Leeds Care Record – Mental Health Findings

November – December 2014

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1. Introduction

This report presents the findings from the three focus groups and five interviews which were held about the mental health information that people did or did not want sharing in the Leeds Care Record.

2. Background

Leeds Teaching Hospital Trust has been leading the development of the Leeds care Record as part of the programme of work to look at how health and social care information is shared at a city-wide level.

The Leeds Care Record is an electronic patient record, which health and social care professionals can access to find out information that may help the treatment of the patient that they are treating.

Four GP Practices have already piloted the Leeds Care Record, and engagement has been done around public perception.

The majority of GP Practices in Leeds have signed up to the Leeds Care Record, and this will roll out across them in the new year.

During the public engagement, concerns were raised about what mental health information was being shared in the Leeds Care Record, and who would have access to it.

Before the Leeds Care Record is to be rolled out throughout the city. Leeds Teaching Hospital Trust would like to know what information people do and do not want sharing about their mental health on the Leeds Care Record. People cannot opt-out of certain pieces of information being shared. They can opt-out of the Leeds Care Record as a whole, but they cannot say that they do not want certain pieces of information sharing about them.

It is important to engage with people living with mental health conditions to find out what the cut-off point is for them in terms of information that is necessary to share with health professionals treating their physical health, and what is too personal and/or unnecessary.

3. Engagement process

Leeds Involving People (LIP) and the Leeds Care Record Project Worker arranged two focus groups for members of the mental health community to attend. The focus groups were recruited for using Leeds Teaching Hospital Trust's Service-user Network (SUN) and LIP's contacts.

A further focus group was conducted at the SUN group meeting.

Five one-to-one interviews were also conducted.

Participants were read a list of items that would be included in the Leeds Care Record, and asked about the inclusion of each one. From this there is both a quantitative and qualitative summary of what mental health information people are comfortable with being shared in their Leeds Care Record.

4. Summary of Findings

Item	Focus group one	Focus group two	Focus group three	Interview one	Interview two	Interview three	Interview four	Interview five	Conclusion
Presence of a Mental Health Record	Yes	Yes	N/A	No	Yes	Yes	Yes	Yes	Yes
Medication*	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Allergies*	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Date of last Outpatient Clinic	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Date of next Outpatient Clinic	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Date of last community team visit*	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Date of next community team visit*	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Name(s) of Involved team(s)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Name(s) of involved staff (and contact numbers*)	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Dates of admission to ward/ICS/CAS	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes
Clinical Trial involvement	Yes	Yes	N/A	N/A	Yes	Yes	Yes	Yes	Yes
End of Life Plan	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Yes	Yes
Alerts (includes allergies currently) (i.e. that a patient has been previously been aggressive or violent with staff)	Yes	Yes	N/A	Yes	Yes	Yes	Yes	Undecided	Yes
Presence of Advanced Statement	Yes	Yes	N/A	No	Yes	Yes	Yes	Yes	Yes
Content of Advanced Statement*	No	Undecided	N/A	No	Yes	Yes	Yes	Yes	No
Discharge summary*	Yes	Undecided	N/A	No	Yes	Yes	Yes	Yes	Yes
Care Plan	Yes	Yes	N/A	No	Yes	Yes	Yes	Yes	Yes
Clinical Letters*	Yes	No	N/A	No	Yes	Yes	Yes	Yes	Yes
CTO active	Yes	Yes	N/A	No	Yes	Yes	Yes	Undecided	Yes
CTO restrictions	Undecided	Undecided	N/A	No	Yes	Yes	Yes	Undecided	No
Diagnosis*	Undecided	No	No	No	Yes	Yes	Yes	No	Undecided

Risk Assessment Document (FACE/SAMP)	No	No	N/A	No	Yes	Yes	Yes	Undecided	No
Holistic Assessment Tool	No	No	N/A	No	No	Yes	Undecided	Yes	No
*Not available on Leeds Care Record yet									

5. Responses

Focus group one – 25th November 2014 (See Appendix 1)

There were seven participants in the focus group.
The participants agreed that most of the listed items should be on the Leeds Care Record (LCR). Some of the participants shared concerns about being judged by members of healthcare staff based upon their diagnosis. This was particularly apparent with those who were living with Personality Disorders. There became a point in the focus group where participants felt that there should be a flag to say a patient has a certain document, but it shouldn't be listed as the details were too personal and someone dealing with your physical health generally wouldn't have to know this information about you. This was the Advanced Statement, Community Treatment Order and Risk Assessment Document. Some of the participants said that they felt their diagnosis was too personal to share, as they were concerned about being judged. The whole group agreed that the Holistic Assessment Tool was too personal to share.

Focus group two – 25th November 2014 (See Appendix 2)

There were seven particpants in the focus group.
All the particpants agreed that most of the listed items should be on the Leeds Care Record (LCR). One of the participants said that some of the information should be time-limted to an extent, as when it is written down, it is hard to move on from in the eyes of healthcare professionals. Again, there became a point in the focus group where participants felt that there should be a flag to say a patient has a certain document, but it shouldn't be listed as the details were too personal and someone dealing with your physical health generally wouldn't have to know this information about you. This was the Advanced Statement, Discharge Summary, Clinical Letters, Community Treatment Order and Risk Assessment Document. The participants felt that their diagnosis and Holistic Assessment Tool were far too personal to share with someone dealing with their physical health.

Focus group three – 3rd December 2014 (See Appendix 3)

There were 21 particpants in the focus group. Due to time limitations, not every question was asked.
The participants didn't answer the question about whether a mental health record should be listed on their Leeds Care Record (LCR). There was a lot of discussion about whether diagnosis should be shared. Some participants felt that they had been misdiagnosed, so didn't agree with their diagnosis, therefore

didn't want it sharing. Some felt that they would be judged based upon their diagnosis. One of the particpants identified himself as a carer and said that he would want his details on the LCR of the person that he cares for, so he could be contacted in case of emergency.

Interview one
The participant has a Personality Disorder. He said that he wouldn't want anything to do with his mental health shared on the Leeds Care Record (LCR), as he had a bad experience in hospital when they learnt about his diagnosis. He said that they treated him perfectly well, until they learnt that he had a Personality Disorder, from this point onwards he felt that they stopped believing what he was saying. He said that there is a stigma in the physical side of the NHS when it comes to mental health, and until this is quashed, he doesn't want them knowing a thing about his mental health.

Interview two
The particpant carers for her mother who is living with Paranoid Schizophrenia. The particpant was happy with everything except for Clinical Letters and the Holistic Assessment Tool to be shared on the Leeds Care Record (LCR). She said that she didn't see the point of Clinical Letters being shared, and that the Holistic Assessment Tool was too personal to share. She said that she would like her information to be on the LCR of her mother, so she can be contacted in case of emergency. She said that her mother doesn't mind too much about what's shared about her mental health, as she is proud of how much she has overcome. However, this wasn't the case when she was first diagnosed, as at the time Schizophrenia was seen in a very negative light.

Interview three
The participant has Bi-polar and Emotional Personality Disorder. She said that she would want anyone working with her physical health to have access to information about her mental health, as she considers the two to go hand in hand. She said that she has been in Crisis many times, and has not been in a fit state to make any comments or decisions about her health, so she wants the people who are making them for her to know as much as possible about her.

Interview four
The participant has Anxiety, Depression and Bi-polar. She said that she believes physical and mental health go hand in hand, so she doesn't mind what information is shared about her mental health with physical healthcare professionals. She said that when you take medication for your mental health, it is important for this dose not to be stopped when you are admitted into hospital, for this reason she is particularly keen on the Leeds Care Record (LCR). She was unsure about the Holistic Assessment Tool being shared, as she considers this to be very personal information.

Interview five
The particpant cares for her son who has Pyschosis and Schizophrenia. She was keen on the Leeds Care Record (LCR), as it will mean more joined-up care between physical health and mental health professsionals. She said that her son has had problems with his physical health, and this has knocked onto his mental health, but no one is able to say exactly why. She said that they would probably be closer to an answer if they were all able to access the same information. She said that she would like her details to be shared on the LCR of her son in case of emergency, and also because she knows her son's behaviour and when to be worried, and when not to be. She said that carer confidentiality should be respected more, as it can break down important trust boundaries if it isn't followed. She felt that Risk Assessment Documents can be problamatic, as people need to be able to move on from poor mental health, and the existant of documents without time limitations on them may not allow for this. She felt that diagnosis was too personal to share, as not everyone agrees with the diagnosis they have and labelling people can be detrimental for their health.

6. Conclusion

In conclusion, there should be a tab for mental health on the Leeds Care Record (LCR). However, there should be caution taken with the amount of information shared. The majority of particpants didn't want the content of the Advanced Statement, Community Treatment Restrictions, Risk Assessment Document and Holistic Assessment Tool sharing.

There was quite a lot of discussion around diagnosis. The majority of particpants had no concerns about it being shared, but those who did felt very strongly about it. They shared concerns about judgement from staff members treating their physical health based upon their mental health. This came particularly in relation to Personality Disorders. Those who had been living with their mental health condition for a long period of time, seemed to be accepting of their diagnosis. They also had an understanding that in times of crisis they aren't able to make decisions for themselves, and that the healthcare professionals treating them need to know as much as possible about them in order to make the best decisions possible.

Some of the participants shared concerns about not being able to move on from bad patches of mental health if they were recorded in the LCR. They felt that they may be judged unduly for behaviour that occurred many years ago, and that they should be able to move on from this.

Carers said that they would like their details on the LCR of the person that they care for, so they can be contacted in case of emergency. They said that they often attend appointments with the person that they care for, be it for their physical or mental health.

Overall, the participants were happy for their information to be shared on the LCR. They felt that it would make for smoother, more joined-up care.

7. Recommendations

The findings suggest that people living with Personality Disorders are fearful of being judged by members of staff dealing with their physical health. Further research could be done with the Personality Disorder Clinical Network group to find out more about this, and what could be done, if anything, to alliviate this concern.

Diagnosis was a controversial subject, particularly for those who weren't happy with their diagnosis, or still in the process of being diagnosed. Diagnosis could be something that people consent to being shared, or have to confirm, or even left out completely. As it may cause people to opt-out of the LCR, if they are unhappy with the diagnosis that is stated on there.

There should be a time-limited element to some of the alerts that are shared. Participants were concerned about past poor patches of mental health coming up, and being judged for them. They felt this was unfair, as they have moved on from that time and don't want reminding of it, or being judged based upon it.

Glossary of terms

Advanced statement
An advanced statement describes a document written in case someone becomes seriously unwell in the future and incapable of making decisions. The document expresses the wishes of the individual regarding care and must be followed where possible, by the treating care team. They are sometimes referred to as *living wills*.

Clinical trials
These are research studies that recruit people to help test the effectiveness of a new treatment, drug, therapy, or support package. Clinical trials might also be used to compare different procedures, or to look at the effectiveness of a new-style service, or the effectiveness of training for health professionals. Carrying out clinical trials is the only way to find out if a new treatment or new service works well and is better than treatments or services currently available. Clinical trials that run within the NHS recruit participants through hospitals or community based services. People who take part in clinical trials must be given enough information about the study to enable them to give 'informed consent' – to agree to take part in the trial with full knowledge of what participation involves, the potential benefits of the treatment or therapy being tested, and the potential risks. Clinical trials are often 'randomised' (and thus called randomised controlled trials – RCTs). People who agree to take part are randomly chosen to have different treatments or services so researchers can compare the effectiveness of each one. The random selection means the results are not biased.

Community Treatment Order
This is the Order, a legal document from the Mental Health Act, which gives mental health professionals the power to make a detained person subject to Supervised Community Treatment (See below).

Holistic Assessment Tool
People entering a mental health service who have complex needs requiring multidisciplinary input, should receive a holistic assessment, which includes an assessment of strengths needs symptoms and other issues relevant to care.

Joint crisis plans
Joint crisis plans are a type of 'advance statement' or 'advance directive' – a document containing someone's wishes about treatment and care if they become seriously unwell again. Joint crisis plans are drawn up after a discussion with mental health professionals and that discussion can include someone who is not involved in an individual's treatment. The role of that independent person is to negotiate a way forward if the person who is unwell and the mental health professionals do not agree on the best plan.

Risk Assessment Document (FACE/SAMP)
Tools used by mental health professionals to document issues of risk. This may be risks to services users and other persons where this is caused by mental disorder.

Supervised community treatment
A means by which a small group of people can be made subject to conditions, with which they have to comply, to enable them to live in the community. The purpose of this is to shorten the time they would spend detained in hospital under the Mental Health Act.