

## Data Forum 1 of 3 Notes

**Thank you everyone who came along to the first of three data forums.**

Scotland is data rich, but intelligence poor. There are many different data storing systems which make the space fragmented. Social Care is an intervention grounded in human rights so it follows that the way that we collect, hold and use data in the sector should align. It also means that people only have to tell their story once which is one of the things we hear most often from people accessing care and support. We also know that people change their story the more they have to repeat it, often missing out the most challenging and therefore most pertinent parts the more they repeat themselves. It also reduces the risk of professional bias or misinterpretation. As David Alexander from Mydex CIC described it in the forum, we will hear “the person’s version of the truth about their circumstances”.

The purpose of this meeting was to bring together people across social care who have an interest in the potential of data, but with a specific aim to explore a proof of concept around citizen held data. Discussion was wide ranging covering challenges, ethics and recommendations to be explored.

### Speakers

- David Alexander from Mydex CIC presented the *Vision*
- Jonathon Waldheim from NDS Scotland on the *National Digital Platform*
- Chal Chute from DHI on *Between the Scenes*

### Discussion

*What would an ideal data system look like and do for social care?*

### Key themes

#### The Value of the data we hold

Simply, we do not know because we cannot currently accumulate and analyse it in a reliable and ethical way. We have lots of data which is simply not used, but full of potential. We need to reconcile that currently we don’t apply data to support individual people who access care and support. That is a very different sort of data from the national and international examples of tools for instance.

- Map other systems and data collections
- Co-design product.

### Ethics

Whilst there is a lot of really good care planning software out there, just because you access care and support, doesn’t mean that should be brought into other fundamental information. There is a balance to be sought in what is good for individuals and what is good for society and for reducing the burden of

effort on professionals – see recent paper by Lucy Johnstone and Suzy Shenkin. Open source is a platform which can host that personal information that supports the person’s journey.

- The ethics must be fully considered from a human rights basis

### **Power and culture**

There is an unseen barrier whereby the NHS does not recognise the value and potential of care providers. It is currently impossible as someone from the NHS to access simple answers to simple questions which would help you to understand and identify people, organise services and create evidence based pathways. People who access care and support are an invisible population because only part of their data is known to different people in the systems. Equally for those who work in care. Covid response has highlighted this and gives political incentive to push things forward, but this needs to happen in a planned and ethical way. Before COVID, NIHR and the Health Foundation work included concept of minimum data set. In England it is more challenging – Scottish care providers are used to sharing data at a national level providing better coordination, but the content is not determined by them. Although data is time away from bedside, it makes the care better and applies resources better.

- Better comparisons could be made across existing systems which could affect policy and practice.
- The potential of the census should be explored.

### **Minimum data set**

Pros and cons – on the face of it, a ‘top 10’ valuable data items for particular care and support groups could be incredibly useful but there is difficulty in finding agreement and danger in limiting the data collected.

Example given by Chal on co-design work in Grampian to reduce nursing record forms from 42 pages to 1 piece of paper (2 sides) that did everything that the MDT needed it to do. Premise was to start with what that team required and to add more on request. Made sure to remove questions which could be answered by someone in their own home to remove duplication and effort.

- There is currently a huge amount of data which the system requires even if no one can determine why. Data sets must have purpose.
- Minimum data sets risk a trade off between information and quality and care. We need to start from the position of what a person needs and what those who provide care and support need to understand the components.
- Need to find ways to make data collection and analysis more granular where it is required.
- Forum needs to establish its intent for data collation, interpretation, and analysis e.g. machine learning, predictive analysis, management, achieving outcomes.

### **Purpose**

Data can be used to improve lives if it can work across systems.

Example given by /Duncan of Everylife technologies: CASPA work on hospital to home on flow to ensure that people end up in the right destination for them using simple tools. The reduced time spent in acute services and gave confidence to commissioners. This example could be applied in other circumstances.

- For providers, there are key outcomes which data should drive us towards such as quality and healthy aging.

- Care providers should have access to relevant data and be able to make data led decisions within an ethical framework. This needs to respect the capacity and competence of the care sector.

### **Involvement**

Involving all interfaces of health and social care provision will ensure that what is developed is fit for purpose. From a care providers perspective, this co-design would also include use interface of both system and data and intelligence.

### **Learning and Skills**

The context of implementation is important as it will fail if not applied in a realistic and achievable way. If the workforce are required to upskill this should be as simple as possible, and they should have adequate support and resource to do so.

- Important to link with existing and pre-planned learning systems/ requirements such as SSSC 23 things digital.

### **Money**

Money has to factor into the conversation. Current data systems were created in a competitive market where the data itself holds value. Updating and amending those systems will cost money to developers, but also for those who currently use them. If we continue on current procurement-based exercises, there risks market domination by a small number of large developers with a wide offer, rather than a dynamic market where innovation thrives.

- Financial conversations should be transparent.
- The forum must involve policymakers.

### **The role of Government**

Lorna Ascroft from Scottish Government spoke about their position in February, where they had approval to move to revolutionise the data and evidence system and to build a new framework. Things have now changed because of covid response, but they recognise the need for a national approach to what we value in terms of data and evidence. There was a paper produced which outlines stages of this, and they were pre-pandemic at a position to engage with stakeholders. They had recognition of blocks and challenges, such as the ability to capture outcomes. Data needs to augment and offer wellbeing outcomes tracking right through the system to influence the persons wellbeing. Social care needs to be about supporting them to have best life possible in their own circumstances, we should be able to know that services are assisting and supporting people to enhance their wellbeing. Data collection could enable analysis at different levels up to national. This picture could allow us to understand what needs to happen to support system continuity. In addition, the Scottish Government were about to redesign the national data set - management data, to shift the focus from what can be counted, to understanding flow and people's experience. Overall the strategy has been trying to influence which IT system is procured by local government. The current system they have doesn't function optimally and one of the systems was to become obsolete. They have been working with CCPS on the shift to get to a place where they would co-purchase as a set of providers and digital directors. This raises questions of interoperability. Overall a data-centric model that sits at the heart of things could offer a combination of graphs over various layers and interrogate data from at different levels including the ability to capture experience.

It is advantageous that Scottish Government does not have any directive, local purchasing around social care, it allows them to focus purely on getting the specification right for what really matters. This is the intent of Scotland Excel. The IT system changes have come out of necessity, but there is opportunity if possible to capitalise on it quickly. With COVID some of the timescales might not be helpful.

### **Assessment**

Care at home assessment sometimes does not mirror Social work assessment. Should consider a core minimum data set for everyone as this would eradicate multiple assessments. This led to a discussion on the risks of limiting potential via a min data set but the need to solve that problem. Principles and professional judgements are hard to capture, we do not know which data different parties need. There is current ambiguity around process of assessment/inspection – was this done to the same standard we do. Confidence that the data has been gathered, generated, inspected, verified in reliable way. Need to align processes and assessments – have to build confidence.

### **Trust**

Need to get trust through the system – e.g. assessment has to be transferable, needs to be recognition of multi-disciplinary completion and self- entry. So many practical elements haven't been worked through yet. This also leads on to conversations around cross-sectoral skillset and training.

### **Assets and Potential areas for exploration**

In this section, we discussed resources we could contribute to support a test of change around citizen owned data.

DHI: demo and sim environment, including 'art of the possible' demos, They have a prepaid set of infrastructures and sandbox environments which accompany or existing provider that has an app development initiative could access. They could also show how our standalone app can work with personal data store etc. Limited design work/facilitation, there would need to be a funding bid to do something bigger

MyDex CIC have an interest in the telescopic and microscopic - big data AI then , and the concept and context of removing risk. They would be interested to explore applied research - to map out friction/effort/risk/cost around a challenge that care providers have with third sector etc. around particular condition. use cases in a cluster that cross organisational boundaries, support particular person with specific situation.

DataLab – keen to keep engaged. Interested in work by Blackwood Housing smart meters and Fit Homes, - they have got connections and interest in sensor data, Wallet services and other blockchain providers, popular tech with a lot of expertise in these areas. They can make a core contribution on data set and data curation, art of the possible in terms of future analysis predictive analysis – the project should be ambitious and innovative. Potential also to access funding – would need to align to other work etc.

Worth exploring a call by the Health Foundation - one of the things in David's introductory piece was around transitions of care and flows of information. It would be helpful to explore bias about people moving into care from hospital, going into hospital from a care home or care at home setting and the transmission of information. The challenge will be to keep to something that is manageable and has reciprocal benefits; homes and providers good at recording information but when someone goes to

hospital it is often as an emergent, so the care home do not have time to print off loads of docs, nor does the hospital have time to read them. The focus should be on how to transfer care home or care provider information to help facilitate care, something smaller which could be possible within the scope of funding. Transition support.

Consider linking to the work on RESPECT. Already in existence in hospitals in Forth Valley, but it could be helpful if care homes also have access to view and update RESPECT forms. This is an invitation to care homes we would like to be involved in this work. It would involve open EHR modelling.

Another pinch point is the assessment process for people coming into services – precedent shows it is not an ideal process anyway; there is variation across local authorities, process flow, lack of clarity for people coming into the social care system. All of this leads to long delays and has impact on people accessing appropriate care support.

CASPA perspective, the collaboration is about promoting tech, enhancing data flow and contributing to standards. A lot of work has happened across sector, they would be happy to share in future. Happy to share insight from there and also lessons learned from collaboration. Their data has been feeding info into situational support and got to a point where there was a daily feed going in from care homes and software providers via an open dataset which has appropriate terms and conditions around it that allows it to be shared. They have also been working on another initiative around flow, with quite a few projects looking at different transition points, also links to care systems where a whole commissioning area have adopted digital to resolve the 'wicked' issues they're looking at. For instance, Liverpool managed to reduce medication errors by 90% and Wirrell has done work on intelligent commissioning – 'how do you undertake assessments and match up need with commissioner competence and capacity'. We must ensure throughout that we're not throwing a solution in where there's not a problem.

Scottish Government presented the offer of keeping connection to overall strategy around data and evidence, also to link with ongoing work assessments with Social Work Scotland who have been working with HSCPs to bring greater consistency to approach to assessment. They identified good practice approaches and analysed them. This sits behind a commitment to people to increase the consistency of experience and expectation across country. Anything that we can do at entry door level will help with whatever systems and apps are used beyond that. Need to connect in with Social Work Scotland findings.

## **Next meetings**

### **Data Forum 2 of 3**

This is the meeting where we get it right. Where we can invite those people who we did not know to invite to the inaugural session. It is where we set clear intentions and goals for the future to lay out a vision for data in social care. Scottish Care's contributing asset would be to write and produce this in collaboration with interested parties. It will also be a place to do further scoping on the test of change. We will also ask for a presentation from CASPA. If there is anything else which you would like to see, or would like to offer, please get in touch.

### **Data Forum 3 of 3**



This meeting should end with a group of individuals looking to get a test of change off the ground. It is effectively for matchmaking and for exploring funding avenues.

The forum is open to new members. If you would like to get involved or know more, please contact Karen Hedge, National Director [karen.hedge@scottishcare.org](mailto:karen.hedge@scottishcare.org)