

CONFERENCE ABSTRACT

A Scotland-wide conversation: People's attitudes about sharing data on social determinants for health and wellbeing outcomes

21st International Conference on Integrated Care, Virtual Conference – May 2021

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Introduction

Our health is influenced by much more than healthcare. Clinical care is less of a social determinant in comparison to health behaviours and socio-economic environmental factors¹. The 'My World, My Health' project explored three questions:

- Are individuals aware of the wider determinants of health?
- How much wider determinants data is currently collected and shared, within or out with the health system?
- How do individuals feel about sharing data on wider determinants of health?

Theory/Methods

We engaged over 100 individuals, November 2020 to February 2021, through:

- 14 online workshops with key groups: people with long term conditions, LGBTQI+ community, ethnic minorities, people living in areas of multiple deprivations, people with sensory loss, older people and those living in remote / rural locations.
- Six individual phone interviews to supplement workshop findings, with underrepresented groups and those experiencing barriers to online participation.
- A public survey.

Results

Interim findings:

- Most participants see a link between health and lifestyle choices, particularly those living with long term conditions.
- If people collected or shared personal data themselves, it was for personal wellbeing reasons or peer support (sharing stories).
- Participants requested clear safeguards surrounding data collection and use: consent, personal control, clear purpose / outcomes, secure systems. Further assurances included no unwarranted commercial gains and no grounds for discrimination.

Discussions

Some participants saw added benefits in automatically sharing data with health professionals, though personal relationships based on trust were preferred and regarded as more empowering. Participants were more likely to share personal stories for peer support or advocacy. The fear of discrimination was another key factor influencing attitudes with the LGBTQI+ and ethnic minority communities showing more concern around data misinterpretation. This preference for stories over data highlights the importance of authorship, and language within the common political discourse.

Conclusions

Opportunities are increasing where data can inform personalised health interventions which contribute to better health outcomes. However, data collection should not be used as a replacement for targeted social interventions. Blended approaches are necessary to ensure we capitalise on the opportunities of the digital age whilst protecting personal approaches, particularly in health and care.

People want to be in control of how their data is collected, used and shared with safeguards implemented and flexible systems built in to ensure transparency and allow choice. Further data awareness is needed amongst professionals and the general public.

Lessons learned

Online engagement:

- Small groups (3-5) lead to a better understanding of the subject and in-depth engagement.
- A variety of engagement opportunities over three months facilitated engagement with a more balanced demographic.

Limitations

- Relatively digitally confident participants due to predominantly online delivery.
- Demographics: we engaged ethnic minorities but no traveller communities.
- Public attitudes were impacted by COVID-19.

Future research

How can we bridge the perception gap between sharing stories and data?

How will people's attitudes and practices shift entering a 'new normal'?

1. DHI. The Relative Contribution of Multiple Determinants to Health. Health Affairs Health Policy Brief; 2021