On page 11 of The Feeley Report, the authors write:

"Scotland needs to shift its attitude towards technology and data sharing to improve people's experience of social care … Technology is not a replacement for support provided by another person but it can play a much bigger role in improving the lives of people who use social care services and supports. It can also help with people's ownership of their care and support, particularly when people "own" their own data or information that is about them and share it with the people who support them" ~ Scottish Government, 'Independent Review of Adult Social Care'

We agree individuals should control their own data and proof of identity, and have done a great deal of work on making this happen. Individuals have a right to choose and to share whatever data whenever they decide suits them best. We think basic human rights extend to the digital realm.

Introducing Personal Data Stores

Just now, all of our personal data is stored with the organisations that use it. The NHS stores all of our health records, often many times. SQA holds and provides your qualifications, HMRC has all your earnings and tax records, Glasgow City Council and all of the above hold your name and DOB and so on. Common data, like our names and addresses, are duplicated in hundreds of different places. We give information to organisations they need to provide services for us and, perhaps after asking our permission, they occasionally share it between one another when we need them to.

This is the organisation-centred model for managing data. It's complex, doesn't scale well, has many data governance challenges and isn't very responsive to change. It also creates a lot of effort for people as they're asked to enter the same information with each new relationship. As well as the difficulties, there's a missed opportunity: all of that data provided or asked for by organisations is useful for interacting with many of them throughout our lives.

A Personal Data Store is simple, but it represents a radical innovation in how we manage our data. Instead of personal data only being stored by organisations, it's also stored in a virtual vault by the individual it's about. The individual has complete control over it and can give permission to organisations to connect to their PDS so they can send or receive information to help that individual, all without the individual needing to find, send or explain anything. It's in the cloud, which means it's stored in secure, UK-based data centres. We call this the person-centred model for managing data.

In its recent report, subtitled *'A human rights-based perspective on creating value in social care data',* Scottish Care writes: *"we need to reconcile that we currently collect and apply data to suit the needs of services, regulators and wider aspects of the system. If we apply a*

rights-based approach to the way that data is collected, analysed and applied, then we need to reframe this perspective to facilitate a citizen-led approach. Data would become the commodity of and under the ownership of the individual, collected and applied to meet their needs, wishes and aspirations for support."

Through working with organisations to make person-centred data the norm, we see our work as building a new layer of infrastructure; one that will underpin and enable the future of person-centred services throughout the economy.

By introducing person-centred data infrastructure, the social care sector in Glasgow and beyond could directly improve the wellbeing of those receiving care, their loved ones and those who provide support to them, whilst increasing the efficiency of service delivery overall. This blog post describes how we think empowering people with their data will lead to seamless service delivery, more personalised care, a better sense of cohesion and less effort for everyone: from those receiving support and those close to them to frontline staff and management.

Collaborating around people

Social care, as understood by the Feeley report, is provided by various organisations and there is often a significant need to communicate and coordinate between many of them about a single individual, depending on the type of care being provided - whether its statutory health or justice bodies, advice services, or other private sector care organisations. Scottish Care notes that *'the issue around interoperability is well defined with the need to translate between different systems and be able to rely upon the trustworthiness of the data.'*

From the perspective of people using the services and those closest to them, nobody wants or needs to see demarcations between sectors, organisations, policy or departmental functions. They want a truly holistic approach that fully understands their particular needs and circumstances responding to their particular situation sensitively and appropriately. A significant barrier to achieving this is the sharing of personal information and translating data from different organisations to do so. At present, the infrastructure that enables this is not in place.

Such an infrastructure cannot logically, legally, or operationally be provided by any one particular care provider. It is not possible or desirable for a GP surgery to hold or share data collected by a care home or social services, or vice versa. What is needed is an extra level of data infrastructure - a new 'layer' - specifically for safe and secure data sharing. This would form a new part of the fabric of delivering and accessing services - one that helps each separate agency to join the dots, sharing what information needs to be shared safely, seamlessly and efficiently via a Personal Data Store under the control of those they serve.

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Personalisation

Detailed information and nuanced, intimate knowledge of an individual is incredibly important to providing good care. A personal assistant knowing whether or not glasses are for reading or for distance, or whether the person they're assisting prefers to drink a cup of tea before or after breakfast would make all the difference to the quality of support people in social care would receive. It's difficult for busy frontline staff to have that sort of information to hand and difficult to recall. Were this new layer of infrastructure in place, this level of detail would just exist, placed in people's Personal Data Stores by themselves or those that know them best. Organisation-centric models of data management will never achieve this intimacy of detail, because they naturally lead to information being managed to serve the purposes of the organisation rather than the individual and they create such a level of overhead in collecting and sharing data so as to thoroughly disincentivise true personalisation.

Not only feeling, but being, in control

The individual feeling in control over their day-to-day life (including over care and support provided and the way they are provided) is an important aspect of wellbeing. This would be facilitated by putting people in control of their data too: what information about them is created, how it is shared, and to whom it is sent and why. Whether the ability to make decisions about that data lie with the individual themselves or those nominated to control their affairs on their behalf, this aspect of wellbeing would be increased and in many ways assured by including control of their personal data.

For informal carers, friends, and family, it would mean they can finally have consistent access to the information they need, all in one place, in a way that would really help the people who rely on their support.

Consistent fidelity over a lifetime

Everybody accessing social care services have or are about to create a history. Their lives and needs change. All of the above could be maintained from cradle to grave by the adoption of a person-centred data infrastructure. Each individual would have a rich record of everything about them, under their control, updated whenever it needs to be either by them or the social care providers that need and alter that information to provide services to them. In *'Seeing The Diamond in Social Care Data'*, Scottish Care's number one principle for better use of data is that *'People should only have to tell their story once.'* Having data from multiple sources stored and used repeatedly from a Personal Data Store would ensure people never have to repeat themselves.

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The comprehensiveness and permanence of this becomes especially pertinent where people with cognitive impairment access support, where that history - their memories, or crucial facts about themselves - may be hard for them to access without help. A Personal Data Store would, in these cases, give a voice to those who're often voiceless.

Making it happen

The way we as people manage our data has to match up to the way we approach our activities, and this is particularly relevant to the social care sector. Our pilot project with Macmillan Cancer Support in Glasgow and West Dunbartonshire is an example of how multiple organisations collaborating around individuals in receipt of support can make that service journey far easier and conducive to individuals' wellbeing by moving toward a person-centred data management model.

We also recently announced our involvement in a three-year, £12.5m project with Blackwood Homes & Care through Innovate UK. By providing the underpinning infrastructure for managing personal data to the three 'Neighbourhoods for Independent Living', the project will show how person-centred data leads to improved outcomes for people and dramatically reduces the friction, effort, risk and cost of joined-up services.

Blackwood Neighbourhoods for Independent Living will be an example to anyone the world over involved in designing and implementing the next generation of person-centred, responsive and efficient health and social care services. We see better management of personal data as key to realising this.

We're always interested in finding more partners who are willing to trail-blaze new approaches to service re-designs, pilot projects, or anything else that organisations are doing to innovate and push forward the person-centred values we all share. If you're interested in developing the future of services together, get in touch at hello (at) mydex.org. We particularly like to work with third sector, social enterprises like ourselves: organisations prepared to legally bind themselves to a mission and purpose, focussing on delivering positive outcomes for people and those they support.

About Us

Mydex is a Scottish community interest company and social enterprise that provides citizens with the tools they need to achieve the above. We do this by designing and building platforms based on Personal Data Stores - they're free for citizens, paid for by organisations who want to provide better services. We work with organisations

providing public services to prove that empowering people with their data enables services to be genuinely person-centred.

Our strategy is to create, evolve and maintain a secure, trustworthy and convenient open personal data ecosystem that achieves our mission, realises our vision and aligns with our values. In doing so, we remove the extensive friction, effort, risk and cost experienced today in trying to innovate and deliver services to people.