social Care partnership reflects that people of all faiths and none do want to keep their loved ones at home where possible: the problem is a lack of support and in particular a lack of respite care allowing many people to do so. Whilst there may be a more formal emphasis on keeping people at home, within certain cultures and traditions, this does not mean that those who not share that tradition do not hold the same aspirations.

Data gaps identified and action taken

GAP:

- There is a lack of evidence about the impact of religion or belief on dementia in Scotland.

Action:

- The available evidence has been considered and the work of faith communities supporting people with dementia has been taken into account. This equality

impact assessment has approached specific groups representing religion or belief in order to consider the intersection of religion/ belief and dementia more closely.

Source

[‘Dementia and Equality: Meeting the Challenge in Scotland’](#)

[Dementia and equality briefing paper](#)

[Jewish Care Scotland](#)

[Living Well Project](#)

[One step at a time](#)

Equality impact assessment engagement event including REACH, Colourful Heritage, Faith in Older People and Scottish Council of Jewish Communities.

[Swinton-dementia-report-14-12-2017-2.pdf](#)

Other – Socioeconomic inequality:

There is limited evidence to date that suggests that dementia is socially patterned. There is a correlation between socioeconomic status and the impact of COVID-19: the pandemic has had a greater impact upon Scotland’s poorest families financially. [Moreover, during the first wave, those in the most deprived areas of Scotland are 2.1 times more likely to die with COVID than those living in the least deprived areas.](#) Socioeconomic inequality intersects with other issues, such as digital exclusion.

Evidence gathered and Strength/quality of evidence

- Currently, [there is limited evidence that suggests that dementia is socially patterned.](#) A meta-analysis of eleven community studies determined that an association exists between lower occupational social class and dementia death in men, but not in women, after adjustment for alcohol consumption, smoking, cardiovascular disease, diabetes, psychological distress and age of leaving full-time education. However, this association was not statistically significant.
- Public Health Scotland’s report [‘Dementia and Equality: Meeting the Challenges in Scotland’ \(2016\)](#) concluded that, since health inequality persists into old age and many of the risk factors for dementia are associated with socioeconomic disparities in mortality and morbidity, it is possible that – as the age structure of the population changes – social patterning in dementia may become apparent. Alternatively, it may be that people suffering the worst health die before dementia is diagnosed.
- People with dementia who are homeless are potentially disadvantaged as they have no address; are acutely vulnerable due to the impact of dementia in a transient situation, and are at a higher risk of exploitation if symptoms of dementia are obvious to others. [‘My Support, My Choice’ report on SDS](#) highlighted that people who have been homeless need better info about self-directed support.
- [COVID-19 has hit Scotland’s poorest families the hardest.](#) Two thirds of the young people and families reliant on social security are in a worse financial position than they were pre-pandemic and half reported that their debt was greater. [Figures from National Records of Scotland](#) show that people in the

most deprived areas were 2.1 times more likely to die with COVID than those living in the least deprived areas.

- The roles of people actively employed as 'key workers' since lockdown measures were introduced include many that are characterised by low and/ or unstable income. In addition, [the Institute for Fiscal Studies estimates](#) that low earners were seven times more likely than high earners to have worked in a sector that has shut down as a result of the lockdown. This, coupled with the cramped accommodation without private outdoors space and more frequent smaller purchases that are common for households experiencing poverty, could significantly increase the chances of infection during lockdown and early release phases.
- As [other Equality Impact Assessments](#) have noted, the effects of COVID-19 layer on top of existing structural imbalances and are predicted to be particularly severe for people on low incomes, who are more likely to have poorer health and are also more likely to be in insecure work without financial reserves. [Other Equality Impact Assessments](#) have also shown that lower income households are less likely to have a broadband connection, may lack access to smart devices (phones or tablets) or sufficient data, and may rely on libraries and other community resources now closed to make use of the internet. This may have left them without access to home learning materials, justice procedures, advice, information, job or benefits applications, shopping, and entertainment during the pandemic.

Data gaps identified and action taken

GAP:

No information was found about effective interventions to raise awareness of dementia in different socio-economic groups. There are few large scale studies that have looked at social inequality in dementia in Scotland.

Action:

The consultation for the equality impact assessment has included a focus socioeconomic inequality as part of wider inequality, including digital exclusion and rural/ remote location.

Source

[Dementia and Equality briefing paper](#)

['Dementia and Equality: Meeting the Challenge in Scotland'](#)

[Rapid EQIA: Post-Diagnostic Support \(Edinburgh\)](#)

[Poverty and the Impact of Coronavirus on Young People and Families in Scotland](#)

[Sector shutdown during coronavirus: which workers are most exposed?](#)

[My Support, My Choice - Self Directed Support Scotland | Self Directed Support Scotland \(sdsscotland.org.uk\)](#)

[Equality and Fairer Scotland Impact Assessment: Evidence gathered for Scotland's Route Map through and out of the Crisis](#)

[Deaths involving COVID-19 Week 28 - 6th to 12th July](#)

Other – Digital Exclusion:

Addressing the digital divide has been highlighted as key to reducing health inequality. COVID-19 has seen an increasing move towards digital services, in social care, healthcare and general settings. However, this move may have left behind those who are digitally excluded, which is more likely to include those of lower socioeconomic status and older people. The move to digital services may not be suitable for many people with dementia or their carers.

Evidence gathered and Strength/quality of evidence

- The [NHS Widening Digital Participation Programme](#), delivered by NHS Digital, found that tackling the 'digital divide' is essential to reducing health inequality.
- Digital Exclusion refers to both digital access (availability and confidence as well as available infrastructure), ability and affordability: a good Wi-Fi connection and the right equipment as well as the skills to use this equipment and being able to afford it. Digital exclusion intersects with other categories considered here. There can be connectivity issues (including but not only in) rural or remote areas, or there may be limitations in possible internet providers. People may have no workarounds to be able to use mobile technology. Those who are most likely to be digitally excluded are people and families on low incomes, people from minority ethnic communities, and those with additional challenges such as care leavers, disabled people, those who have a communication difficulty, sensory impaired, those shielding and older people. Research from Glasgow Disability Alliance for instance notes that disabled people are nearly 4 times as likely to be digitally excluded.
- [Evidence gathered for other EQIAs](#) already suggests that older people are less likely to use the internet and digital devices than younger people, and when they do they can sometimes be less confident meaning they don't always benefit to the same degree.
- Evidence gathered during our engagement sessions showed that unpaid carers may not have had access to the correct tech or necessary technical knowledge in order to maintain contact with the person with dementia they care for at points during the pandemic; though carer centres have worked hard during the pandemic to address this and many carers have used the time to live fund to buy IT equipment such as tablets.
- Moreover, paid carers may not have the right tech or the have the required knowledge/ training to ensure family and friends can maintain contact with the person they are caring for.
- Age Scotland noted that it is important not to make assumptions around people becoming more digitally savvy during the pandemic, or necessarily becoming more isolated through lack of tech access. A lot of people living with dementia are not using care tech or traditional IT care methods, but are happy to use voice activation devices. In line with digital Carers Centres services and support, Scotland adopted a digital approach during lockdown, which saw a huge increase in levels of engagement via Zoom for carers and removed a lot of the barriers to engagement. However, they felt that 'Zoom fatigue' is setting in for many people.
- Digital exclusion may interact with protected characteristics, such as disability, and there may be specific obstacles for people with e.g. learning/intellectual disabilities having digital access.
- Obstacles to digital access were outlined by People First Scotland at one engagement session, including availability and training gaps to facilitate family and paid carers in offering or accessing digital connection; insufficient funding for tech provided by benefits and lack of decision-making enabling digital connection. It was noted that, many people are online but that the psychological impact of COVID-19 has meant many are not in the right head space to try to

learn something new or to cope with technological malfunctions. Any barrier to accessing online support quickly becomes a reason not to use it and for many, once they have had an unsuccessful attempt they may not try again, meaning there is a need to aim for the first connection on line to be successful so people will keep trying.

- The need to get the right information out to people at the right time was emphasised at the engagement events, with best practice highlighted regarding carer groups looking up phone numbers and sending out packs to their groups to ensure accessibility. Other people want to still use telephone calls and on a landline. There needs to be options available to people, particularly as some people will never be comfortable with anything on-line, they are people who did not grow up with computers and will never be comfortable on-line no matter what we do. People using on-line need trained on how to get the message across to people they are engaging with, but dementia still traditionally poses a multi-layered series of barriers to accessing information online.

Data gaps identified and action taken

GAP:

There is a lack of literature about the impact of digital exclusion on those with dementia.

Action:

Questions were specifically asked about inequality at consultation engagement events around this strategy. Several respondents focused specifically on digital exclusion and its intersection with other equality factors, such as age. An engagement event focusing specifically on this theme was organised with relevant stakeholders as part of consultation on the equality impact assessment.

Source

Interim National Equality Impact Assessment – Protect Scotland App

[Equality and Fairer Scotland Impact Assessment: Evidence gathered for Scotland's Route Map through and out of the Crisis](#)

Engagement events with Age Scotland, Connecting Scotland, National Rural Mental Health, People First Scotland, University of West of Scotland, Befrienders Highland, Spirit Advocacy/ HUG, TIDE and Alzheimer Scotland.

[Digital inclusion fundamental to tackling health inequality](#)

Other – Rural and Remote locations:

COVID-19 has had a differential impact on those within rural or remote locations who have dementia or care for someone who does. Oftentimes this may intersect with digital exclusion, as access to a good broadband connection may be limited for those in these areas. In some rural or remote areas there has been an almost complete withdrawal of public transport during some periods of the pandemic and home deliveries – which may be vital for those with dementia or their carers living at home – may be more costly or difficult for those living in a rural or remote area.

Evidence gathered and Strength/quality of evidence

- [Rural areas are defined by the Scottish Government as those with less than 3,000 people](#). Accessibility is measured in terms of drive times to an urban area. Remote areas are those that are more than a 30 minute drive time (6-fold classification), or areas that have a drive time between 30 and 60 minutes (8-fold classification) from a Settlement with a population of 10,000 or more.

900,000 people live in rural locations in Scotland, one-third of whom live in remote-rural areas.

- Evidence from our engagement sessions and from existing EQIAs shows that people who live in remote and rural communities may lack proper or good access to the internet, due to a lack of available tech and/or poor broadband connection.
- Lack of broadband access in some areas was emphasised – some need special satellites as they have no broadband supply and this has continued throughout the pandemic. Some people don't even have a mobile phone signal, let alone 4G or Wi-Fi. This makes it difficult for them to use technological alternatives offered in place of face-to-face services. Income and infrastructure is key to digital access, as is capability and trust. There is a huge amount of demand for this, beyond available capacity: the Scottish Government had a £25 million grant to train 9,000 people, but up to 250,000 people expressed demand (though some were likely to have been double counted due to the bidding system).
- The work of [Connecting Scotland](#) (CS) to address lack of devices, lack of affordability and lack of competence for people was noted; but so was the continuation of black spots, as this work is not tackled by CS. Superfast broadband and a 4G connection is key to technological access for care providers and care homes, yet many lack this access and have no plans to ensure this. CS have been leading a programme to provide iPads to care homes.
- COVID-19 is likely to have impacted upon transport connectivity in rural and remote parts of Scotland in particular. In some rural or remote areas there has been an almost complete withdrawal of public transport during COVID-19. In some remote-rural locations, residents pay substantial amounts of money more than the mainland to access home deliveries, which many people have relied on during the pandemic.
- At the engagement event, stakeholders expressed concern about there being too few dementia services available in remote areas, and those available having been cut. They felt COVID is being used as an excuse to strip back provision, but noted some examples of good services and people going an extra mile to help people – e.g. an organisation funded to provide befriending service over the telephone and some face to face when not able to be reached on phone – but also there is the other end of the spectrum where there is nothing available and no willingness to provide anything.
- It was suggested that building resilience is key to being part of the community in rural/ remote areas, with an emphasis on 'peer support' alongside befriending or buddying. Particular challenges were noted for LGBT people in rural/ remote areas, with organisations such as the Far Out Equality Network aiming to support this group. 62% believe that LGBT people outside of Scotland's big cities face more inequality than those who live within and 51% of LGBT people living in rural areas have personally experienced prejudice or discrimination for being LGBT.

Data gaps identified and action taken

GAP:

There is a lack of literature about the impact of living in a rural/ remote area on those with dementia. There is also a lack of literature about the impacts of COVID-19 policy decisions on rural and remote areas, such as the impact of removing access to transport services on the rural economy and residents' wellbeing.

Action:

Questions were specifically asked about inequality at consultation engagement events around this strategy. Several respondents focused specifically on remote/rural locations and their intersection with other equality factors, such as digital exclusion. An engagement event focusing specifically on this theme was organised with relevant stakeholders as part of consultation on the equality impact assessment.

The specific impact of COVID-19 on Scotland’s transport services and the rural economy is set to be investigated by MSPs for The Scottish Parliament’s Rural Economy and Connectivity Committee.

Source

[Scottish Government Urban Rural Classification 2016](#)

[Rural Scotland: key facts 2018](#)

Interim National Equality Impact Assessment – Protect Scotland App

COVID-19 engagement events including National Rural Mental Health, Connecting Scotland, Age Scotland, National Rural Mental Health, People First Scotland, University of West of Scotland, Befrienders Highland, Spirit Advocacy/ HUG, TIDE and Alzheimer Scotland.

[Further Out: The Scottish LGBT Rural Equality Report](#)

Stage 3: Assessing the impacts and identifying opportunities to promote equality

Having considered the data and evidence gathered, this section focuses on considering the potential impacts – negative and positive – that the policies in this plan might have on each of the protected characteristics. Each of these aspects also relates to the wider commitments in the plan around human rights and equalities.

Do you think that the policy impacts on people because of their age?

Aspect	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination, harassment and victimisation	<p>Being part of the community – benefit: Efforts around buddying and befriending are likely to improve awareness of dementia, a condition which mostly effects older people, and to therefore reduce unlawful discrimination, harassment and victimisation on the basis of age.</p>
Advancing equality of opportunity	<p>Preventing dementia – benefit: The majority of those with dementia are over 65, though work on preventing dementia is also likely to positively impact those who are at risk of being diagnosed with dementia under 65.</p> <p>Support for family carers – benefit: 17% of people aged 50 to 64 provide unpaid care to a relative, friend or neighbour. This compares to 2% of under-25s, 10% of 25-49 year olds and 11% of over-65s. Support for family carers is likely to particularly benefit those between 50 and 64, or who are over 65.</p>

	<p>Family carers for those with dementia under 65 may face particularly challenging circumstances, e.g. longer periods of uncertainty, dual loss of employment and income due to caring, frustration and grief, lack of peer support, and responsibility for families and young children. Supporting family carers is likely to help aid these challenges.</p> <p>Supporting a skilled and knowledgeable workforce and service modernisation – benefit: Upskilling the workforce and modernising service is likely to benefit those under 65 with dementia by making the workforce more knowledgeable about diagnosing, treating and aiding those of a younger age with dementia.</p> <p>Being part of the community – barrier: Those under 65 with dementia often have different needs around issues including childcare, employment, age appropriate peer support and financial impact, and may particularly benefit from efforts to keep them integrated in the wider community and provide appropriate peer support.</p> <p>Support for a timely diagnosis and post-diagnostic community support – barrier: There are a number of barriers to people being diagnosed, even under the proposed policy. Symptoms may be misattributed to other conditions such as stress, depression, menopause, excess alcohol use and relationship difficulties. Younger people are more likely than older people to have one of the rarer causes of dementia where the symptoms are less familiar to clinicians.</p> <p>Living well at home – barrier: There are barriers to living well at home for those with dementia under 65. Many of those diagnosed with dementia under 65 are still working and/or have mortgages, children, car etc. They are often not told about the benefits they are entitled to, leading to debt. Filling in benefits forms can be a very stressful and disempowering experience, too.</p>
Fostering good relations between people of different ages	<p>Being part of the community – benefit: Initiatives around befriending are likely to encourage those of younger age groups to build up contact with older people, given the higher incidence of dementia amongst those who are 65+.</p>

Do you think that the policy impacts disabled people?

Disability	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination, harassment and victimisation	<p>Supporting a skilled and knowledgeable workforce and service modernisation - benefit: Having a person who is profoundly deaf being cared for and supported by health and social care workers who can't communicate with them using BSL is a deprivation of human rights and severely affects the wellbeing of the Deaf BSL user, as well as creating anxiety for their unpaid carers. Stakeholders argued that the emphasis on upskilling staff could be reframed by specifically employing staff who are BSL users. Supporting a skilled and modernised workforce through education regarding the needs of people with learning/intellectual disabilities and dementia will move towards</p>

	<p>eliminating discrimination, harassment or victimisation against these people on account of their disability.</p> <p>Being part of the community – barrier: In all areas of life, citizens with a learning/intellectual disability experience significant discrimination and prejudice. These attitudes are very likely to present a barrier to citizens with a learning/intellectual disability having equal access to this policy.</p> <p>Living well at home – barrier: The lack of high quality social care support for people with learning or disabilities may present a barrier to realising this policy. Isolation is more pronounced for these people, because of overall and society wide prejudice. Neighbours may abuse or intimidate rather than provide support, which presents additional barriers and undermines living safely at home as an option.</p>
Advancing equality of opportunity	<p>Support for family carers – benefit: 16% of people who provide unpaid care to a relative, friend or neighbour are deaf or have partial hearing loss; 16% have a physical disability; 11% have a mental health condition. Supporting unpaid carers would therefore intersect with supporting those with a disability, a significant proportion of whom provide such unpaid care. For people with learning/intellectual disabilities, a key concern during the pandemic has been the removal of their support hours at the start of the pandemic, which has had a detrimental impact both on people with learning/intellectual disabilities and their family carers. Further support for carers through implementation of the Carer's Act will help to recognise the burden that this pandemic has placed on them through the removal of available support services/ reduction of support hours; particularly where they are caring for someone with dementia and a learning/ intellectual disability. Supporting carers and involving them in care decisions is key as they are likely to notice issues for people with learning/ intellectual disabilities and dementia early on.</p> <p>Preventing Dementia - benefit: Social isolation has been identified as a later life factor for dementia. As such, establishing the connection with hearing loss has the potential to positively impact two of the 9 factors which, if eliminated, could help prevent 35% of dementia cases. Sight Scotland research has shown that two thirds of blind and partially sighted people say their visual impairment has contributed to problems of loneliness and social isolation. So far there has been insufficient work done to support Deaf-blind people to access the health improvement efforts around heart health, brain health etc. and healthy lifestyle choices and behaviours such as exercise, healthy eating, which could help prevent dementia. Targeted efforts to focus on preventing dementia amongst those who are Deaf-blind would be of particular help.</p> <p>Being part of the community – benefit: Those with hearing loss are potentially at risk of social isolation; those with hearing loss and dementia are doubly susceptible and the limited social interaction during lockdown increases the risk even further. Those with a learning/ intellectual disability and dementia may also be particularly at risk of social isolation during lockdown, particularly with the shutting of day services, and the increased risk of COVID-19 for some people with learning/ intellectual disabilities, meaning many may have had to shield. 57% of people with learning/ intellectual disabilities who responded to the SCLD's survey said they felt lonelier since lockdown measures were put in place. This issue appears to be particularly felt by those in residential settings (including supported accommodation) who can no longer receive visits from their family. Commitments to supporting people safely, e.g. through buddying or befriending, and commitments to strengthen national and local linkages on the Scottish Government's</p>

Social Isolation and Loneliness Strategy will be particularly beneficial to those most at risk of isolation during the pandemic (and beyond).

Living well at home – benefit:

Using technology can make a huge difference to keeping someone with a learning/ intellectual disability, or who is blind, Deaf, Deaf-Blind, or faces sight or hearing loss, at home and therefore in the space they feel most comfortable. This can be done by making them feel safe and secure, e.g. through use of key safes, installing door monitors. From a visual impairment perspective it may be useful to add voice activated and responsive technology. Design features which are dementia friendly, such as lighting aids, are often visual impairment friendly too. For people with learning/ intellectual disabilities, access to digital connection can help to facilitate equality.

Living safely in a care home - benefit:

A third of those with learning/ intellectual disabilities who have died from COVID-19 lived in residential care homes. Ensuring safety in care homes will help ensure people with learning/ intellectual disabilities and dementia are properly protected. For people with hearing loss or who are Deaf or Deafened, there may be issues around care home staff wearing masks, as they may need to lip read – although there is officially an exemption for care home staff around wearing masks when caring for with people with a sensory deafness, blindness.

Supporting a skilled and knowledgeable workforce and service modernisation

– benefit: Currently, not all health and social care workers or families will be knowledgeable about dementia in people with learning/ intellectual disabilities, so they may miss signs and symptoms of early stages of dementia. There is a national shortage of both interpreters for British Sign Language (BSL) and health and social care workers who can communicate in BSL. Blind and partially sighted people also have communication and care needs which require visual impairment awareness in health and social care services. For Deaf-blind people, the ideal for hospital appointments, as outlined in the MEL 1998(4), is to have access to a specialist Guide Communicator Service. For people with learning/ intellectual disabilities and dementia, communication around understanding a diagnosis is key. Non-verbal communication should be taken into consideration, such as easy read, talking mats, etc. This has an influence on the support and care they receive and their specific communication needs. Best practice information and guidance, e.g. from Dr Karen Watchman, should be disseminated and involvement of learning/ intellectual disabilities nurses could be crucial. Modernisation and upskilling the workforce should help to address these particular issues for people with dementia and learning/ intellectual disabilities difficulties or a sensory deafness, blindness – if new staff are suitably recruited and existing staff trained.

Improving the hospital experience - benefit: People with learning/ intellectual disabilities and dementia are sometimes prescribed inappropriate medication acting as a sedative. Improving the hospital experience would include a move away from this practice. Moreover, their paid carers are too often not allowed into hospital due to double-funding. Continuity of care would be key to improving the hospital experience for those with learning/ intellectual disabilities and dementia.

Support for a timely diagnosis and post-diagnostic support – barrier:

Communication difficulties, and an increased potential for sensory loss also hinder diagnosis as the person with learning/ intellectual disabilities may be unable to

	<p>articulate what is happening to them. There is also a high risk of misdiagnosis. People who are deaf, deafened, blind, deaf-Blind, partially sighted or hard of hearing and who develop dementia face additional challenges, including an increased sense of disorientation and risk of social isolation. The onset of dementia may be more difficult to detect by family and carers. The Scottish Human Rights Commission has raised concerns that disabled people may end up with an inappropriate or inadequate care or support package due to lack of proper assessment, or in the case of adults with incapacity, the lack of a full assessment may have further repercussions with respect to procedural safeguards (as a result of removing the requirements of the Self-Directed Support Act). Deaf-Blind Scotland reported that sensory loss is often not viewed as a priority for self-directed support assessment, ignoring inclusive communication as a pivotal mediator in achieving all desirable health and social outcomes. Likewise, for people living with sight loss or who are Blind and have dementia, there is a concern over diagnostic overshadowing – support being provided for the person with dementia, but their visual impairment not being properly identified and treated. This can apply in care home environments too. Even with a diagnosis, there are issues with getting the right support for people with learning/ intellectual disabilities as services are too often not tailored to their needs and there may be issues accessing "mainstream" services.</p> <p>Preventing dementia – neutral: People with learning/ intellectual disabilities have a higher risk of developing dementia compared to the rest of the general population, with a significantly increased risk for people with Down’s syndrome at a much earlier age. There is not enough evidence to say whether targeted efforts at preventing dementia would be successful at reducing this risk.</p>
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Do you think that the policy impacts on men and women in different ways?

Sex	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	<p>Preventing dementia - neutral: Women are more likely to be diagnosed with dementia than men, in part due to their higher average life expectancy.</p>
Advancing equality of opportunity	<p>Support for family carers – benefit: Survey data published for Carers Week 2020 suggests that there are now as many as 1.1 million unpaid carers in Scotland, of which 61% are women. This is an increase of 392,000 since the start of the pandemic, with 78% of carers having to provide more care than they were prior to the coronavirus outbreak. Since the start of the pandemic, a lot of carers lives have changed dramatically, as has the physical/mental health of the person they are caring for, the lack of day services and respite has resulted in real negative impact upon carers. A policy of supporting family carers is likely to help women, who are more likely to be carers and may have been doubly impacted from a loss of income (women were more likely to have been furloughed than men during the first wave of the pandemic), and extra caring responsibilities.</p>

Do you think that the policy impacts on women because of pregnancy and maternity?

No foreseen impact of these policies on women because of pregnancy and maternity.

Do you think your policy impacts on people proposing to undergo, undergoing, or who have undergone a process for the purpose of reassigning their sex? (the Equality Act 2010 uses the term ‘transsexual people’ but ‘trans people’ is more commonly used); or on people who are intersex or who have a variation in sex characteristics?

Transgender	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	<p>Supporting a skilled and knowledgeable workforce – benefit: Training would help staff to recognise instances of unlawful discrimination within healthcare/ care settings, including from other residents, and would ensure staff do not unlawfully discriminate against those with dementia in their care according to their gender identity. This would improve how comfortable trans people feel openly expressing their gender identity in care homes, hospital or healthcare settings and/ or when accessing support services. Evidence gathered during this equality impact assessment will be used to help develop specific training to ensure a skilled and knowledgeable workforce.</p>
Advancing equality of opportunity	<p>Supporting a skilled and knowledgeable workforce – benefit: This could help advance equality of opportunity for trans people by ensuring staff are aware of their specific needs, including the possible impact of cessation of hormones due to the onset of dementia (for trans people who have gone through a process of gender reassignment); or by encouraging trans people to feel comfortable being open about their gender identity with health and care staff. Targeted training is needed to realise this.</p> <p>Support for a timely diagnosis and post-diagnostic community support – barrier: For transgender people, widespread discrimination and poor experiences of healthcare can present significant barriers to help-seeking for dementia, including accessing diagnosis and post-diagnostic support. Trans people are more likely to live by themselves or to not have a partner. This can impact upon their diagnosis, as people living alone are less likely to have a timely diagnosis, as someone else is less likely to notice a change in their behaviour. Dementia plans have to acknowledge that trans people are still routinely pathologised.</p> <p>Living safely in a care home or living well at home – barrier: Personalised care plans are key to ensure people can express and recognise themselves, but the discrimination and lack of understanding in some environments limits these care plans being truly personalised for trans people with dementia. Care environments are still often unwelcoming environments for LGBT people and this needs to be addressed. Massive work is needed to ensure trans people feel safe expressing their gender identity in a care home, sheltered housing or acute care setting.</p> <p>Being part of the community - neutral: For many trans people, community will not be geographic, but rather about befriending or buddying with people from the wider trans or LGBT community. Some trans people have found themselves more included in their local community due to the local support offered by COVID-19, but others have not. Many people may have been shut off from a community that is geographically dispersed. Digital exclusion is still a big issue, as online connectivity excludes people further who can't deal with tech due to neuro-diverse challenges and technology accelerates beyond capabilities of older people in particular.</p>

Do you think that the policy impacts on people because of their sexual orientation?

Sexual orientation	Policy, Benefit/ Barrier/ Neutral and Reason
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<p>Eliminating unlawful discrimination</p>	<p>Support a skilled and knowledgeable workforce and service modernisation - benefit: Training would help staff to recognise instances of unlawful discrimination within healthcare/ care settings, including from other residents, and would ensure staff do not unlawfully discriminate against those with dementia in their care according to their sexual orientation. This enable lesbian, gay or bisexual people to feel more comfortable openly expressing their sexual orientation in care homes, hospital and/or healthcare settings and when accessing support services. Evidence gathered during this equality impact assessment will be used to help develop specific training to ensure a skilled and knowledgeable workforce.</p>
<p>Advancing equality of opportunity</p>	<p>Support a skilled and knowledgeable workforce and service modernisation – benefit: Lack of contact with outside support networks due to COVID-19 may be particularly distressing for those with dementia who are not ‘out’ to staff about their gender identity. Many LGB people say they would be uncomfortable with care home staff or paid carers knowing their sexual orientation. Training the workforce to be more knowledgeable and sensitive about sexual orientation will help ensure more LGB people with dementia feel more comfortable in health and care settings. Very few care homes identified that they had LGB people in their care when asked: more awareness is needed, but this requires tailored training for staff.</p> <p>Living safely in a care home – barrier: Psychological safety is important in care homes – LGB residents will have grown up in a different era, in which their sexual orientation was pathologised, meaning proactive action is needed for them to feel psychologically safe in this environment. Very few care homes identified LGB people in their care – more awareness is needed in the care residents receive. Massive work is needed to ensure LGB people feel safe expressing their sexual orientation in a care home, sheltered housing or acute care setting.</p> <p>Support for a timely diagnosis and post-diagnostic community support – barrier: Many LGB people are not ‘out’ to their GP and may be reluctant to engage with dementia and mental health services because of the history of LGB sexual orientations being pathologised, as well as ongoing prejudice in health and social care settings. This may present a barrier to LGB people accessing timely diagnosis and post-diagnosis support. LGB people are also more likely to live by themselves and to not have a partner. This may impact upon their diagnosis, as people living by themselves are less likely to have a timely diagnosis, as less likely to have someone else notice a change in their behaviour.</p> <p>Being part of the community - neutral: People who are LGB are more likely to live alone, be single as they age, not have children, and are less likely to be in regular contact with their biological family. Older LGB people may feel out of place in traditional dementia support groups and dementia cafes and may fear that others will react negatively if they talk openly about their partner or family of choice. For many LGB people, community will not be purely geographic, but rather about befriending or buddying with people from the wider community. Some LGB people will have found themselves more included in their local community due to the local support offered by COVID-19, but others will not have. Many people may have been shut off from a community that is geographically dispersed. Digital exclusion is still a big issue, as online connectivity excludes people further who can’t deal with tech due to neuro-diverse challenges</p>

	<p>and technology accelerates beyond capabilities of older people in particular.</p> <p>Support for family carers - barrier: LGB carers may be caring for family of origin or ‘family of choice’; be dealing with challenging birth family dynamics, assumptions around being single, having no dependents; lack of acceptance of LGB identity; find they are excluded as their relationship is not accepted by a partner’s biological family; face discrimination and assumptions when using services. Focusing only on family in a biological sense and failing to provide appropriate support for LGB carers further contributes to stress of carers who may already be experiencing financial, physical and emotional pressures. An LGB person who is caring for their partner with dementia may also face exclusion from decision making by their partner’s biological family in relation to formal care and end-of-life arrangements.</p>
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Do you think the policy impacts on people on the grounds of their race or ethnicity?

Race/ ethnicity	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	
Advancing equality of opportunity	<p>Improving the hospital experience - benefit: There is a need to make hospital settings culturally sensitive. The use of interpreters can be challenging as individuals may request the translator’s gender is the same as theirs. Improving the hospital experience would include greater awareness of these challenges and sensitivities.</p> <p>Supporting a skilled and knowledgeable workforce and service modernisation – benefit: Service providers are often overwhelmed when it comes to the needs of the general population, meaning the needs of marginalized communities often get overlooked, including people from minority ethnic communities. Service modernisation and ensuring a skilled and knowledgeable workforce could well improve the experiences of minority ethnic people with dementia and/or their carers, if this includes upskilling the workforce on the particular needs of minority ethnic communities and the potential barriers to them seeking or receiving necessary support.</p> <p>Support for a timely diagnosis and post-diagnostic community support – barrier: Research by the Life Changes Trust highlighted that Black and Minority Ethnic communities often have specific barriers to diagnosis such as very low levels of knowledge of dementia and the different forms it can take; very little understanding of diagnosis and prognosis; difficulties in obtaining a formal diagnosis; problems of accessibility and appropriateness of existing information materials; stigma of dementia leading to isolation and withdrawal from the community; difficulties in accessing support services, particularly as the condition worsened; the need to challenge assumptions about an individual’s ability to care as part of an extended family network and lack of accessible support services. All these present significant barriers to timely diagnosis and post-diagnostic support. Moreover, most cognitive tests are developed and standardized in one ethnic group, which may not transfer appropriately to another ethnic group due to culture, education, language or other factors. People from minority ethnic communities who experience dementia are less likely to present to services and tend to make contact at a later stage of the illness.</p>

	<p>Evidence from systematic reviews of qualitative research suggests that barriers to help/support-seeking for dementia are knowledge, society and/or healthcare related. Language barriers may contribute. There are also particular barriers for people of minority ethnic backgrounds, such as those from gypsy/ traveller communities accessing services, including around literacy, discrimination and a lack of knowledge around service provision or accessing services. All of these factors may act as barriers to people from minority ethnic backgrounds accessing a timely diagnosis and post-diagnostic support.</p> <p>Being part of the community – barrier: Community approaches to dementia differ according to specific cultural backgrounds. There may be barriers to community integration after diagnosis in some communities, which may prevent those diagnosed with dementia from being part of their community. People from minority ethnic backgrounds are generally less likely to feel they belong to their community: in 2018 72% of minority ethnic adults said they felt a very or fairly strong sense of belonging to their community, compared to 79% of adults from white ethnic groups.</p> <p>Palliative and end of life care – barrier: When planning for the future, some cultures may be more resistant to developing personal plans around end of life. There may be a lack of buy-in for the process of planning for end of life and bereavement. Some people of minority ethnic backgrounds can lack faith in the future and the services that would be available to them, due to previous experiences of poor service provision, and navigating the system can be very daunting.</p> <p>Support for family carers – neutral: In some cultures, it may be more common to regard caring as something to be kept within the family or seen as part of the role you take on as a relative or spouse, particularly for women, with paid support being seen as unsuitable. However, that can also mean public sector providers assuming, often incorrectly, that everyone from a minority ethnic community has strong community/ family support networks or can readily provide unpaid care. Support for family carers may particularly benefit those who are expected to support relatives or a spouse with dementia, but this may need to be particularly targeted or tailored to people from ethnic minority communities, including those who may have less trust in institutions. Research by MECOPP has shown specific barriers to carers from Gypsy/ traveller backgrounds accessing support, for example.</p>
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Do you think the policy impacts on people because of their religion or belief?

Religion or belief	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	
Advancing equality of opportunity	<p>Living well at home – benefit: For some religious communities, living in multi-generational households is more common, meaning a greater chance that the dementia patient will receive support at home for longer. Efforts to support those with dementia living well at home may be particularly beneficial to people of certain religious or cultural backgrounds.</p>

	<p>Supporting a skilled and knowledgeable workforce and service modernisation - benefit: It is not enough for staff just to know the basics of cultural awareness. Staff also need to be able to deal with dissonance and the fact that someone may no longer want certain things as their dementia progresses. The issue of autonomy and choice in times of change and transition becomes very important. A policy of supporting a skilled and knowledgeable workforce could help to ensure this, if it is properly targeted.</p> <p>Living safely in a care home, improving the hospital experience - barrier: A patient with dementia living in a care home or being treated in a hospital setting may struggle to explain their needs/ preferences for intimate care that relate to their religion and culture, for example a strong preferences for washing in running water (Hindu, Sikh, Muslim) or not having hair trimmed or cut (Sikh). This could act as a barrier to realising these policies.</p> <p>Palliative and end of life care – neutral: There are varying ways in which people approach bereavement and end of life according to religious differences, as NHS Scotland resources such as this show. Support should be sensitive to different end of life approaches according to religious beliefs, and aware of different beliefs and customs.</p> <p>Being part of the community – neutral: community approaches to dementia differ according to specific religious backgrounds or beliefs. In some faith communities, there may be barriers to integration in community after diagnosis related to taboos around dementia, while others may have specific services for people with dementia. For some cultural and religious minorities, there may be preferences for providing care within the community.</p>
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Do you think the policy impacts on people on other grounds?

Socioeconomic deprivation	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	
Advancing equality of opportunity	<p>Living well at home - benefit: COVID-19 has had a more negative impact on the most deprived in Scotland, which may prevent those with dementia who experience socioeconomic deprivation from living well at home, particularly as people in the most deprived areas were 2.1 times more likely to die of COVID-19 than those living in the least deprived areas. Measures to ensure everyone with dementia is able to live well at home will help those who are struggling most as a result of COVID-19's disproportionate impact (if properly targeted).</p> <p>Support for a timely diagnosis and post-diagnostic community support – barrier: This policy promotes “virtual” post-diagnostic support using a range of on-line tools and a promotion of mixed type of service for the foreseeable future. Socioeconomic disadvantage is a defining factor in digital exclusion and policies focused on virtual post-diagnostic support may limit the access of those from</p>

	<p>lower socioeconomic backgrounds.</p> <p>Preventing dementia – neutral: It is important to recognise the disproportionate economic impact of COVID-19 on the poorest, and the potential for this to disrupt work to prevent dementia.</p>
Rural/ remote location	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	
Advancing equality of opportunity	<p>Being part of the community – benefit: Efforts around befriending and buddying via community groups could help to include those from rural/ remote locations who may feel particularly isolated as a result of COVID-19, particularly where groups can be set up for people in these locations to meet safely and third-sector organisations can assist at the local level.</p> <p>Living well at home and support for family carers - barrier: Accessing the right technology for supported living is likely to be more challenging in a rural/ remote area, as there are many connectivity issues due to geographical remoteness. This causes frustration for the person with dementia and problems for their carer. Ensuring correct access to tech for people with dementia and their carers is key to ensure they can live well at home and that their family carers are supported.</p> <p>Support for a timely diagnosis and post-diagnostic community support - barrier: Virtual post-diagnostic support using a range of on-line tools and a promotion of mixed type of service for the foreseeable future is likely to exclude those who are already digitally excluded and rely on face-to-face services. Many of those in rural/ remote communities do not have good access to the internet, due to a lack of available tech or poor broadband connection. This makes it difficult for them to use technological alternatives offered in place of face-to-face services.</p>
Digital exclusion	Policy, Benefit/ Barrier/ Neutral and Reason
Eliminating unlawful discrimination	
Advancing equality of opportunity	<p>Support for a timely diagnosis and post-diagnostic community support – barrier: Virtual post-diagnostic support using a range of on-line tools and a promotion of mixed type of service for the foreseeable future is likely to exclude those who are already digitally excluded and rely on face-to-face services.</p> <p>Living well at home – barrier: The transition to digital during COVID-19 will have left behind those who are digitally excluded. Older people are also less likely to use the internet and digital devices than younger people, and digital exclusion may present a significant barrier to people with dementia living well at home, both during COVID-19 and beyond.</p> <p>Being part of the community – neutral: Efforts around befriending and buddying via community groups could help to</p>

	include those who are digitally excluded and are likely to feel particularly isolated as a result of COVID-19; however, this relies on alternative means than technology being used for these efforts. Otherwise, this would further exclude those without digital access.
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Stage 4: Decision making and monitoring

28. Based on the evidence gathered in stages 1, 2 and 3, this process has identified that commitments in the Dementia and COVID-19 National Action Plan will require attention to the issues identified in this EQIA, to ensure equitable implementation of the Dementia and COVID-19 National Action Plan.

29. It is expected that the actions proposed in the strategy will have a positive effect on a number of Protected Characteristics and other equality considerations. However, barriers to equitable provision of or access to some of these policies have been identified. It is important to take action to mitigate this, to ensure these policies are equally accessible and to the benefit of everyone with dementia, and to their carers.

Mitigating barriers to accessing these policies

30. As a result of the impact analysis, a sub-group has been created which will report back to the main national dementia group. This sits alongside a separate recommendation tracker from the National Advisory Group, on the Dementia and Equality report from Public Health Scotland.

31. Next steps include work to ensure that the policy implementation includes specific groups such as those with younger onset dementia, ethnic minorities and people with learning/ intellectual disabilities; as well as working with delivery partners to ensure they fully understand the equality impacts of this National Action Plan. Suggested next steps relating to the distinct equalities categories include:

32. **Age:** Policies for which barriers were identified according to age were: supporting a skilled and knowledgeable workforce and service modernisation; being part of the community; support for a timely diagnosis and post-diagnostic community support and living well at home.

33. In order to ensure these policies benefit people with younger-onset dementia as much as they do those who experience dementia later in life, work should be done to ensure the explicit inclusion of those with younger-onset dementia. This includes working closely alongside specific support groups such as the Stand Younger Onset Dementia Group in further developing and implementing these policies. Targeted support should be made available which takes into account the specific and differential needs of those with younger onset dementia, for example in claiming benefits where they lose entitlement or capacity to work. There should be work on removing the barriers for younger people to get a diagnosis of dementia and tackling misdiagnosis. For younger carers of people with dementia, efforts to signpost what financial help is available through the Scottish Young Carer Services Alliance or by setting this out on a blog post on the Young Scot young carer page will be explored with the carers team.

34. **Learning/ intellectual disabilities:** A number of barriers to accessing policies within this National Action Plan were identified for people with learning/ intellectual disabilities and dementia, or for their carers. These included barriers to policies around living well at home; being part of the community and support for a timely diagnosis and post-diagnostic support. In all areas of life citizens with a learning/ intellectual disability experience significant discrimination and prejudice. These attitudes are very likely to present a barrier to citizens with a learning/ intellectual disability having equal access to being part of the community. Likewise, the lack of high quality social care

support for people with learning/ intellectual disabilities may present a barrier to ensuring this group can live well at home. Diagnostic overshadowing is also a pronounced issue for people with learning/ intellectual disabilities, as is getting the right support post-diagnosis, as “mainstream” services may not be tailored to their needs.

35. In order to ensure these policies benefit people with learning/ intellectual disabilities and their carers, there should be a continuation of the coordinated work between the dementia and learning/ intellectual disabilities teams within the Scottish Government. Wider work around these two points should continue, including research into the impact of COVID-19 on people with learning/ intellectual disabilities and dementia in Scotland. These policies should be developed in coordination with learning/ intellectual disabilities stakeholder organisations and communicated through their networks, in an easy-read format – as with this National Action Plan itself. The policy around supporting a skilled and knowledgeable workforce and service modernisation should include better education for health and care workers around the complex needs of people with learning/ intellectual disabilities and dementia, including tailoring assessments pre-diagnosis.

36. Blind, Deaf, Deaf-blind, hard of hearing or deafened people: Barriers to accessing timely and linguistically/culturally appropriate diagnosis and post-diagnostic support, a policy of this National Action Plan, were identified for these groups. People belonging to one of these groups and who develop dementia often face additional challenges. Deaf people who sign BSL also have social, cultural and linguistic needs that can be unmet or overlooked, with their deafness being viewed solely as a medical condition or disability. Sensory loss may not be viewed as a priority for self-directed support assessment and diagnostic overshadowing may occur in which support is provided for the person with dementia, but their visual and/or hearing impairment is not properly identified and treated or supported.

37. Ensuring these barriers are removed will require close working with relevant stakeholder groups as these policies are developed and implemented, to ensure these policies are both accessible and affectual. In the short-term, care home staff should be aware of the exemption regarding staff wearing of masks for those who need to lip-read, or ensure use of clear masks if suitable. Adaptions and support should be in place – e.g. equipment, changes to the environment, clear communication strategies, the booking of interpreters and communication support, and other person-centred adjustments. In the longer-term, training and upskilling of staff will be key to ensuring a timely diagnosis and quality post-diagnostic support – this could mean ensuring there are more BSL-signing staff or developing a diagnostic toolkit around dementia diagnosis for those who are Deaf/BSL-signing; deafened or hard of hearing; or those who are blind or Deaf-blind, for instance.

38. Trans people: Barriers to accessing timely diagnosis and post-diagnostic support and living well at home or living safely in a care home, each a policy of this National Action Plan, were identified for trans people. The lack of data around the number of people with dementia who identify as trans presents a significant barrier to ensuring trans people benefit from these policies. Trans people report experiencing widespread discrimination and poor experiences of healthcare, which present significant barriers to trans people seeking medical help. Dementia may be pathologised for trans people, or changes in behaviour may be more likely to go unnoticed. The ongoing prejudice and discrimination trans people report experiencing in health and social care contexts presents a barrier to living well and safely at home or in a care home and places limits on ensuring psychological safety and the ability for trans people to be open about their identity.

39: Proactive actions are needed from the government and public bodies to seek information on prevalence of dementia amongst trans people. The Scottish Government is taking an important first step in this regard, by asking questions about gender identity on the next census. Efforts around the inclusion of trans people are required alongside these policies. These should focus on

concrete examples of best practice, such as guidance provided by Dementia Australia on [LGBTI and dementia](#), or the dementia cafes for LGBT people being run by Alzheimer's Society in England. It would be highly valuable to explore the possibility of replicating these resources and services in Scotland, with stakeholders such as Alzheimer's Scotland. Substantial and much wider work is needed to ensure trans people feel safe expressing their gender identity in a care home, sheltered housing or acute care setting; to end the pathologisation of trans people and to break down barriers to help-seeking for dementia.

40. Sexual Orientation: LGB people face barriers to accessing timely diagnosis and post-diagnostic support and to living well at home or living safely in a care home. Many of these barriers are similar to those detailed above.

41. As with above, proactive actions are needed by government and public bodies to seek information on prevalence of dementia amongst LGB people. The Scottish Government is taking an important first step in this regard, by asking questions about sexual orientation on the next census. Efforts around the explicit inclusion of LGB people are required alongside these policies. These should focus on concrete examples of best practice, such as guidance provided by Dementia Australia on [LGBTI and dementia](#), or the dementia cafes for LGBT people being run by Alzheimer's Society in England. It would be highly valuable to explore the possibility of replicating these resources and services in Scotland with organisations such as Alzheimer's Scotland. Wider work is required to ensure LGB people feel safe expressing their identity in a care home, sheltered housing or acute care setting and to break down barriers to help-seeking for dementia caused by a reluctance to engage with dementia and mental health services.

42. Race and ethnicity: There are several policies outlined in this National Action Plan for which there may be barriers related to race and ethnicity. Black and Minority Ethnic communities often have specific barriers to diagnosis and face barriers accessing necessary post-diagnostic support, once diagnosed. There are specific barriers to being part of the community due to community approaches differentiating according to cultural backgrounds, for instance, and approaches to palliative and end of life care may well also differ.

43. In order to ensure equitable access to these policies, investment in wider awareness-raising amongst communities about dementia and the services available (and amongst decision makers), as well as upskilling providers about delivering culturally appropriate and accessible service, should occur. There are several major reports which have been published which are incisive in their recommendations and should be drawn upon, such as the Scottish Government's report 'Improving the Lives of Scotland's Gypsy/Travellers (2019-2021)', which makes specific recommendations around improving access to public services and testing new ways to tackle health inequality in these communities. Other guidance should be disseminated, such as guidance produced by Alzheimer Europe, for health and social care workers, which calls for HSC workers to for e.g. provide people from different ethnic communities with culturally appropriate and understandable information about dementia and existing services and support. [The Life Changes Trust's publication](#) on their ethnic minority dementia carers project also makes useful recommendations which would help to ensure these policies benefit people from minority ethnic communities. There should be targeted efforts to ensure these policies benefit ethnic minority communities.

44. Religion and belief: Some of the barriers regarding race and ethnicity will intersect with those regarding religion and belief, given the overlap between faith and ethnicity in some instances. Two specific policies for which there may be barriers according to religion or belief concern living safely in a care home and improving the hospital experience. A patient with dementia living in a care home or being treated in a hospital setting may struggle to explain their needs/ preferences for intimate care that relate to their religion and culture.

45. As above, ensuring a policy around supporting a skilled and knowledgeable workforce and service modernisation – as promoted in this National Action Plan – gives staff more than just the basics of cultural awareness. This will be key to removing these barriers. Guidance is needed to prevent stereotyping: staff should be made aware of cultural and religious diversity while taking a person-centred approach.

46. **Socioeconomic deprivation, digital exclusion and rural/ remote location:** Socioeconomic disadvantage is a defining factor in digital exclusion and focusing virtual post-diagnostic support may limit the access of those from lower socioeconomic backgrounds. Barriers to living well at home and support for family carers may likewise arise for those who live in rural/ remote areas, due to connectivity issues and potential digital exclusion. Digital exclusion itself acts as a barrier to accessing these policies, with the transition to digital during COVID-19 having left behind those who are digitally excluded.

47. Any move towards virtual post-diagnostic support or diagnosis should be balanced out with a consideration of the needs of those who are digitally excluded. Where necessary and safe, practitioners should be supported to do home visits and phone calls should be offered as an alternative to video consultations. In the longer-term, work is being done by Connecting Scotland to address issues around receiving an internet connection and access to table devices. Digital connectivity is already being promoted by the Scottish Government via the Digital Health and Care Initiative: Connecting Scotland. This is likely to benefit both those facing socioeconomic disadvantage and those in rural/ remote areas, who are more likely to be digitally excluded. Addressing digital exclusion will enable better access to these policies, including improved home living through the use of smart technology for those with dementia.

48. Inclusivity and equality are at the heart of the National Action Plan's policies and as such the *Equality Impact analysis* has been a key driver in shaping how we intend to build upon, continue and expand the national action we have been taking since March to support people with dementia and their carers during the pandemic, and to strengthen the resilience of our communities across Scotland to recover through the complementary action of the NHS, local authorities and the third sector.

49. It should be reiterated that this EQIA applies to the National Action Plan's overarching policy proposals and that further *Equality Impact analyses* will be required for individual policies.

Monitoring and Review

50. It is intended that our progress in meeting the actions described in the Strategy will be **monitored and reviewed** regularly over the next 2 years and formally at 12 and 24 months post-publication. A sub-group has been created which will report back to the main national dementia group regularly and oversee this monitoring. Equality impact will be a key factor in measuring and determining our progress and as such will be fully scrutinised at these points.

Stage 5 - Authorisation of EQIA

Please confirm that:

◆ This Equality Impact Assessment has informed the development of this policy:

Yes X No

◆ Opportunities to promote equality in respect of age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation have been considered, i.e.:

- Eliminating unlawful discrimination, harassment, victimisation;
- Removing or minimising any barriers and/or disadvantages;
- Taking steps which assist with promoting equality and meeting people's different needs;
- Encouraging participation (e.g. in public life)
- Fostering good relations, tackling prejudice and promoting understanding.

Yes X No

◆ If the Marriage and Civil Partnership protected characteristic applies to this policy, the Equality Impact Assessment has also assessed against the duty to eliminate unlawful discrimination, harassment and victimisation in respect of this protected characteristic:

Yes No Not applicable X

Declaration

I am satisfied with the equality impact assessment that has been undertaken for Dementia and COVID-19 - The Scottish Government's response plan and give my authorisation for the results of this assessment to be published on the Scottish Government's website.

Name: Jacqueline Campbell

Position: Group Lead – Learning disabilities, autism and dementia

Authorisation date: 03/03/21



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