**Health and Social Care Alliance Scotland (the ALLIANCE)**

Further written evidence: Health and Sport Committee Inquiry: Technology and Innovation in the NHS  
10 October 2017

The ALLIANCE would like to thank the committee for the opportunity to give oral evidence at its 3 October evidence session for the above inquiry.

We understand the committee will be discussing data and information governance issues at a further evidence session later this month. We are therefore providing further written evidence on these issues and would be grateful if this could also be considered as part of the inquiry.

**More consistent Information Governance**

We previously highlighted that information assurance and governance (IG) arrangements have been linked to perceived barriers to more effective use of digital technologies in health and care. We cite one third sector example below to illustrate the specific need for a more consistent IG approach.

Penumbra (one of Scotland’s largest mental health charities) developed an online outcomes tool called I.ROC ([www.irocwellbeing.com](http://www.irocwellbeing.com)) that measures personal wellbeing over time. They offer this with access to a secure database where service user information can be stored along with their results from facilitated assessments from the I.ROC.

Two health board areas have been interested in accessing the same I.ROC online tool but Penumbra have had to go through separate information governance processes with each board. For Penumbra, this all takes additional time and resources to answer the varying questions they receive. Penumbra want more health boards to take up the I.ROC tool but are concerned they will have to go through different questions and IG processes with each board – potentially delaying or inhibiting rollout.

Penumbra suggest a solution might be to take a ‘once for Scotland’ approach to checking their information governance approach and security, as this would not only speed up implementation of their digital tool but also make implementation consistent.
Building reciprocal arrangements for data in the third sector

More broadly, we believe that an opportunity exists for third sector data to be combined with statutory sector (and other) data, on a reciprocal basis, to deliver wider benefits and to help achieve health/social care integration.

We understand there are limited examples where third sector data e.g. on people who access services, service usage, assets and research, has been combined with statutory sector data in primary, secondary, community and social care.

This needs to be addressed to ensure a joined-up care record (with appropriate consent) can be developed for individuals, to improve wider research and to enable strategic needs assessments and service redesign/provision to take an improved, holistic approach which looks beyond just clinical interventions locally and nationally.

Some of this will require more digitisation of data in the third (and other) sector(s), achieving digital maturity (the skillsets and capability) to record, share and interpret data effectively as well as ‘interoperability’, so that statutory and third sector systems can exchange information with each other effectively.

This data flow should not however be a one-way street. Arrangements should be developed to ensure reciprocity, so that for instance (where it is appropriate) the third sector can receive and use more aggregate data from the statutory sector to understand where there is a need to target and further develop their services within localities.

Citizens and data

In our previous written response, we suggested there should be an action to engage with the public to help build an understanding of how their data is being used for the public benefit in health and care, and of the arrangements in place to guarantee the security of their data. We would like to add three further related points:

1. People need good information on data usage to help make informed decisions

A Wellcome Trust report¹ found that just one third of people in Britain have heard a fair amount (or more) about how the NHS is using health data. This suggests public awareness in this regard is low, which is of concern as data will be increasingly used to support health/care provision and because people do have some options on (consenting to) how their data will be used.

We therefore believe that the public should be offered better and lay information how

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¹ The One-Way Mirror: Public Attitudes to commercial access to health data (March 2016), Report prepared by Ipsos MORI for the Wellcome Trust - https://www.ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf
their data is used within health and care – to help build more awareness and understanding. This would also support individuals to make informed decisions to exercise any rights they have around consenting to their data being used or (in a more radical model – see our later point on citizen-controlled models) potentially ‘managing’ how their data is used.

The provision of such information should be a collaborative effort. The ALLIANCE certainly wants to work with stakeholders and help facilitate the provision of better information. With this purpose in mind, we have commissioned a jargon-free tool (to be launched next month) aimed at providing a simple explanation and resource on how data is used in health and care. We hope this will be helpful for public and professionals alike in supporting dialogue and decision-making on data usage.

2. We should enable digital (as well as written) consent for data usage

In Scotland, citizen opt-outs for their healthcare data can require people to obtain, fill out and return a form – for example, this is this case with ‘SPIRE’:\(^2\).

In England however, there are plans to enable digital consent for opt-outs and to provide more transparency around data usage. The Department for Health recently made several commitments suggesting:\(^3\):

- People in England will get access to an online service by end of 2018 showing who has accessed their summary care record – and by 2020, be able to see how their personal confidential data has been used for purposes other than their direct care
- People there will be able to opt out online (as well as in person) with respect to their personal confidential data being used for purposes beyond their direct care
- They will work with stakeholders to develop communication tools to explain effectively to the public, data and information sharing in health and care – and that they will involve the third sector in this work.

We believe it would be useful to explore whether similar commitments could be made in Scotland as part of the Scottish Government’s new Digital Health and Care Strategy.

3. We could learn from other countries and also consider moving to a ‘citizen-controlled’ model for healthcare data

Moreover, we believe that Scotland could go further and consider whether it can shift towards a fundamentally different model for healthcare data where the citizen is

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essentially in control. Countries like Estonia and Finland have adopted this model and we believe learning from these nations could be beneficial in understanding how this might unlock some of the barriers to innovation and facilitate wider service improvement and research.

Ultimately, we note that the longer-term ambition in Scotland for healthcare data is to introduce the inclusion and combination of citizen generated information (which they author and/or have from their apps/devices and **choose to share**) with data held by organisations involved in their care. In this model, we envisage citizens will be exercising some/partial control of what healthcare data they share and who they share it with and it seems sensible, for consistency, to also consider giving citizens control of the data that is held (on them) in the statutory and other sectors.

**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 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.

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