

## **Follow-up to attendance at HSCS Committee, 22 November 2022 - SOLAR**

The Committee posed a number of supplemental questions. Those questions, with corresponding responses, are given below.

### **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?

### **Response:**

Any period of transition runs the risk of inadvertently disrupting ongoing service delivery and this is no different. The main transition risks for data migrations can be summarised as: data being lost (which can include data losing important context, or data not being readily available to those who need it, as well as actual loss in the sense of destruction), data being exposed to more people than necessary, and data residing in two systems at the same time which can cause problems if one but not both systems are updated. All of these can potentially result in professionals making decisions relating to service users which are not fully or correctly informed.

On the point about new approaches to information sharing, we would reiterate that there is already a very significant amount of information sharing in this area, which has developed over time and is supported by a mature set of principles, governance documentation, service user-facing explanations etc. These need to be replicated in the new environment to ensure service users' information rights continue to be respected.

Addressing the above issues requires careful planning and implementation of data migration strategies which need to proceed in tandem with the correct information governance processes. This is in itself a very significant piece of work. It is worth noting that the provisions of Part 2 of the Bill do not presently extend to local authorities so any specific powers for local authorities to transfer or copy records to Care Boards or other constituent parts of the NCS will need to be contained in subordinate legislation to allow for proper planning of the data migrations. Attempting to do this as a "big bang" on the day services transfer would be a recipe for disaster. Experience tells us that resourcing new systems is the only way to ensure they are effective. This resourcing would include: robust impact assessments, investment in technology and the ability of systems to be compatible with each other, agreements between all Data Controllers and processors which reflect the key legal basis and processes (and therefore responsibility) of the data held and to be shared and the onward maintenance of systems.

### **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?

**Response:**

This is a huge question and one that doesn't fully reflect the complexities of the human rights issues we currently experience within adult social care, such as capacity/ mental health considerations versus the services provided. Privacy by design and a robust DPIA should go some way to evidence that human rights are considered, addressed and, where these rights are adversely impacted, a reasonable response provided justifying this interference.

It is also hard to answer this question as Part 2 of the Bill is extremely sparse and it is only when the actual subordinate legislation is published that we will be able to ascertain the extent to which the proposals reflect a human rights-based approach. It would be helpful if the Scottish Ministers published indicative draft subordinate legislation to allow for more informed discussion on this issue. The DPIA that goes with the Bill is also very high level and has no meaningful information within it to allow the actual impact being discussed. An in-depth and robust DPIA needs to be completed for the broader proposals set out in the Policy Memorandum.

- 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?

**Response:**

As noted in our written submission (and the submissions of others), the Bill does not make it clear what the legal personality (more likely, legal personalities) of the NCS will be, which in turn makes it unclear who the controller(s) of particular data sets is/are likely to be. However if the role of the Scottish Ministers is one of strategic direction rather than actual service delivery then it would not be appropriate for the Ministers to exercise the role of controller of service user data – we expand on this point in the context of service planning below but it applies equally to setting strategy.

Existing joint working arrangements have progressed to the point that in a number of areas, control of data is exercised jointly by health boards and local authorities. It is unclear at this point whether such joint data control would continue under the NCS and if not, what will replace it.

- 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?

**Response:**

As noted in evidence to the Committee, the concept of the personal data store - which is attractive in many contexts as a privacy-respecting, rights-enhancing way of re-using and sharing personal data across organisations - is one which needs to be applied with great caution in the context of social work services. All the major reviews and inquiries which have followed on from adverse outcomes involving social work involvement have highlighted that where mistakes were made or opportunities for positive interventions missed, this was due to the staff and agencies involved lacking a holistic view of the individual, and specifically a "chronology" of all significant events and interventions relating to the individual (and often, to the wider family unit). It is hard to reconcile this crucial safeguarding tool with the fundamental principles of a personal data store. A recurring theme in child protection, and also in the protection of vulnerable adults, is that those who commit abuse or are guilty of neglect, are extremely adept at concealing their activities and misleading agencies whose job it is to protect the vulnerable. The laudable aims of the personal data store would unfortunately lend themselves to misuse in the hands of these individuals.

There may well be mileage in the concept of an abbreviated care record; as noted in evidence, the personal data a home care worker needs to have access to in order to provide (for example) assisted living services such as personal cleaning, is very different to the data a child protection officer or Mental Health Officer would need to access. Any deployment of abbreviated care records should take cognisance of the fact that there will always be a need for at least some staff to have access to the holistic record regardless of personal preferences.

**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?

**Response:**

SOLAR is not aware of any such gaps but this question may be better answered by those with more of a role in monitoring and evaluation of services.

- 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?

**Response:**

There is no clarity on what such a scheme is likely to include. It may be similar to the various data sharing agreements/memoranda of understanding which local authorities currently have in place with other organisations, and proceed on the

same legal bases for lawful sharing of data in terms of the 2018 Act. It may, alternatively, proceed on an entirely different footing. The issue of gathering data and the collation of this is another matter entirely and will be an additional burden on local authorities and NHS Boards. Some members identified that there were issues previously with the Multi Agency Store (which we understand was a Scottish Government-promoted idea) and which never got off the ground because of the inability of NHS systems to interact properly with Council ones. This also highlights one of the main problems which would need to be overcome if the concept of an integrated, single health and social care record is to ever come to fruition.

As a general principle we would suggest that planning of services should be decoupled from access to personally-identifying information. This is in accordance with the data minimisation and privacy by design principles. Planning of services should be informed by knowledge that area X has a particular number of service users requiring particular services but there is no obvious need for those involved in that planning activity to know who these people are, or even their exact address. This should be the case regardless of the detail of who the personalised care record (or parts thereof) is accessible to or shared with.

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On behalf of SOLAR  
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