

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

**Summary of Equality Impact Assessment
Record**

March 2021

Summary Version of EQIA

1. This Equality Impact Assessment (EQIA) is for the Dementia and COVID-19 National Action Plan. This plan explains how the Scottish Government plans 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. Consensus on overall estimated dementia prevalence in Scotland is approximately 90,000 people currently living with dementia. Around two-thirds live at home with the remaining one-third living in residential care.
3. Dementia is most common in older people but can affect people in their 40s or 50s, or even younger.
4. The number of deaths from dementia including Alzheimer's disease rose by a quarter during the first wave of COVID-19 in Scotland. Dementia is also the most common underlying condition in people dying from COVID-19 in Scotland.
5. 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.
6. 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,

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- Foster good relations between people who share a protected characteristic and those who do not.

Step 1: Framing

7. The first step of the EQIA was to conduct a framing exercise regarding the protected characteristics considered.
8. Evidence was considered about a range of characteristics including age, disability, sex/ gender, sexual orientation, gender reassignment/ transgender, race or ethnicity and religion or belief.
9. Other characteristics were also considered, including socioeconomic inequality, digital exclusion and the impact of rural/ remote location, as these had a strong relationship to COVID-19's impact upon a person.
10. For age, one aspect discussed was the need to consider evidence about self-directed support.
11. For disability, two aspects discussed were being conscious of the language and data used, acknowledging where Scottish data was not available.
12. For sex/gender, two aspects discussed were the gender differences between men and women with regards to dementia diagnosis and the disproportionate impact of the pandemic on women.

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13. For sexual orientation, it was discussed that older lesbian gay and bisexual (LGB) people sometimes avoid using social care because of the discriminatory attitudes.
14. For transgender/ gender identity, the need to separate out sexual orientation from transgender identity was addressed, as was the need to use recent data.
15. For race and ethnicity, the need to be consistent in using terms such as 'BAME' and 'BME' was addressed, as was the need for sensitive language.
16. It was noted that much of the evidence regarding religion or belief overlaps with evidence on race and ethnicity.
17. For socioeconomic inequality, the need to find evidence about lockdowns and the impact of COVID-19 on people from lower socioeconomic backgrounds was stressed.
18. For rural/ remote areas, the removal of public transport during the first wave of the pandemic was noted.
19. It was noted that digital exclusion issues extend beyond remote and rural areas, as there can be connectivity issues due to limitations in providers.
20. The evidence gathering exercise outlined the necessity of conducting a full equality impact assessment on this plan, including external engagement.

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Stages 2 and 3: Evidence gathering and assessing the impacts and identifying opportunities to promote equality

21. This section focuses on the evidence gathered for each of the characteristics.
22. It also focuses on the potential impacts that the policies in this plan might have on each of the protected characteristics.
23. Evidence-gathering exercises did not raise any specific evidence in relation to Pregnancy and Maternity or Marriage and Civil Partnership.

Age

24. Older people are more susceptible to the severe negative health effects of COVID-19.
25. 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.
26. Over half of older unpaid carers provide 35 hours of care a week.
27. Though dementia is primarily an illness associated with this age group, it can also develop in younger people under the age of 65.

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28. An estimated 3,200 people in Scotland have younger onset dementia.
29. 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.
30. Those with younger onset dementia may face particular challenges around accessing, for example, SDS or employment benefits.
31. Younger carers may also face particular challenges when caring for people with dementia.
32. The policy of being part of the community may help to eliminate unlawful discrimination, harassment and victimisation, through befriending and buddying reducing discrimination based on age.
33. The policy of preventing dementia would likely benefit older people in particular, who are more likely to have dementia.
34. It was considered that support for family carers would likely benefit those older than 50 or over 65, as they are more likely to be carers.
35. Upskilling the workforce and modernising service is likely to benefit those under 65 with dementia, by making the workforce more knowledgeable about younger onset dementia.
36. A barrier to being part of the community was noted for those under 65 with dementia, who may have particular needs around financial

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support, childcare, employment and other matters.

37. A barrier to support for a timely diagnosis and post-diagnostic community support was noted for people with younger onset dementia, who are more likely to be misdiagnosed due to their age.
38. Barriers to living well at home were addressed for those with dementia under 65. This may relate to lack of knowledge about benefits entitlements, or stress around this, or to other needs.
39. The policy of being part of the community may foster good relations between people of different ages, as initiatives around befriending are likely to encourage those of younger age groups to build up contact with older people with dementia.

Disability

40. 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.
41. Many disabled people have reported that their social care support has been affected or reduced as a result of the pandemic.
42. 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.

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43. 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.
44. Many people with learning/ intellectual disabilities have found their social care provision reduced or changed as a result of the pandemic.
45. 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.
46. [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.
47. People with a learning/ intellectual disability or autism and dementia face particular challenges regarding dementia, including misdiagnosis.
48. 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

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misdiagnosis.

- 49.** Those who are Deaf/BSL users, deafblind, deafened, hard of hearing, blind or face sight loss and have dementia face particular challenges.
- 50.** 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.
- 51.** Likewise, many people with dementia also have hearing loss or deafness. Hearing loss is also considered to be a modifiable risk factor for dementia.
- 52.** These groups of people face additional challenges if they have dementia, including an increased sense of disorientation and risk of social isolation.
- 53.** Deaf-blind people may face misdiagnosis, due to significant communication barriers, social withdrawal and lack of trust in health and social care practitioners.
- 54.** The groups who attended the engagement session 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.

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55. Major obstacles to dementia diagnosis for BSL users were highlighted by the British Deaf Association.
56. [Glasgow Disability Alliance research](#) has reported that food insecurity for those with sensory loss, deafness or blindness was worsened during COVID-19.
57. Supporting a skilled and knowledgeable workforce and service modernisation was outlined as eliminating unlawful discrimination, harassment and victimisation, both for BSL users and people with learning/ intellectual disabilities.
58. A barrier to being part of the community was identified for people with learning/ intellectual disabilities, as they will often experience significant discrimination and prejudice.
59. The lack of high quality social care support for people with learning or disabilities may present a barrier to realising the policy of living well at home.
60. Support for family carers is likely to benefit disabled people with dementia and their carers, helping to recognise and ease the burden that this pandemic has placed on them.
61. Preventing dementia is likely to benefit those with a visual impairment or facing hearing loss. These aspects relate to social isolation, which can contribute to or worsen dementia.

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62. Targeted efforts to focus on preventing dementia amongst those who are Deaf-blind would be of particular help.
63. Those with hearing loss and dementia are doubly susceptible to social isolation. Lockdown has worsened this and efforts to ensure these people are part of the community could benefit them.
64. Those with a learning/ intellectual disability and dementia may also be particularly at risk of social isolation during lockdown. Efforts to ensure these people are part of the community could benefit them.
65. Using technology can make a huge difference to keeping someone with a learning/ intellectual disability and dementia at home. A policy of living well at home is likely to benefit them.
66. Using technology can make a huge difference to keeping someone with sight or hearing loss, or who is blind, Deaf, deafened or Deaf-blind, and who has dementia, at home. The living well at home policy could benefit them.
67. A third of those with learning/ intellectual disabilities who have died from COVID-19 lived in residential care homes. A policy of ensuring safety in care homes could help ensure people with learning/ intellectual disabilities and dementia are properly protected.
68. Supporting a skilled and knowledgeable workforce and service modernisation could benefit people with a disability and dementia by making the workforce more attuned to and reflective of their needs.

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- 69.** A policy of improving the hospital experience could help prevent people with a learning/ intellectual disability and dementia being inappropriately prescribed a medicine.
- 70.** Barriers to support for a timely diagnosis and post-diagnostic support may exist for people who are deaf, deafened, blind, deaf-Blind, partially sighted or hard of hearing. They may be misdiagnosed or not have the support they need for a diagnosis, such as BSL translator. They may not receive a proper support package through self-directed support, due to an improper assessment.
- 71.** Barriers to support for a timely diagnosis and post-diagnostic support may exist for people who have a learning/ intellectual disability, as 'mainstream' services may not be tailored to their needs.
- 72.** There is not enough evidence to say whether targeted efforts at preventing dementia would be successful at reducing the higher risk of dementia for people with a learning/ intellectual disability.

Sex

- 73.** Women are at greater risk of dementia due to slightly longer life expectancy at a population level. Targeted efforts at preventing dementia are unlikely to change this.
- 74.** Women are also more likely to be social care clients, both in long-stay care homes and at home, due to longer life expectancy.

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- 75.** Women are also more likely to be unpaid carers than men in Scotland.
- 76.** 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.
- 77.** 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.
- 78.** Women have also been disproportionately affected by the economic impact of the pandemic, which has compounded difficulties around caring responsibilities.
- 79.** At the engagement event stakeholder representing carers organisations noted an assumption that unpaid carers do not have another role, even though a significant number have another paid job.
- 80.** A policy of support for family carers is likely to benefit women in particular.

Gender Reassignment/ Transgender

- 81.** There is a lack of evidence regarding transgender people with dementia in Scotland.
- 82.** At the engagement event it was noted that data collection around the transgender identity of those with dementia does not occur,

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rendering this group invisible.

- 83.** 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.
- 84.** 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.
- 85.** Stonewall Scotland [has reported](#) that almost two in five trans people (37 per cent) avoid seeking healthcare for fear of discrimination from staff.
- 86.** For older transgender people in particular, discrimination is something that is likely to have affected many aspects of their life.
- 87.** At the engagement event it was argued that explicit inclusion is needed to actively include transgender people with dementia.
- 88.** Supporting a skilled and knowledgeable workforce could help eliminate unlawful discrimination against trans people and prevent this discrimination from staff. Training would help staff to recognise instances of unlawful discrimination within healthcare/ care settings.
- 89.** This policy could help advance equality of opportunity for trans people by ensuring staff are aware of their specific needs and making transgender people feel more comfortable disclosing their identity in a

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health or care setting.

90. Widespread discrimination and poor experiences of healthcare can present significant barriers to transgender people seeking help for dementia, including accessing diagnosis and post-diagnostic support. This would act as a barrier to this policy.
91. Discrimination and lack of understanding in some environments may limit care plans being personalised for trans people with dementia. This would limit their access to the policies of living safely in a care home or living well at home.
92. For many trans people, community will not be geographic, but rather about befriending or buddying with people from the wider LGBT community.

Sexual orientation

93. Many of the same issues around prejudice and discrimination which impact upon transgender people also impact upon lesbian, gay and bisexual people (LGB people).
94. 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.
95. [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

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health and social care settings.

- 96.** Many LGB people say they would be uncomfortable with social or healthcare providers knowing their sexual orientation.
- 97.** For many older LGB people, the legacy of criminalising sexual orientation for LGB people remains. This prevents these people from seeking help for dementia.
- 98.** There are particular challenges for LGB people with dementia and their carers. For example, they may face assumptions, discrimination or a lack of acceptance.
- 99.** At the engagement event, the difficulties being counted that LGB people with dementia face were noted. This is due to the lack of data gathered on LGB people with dementia.
- 100.** Stonewall noted that Alzheimer's Society have resources on LGB people with dementia, which could be used. Reminiscence groups could be adapted.
- 101.** Supporting a skilled and knowledgeable workforce and service modernisation would help staff to recognise instances of unlawful discrimination within healthcare/ care settings and prevent this discrimination from staff. This would eliminate unlawful discrimination against people on the basis of their sexual orientation.
- 102.** Training the workforce to be more knowledgeable and sensitive about sexual orientation would help ensure more LGB people with

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dementia feel more comfortable in health and care settings.

- 103.** There are barriers to living safely in a care home for LGB people. Work is needed to ensure LGB people feel safe expressing their sexual orientation in a care home, sheltered housing or acute care setting.
- 104.** There is a barrier to support for a timely diagnosis and post-diagnostic community support for LGB people. Many LGB people are not 'out' to their GP and may be reluctant to engage with dementia and mental health services.
- 105.** A policy of being part of the community may or may not benefit LGB people. For many LGB people, community will not be just geographic, but about befriending or buddying with people from the wider community.
- 106.** A barrier to the policy of support for family carers may exist for LGB people. This is because LGB carers may be caring for family of origin or 'family of choice'; may face assumptions or be excluded from caring decisions. Focusing on family in a biological sense may exclude LGB carers.

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Race

- 107.** 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.
- 108.** 2013 evidence suggests that dementia is more common amongst minority ethnic communities.
- 109.** 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.
- 110.** 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.
- 111.** Evidence suggests that barriers to seeking help for dementia are knowledge, society and/or healthcare related. Language barriers may also contribute.
- 112.** People from minority ethnic communities with dementia, or who are unpaid carers for those with dementia, may have specific needs.
- 113.** They may facing specific challenges relating to cultural attitudes around dementia, or to stereotypes or assumptions from health and social care providers.

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- 114.** Stakeholders at the engagement event highlighted that employers have an important role to play in delivering inclusive services and being culturally aware.
- 115.** Improving the hospital experience is likely to advance equality of opportunity as this would entail making hospitals more culturally sensitive.
- 116.** Supporting a skilled and knowledgeable workforce and service modernisation is likely to advance opportunity of equality by making the workforce more aware culturally sensitive and aware of the particular needs members of minority ethnic communities may have.
- 117.** [Research by the Life Changes Trust](#) highlighted that Black and Minority Ethnic communities often have specific barriers to diagnosis and accessing post-diagnostic support, such as dementia awareness, language barriers, stigma, or inaccessible materials. These may act as barrier to ensuring support for a timely diagnosis and post-diagnostic community support.
- 118.** Community approaches to dementia differ according to specific cultural backgrounds. For some, there may be barriers to community integration after diagnosis, which may prevent those diagnosed with dementia from being part of their community.
- 119.** 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. This may act as a

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barrier to accessing palliative and end-of-life care.

120. 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. However, that can also mean public sector providers assuming incorrectly, that everyone from a minority ethnic community can readily provide unpaid care. Different approaches and assumptions may act as a barrier to this policy for people of minority ethnic backgrounds.

121. Research from MECOPP has highlighted particular issues Gypsy/ Traveller carers for people with dementia face, such as community isolation or a lack of knowledge around carers' entitlement.

Religion or Belief

122. Religion or belief can intersect with race and ethnicity.

123. There may be similar challenges according to a person's religion or belief, around cultural perceptions or awareness of dementia; differing approaches or stereotyping and assumptions.

124. Faith and cultural norms can impact all aspects of dementia care in all settings.

125. Many faith communities have developed specific resources or services to support people with dementia.

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- 126.** 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 people to live well at home may advance equality of opportunity through benefiting these families.
- 127.** Supporting a skilled and knowledgeable workforce and service modernisation would advance equality of opportunity through moving beyond the basics of cultural awareness.
- 128.** 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. This may act as a barrier to the policies of improving the hospital experience and living well in a care home.
- 129.** 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. Palliative and end of life care should take this into account to ensure equality of opportunity.
- 130.** Community approaches to dementia differ according to specific religious backgrounds or beliefs. A policy of being part of the community would need to recognise this.

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Other grounds – socioeconomic deprivation, rural/ remote, digital exclusion

131. There is limited evidence to date that suggests that dementia is socially patterned.

132. The pandemic has had a greater impact upon Scotland's poorest families financially.

133. [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.](#)

134. Socioeconomic inequality intersects with other issues, such as digital exclusion.

135. Addressing the digital divide has been highlighted as key to reducing health inequality.

136. COVID-19 has seen an increasing move towards digital services, in social care, healthcare and general settings.

137. 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.

138. The move to digital services may not be suitable for many people with dementia or their carers.

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139. Obstacles to digital access were outlined by People First Scotland at one engagement session, including availability and training gaps.
140. [Connecting Scotland](#) (CS) is working to lack of devices, lack of affordability and lack of competence for people.
141. COVID-19 has had a differential impact on those within rural or remote locations who have dementia or care for someone who does.
142. Access to a good broadband connection may be limited for those in rural/ remote locations.
143. In some rural or remote areas there has been an almost complete withdrawal of public transport during some periods of the pandemic.
144. Home deliveries may be more costly or difficult for those living in a rural or remote area.
145. At the engagement event, stakeholders expressed concern about there being too few dementia services in remote areas.
146. COVID-19 has had a more negative impact on the most deprived in Scotland. A policy focused on living well at home may help those who have been most materially affected by COVID-19.
147. Socioeconomic disadvantage is a defining factor in digital exclusion and policies focused on virtual post-diagnostic support may limit the access of those from lower socioeconomic backgrounds.

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- 148.** 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.
- 149.** A policy centred on being part of the community could help include those from rural/ remote locations who may feel particularly isolated as a result of COVID-19.
- 150.** 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 may present a barrier to policies of supporting family carers and living well at home.
- 151.** The same barriers exist for those who are digitally excluded, though they may not live in a rural or remote location.
- 152.** Virtual post-diagnostic support is likely to exclude those who lack digital access and rely on face-to-face services.
- 153.** Efforts around befriending and buddying via community groups could help to include those who are digitally excluded and are likely to feel particularly isolated as a result of COVID-19, if technology is not relied upon.

Stage 4: Decision Making and Monitoring

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154. Based on the evidence gathered, attention is required to the issues identified in this EQIA.

155. It is expected that the actions proposed in the strategy will have a positive effect on a number of equality considerations. However, barriers to accessing or equally applying some of these policies have been identified.

Mitigating Barriers

156. As a result of the impact analysis, a sub-group has been created which will report back to the main national dementia group.

157. Next steps include work to ensure that the policy implementation includes specific groups.

158. 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.

159. 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. Policies should be developed in coordination with relevant stakeholder organisations.

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- 160.** Ensuring barriers for blind, Deaf, Deaf-blind, hard of hearing or deafened people 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.
- 161.** Proactive actions are needed from the government and public bodies to seek information on prevalence of dementia amongst trans people. Efforts around the inclusion of trans people are required alongside these policies.
- 162.** Proactive actions are also needed by government and public bodies to seek information on prevalence of dementia amongst LGB people and to include them.
- 163.** Investment in wider awareness-raising amongst communities about dementia and the services available is needed. Upskilling providers about delivering culturally appropriate and accessible service should occur. There are useful recommendations to follow from third-sector organisations and guidance which can be disseminated to ensure better dementia care for minority ethnic communities.
- 164.** Ensuring a policy around supporting a skilled and knowledgeable workforce and service modernisation gives staff more than just the basics of cultural awareness. This will be key to removing these barriers.

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- 165.** Consideration of virtual post-diagnostic support or diagnosis should be balanced out with a consideration of the needs of those who are digitally excluded.
- 166.** Work is being done by Connecting Scotland to address issues around receiving an internet connection and access to table devices.
- 167.** Inclusivity and equality are at the heart of the National Action Plan's policies. The *Equality Impact analysis* has been a key driver in shaping our continued work.
- 168.** This EQIA applies to the National Action Plan's overarching policy proposals. Further *Equality Impact analyses* will be required for individual policies.

Monitoring and Review

- 169.** Our progress in meeting the actions described in the Strategy should be **monitored and reviewed** regularly over the next 2 years. Formal reviews should happen 12 and 24 months after publication.



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