

Joined Up Leeds
Citizen engagement
in **Leeds**



Leeds has a vision to be the best city for health and wellbeing and a global leader for health innovation. Using and sharing information supports this ambition and any changes that need to be made to help achieve it.

Background

As part of their commitment to integrated health care services across Leeds, key health partners wanted to understand what local people understood by 'information sharing'.

To help with developing integrated care services, Joined Up Leeds was set up; as a project to start and continue on-going conversations with local citizens, to find out how they felt about information sharing related to health and social care services. Information sharing is at the heart of health and social care transformation in Leeds and citizen engagement was critical to the success of service integration.

What is Joined Up- Leeds?

Joined Up Leeds is a facilitated conversation between local people and health care providers to provide an insight into the motives behind people's current decision-making when sharing information for different purposes.

It was an initially a city-wide, two-week conversation where local people had the chance to discuss how their health information could and should be shared, the benefits of sharing, concerns they have, and how information could be used for the benefit of people in Leeds.

The conversation provided health care services with some insight into how people felt information could be used to benefit health provision across the city. The evidence gathered through this consultation provided key partners with insight to support on-going citizen engagement and communication messages when commencing new health and social care integrated initiatives and information sharing across Leeds.

The project was initiated by the Chair of the Leeds Health and Wellbeing board, and it was a joint project with health and social care partners across the city. It was led by the local Leeds North Clinical Commissioning Group (CCG) and Leeds Informatics Board.

Steps taken to deliver the Joined-Up conversation

The initial evidence gathering, through these conversations, was undertaken by an independent researcher. Partners across Leeds recognised the need for independence when working with local citizens and this was a key element in the procurement process to identify a consultancy to support this work. Leeds Health and Wellbeing Board and Leeds Informatics Board wanted to understand the behavioural reasons that people made when making decisions about what information to share and who with.

Following procurement, the contract was awarded to Brainbox Research, a health and social care research organisation based in Leeds. The project commenced by interviewing people identified as 'key thinkers' from across the city to provide a baseline of current experience of information sharing. These 'key thinkers' ranged from service users and people who ran local health projects through to Chief Clinical Information Officers.

The conversations

Events took place across a range of venues in Leeds (including cafes, pubs, libraries), over a two-week period to ensure maximum publicity and engagement within a short period of time. The branding for the Joined Up Leeds conversation was very important, as it says and depicts exactly what was going to happen – people having a conversation.

Citizens of Leeds could get involved in Joined Up Leeds through four different formats:

- ▶ **A city conversation – facilitated workshops on the key questions of sharing health and social care data**
- ▶ **A network conversation – using a chat pack designed to support the conversation with people in their social, work or community network using four case studies**
- ▶ **Media conversations – commenting on Twitter, Facebook and email**
- ▶ **A survey – on-line, paper or an event card to record their views**

What happened as a result?

Through the work of the Joined Up Leeds conversations, Leeds health and social care partners have a solid evidence-base on which to continue the work of communicating key messages to the public about information sharing projects. The Joined Up Leeds conversation has provided service areas with an understanding of how the general public are not familiar with terms currently being talked about, for example Leeds Data Mill now knows that the public does not understand the term open data and therefore more needs to be done to communicate what this means and how it could benefit citizens.

Following these local conversations the following was identified:

► Who sees information about me?

It was important to identify how local people understood who had information on them and why – providers across Leeds want local people to understand that information sharing can help to improve quality of care and services.

► Who owns information about me?

Through these conversations, it was also important to ensure that citizens were aware of the types and

range of information that could be shared, and overall people taking part had a good understanding of this as long as there was ownership of information and people were allowed to be involved in sharing and understanding their information.

► Missed opportunities

Health providers want people to benefit from information sharing, particularly those people that may have a long-term health condition. Those involved in the conversations welcomed this as it could and would improve on-going care.

What might the future look like?

All those involved in local conversations were asked about what information sharing might look like in the future. Most people want their information to be used to plan services across Leeds. This was significant for providers, as this is the basis for integrating health services across Leeds and improving outcomes for all citizens.

Four themes were identified:

► Greater sharing of personal records

Services across Leeds are able to work towards solutions to enable improved sharing of information, not only to help individuals but to improve overall service provision.

► Citizen-owned, IT-enabled information

This is not just about health data, but enabling and empowering all services and citizens in Leeds to use their data and have ownership of it, by being in control you are more likely to share relevant information.

► Open data

This is a relatively new phenomenon and many organisations and people are not sure of how this will benefit them. However, like data and information sharing being citizen owned, this might help people to make more informed decisions about care and health choices and sharing their information.

► Resources where they are needed

The better use of information means that resources can become more flexible and can move to areas where they are needed most. This could shorten waiting times for healthcare, and by anticipating people's needs, services could become proactive rather than reactive.

A full report has been published on the outcomes of this innovative approach to gathering information and encouraging citizen engagement, to help shape services and support information sharing, please see www.leedsdatamill.org/dataset/joined-up-leeds-results for more information

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