

Response ID ANON-V2PC-13SQ-3

Submitted to Data Strategy for health and social care
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Part 2: Empowering Those Delivering Health and Social Care Services

6 Considering skills and training opportunities for those delivering health and social care services:

Ranking Table - Data visualisation:

Ranking Table - Understanding/use of management information by managers:

Ranking Table - Understanding of what data exists and where to find it:

Ranking Table - Knowledge of how to access data:

Ranking Table - Confidence in using data:

Ranking Table - Understanding of governance:

Ranking Table - Other (Please specify below):

Single Text Line:

Text Box (Multiple Lines):

There needs to be a focus on how opportunities for upskilling and training are directly linked to and supported into implementation, in order for them to be made meaningful and valuable in practice for the social care workforce. This includes understanding organisational needs and ensuring access to opportunities for social care providers to acquire skills that are identified as required. Use of a Digital, Data and Technology (DDaT) Capability Framework can support this planning to be undertaken and therefore particular effort and resource should be focused on supporting this work.

The Strategy recognises the significant recruitment and retention crisis that the social care sector is experiencing. This, in many ways, appears to be worsening. Latest data shows that 36% of social care services have vacancies (three times more than the national employer vacancy average across all sectors) and given anecdotal evidence since latest publication, this figure is likely to be even higher. Scottish Care's 2021 workforce data highlighted that 87.8% of our members are finding recruitment and retention problematic. There needs to be very careful attention paid therefore to how the ambitions of the Data Strategy can be sensitive to this as well as support positive change. There is a real risk that policy & practice developments create a continual 'adding on' to existing job roles and skillsets within social care, including in relation to data, digital and technology, creating unreasonable or unachievable expectations not least when there has not been a fundamental review of social care roles and associated pay levels. Rather, work on an ambitious Data Strategy for Health & Social Care must coincide with and contribute to wider efforts to scope what social care is, what we will want and need it to be in the future, and what roles are required within the health and social care workforce to underpin this. This includes but is not limited to connectivity with the development of a National Care Service, with work around data requiring to be central in planning and agility for future models of care and accompanying job roles.

Text Box (Multiple Lines):

Scottish Care commends the work currently underway which is seeking to normalise data and datasets and make these understandable and useable, including the work of Dr Jenni Burton and Data Driven Innovation at the University of Edinburgh. We would hope to see the learning from these areas used to inform further work.

It must be recognised that health and social care navigation, from data right through to the individual experience of accessing care and support, is incredibly complex. If the Strategy seeks to support more accessible and comprehensible data, it must start with considering how it can contribute to a more informed understanding of the sector in general. Otherwise, there is a risk that people are unable to interpret data at both micro and macro levels or to position it in context. Unless information and data is truly accessible and can be used to support informed choice and empowerment, access alone is insufficient. For genuine involvement, those who access care and support need to understand how they have control and ownership of their data, what that means for them and how this creates value in their care experience.

A number of care services will already seek to support access to appropriate data, for instance through facilitating access to portals attached to digital care planning software for individuals and their families. However it is clear that digital exclusion remains a considerable challenge and this becomes a particularly grey area for responsibility within social care support settings. For instance, to what extent is it the role of social care providers and staff to support the digital literacy of people they support, and their wider networks? These broader questions of aspiration, expectation, roles, skills and inclusivity must be addressed and resourced appropriately if meaningful progress regarding data access and understanding can be made. The Strategy and related actions must maintain a 'digital by choice' ethos, prioritising the design and development of analogue versions alongside digital options in order to support inclusive, rights-based practice that benefits all.

As identified in Scottish Care's 'Seeing the Diamond in Social Care Data' report, language and communication changes are required in order to support clarity of message and understanding around data and its value, both for the wider public but also to challenge health and social care professionals to carefully consider how best to utilise and share data in a way that promotes accessibility and transparency. Examples of work already tackling this challenge are shared within the report.

Public and sectoral buy-in to data sharing would also need to be achieved. Contributors to Scottish Care's Data Forum – a series of events held in 2021 involving colleagues with interest and expertise in data from across the social care sector, industry, academia, and government - proposed a groundswell campaign to highlight the benefits of data sharing. To support this, Scottish Care designed a template for sharing across networks to create a campaign to demystify data, using the hashtag #datachangeslives This work could be developed further.

7 Thinking about improving the quality of data that is used by health and social care services:

Text Box (Multiple Lines):

Scottish Care supports the concept of a digital 'front door' and shared data plan to provide a single source of truth and shared vision. This rationale helps people to utilise a 'one stop shop' approach to their data. However, it is important that the Strategy is mindful of the implications of this for, for instance, small & medium-sized social care providers in achieving the required inter-operability of data systems:

- Are organisations business-ready?
- Do they have legacy systems that they are tied into?
- Are there incentives or funding streams available from the Scottish Government to support required upgrading or changes?

Given the diversity of provision and providers within the social care sector, these sorts of infrastructural factors must be considered and supported appropriately in order that consistency of data accessibility and quality can be achieved in an inclusive and collaborative way.

Real time sharing of data is a key 'ask', but it is critical to ensure that people are presented with the right information, with appropriate safeguards in place. For instance, this raises particular questions of informed choice, consent and control in situations where both an individual supported by social care services and their family may seek different degrees of accessibility to data.

Linked to the previous point regarding navigation, it is important to note that health and social care, not least in relation to data sharing, can remain very siloed. For the wider public, there can be an expectation that different professionals and stakeholders within parts of the 'system' will have access to particular data when this is not necessarily the case. These systemic barriers must be overcome whilst also supporting information management and expectation setting to ensure that people can make decisions related to access, sharing and data use based on understanding rather than assumption.

Text Box (Multiple Lines):

Scottish Care has been engaged in and leading work around the development of technology, digital and data within social care for a number of years and has created and co-produced a number of resources that can add value and direction in this space. We advise that these are considered carefully in the context of the data strategy and resulting work, and welcome further engagement around these and how they can support progress:

- TechRights: Human Rights, Technology & Social Care (2018)- TechRights-Human-Rights-Technology-and-Social-Care.pdf (scottishcare.org)
- Human Rights Charter for Technology & Digital in Social Care (2019) – Tech charter (scottishcare.org)
- Guidance Document for Human Rights Charter for Technology & Digital in Social Care (2019) - Tech guidance (scottishcare.org)
- A Vision for Technology & Digital in Social Care (2020) - A vision for technology & digital in social care (scottishcare.org)
- Seeing the Diamond in Social Care Data (2021) - Data-Report-Seeing-the-diamond-in-social-care-data.pdf (scottishcare.org)

Additionally, Scottish Care has been involved in practice-based innovation to support change around data accessibility and quality.

It is likely that across social care settings, there will be a need to expand the workforce in ways that enable data to be used more intelligently to improve outcomes. For example, data analysts may be needed with the required skills to understand and analyse data for care outcomes and improvement and these skills cannot continue to be layered on top of those that exist in current frontline social care roles, particularly when current budgeting and commissioning models do not reflect these aspirations or facilitate flexibility and workforce innovation.

With more emphasis on data sharing contained within the Strategy and the establishment of a single care record, there will inevitably be an expectation on social care providers to feed into these digitally using datasets. Further interrogation is required as to roles, responsibilities and expectations related to these needs, including who currently undertakes these processes (for example, social care managers) and what is anticipated into the future (when more widespread engagement with data may be sought). It requires an analysis of the different levels of skills that are needed, from generalist to expert.

Scottish Care and its members, in partnership with the Innovation School of the Glasgow School of Art, have developed a programme of work exploring speculative future workforce roles – comprising a care navigator, coordinator and technologist – to reflect different aspirations and expectations in the future, including those related to data. This work was co-designed with the sector and the Care Technologist role – which incorporates a strong data management component - is now being implemented in three areas of Scotland following pilot work. This evidences how the independent social care sector can play not only an important but an innovative role in shaping future data collection, analysis, use and access in a way that is grounded in sectoral needs. It is hoped that these sorts of approaches can support the social care sector to become more aspirational from a skills and careers perspective, providing solutions to the endemic recruitment and retention crisis that exists and moulding the future workforce around what is required to meet future needs and deliver outcomes. Close links across different aspects of policy & practice planning will therefore be essential to the future success of the Strategy and in it playing a role in shaping future service provision and care outcomes.

Text Box (Multiple Lines):

It will be important that effective links are made with data related to areas such as population growth, demographics (including older people and people within working age), immigration, the environment, the economy and housing. In terms of existing data collection exercises, exploring the potential of connection with the Census may be valuable. This connected data would have both national and local value depending on context and use. Recent experience of the cost of living crisis, energy and fuel price increases have also further highlighted the need for more real time data that can inform workforce and service planning and monitor impacts on individual health and care outcomes.

8 We have heard that a more consistent approach to data standards will help improve insight and outcomes for individuals:

Agree

Text Box (Multiple Lines):

9 When considering the sharing of data across Scotland's health and social care system:

Not Answered

Text Box (Multiple Lines):

Greater data sharing is certainly an essential component of providing quality care and support services in the future but it is not the only requirement, nor will it succeed in isolation from other measures. Firstly, there must be an emphasis on multi-way and multi-directional sharing – not just to the NHS, statutory organisations, government or regulators. There must also be clear and realisable benefits of data sharing for social care providers and their workforce, as well as for individuals and communities. In order to obtain and retain both buy-in and trust, all stakeholders must be treated as equal and valued partners. Data sharing must not be seen as a one-way street or to serve a top-down mandate. Secondly, sharing in and of itself is insufficient for assuring or achieving quality. Instead, the focus must be on how data is used to inform positive action, in order that stakeholders can see evidence of how their data is used ethically and to drive change. Finally, sharing must be driven by an ethos of 'do it once, share it often' or 'collect once and reuse', maximising opportunities for effective data collection and sharing rather than reinforcing the current articulated challenges of duplication and individuals having to tell their story multiple times. This will require greater professional recognition and understanding of the diversity of health and social care skills and roles and a foundational culture of trust, partnership and esteem in order to move away from siloed and risk averse ways of working. As articulated in 'Seeing the Diamond in Social Care Data': 'there must be trust in the data provided by those from other disciplines and with different skillsets, as well as including self-entry from citizens. For example, an assessment must be transferable and have co-created value for each perspective involved.'

10 Thinking about the actions needed to improve the quality of management information and internal reporting data across health and social care:

Text Box (Multiple Lines):

Comprehensive, responsive and real-time workforce data is required that can support, for example, recruitment and retention and understand workforce movement. It needs to be able to respond and adapt to arising challenges and circumstances at national and local level.

Further work is also required to fully understand and then incorporate all elements of the social care sector into data collection and analysis. A number of barriers currently exist in this regard, such as homecare organisations who operate outwith Local Authority frameworks for referrals and care homes who predominantly or exclusively support self-funding residents. In order to effectively map and develop required supports and services - for instance when planning new provision to meet local needs, understanding pressure points or supporting business sustainability - this comprehensive intelligence is required at national and local level.

Text Box (Multiple Lines):

The conditions and culture need to be right in order to develop a truly functional and effective system. It must be secure, trustworthy and anonymous but most importantly, it must be clear and transparent regarding its intent and who is benefiting from the intelligence collected and generated. A human rights-based approach to its development must be prioritised which focuses on how all aspects of business intelligence can support outcomes for people. There needs to be confidence in how data is going to be used ethically, for example it should not be used as a mechanism for driving down costs or creating efficiencies but as a means of tracking and supporting business sustainability. This will involve recognition and a deep understanding of the range of 'businesses' that comprise health and social care, and careful consideration will need to be given to how to build a system without perpetuating inherent bias.

11 Thinking about improving the quality and ability to reuse data sets across health and social care setting and for innovation & research:

Text Box (Multiple Lines):

It should be noted that the social care sector is not working with good quality data at the moment. More work needs to be undertaken to identify and define key datasets and data points. Currently, partial data is held across a range of places with a distinct sense of incompleteness, limited relevance due to age and inconsistent collection mechanisms, and a lack of connectedness. This also leads to duplication and waste, with opportunities to use valuable data missed.

Consideration of a core minimum data set has potential to eradicate multiple assessments and duplication of formats of data required. Recognising the reality that data requirements for different parties will always vary, participants in Scottish Care's Data Forum events suggested identification of 10 most valuable data points as the basis for sharing. This could support consistency and confidence that the data has been gathered, generated, inspected, and verified in a reliable way. Insights from the Care Home Innovation Partnership discovered 15 core items of data collected by care homes which could be used to create the foundation for a minimum data set for care homes, as a starting point for this approach.

Part 3: Empowering Industry, Innovators and Researchers

12 When considering the ethics of accessing health and social care data for commercial, development and research purposes:

Text Box (Multiple Lines):

Working with good quality data would enable industry and innovators to improve their products and services, but their relationship with that data will need to be carefully managed. We would recommend that access to and use of health and social care data should be qualified by or premised on

engagement with services and citizens, since data alone may not tell the full story.

It will also be important to incentivise - through appropriate funding and resource - to enable engagement by and with industry and innovators. There is an appetite for innovation within the social care sector but it must be resourced appropriately to ensure organisations and the workforce have the capacity to engage and participate in innovation opportunities. This can in turn support the development and innovation which is truly grounded in the needs and aspirations of citizens, services and the health and social care sector.

Text Box (Multiple Lines):

As we have highlighted across responses to Digital, Technology and Data strategies for health and social care, there is a need to consider the ethics of procedures and approaches but also in mindsets and practice. By building on existing work such as Scottish Care's 'Human Rights Charter and Guidance Document for Technology and Digital in Social Care' and 'Seeing the Diamond in Social Care Data' data principles and using mechanism such as these for endorsement or mandating, we can help to provide assurance that all who contribute to, access and use health and social care data are doing so for a common purpose and shared vision. In addition to frameworks and principles we also recommend developing scenario examples to support ethics in practice.

Text Box (Multiple Lines):

Anything which goes against the vision, aims and ethical foundations of the Strategy would be unacceptable usage.

Text Box (Multiple Lines):

As previously articulated, we strongly suggest that Scottish Care's work on a Charter and accompanying Guidance is used as a tool or framework for mandating the ethical foundations of work in this area, and the co-produced principles for social care data contained within our 'Seeing the Diamond in Social Care Data' report can provide practical parameters for access and use. Consideration could also be given to what assessments, standards or kitemarks could be developed to signify compliance and commitment to an ethical and human-rights based approach. Transparency, clear information and evidencing value must be central to the vision in order to encourage and maintain the widespread buy-in, trust and culture change required across all stakeholders to achieve the Strategy's aims.

13 We want to create an infrastructure that supports access to data for research and innovation in a safe, secure, and transparent way:

Text Box (Multiple Lines):

Text Box (Multiple Lines):

A key data need and current gap is the ability for real time data sharing and the reality of fragmented data. We do now know much is presently being missed - in terms of intelligence and opportunity - by not having right information in the right place at the right time.

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:

Text Box (Multiple Lines):

Scottish Care's 2020 'TechRights' report provides an analysis on the benefits of using AI in these contexts and details some examples of adoption in practice in Scotland where AI is already supporting citizen independence and preventative care approaches. It also highlights the human rights risks associated with automation in decision making and particular issues related to empowering the workforce, as well as articulated concerns regarding the ethical use of personal data and ownership ambiguity. In summary, we believe there is a place for AI in health and social care where it serves to complement rather than replace, and it must be moderated by people. We recognise there are aspects of data collection and analysis where AI can potentially improve accuracy but it must also be recognised that it can also have blind spots and be impacted by inherent bias, and therefore does not always provide 'truth' or the full picture. There must therefore be parameters developed and shared around where AI is acceptable and useful.

Text Box (Multiple Lines):

Overall Reflections

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

Text Box (Multiple Lines):

We strongly recommend that the Strategy is informed by Scottish Care's 2021 'Seeing the Value in Social Care Data' report, which is referenced throughout our response. It provides a human-rights based perspective on creating value in social care data and addresses many of the questions contained within this consultation, as well as providing a set of principles for social care data which have been co-produced by cross-sector data forums including those with direct sectoral experience.

As highlighted by this report, we wish to reiterate the need for developments of technology and digital in health and social care - including those related to data - move away from a continued focus on the needs of the service and system. Defining, designing and developing the role and use of technology and digital in social care needs to be framed by the aspirations of the person, the care context and situation, and the intention, outcomes and appropriateness of the role of technology and digital before considering the functionality and form of the resulting technology/digital enabler or support.

Specifically in the context of social care, we also call for more design and development that begins with social care at the outset, emerging from a process of understanding, identification and exploration to meet the needs, challenges and aspirations of the people and the sector, rather than be ported,

modified or adapted from an initial health context focus and perspective. This is especially important in the context of data. It required in-depth exploration of the infrastructure, dynamics and rhythms of care practice to establish what data exists, what is needed, where it is held and what it can't tell us, as well as what it can.

Therefore to achieve the ambitions of the Health & Social Care Data Strategy and to deliver what is required for the diversity of contexts, circumstances and individuals encapsulated by health and social care, there is a need for a rights-based approach to design, development, implementation and scale. We recommend prioritising a human rights mindset and approach to enabling many of the ambitions included in the strategy and as a vehicle to realising collaboration across multiple groups, partners and sectors. Prioritising human rights as a foundation and embedding human rights as an approach will help to ensure that the responses to the areas and actions proposed within the strategy meet the needs of the people and groups intended, by recognising and involving their voice throughout the process.

It is critical that the independent sector, particularly the independent social care sector, is recognised, valued and included as providing a key voice and contribution in driving forward and realising many areas of the strategy. The independent sector provides 90% of care home places for adults in Scotland, delivers over 55% of home care hours for older people and employs over 104,000 people.

Scottish Care commends the approach taken by those engaged in the development of the Strategy, which has prioritised meaningful and regular engagement with the independent social care sector as well as other stakeholders. We hope this approach will be maintained and built upon as the Strategy develops and implementation gets underway, and we look forward to further contributing positively.

About you

What is your name?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:

Scottish Care

If answering for an organisation, from which sector is your organisation?

other

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

Publish response with name

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent

Evaluation

Please help us improve our consultations by answering the questions below. (Responses to the evaluation will not be published.)

Matrix 1 - How satisfied were you with this consultation?:

Very satisfied

Please enter comments here.:

Matrix 1 - How would you rate your satisfaction with using this platform (Citizen Space) to respond to this consultation?:

Very satisfied

Please enter comments here.: