Data Strategy for Health and Social Care

Engagement Summary

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Engagement

- **CITIZENS:**
- NESTA deliberative work with the public
- Carers network
- Inclusion Scotland's People Led Policy Panel
- Scottish Consortium for Learning Disabilities panel
- ALLIANCE Digital Citizen Panel

- **THIRD/INDEPENDENT SECTOR:**
- Children's organisations
- Third Sector Equality/Advocacy organisations
- Scottish Care
- Voluntary Health Scotland
- Scottish Federation of Housing Associations
- Coalition of Care and Support Providers Scotland
- Care Centre Staff

- **ETHICAL EXPERTS:**
- Civil liberties group
- Ada Lovelace Foundation
- Digital Identity Expert Group

- Public Benefit and Privacy Panel for Health and Social Care
- Data Standards Lead

- **LOCAL AUTHORITIES:**
- CoSLA
- Local Authority Digital Office
- Health & Social Care Partnership & IJB leads.

- Police Scotland

- **HEALTH SECTOR:**
- NHS Information Leads
- NHS Digital Health Leads
- Scotland's Digital Health and Care Network
- Public Health Scotland
- Healthcare Improvement Scotland
- National Services Scotland

- **INDUSTRY/INNOVATION:**
- Chief Scientists Office Stakeholders Group
- The Association of British HealthTech Industries
- Scottish Partnership Forum
- Association of British Pharmaceutical Industry
- Data & Intelligence Network Data Showcase
- Public Health Scotland Digital Transformation Group
- Digital Health & Care Innovation Centre
- The Data Lab
- Netapp

- **GOVERNMENT/GOVERNANCE:**
- Scottish Government Policy Colleagues
- Health Workforce Policy
- Cancer Medicines Outcome Programme
- Digital Equality and Inclusion Group
- Strategic Portfolio Board for Digital Health and Care

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Themes Identified

Communication & Engagement

Ethical Approaches to Data

Data Access

Digital Exclusion

Technology & Infrastructure

Information Governance & Security

Talent & Culture

Data Standards & Interoperability

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Communication and Engagement

- Engagement to ensure we develop a Strategy that is fit for purpose, that addresses the current challenges that exist across the sector and inequalities.

- Engagement should continue after Strategy is published to enable us to identify where the Strategy is working well and consider future improvements.

Good communication will be key to:

- Explaining how data will be used and the benefits of using data.
- Informing the public of their rights to access their data to increase public confidence.

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Data Access

- Individual's want to have control over their data.

- The strategy must consider different groups of rights holders in society such as children and disabled people.

- Where people don't have the capacity/capability to control their own data, the strategy must consider appropriate safeguarding.

- Data must be presented in a way that is understandable to the user. For example, where data is available to children and young people it must be age/stage appropriate.

- Giving citizens control provides transparency.

- Enables self management of conditions.

- Strategy should set out importance of obtaining consent before data can be shared.

- There is currently a lack of access to the right systems for staff working within the sector which is a current barrier to accessing and sharing data.

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Technology & Infrastructure

- Current technology can lead to data being held in silos, requiring the same data to be re-recorded multiple times.

- Multiple systems act as a barrier to sharing across the sector.

- It is time consuming to access and share data.

- We need cutting edge technology to help interpret and visualise data in a way that is meaningful and insightful.

- Need new technology that validates the data when it is input to the system. This will result in improved data quality and enable sharing.

- A single interoperable system is needed to store and share data, to enable joined up working and strategic understanding of the data.

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Talent & Culture

- Staff are unaware of data sources and benefits of collecting and sharing data.

- Accessing data is a challenge, results in delays and increased workload.
- Lack of resource, reliant upon data teams to action requests.

- Difficulty recruiting and retaining skilled staff.

- Upskilling is required in data handling, analysis and use of language to explain data to citizens.

- Clear guidance needed to understand data terminology and roles/responsibilities in relation to data.

- A national approach to Data Standards and Internal Governance is needed.

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Ethical Approaches to Data

Strategy must be transparent regarding:

- What data is held.

- Who can access the data.

- How data be used.

- The benefits of sharing data.

- Citizens rights to their information. Must clearly balance children and disabled people as rights holders versus parents and carers as rights holders.

- Strategy needs to address ethical concerns raised by public and must not cause inequality.

Digital Exclusion

To address digital exclusion we could:

- Allow access of data to be delegated to friends/family.

- Provide data in multiple formats, not just digital.

- Link in with other strategies, charities and support organisations.

- Ensure professionals within the sector have access to digital devices.

- Provide financial support to third sector organisations to allow them to purchase devices for public use.

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Information Governance and Security

- Lack of understanding of GDPR and IG processes overall which act as a barrier to sharing.

- There is a lack of clear IG guidance = implementation of local processes = inconsistent approaches being taken.

- A joined up approach is required.

- A clear IG framework that outlines handling of data is needed for those within the Health and Care Sector.

- Staff training is needed to enhance understanding of anonymization and access controls, to ensure that data is held securely and privacy is upheld.

- Building interoperable systems = facilitate data sharing = benefit to citizen.

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Data Standards and Interoperability

- Implementing data standards and sharing agreements would enable interoperability and increased sharing across the sector.

- Standards will create better quality data which could be easily shared, enabling citizen focused outcomes.

- Standardisation is needed to enable links and trends to be identified across multiple data sets.

- Applying data standards would assist with data analysis and enable data to be used in meaningful ways.

- Mandating standards to support practitioners.

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Industry & Innovation

- We need to recognise Scotland's health and care data as a national asset.

- Access to data for innovation and research needs to be easier and could be achieved through a national data platform.

- A 'Once for Scotland' approach to IG is needed.

- Establishment of a real-time dataset for research and innovation will benefit the health and care ecosystem.
  - We need to create an infrastructure that allows us to accelerate the use of data and AI in health and care.

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Citizen Dialogue

Participant talked about "necessary data", data which optimises the health and care that they receive. They want control of that data where control means:

- It is visible to them.

- They can update inaccurate or discriminatory data.

- They have control over who has access to it and for how long.

Key themes amongst different groups spoken to include:

- Trans people expressed a fear that their data might be used against them.

- BAME people concerned that data was used in a racially discriminatory way.

- Disabled people want a joined up system so they do not need to keep telling their story over again.