

# Response to the Scottish Government and COSLA Digital Strategy Consultation Document.

## Renewing Scotland's Full Potential in a Digital World: Updating the Digital Strategy for Scotland, December 2020

About Dementia is a five-year project, funded by Life Changes Trust and hosted by Age Scotland. We bring together people affected by dementia with professionals in the public and third sectors to influence change around policy and practice in Scotland.

This response relates to the following questions of the consultation:

1. *Do you think there are opportunities to realise this collaborative approach? Yes / No Please explain why:*
2. *Of the opportunities which you have identified, which do you think are the priority ones?*
3. *Is the vision that we have set out in the supporting narrative of each of these sections the right one? Yes / No  
If you have ticked 'no' or you think we could improve the vision please explain why:*
4. *Do you think that the potential actions set out in each section will deliver the vision set out in the supporting narrative? Yes / No  
If you have ticked 'no' or you think we could improve the actions phase please explain why:*
5. *Are there any of the potential actions more important than others? Yes / No  
Please explain why:*
6. *How realistic do you think it will be to deliver these potential actions?  
Please explain why:*
7. *Is there anything else you wish to comment on that has not been covered elsewhere?*

Throughout our response to this consultation, we will make it clear that the digital world cannot and should not replace real human interaction. Whilst there are opportunities which may maximise the impact of the digital strategy, the Scottish Government should accept that for many people living with dementia the transition to a digital world is neither pleasant nor desirable. For some people, their dementia diagnosis will prevent them from living in a digital world. As the pandemic has progressed, members of About Dementia have shared feeling scared that digital interaction will replace human connection. We do not feel the vision alleviates the concerns of our About Dementia members, neither does the strategy fully explain how it will support those who cannot or refuse to engage with the digital world.

### **Opportunities to realise a collaborative approach to the Digital Strategy**

We believe there are some opportunities in which the collaborative approach laid out in the Digital Strategy could positively impact the lives of people living with dementia and the unpaid carers of people living with dementia. In particular, we recognise the benefit of adopting common digital and data standards, allowing services to share data with each other. By embedding the Scottish Approach to Service Design, we understand the strategy aims to reduce duplication and save time for both services and the individual.

This is especially important to unpaid carers of those living with dementia who find their time is diverted from their caring role by the amount of duplicated paperwork that is required. One unpaid carer confided to About Dementia that they regularly spent their allocated two hours of respite a week hand-delivering documents to their local authority after paperwork was repeatedly lost. Commenting on the amount of administration involved, the same carer expressed, “All the time and energy should have been spent with my mum ... I feel a loss for that time and focus”.

The proposed digital identity service may improve the fragmentation of services that About Dementia members regularly experience. A digital identity service would also allow new ways of sharing between health and social care. However, we believe a collaborative approach can only be achieved by sharing relevant information with third sector care providers, such as day centres, who have often been overlooked in terms of information access. The third sector responded flexibly and fast during the pandemic and their contributions to providing social care have been identified as one of the biggest strengths of the social care system (ALLIANCE, 2020). Despite this, third sector care providers do not automatically have access to information which may assist them in their care, such as other care package details or medication currently taken. These details can only be obtained by seeking it from health and social care professionals directly or by asking an unpaid carer to relay the information again to each service.

The current approach relies solely on people living with dementia or unpaid carers of people living with dementia to update third sector care providers when there is a change to home life or medication. This approach could allow updates to go unnoticed, increasing the risk of potential harm and placing the burden of administration again on unpaid carers or the individual living with dementia. We submit that the digital strategy could support an opportunity to demonstrate value and respect for the role of the third sector as a partner in the provision of care.

### **Opportunities identified as a priority of the Digital Strategy**

We maintain that the opportunity which will have the greatest positive impact for people living with dementia and the unpaid carers of people living with dementia will be the increased ability of data sharing between public and third sector services. The benefit of reduced duplication and saved time will be allowing unpaid carers to spend more quality time with the person they support or enjoy respite from their role. We also welcome the changing ways to submit documents, such as uploading paperwork from home and ask that unpaid carers are supported to do the same. However, in 2018 Citizen Advice Scotland found around half of the people they support could not download, complete, save or upload electronic forms independently (CAS, 2018). Therefore, we add that appropriate training must be given if the older people we support are to utilise this development and benefit from the time-saving potential.

Elements of the digital strategy could free unpaid carers from the burden of bureaucracy, but only if considered alongside a review of Adult Health and Social Care. Unpaid carers who use Self-Directed Support have shared with us that despite the lack of training they have been given in regard to using SDS, they have been penalised for submitting paperwork incorrectly (About Dementia, 2020). In addition, unpaid carers have reported feeling exhausted by the level of organisation required (Ramasawmy,

2016). There is a lack of empathy in the demands placed upon unpaid carers utilising SDS and About Dementia members have expressed getting “flexibility was a battle, too much rigidity”. While it is of course important to account for public funds, the lengths required of unpaid carers and social care users are often disproportionate to the sums they receive, and the penalties are punitive. In our engagement with unpaid carers of people living with dementia they have been vocal about their need to be treated as equal partners in care. The streamlining of administration alone does not afford unpaid carers or people living with dementia more fluidity in their care packages, nor does it educate professionals in the lived experience of those affected, and therefore the proposals in this strategy form only part of a wider picture.

### **Improving the vision set out in the Digital Strategy for people living with dementia and the unpaid carers of people living with dementia**

Older adults are part of the most digital excluded group in the UK (Age UK, 2018). Following on from this, older adults make up 40% of those in the UK with low digital and low financial capacity (Lloyds Bank, 2018). This exclusion is even more prevalent in Scotland, which has the highest percentage of those with low digital and financial capability (Lloyds Bank, 2018). Whilst the digital strategy has been comprehensive, we feel an appreciation of how alienating this move will be for people living with dementia has been overlooked. Our members are already afraid that technology will replace human interaction and the digital strategy detailed does little to reassure them. When asked about creating dementia-friendly communities in Scotland, 68% of Age Scotland members ranked combatting loneliness as very important to them, and we are apprehensive that the move to online will further compound isolation (Age Scotland, 2018). The same survey found that closures of banks and post offices were a significant barrier to creating dementia-friendly communities. It's understandable that people living with dementia and unpaid carers feel a digital strategy could further reduce the limited opportunities for face-to-face interaction. Whilst we accept that businesses have made some effort to replicate their service online, it's unrealistic to consider the online service as a suitable replacement for the people we support, taking into account that the over 65's make up 76% of those with zero basic digital skills (ONS, 2019).

We recognise that attempts have been made to include this digitally excluded group by the Digital Champion initiative and the availability of online training. However, the Digital Champion may fail to impact those who will be most isolated by digital advancement, those with no family support or prior involvement with services. Isolation due to digital exclusion has been only been further amplified by the pandemic. Therefore, the challenge in meaningful virtual engagement with the dementia community during and in the aftermath of the pandemic cannot be underestimated.

We have experienced our own challenge in reaching people living with dementia virtually, despite our best efforts. Issues surrounding digital engagement can be complex, and the strategy may require further consideration if it is to fully address the barriers involved. There are various obstacles to connecting online be that an unease of the digital world, lack of basic digital skills or the sensory overload that online interactions can induce. We believe that entering the digital world should be choice which takes into consideration the Human Rights of people living with dementia, primarily the right not to be treated in a degrading or inhuman way, and the right not to be discriminated. It is our fear that the move to digital could lead to sub-standard and

insensitive communication with people living with dementia. People living with dementia can struggle to find dementia-friendly public health information and many attending our meetings have suggested audio versions of information would be a valuable supplement. Therefore, we recommend that the digital strategy incorporates simplified web pages and audio versions of public health information to include those living with dementia.

The pandemic has forced everyone to adapt their approach and move more firmly into the digital realm to retain connection. Our project has been no different and we have striven to offer flexible ways of interaction, either by telephone, email or, prior to the pandemic, face to face meetings. We encourage the Scottish Government to take a similarly adaptive approach towards continuing to ensure a plurality of points of contact and engagement beyond the digital world in order to maintain a meaningful impact for people living with dementia and the unpaid carers of people living with dementia.

### **Exploring how the potential actions set out in the Digital Strategy could deliver the vision for people living with dementia and the unpaid carers of people living with dementia**

About Dementia holds the view that despite the barriers that some people living with dementia may have in accessing the digital world, there is still opportunity for our members to benefit from technology. However, if the vision set out in the digital strategy is to have a meaningful impact to people living with dementia then the role that health and social care and third sector should be carefully considered as part of this process.

We welcome the plans to develop a public centre of excellence for process automation which aims to reduce the need for staff to undertake repetitive administration tasks. We recognise that efficient digital processes could lead to the reduction of paperwork for frontline staff and create extra capacity for services. Although, it would be beneficial to have more clarity as to how the extra capacity will be utilised. We hope that the extra capacity will be used to address the length of time older people in Scotland wait for care packages, with 43% of older people assessed as having critical or substantial needs waiting longer than the 6 weeks outlined in the National Eligibility Criteria (Age Scotland, 2019).

For people living with dementia who live alone, it is possible to imagine how digital technology could be of benefit but only alongside a package of support which incorporates access to the digital world as an essential part of care. By utilising Self-Directed Support, people living with dementia could be supported by paid carers who aid digital citizenship by assisting and enabling online connections as part of their home visits. If it is identified as an outcome by the individual living with dementia, extra capacity could be distributed by adopting a person-centered approach which aims to improve quality of life. In doing so, the individual living with dementia could be assisted to rediscover music from their past by building personal playlists, aided to order online groceries or helped to facilitate video calls with family members or friends, if those actions were put forward as being important to the person. The later possibility could be life-changing for the people we support as 14% of over 55's recently reported fearing they have lost friends forever during the pandemic as a result of not being able to visit

them (Santander, 2020). However, as we have noted, the degree to which people living with dementia will benefit from the digital strategy will depend upon how the extra capacity created by effective digital processes will be made use of in practice.

Whilst there are clear ways for the quality of life of people living with dementia to be enhanced by the support to digitally engage, considering the current climate of dementia care, it's difficult to conceive the advantages of a digital world being felt by people living with dementia in the coming years that will follow the pandemic. In response to our Covid-19 impact survey, unpaid carers spoke of the increasing the level of support that they were expected to provide as home care visits were reduced, or altogether stopped (About Dementia, 2020). Likewise, the recent Independent Review of Adult Health and Social Care in Scotland detailed the very limited time that paid carers have to spend with people (ALLIANCE, 2020). This was echoed during one of the engagement events in which a professional shared the story of a person living with dementia who went without food because the microwave meal in their fridge could not be cooked within the allocated 15-minute timespan of their home care visit (ALLIANCE engagement event, 2020). We present this example to show that very basic needs and human rights for people living with dementia and the unpaid carers of people living with dementia are still failing to be met in 2020. As a result, we are concerned that talk of a digital strategy may appear irrelevant to the lives of people living with dementia and the unpaid carers of people living with dementia, and at worst, could be interpreted as potentially insulting to their current everyday struggles. We therefore appreciate and respect the challenges that the digital strategy will have in appealing to with lived experience of dementia. To improve the chance of inclusive and effective engagement, we propose that people living with dementia and the unpaid carers of people living with dementia are consulted throughout the development of the digital strategy. We ask that consultation is approached sensitively and understands the context of wider adult health and social care. To do so, we suggest consultation that focuses first on aiding the actualisation of primary needs, before promoting secondary advantages that the digital strategy may offer.

### **Potential actions which may be more important than others**

About Dementia upholds that for people living with dementia and the unpaid carers of people living with dementia increased community engagement and participation will be the most important action, in particular the aim of promoting wellbeing. However, as laid out in our response to question 3, we do not feel that the complexity of digital engagement with people living with dementia has been properly taken into account. Equally, the barriers to engagement of unpaid carers of people living with dementia must also be considered in their own right. Caring can limit the amount of time and energy an unpaid carer has to engage, and this is especially pertinent in regard to availability or motivation for digital training.

Without sensitive and accessible engagement with the dementia community, the digital strategy could alienate the 90,000 plus people living with dementia in Scotland (Scottish Government, 2017). In addition, there is a risk that unpaid carers and people living with dementia who are not already in contact with services may become altogether invisible in a digital world.

For these reasons, we stress the importance of unpaid carers, third sector and health and social care to be considered as equal partners in care, and for all to be included in developing a digital strategy which positively impacts people living with dementia and the unpaid carers of people living with dementia. By working in collaboration and sharing common digital and data standards, it may be possible for digital mechanisms to be put in place which alert the appropriate services should unpaid carers or people living with dementia fall through the gaps of support.

### **Achieving a realistic and meaningful impact for people living with dementia and the unpaid carers of people living with dementia**

We recognise that the document does provide digital opportunities which may lead to an improvement of quality of life for people living with dementia and the unpaid carers of people living with dementia. However, to achieve a realistic and meaningful impact we ask that the barriers faced by people living with dementia and unpaid carers are sensitively and thoroughly considered in the wider context of adult health and social care.

We would argue that for people living with dementia and the unpaid carers of people living with dementia to benefit from the potential actions detailed, the digital strategy should work in partnership with health and social care. The transformation that the digital strategy offers could be a valuable opportunity for health and social care to incorporate a more person-centered approach in their administration processes. For unpaid carers or those living with dementia the adoption of digital technology will have a better chance of success if promoted alongside adequate support which is based on the 'whole life approach to dementia' (Life Changes Trust, 2018). There cannot be one size fits all approach when it comes to digital inclusion, and people living with dementia should be assisted to understand the potential of digital in improving quality of life.

We put forward that post-diagnostic support would be the most effective time for any digital strategy intervention. This approach could come at a pivotal moment for professionals to work with the individual diagnosed to capture their digital preferences with the purpose of maintaining what is important to the person. The individual living with dementia could consent to who their information may be shared with at a later date. The person living with dementia could also be supported to incorporate technology into their care plan, such as regular video calls to family members. The idea of a written technology plan which captures individual preference has already been well received as part of About Dementia's Technology Sub-Group for people living with dementia.

If elements of a digital world are to be embedded into a person living with dementia's life it has to be done with the individual, aiding them to understand the potential of digital to sustain independence and relationships. Any extra capacity released by efficient digital processes should ideally be redistributed to directly improve quality of life for people living with dementia and should not be used as an opportunity to cut costs. About Dementia members speak of the loss that is felt by a dementia diagnosis in terms of friendships and ability. Human interaction should not be added to that list. Instead, we believe the only digital strategy that would be of benefit to people living with dementia should focus on what can be maintained by digital technology or gained by additional capacity.

### **Other comments which have not been covered elsewhere**

The document proposed that a digital democracy could be enabled through the use of technology, stating this may enable parliamentarians and elected council members to engage with their constituents. We recommend that the potential for people living with dementia and the unpaid carers of people living with dementia to become more involved in politics or activism should also be highlighted. Despite this year's challenges, About Dementia has been able to facilitate meetings with people living with dementia and unpaid carers from all over Scotland. Many unpaid carers have highlighted the benefits of engaging remotely, such as decreased travel time and improved peer-to-peer support. The digital strategy overlooks how empowering a digital democracy could be for people, if supported properly. Following from this, we would also like to see the incorporation of peer-to-peer support as part of any digital strategy. This is of particular importance for the people we support who have told us they would trust and value technology advice more from someone with lived experience of dementia or caring.

Lastly, we would advise that people living with dementia and the unpaid carers of dementia are consulted in order to appreciate the value of human interaction in public services. We are concerned that the use of language in the document may be alienating, in particular; "We will ensure that face-to-face services continue to be provided when they are necessary and enhanced, where possible, by technologies that support staff with local decision making and service delivery".

In response to our Covid-19 survey, unpaid carers and people living with dementia noted anxiety, loneliness and deterioration of dementia symptoms as impacts of the pandemic, and there is fear that digitalisation will exacerbate these effects (About Dementia, 2020). It will be hard for anyone who lacks lived experience of dementia to determine how necessary and important human connection can be in improving quality of life or easing carer stress. We believe consultation with people living with dementia and the unpaid carers of people living with dementia will contribute an insight into the effects of digital exclusion. Perhaps of equal importance, we hold the view that consultation will also alleviate concerns being left behind, and reassure people living with dementia that their voice is valid in the development of the digital world.

For some people living with dementia, it is a reality that they may never be able to fully access the digital world. It should be considered that attempts to interact digitally may cause further distress. We suggest that any digital strategy proposed offers an alternative to the digital world which details how people unable to engage digitally should be supported and advocated for. If alternative support will be delivered as part of the digital strategy, we urge the Scottish Government to share how they would plan to do so and to ease the anxiety of people living with dementia and the unpaid carers of people living with dementia.

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## **Links to About Dementia Evidence**

### **Policy Reports**

About Dementia (2020) Submission to the Independent Review on Adult Social Care in Scotland, October 2020. Available at: [Submission\\_to\\_Independent\\_Review\\_About\\_Dementia\\_November\\_2020.pdf](#) (mcusercontent.com)

About Dementia (2020) Locked Down but not Forgotten: Covid-19 Impacts and Survey Findings. Available at: [locked-down-but-not-forgotten-about-dementia-report-sept-19.pdf](#) (ageuk.org.uk)