

Health and Social Care Alliance Scotland (the ALLIANCE)

ALLIANCE response: Data Strategy for Health and Social Care

12 August 2022



Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the Scottish Government's consultation on a Data Strategy for Health and Social Care.¹ The development of Scotland's first ever dedicated Data Strategy for Health and Social Care presents an opportunity for Scotland to become a world leader by building the infrastructure to allow people to have more choice and control over their data.

This response is informed by consultation and engagement with our members and partners on digital health and social care policy and practice across Scotland. Our 'My World My Health' project (in partnership with the Digital Health and Care Innovation Centre) explored people's views on how data related to the wider determinants for health might be used for health and wellbeing.² In November 2021, we published our response to the refreshed Digital Health and Care Strategy for Scotland,³ and in January 2022, we held a member's event to inform the draft Data Strategy for Health and Social Care. This response also reflects on insights from research carried out by the ALLIANCE and Self Directed Support Scotland, 'My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland'.⁴

Since 2011, the ALLIANCE has also managed the ALISS (A Local Information System for Scotland) Programme.⁵ ALISS is a national digital service funded by the Scottish Government and co-produced with citizens and professionals living and working within communities throughout Scotland to help people find and share information about a wide range of organisations, groups, services, and activities that can support health and wellbeing and help people to live well. ALISS was developed as a tool to support asset based approaches to health by helping people to find and connect with the assets that exist in their own local communities, based around the things which matter to them across a range of sectors and agencies.⁶ ALISS information is crowdsourced, meaning that organisations, groups, and individuals across Scotland can work together to build and maintain this.

Part 1 – Empowering People

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?

Good quality data is essential to inform health and social care, both to ensure people receive person centred care, tailored to their rights and circumstances, and to improve health, care, and services at a system-wide level. This can mean ‘individual level data’ about individual people, whether they are identifiable from the data or not. It can also mean ‘aggregated data’ which is information taken from the health records of many different people that has been pooled together, for example to produce statistics.

It is important that what is meant by ‘data’, including ‘individual level data’ and ‘aggregated data’ is explained clearly to the public using consistent messaging in an inclusive and accessible way. As outlined in our response to Question 3A, information should be made publicly available in multiple and inclusive formats.

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?

Access to - and having greater control over - personal data were important issues which surfaced through the ALLIANCE’s ‘My World, My Health’ project. We welcome the inclusion of these themes through the development of a Health and Social Care Data Strategy. ALLIANCE members and partners have raised several considerations and priorities in relation to access and control over data. These are summarised below:

1. **Access to their own health and social care records.** ALLIANCE members and partners have raised repeatedly that individuals are unable to see all their health and care data. This inability to see one’s own data can affect people’s ability to make informed choices about their own care. People being unable to correct inaccuracies within their health records is also seen as disempowering, as well as potentially leading to inappropriate treatment pathways. Participants have emphasised the importance of being offered full control over their data, enabling them to see ‘the full picture’ across health and social care. This would enable person centred care, greater collaboration and ensure informed consent is in place. It would also mean that administrative burdens on agencies could be reduced. Individual health and social care records should also be able to be shared across relevant health and social care services if the person grants permission.
2. **Right to contribute information.** Individuals should have the fundamental right to contribute information to their personal records. Having the right to

contribute information to personal records can help to enhance understanding of conditions and enable better care, particularly where several healthcare practitioners are involved. Notably, however, this will require a cultural power shift, moving away from closed notes written by practitioners to a more transparent approach where individuals can access correspondence and information related to them and add their own perspective.

3. **Options to allow or withdraw access to their data.** Having options to allow or withdraw access to individual data recognises the fact that circumstances can change, affecting people's willingness to share their data. It also accounts for certain types of data being more sensitive than others.

It is important to note, in the context of access and control, that consideration must be given to individuals who may not want to – or might be unable to – take on this level of responsibility. Individuals should be offered the choice of how involved they wanted to be in managing their health and care data. For example, individuals might not want to have to authorise each of a series of interdependent referrals within NHS departments, if they were all linked to the treatment of a specific issue. This could instead be consented to at a higher level, under specific conditions (for example, that the data is only being shared with relevant professionals, for care provision and not sold to any third parties). Additionally, various personal circumstances should be considered (for example, homelessness, experiencing domestic violence), digital skills and competencies, health conditions (including those who have carers with Power of Attorney rights), guardianship, and people who lack capacity due to disability.

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?

We agree that where people are unable to interact with their own health and social care data, delegating access to a trusted individual would be appropriate. However, it is important that robust safeguards are in place to mitigate risks of harm and to prevent decisions being made that would go against the will and preference of the individual. The ALLIANCE recommends implementing a supported decision making model, in line with the underpinning principles and articles of the United Nations Convention on the Rights of Persons with Disabilities.⁷ Adopting a human rights based approach will help to ensure that the individual's rights, will and preferences are fully considered throughout decision making.

Similar consideration needs to be given to empowering individuals in coercive circumstances – such as abusive relationships – to maintain their own access and control to their personal information, alleviating the risks of harm.

3A. What information would you find most useful in providing clarity over how your data is used in a consistent and ethical manner?

It is important that information on how data is being used is clearly communicated to the public. As a starting point, information should be made publicly available in plain English and free from jargon. As outlined elsewhere, information should be accessible in multiple, inclusive formats. Accessible communication should follow the Six Principles of Inclusive Communication,⁸ and should be publicly available in multiple formats, including Community Languages,⁹ British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats. The ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communications and information provision is inclusive for all.

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.

Research carried out by the ALLIANCE and Self Directed Support Scotland, 'My Support My Choice', highlighted that there are concerning gaps in national and regional data gathering and analysis around social care.¹⁰ Disaggregated data gathering and intersectional analysis is essential to inform health and social care service design, delivery and improvement.

To avoid gaps and improve analysis, we recommend systematic and robust data gathering by local and national public bodies on people who access social care, disaggregated by all protected characteristics, as well as other relevant socio-economic information like household income and the Scottish Index of Multiple Deprivation (SIMD), in line with the principles of consent, choice and ownership.¹¹

Equalities monitoring data should be gathered, including demographic groups outwith the protected characteristics, to ensure a robust human rights based approach. This will help to ensure that the rights of those who are potentially most at risk of health and social care inequalities, and who have least access to services, are protected. For example, this may include (but is not restricted to) care experienced people, survivors of trauma and/or abuse, and victims of crime. This data should be published regularly and made available to the public, after following standard research ethics around anonymity for respondents.

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?

During an ALLIANCE engagement event to inform the development of the Health and Social Care Data Strategy, participants indicated that it may take some time for the public to gain trust in how their data is being used. Efforts are needed to continually increase digital confidence and understanding of how data is collected, used, and stored.

The ALLIANCE's 'My World, My Health' project provided an opportunity to explore public trust around health and social care data. The report found that individuals shared concerns around privacy and mistrust of sharing information. Participants valued relationships based on trust where they were empowered to share information themselves.¹² Additionally, mutual trust and respect between systems and citizens was identified as an important element in empowering people to understand and make decisions relating to data sharing. The following considerations were identified as important in improving trust:

- People who access and provide social care support should be educated in data collection and digital health and social care, to ensure meaningful consent and understanding, and maximise opportunities to engage with digital technology while still ensuring people's safety and privacy are preserved.
- Transparency is key to building trust in healthcare professionals and the wider systems in which they operate. It is important that the purposes for data collection, use and sharing is clear and transparent. Data should also be used to benefit the individual, community, or wider society. As summarised by one participant, people "need to know exactly where that information is being taken and how it's being used to their benefit, not the agency's benefit".¹³
- Clarity was identified as an important method for improving public trust and confidence. Simple changes, such as professionals avoiding the use of jargon and complex terminology, can help to mitigate existing power dynamics, and create more accessible systems and information.
- It is important that people are able to decline sharing data at any time, and at no detriment to them or to the quality of health and social care support they are accessing.
- Data must be used or collected appropriately, and only in line with the informed consent of the individual. There should be no collection, use or processing of personal data without full and informed consent of the individual.

Public trust could also be improved by embedding human rights principles in data systems. Alongside Scottish Care and VOX, the ALLIANCE engaged with stakeholders and individuals across Scotland to co-produce a set of five Human Rights Principles for Digital Health and Social Care.¹⁴ The ALLIANCE recommends that these principles are adopted by all developers, providers, commissioners, and supporters of digital in health and social care to ensure that the provision of new services and digital systems do not inadvertently impact on the rights of people living in Scotland.

4A. Are there any health and social care situations where you might be uncomfortable with your data being shared?

The ALLIANCE recognises that there are situations where people may be uncomfortable with their data being shared. It is important to acknowledge that this will vary between people, and between situations and circumstances. We recommend that robust safeguards are put in place to ensure that people have choice and control over how and when their data is shared, and that decisions to share data are based on informed choice. People should also be offered meaningful opportunities to support them to make decisions.

4B. Under Data Protection legislation, your health and social care data can be shared in order 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 section?

As outlined in our response to Question 4A, it is important to recognise that the situations where people may be comfortable with their data being shared will vary between people, and between situations and circumstances. It is important that a person-centred approach is taken to data sharing.

During a recent ALLIANCE engagement event, participants identified certain circumstances in which they would be comfortable sharing health and social care data. It was recognised that there is value in sharing data with third sector organisations providing services to people, as well as health and social care staff working for public bodies, where appropriate.

Participants also shared that health and care data could be used by research professionals, but only under strict conditions that protect confidentiality. This is often facilitated by placing data in a 'Data Safe Haven', where it can only be accessed by authorised individuals after the research project has been signed off by a panel of information governance experts. One participant noted that they would also be happy to share personal data, without anonymity, if it were intended for the use of students, academics or researchers, through university teaching or research settings, and for the purpose of helping avoid other people having to experience what they themselves have gone through.

Participants also noted that they would like to see health, social care, and public services (for example, NHS, councils, social care, education) using systems that were compatible with each other and that could share vital information between them. Again, it would be imperative that these systems were underpinned by full and informed consent from the individuals whose data they handle. The main reasons given for this were:

- **To avoid repeating one's story:** individuals should not have to keep repeating their story, needs and circumstances to access services. The administrative and emotional burden of having to do this was highlighted to be particularly high for people living with sensory loss, long term, or rare conditions.
- **To provide safe care:** when people engage with different parts of the health and social care service, they may be offered conflicting advice or solutions if data is not shared; for example, medications with adverse interactions could be prescribed in parallel.
- **Reporting:** systems should have the ability to analyse data quickly and easily, on various levels. For example, at an individual level, those providing care should be able to see all the relevant information for the person they support; at a population level, public services should be able to draw anonymised reports on demographics and real-time needs to better target their services.
- **Improving data gaps:** the issue of the gender data gap was raised as an example, noting that we need to ensure that the needs of seldom heard and marginalised population groups are considered on an equal footing to meaningfully improve services.

5A. Do you gather your own health data for example measuring activity, sleep patterns or heart rate through a mobile phone or watch? 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?

Our 'My World, My Health' project explored what information people collect and hold themselves on the wider determinants of health, and why they do it.¹⁵ Where participants said that they did collect information, it was mostly related to activity levels or specific symptoms, with the direct aim of benefiting their health.

The findings highlighted that people with long term conditions were likely to collect more data than others and in a more structured way, which was a necessity rather than a choice. This information was most often used for self management or for sharing with health and social care practitioners. Some participants collected raw

data using digital means, such as activity levels, glucose levels, and diet. However, others collected more general information using a mix of paper and digital methods, such as appointments, and journaling.

Participants living with sensory loss were also more likely to collect information about their daily habits, meetings and commitments:

“This was due to the nature of living with sensory loss, which made them more reliant on technology to take part in everyday activities. This in turn also meant there were more data flows and integrations to consider. A large proportion of participants living with sensory loss also tracked health and fitness data [...] Fitness data was mainly tracked and recorded for motivation, lifestyle and diary data was captured to help them keep track of appointments, help with memory issues and to ‘keep busy’.”¹⁶

Those who collected information mostly shared it with health professionals and friends or family. However, participants did share some concern about how healthcare professionals may interpret data, particularly towards marginalised groups:

“LGBTQI+ participants seemed more comfortable sharing information with health professionals in comparison to friends or family. In the ethnic minority workshops the opposite applied. However, in both these communities there was increased concern that prejudiced or biased professionals might misinterpret data and offer inadequate treatment in response.”¹⁷

Part 2 – Empowering 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?

The ALLIANCE agrees with the skills and training gaps outlined in the consultation document. In addition, we would also highlight the need for understanding of equalities and intersectionality in the context of health and social care data, as outlined in our response to Question 3B.

6B. How do you believe they should be addressed?

We welcome the commitments within the strategy which focus on data skills and training of the workforce. When new IT systems are introduced, there should be training programmes or modules available for health and social care professionals to work through, to support them being able to use the systems with proficiency.

In addition to this, we would like to highlight that there are additional and alternative roles emerging, which are increasingly required to support people to access digital

and develop the necessary skills and confidence. These new roles will be paramount to supporting a more connected and equitable society and therefore need their own investment and resource, as well as ensuring that there is equity in support provision across sectors. This includes sustainable and long-term funding for third sector health and social care organisations.

As highlighted in our response to the Digital Health and Care Strategy, there is no specific reference to supporting, upskilling and empowering unpaid carers.¹⁸ We know that unpaid carers make a substantial contribution to the provision of care and support across Scotland. The Health and Social Care Data Strategy, as well as other overarching digital strategies, should explicitly recognise their contribution and outline the tailored support that will be provided.

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?

To ensure that the public have access to health and social care data that they can understand and use, the ALLIANCE recommends:

- Embedding meaningful co-production with people with lived experience, and the third sector organisations that support them, to ensure that accessible design and inclusive communication is at the heart of the new Health and Social Care Data Strategy.
- Improving understanding of digital inequality, and the barriers people face that can limit their digital interactions even when they have the necessary resources, confidence and skills. People living with sensory loss, dementia or other conditions often have to navigate systems and services that have not been designed to suit their needs. Additionally, people are often unable to access digital health and social care due to rurality and poor or slower connectivity compared to urban counterparts. This lack of inclusive design within mainstream services, as well as a lack of integration with assistive tools, can mean that some population groups are often left behind.
- Investing in training, upskilling and resources to support people to access, use and understand health and social care data. This must include individuals, unpaid carers, third sector health and social care organisations, and the wider health and social care workforce.

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

Please refer to our answer to Question 6C.

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?

The ALLIANCE's role will be to promote best practice in the collection of health and social care data. We will continue to engage with our individual and organisational members across the third sector and public sector on the future uses of health and social care data. In all aspects, the ALLIANCE will put people at the centre, upholding the principles of equalities, human rights and intersectionality to empower people to access their health and social care data.

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?

Health and social care professionals should be able to access and overlay data sets from external sources with a view to improving the services they provide. For example, this could include census data or other demographic information (e.g. household income or Scottish Index of Multiple Deprivation (SIMD) classification), enabling providers to better target or promote their services.

Data from ALISS could be integrated into health and social care systems to enable professionals to easily suggest or make referrals to appropriate community assets for the people they are working with.

The ALLIANCE believes that prioritising both qualitative and quantitative data is essential if people's personal outcomes and rights are to be monitored and measured with a view to continuous improvement and progressive realisation of people's rights.

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?

Strongly agree.

The ALLIANCE supports the development of national data standards to ensure the safety, quality, and reliability of how data is used, collected, and stored across Scotland. Data standards will also help to ensure accuracy, consistency and interoperability of systems and can assist in data collection.

The ALLIANCE's ALISS Programme is built on Human Service Data Specification, which provides a 'common language' for information about services, the organisations that provide them, and where they can be accessed.¹⁹ For example, through partnership work with NHS 24 and Macmillan Cancer Support, data from

ALISS can also be found through Scotland's Service Directory on the NHS Inform website.²⁰

The ALLIANCE recommends that this approach is built upon and embedded within the Health and Social Care Data Strategy to promote interoperability and to enable resource directories across different sectors to 'talk' to each other. The Data Strategy for Health and Social Care should also be used to inform development of key policy areas, including the proposed National Care Service and Mental Health Law reform.

The ALLIANCE recommends that national standards are co-produced to ensure that standards improve outcomes of disabled people, people living with long term conditions, and unpaid carers. Public Health Scotland and groups responsible for data collection should work closely with the Scottish Government to highlight areas of concern and improvement within existing and emerging datasets. Meaningful co-production should include people with lived experience of accessing health and social care services, third sector health and social care organisations, and the health and social care workforce.

8B. What data standards should we introduce?

The ALLIANCE recommends that data standards should be developed in line with the nine Core Principles for good practice in data collection and digital systems for healthcare, from the 'My World, My Health' project.²¹ These are:

- **GDPR:** Data should only be collected, processed and shared in line with the GDPR key principles: lawfulness, fairness and transparency; purpose limitation; data minimisation; accuracy; storage limitation; integrity and confidentiality; accountability.
- **Consent:** Individuals should be empowered to make informed decisions about any uses of their personal data. Consent should be given freely, without any pressure, repercussions, or fear of discrimination.
- **Purpose:** The purpose for any type of data processing must be clear, transparent and for the benefit of either the data subject or wider society. Personal data should not be collected, used and shared for commercial gains unless informed consent for this specific purpose has been granted.
- **Lived Experience:** Data processing should not replace opportunities for people to share their own stories and experiences with those involved in their care. Data might be used to complement and provide evidence in support of one's narrative but should not replace it fully.
- **Choice:** Care must be taken to ensure that if individuals do not want to opt-in to data-enabled processes there are no negative consequences to them

because of this.

- **Ownership:** Data subjects should have the right to own and control their own data unless they take an informed decision to pass this responsibility to someone else. Owning their information, individuals can amend it, grant and remove access permissions as necessary. This can help build one-source of truth whilst also empowering individuals to control their own information.
- **Trustworthiness:** Consideration needs to be given to whether data is accurate. Do people have the devices, skills or connection required to gather it? If the data effects any benefits or sanctions, will the quality of self-reporting be influenced? We must also ensure that any data which will affect decisions is validated and interpreted without biases or prejudices.
- **Education:** Data education is needed for members of the public, professionals and support workers to ensure that: those whose data is collected, processed, and shared fully understand what they are consenting to and are empowered to make decisions with regards to their own information; and those using data understand its potential uses and can maximise on the opportunities provided, while ensuring the safety and privacy of those they are supporting.
- **Safeguarding:** Data must not be used to stigmatise or discriminate against individuals unfairly. We must ensure that decision making processes, whether automated or made by individuals, do not have inherent biases that could be detrimental to individuals' wellbeing. Steps must also be taken to ensure data is not misinterpreted or used for malicious purposes.

We also recommend that national standards are informed by Human Rights Principles for Digital Health and Social Care, as developed by the ALLIANCE in partnership with Scottish Care and VOX.²² These are:

- **People at the centre:** People should have access to inclusive and flexible digital services that meet their needs, rights, preferences and choices, with support if appropriate. Digital services should be focused on the best outcomes for the person, not the needs of the service or the health and social care system.
- **Digital where it is best suited:** People should be involved in deciding how, where and when digital is used in health and social care, and co-create rights based digital services to ensure they are appropriate and effective. Digital services are not always appropriate and should not automatically be the

default health and social care service.

- **Digital as a choice:** People should be able to make an informed choice between using digital or non-digital health and social care services – and to switch between them at any time – without compromising the quality of care they experience. People should be fully involved in decisions made about their care. This should include information about any digital options being considered, and the non-digital alternatives.
- **Digital inclusion, not just widening access:** People should have access to free training and support to develop the skills, confidence and digital literacy they require to make a meaningful choice whether to access digital health and social care services. Digital services should be accessible, trustworthy and inclusive.
- **Access and control of digital data:** People should have access to data held about them by health and social care services and have control over this data and how it is used. People should give free, prior and informed consent to the use and sharing of their data, particularly outside health and social care. If consent is given, sharing should allow people to avoid ‘re-telling their story’, be straightforward for all involved, and maintain the highest possible security before, during and after sharing.²³

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?

Yes.

With regard to data sharing, many research participants in ‘My Support My Choice’ reported a lack of communication between different service providers (especially between health, housing, and social care sectors). This disconnect meant they were required to revisit trauma and recount their experiences unnecessarily. In addition, many ALLIANCE members who work with children and families as they transition into adult services describe a similar disconnect and lack of joined up support planning and communication taking place.

Greater sharing of an individual’s health and social care data between organisations in the health and social care sector could help to alleviate some of these problems. It is important that systems for record keeping and data sharing should include varied levels of access to people’s health and social care data – and that the criteria for what data is available to whom is co-produced with disabled people, people living with long term conditions, unpaid carers, and health and social care professionals.

Data sharing should also not be restricted to health and social care staff working directly for Community Health and Social Care Boards or local authorities. It is important that third and independent sector organisations providing services to people should have access to data where it is appropriate and the assessment of appropriate access should be in dialogue with and led by the person accessing support. For example, third sector organisations providing shopping for people should have access to information on their allergies, dietary requirements, food preferences, and any factors that affect their food preparation habits.

As outlined elsewhere, data sharing must be underpinned by full and informed consent, choice and control. In the ALLIANCE's 'My World, My Health' project (in partnership with the Digital Health and Care Innovation Centre), one of the key conclusions was as follows:

“An overwhelming majority of our participants stated that the individual whose data is collected, processed, and shared should be in control of how this is done. It was also argued that there needs to be rigour in the use of data, in line with the individual's consent. Furthermore, the purpose of the data processing should be for the benefit of the individual or wider society. There should be no adverse effects to individuals whether they opted-in or -out of sharing data.”²⁴

It is important that service users' personal information is only shared with their consent and/or that of their Guardians, and that the use and retention of that information, as well as who will access it and for what purposes, is clearly conveyed to the individuals in question.

10A. What are the priority pieces of management information needed (that are not currently available) to provide better health and social care services?

We agree that the Health and Social Care Data Strategy should include management information in addition to individuals' data. This will help to inform decision making around the design and delivery of health and social care services. Improved data is needed in areas including NHS waiting times, the scale of the health and social care workforce, and improved data collection and analysis around people's experiences of accessing social care and support.

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

It is important that data is gathered on people's experiences of accessing health and social care services across Scotland. As detailed elsewhere, disaggregated data gathering and intersectional analysis is essential to improve service design, delivery and development at national and local levels.²⁵

The ALLIANCE recommends systematic and robust data gathering by local and national public bodies on people who access social care, disaggregated by all protected characteristics, as well as other relevant socio-economic information like household income and Scottish Index of Multiple Deprivation (SIMD) classification. Non-protected characteristic data should be gathered to ensure a robust human rights based approach – so that the rights of those who are potentially most at risk of health and social care inequalities, and consequently have least access to services, are protected.

The ALLIANCE also recommends that a mixed methods approach to data collection is adopted. Data collection to provide business intelligence for health and social care organisations should allow for personalised, qualitative responses as well as quantitative data analysis, should be developed in co-production with people who access services and their families and unpaid carers, and draw upon existing expertise within the third sector.

This prioritisation of both qualitative and quantitative data is essential if people's personal outcomes and rights are to be monitored and measured with a view to ensuring continuous improvement and progressive realisation of people's rights. A mixed methods approach that embeds a human rights based approach would help to ensure that appropriate weight and priority is given to people's experiences alongside nationwide statistics.

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?

As referred to in our response to Question 7C, there are multiple existing open data sets which could be accessed and overlaid onto health and social care information to improve and better target services.

Organisations collecting data should be encouraged to make it openly accessible to others who may make use of it for health and social care purposes, subject to data protection legislation.

A personal data store and personal data architecture would help to reduce duplication of effort and stop people having to re-tell their story multiple times. Personal data stores can enable greater integration between health and social care data sharing, improve personal outcomes, and embed principles of trust, privacy and human rights into health and social care practice. As summarised by Mydex CIC:

“The most important thing is ensuring easy, safe and secure sharing is possible; that, provided they want to, citizens can share information about health and care needs with the minimum of friction, effort, risk and cost across the services they use to receive care and support.”²⁶

Part 3 – Empowering Industry, Innovators and Researchers

12A. How do you think health and social care data should be used by industry and innovators to improve health and social care outcomes?

As outlined in our response to Question 10B, data should be collected using a mixed methods approach to survey people's experiences. Prioritisation of both qualitative and quantitative data at industry and innovator level is essential if people's personal outcomes and rights are to be monitored and measured with a view to ensuring continuous improvement and progressive realisation of people's rights.

Additionally, analysis of results should be published in accessible and publicly available format on at least an annual basis, in accordance with standard research ethics regarding participant anonymity. This should include intersectional analysis on how health and social care is working for different groups of people across Scotland. This would enable targeted action to ensure everyone has access to high quality health and social care and support. Relevant organisations should be appropriately and sustainably resourced to carry out this data collection and analysis at national and local levels. This analysis should include use of Equalities and Human Rights Impact Assessments as practical tools to inform policy and assess its impact.

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?

As more public services move to digital platforms, personal privacy and digital security concerns are crucial. This is particularly true in the health and social care sector which inherently revolves around discrete and confidential personal information. We recommend that the considerations outlined in our response to Question 3C are considered in relation to industry and innovators, as well as health and social care professionals and organisations.

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

Any use of health and social care data by industry, innovators, and researchers, which was not underpinned by full and informed consent of the individual whose data is being used would be unacceptable. As outlined elsewhere in this response, the principles of consent, choice, control and transparency must be upheld.

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 recommend that industry, innovators, and researchers develop robust processes to support people to understand and – if they are then happy to do so – consent to

their anonymised data being collected and used to inform analysis. These actions would increase public understanding of and trust in data collection for health and social care, and support wider public health.

Data should be made publicly available on at least an annual basis and include information on how health and social care data is being used, for what purpose, and its impact on different population groups. Information should be available in a range of accessible and tailored formats (for example, hard copy and digital; large print; Braille; Easy Read; BSL).

People should also be able to access information easily and quickly to enable control over their own individual level data. This should extend to trusted individuals, provided that robust safeguards are in place to mitigate risks of harm.

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?

During an ALLIANCE engagement event to inform the draft Health and Social Care Data Strategy, members shared views on what technology should be used to access data. Members proposed various examples and suggestions, including:

- **Blockchain technology.** Use of Blockchain technology to ensure that the individual is in control of data and can share it as they wish, allowing them full choice and control. It was highlighted however that there is not enough awareness of this opportunity and that the public need to be better informed of the possibilities.
- **Personal data store function.** Based on current practice in England, it was suggested that individuals could have access to a personal data store function. This would enable the person in control of their data to assign control to others, such as friends or family. Mydex CIC are currently helping individuals and service providers use personal data to better manage chronic health conditions, access debt advice, improve independent assisted living and assure digital identities.²⁷
- **Interoperability:** There is currently a lack of consistency, or complete lack of interoperability of systems currently in use. We welcome the commitment to facilitating enhanced interoperability as outlined in the Health and Social Care Data Strategy. Consistency across the Scottish health and social care landscape is key to ensure information is shared effectively. As outlined in the consultation document, “health and social care data is often held in silos”. We therefore welcome the aim to bring greater interoperability to health and social care data and systems by seeking to apply a more consistent approach to data standards. This will help to create greater consistency in how

organisations across health and social care gather, store and share data.

- **Open data:** There is a need to embed open data principles and open referrals standards within this as well to reduce homogeneity. ALISS is an example of good digital practice that is founded on open data principles. ALISS plays a specific and practical role in relation to both access and infrastructure by enabling organisations to use the ALISS platform for developing or enhancing their own directories, or for creating signposting systems by surfacing the co-produced ALISS dataset, rather than using scarce resources to create new, siloed directories which can in turn contribute to an already cluttered landscape. Developers should use open source platforms which can be built on and improved upon by others to ensure inclusivity and accessibility across digital services.

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?

We have referenced some of the key data needs and gaps in health and social care throughout this response. There is a need for robust and systematic data gathering in the following areas:

- Data gathering by local and national public bodies on the number of people who access social care and support;
- Data collection and analysis around people's experiences of accessing social care and support;
- Gathering of equalities monitoring data, including demographic groups outwith the protected characteristics; and
- Improved data on management information, including NHS waiting times, and the scale of the health and social care workforce.

14A. What are your views on the benefits of using AI to improve the delivery of health and social care services?

The introduction of Artificial Intelligence brings new opportunities to ensure that the best use is made of data to achieve health and wellbeing outcomes.²⁸ However, we must ensure that people's rights, voices and preferences are continuously sought in the development of Artificial Intelligence solutions and that there is public awareness on the issue.

14B. What safeguards do you think need to be applied when using AI?

The use of Artificial Intelligence should be based on robust evidence gathering and information, which considers the potential risks and impacts on different population

groups. The ALLIANCE recommends carrying out Equality and Human Rights Impact Assessments to fully consider the impacts of Artificial Intelligence.

Robust regulatory frameworks will be needed to mitigate risks of harm and to ensure that the rights of people are actively respected, protected and fulfilled. Systems of Artificial Intelligence will need to be carefully implemented, monitored and maintained to ensure they are fit for purpose and do not infringe human rights. It is important to guard against algorithmic biases that can contain skewed human decisions or represent historical or social inequities.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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² The ALLIANCE, 'My World, My Health'. Available at: <https://www.alliance-scotland.org.uk/digital/get-involved/my-world-my-health/>

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⁷ United Nations, 'Convention on the Rights of Persons with Disabilities (CRPD)'. Available at: <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html> ; United Nations, 'Chapter Six: From provisions to practice: implementing the Convention – Legal capacity and supported decision making'. Available at: <https://www.un.org/development/desa/disabilities/resources/handbook-for-parliamentarians-on-the-convention-on-the-rights-of-persons-with-disabilities/chapter-six-from-provisions-to-practice-implementing-the-convention-5.html>

⁸ Inclusive Communication, 'Six Principles of Inclusive Communication'. Available at: <https://inclusivecommunication.scot/the-six-principles-of-inclusive-communication>

⁹ Community Languages are languages spoken by members of minority groups or communities within a majority language context. Examples in Scotland include: Arabic, Hebrew, Hindu, Makaton, Punjabi, Polish, Urdu.

¹⁰ The ALLIANCE and Self Directed Support Scotland, 'My Support My Choice: People's Experiences of Self-directed Support and Social Care in Scotland' (October 2020). Available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2020/10/ALLIANCE-SDSS-MSMC-National-Report-Oct-2020.pdf>

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¹² The ALLIANCE, 'My World, My Health'. Available at: <https://www.alliance-scotland.org.uk/digital/get-involved/my-world-my-health/>

¹³ As above, p.23.

¹⁴ The ALLIANCE, Scottish Care, and VOX, 'Human Rights Principles in Digital Health and Social Care' (2021), pp. 2-3. Available at: https://www.alliance-scotland.org.uk/digital/wp-content/uploads/2021/04/The-Next-Iteration-of-the-Human-Rights-Principles-for-Digital-Health-and-Social-Care_August2021.pdf.

¹⁵ As above, p.14.

¹⁶ As above.

¹⁷ As above, p.15.

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²³ The ALLIANCE, Scottish Care, and VOX, *Human Rights Principles in Digital Health and Social Care* (2021), pp. 2-3. Available at: https://www.alliance-scotland.org.uk/digital/wp-content/uploads/2021/04/The-Next-Iteration-of-the-Human-Rights-Principles-for-Digital-Health-and-Social-Care_August2021.pdf.

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²⁶ Scottish Government, 'National Care Service: consultation analysis' (10 February 2022). Available at: <https://www.gov.scot/publications/national-care-service-consultation-analysis-responses/pages/1/>

²⁷ Mydex CIC, 'About us'. Available at: <https://mydex.org/about-us/about-mydex/>

²⁸ Scotland's AI Strategy, 'About us'. Available at: <https://www.scotlandaistrategy.com/>

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