Alzheimer Scotland

Health and Sport Committee – Technology and Innovation in the NHS

Introduction

Alzheimer Scotland is Scotland's leading dementia voluntary organisation. We work to improve the lives of everyone affected by dementia through our campaigning work nationally and locally, including facilitating the involvement of people living with dementia in getting their views and experiences heard. We provide specialist and personalised services to people living with dementia, their families and carers in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.

Alzheimer Scotland's response is primarily focused on technologies, both established and emergent, which have the potential to benefit people with dementia, their families and carers. This submission is broken down into the following sections:

- Scottish Government vision for Digital Health and Social Care 2017-2022.
- Technology Charter for People Living with Dementia.
- Challenges in health and social care.
- Opportunities for the use of technology.
- Considerations when using technology.

Scottish Government vision for Digital Health and Social Care 2017-2022

Alzheimer Scotland believes that the vision set out is broadly agreeable but limited in scope. We believe that the 'I' statements developed are helpful as they reflect that the strategy must primarily have consideration for the needs and wishes of individuals using health and social care services, whilst also being consistent with other health and social care policy drivers, including the new national health and social care standards.

The final vision statement (*digital technology and data will be used appropriately and innovatively...*) is welcome, as it is crucial that data collected is used to improve services and ensure a sound evidence base for health and social care interventions. However, for people using health and social care services it is less likely to have a direct and immediate impact on their lives, will potentially be less important by comparison to the other statements and seems inconsistent in nature sitting alongside the other vision statements which are focused on the individual.

Technology Charter for People Living With Dementia

In 2015, the Technology Charter for People Living with Dementia in Scotland¹ was launched, having been developed collaboratively between Alzheimer Scotland, NHS Scotland, Scottish Government, Scottish Fire and Rescue, Tunstall and Tynetec.

¹ <u>'Technology Charter for People with Dementia in Scotland'</u> (Scottish Government et al., 2015).

The Technology Charter is a call to action for the delivery of health and social care to incorporate and promote the use of technology to help people living with dementia to live healthier, safer, more active and confident lives. It also seeks to raise public and professional awareness of how technology can enhance lives, promote independent living and complement traditional care and support services. The Technology Charter has six key values:

- Practice and service provision is rights based, personalised and free from discrimination.
- Unpaid carers and families are recognised and valued as equal partners in care.
- Information and advice about technology is available in clear everyday language and in a variety of formats.
- Routes and access to technology are ethical, equitable, simple, understandable and userfriendly.
- Consideration of technology is embedded at all key points in the integrated dementia care pathway.
- Technology augments but does not replace human intervention.

We believe that these six values are a strong basis for the use of technology in health and social care, regardless of condition and suggest these could be incorporated as part of the Scottish Government's vision for digital health.

Challenges in health and social care

Alzheimer Scotland understands that the current use of technology by health and social care services to allow people to stay at home is limited. We are aware of technology being offered in community settings, such as community alarms and/or pressure mats in sheltered housing, however, it is not apparent that more modern and innovative technologies are being offered widely as part of personalised packages of support. The opportunities to use technology not only have the potential to improve the quality of life of a person with dementia but may also work as preventative measures which can help keep a person in their home for longer, engaged and active within their community and prevent the need for admission into more formal care settings.

Knowledge, Skills and Understanding

However, this requires health and social care professionals to have the knowledge, skills and understanding of different types of technology, as well as their potential application and suitability in supporting an individual and/or a carer. Alzheimer Scotland understands that there are limited accredited training schemes which are recognised across all health and social care settings and professions, with few platforms available for innovative use of technologies to be shared. We believe that these factors are substantial barriers to the implementation of innovative technological supports for people using health and social care services. Additionally, with tightening eligibility criteria and a rising demand for supports, too often the preventative potential of technology is not being utilised; technological interventions are primarily used where people's needs are immediate and their capacity and ability to adapt and learn to use new technologies may be diminished. This is a missed opportunity which we believe should be examined to ensure that conversations about technology take place earlier to inform and raise awareness of technological interventions which may be helpful in future; this would be particularly helpful for people with neurodegenerative conditions such as dementia.

IT systems compatibility

Alzheimer Scotland is aware of the ongoing challenges in the health and social care sector between systems which are incompatible and do not 'speak' to each other; this is the case both within and between different sectors. For example between primary and secondary healthcare settings, different ways of recording patient information can mean important information about personal plans, advanced care plans or powers of attorney may not always be recorded in a consistent way which is easily transferable between systems and accessible by the range of different professionals providing care and support to an individual. If low level challenges such as these continue, achieving the more ambitious aims of the Scottish Government's digital health vision may be difficult.

Procurement

Additionally, Alzheimer Scotland understands that the current procurement framework disadvantages more bespoke technologies from being provided where they not being bought in larger numbers by commissioning bodies, as such purchases would not align with guidance on achieving value for money, which often results in procurement in bulk. This means that the full potential of technology cannot be harnessed to provide innovative and personalised interventions which meet the unique circumstances of people with dementia and their carers. Whilst Self-Directed Support has the potential to overcome this issue, it implementation of SDS remains some way off.

Opportunities for the use of technology

Scotland's third National Dementia Strategy² was published by the Scottish Government and describes its ongoing work to design a training programme which will apply technology-based solutions and will support implementation. Additionally, we welcome commitment 11 of the new strategy which commits the Scottish Government to implementing the Technology Charter for People in Scotland with Dementia, ensuring that everyone with a diagnosis of dementia and their carers are aware of and have access to a range of technologies which support people to live safely and independently.

Global Positioning Satellite technology

One area of technology which has become more common in recent years is Global Positioning Satellite technology which has become a normal part of everyday life for many people as part of navigation systems in cars, smartphones and applications, and health and fitness technology which can track routes. This technology is increasingly being used to support people with dementia to continue living within their community, enabling them to walk and travel safely and independently, whilst providing some measure of assurance to carers.

Alzheimer Scotland has been working in partnership with TEC Scotland, Police Scotland, the University of Stirling and some IJBs to produce a resource primarily for health and social care practitioners who may be considering GPS technology to enable people living with dementia. In addition, it covers some of the different types of products available and how they may be used as a stand-alone intervention or as a part of a wider range of measures, whilst also covering some of the principles around consent and privacy when using GPS technology.

² 'Scotland's National Dementia Strategy (2017-2020)' (Scottish Government, 2017).

Self-Directed Support

Self-Directed Support (SDS) continues to be a missed opportunity for a radical transformation in the way in which people are able to exercise choice and control over the care and support they receive. The recent 'Self-Directed Support: Your Choice, Your Right'³ has highlighted the shortcomings in the implementation of this policy. Alzheimer Scotland understands that in many areas, people are severely restricted as to what can be bought using SDS, with support still being conveyed in terms of the hours of support for which a person is eligible. We believe there is potential for SDS to be used to overhaul the way in which people support themselves at home and allow them to use technology in innovative and creative ways which meet their specific needs and improves their health and wellbeing.

Considerations when using technology

Alzheimer Scotland is fully supportive of technology being used to help uphold the rights of people with dementia and help improve their quality of life, living as independently as possible in the communities in which they live. Whilst it is the case that telehealth and technological developments are crucial in achieving this aim, it is also necessary to recognise some of the unintended consequences of other technologies.

Maintaining autonomy, freedom and privacy for the individual

Even where the use of technology is well intentioned and perceived to be in the best interests of the person with dementia, it is important to recognise the potential consequences of it being used in a restrictive manner which limits the autonomy, freedom and privacy of the individual.

The Mental Welfare Commission has written helpful guidance⁴ on the use of technologies and the legal framework which surround the use of specific technology, particularly where a person may have diminished capacity. The report identifies the use of a rights-based approach to decision-making and its identification of restrictions which limit the freedoms of an individual. In addition, the guidance notes that:

If it has been established or appears likely that the use of assistive technology or telecare would amount to a deprivation of liberty, then that deprivation of liberty must have a legal basis and be in accordance with a procedure prescribed by law.

The issue of deprivation and statute is one which is one which has previously been identified by the Scottish Law Commission's report on adults with incapacity and the associated legislation.⁵ As reform of this legislation is ongoing, there is no clear resolution as to the use of technology.

Therefore, technologies such as GPS tracking systems, whether in community or acute settings, should only be used in some circumstances, where its use is in keeping with the principle of the 'least restrictive' option, as per the Adults with Incapacity (Scotland) Act 2000. However, we also understand that such technologies have been used in both acute and community settings, including

³ 'Self-Directed Support: Your Choice, Your Right' (Centre for Welfare Reform, 2017).

⁴ '<u>Decisions about Technology</u>' (Mental Welfare Commission, 2015).

⁵ <u>'Report on Adults with Incapacity'</u> (Scottish Law Commission, 2014).

with people who have dementia. Where technology is used as de facto restraint to monitor and restrict a person's movements, resulting in them being confined within a hospital environment or community setting (including the person's own home), this may be considered as depriving the person of their liberty.

As noted above, in rural settings where access to services may be difficult, the use of technology for video consultations may be an appropriate and helpful way to ensure that people are still supported and have regular communication with professional support. However, Alzheimer Scotland has always been clear that the use of assistive technologies cannot and should not be considered a substitute for high quality care and support delivered by professionals.

Conclusion

Alzheimer Scotland believes that the use of technologies to support people with dementia offers opportunities to radically transform the lives of people with dementia, their families and carers. We have seen how the introduction of technology can be used to promote people's independence, as well as improving their wellbeing and that of their, families and carers.

However, more needs to be done to ensure that staff working in health and social care settings feel confident having conversations about technology that can be used to support the current and future needs of people with dementia, their families and carers.

Additionally, whist we are broadly supportive of the aims of the digital strategy for health and social care, we realise that the infrastructure for technology must be better if services and supports are to reflect the vision articulated by the Scottish Government. At present, the divide between health and social care infrastructures, with systems which do not speak to each other, continues to be a problem.

Alzheimer Scotland is happy for this submission to be made publicly available. A copy will also be placed on Alzheimer Scotland's website.

Owen Miller Policy Officer, Alzheimer Scotland 10 July 2017