

Using data to improve health: are the publics engaged?

What the project is about

In partnership with five HealthWatch organisations across the East of England, the University of Cambridge ran a project to explore what people think of the drive to bring different types of health data together to inform care, public health and research.

At present, much of the data relating to people's health is held separately in different organisations. Joining up data has the potential to directly benefit patient care and provide a more complete picture of the health of a community. This could help improve provision of health and social care services. In addition, this can provide a rich source of information for research that aims to improve the health of the population.

But before joined-up datasets can be developed, people need to be confident that any information that they share is held securely and used appropriately. This project was about engaging the public in a few East of England communities to discuss the following topics:

- What kind of "data" we are talking about
- How joined-up data can be used to improve health
- Who can share and who can use our data
- What are the expectations and concerns about joined-up data

What we did

The project team organised a series of conversations for the public to have their say. The original plan was to have these conversations face to face. Instead, they took place remotely to comply with restrictions due to the pandemic.

A total of 30 people from five communities across the East of England engaged with the project, 13 via one to one phone discussions and 17 via four virtual group discussions. Participants were from a range of age groups and had varied backgrounds. All the phone discussions and two of the virtual discussion groups were recorded and transcribed; for two of the virtual groups, a scribe took detailed notes of the conversations. All the findings were analysed and summarised according to the topics listed above.

What we found

The kind of data are we talking about

There was clear understanding that data to improve health is “massive”, that it consists of a whole host of information about the individual, and that it could come from a variety of sources. At the same time, participants found it very difficult to define or set boundaries to capture what it means. The most common view on data seemed to be as health information in the form of medical records. For those who interpreted “data to improve health” in a broader sense, data was presented as the raw material to understand what influences health in an individual or a population, and find solutions to maintain and improve health.

Topics and examples of types of data that participants mentioned fall into four broad groups. Data about:

- Individual personal characteristics, health status, or determinants of health (e.g. age, ethnicity etc)
- Where we live and communities
- Our behaviours and lifestyles
- How we use the health system infrastructure (broadly defined)

How joined-up data can be used to improve health

There was acknowledgement that information – often the same information – is being collected by different organisations and for different purposes:

- To identify health concerns and emerging needs for individuals or whole communities
- To understand trends, generate models and to solve future problems
- To support planning of services and monitor the quality of service provision

The dominant view was that data for health is used to address individual needs. This was closely followed by recognition of the crucial importance of data for the benefit of the public. That routinely collected data could also be used for research was not anybody’s first thought - this came later after the benefits and concerns of using individual’s data were voiced.

Who can share and who can use your data – expectations & concerns

For direct patient care

There was broad agreement on the benefit of data sharing for direct patient care as long as security, confidentiality and transparency are cornerstones of any endeavours to join up data. Consistent with previous studies, participants voiced strong concerns around who has access to data; what the data is used for; and the implications this has for privacy and consent.

The main perceived benefit of data sharing is its potential to make sure that, across service providers, the right people have the information they need in a timely manner about any given person in their care:

- for safety concerns (e.g. allergies; complex conditions)
- for convenience and quality considerations (e.g. not having to repeat oneself)
- for efficiency (e.g. not having to redo tests; for a more responsive and agile system)

Many of the concerns around data sharing and data linkage are perceived to arise from lack of good communication and transparency on:

- what data is shared (e.g., some data are more sensitive than others)
- data quality
- whom it will be shared with and who will have access (e.g., there is a clear mistrust of private entities)
- why it is needed and how it is used (including concerns that it was collected for one purpose and used for another)
- where accountability lies and where the safeguards are (e.g., whether we have suitable systems and processes to prevent breaches and misuse)

For public health and research

Moving from sharing data for direct patient care to sharing data for public health and research was challenging for some participants. Whereas the benefits gained versus the risks involved in sharing data for direct patient care are very concrete; this is not necessarily the case for public health and research. This appeared to be related, to some extent, to the participants understanding of the scope of public health, their understanding of the research process, and whether they had been involved in some form of research or another. For example, the fact that public health and research data is usually anonymised and/or not individual specific had to be articulated several times.

Broadly, the types of benefits and concerns around data sharing and linkage for research and public health were the same as those raised in relation to direct patient care. For public health, the scale of the potential benefit of data sharing was broadly acknowledged but this came with a “scaling up” of the concerns listed above. Participants underscored the need for better public understanding of the relative risk and benefits of sharing data for public health. For example, very few people knew that cancer data is automatically shared with cancer registry unless the patient opts out; the same is true for declarable infectious diseases.

For research, the main distinction is that participants appear to trust the structures in place to protect their data and privacy – at least as far as academic research is concern. However, participants from the group discussions also argued that the general public does not understand data and research and how their data will be used, and that more education is needed. There was also a call, by some, for a rebalancing of the public narrative around data sharing to a more informed and positive one; one that is not so driven by negative media coverage.

Participants in the group discussions felt strongly about the need to consider those who are least resourced and equipped to use or benefit from data linkage. There is a need to understand how different groups of vulnerable people in communities are impacted by issues in data sharing and linking, especially when they can’t give consent or may not understand how their data is being used.

Finally, most participants were unaware of ongoing data sharing or data linkage initiatives in their community, despite the fact that a lot of initiatives are ongoing.

Insights from the multiple perspectives represented in the project will make an important contribution to the wider public understanding of how individual data could be used to improve health in the East of England. This summary is available on the [project webpage](#) and will be disseminated to researchers and practice stakeholders across the East of England to inform their approaches to using health data for population health management.

Collaborators and funders

The project was led by Dr Louise Lafortune, University of Cambridge in collaborating with HealthWatch Cambridgeshire & HealthWatch Peterborough; HealthWatch Essex, HealthWatch Suffolk, HealthWatch Norfolk, HealthWatch Hertfordshire, and Public Health England.

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