

Scottish Parliament: Health & Sport Committee

Technology and Innovation in the NHS: Call for Views

Response from Chest Heart & Stroke Scotland

Introduction

Chest Heart & Stroke Scotland provides advice, support and services to people affected by heart and lung disease or living with the effects of stroke, including online self-management resources and training modules for health professionals. With an ageing population, the increasing prevalence of lung disease and stroke, a decreasing mortality rate from previously life-threatening diseases such as heart attack, more people than ever in Scotland are living with the impacts of these life changing conditions. We conservatively estimate that over half a million people are living with them, and when considering the wider impact on families and carers, the impact is in reality far greater.

- 1. What do you consider have been the main successes of the existing Scottish Government's eHealth and telecare/telehealth strategies and why?
 - 1.1 Existing strategies have led to the exploration of a number of digital solutions for health and social care services, which are particularly valuable in more remote or rural communities. These include the remote delivery of cardiac and pulmonary rehabilitation programmes via the web. The Scottish Centre for Telehealth & Telecare has been effective in working with health professionals, service users and the third sector to scope and pilot digital solutions.
- 2. What do you consider have been the main failures of the existing Scottish Government's eHealth and telecare/telehealth strategies and why?
 - 2. 1 There have been many telehealth projects across the country, funded by a range of sources, however the frustration with these projects is that they are carried out in pockets across the country, largely with short-term funding for research purposes. There needs to be a move towards identifying effective and efficient use of telehealth care, and allocating sustainable resources to widen delivery. These resources are required to: maintain and update web initiatives such as STARS (Stroke Training and Awareness Resources) to ensure they remain current and accessible; provide support to professionals and service users in



using digital services; and improve knowledge among health professionals and service users of the digital services which are available.

- 3. How well does the Scottish Government's <u>draft Digital Health and Social Care Vision 2017-2022</u> address the future requirements of the NHS and social care sector?
 - 3.1 The draft Vision is insufficiently developed yet for detailed comment, but it needs to reflect a move towards care in the community, supported self-management, and more effective communication between sectors and professionals. Communication of health information and patient wishes such as anticipatory care plans and Key information Summaries continues to be a challenge, meaning that people are repeatedly questioned and may not have their choices about their own care recognised.
 - 3.2 We welcome the focus on putting the citizen at the centre of the draft Vision, which reflects the strategic shift towards creating care that is person-centred, as highlighted by the Chief Medical Officer's focus on 'Realistic Medicine', the National Clinical Strategy, and the National Health & Social Care Delivery Plan.
 - 3.3 Although the benefits of supported self-management are well documented, and there are many strategic drivers now to support it, there is a need for education of health-care professionals and the public. There has previously been discussion of patient-centred or patient-held records, and clarity about progress with this would be valuable. Similarly, a 'citizens' account' was piloted in Lothian but the results of that are not known.
- 4. Do you think there are any significant omissions in the Scottish Government's <u>draft Digital</u>
 Health and Social Care vision 2017-2022.
- 5. What key opportunities exist for the use of technology in health and social care over the next 10 years?
 - 5.1 The full integration of health and social care needs underpinning by the **joining up of data** between (and within) the two systems, and the better recognition of the role the third sector plays in providing health and social care support. People like having one central point of contact for healthcare; technology could enable this for both health and social care, as well as provision of third sector and community information. This also has a key role to play in improving equity of services across more remote and rural communities.
 - 5.2 An integrated IT infrastructure for both health and social care would present significant opportunities for **supporting people with long-term conditions to receive person-centred care**, **and better self-manage their conditions**. This support extends from NHS acute care



through to primary care, and into community support provided by partners such as the third sector. Such community support includes broader social support (such as befriending) which is a key component of maintaining health and wellbeing. NHS Fife for example has successfully integrated referrals to community/third sector services within its IT systems, enabling health professionals to easily refer people onwards, and transition from NHS services.

5.3 The numbers of people with multi-morbidities is predicted to increase significantly, as mortality rates decrease and the population continues to age. Accordingly there needs to be a shift away from resourcing acute care within the NHS towards community-based services and self-management, in line with national strategic priorities and the Chief Medical Officer's focus on 'realistic medicine'. This should be reflected in the future use of technology.

5.4 People with long-term conditions receiving care will frequently pass through a number of different medical teams (from acute care, primary care, mental health, allied health professionals, and onto social care) and without systems communicating with each other, patients must often repeat their own history a number of times. This is often a complex picture and there is a risk that elements are missed which can impact on the care and support provided, particularly where there are both physical and mental health issues. Different teams currently will also have different practice in respect of what information they record about patients. Technology presents an opportunity to address this issue.

5.5 There is scope for future integrated systems to provide opportunities for **patients to have greater input to the information which is recorded**, particularly if systems were to be based in primary care. The Alliance's Digital Health and Care team's 'Our GP' project includes some excellent innovative ideas, one of which allows patients to create their own personal profile which they share with their GP. The 'me & my GP' facility includes personal (non-medical) information, lifestyle and goals. By using 'what matters to you' as a starting point in all interactions with patients and service users, broader health and wellbeing can be better supported. Within the third sector this approach is often already at the core of what we do, whilst the health profession still at times retains a paternalistic approach to care.

5.6 People living with long-term conditions need a range of resources which they can draw upon to enable them to self-manage their conditions; **technology could play a significant part in enabling health and social care professionals to more easily signpost** or refer people to these resources. Chest Heart & Stroke Scotland has a number of free online tools available which support people to self-manage their conditions or help the people they care for: (www.selfhelp4stroke.org, www.mylungsmylife.org, and www.stroke4carers.org. These were co-designed with service users and health professionals, and are freely available. In



Scotland, user numbers last year ranged between 4,000 and 10,000, which is not insignificant, but as a proportion of the people living with stroke (124,126) and lung disease (129,103 living with COPD) there is clearly scope to reach far more people who might benefit. GPs and social care professionals could for example have a system which incorporated patient information and matched them with the wider resources available, or which could even link with patients directly via email/text and automatically update them.

- 5.7 There is also a role for telehealth in **supporting people to access community support** and service, outwith the NHS. For people after a stroke, heart attack or living with lung disease, community rehabilitation and exercise are key components of long term health and wellbeing. There can be challenges however to accessing opportunities to be physically active, particularly where people have fluctuating health, difficulties with transport, or live in more rural areas. The PARCS project (Person-Centred Activities for people living with Respiratory, Cardiac or Stroke) examined the barriers and opportunities to physical activity for people living with long-term conditions. The project's findings included a recommendation for the better use of telehealth and other innovative approaches to support people to be physically active. This could include the better signposting to support services, and the use of technology to remotely deliver exercise classes and advice.
- 5.8 Online resources have also become an important tool into the **training and continued development of health and social care professionals**. Chest Heart & Stroke Scotland's Stroke Training and Awareness Resources 'STARs' (www.stroketraining.org) cover 20 core competencies and advanced modules for staff working with stroke patients, which was last year accessed by 29,000 users in Scotland. Our 'HEARTe' online resources (www.heartelearning.org) provide similar training for professionals supporting cardiac patients, and we will be developing a further resource for lung health professionals. In developing any such tools, the importance of long-term resourcing must be factored in to ensure they remain current.
- 5.9 There is also scope for technology to take care and services directly to the user. Some of our service users in the Western Isles have benefitted from telehealth solutions such as the 'Florence' app, which through text alerts helps people self-manage their conditions such as heart disease and diabetes, by tailoring medication prompts, enabling remote blood pressure reads, heart rate and weight measurements. These are then used by health professionals to monitor health fluctuations. The app is available to NHS organisations on a licensed basis.
- 5.10 The Higher Education sector is also involved in partnership work with the NHS to develop innovative telehealth solutions. Napier University for example has a Medical Technology project in place ('Solution') within its School of Health and Social Care, drawing



on a multi-faculty team with expertise in healthcare, engineering, and design. This model – which works with both NHS and wider partners including the third sector – provides an example of a **collaborative design approach which should be supported and fostered** by NHS and government in the long-term.

6. What actions are needed to improve the accessibility and sharing of the electronic patient record?

6.1 An infrastructure that is fit for purpose is required, addressing issues including access to IT, internet access, compatibility of systems, and security. Resources need to be directed towards improving patients' digital literacy, and there is potentially a role for the third sector in providing training and volunteer/peer support. IT policies for the transfer of information to services outwith the NHS need to be reviewed, as many Health Boards currently have to restrict information sharing due to concerns about breaching data protection rules. A National Directive to Health Boards could set out how to best protect data whilst responding to the need to move to community-based services, and facilitating data transfer.

7. What are the barriers to innovation in health and social care?

- 7.1 The **significant resources and time required** in developing, testing, and implementing new innovative approaches are clearly a challenge. Patients and service users themselves must be involved and engaged in the development of new technology (and of the strategy itself), which can be resource intensive. They should represent different geographical areas and socio-economic backgrounds, people living with a range of health conditions, and communities for whom there are cultural barriers to engagement. Service users need to help identify where there are currently unmet needs, and help develop digital solutions to maximise their impact.
- 7.2 Collaboration must also draw on the expertise of the third sector, but within the NHS and Government there is sometimes limited awareness of the value and experience which the third sector can bring, particularly within primary care.
- 7.3 **Health literacy and digital literacy is a barrier** to many of our service users fully engaging with technology. Up to half of people in Scotland have limited health literacy, including people who struggle with reading and numeracy, have English as a second language, have visual or cognitive impairments such as aphasia or dementia, or physical disabilities with poor hand function as can be common after a stroke. Telehealth and technology must therefore be seen as an additional tool available to healthcare



professionals and patients, not a panacea. The additional support that many people may need to access it must also be factored into new innovative approaches and system design.

7.4 Patients and users also need confidence that their information is secure and only accessible by those health and social care professionals working directly with them. Some of our service users can feel that widely sharing information about them (even within the health context) can be an invasion of privacy. From the perspective of healthcare professionals there would need to be **clear guidance and confidence in handling sensitive patient cases** and how data is recorded and shared. Health care records may be produced as legal evidence if there is any complaint, enquiry or negligence implied, but patients may disclose information in confidence.

7.5 Internet access is an issue in more remote areas of the Highlands and Islands, with limited broadband connection in turn limiting access by health professionals and users to digital services.

7.6 Whilst there has been short-term funding of project to test and pilot new digital solutions, long term investment in proven initiatives will be key if technology is to successfully provide long-term cost savings and health benefits.

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