Consultation Response

vhs
voluntary health scotland

Data Strategy for Health and Social Care
August 2022

Background
Voluntary Health Scotland (VHS) is the national intermediary and network for voluntary health organisations in Scotland. We work with our members and others to address health inequalities and to help people and communities live healthier and fairer lives.

VHS has undertaken significant engagement and research with our members over the last few years on digital healthcare and data. During the pandemic we all experienced an acceleration in the use of digital healthcare and much more frequent use of healthcare data in the daily reporting of COVID-19 cases. In this context VHS has been working to ensure no one is left behind and health inequalities are not worsened by advances in technology.

In February 2022 we held a consultation engagement event with our members and the Scottish Government's Directorate for Digital Health & Care to garner the third sector's priorities for the data strategy. This gave our members the opportunity to feed into the strategy as it was being developed by government. Our response to this consultation takes into account the views expressed during that event and our previous engagement with members on data in health and social care.

Part 1 - Empowering People

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 (read our ethical principles on gov.scot) that must be maintained when gathering, storing, and using health and social care data:

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?

The collection of data to enable health and social care services to understand how they are serving those with protected characteristics is essential. It is also important that, where appropriate, this data is anonymised and made public to improve scrutiny and trust in systems. For example, during the COVID-19 vaccine rollout Public Health Scotland began publishing data on vaccine take-up by ethnicity in March 2021.[1] This was a welcome move, but an example of data collection which should have been built in from the beginning of the rollout. The data became a very important tool for policy makers in understanding the gaps and barriers for different marginalised groups in taking up the vaccine. Additionally, having this data publicly available allowed for third sector organisation to support the vaccine rollout by focusing resources on those in danger of being missed by the programme. Collecting data is key to our understanding of inequalities and without reporting it is more likely people will fall through the gaps. Reporting on the full range of protected characteristics also allows for a more intersectional approach to be taken in analysing and developing solutions.

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[1] https://publichealthscotland.scot/news/2021/march/vaccine-uptake-by-ethnicity/

Transparency and honesty need to be central to data collection to help build trust in services and reassure individuals about the purpose of data collection. Basing the collection, storage and use of this data on ethical principles is paramount. Some marginalised groups deeply distrust public services due to their own experiences of discrimination, inequality and fear of how these services interact. For example, in 2018 the Equalities & Human Rights Commission published a report which found fear of health service data being shared with the Home Office had a deterrent effect on asylum seekers engaging with health services.[2] This illustrates how distrust in services can worsen health inequalities, which underlines the importance of trust and consent in collecting data on people's health.

There are great examples in the third sector of organisations working to build trust in services, which will be essential as part of this strategy. For example, Circle works with families to identify and address unmet needs including providing information and support to help people to engage with health services. Actions are tailored to individual families and may therefore vary. They include: supporting a family to register with the local GP or optician; encouraging someone to engage with mental health services; helping an individual to plan a journey to the dentist; or building confidence so that an individual is more likely to participate in medical interventions. VHS published a report called Living in the Gap in 2015 which included a case study on the work Circle does.[3] It highlighted one example of a mother who was encouraged to engage with services after Circle supported her to do so:

> "We supported a single mother to undergo treatment for Hepatitis C that she had previously 'put off' for two years because of fears about being able to care for her children over the lengthy recovery. Her support worker researched treatment types and identified alternative medication with a shorter convalescence time-span and the mother engaged with this treatment as a result." – Circle

There is often a significant amount of fear and stigma associated with sharing health data for the reasons outlined in these two examples. Vulnerable people and families are reluctant to share data with authorities and health services as they don't know what the repercussions of that data sharing might be between services. A significant amount of trust will need to be built between services and marginalised communities as part of this strategy. The strategy itself will not solve all these problems, so it must be mindful of the people who will likely be missed or reluctant to share their data.

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?

From an organisational perspective, providing patients with the knowledge and tools to understand how their data will be collected, processed and stored along with what it will be used for is important. To that end, it is especially important to make clear that individuals' data cannot be passed on to another body, like the Home Office, without their permission. We have outlined the reasons for this in our answer to 3B citing the 2018 Equalities & Human Rights Commission report which found fear of health service data being shared with the Home Office had a deterrent effect on asylum seekers engaging with health services.[4]

We welcome the concept of patients being in control of their own health and care record. We believe this will improve trust in services and empower patients to better understand their

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[2] https://www.equalityhumanrights.com/en/publication-download/making-sure-people-seeking-and-refused-asylum-can-access-healthcare-what-needs

[3] https://vhsscotland.org.uk/wp-content/uploads/2015/03/VHS_LIVING_IN_THE_GAP_full_report_MARCH_15_WEBFRIENDLY_VERSION.pdf

[4] https://www.equalityhumanrights.com/en/publication-download/making-sure-people-seeking-and-refused-asylum-can-access-healthcare-what-needs

own health record and rights. We are hopeful the record may also prevent patients from having to constantly retell their story which we know from our members is extremely frustrating for patients and erodes their confidence in health services. We are pleased this has been recognised in the consultation document and welcome the ambition to "empower individuals to have greater access to, and greater control over, their own health and social care data."

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?

- **Understanding of what data exists and where to find it**
- **Knowledge of how to access data**
- **Confidence in using data**
- **Understanding of governance**

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

Third sector access to data

Third sector organisations working in health and social care often face significant barriers in accessing data from the NHS, even when they are involved in delivering care. Our members also highlight that it is a significant challenge having to reach out to each health board individually and then implement data sharing agreements with each one. They felt the single patient record could create a significant opportunity and streamline this process for charities involved in delivering services across multiple health boards.

Valuing third sector data

Barriers in data sharing are also often caused by misconceptions of data collected by the third sector. There needs to be a concerted effort to better understand the rich data source third sector providers and researchers collect. Many voluntary organisations deliver health and social care services and have a rich understanding of the people and communities they support. Policy makers need to better understand the data that exists in the third sector and have confidence in using it.

Training for the third sector

Additionally, once this strategy is developed any training on new frameworks for health and social care providers must also be provided to the third sector as a key provider of services. Networks like the Third Sector Research Forum (TSRF) would be a valuable partner in this. The Forum brings together third sector, academic and public sector partners to:
- promote and share research about and from the third sector
- encourage the use of third sector research to improve policy and practice
- produce resources and deliver events to support third sector researchers and encourage collaboration with academic partners.[5]

With the creation of a new Data Strategy for Health and Social Care it would be valuable for networks like the TSRF to receive resources to support the third sector and partners in addressing any training gaps. Equally the Scottish Government's Analytical Exchange programme is an excellent example of investment in the third sector to build research skills, which also benefits public sector analysts through partnership working.[6] Voluntary Health Scotland has taken part in the exchange programme this year and found it to be an incredibly valuable experience which will tangibly upskill our workforce. We also believe there could be a stronger role for NHS Education for Scotland in upskilling the sector.

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[5] https://evaluationsupportscotland.org.uk/tsrf/
[6] https://blogs.gov.scot/statistics/2022/01/31/analytical-exchange-programme-2022/

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?

Population level health and social care data
During the pandemic we saw some very creative ways of presenting health and social care data that made it very easy for the public to understand. For example, Public Health Scotland's COVID-19 Daily Dashboard allowed for people to search for anonymised data on case numbers in their own neighbourhood.[7] People were able to track the prevalence of the virus in the area they live which kept people informed at a very local level. This kind of creativity in presenting population level data should be encouraged as it empowers individuals to easily understand and search for data most relevant to them.

Sharing population level data publicly needs to go hand in hand with education to understand that data or it could result in stigma and discrimination in communities. Public health communications have a significant role in this. Equally the strategy needs to acknowledge the challenges in confidentiality if data is very localised especially in remote and rural populations. Data sharing must always be mindful in smaller communities of the potential stigma and loss of anonymity associated with smaller data sets.

Digital access and health literacy
People need better access to their own health and social care data and they must be supported to understand it. There is a clear and strong relationship between groups that are digitally excluded and those at greater risk of poor health. People from excluded groups or living in deprived areas often lack the skills, ability and means to get online. This could worsen health inequalities if people are not supported to access and understand their health and social care data. VHS was clear throughout our engagement on the Digital Health & Care Strategy that digital cannot be the only option in health and social care as this will inevitably leave those without access behind. The same applies with the collection of data in health and care, those without access to technology must not be left at a disadvantage due to the systems being created. Digital cannot be the only option for patients, this would serve to entrench health inequalities between those who can access their data and those who face barriers in doing so. Health inequality impact assessments must be built in to ensure no one is left behind.

Patients must also be supported to understand how they can share their data with other healthcare professionals to avoid having to retell their story multiple times. Supporting people to use their health and social care data involves empowering people to understand their right to health. Having a patient record will not improve access to health and care data for everyone. VHS held an event in partnership with NHS Education for Scotland on health literacy and health inequalities in June 2020.[8] Those in attendance heard that implementing digital technology has the propensity to widen inequalities and we need to ensure that tackling this is designed in from the very beginning. Tackling health inequalities needs to be central to this data strategy to avoid deepening this digital divide.

Apps may increasingly be part of the suite of options available to patients to enable them to both manage their own health condition and to share personal data with health care providers. VHS is currently working with the Digital Health & Care Innovation Centre (DHI) to support up to six third sector organisations to pilot use of the national Right Decision Service platform to deliver web and mobile apps. This is a key opportunity to deliver information in an easily accessible and engaging format to support third sector service users in making

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[7] https://public.tableau.com/app/profile/phs.covid.19/viz/COVID-19DailyDashboard_15960160643010/Overview/viz/COVID-19DailyDashboard_15960160643010/Overview
[8] https://vhscotland.org.uk/key-messages-digitally-healthy-health-literacy-and-health-inequalities/

informed decisions about health, care and wellbeing. Smaller third sector organisations do not generally have the inhouse technical knowledge or resource to develop and deliver apps, so the partnership with DHI will provide important lessons about how third sector capacity in this area could be strengthened. One small organisation that has applied for DHI support told us, "We envisage the App being first point of contact working in conjunction with other organisations, Health and Social Care Locality Partnerships and other third sector and statutory bodies. This would not only provide information to service users to allow them to take control of decisions as a strength-based system approach but would also highlight local activities, which we know local organisations can struggle to promote.'[9]

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?

Data sharing between the NHS and third sector health and social care providers needs to be easier. We have provided further details about this in response to question 6B.

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?

Third sector data provides a valuable insight into the communities we support in Scotland. Third and voluntary sector colleagues are well versed in providing rich qualitative data and insights from "experts by experience" as part of our work. The nature of the sector means we are often agile and able to react to developing or unforeseen situations, for example stepping in to support service delivery during the pandemic. This ability to react and support communities on the ground means the sector is a goldmine of valuable insights. However, third sector organisations need resourced to share these insights and maintain this agility. The sector is facing incredible pressure and burnout following on from the pandemic. Long-term and sustainable resourcing would enhance the third sector's role as a valuable source of person-centred data.

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?

If standards are mandated by the Scottish Government for gathering, storing, and accessing data at a national level then the third sector and voluntary organisations need to be supported and resourced to make these changes. We would support any move that makes accessing health and social care data easier for the patient and those supporting that patient. However, training would be required in the new standards along with time to adjust systems. This must also be mindful of the significant pressure health and social care services and the third sector are under as part of the recovery from the pandemic.

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

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[9] https://vhscotland.org.uk/event/data-strategy-for-health-social-care-scottish-government-engagement/

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, we believe 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. We have discussed the benefits of improving data sharing between third sector organisations involved in service delivery and health and social care services in response to question 6B. This will reduce the number of times patients have to repeat their story and allows for services to be better informed about patient care. Ultimately, we believe data should be within the patient's control with their right to share as they see fit.

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?

Publishing anonymised and population level health and social care data should be encouraged as it allows for policy makers and stakeholders to create evidence-based solutions. The Scottish Government long-term monitoring of health inequalities is an excellent example of useful data at a population level that is easy to understand.[10] Making data accessible is also about making data understandable. However, sharing data safely also involves acknowledging that in smaller communities and other small data sets individuals might be identifiable. Protecting people's anonymity must always be the utmost priority. More information on this is provided in response to question 6C.

Personal data which is not in the public domain and could be considered more sensitive must be handled robustly and transparently. Equally individual confidentially and trust must always be at the forefront. This must be balanced with ensuring data sharing agreements are not so laborious that they hamper research and development in services. Accessing data from health and social care system for research needs to be made more straightforward and the third sector must be consulted as a key partner in delivering services.

At the same time, it needs to be much clearer to patients what rights to confidentiality they have and how they can opt out of NHS data sharing in Scotland if they wish to, including how to opt out from their primary care practice sharing their data for research purposes. The law protects patients' confidentiality, and the NHS should not share personal information with others unless there is a clear legal basis to do so. Patients are generally aware of that but it is currently very complex and confusing for a patient who wants to find out how to opt out of data sharing and then follow the process for opting out, particularly if trying to do this online. The various national NHS websites offer a very confusing and complex array of information about data sharing rights and opt-outs, some of which is contradictory. For patients in Scotland, it is not at all clear where to source authoritative information in relation to Scotland, and NHS England websites are potentially very misleading for patients here.

Additionally, information for primary care patients on data sharing seems to vary widely between practices, and although information may be accurate, there seems to be little consistency in terms of the information conveyed to patients. The Tryst Medical Centre in Larbert website states: "Collecting and sharing information is essential to provide safe and effective healthcare. Appropriate information sharing is an essential part of the provision of safe and effective care. Patients may be put at risk if those who provide their care do not

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[10] https://www.gov.scot/publications/long-term-monitoring-health-inequalities-march-2022-report/

have access to relevant, accurate and up-to-date information about them. All staff have an ethical and legal duty to keep patient information confidential. If you do not wish your health information shared please notify the Practice in writing, so we may update your record." Whereas Davidson's Mains primary care practice publishes this statement on their website, "We would like to reassure our patients that the proposed extraction of GP Data by NHS Digital does NOT include any patients registered at this practice or in NHS Scotland. NHS Digital provide services in England so are not able to access any data held in Scotland. You are not required to opt out as your data is already safe. We take patient confidentiality extremely seriously and safeguards are in place to protect this, including when data is used for research."

This all creates a significant health literacy issue that is not of patients' making. If patients are confused about their rights in relation to data sharing, this will lead to suspicion and reluctance about data sharing (as we already saw in relation to the roll-out of SPIRE).[11] This would have an unfortunate impact on healthcare services and on research. The NHS needs to do much more to provide clear and consistent information for patients, and to educate its own workforce as well as patients about the nature and importance of data sharing.

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?

Currently data on ethnicity, gender, sexuality, socio-economic status, caring responsibilities and disability are not routinely collected as part of health and social care data. To fully understand the extent of health inequalities in Scotland the collection of data on inequalities and marginalised groups needs to be significantly stronger. In response to question 3B we have cited the COVID-19 vaccine programme as an example of a programme that did not include the collection of data based on health inequalities from the beginning. This was remedied as the rollout progressed but left a gap in our understanding of who was in danger of being missed by the vaccine programme. Without collecting data on marginalised groups and inequalities we do not have a clear picture of who is "missing in health" and in danger of falling through the cracks.[12]

Unpaid carers are an example of a group who until the pandemic were largely left out of data collection in health and social care. There was no official register of unpaid carers, despite the significant health inequalities they often face. However, as the vaccine rollout progressed and unpaid carers were included as part of the priority groups, better data began to emerge on unpaid care. Although this is progress, there remains a significant gap in the data collection on unpaid carers which makes it challenging for researchers to fully understand the health inequalities they face.

Conclusion

The overarching vision of this strategy is "to improve the health and wellbeing of the Scottish population through innovative, collaborative, and ethical use of data." We endorse that vision and welcome the ambition to "empower individuals to have greater access to, and greater control over, their own health and social care data." We strongly believe this will improve people's experience of the health and social care system and will empower them to better understand their right to health.

We also support the second ambition to "empower the people who deliver health and social care services by giving them the confidence and ability to securely access, gather and share

[11] https://spire.scot/

[12] https://elearning.rcgp.org.uk/pluginfile.php/149461/mod_page/content/46/Missingness%20in%20health%20care-%20a%20%E2%80%98new%20normal%E2%80%99%20is%20not%20a%20level%20playing%20field.pdf

relevant information to make timely decisions and deliver better outcomes." However, it is vital that the third sector is recognised as part of this delivery. The third sector must be a central partner as the Data Strategy for Health and Social Care is developed. Our sector is a trusted voice in communities, a valuable resource in research and a vital partner in the delivery of health and social care services. However, without consistent access to data we are constantly working with one hand tied behind our back. We need access to data to improve delivery and ensure our services are tailored to the communities and people we serve. We also need to be recognised as a rich source of data on the ground working with communities.

Equally we support the third ambition to "ensure use of high-quality data to drive the development of new and improved, treatments, technologies, and ways of working for public benefit." The third sector needs to be recognised as a high-quality data source with invaluable insight into communities and the people we support.

The recent information revolution has allowed more people to have access to the most up-to-date information; however, inequities in access persist. The pandemic highlighted how many people had access to up-to-date information via social media and other digital platforms; however, those without access to digital had to wait for accessible and timely information and in some cases struggled to get this at all.[13] The same is the case with data, this strategy must have tackling health inequalities at its heart and to do that we must significantly improve the data we collected on inequalities. We welcome the commitment that the strategy will "ensure an inclusive approach to any solution or ambition for those who do not or cannot access services digitally." Diversity needs to be built into the creation of this strategy to ensure no one is left behind.

For more information please speak to VHS Policy & Engagement Lead:
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[13] https://vhscotland.org.uk/wp-content/uploads/2020/12/VHS-Response-to-Renewing-Scotlands-full-potential-in-a-digital-world-final.pdf