Data Strategy for Health and Social Care

SUBMISSION FROM SOCIAL WORK SCOTLAND TO SCOTTISH GOVERNMENT CONSULTATION

12 August 2022

Social Work Scotland is the professional body for social work leaders, working closely with our partners to shape policy and practice, and improve the quality and experience of social services. Data is an important resource in improving social work and social care services, and we welcome this opportunity to comment on the Data Strategy for Health and Social Care.

Question 1. We all have different perceptions of what our health and care data may be:
1A. When considering the term 'your health and social care data' what does this mean to you and what do you consider it to be?

In our view, this catch-all term describes a broad and ill-defined basket of discrete data sets. We would define it to include any information about an individual which is needed by health and social care services to work with them or their family or other key people to help to maintain or improve their welfare and general wellbeing. Our definition deliberately doesn't presuppose the data is currently held in NHS or local authority information management systems, so it covers unmet needs, and also as yet unrecognised needs. The term does not include, unless it has been volunteered by an individual to a public authority, data which an individual holds (exclusively or with private sector partners) relating to their health or social care.

If a national, mutually agreed and understood definition of 'health and social care data' is to be arrived at, in order to further this strategy, Social Work Scotland believes greater precision is needed to avoid confusion among delivery and strategic partners and people getting support, to avoid inequity and potential rights infringement. Clarity and consistency of understanding is essential.

Question 2. Our ambition is to give everyone greater access to and a greater say over their health and social care data. Health and social care data examples include results from a blood test, a diagnosed condition or interaction with specific health and social care services.

Question 2A. When thinking about accessing your own health and social care data, what data about you would be your priority for having access to and greater control over?

N/A

Question 2B. When considering the rights of individuals who are unable to interact with their own health and social care data, do you feel that delegating access to a guardian/carer/trusted individual would be appropriate?

Yes
No
- ➢ **Unsure**

If yes, what safeguards need to be in place?

We urge deeper consideration of specific terms used; both ‘guardians’ and ‘carers’ are roles described in legislation with specific responsibilities, whereas a trusted person is a much more informal relationship with less defined boundaries. Where possible, the aim of this strategy should be to take an asset-based approach, and support people to access their own data, and to focus on what individuals can manage, rather than what they can’t.

There are specific considerations when thinking about access to data, however, and further clarification will be needed on exactly who can, and why, access data belonging to someone else – being a guardian or carer is insufficient of itself. Relationships are complex and the individual’s wishes must be obtained and respected; there are many reasons why someone might not want a parent or guardian to access their records on their behalf. The same applies to adult children of older people. There are significant implications here for Adults with Incapacity (AWI) - Social Work Scotland gave a full response on this issue (particularly around supported-decision making) to the Mental Health Law review consultation[1]. Similar implications apply to people subject to power of attorney.

While the intention of the strategy is to support children and young people as well as adults, it appears that very little consideration has been given to the specific needs of children and young people and how they may want more control over their data. Under current legislation, until a child reaches the age of capacity, the parent or person with parental responsibilities is the one with the responsibility, and they may 'speak' on behalf of the child and take decisions. (At around 12, young people are considered to have the capacity to make some of their own (legally significant) decisions around consent, including access to information etc.) It is important to note, however, that regardless of the child’s age and or the subject in questions, all children have a right to express their views, or for these to be taken into account by those taking decisions on their behalf, including a parent.

The Promise Scotland (responsible for driving the work of change demanded by the findings of the Independent Care Review) makes clear that considerations must be made on the quality and type of data that is routinely collected, and with additional qualitative data collected relating to outcomes and reflections of experiences, as this will enable a deeper

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[1] https://socialworkscotland.org/consultations/mental-health-law-review/

understanding of the lived experiences of children and young people within the care system.

One of the aims of the strategy is – rightly – to allow people better and access and control over their health and care data, including the ability to view and update their personal data contained in records. We would welcome further information about what that ‘control’ actually means – is the strategy suggesting that an individual could delete items, access all records easily, add to or contest records? Could they share records with third parties?

Furthermore, Social Work Scotland’s members would like more detailed discussion, prior to any agreement, about the data people will *specifically* have access to. The consultation only gives the example of someone accessing and updating their ethnicity. Social work professionals would need to know which elements of our records, case notes, assessments etc. would be viewable and/or accessible to agreed amendment. This is a critical consideration – there is already legislation[2] around access to files, and any access to personal data as part of this strategy must be compliant with this and general data protection legislation. Case records and assessments will include third party information, including details of risks. It would be inappropriate, and in conflict with data protection, for individuals to have unrestricted access to some kinds of information.

For access to specific 'core' details, such as name, address, ethnicity, telephone number, there will need to be security measures in place, and current systems in use may need to be adjusted - and there will be a significant cost implication attached to this.

With regards to children and young people, we infer from the strategy that the right to access data would apply to the person with parental rights, meaning they could potentially see (and possibly alter) some data in a child’s record. This carries substantial risks, and will need further clarification. Especially when we think about potential access to chronologies, case records, and looked after plans relevant to child protection, or parents being able to see the views of a child or young person contrary to theirs, which could potentially put a child at risk. As we stated above, in considering the role of guardians and carers of adults, there is a need for caution and clarity. More than one individual may have parental rights, and those individuals do not always agree. For example, there may be domestic abuse involved, or conflict over custody of the child. Access to core details could be a potential risk. This is even more so if a 'non-disclosure' order is in place in relation to the child's whereabouts due to risk factors, or if the child is placed for adoption but the order has not yet been granted. Other risks include details of the child's current carers being visible, details for other siblings, etc.

The ability to have greater access and control over key data and information also requires systems capable of presenting in a way that is truly accessible and understandable. Some people may not possess the capacity to do this, and collaborative design work – with individuals accessing data at the centre - would need to be done to ensure that the data

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[2] https://www.legislation.gov.uk/uksi/1989/251/made

strategy works for all; thinking in particular about people with communication needs, sensory impairments, and cognitive impairments.

Finally, in holding information digitally, there is a significant risk that we may create greater inequality through a lack of access and digital exclusion, which is strongly correlated with other factors, such as poverty[3]. The current cost of living crisis is a reality facing many people, and such critical information should be accessible via a number of routes.

Question 3. We are committed to providing clarity over how your data is used and the need for this to be built on ethical principles. When thinking about the ethical principles that must be maintained when gathering, storing, and using health and social care data:
3A. What information would you find most useful in providing clarity over how your data is used in a consistent and ethical manner?

N/A

Question 3B. To what extent do you believe it is important to collect data to enable our health and social care services to understand how they are serving those with protected characteristics?

- **Very Important**

Fairly Important
Neutral
Not Important

Social work is a profession rooted in social justice and human rights. Although everyone's lives are intersectional, and protected characteristics only serve to highlight some parts of an individual's identity, it is critical have aggregated and anonymised data around protected characteristics to understand how social work can best support people who experience multiple forms of discrimination. This applies equally to our own workforce and other professions involved in health and social care; as diversity, representation and support are equally important for those who deliver services.

Social Work Scotland also recognises that there are reasons why people who are frequently marginalised may be suspicious or less willing to provide sensitive data around protected characteristics, and we believe that training and support for professionals carrying out assessments and delivering support (who may be gathering this data) is vital to ensure understanding and confidence in how data will be stored and used.

We know digital exclusion is caused by lack of connectivity, equipment, skills, awareness and support; health and social care, and social work professionals also need to understand

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[3] https://www.inspiringscotland.org.uk/wp-content/uploads/2020/06/Digital-Exclusion-in-Scotland-final-full-report-1.pdf

the detail of this. We need better data on digital exclusion in order to understand how better to support those people's rights and outcomes.

What we do know is that some groups of people, for example, Black and Minoritised Ethnicities (BAME), already have poorer health and social care outcomes[4], and while digital tools and approaches can be used to amplify their voices, there's a significant risk that if we do not address digital exclusion they will find themselves doubly disadvantaged once digital exclusion is added to the existing inequality lens. Rigorous and robust data collection and well-supported, implemented and understood sharing protocols could help identify inequalities, and allow better focus on addressing these matters. Whilst we highlight the issue using the example of BAME people, similar experiences are likely to be had by other protected characteristics (as defined by the Equality Act 2010) and marginalised groups in society, and the intersectional impact of these is likely to be considerable.

We also know that health and wellbeing is closely associated with economic insecurity and poverty[5], and is so much worse in households and deprived communities where people struggle to stay afloat. These are not protected characteristics but equally important when considered data collection – particularly in considering the cost of living crisis.

Question 3C. When thinking about health and social care professionals accessing and using your health and social care data, what more could be done to improve your trust?

N/A

Question 4. When considering sharing of your data across the health and social care sector:
Question 4A. Are there any health and social care situations where you might be uncomfortable with your data being shared?

We are replying this consultation on behalf of a membership organisation, and our response therefore reflects the summation of many discrete conversations; members had specific examples of where they would be uncomfortable, well illustrating how important it is for people being supported to have the first and final say over how, and who with, their data is shared with.

Looked at in aggregate, a commonly cited area of concern was around care experience during childhood, and historical treatment for diseases such as HIV; both of which continue to carry stigma, with individuals facing discrimination. Another example was the location in which certain health and social care services were provided, the detail of which might reveal a history of incarceration, whether for criminal or mental health reasons.

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[4] http://www.race.ed.ac.uk/wpcontent/uploads/2020/07/Taking_Stock_Race_Equality_in_Scotland.pdf#page=24

[5] https://www.jrf.org.uk/blog/not-even-wee-bit-security

There may also be records which – under the Equality Act 2010 – are protected and sensitive; for example, gender assigned at birth, which is likely to be information that many professionals do not need or should not be privy to.

Question 4B. Under Data Protection legislation, your health and social care data can be shared to administer care. For what other purposes would you be comfortable with your health and social care data being shared within the health and social care sector?

We would note that there are also public protection reasons why information may be shared – for someone's own safety, or that of another. There is also an important distinction to be made between information shared about an individual to facilitate the delivery of a service, including protection, and information shared to evaluate and improve the quality of a service overall. The former requires detailed personal, identifying information to be shared, the latter does not. However, it is all "your health and social care data". The NHS has a framework for the safe use of individual's data for research and evaluation purposes, developed over decades. Any 'health and social care' data strategy should learn from, and where relevant replicate, this framework, The strategy must also make clear the distinction, described above, between purposes linked to the delivery of a service, and purposes linked to the administration / management / evaluation of a service.

Question 5. More people are using wearable devices to track their own health including sleep activity, mindfulness, heart rate, blood pressure and physical activity.
5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?

Yes
No
(If yes, would you want to share this data with health and social care professionals, and for them to use it to improve the services you receive?)

N/A

Question 6. Considering skills and training opportunities for those delivering health and social care services: 6A. What are the top skills and training gaps relating to data in Scotland's health and social care sector? Please rank the following list in order from 1 to 7, with 1 being the most important.

6. Data visualisation
2. Understanding/use of management information by managers
3. Understanding of what data exists and where to find it
4. Knowledge of how to access data
5. Confidence in using data
1. Understanding of governance

7. Other (Please specify below)

In answering this question, Social Work Scotland would like to note that skills and knowledge gaps will be different across the social work profession, let alone the wider ‘health and social care’ sector, and that these judgements are based on no evidence other than our own interactions with members and partners.

Question 6B. How do you believe skills and training gaps should be addressed?
Social workers and social work leaders must first feel confident in, and then feel empowered to support clients to understand the realities of data sharing as it happens in day-to-day life, and relates to health and social care information.

Many – if not most - people willingly share a lot of data online through social media, shopping and use of free software (where data is the ‘price’), but feel concerned about their health and care data being shared. This is understandable; it is one thing to accept a private company knows you buy certain products and can therefore infer you have a dog, quite another to accept that organisations might share the fact you have a stigmatising disease, for example. Understanding the exchange of data, and making informed and safe decisions, allows the potential for huge benefits e.g. Smart Watch monitoring falls, or sharing blood sugar data with diabetes clinicians, but those risks must be equally well understood and people must have the right to make their own choices.

In order to address the skills and training gaps identified, we cannot ignore significant capacity challenges in the workforce, which are exacerbating the challenge of supporting our workforce into digital confidence and capability. Our Setting the Bar report [6]– building on similar evidence from Unison and Scottish Care, identifies an ageing workforce who are cracking under the burden of an increasing workload and the impact of austerity – particularly those support services (and training budgets) which have been stripped out as savings have been made. It will be critical to assign sufficient resource and time to allow training and skills improvement to bed-in.

Question 6C. What actions must be taken as a priority to ensure that the public have access to health and social care data that they can understand and use?

Better and more engaged public perception of acceptable data use and as it relates to supported people is essential. For example, is it assumed that someone knows what is meant by ‘data’? Should we instead be referring to ‘information that is recorded about you’? Further work is needed in helping the people of Scotland to grow their understanding of acceptable information use, and how their data can be used for wider public good. We agree that there is a critical need to give supported people the confidence and ability to securely access, gather and share relevant personal information to make timely decisions and deliver better outcomes. Making this shift will take resources and support and time; and

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[6] https://socialworkscotland.org/reports/settingthebar/

social workers and social care professionals will be key in delivering that. Social Work Scotland believes that there is considerable work to do in equipping and supporting our health and social care workforce to gain that confidence and expertise, alongside ensuring understanding, ability and confidence in the general public – see our answer to question 6B.

7. Thinking about improving the quality of data that is used by health and social care services: 7A. What three things are needed to improve quality and accessibility?

1. More consistency and support around recording; acknowledge capacity of the workforce in social work to do this (Setting the Bar, *ibid*) but the critical importance of being able to act based on best and most accurate information.

2. Exploring the capacity for shared systems – there are currently 32 different approaches within local authorities, outwith multiple health systems, and those used by HSCPs for adults will also not be linked to children and families and justice social work systems. These systems are often tailored to meet local requirements as well as feeding into national requirements for data. The quality of aggregate social work and social care statistics is very poor in Scotland, at all levels including population need, characteristics of people being supported, the services they receive, their cost, and outcomes. Improvement programmes need to be designed and funded, but only after a thorough, accurate, and shared diagnosis and understanding about why these data problems persist.

We also note that the inclusion of the private and third sector is important here.

3. In our view, multiple different platforms and data sets can result in loss of national focus on investment for, and individual outcomes for people. Data is so fragmented across the system, there is great value in bringing together health and social care data, but it needs to be curated. Social work is a complex profession which interacts across someone’s life – for a child, that might mean education systems, children’s social care, health and more, and data is often duplicated and tracked across them. The same can be said for adults – many of whom are parents to children. For this reason, Social Work Scotland urges consideration of how these could be improved and their value enhanced before replacing this with a national system which may take years to reach fruition. We have a real opportunity to understand needs with data, but we need easier access to data to improve innovation and delivery.

Question 7B. If you are responding on behalf of an organisation, what role do you believe your organisation has to play in improving accessibility and quality of health and social care data?

As an organisation representing leaders in social work, our responsibility continues to be to surface challenges and opportunities facing the profession- and the people we support - in regards to data use and gathering, and also to provide context as to why some of these challenges arise. For example, our Setting the Bar report (IBID) offers some insight into the daily workload of case holding social workers, and the realities of opportunities for training, support and development of digital skills and data gathering.

Social Work Scotland believes that the social services workforce must embrace digital working and use the experiences of Covid-19 to best advantage. We see our role as prompting consideration of the future profession; we accept that in the future there will be no divide between ‘digital’ and ‘face to face’ social work; instead there will be approaches to best suit people’s needs, and accordingly our workforce must adapt their own skillset and values, through our members, our networks and our close work with partners and the Scottish Government.

We also believe there is work to be done in challenging assumptions, and supporting people to understand what data is actually collected *and shared* currently. Our sense is that the public generally think that health, social work and social care professionals have more access to information than we have. For example, one of our members recounts a situation where, in a corporate parenting group, the young people were concerned about their treatment at GP practices, and had no sense that information about their care experienced status might not be recorded on the GP system. There are also assumptions – especially amongst older people supported by social work – that NHS systems across primary, acute and emergency care are linked, when we know that isn’t always the case.

Innovation and alternative models of record holding may also come from further afield; we are aware of positive and interesting developments in Seville, where, (albeit only health information), people and services have access across all areas of the system. The member of the public only has access to certain parts, and are limited in making changes (address, for example). Individuals have access to test results, but with a time delay which allows for professionals to make contact with patients to advise them and explain rather than just getting complicated info. People do not have access to all of the case notes etc; just broad level information. We are aware that similar options are being investigated through the Digital Front Door Steering Group in Scotland, incorporating social work and social care information too.

Question 7C. What data, that is generated outside of the health and social care sector, do you think could be made available to health and social care professionals to improve health and social care outcomes in Scotland?

Social Work Scotland wishes to note that there are already existing protocols for sharing information outwith the health and social care sphere, which inform critical public protection duties for social workers. For example, S5 of the Adult Support & Protection (Scotland) Act 2007 sets out the duty of cooperation placed on organisations such as Police Scotland, in respect of adults at risk (as per the legislation). In order to meet this obligation, each locality in Scotland has developed a set of information-sharing protocols which clearly set out the basis, and limits, of information sharing, the primary guiding factor being that information is shared to benefit the adult in question.

Additionally, consideration of refugee legislation is particularly pertinent here; and we would encourage colleagues at the Scottish Government to consider better data sharing protocols with partners such as Social Security Scotland, education and housing (as examples) rather than seeking to combine these into a shared health and social care record.

The question appears to concern only data about individuals. Planning health and social care also needs survey data about population needs, and current levels of support from all sources, including unpaid care from family members and others, capable of being used to estimate the extent of unmet needs. The existing suite of regular Scottish Government funded surveys should be reviewed against that objective.

Question 8. We have heard that a more consistent approach to data standards will help improve insight and outcomes for individuals:
8A. To what extent do you agree with the proposal that Scottish Government should mandate standards for gathering, storing, and accessing data at a national level?

Agree
Disagree
- ➢ **Unsure**

By “data standards” we understand you to mean in part the data and recording definitions that are intended to allow data to be shared with common meanings, and also aggregated across, providing agencies to produce coherent and meaningful statistics.

Standards in this sense cover data syntax, the structured formats in which it is input to systems and stored by them, and data semantics which directly address questions of classification and meaning. At times in the past, the Scottish Government has produced such data standards for parts of social care, but these have not been further developed or maintained. For any statistical data collections which are based on individual records held in local authority client information systems, data definitions are co-produced with the relevant data provider communities. However, the main examples in social care, such as the “Source” data collections now run by Public Health Scotland and the more recent Carers Census, have not yet produced statistics of sufficient quality to be badged as “official statistics” on Government Statistical Service criteria. Instead they are still published as “Experimental Statistics” and “Data under development” respectively, because the data quality issues, including missing data or records, are still serious. Part of the problem may be that 32 local authorities (plus Carers Centres in the second example) have not fully adopted the data definitions, or put in place the recording practice by social workers and other practitioners that is required to underpin consistent data collection, and subsequent retrieval. The creation of a National Care Service offers an opportunity and a strong reason to identify and address the underlying problems in a funded improvement programme.

In relation to data *protection* standards, Social Work Scotland believes that there are already sufficiently stringent guidelines and standards in place which concern gathering, storing and accessing data, and we stated in our response to the National Care Service consultation in October 2021 that GDPR regulations are already well-established and accommodated in Scotland.

However, we do note the importance of agreeing better protocols locally within local and national organisations, and acknowledge the important roles that partner organisations outside of 'health and social care' play in sharing information, particularly in reference to public protection duties and managing risk.

Question 8B. What data standards should we introduce?
We believe it is important to introduce any data syntax standards required for interoperability and any semantic data standards required for common understanding of shared data items, or for items from which aggregated statistics are derived.

It is no easy task to establish a specification of requirements for social care data standards, a task which should be undertaken iteratively. For example, from the statistics side, the data specification and definitions exists for local authority downloads from client information systems to be provided to PHE/ISD for "Source". That could provide a template to audit on-site the CI systems in councils, which currently cannot meet the specifications in order to understand the local constraints and identify solutions. Something like this is required as part of the build up to the National Care Service, given the importance of data to service and planning. A larger set of data standards will be needed to support the development of individual's electronic social care records.

9. When considering the sharing of data across Scotland's health and social care system:
9A. Do you agree with the idea that greater sharing of an individual's health and social care data between the organisations in the health and social care sector will lead to better quality services?

Agree
Disagree
➢ **Unsure**

Greater data sharing will not, in itself, make any improvement to the quality of services. The data / information is neutral and inert; it is what people do with it that matters, be that positive or negative. At present our systems and data sharing culture are significantly orientated towards preventing negative (intentional or accidental) uses, and we therefore lose much potential to do positive things with the data; particularly around prevention. But whereas nearly everyone will agree about what constitutes a negative use / outcome of data sharing, the potential positives are still very much a matter of perspective, subjectivity and debate. For example, more extensive, real-time information sharing between health and social care professionals might enable better falls prevention, with benefits for the individual, their family, the health service and social care provider. But it would require sharing information about the individual's lifestyle that they are reluctant to be shared, for fear of how they might be perceived. Do the ends (falls prevention) justify the means (data sharing) if the means are not supported by the individual?

Moreover, people's lives are complex. Social work seeks to support people to live as independently as possible, but we also have public protection duties – for children and adults – that sometimes demand a degree of intervention in people's lives. Greater data sharing would make some aspects of public protection more effective, potentially equipping social workers to act before an incident has occurred (on the basis that data is flagging a significant likelihood, as with falls prevention). It should also be noted that the desire to avoid social work intervention might encourage people to not seek support from health and social care providers, if they felt information might be shared.

'Health and social care' is discussed in this consultation as one entity, but the first question acknowledges the need for clarity around what is an extremely complex landscape, before we even consider the implications of existing agreements about sharing data from the police, fire service, education, prisons, court systems, etc.

Data sharing and access is a complicated issue, and privacy and confidentiality are core values of social work practice. Furthermore, people's lives are complex and therefore any big amounts of data captured risks being "messy" and requiring a lot of work to clean and organise it. Whilst we agree that greater sharing holds potential, we recognise the amount of work needed to ensure that the data shared is both accurate, meaningful and appropriate to those accessing it – and that work starts with accurate data records.

Question 9B. If you are a clinician – how could we improve patient safety through better sharing of data and information?

Social Work Scotland would like to challenge the assumption in this question that only clinicians are in a position to comment on improving patient safety through better sharing of data and information. There is great value in bringing together health and social care data, which is currently fragmented; but it needs to be curated. We have a real opportunity to understand needs with data, but we require easier access to data to improve innovation and delivery.

We live in a digital culture where people bank, shop and communicate online. It's a necessity to adapt social services to what digitalised citizens expect or we are at risk of being left behind. Covid-19 has been a great accelerator for digital social work practice, and as we move out of the pandemic we need to explore what has worked for us and keep the best of what digital has offered. We have highlighted in earlier questions, also, the barriers facing many people in both access to digital tools, and the skills and capacity required to use them in an informed way.

There is a documented workforce crisis building in social work and social care[7], and the more digital technology and data can add to making working lives easier as well as provide better outcomes for those we work with, is a critical dimension. It is important that we consider how best to use technology to free up existing workforce to do things that are most important to people’s outcomes and the profession’s skillset

Social Work Scotland believes that it is of critical importance to build data skills across the health and social care sector, but we also recognise that where specific technical data skills exist, staff are often subject to extreme workloads and that recruitment and retention has proven difficult. Our own report, Setting The Bar[8], identifies specific challenges in the workforce and lack of support for training and development, and we are at a tipping point where social work professionals feel they are at or above their capacity, both with workloads and background support.

To build data skills across the sector there must be skills based training and clear guidance to enable staff to understand data terminology and their roles and responsibilities in relation to data, standards and sharing. While clear guidance will help ease some of the apprehension and fear staff may feel when asked to share data across the sector. But producing guidance and training courses is not enough. Implementation Science tells us that we cannot just issue guidance and expect people to act upon it, nor can you just train and hope; you must train and coach[9]. Workers need access to good quality skills-based training which is delivered on an ongoing basis, and they must receive high quality coaching and supervision from management.

The Data Strategy aims to facilitate a landscape where technology and digital tools can enable people to interact seamlessly across health and social care services, while being designed in a way that allows professionals to easily capture and share data. In order for social workers to practice effectively, they need systems that are designed in a way that align with practice requirements (e.g. allows them to easily capture and record data) but also a system that allows them to practice in a way that aligns with the values and principles of social work.

In terms of Self Directed Support, the system allows people working in the social work profession, as well as social care, to easily access quantitative data (e.g. how many

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[7] Setting the Bar, Social Work Scotland
[8] Setting the Bar, Social Work Scotland
[9] https://www.activeimplementation.org/resources/implementation-practice-and-science/

supported people have a direct payment), but we do not readily capture qualitative data (e.g. people's experiences of using a direct payment).

Social work must attract, train, and retain a generation of social workers who are confident about data, and able to work with other professionals – such as research, performance and quality assurance and information staff (where those are there to support) to manage, curate, analyze, interpret, data for social good. While it is would be ideal to have social workers who may specialize in this field, it is essential that all social workers understand their role in data collection and become adept at using data in their practice, as well as translating research and evidence-based practice into daily work.

Digital adoption within the social work profession has been slow and often treated with suspicion and reluctance. Our members indicate that that they do not confident in their skills and abilities to engage in digital practice and their social work training has not prepared them for digital readiness.

A significant problem is that most social work degree programs do not necessarily prepare students for the modern practice setting, including digital practice, or offer education on data science. Social workers will need specialist training and support in data usage. Perhaps some consideration for joint training between social work departments and computer science departments is required to appropriately train social workers.

If social work is to fully embrace digital technology within practice we may well find that we are able to attract and retain a new wave of talented individuals who want to be part of the digital revolution in social work.

10. Thinking about the actions needed to improve the quality of management information and internal reporting data across health and social care:
10A. What are the priority pieces of management information needed (that are not currently available) to provide better health and social care services?

Social Work Scotland is keen to see social care, social work and health embrace technology, harnessing its potential to improve the experiences and outcomes of supported people. We are also supportive of moves to modernise and streamline the muddle of information management systems currently in place, making interoperability a priority. With the appropriate safeguards, a more interconnected, digital information infrastructure should facilitate better planning, delivery, monitoring and continuous learning, as well as enhancing the support provided and reducing costs (as well as staff time tied to computers, rather than supporting people). However, it will be some years before individualised electronic social care records are in widespread use and thereby able to provide the basis for aggregated management information. Meanwhile, existing and improved client information system will continue the provide the main source of aggregated social care statistics.

Social Work Scotland's members have reflected that national management information available in Scotland could do with significant improvement – something that we're pleased to note is recognised in the Data for Health and Social Care Strategy. Social care statistics about people's needs, the services or support they receive, and their costs is not available in Scotland on anything like the volume, scope and quality required for effective service planning, management, evaluation and monitoring.

We believe that a funded improvement plan is necessary now, and must be outwith the plans for building electronic care records, and incorporated into the timeframe for the National Care Service plans. This should incorporate a systematic review of the data currently collected by the various national agencies from local authorities, regulatory bodies, and private and third sector care providers, against a statement of requirements that should be developed with all stakeholders and partners. Population surveys are also needed to supplement data about people already in touch with social care and social work services – these alone can provide information on population needs, on unpaid care and carers, and the extent to which people receive support of different kinds from different sources.

Current population surveys provide some useful data but not on the scale required, and should be included in the systematic review recommended. In the last ten years there has been an increasing emphasis on sourcing social care statistics from anonymised data downloads from local authority and service provider databases that hold data for individual people receiving or otherwise in contact with services. The resulting statistics, while improving, still have many gaps requiring estimation, often due to differences between councils and between service providers in data recording and collection, database functionality and configuration, and data extraction. During the decade of austerity, many local authorities have reduced the "back office" staffing supporting such systems in order to protect numbers of staff in direct contact with the public. This problem requires more detailed diagnosis of the actions and investment required to deliver a step change in progress.

In the transition from the current service delivery to the aims set out in the National Care Service Bill, it is essential that the assessment and support planning process delivers much better data on people's needs, the solutions, support and services in the care and support plan, their costs, and any remaining unmet needs, alongside the development of community resources to support prevention. We note that there is a dearth of information on unmet need[10], and hope to be able to contribute what we can through the experience of our members in future to this area. The assessment and planning process also needs to take account of a situations where some of the social work and social care workforce many not be part of the NCS, and the issue of interface and sharing of data in that context. This will require recording practice to be reviewed to enable IT systems to be able to capture this information in a form in which it can be aggregated and fed back to influence budget-setting, commissioning and policy development. In this way the range of solutions, support, and services can be monitored alongside data on unmet needs, so that over time a clearer

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[10] https://healthandcare.scot/default.asp?page=story&story=2979

picture emerges of the costs of the new paradigm, and the extent of any unmet need. Investment in IT systems, information recording, and data extraction and analysis is necessary at both local and national levels to achieve these ambitions.

Additionally, Social Work Scotland believes there are considerations and implications particularly for rural, highland and island communities in particular, and considerations about privacy and anonymity.

10B. What is needed to develop an end-to-end system for providing business intelligence for health and social care organisations in Scotland?

N/A

Question 11. Thinking about improving the quality and ability to reuse data sets across health and social care setting and for innovation & research:
11A. What key data sets and data points do you think should be routinely reused across health and social care to reduce duplication of effort and stop people having to re-tell their story multiple times?

We urge caution in the central handling of data, as detailed in our response to the National Care Service consultation. Whilst we fully support effort to reduce duplication and stop people from having to re-tell their story, from a practical of view, there are ethical considerations when considering how to hold information that is accessible to a wide selection of professionals and the individual concerned (as well as parents, carers, etc). Who decides, for example, how much of a social worker’s assessment is included in the record? Social workers currently engage with multiple services and agencies in order to coordinate support for individuals. This operates through information sharing protocols that have been developed in line with General Data Protection Regulations (GDPR).

Despite how this consultation presents ‘health and social care’, neither are simple domains in themselves, and few people in Scotland simply have ‘health’ and / or ‘social care’ needs; people are much more than the consultation’s sometimes transactional and consumerist framing suggests. Individuals have a range of social, emotional and material needs existing alongside and entirely bound up in their ‘health and social care’ needs. To what extent should an individual’s material / economic / family circumstances be reflected in their national record? Do all professionals and workers who come into contact with that individual need to know? What if that person also had care experience as a child, should this be knowledge open to all? There are instances when specific professionals may need to know such information, to enable them to fulfil their duties to safeguard the individual. But context is all-critical.

Apart from in these rare, specific circumstances, individuals should have the right to determine who knows what about them, even if it impacts negatively on the efficiency and /

or quality of the support they receive. That is a system built on human rights. And it is a system which underlines the importance of social work as a thread which runs through multiple parallel systems. As an individual’s ‘lead professional’, a social worker can make sure that the individual’s choices around information sharing are fulfilled, while retaining the responsibility to take action (including sharing of information) when the individual’s wellbeing demands it. Whatever approach to information sharing is adopted it must start from a coherent understanding about current legislative requirements. The Scottish Government’s Children and Young People (Scotland) Act 2014 remains only part-commenced due to the Supreme Court’s judgement around its permissive data sharing provisions. The development of any new system where personal data is stored would require rigorous adherence to the legislative basis under which this information could be shared, with clear information sharing agreements and protocols between services to protect the confidentiality of those receiving services. Particularly when, as in the case of social care, support will be provided by organisations who are not formally part of the NCS itself (being private or voluntary organisations).

Question 12. When considering the ethics of accessing health and social care data for commercial, development and research purposes:
12A. How do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?

Good quality data is a key component for delivering and improving on health and social care services. Data should be harnessed for the benefit of the people of Scotland, which means understanding the impact that each piece of data collected can have on the delivery and quality of health and social care services – as well as relational, person-centred social work which supports human rights. It can also encourage more innovation, and people themselves having greater access to and more choice and control over their own health and social care information.

Well-implemented and resourced data sharing protocols can support services to collaborate and come closer together with the overall objective of improving outcomes for supported people. While integration has gone some way in doing this, there are still significant barriers in relation to data sharing amongst health and social care professionals which is having a negative impact on practice e.g. Self-Directed-Support not being fully and consistently implemented.

Covid-19 has projected some health and social care data and statistics into everyday discussions, and while we ‘technically’ have the ability to easily access world class data that could lead to significant changes; considerable data gaps remain for social care and social work professionals, who are constrained by localised agreements and a lack of confidence and knowledge, as well as capacity issues. These gaps to improve social care and social work in the future, and support the professions to deliver the policies and legislation set out by the Scottish Government.

It is also critical to pay close attention to how data is gathered, shared and used- it must be ethical and transparent. We must ask ourselves, how do we develop the next generation of treatment and technology using data driven research without compromising people's privacy? There has been excellent work so far, but still much to be done, and – when given the capacity and support to work in the way they are trained - social workers play a key role in balancing people's human rights and privacy concerns alongside ensuring the best possible support and outcomes for their lives.

One of the main issues we face is how we align current developments and innovations with better data recording in health and social care for the benefit of people in Scotland.

The process of capturing and recording such data needs to be right, and in terms of health and social care data collection the role of social worker is key. The Social Work Scotland SDS Project Team have developed a national framework for the implementation of Self-directed Support, which includes twelve standards focussed on improving SDS implementation, with one standard focussing particularly on Meaningful and Measurable Recording Practices. The standard states: *Good recording practices clearly capture conversations between people and workers identifying what matters to the person, resulting in agreed personal outcomes that are clear and comprehensive. This information is used for ongoing review as well as for continuous improvement and planning of future supports.*

What this means for practice is that recording practice and information systems must be able to demonstrate the extent to which practice is carried out in line with the values and principles of relationship-based practice, as noted in the SSSC standards[11]. Records need to show how the person's lived experience and preferences have been acknowledged and expressed in their support plan, and connect personal outcomes to the subsequent review process. Recording systems are designed such that data can be aggregated and used for continuous improvement, resource planning and commissioning purposes. Our members tell us that there are significant challenges around this, both in Health and Social Care partnerships (HSCPs) and local authorities, where children and families and justice data is held.

The values and principles of the Social Care (Self-directed Support) (Scotland) Act 2013 include respect, fairness, independence, freedom and safety and the statutory principles of participation and dignity, involvement, informed choice and collaboration. These values and principles are also the principles underpinning SSSC registration of the social care and social work workforce and must be taken into account in relation to data collection and sharing - all practice related to this must be underpinned by these values and principles. It is a fundamental expectation that all professionals recording information about people (social workers, health professionals, social care professionals, etc) do so well, and consistently – and that there's support for them to know what to record (what's relevant), and have time to do so. Good recording, supported by good data systems, will help this strategy's implementation, and place people at the centre.

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[11] https://www.sssc.uk.com/the-scottish-social-services-council/sssc-codes-of-practice/

We know, however, that this is currently not the case. As highlighted in the Care Inspectorate's Thematic Review of Self-directed Support (SDS) in Scotland, Health and Social Care Partnerships are not consistently collecting, aggregating, analysing or reporting data in relation to personal outcomes. This has caused difficulties in evaluating progress in SDS and made it difficult to drive innovation and improvement across the whole system.

The Care Inspectorate's Thematic Review of Self-directed Support[12] (as well as other bits of evidence) have highlighted tensions for social workers between practicing in line with the principles and values of SDS, and at the same time capturing and recording the data required for the system: *"In some partnerships, staff had robust asset-based, outcome-focused tools to support their practice. Yet most resource allocation systems were such that staff still felt that they had to highlight people's deficits in order to get the level of services required. Doing so made securing the necessary resources to meet assessed need more likely but contradicted the principles of SDS".*

Social workers also reported they often find themselves having to speak "two different languages". One being the language of working with the supported person, and the other being the language required when inputting the data into the system: "*In practice we found that staff in many partnerships were essentially having to speak in two different languages. The first language was with supported people and unpaid carers and appropriately based on the principles of personal outcomes approaches and self-directed support. The second language was that of deficits, when they were seeking resources from decision-makers and budget-holders in their partnership".*

This contradicts the philosophy, principles and values of SDS, and causes a lot of frustration for frontline staff. Processes and procedures need to support the outcomes focussed conversation, rather than pulling discussions back to deficit language.

The data strategy is looking minimise duplication of effort in data capturing and recording. This involves supported people only telling their story once, avoid re-traumatisation, but many current systems are not built this way.

Social Work Scotland believes it's important to accept that supported people may only wish to share certain personal data about themselves, and while this data may not be telling us what we want to hear or what the system requires, we need to think about we can best harness what has been given to us and not just dismiss it. The Scottish Transitions Forum in their recent work around Principles into Practice[13] did widespread consultation with young people with additional support needs who were very clear on what data they wanted to share and what data they did not want to share. Feedback from professionals was that this data was not useful to them, but in these cases (and in line with the objectives of the Promise) the system should be flexing to ensure this data can be used.

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[12] https://www.careinspectorate.com/images/documents/5139/Thematic%20review%20of%20self%20directed%20support%20in%20Scotland.pdf

[13] https://scottishtransitions.org.uk/7-principles-of-good-transitions/principles-into-practice

Social work must consider the ethical matter of using personal data for purposes of which individuals may not have been aware when providing personal information. There are also related difficulties concerning data ownership and control, especially when data from various sources are combined to create “hybrid” beyond the scope of the original intent. While this may create information of very high value, we need to carefully consider the legal and practical complications this may have.

Question 12B. How can industry and innovators maintain the trust and confidence of the people of Scotland when using their health and social care data for research purposes?

N/A

Question 12C. What do you believe would be unacceptable usage of Scotland’s health and social care data by industry, innovators, and researchers?

In our view commercial gain is the critical issue here; and something which we believe would be unacceptable usage. ‘Industry’ is a wide term, as referenced in our answer to 12A, and rather than list unacceptable use, we believe this refers back to the need for improved clarity and understanding for people who get support, and professionals, in how generated data might be used (and whether it would be anonymised, aggregated, etc.), and the importance of express permission for those uses and the risks that may entail.

Question 12D. How should industry, innovators and researchers be transparent about their purposes in accessing, and the benefits of using, health and social care data?

We note that much of the ‘industry’ interested in this data sits outside health and social care and is regulated in different ways. Household technology is a good example; local authorities are concerned about how data gathering would work through more popular routes such as Amazon Alexa, but struggle to find realistic alternatives, which also create stigma for users. Alexa is not a health and social care developed tool, but it has multiple uses and it is something that many people may use already for medication reminders, to combat social isolation etc.

Education and understanding needed for people using this tech so they understand, but also empowered to manage it. Equally so for professionals prescribing and commissioning services which gather personal data and make it available for innovation and research.

There is widespread public support and understanding for harnessing data for public benefit (e.g. creating vaccines and other new drugs) but people are rightfully concerned that their data could be used for other purposes, such as marketing, financial gain, or activity related to privatization of health and social care services.

Any system designed must be transparent and facilitate the building of trust and enable people to understand the benefits and outcomes of researchers and innovators using their health and social care data for the public good.

Question 13. We want to create an infrastructure that supports access to data for research and innovation in a safe, secure, and transparent way:
13A. How should the Scottish Government seek to store and share health and social care data for research in order that it can best facilitate easier access that is still safe and secure?

N/A

Question 13B. What do you believe are the key data needs and gaps that are faced by industry, innovators, and researchers when it comes to Scotland's health and social care data?

Scotland's available statistical data about the care needs of its population; how those are met or not met; the types of services available and their capacities, use, costs, and performance; the workforce; budgets, expenditures, and income; the outcomes achieved and their durations, are all either not available, or in most cases only scantily available with attendant data quality issues. That is a problem for new potential service providers, as it is also for planners and researchers seeking to understand aspects of the social care system.

Question 14. Used appropriately and well, technologies such as Artificial Intelligence can help to improve decision making, empower health workers and delivery higher quality health and social care services to citizens, improving how you receive health and social care services:
14A. What are your views on the benefits of using AI to improve the delivery of health and social care services?

Social Work Scotland is interested and keen to see more practical pilots and tests of change projects initiated in using AI and predictive technology to support social work and risk-based decision making.

Social workers are keen to do the best job they can, and to utilise all available tools to do so - this has generated interest and appetite for the use of technology and data analytics. At the same time, government initiatives (programmes and/or funding) have encouraged the piloting and adoption of new technology austerity and research driving a shift to 'prevention', 'spend to save', 'innovation funding', etc. Balanced against this, we also acknowledge the capacity and resources available to social workers are thin on the ground at present, as evidenced in our Setting the Bar survey, and this cannot go un-addressed.

We have seen excellent and interesting case examples of AI being used successfully globally – for example, in the USA, using algorithms to determine individuals at risk of HIV in a network of homeless young people, and prediction of suicides, and closer to home in the UK, prevention of falls among older people and use of predictive algorithms in children's social work. We know there is this evidence emerging from across the UK of successes in this area, and these can be learned from in local areas, however we also note that a more coordinated and collaborative approach to testing and reviewing would be beneficial. However, we also need to learn from failure.

As stated across our response, we believe that what is needed is more confidence and an enabling context to undertake this learning and to share evaluations and outcomes across Scotland, and there are opportunities in taking a national approach which may support this. For example, we would like to see a national database of innovation, research and data-driven projects which are available to social work and social are organisations to better enable digital-first solutions, and to empower professionals and people who get support to work together, collaboratively, to find solutions to outcomes.

Question14B. What safeguards do you think need to be applied when using AI?
We need a culture of caution when using AI systems to replace human interaction, and also to replace human judgement in areas which are immensely more complicated than that required to mow a lawn, drive a car safely, or even fly a plane, and where no intelligible account can be given of the rational and ethical bases of the AI system judgement, as is generally the case with self-learning programs, which are based on countless inductions.

The 2021 BBC Reith Lectures, “Living with AI”, by Stuart Russell, Professor of Computer Science and founder of the Center for Human-Compatible Artificial Intelligence at the University of California, Berkeley, are a good starting point for thinking about how we ensure machines do the right thing,

15. Please use this box to provide any further information that you think would be useful, which is not already covered in your response.

N/A

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