

Data Forum 3 of 3
Notes 3rd Dec

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

This paper follows on from the notes of the previous two meetings, thus concluding this phase of the data forum. The information contained within the papers from the three forum meetings will be developed into a position statement on data for social care.

The concept of technology in care should not be unusual – as citizens, we use it in our day to day lives. This normalisation should prevent unnecessary barriers to adopting technology in care.

Social care are exemplars if keeping the person at the heart of decisions, this needs to be taken on board by those working with social care to augment the experience. To do this, we need to shift the focus from operational measurements, to be able to understand and evaluate how technology can enhance experience.

Partnership working also goes a long way towards achieving this and towards making investment in technology, an investment in people's lives. This extends to policymakers - the group were aware of the forthcoming Digital Health and Care Strategy but did not feel engaged in the process. Part of this may be down to the embedding of the team and fragmentation across policy making departments.

Key theme from discussion:

Measurable intervention needs to be meaningful.

Speakers

- Taffy Gatawa

Taffy is the Chief Information and Compliance Officer at everyLIFE. She also a member of the CASPA Board. Currently, she is seconded to the Department of Health and Social Care to support the delivery of the Winter Plan. Taffy is a Registered Nurse and a Certified Information Privacy Professional.

Discussion and themes from presentations

Current situation in pandemic response has driven the need for data.

In England, there was a lot of activity around technology shaping the way care is delivered. This put a focus on data and advocacy around use of data in social care. CASPA have been collecting data on impact of COVID on social care, it is now possible to look back at what that data looked like at beginning, the change in data over time, plotting news and headlines from Gov against data. The programme started at the beginning of the first wave and while there was not total coverage (there are gaps), it was initiated by identifying like-minded people who were interested in how COVID was impacting the sector, driven by a need to do something meaningful.

Work with care providers

We have seen local initiatives around data, looking at social care data collected within social services, but there needs to be further work on how to we bring that data in together with care providers, understanding transitions in care, how individual needs change over time after a

person starts a care package. There are some Local Authorities working collaboratively with providers to understand the care they are commissioning, using data to identify how we can build in quality and take in a more preventative approach.

Removing 'Friction Effort Risk and Cost' - a single source of clinical truth, single source of personal truth.

Work must look to removing 'Friction Effort Risk and Cost' towards a single source of clinical truth, single source of personal truth. There must be the semantic interoperability to translate from one environment to another, but also carry the trust so each party knows it was genuinely measured. Portability is fundamental also.

Duplication of data - all the different formats of data, going to different people. There is a lot of work going on with the Safety Huddle tool hosted on TURAS.

De-mystify data and data-sharing

The sector must make it easier for the person to understand their data, how it is held and used - residents and relatives being able to explain how they have control and ownership and what that means.

How do we speak plainly about data? How do we keep it real for people? We need to explain data responsibly, clearly. We need to think through who we are sharing data with, how much do we need to share rather than traditional just share everything - challenge thinking. Need to streamline data, collect once and reuse. In England, engaging with the regulator and care association (Care Provider Alliance) are starting to have useful dialogue about this point, recognising the burden it places on care provider, taking people away from direct care to serve data requests. In terms of systems what can we do and build in to make sure this burden is lessened. They are also doing work to produce a data protection and security toolkit.

NHS digital - recasting all information governance guidance to make it easier for frontline teams to know what can and should be shared. Might be a useful resource.

We need to work to demystify data sharing, to be a reassuring experience, and to find simple and effective ways to make sure it's shareable.

Drivers and barriers

There are many reasons to push this work – e.g., legal, duty of care, regulatory, funding, covid response. Top down/bottom up - better has been the enemy of good enough. Maybe bottom up where there is a reason to do a bit of data collection, that can be a way in, to proof of concept to do something that has all the touchpoints.

We need to identify key outputs and drivers - what do you want to know? What data should we be collecting? What should be shared and how to share it?

Research - Susan Shenkin's work in care homes, what information should be collected in care homes, but we can consider similar for other settings - mental health provision, what should we be collecting for services to make a difference?

Also consider what individuals are collecting on their own e.g., wearables. Drive projects and support projects around how you collect data.

Pressure points become potential

Points of transition.

Care at home - Having multiple professionals in the home at one time, inner circle and outer circle - what's going to happen this week, next week. Could we do a small test of change that provides that.

Care homes - another project, challenge between care homes and hospital, discharge and sharing of documents. Print all the documents, admission forms do not match discharge from care home. How can we create a digital discharge and admission form that can be shared between agencies?

The real step change we can make with data within care is to acknowledge the whole system and the choices, new care pathways and journeys because we've got the data to support that. Care at home to acute - back into care at home and then into care homes. That becomes exciting and transformational. Need to chunk this up - but those transitions and how we can enable those transitions could be very interesting.

The assets that we create are equally as applicable across all care settings.

A regional and national asset

Data Driven Innovation at Edinburgh University are working on a project in the Lothians – if you pull all data together from health and social care, huge regional asset, but you need to identify, what is meaningful to collect, what can inform service provision. There is a wealth of information around, social care information is disparate. Information that we can combine provides much more potential, to get insights into what interventions are effective, identify vulnerable people, underlying asset is a project called data log, pulling together information across hospitals right through to social care. Starting in Lothian, 4 years of funding from university then has to be self-sustaining. Have started with secondary care information, primary care data from Lothian on Monday, advanced discussions with IJBs and Lothian to bring in social care data, statutory side. Three of the 4 key pillars, fourth pillar providers info plus service user owned controlled information. Aiming by March to have these. Next year into Fife and Borders.

Governance and ethics

Streamlining lots of processes in terms of access to data. It is like having a big box of lego, but what are we going to build from it, what do people want to know from it? We must consider current process of accessing data. Speed and robustness of governance. The stripping out confusion.

Starting point is the person - what will make the difference to them, their outcomes/meaning and then understand how that translates to what data we need to collect - need to collect data for the system for what it needs, but to make a difference to people we need to understand how to collect data that will make a difference to them - this is where the complexity and challenge is. We need to be measuring the right things. We can't build and create new services that are person-centred unless we understand what is important to people supported and collect data specific to that.

Make a difference

Telescopic vs the microscopic - proof points that show what can be done, get rid of the friction effort risk and cost, improve outcomes for citizens.

We must not lose sight of making it real, how do we unleash the potential of care. How do we piggyback – use the NHS data as a 'spine' - allow registered nurses to ensure that managers can gain access to GP records, real time, read only initially but subsequently care can then update GP records.

Mapping of data

<https://kumu.io/ruchirshah/data-infrastructure-for-scotland>

a hefty job as the landscape is always changing

Taskgroup

After rich discussion and reflection over the three forum discussions it is time to take action. Scottish Care will pull together the intelligence gathered from the data forum discussions to host a task group to narrow the scope and identify projects. We will facilitate this process and then allow the project groups that form to take forward this work via funding opportunities and wider programmes.

Groundswell

As requested at the previous data forum, Scottish Care produced a template which can be shared via our networks to create a campaign to demystify data #datachangeslives.

Actions

- **Add to set of Principles: prevention and quality.**
- **Engage regulators - Care Inspectorate, SSSC.**
- **Scottish Care to publish set of principles and write up from the 3 data forums.**
- **Scottish Care to host 1 task group to move discussion to action.**
- **Influence forthcoming Scottish Government Data Strategy - ALL**
- **Groundswell - #datachangeslives template shared. Push via your networks – ALL.**

If you would like to get involved or know more, please contact Karen Hedge, National Director karen.hedge@scottishcare.org