



**Supporting people to become active participants in their health and care.**

January to February 2021



## About Us

Your independent watchdog ensuring people's voices are at the heart of shaping health and care services in Leeds.

## CONTENTS

Page 1	<b>Summary and key findings</b>
Page 2	<b>Background</b>
Page 3	<b>What we did</b>
Page 4-6	<b>Survey findings</b> <ul style="list-style-type: none"><li>• information and communication</li><li>• appointments</li><li>• involvement in care</li></ul>
Page 7-9	<b>Focus group findings</b> <ul style="list-style-type: none"><li>• understanding health information</li><li>• involving people in decision making</li><li>• tools and resources</li></ul>
Page 12	<b>Next steps and acknowledgements</b>
Page 13	<b>Appendix 1</b>

## SUMMARY: Introduction



Healthwatch Leeds worked in partnership with Leeds City Council (Public Health) and partners to find better ways to support individuals and their carers to understand the health information they receive about their care and treatment.

We gathered feedback about people's experience of receiving health information through a short survey with a focus on those groups who experience disproportionately low or inadequate health literacy.

There has been valuable national and local effort in creating resources and tools (Appendix 1) to support people and their carers to become equal decision makers in their care. One of the key questions discussed collectively at the focus groups considered which tool or resource worked best for people. Participants also shared their ideas about how to embed the tool across the system.

## KEY FINDINGS: Survey and Focus Group



- A number of people told us they were not asked about their communication needs or that their preferred communication needs were not met.
- Over half (58%) of respondents needed help either sometimes or often to understand the health information they had received.
- Some people felt they could not ask questions at their appointment.
- People with multiple conditions or complex health problems faced additional barriers when making decisions about their health and care.
- There was support for the tools, the most popular being 'It's OK to ask'.

## WHY WE DID IT: Survey and Focus Group



Personalised care is about people having choice and control over the way their care is planned and delivered and based on what matters to them. For this to happen, people need to be supported to be more actively involved in decisions about their care.

This means that people have an equal say in decisions about their health and care and they are given the information and support needed to help them make these decisions.

This approach involves discussing the care, treatment and support options available as well as looking at the risks, benefits and

consequences of those options. Based on these discussions and the available options a joint decision can be made by the person receiving the care and those providing the care.



We know that 43% of working age English adults do not understand health information. Information and this is a challenge in doing this shared decision making approach.

Health literacy is the ‘personal characteristic and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decision about health (WHO, 2015)



People with low levels of health literacy are less likely to be confident about talking to health professionals, less motivated to engage in decisions about their health and less willing to let health professionals know when they haven't understood what they have been told.

At the same time health professionals are not always likely to spot people with lower levels of health

literacy, which means they do not adjust their practice to take account of it.



Written information is also less likely to be understood by those with lower health literacy. The effect of this is those with higher levels of health literacy both expect and receive shared decision making while those who are less literate neither expect nor get it. [Ref 1](#)

The following groups have been identified as those who experience disproportionately low or inadequate health literacy:



- more disadvantaged socioeconomic groups
- migrants and people from ethnic minorities
- older people
- people with long term conditions
- disabled people (including those who have a long- term physical, mental, intellectual or sensory impairment) [Ref 2](#)

Health literacy therefore contributes to health inequalities because the population groups most at risk of health illiteracy are also known to have the poorest health outcomes.

## WHAT WE DID



Between January and February 2021 we gathered information using an online survey and two online focus groups. We also offered those who could not join online the opportunity to feedback over the phone. British Sign Language interpreter was present at the first focus group, each lasted an hour and a half.

The online survey was coproduced with Healthwatch Leeds volunteers and mainly consisted of closed questions with a focus on gathering insight on written health communication and appointments. People

were also given the opportunity to share any comments and make suggestions about their care or treatment.

The in-depth discussions asked three questions:



- How do people engage with health information?
- What would help people be more engaged in decisions about their health and care?
- What resource/tool would help people be confident about talking to health professionals about their health and care?

In total we engaged with 96 people. The survey was completed by 78 people, 14 people attended the focus groups and 4 people gave their feedback over the phone.



Participants who responded to the survey and took part in the focus groups were from diverse backgrounds including carers; older people; people with a mental health condition; people with sight, hearing, mobility, and physical impairments. One person at the focus group had a disability and majority of participants had one or more long-term conditions.

# SURVEY FINDINGS

## Respondents

78 people carried out this survey

### INFORMATION AND COMMUNICATION

25 (32%) people had received communications which included information about their health eg diagnosis, test results etc.

6 people felt they could not understand the information and over half (58%) of respondents needed help either sometimes or often to understand the information. People often relied on their family members.

*"There was too much jargon, I prefer pictures. Having pictures helps me to explain to family members over the phone what the letter is about".*

*"I've asked my GP to note down my communication preferences*

*but they still contact me like*

*they always have".*

*"I've never been given the choice of how to receive information."*

*"Simpler language for people with learning disabilities".*



11 people also felt that the communication received did not guide them on what to talk about in their next appointment

*I am deaf and can't call them, they should explain what to do next either to book an appointment, pick up a prescription or have further tests,*

### WHAT WOULD MAKE THE WRITTEN MATERIAL BETTER?

- Use clear everyday language and avoid jargon or acronyms.
- Keep messages simple, clear and concise.
- Use pictures or graphics to help explain things more clearly.
- Write short paragraphs and use bullet points.

### OTHER SUGGESTION TO IMPROVE INFORMATION AND COMMUNICATION

- Ask individuals about any communication needs and preferences and take action to meet these needs in line with the Accessible Information Standards where appropriate.
- Provide alternative methods of communication and information. Eg. Easy Read

## APPOINTMENTS



Most people felt they understood the information they received at their appointment, however a significant number (28%) did not understand all the information.



*"My specialist nurse tends to use technical language which is not too helpful".*

*"I would prefer to discuss all my conditions at one review appointment".*

*"One time I turned up for a medication review which takes about 10 mins but was in for 45mins as it was my annual review".*

### Asking questions

*11 people felt they could not ask questions about anything they did not understand.*

*"I did not get the opportunity to ask questions. The appointment felt rushed".*

*"I am very conscious that GPs are really busy and know that appointments are only allocated about 5 minutes. This makes me feel rushed".*

## REASONS FOR NOT UNDERSTANDING INFORMATION AT AN APPOINTMENT

- Interpreter not provided.
- Limited appointment time.
- Use of technical language by professionals.

## WHAT WOULD HAVE MADE THE APPOINTMENT BETTER?

- Clear information on which appointment (annual review, medication review) is being attended.
- A guide to what to ask before during and after an appointment.
- Information about rights of access to and who is responsible for booking interpreters.

## INTERPRETERS

Two people felt uncomfortable using family members as interpreters.



## INVOLVEMENT IN CARE

The majority (48%) felt they have a say in their treatment, however, 35% felt they did not have a say.

Some people were not taken seriously or did not have the confidence or opportunity to ask questions.

*"I have tried so hard to get help with my mental health but all I get offered is tablets".*

*"I want to ask questions but sometimes feel I already have taken up a lot of time".*

## MAKING DECISIONS

Some people would like to make decisions about their care and treatment but they lack the necessary information.

*"To be involved in my care I would like further information about my condition so I could manage my health better".*



*"I would like more time to ask questions so I can understand how to manage my health better".*

## OTHER WAYS PEOPLE WOULD LIKE TO RECEIVE INFORMATION

Majority of participants would like to receive information by email but text and telephone calls still had a significant number of votes.

## BARRIERS

People with multiple conditions or complex health problems faced additional barriers when making decisions about their health and care.

*"I'm autistic, I need more time to process things and make decisions".*

*"If I understood what was being said I would be able to make decisions about my care."*

*"I am diabetic and struggle to communicate because I am deaf".*

## WHAT WOULD HELP PEOPLE TO BE MORE INVOLVED IN CARE?

- Jargon- free communication (letter/email/video/text) on how to prepare, what to ask and what happens after an appointment.
- Information on alternative treatments and options available.
- Offer longer appointments for people with additional communication needs.
- Provide sufficient information on individual health conditions.



# FOCUS GROUP (FG) FINDINGS

## UNDERSTANDING HEALTH INFORMATION

Participants were asked to think about the last communication they had received from their GP/Hospital that included information about their health. We wanted to know what was good or not so good and if they had any suggestions on how it could have been improved.

## SUGGESTIONS

- Flag individual patient records so it is clear they have information or communication needs and details of how these needs should be met.
- Provide a contact number on the letter to clarify content of communication.
- Provide easy read information that is simple to understand, with pictures.

*"I did not know I could ask and have never been asked about my preferred method of communication." (Louise, FG1, Learning Disability)*

## COMMENTS

Jane had an instance where the sensory clinic did not know her communication needs for an appointment although she has been attending for over 20 years. She also had difficulty when she had to take a medication by injection but was given little information on how to inject the medication, which ended in her having to go to the hospital. (FG2, Partially Sighted)

*"Small print and difficultly to understand language does not give the average person the position to understand". (FG1, Mark C, Carer)*

Alison has difficulty with online access and text messages. Sometimes she would like to ask about the information received but there is not usually a number for her to call. (FG1, Partially Sighted)

*"I received a letter 10 pages long and needed a family member to help read and understand the information". (Jane, FG2, Partially Sighted)*

*"My mum does not speak or read English but sometimes she is able to describe the logo which helps me to identify where the letter has come from". (Parveen, FG1, Carer)*

## INVOLVING PEOPLE IN DECISION MAKING ABOUT THEIR HEALTH AND CARE



### DISCUSSION

A more holistic approach to health was discussed where appointments should cover multiple issues not one specific health condition.

Diane spoke about her needs not being met when her daughter is unable to interpret for her. She prefers her daughter, as interpreters sometimes do not turn up and there is difficulty in booking them. She also felt frustration with health professionals addressing her carer/interpreter rather than her in appointments which made her feel disconnected from her care. (FG2, Deaf)

Harriet didn't feel like she was involved in her care and does not think alternatives are suggested to her. (Telephone)

Frances said she also didn't feel involved in decisions about her care and what medication she takes. (Telephone)

Information on long term side effects of medication is not discussed as well as the alternatives (FG1, Paul, Mental Health and Mark C, Carer)

### GOOD PRACTICE

Two people with multiple health conditions spoke about having built long term relationships with their health care professional. The relationship has helped them stay in control of their health and has enabled them to make informed decisions about their care and treatment.



### HOW CHALLENGES AND BARRIERS CAN BE RESOLVED

- Provide longer appointments so individuals are able to fully discuss health concerns, ask questions etc.
- Work as equal partners to make decisions.
- Health professionals to take responsibility for booking interpreters.
- Clare and Mike both said taking notes before and during the appointment would help them remember questions and concerns they may have and give them something to refer back to after appointments. (FG2)

## TOOLS AND RESOURCES THAT WOULD HELP PEOPLE TO TALK WITH HEALTH PROFESSIONALS

## HIGHLIGHT

We asked participants to tell us which resource/tool they preferred, in what format and how it could be used.

All participants in both focus groups and over the phone agreed that some sort of resource would be useful. It would empower people to ask questions and, in turn, this would increase their confidence and help them make informed decisions about their health and care.

## IT'S OK TO ASK

1

The majority (7) of participants in focus group two voted for 'its OK to ask' leaflet. Mike liked its simplicity, as it gives the 'permission to ask' and helps 'guide' people what to ask. Jane said "this can act as a coach to get people involved in their care".

## BRAN (Benefits Risk Alternative Nothing)

5 people preferred BRAN. They said it was simple and easy to remember. However, in focus group one, 2 people felt it was too medical and only related to making decisions about medication.

2

3

## TOP TIPS

This was on a Word document so didn't appear as attractive. Participants from focus group one said some of the questions can be added to the 'its OK to ask' leaflet.

## ASK 3 QUESTIONS

We did not receive any feedback on this

4

## WHICH FORMAT

Participants said that materials should be available in a range of accessible formats, for example leaflets in plain English with pictures or videos in simple English with subtitles. It should also be made available in the most commonly used community languages.

## WHERE TO PROMOTE

Participants proposed materials be placed in a wide variety of health settings eg GP, pharmacy, clinics and outpatients departments.

They also suggested voluntary and community organisations provide support in promoting the materials to their groups.

## NEXT STEPS

This report will be shared with Leeds City Council (Public Health) and relevant health and social care providers and commissioners. We will agree with them the next steps and ensure any agreed actions are followed through and implemented. We will undertake any follow up work required to ensure there are real changes made to personalise care.

We will share the findings with people who took time to share their views and the report will be published on the Healthwatch Leeds website.

## ACKNOWLEDGEMENT

This report has been written by Parveen Ayub, Community Project Worker, in collaboration with our volunteer Charlie Smuger.

We would like to thank everyone who completed the survey and participants that took part in the focus groups to express their views with us.

## REFERENCES

Ref1 (page 4):

<https://www.england.nhs.uk/shared-decision-making/making-shared-decision-making-happen-the-common-challenges/>

Ref2 (page 4):

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/460710/4b\\_Health\\_Literacy-Briefing.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf)

## SHARED DECISION MAKING TOOLS

### BRAN

What are the Benefits?

What are the Risks?

What are the Alternatives?

What if I do Nothing?

## 3 Top Tips (Developed by LTC Coproduction Group)



### **Leeds Long Term Conditions Coproduction Group**

#### **3 Top Tips – How to get the best out of your health and social care services.**

These Top Tips have been developed by a group of local Leeds people who all live with or care for someone living with a long-term health condition they are members of this coproduction group to share their knowledge and experience of self-management and personalised care.

These 3Top Tips reflect some of the approaches that have empowered them to have a better and more personalised experience when accessing their health and social care services.

The Leeds Coproduction group would like to see these 3 Top Tips shared with the people of Leeds.

#### **Building blocks of coproduction**

Developing the following top tips was a task that took the group through wide and varied discussions. They have thought deeply about their own positive and negative experiences of accessing health and social care services. The tips are designed to recognise that services and staff can be short on time and often experience high levels of demand. The group have explored and researched aspects of self-management, personalised care as well as local and national structures of the health and care system, this has assisted them in the process of forming and developing on their own path as a coproduction group

**Confidence, planning and advocacy** are the key themes that come through the 3 Top Tips. Members of the group have been keen to emphasise the importance of being able to take a full part in their encounters with health and social care services to ensure the best outcomes.

**1. Write a reminder note/ think about what you want to say beforehand - Give ALL the symptoms, All the information.**

This tip came out of discussions around groups members' experience that the whole person and their whole situation needed to be in the mix to fully ensure that services have a full understanding of the situation to get the best outcomes. Writing things down or taking a bit of time beforehand to think about what they wanted to say, both saved time and kept things focused. Group members gave examples of situations where their health and social support needs had not been met appropriately because the professionals did not have the full picture of what was needed or situations where miss diagnoses had occurred for the same reason.

**2. Have the confidence to ask questions especially if you do not understand something.**

The principle behind this tip is that to get the most out of encounters with health and social care services it is necessary to fully understand what the professional is saying. Group members shared their experiences of being confused and unsure of what had been discussed on some occasions which had left them feeling disempowered. Group members spoke about how they needed overcome their shyness or deference to the "dr/ professional", so they could feel more in control and have greater input so that they could fully understand what was being discussed with them.

**3. Ask "what can I expect next?" Ask for advocacy/help when needed.**

This tip came out of discussions where members expressed that being left unsure as to what the next step or follow up from appointments or consultations would be led members to feel powerless and uncertain. The members also felt that time and resources had been wasted in such situations.



Group members experience was that they needed to be proactive and ask about what they could expect next ,what the follow up would be, this allowed them to plan and take matters forward themselves. For some people this may mean seeking extra support from a friend/ carer/relative of other advocacy service.

### **Moving Forward to Communicating the 3 Top Tips**

These top tips could easily be changed round to become 3 questions if they were to be used in some sort of campaign , to;

- 1."What do I give"(information /symptoms/living conditions)
2. "What do I want to know " (improvement prospects, medication side effects ,remedy, self care techniques)
3. "What can I expect next "(time frames for delivery, future planning )

Aside from the 3 Top Tips the group's discussion included many ideas and suggestions around how tips could be communicated to people in Leeds living with long-term conditions.

- All communications need to be sent in Plain English.
- Messages should be available in community languages.
- Distribution could be effective if included in large every household communications such as council tax letters.
- Use of local radio ads, local Facebook groups, other online platforms and wider local networks such as neighbourhood networks and NHS appointment letters.
- Delivering the 3 Top Tips by using bigger communications campaigns similar to larger local campaigns such as the personal stories of Leeds people to promote the stop smoking initiative on the back of Leeds buses and stop domestic violence.

Jo Gibson

Leeds Involving People



**It is important that you understand the information you are given to help you get better and stay well**

It's OK to ask:

- 1** What is my main problem?
- 2** What do I need to do?
- 3** Why is it important I do this?

Asking questions can help you to:

- Take care of your health
- Prepare for medical tests
- Take your medicines in the right way

### Tips for clear health communication

It's ok to ask again if you don't understand something  
Don't feel rushed or embarrassed

It's ok to bring a friend or someone from your family  
It's ok for them to ask questions and to help you

It's ok to make a list of things you want to talk about

It's ok to make a list of the medicines you are taking, and take it with you  
It's hard to remember all the names

It's ok to ask at the pharmacy too  
They are there to help you

# Ask 3 Questions

There may be choices to make about your healthcare.  
Make sure you get the answers to these three questions:\*

What are my choices?

How do I get support to help me make a decision that is right for me?

What is good and bad about each choice?



Your healthcare team needs you to tell them what is important to you.  
**It's all about shared decision making.**