



# Leeds Care Record Report

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## Introduction and Background

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The Leeds Care Record is an integrated digital care record which enables care professionals to view real time health and care information across care providers and between different systems.

Since its inception, Adult Social Care; Leeds Community Healthcare NHS Trust; the two Hospices (St Gemma's and Wheatfields) and Leeds and York Partnership Foundation Trust have joined the Leeds Care Record alongside Leeds Clinical Commissioning Groups Partnerships and Leeds Teaching Hospital Trust in sharing integrated patient information to improve the care that they provide.

Patients need to be made aware of the sharing of care plans, and all the care providers that are now integrated into the Leeds Care Record, so the Leeds North Clinical Commissioning Group asked Leeds Involving People to carry out a number of focus groups with a variety of community groups to ensure that the suggested publicity is fit for purpose.

Leeds Involving People responded to this by suggesting that the nine protected characteristics outlined in the Equality Act 2010 are targeted. These are:

- Age
- Disability
- Gender reassignment
- Race
- Religion or belief
- Sex
- Sexual orientation
- Marriage and Civil Partnership
- Pregnancy and maternity

# Engagement

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To engage with communities, Leeds Involving People made contact with known community groups to arrange focus groups with their members. The focus groups discussed three different parts of the proposed promotional materials:

- Content of the leaflet
- The preferred two scenarios from a choice of five
- The preferred poster from a choice of two

In total **10** focus groups ran with **76** participants.

Equality monitoring can be found in Appendix One.

The following community groups were represented:

<b>Group</b>	<b>Number of Participants</b>
Carers	Seven
South Asian Women	Six
Mixed Group	Eleven
Young People	Twelve
Young Pregnant Women	Four
Deaf Community	Eleven
People living with Disabilities	Seventeen
Learning Disabilities	Eight
Those living with Mental Ill Health	Six
Young Men	Four
<b>TOTAL</b>	<b>76</b>

## Summary of Findings

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- Generally, participants thought that their information was shared already between health and social care service providers. This was particularly true of the younger participants, who were much more trusting of the Leeds Care Record (LCR).
- The awareness of the LCR as a brand name was very low amongst the participants, with only six of the 76 participants engaged with having an awareness of it, and there was confusion between the LCR and the Summary Care Record.
- Generally, participants liked the LCR as it saves patients having to repeat themselves, and is a more joined-up approach to the provision of health and social care. Not having to repeat themselves was particularly favoured by the South Asian women's group, due to language barriers in the older generations.
- Those that cared for people who had care plans, or had them themselves wanted them to be available in the LCR.
- Amongst the groups, there was a consensus that participants wanted the preferred method of contact and any access needs to be shown in the LCR e.g. first spoken language, British Sign Language interpreter needed.
- The participants who were living with either emotional ill health or mental ill health shared concerns about being judged by healthcare professionals due to some of the things that have happened in their pasts. There was also some mistrust around diagnosis being available in the LCR, in particular for those living with a Personality Disorder due to past stigma experienced.

### THE LEAFLET

- Participants considered the front cover of the leaflet to be eye-catching, and were generally positive about the leaflet.
- When it comes to the accessibility of the leaflet, participants found it hard to read the white text on the coloured background, and they also struggled with the font size. They found some of the sentences to be too long, particularly those in the 'what's in the LCR section'. They felt could be broken up with images as it is a large chunk of text, which they would lose interest in reading.
- The content of the leaflet is straightforward, and the images used are clear. However, there were some words which participants considered to be jargon or too medical to understand.

- Participants felt that there needed to be information about the leaflet being available in different formats/languages.
- ‘Who can see my records?’ reads more reassuringly than ‘can anybody see my records?’
- Information needs to be provided about how you can object to your LCR being shared.

## THE SCENARIOS

- Scenario one was the most popular in all the groups, as it showed a child getting the care they needed. However, participants commented it needs to be specific to Leeds.
- Scenario three was the next most popular scenario, as it shows the benefit of the LCR where the patient isn’t having to repeat themselves to different healthcare professionals.
- The younger participants felt scenario three would be more realistic if an emergency admission is shown, as it is more relatable across different age groups.
- Participants preferred patients to be named in the scenarios, as this made them more personal.
- Scenario two was considered to be too wordy, and parts of scenario three were also considered to be too wordy. Participants preferred shorter sentences, which were written in a patient-centred way, as opposed to a medical way.
- Scenarios four and five were considered to be too similar by almost all of the Groups. They were considered to be the most simple and straightforward scenarios, but too specific in their nature.

## THE POSTERS

- Following the first focus group, the posters used were changed as participants were generally happy with the content of the posters, but felt the LCR logo was better placed at the top, as it served as a ‘title’ informing patients specifically what health and social care professionals were working together on to improve their care.
- Just over half of the focus group participants preferred the poster with the logo at the top, for them it served as a title.
- Those that preferred it in the text at the bottom, felt it broke the text up well and generally looked better. This came particularly from participants who said that they were unlikely to read such a large amount of text.
- In terms of accessibility, participants considered the font size to be too small, and found the contrast between the coloured background and white text hard to focus.

# Focus Group Findings – Leaflet Content

## What's in the Leeds Care Record?

Leeds Care Record is an integrated digital care record which enables care professionals to view real time health and care information across care providers and between different systems. It is a secure computer system that brings together certain important information about patients who have used services provided by their GP, at a local hospital, community healthcare, social services or mental health teams. All health records are strictly confidential and can only be accessed by care professional who are directly involved in a patient's care.

The secure computer system Leeds Care Record holds certain information about a patient or service user, for example:

- Address and telephone numbers.
- A list of diagnosed conditions, to make sure your health or social care professional has an accurate record of your care.
- Medication- so everyone treating you can see what medicines you have been prescribed.
- Allergies- to make sure you aren't prescribed or given any medicines you can have an adverse reaction to.
- Test results - to speed up your treatment and care.
- Referrals, clinic letters and discharge information- to make sure the people caring for you have all the information they need about other treatment you are having elsewhere.
- Care plans.

## Why do you need to share my information?

The Leeds Care Record provides health and social care professionals directly involved in your care access to the most up-to-date information about you. It does this by sharing appropriate information from your medical and care records between health and social care services in Leeds.

## What are the benefits of a single care record?

- Joined-up and safer care.
- More time to spend on care.
- Less paperwork.
- Your information in one place.
- Don't have to repeat details to different professionals.

## Can anybody see my records?

No. Only care professionals directly involved in your care will see your Leeds Care Record. We won't share it with anyone who isn't providing your treatment, care or support. Your details won't be made public, passed on to a third party not directly involved in your care, or used for advertising.

## How do I know my record is secure?

Data is pulled from secure clinical systems across the city which is displayed in the Leeds Care Record and remains secure.

## Can I object to my records being shared?

Yes. You have the right to object to your Leeds Care Record being shared. However if a care professional who is involved in your care believes they require information to provide safer direct care they are legally allowed to access the information held in your integrated care record.

## Got any questions?

If you have any queries, please contact:  
**0113 20 64102**

Or you can write to:  
Leeds Care Record,  
Leeds Teaching Hospitals NHS Trust  
St James University Hospital,  
Lincoln Wing/Chancellor Wing Link Corridor,  
Beckett Street, Leeds, LS9 7TF

For more information visit:  
[www.LeedsCareRecord.org](http://www.LeedsCareRecord.org)  
[@LeedsCareRecord](https://twitter.com/LeedsCareRecord)

## LEEDS CARE RECORD

Shared information. Better care for you.

## Working together to improve your care



Leeds Care Record provides care professionals directly involved in care access to the most up to date information about you.

It does this by sharing appropriate information from your health and care records between health and social care services in Leeds.



### Examples of what's included in my Leeds Care Record:

- Diagnosed conditions
- Medications
- Allergies & adverse reactions
- Test results
- Referrals, clinical letters and discharge information
- Care plans
- Contact details

### What's in it for me?

- Joined up and safe care
- Information in one place
- More time to spend on your care
- Secure and confidential

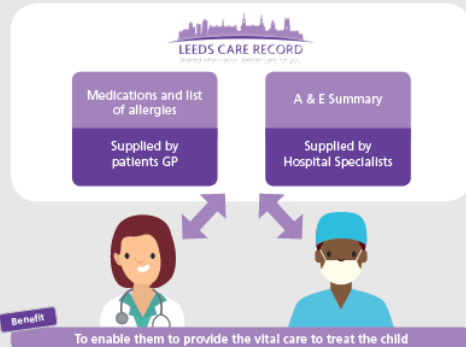
## Scenario 1

### So, how does it work?



Child on a school trip and has an allergic reaction. Parents can't be reached, child is taken to hospital in an ambulance.

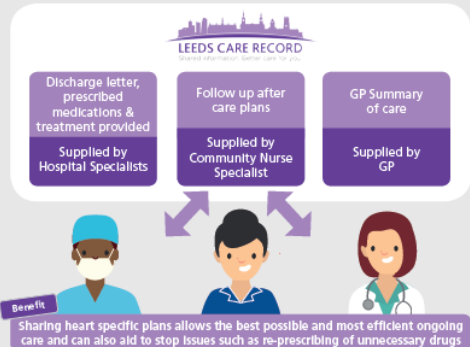
The hospital specialists can access Leeds Care Record to see the child's medication and allergy history.



## Scenario 2



Treatment information provided at the hospital and follow-up after-care plans put in place by the Community Nurse specialist can be accessed through the Leeds Care Record. The patient doesn't have to repeat sensitive information and the relevant care professionals are informed of any patient preferences in line with their future cardiac care, keeping them well informed of the patient's current situation.



In the focus groups, the leaflet was used to explain what Leeds Care Record (LCR) was. This was also a useful way to check the understanding provided from the leaflet.

### **AWARENESS OF LCR BY COMMUNITY GROUP:**

<b>Group</b>	<b>Number of Participants</b>
Carers	None
South Asian Women	One
Mixed Group	One
Young People	None
Young Pregnant Women	None
Deaf Community	None
People living with Disabilities	None
Learning Disabilities	None
Those living with Mental Ill Health	Four
Young Men	None
<b>TOTAL</b>	<b>Six</b>

Generally, participants were unaware of LCR, and several Groups confused it with the Summary Care Record.

### **COMMON QUESTIONS WHICH AROSE WERE:**

- How can you access your LCR?
- What happens when you leave Leeds?
- What about care homes? Private care homes?
- Can St John’s Ambulance access LCR if they provide urgent care at an event?
- What about the inclusion of children?
- How is the information kept secure?
- Are carers named on the LCR?



- Can carers access the LCR for those they care for?
- Is there a way that only summary information can be shared as opposed to all of it?
- If you receive care in different CCGs in Yorkshire will they be able to access the LCR? E.g. Harrogate
- What's the difference between the LCR and the Summary Care Record?

## POSITIVE FACTORS ABOUT LCR:

- Don't have to repeat yourself to different healthcare professionals
- This is particularly pertinent for patients living with long-term health conditions
- Joined-up thinking
- Saves time for everyone involved
- Useful if you're on a lot of medication, as it is easy to forget which ones you are taking
- Inclusion of care plans, and information provided by all health and social care professionals involved in your care. It is a much more holistic approach.
- In an emergency situation it can be hard to compose yourself to give medical information, LCR will save you having to do this.

## ACCESSIBILITY AND CONTENT OF THE LEAFLET:

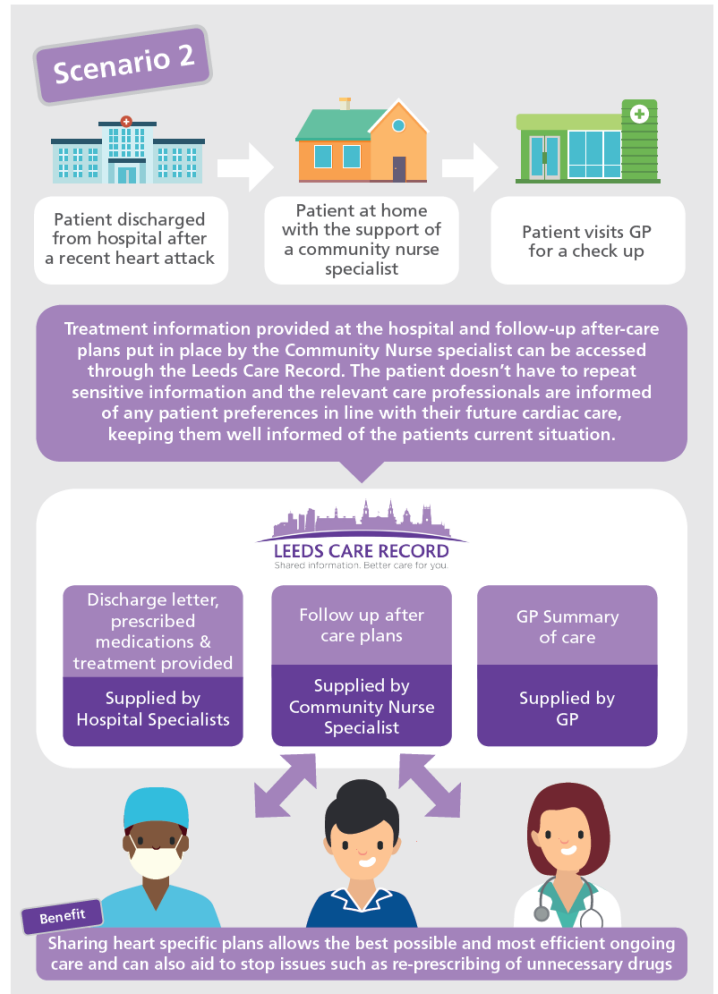
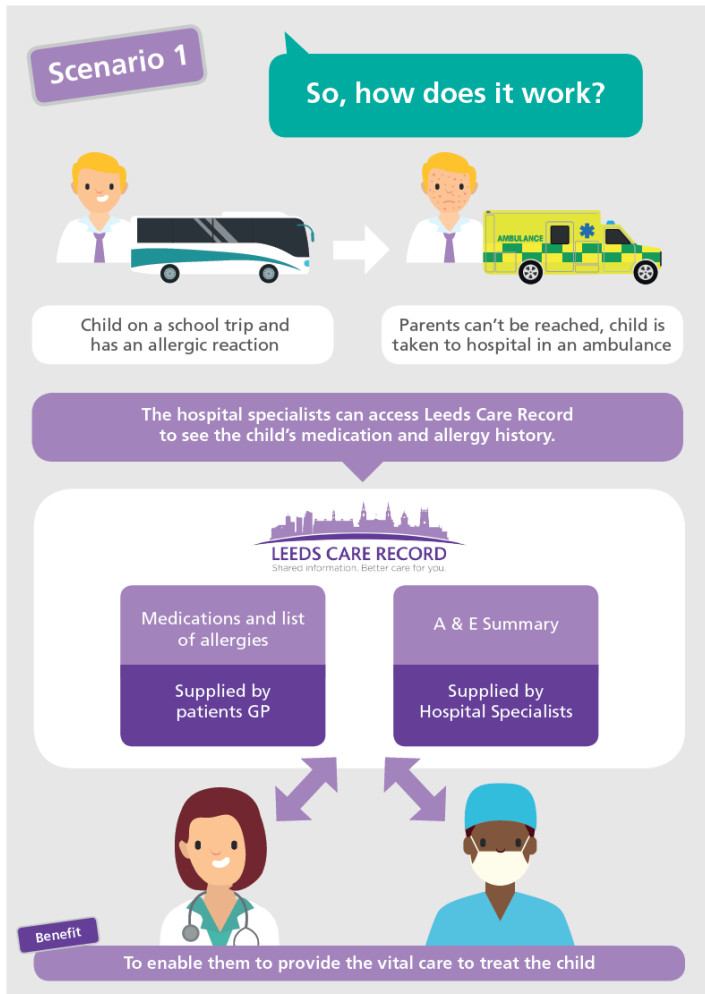
- Black text on white background easiest to read
- White text on coloured background problematic
- Some of the sentences are quite long, and need to be better punctuated
- Too much text on the 'what's in the LCR section', could any images be added here?
- Repetition of information, but necessary to reinforce point
- Clear and straightforward information explaining what LCR is and who has access to it, however some of the medical terms are complicated

- The leaflet may be challenging for someone whose first language isn't English, especially the medical terms. Would like information on the leaflet about it being available in different formats/languages
- Front cover of the leaflet is eye-catching
- Text is quite small, would like font size 16 at least
- Images of health care professionals are clear and make it easier to understand
- 'Who can see my records?' reads more reassuringly than 'can anybody see my records?'
- As well as saying you can object to LCR, it would be helpful if it said how you can opt-out.

### **SPECIFIC COMMENTS:**

- Would like to see a person's spoken language/s on LCR, so Interpreters can be arranged for planned appointments. One participant said that she wasn't able to translate for an elder, which caused delays to the appointment – South Asian Women's Group
- 'Leeds Care Record' doesn't feel clear, it suggests care plans or someone caring for you. 'Leeds Medical Record' would be clearer – Young Pregnant Women's Group
- Concerned about mental health issues being shared and healthcare professionals treating you differently – Young Pregnant Women's Group and Mental Ill Health Group
- Would like to see a British Sign Language video available on the LCR website – Deaf Community Group
- Would like to see preferred method of contact in LCR – Mental Ill Health Group
- It would be good if Chemists can access LCR to see if a patient's medication has been altered – Carers Group.
- Do people in prisons have the LCR? As their medical information can sometimes be hard to track – Mental Ill Health Group

# Focus Group Findings – Preferred two Scenarios

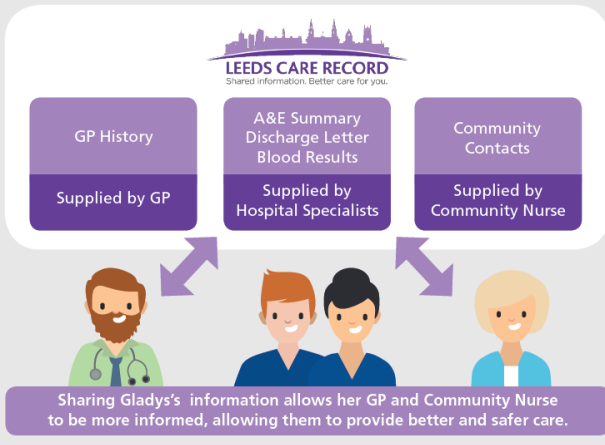


## How does it work?

### Scenario 3



Arriving at A&E, the staff review Gladys's Leeds Care record and investigate the cause of illness by taking some routine blood tests. Following the diagnosis, Gladys is transferred to a hospital ward to recover. After spending a few days in hospital Gladys recovers and is discharged to recover at home.

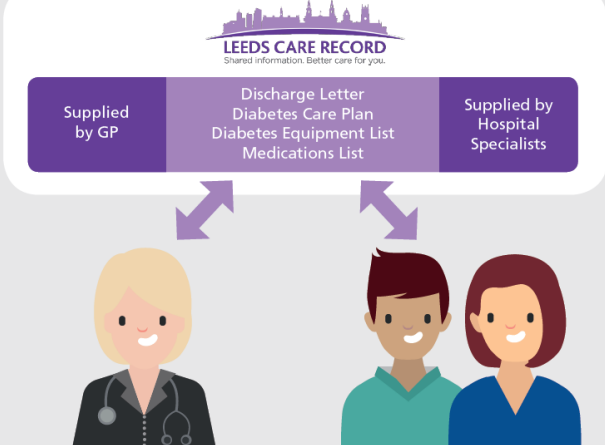


## How does it work?

### Scenario 4



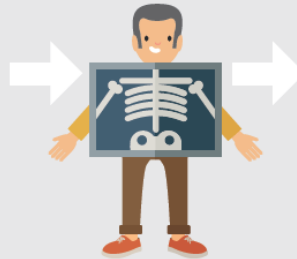
The patient later visits their local GP for a check-up. The GP can view and compare the previous blood tests taken at the hospital, avoiding the need to re-take unnecessary further tests.



## How does it work?

## Scenario 5

A patient attends Hospital for a scheduled radiology appointment.



Following treatment, the patient is well enough to go home.

The patient later visits their local GP for a check-up.  
The GP can view the letters from the hospital detailing the care provided and care plan for future treatment.

The GP can provide well informed support for the patient and family.



Supplied by GP

Discharge Letter  
Radiology Treatment Letter  
Upcoming Appointments

Supplied by Radiology Specialists



Out of all the scenarios, **SCENARIO ONE** was significantly the **most popular** one in all the Groups. They found the example to be clear, and liked that it showed a **child getting the care that they needed** even when their parents/guardians couldn't be contacted. However, it is suggested that the child being on a **school trip in Leeds** is added as the Leeds Care Record (LCR) wouldn't be applicable if they weren't. Scenarios **where patients were named were certainly favoured** by participants, as they made them more personal, so it is suggested that the child is given a name like how 'Gladys' is in scenario three.

The **next popular** scenario was **SCENARIO THREE**. As alluded to above, participants liked there being a **named patient**. The **South Asian Women's Group** were particularly keen on this scenario, as they felt it helped those whose **first language isn't English**, as the patient **doesn't have to repeat themselves to different healthcare professionals**. This was echoed by the other Groups who said that patients not having to repeat information in an **urgent/emergency** situation was a **very important** factor for them in the LCR. However, some of the participants, particularly those living with **mental ill health and/or of a younger age** stated that they would rather see the scenario arise from someone needing **emergency care as opposed to a GP raising the alarm**. They felt this would make the scenario more **relatable** across a wider spectrum of patients. This could be related to age, as the **older** participants were happy with this scenario as it was, and **liked the idea of a GP raising the alarm**. Another factor in this scenario to consider is the **length of the sentences**, and the **medical** way it is written.

Participants **liked SCENARIO TWO** because it showed a **good hospital discharge**, however they found it to be **too wordy** and **lost interest** whilst they were reading it. Again, suggestions were made about it being more of an **emergency scenario** with the emergency admission to hospital being described as well.

**SCENARIOS FOUR AND FIVE** were often **considered together** by participants, as they felt they were quite **similar**. They felt that they were **simple** and **straightforward** scenarios, but **not** as **attention grabbing** and **relatable** as the other ones.

## SCENARIO ONE:

- This wouldn't work if the child wasn't in Leeds, so it needs to be clear that the child is on a school trip in Leeds for the Leeds Care Record (LCR) to work.
- The child being named would add more of a personal touch to the scenario.
- If you have a child or are close to someone who does, this scenario is relatable as you want to ensure the safety of the child.
- Good, straightforward example.

## SCENARIO TWO:

- Great example as it shows a good hospital discharge process, but it is too wordy and some of the language is confusing.
- Relatable example, but it would be better if it was an emergency situation which shows the patient going into hospital and how the LCR works from that point onwards.

## SCENARIO THREE:

- Named person makes it more personalised.
- Could personalise it further by adding, '... sharing Gladys information meant that they were able to provide the right amount of medication' or '... they knew not to give her [a certain medication] because of an allergic reaction in the past'. This would make it less medical in the way it is written, and therefore even more relatable.
- Positive as she got the care she needed quickly and survives.
- Positive as she doesn't have to explain her problems to each different healthcare professional involved in her care.
- There could be less text, for example does it need to state that she is discharged from hospital to recover at home?
- Shorter sentences would be preferred.

- Would be more accurate if the situation arose from an ambulance being called by someone who isn't a healthcare professional, as the GP would have to share information with the Paramedic as to why they were being called.

#### **SCENARIO FOUR:**

- Good, but similar to scenario five.
- Simple to understand.
- The images of hospital professionals aren't specific enough, they look just like regular people.
- Type 1 Diabetes feels too specific, and people may find it hard to relate to. However, those living with Diabetes liked this scenario, as they could relate to it.
- Doesn't explain the benefit at the bottom of the page like the first three scenarios.

#### **SCENARIO FIVE:**

- Good, but similar to scenario four.
- Simple to understand.
- Doesn't explain the benefit at the bottom of the page like the first three scenarios.
- Picture of patient receiving an x-ray is really clear, even if English isn't your first language.



# Focus Group Findings - Posters

## POSTER ONE

**Working together to improve your care**

GP PRACTICES    COMMUNITY HEALTH CARE SERVICES    NHS HOSPITALS    ADULT'S & CHILDREN'S SOCIAL CARE SERVICES    MENTAL HEALTH SERVICES    HOSPICES

Leeds Care Record provides care professionals directly involved in your care access to the most up to date information about you. It does this by sharing appropriate information from your health and care records between health and social care services in Leeds.

Examples of what's included in my Leeds Care Record:

- Diagnosed conditions • Medications • Allergies & adverse reactions • Test results
- Referrals, clinical letters and discharge information • Care plans • Contact details



Joined up and safe care



More time to spend on your care



Information in one place



Secure and confidential



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[@LeedsCareRecord](https://twitter.com/LeedsCareRecord)

# POSTER TWO



## Working together to improve your care



GP  
PRACTICES

COMMUNITY HEALTH  
CARE SERVICES

NHS  
HOSPITALS

ADULT'S & CHILDREN'S  
SOCIAL CARE SERVICES

MENTAL HEALTH  
SERVICES

HOSPICES

Leeds Care Record provides care professionals directly involved in your care access to the most up to date information about you. It does this by sharing appropriate information from your health and care records between health and social care services in Leeds.

Examples of what's included in my Leeds Care Record:

- Diagnosed conditions • Medications • Allergies & adverse reactions • Test results
- Referrals, clinical letters and discharge information • Care plans • Contact details



Joined up  
and safe care



More time  
to spend on  
your care



Information  
in one place



Secure and  
confidential



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[@LeedsCareRecord](https://twitter.com/LeedsCareRecord)

After the first focus group that took place with the **Carers Group**, it was suggested that the 'Leeds Care Record' logo be moved to the top of the poster to show that healthcare professionals 'were working together to improve your health' using the Leeds Care Record, as you would expect the title of something to be at the top of the page.

From this point onwards the above two posters were taken to the remaining nine focus groups. There was variation in the focus groups about which was the preferred poster. Just over half of the participants preferred the logo at the top of the poster, as they immediately knew they were looking at a poster about the Leeds Care Record. Those that preferred the logo amongst the text at the bottom felt it broke it up well, and generally looked better. This was particularly true of participants who struggled to stay focused on a large amount of text, or struggled with the font size being too small.

## GENERAL COMMENTS ABOUT THE POSTERS

- The NHS logo captures your attention, but could this also be moved to the top and/or made larger.
- The cartoon staff are good, and are consistent throughout the Campaign.
- The colour scheme is calming and soft, some participants found this reassuring when thinking about their health, others didn't think it was eye-catching enough.
- The white text on the blue background doesn't stand out enough, especially for people with visual impairments.
- There is a lot of text on the poster, which impacts on the font size as it doesn't stand out enough.
- The healthcare professionals and speech bubble are a good illustration of people working together.
- There isn't enough representation of different ethnicities in the healthcare professionals shown on the poster.
- Fewer examples of 'examples of what is included in the Leeds Care Record' could be used to make the poster less crowded.

## POSTER ONE

- The logo at the bottom breaks the text up, and it stands out more amongst the text.
- The speech bubble is adequate as an attention-grabbing headline.
- Aesthetically, the logo looks better amongst the text at the bottom.

## POSTER TWO

- The logo at the top lets you know what you are reading about straightaway.
- The poster looks more official with the logo at the top.
- Is it possible to move the purple images so they come between the text and the 'examples of what is included in the Leeds Care Record'? This would break the text up in the same way that the logo does.
- Could the speech bubble be expanded to include the LCR logo, as opposed to it being on its own at the top of the poster.

## Conclusion

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Naturally when discussing promotional materials for the Leeds Care Record (LCR), conversations took place about what it actually is. This was useful as it provided an insight into what participants considered to be important, and what concerns they had about the LCR. Awareness of the LCR as a brand was low amongst participants, but they were generally positive about it, and liked the joined-up approach (their words). Those that had care plans, or cared for people who did liked the inclusion of care plans. Participants liked the idea of not having to repeat themselves, particularly in times of urgent/emergency care being needed. This was particularly true for those who had complex health needs, and didn't speak English as their first language. Concerns focused on patients being judged about their pasts and/or diagnosis, particularly those that had experienced emotional or mental ill health.

Both the leaflet and the poster were considered to be eye-catching. However, both suffered due to large amounts of text, which some participants felt would lose their interest. The colours used were well received, but some did struggle to read white text on a coloured background. Also, the font size was considered to be too small.

Scenarios showing patients getting emergency treatment were favoured, as they were considered to be attention-grabbing and relatable across the widest cohort of patients. The scenarios suffered when they had large amounts of text, and were considered to be medical in their approach as opposed to personal.

Marginally, the most popular poster was the one with the logo at the top, this served as a title as participants felt that 'working together to improve your care' was too vague. Those that preferred the logo in the text did so because they felt it broke the text up, and it looked better.

## Recommendations

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- Colour schemes need to be considered, as for participants with visual difficulties struggled to focus on the white text on the coloured background. The font size was also considered to be too small. This could be overcome by the images being made slightly smaller, particularly the speech bubble.
- Marginally, participants preferred the Leeds Care Record (LCR) logo to be at the top of the poster because it served as a title. Those that preferred it in the text did so because it broke the text up. It is suggested if it is to be used at the top of the poster:
  - That it is put into the speech bubble
  - The text below is broken up with the purple images and text coming before the examples to break up the two sections of blue text
  - Only one line of examples is used.
- As per the Accessible Information Standard, the leaflet needs to state that it is available in alternative languages/formats.
- As participants liked personal scenarios, it is suggested that the child in scenario one is named. It is also suggested that scenario one states that the child is on a school trip in Leeds.
- Participants found emergency scenarios to be the most relatable, so it is suggested that scenario three is used, but with an emergency admission as opposed to one directed by their GP. Those that considered this in detail, also found the use of the GP to be unrealistic as the GP would both have to and be able to provide medical information about why they were ringing for an ambulance.
- The amount of text used in the scenarios needs to be considered, and personalised context to be provided rather than medicalised context. A shorter amount of text will help keep patient focus, and a personal context (narrative perhaps) will help keep patient interest.

## Appendix One – Equality Monitoring

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<b>Gender</b>	
Female	57
Male	19
<b>TOTAL</b>	<b>76</b>

<b>Ethnicity</b>	
White British	34
Black African	7
Bangladeshi	3
Pakistani	2
Kurdish	1
Not answered	29
<b>TOTAL</b>	<b>76</b>

<b>Disability</b>	
Mental health	17
Physical	16
Deaf	11
Learning disability	11
Long-term	6
Visual	2
None	16
Prefer not to say	1
Not answered	22

<b>Age group</b>	
Under 18	6
18-25	9
26-35	11
36-45	8
46-55	10
56-65	8
66-75	2
76-85	2
86+	3
Not answered	17
<b>TOTAL</b>	<b>76</b>