

Response to NCS committee letter – Scott Heald, Director of Data & Digital Innovation, Public Health Scotland, 12 December 2022

Implementation risks

- Do you recognise particular concerns about the impact on service users during the period of transition to new data systems and new approaches to information sharing as part of the Bill's implementation? What are those concerns and how might they be addressed?

PHS recognises the scale of effort needed and is committed to working collaboratively with national and local partners to understand the gaps and challenges; and can offer expertise in creating and maintaining national data records. Data requirements of the NCS will require new data developments (either through establishing new data flows, or by modernising existing data flows), and can also build on Scotland's expertise in data linkage, minimising the data collection burden through greater re-use of data which already exists, both in the health and care sector, and in other sectors (e.g. economy, education etc), and greater adoption of common definitions and standards.

A significant enabler will be the design and application of a robust, scalable and consistent Information Governance Framework to ensure legal and appropriate data interactions between multiple parties. This essential design principle might result in a legislative change requirement given that the NCS could require several services, including third and private sectors, to work together across a wide geographical area supporting a shared user community. For this to work effectively and achieve the benefit needed, a mandate would be in place to ensure that the standards are applied consistently.

Information Sharing between all NHS Scotland Boards is supported by an Intra-NHS Sharing Protocol which has been signed by all NHS Boards. So, there is no barrier to sharing information between NHS Scotland Boards.

There is an information sharing framework document for sharing information between PHS and Local Authorities; but this is limited in scope and not all LAs have agreed to sign it. Therefore, for some LAs, sharing of information is quicker and for others who have not signed the framework, the process takes much longer because the LA would normally request the development of a bespoke sharing agreement. There is therefore currently not a once-for-Scotland approach to sharing between PHS and LAs. This sharing framework is accompanied by a data protection impact assessment which needs to be completed for each sharing episode.

PHS would like to see the establishment of the NCS as an opportunity for a sharing protocol to be developed between NCS and all NHS Scotland Boards using a 'once-for-Scotland' approach.

If a sharing agreement is in place between NCS and NHS Scotland Boards, and then sharing commences in both directions, then either party becomes a controller for their different purposes for processing the data. This will be reflected in the various organisations' Privacy Notices. For example, PHS would use the NCS data to link to NHS data it holds (following prior scrutiny from the Public Benefit and Privacy Panel) in order to be able to report on statistics and provide more contextual aggregate information about individuals. PHS would also take this as an opportunity to better understand the associations between

markers of socioeconomic position and various health outcomes, postulate reasons for the gradients observed and co-develop effective strategies for prevention, early intervention, treatment and community engagement.

Appointing a Data Protection Officer and establishing an Information Governance team for NCS will reduce the risks to information sharing. Sharing can only be a positive thing for the benefit of the individual receiving social care or NHS care and treatment.

PHS, due to its vast experience in producing health and social care statistics and safeguarding confidential data, can, with adequate funding, use its expertise and assets, to produce regular statistics on behalf of NCS which comply with the Code of Practice for Statistics. This will reduce duplication of effort.

Ownership and control of data

- To what extent do you believe Part 2 of the Bill as currently drafted reflects a human rights-based approach? What changes might be needed to ensure individuals' human rights are respected and protected in the implementation of this Part of the Bill?

At the core of the development and design of the new National Care Service there must be a strong emphasis on a rights-based approach that includes a citizen's perspective at all stages of service design, planning, delivery, monitoring and evaluation.

We welcome the commitment expressed through the Bill to design and develop the NCS in collaboration with people with lived experience and with service delivery partners. It is important that those people who use or depend on services (as well as their carers), are involved at all stages. In committing to work closely with partners at all stages of design, we do also recognise that there may be partner limitations with capacity to engage. This means that timescales for development could be challenging and optimistic.

- What role would you expect Care Boards and/or Ministers to fulfil in relation to the control of data? Is this sufficiently clear in the Bill?
- The Committee has heard evidence of an appetite among people who use services to own their own data, which Mydex CIC discussed in some detail in their written evidence to the Committee. During the meeting, you raised a range of issues about this concerning regulation, high level data capture and data protection. The Committee would be grateful if you could provide more detail about the nature of these concerns, whether there is an opportunity to create an abbreviated care record that an individual could use/own to prevent the repetition and re-traumatisation people currently experience when seeing different professionals or whether the shared care record scheme outlined in the Bill would be sufficient to address this issue?

PHS is supportive of the approach set out in Part 2 of the Bill which gives the Scottish Ministers powers to establish a scheme for care records to be shared between the proposed National Care Service and the National Health Service. It also makes provision for Scottish

Ministers to produce an information standard which will set out how certain information is to be processed.

Development of a single care record that follows a citizen throughout their care experience enables greater consistency of understanding about individual circumstances. It also makes it easier for service recipients to have control over their own records and to better understand why sharing of key information about them is necessary for receiving better quality of service and care.

Monitoring and evaluation

- Are there specific gaps in currently available health and social care data which will need to be addressed to enable effective monitoring and evaluation of the proposed National Care Service?

Yes, there is a need to strengthen and integrate the capture of outcomes-based information where data about 'what happened next' and the views of individuals who have experienced a health and care journey are necessary for making continuous improvement to quality of care and service provided. This will enable the NCS to continue to provide high quality care and service.

Additionally, Public Health Scotland has a team of experts in Evaluation who can be commissioned to provide evidence-based evaluation of the NCS at agreed intervals, using a model in use for the current evaluation of Scotland's national Minimum Unit Pricing policy for alcohol.

- Are you able to address in further detail the interplay between a scheme that would allow for sharing of a care record and the gathering and collation of health and care information to assist with the planning of services, at a local and national level?

To effectively plan services and local, regional and national levels, the right information would need to be captured, analysed and shared.

PHS has demonstrable experience of providing information to territorial NHS Boards to support planning, performance and decision making at local level. This involves sharing of information at various levels of aggregation which are critical to supporting local and national decision making and response. Therefore the interplay between sharing and making data available for specific purposes is critical.