The ALLIANCE has a partnership Digital Health and Care programme funded by the Scottish Government’s eHealth Division to help increase citizen participation and third sector innovation in Digital Health and Care. In addition, we manage ALISS\(^1\), a digital search and collaboration tool for Health and Wellbeing resources in Scotland.

More broadly, the ALLIANCE and our members have been at the forefront of the self management agenda in Scotland since our inception – including through jointly writing the Scottish Government’s strategy for Self Management, ‘Gaun Yersel’\(^2\) in 2008.

We believe that empowering people and making sure that they have the confidence, skills and information to take ownership in the management of their life and long term condition(s) improves outcomes for individuals and services alike.

We therefore welcome this opportunity to comment on technology and innovation in the NHS. We have provided answers to questions 2, 4, 6 and 7.

**Question 2: “What do you consider have been the main failures of the existing Scottish Government’s eHealth and telecare/telehealth strategies and why?”**

We support the aspiration of the existing Scottish Government eHealth Strategy to support people to manage their own health and wellbeing, and to become more active participants in the care and services they access. We believe that success in meeting this and other aspirations in the strategy is being constrained by:

*The lack of a business plan to support implementation of the eHealth Strategy* – or in other words, no detailed route map showing what actions would be undertaken to achieve the strategy’s ambitions. For example, the strategy aimed for at least 90 per cent of GP practices to offer online booking of appointments and repeat prescription ordering by 2017 – however, with no detailed action plan to accompany this and with (apparently) around half of GP practices currently offering these options, it seems as though this target will not be met on time.

*The potential lack of funding to match strategic ambitions* - We understand the proportion of NHS funds spent on eHealth/technology may be lower than other countries (and sectors) where digital transformation of services has taken place more quickly.

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Insufficient focus on how technology will enable improved (and new models\(^3\) of) care - the narrative and discourse around the strategy has centred on the technology even though what people may really want to know is “what will this mean for me and how might this improve (my) care and wellbeing?” Focussing on the latter instead could have been instrumental in providing a necessary shift in emphasis to - and improving understanding around - the benefits, outcomes and transformation that could be delivered through digital technology.

**Question 4: “Do you think there are any significant omissions in the Scottish Government’s draft Digital Health and Social Care vision 2017-2022.”**

The high level vision will inevitably be succinct. However, we would hope that the new Digital Health and Care strategy will have citizens at its front and centre and make an explicit commitment to embed a co-production/co-design approach into digital health and care services. We believe that services should be driven by people’s needs and people\(^4\) (as well as professionals) should be involved as partners from the very beginning in creating and designing services. This will help ensure that digital health and care services meet real, rather than perceived, needs and help improve their design. In turn, this should help raise the take-up of digital services and deliver more benefits from the investments in digital over time. Such an approach would also align with the Scottish Government’s wider Digital Strategy which seeks to make Scotland an international pioneer on citizen-led service design.

The ALLIANCE has recently managed a substantial co-design project - ‘Our GP’ - funded by the Scottish Government eHealth Division. This has successfully defined three innovative GP digital services for potential implementation, with participation from over 1,000 citizens and professionals across Scotland. The solutions are:

- A Personal Profile (allowing people to create an online summary of non-medical information which is important to them, which they can share with their GP practice to facilitate more person centred care);
- Digital Photo Triage (enabling people to send photos of minor skin conditions/injuries for review by their GP practice, and to get advice on next steps); and a
- Digital Advice and Information tool (so people can receive/save weblinks to relevant, trusted online health information and local support services, which

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\(^3\) This includes the ‘House of Care’ approach, which supports and enables people to articulate their own needs and decide on their own priorities, through a process of joint decision making, goal setting and action planning. See [http://www.alliance-scotland.org.uk/what-we-do/our-work/primary-care/scotlands-house-of-care](http://www.alliance-scotland.org.uk/what-we-do/our-work/primary-care/scotlands-house-of-care/)

\(^4\) When we refer to ‘people’ we mean a representative mix of people who access services and support, across age groups, geographies, socio-economic backgrounds, people living with a range of conditions as well as seldom heard voices.
would help self management, health literacy and the Scottish Government’s aspiration for ‘Realistic Medicine’).

The Our GP project has provided strong evidence that citizens are willing and very able to co-create new services that can help to potentially transform their care.

ALISS provides another example of co-production in the digital health sphere. Developed with people living with long-term conditions and professionals, ALISS has adopted co-production as the foundation of its operational model. The programme provides digital mechanisms and practical support that enables citizens, communities and health and social care agencies to collaborate to add, share and maintain information about community assets that enhance health and wellbeing. To date over 1,300 account holders engaged in this process which has resulted in thousands of resources being listed and shared across a continuously expanding network of ALISS powered information portals.

**Question 6: “What actions are needed to improve the accessibility and sharing of the electronic patient record?”**

The current eHealth strategy commits to providing people with online access to their patient record and we believe that there should be a continued commitment and plan to deliver this. There may be some useful learning on how to do this by looking internationally at countries like Sweden where this has been achieved.

**Question 7: “What are the barriers to innovation in health and social care?”**

We need to tap into and support all the assets and resources we have in Scotland including those of citizens and the third sector so that we can unlock and generate more innovation in health and social care.

The third sector delivers a wide range of valuable and innovative support services for health and wellbeing, provides over a third of registered social care services and is a pioneer in digital technology too. The ALLIANCE has funded, advised or profiled a range of third sector organisations who are developing innovative solutions such as PAMIS (with their Digital Passports) and Revive MS Support (who are taking forward an online video consultation service). More examples of citizen and third sector led innovations are set out in our December 2015 report ‘Realising the Benefits of Digital Technology – Citizen Led Innovation for Health and Wellbeing’.

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5 See [http://dhcscot.alliance-scotland.org.uk/get-involved/] for more details and digital prototypes of these three innovations.

6 See “Patient access to health records; striving for the Swedish ideal”, the BMJ, 2 May 2017, [http://www.bmj.com/content/357/bmj.j2069](http://www.bmj.com/content/357/bmj.j2069).

7 Through administering the Self Management Fund on behalf of the Scottish Government.

We would also highlight the third sector’s provision of a diverse, alternative and useful pool of online information to support carers and people to self manage their conditions. From an innovation perspective, it would be useful to explore how this can be better linked with the NHS’s digital presence e.g. NHS Inform, in future.

More broadly, we would note the following barriers relating to the support for, scaling-up of and use of innovative technologies:

**Joining up and demystifying the innovation support landscape**

There are numerous initiatives, funding sources and support agencies related to innovation in health and care. It can be difficult for innovators to understand and navigate this landscape so they can identify and apply for relevant funding/support for their innovations. There is also some crossover and potential duplication in the innovations that are eventually supported.

It would be useful for the public bodies/agencies involved in health and social care innovation to consider joining up or at least demystifying their support activities so they are less complex for innovators and to help foster more co-ordinated, synergised innovation.

**Measures to help introduce and scale up innovation**

Aside from funding, there are challenges to introducing innovations and rolling them out across health boards and care services in Scotland.

This seems particularly acute for the third sector, despite their ethos of working closely with and co-producing digital solutions with people living with conditions. The example highlighted in Crohn’s and Colitis UK’s response to this inquiry (regarding the IBD portal) highlights the barriers that can be experienced by the third sector in securing appropriate communication, buy-in and technical support from key stakeholders and the NHS to implement innovations that are ‘ready to go’.

Some of this could be addressed through stronger leadership and commitment to embedding innovation within health and care. It might also be useful to look at the actions of other countries where digital health innovations have been rolled out quickly. For example, in Sweden they used a range of measures, including recruiting new ‘digital transformation’ personnel to work alongside those already delivering IT services, to help ensure innovations were scaled up and led to business transformation, shifting the focus from just ‘maintaining existing technology’.

**Accompanying measures for successful adoption and use of innovation**

Even when digital health and care services are made available there are also barriers to adoption (take-up) of those services which means the innovative technology can just end up ‘sitting there’. Multi-faceted change management
programmes need to accompany the introduction of new technologies to make innovation successful within health and care services.

This must include investment and activity in ‘softer’ elements such as marketing/awareness-raising activity, addressing wider digital participation\(^9\) and skills issues (of both citizens and professionals)\(^10\), training as well as actions to create necessary cultural change. As one illustration, despite there being almost pervasive access to GP online patient services (e.g. appointment booking) in England, there is still low take-up of these innovative transactional services and this has been partly attributed to a lack of awareness amongst people that these services exist.

**The approach to health and care data**

Finally, and more generally, the current approach to using data (for example, information assurance and governance arrangements) has been linked to perceived barriers to more effective information sharing and use of digital technologies in health and care.

Furthermore, as noted in the Scottish Government’s wider digital strategy, while data can hold the key to unlocking innovation in public services, the benefits will only be realised “if people in Scotland trust us to hold their data securely and use it in appropriate ways”. To support change and innovation, that wider Digital strategy contains an action to “engage with the public to build an understanding of how their data is being used for the public benefit, and of the arrangements in place to guarantee the security of their data”\(^11\).

We believe there should be a similar action for public engagement and debate on data sharing within health and care. It should also be conducted in a lay and accessible manner. This could play a role in unlocking the barriers to innovation and further support digital solutions which give citizens useful information about their conditions/care, appropriate professionals involved in their care with more joined up information and which enable improved health/care services and research.

**About the ALLIANCE**

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. The


\(^10\) Supported by recommendations (e.g. 5 and 6) in the recent paper “Readiness for Delivering Digital Health at Scale: Lessons from a Longitudinal Qualitative Evaluation of a National Digital Health Innovation Program in the United Kingdom”, Journal of Medical Internet Research 2017, Vol 19, iss 2 [http://www.jmir.org/2017/2/e42/](http://www.jmir.org/2017/2/e42/).

ALLIANCE has around 2,000 members including a large network of national and local third sector organisations, associates in the statutory and private sectors and individuals. Many NHS Boards and Health and Social Care Partnerships are associate members.

The ALLIANCE’s vision is for a Scotland where people who are disabled or living with long term conditions and unpaid carers have a strong voice and enjoy their right to live well.