

# Service users' experiences and opinions of routine outcome measures at Leeds Addiction Unit

Commissioned by Dr Duncan Raistrick, Consultant Addiction Psychiatrist, Leeds  
Addiction Unit, Leeds and York Partnership NHS Foundation Trust

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## Introduction

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### Service Evaluation Context

Leeds Addiction Unit (LAU) is a specialist unit within Leeds and York Partnership NHS Foundation Trust which works with people who misuse alcohol and other substances and who have complex needs. All service users who access the unit have a care plan constructed to address their psychosocial needs. Service users are assigned a keyworker, who they work with to achieve the goals on their care plan, with the collaboration of other specialist staff and services to meet their individual needs.

All service users are sent an initial booklet of routine outcome measures prior to their first appointment, and they are asked to complete a follow up booklet at 3 months into treatment, at 6 months into treatment, and on discharge. In addition to a number of demographic questions, the initial booklet contains: the Leeds Dependency Questionnaire (LDQ) (Raistrick, Bradshaw, Tober, Weiner, Allison, & Healfy, 1994); the Clinical Outcomes in Routine Evaluation Outcome Measure (CORE-OM) (Evans, Connell, Barkham, Margison, McGrath, Mellor-Clark, & Audin, 2002); the Social Satisfaction Questionnaire (SSQ) (Raistrick, Tober, Heather, & Clark, 2007); the EuroQOL 5-D (Brooks, 1996); a self-report chart of substance use; and several self-report scales based on Motivation Interviewing (MI) principles. The follow up booklet consisted of all the same measures except the MI informed scales.

This service evaluation was commissioned to help understand the use of these measures from the perspective of the service user.

### Literature Review

#### *Routine Outcome Measures*

Routine outcome measures are integral for gathering information, clinical governance, and funding purposes. NICE guidance for the treatment of alcohol dependence recommends a comprehensive initial assessment with someone who is

drinking heavily using both clinical interview and standardised measures (NICE, 2011). The guidance recommends assessing consumption, psychological dependence, physical problems, psychological and social problems, and readiness to change. These areas are all currently covered in the initial booklet of measures that are used at LAU. It is also instructed in the guidelines that “All interventions for people who misuse alcohol should be the subject of routine outcome monitoring. This should be used to inform decisions about continuation of both psychological and pharmacological treatments.” (NICE, 2011 p21).

Fitzpatrick, Davey, Buxton, & Jones (1998) outline eight criteria to consider when selecting an outcome measure. These are; appropriateness, reliability, validity, responsiveness, precision, interpretability, acceptability, and feasibility. When measures are developed reliability and validity are commonly quantitatively measured and feasibility is often measured. However service user acceptability is rarely tested or reported in any depth. By attempting to increase the understanding of service user acceptability of the measures used at LAU, this service evaluation contributes to the RESULT research project dedicated to identifying suitable outcome measures for use in specialist addiction services.

### *Service user involvement*

Outcome measures are not just for assessment and monitoring the progress of service users, nor are they just for evaluating services and securing funding. NICE (2011) recommends that clinicians “routinely use outcome measurements to make sure that the person who misuses alcohol is involved in reviewing the effectiveness of treatment.” p21. Using outcome measures collaboratively with service users to initiate conversations about their progress and their treatment provides them with a platform to on which to discuss their views of the care they are receiving. Also, recent developments in case tracking research state that service users appreciate receiving regular objective feedback regarding their progress. Unsworth, Cowie, & Green (2011) reported that service users found case tracking an overall positive process. They appreciated that it

raised their awareness both of the progress they were making, and their right to be involved in conversations regarding the treatment they were receiving.

With this in mind it is important to understand how service users view the outcome measures, both in their content and in the procedure in which they are used. The National Treatment Agency (2002) highlighted the importance of service users being involved in service development in order to increase the services' relevance and acceptability and, in turn, increase effectiveness. With the established literature regarding the importance of service user involvement, and the more recent literature regarding on-going consultation with service users through case tracking, this project exploits both these by seeking service user opinions with regards to the measures at LAU which may in turn lead to more on-going service user collaboration through the use of these same measures.

## **Aims**

1. Develop an awareness of the acceptability of the measures used to monitor routine outcomes at LAU.
2. Develop an understanding of the service users' experiences of completing the battery of measures.
3. Consult with service users regarding how their experiences of routine outcome monitoring could be improved.

## **Methodology**

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### **Design**

Semi-structured interviews were selected to address the research aims as they could be designed to gain both some simple descriptive data and a richer account of the service user experiences. It was decided that using questionnaires would not be appropriate as they themselves would resemble too closely the processes and topics that were being investigated.

## **Participants**

Ten participants were interviewed for the purposes of this study. All the participants had been treated for alcohol addiction at LAU in the past, were no longer in active treatment with a named keyworker, and were attending the post treatment support group. All of the participants were of working age, with 6 females and 4 males included in the sample. Full demographic information of the participants has not been provided as they were recruited from a relatively small pool of potential participants, and thus including this information may have made them identifiable. Three of the participants were mentors to the group, and the other seven were regular members. On analysis, there were no qualitative differences between the responses of the mentors and the regular members, therefore no distinction was made between the two groups to preserve anonymity of the mentors.

## **Procedure**

Potential participants were initially approached at the post treatment support group meeting by an LAU clinician or a group mentor, who explained the study. This gave the potential participants time to consider whether they would like take part. At subsequent meetings, the group was asked if anyone wanted to participate on that day following the meeting. Semi structured interviews were undertaken at LAU by the researcher with the ten participants. The interviews were conducted according to an interview schedule (Appendix 1) devised to capture the interviewees experiences and opinions without guiding them to give a particular response. The schedule was designed to address general views about the booklets, the specific measures within the booklet, and the processes in which they are used. In addition to this several rating scale questions were asked with regards to the booklet as a whole and the individual measures. Each interview lasted between 40-70 minutes. All information given by the participants has been kept anonymous. Participants were informed of their right to withdraw, and the benefits and costs of taking part in the interview as noted in the participant information sheet (Appendix 2).

## Analysis

The interviews were transcribed and analysed using thematic analysis, adhering to the guidelines outlined by Braun & Clarke (2006) of which a summary of the stages of the process is shown overleaf:

| Stage of analysis | Key aspects of stage                                                                                                                                  |
|-------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------|
| 1                 | Familiarisation with the data through transcription of interviews, reading of transcripts and initial memo writing                                    |
| 2                 | Generating initial codes by systematically coding the whole data set with reference to the research aims                                              |
| 3                 | Searching for themes by collating codes into potential themes                                                                                         |
| 4                 | Reviewing themes by checking, noticing overlap, and fitting into thematic map                                                                         |
| 5                 | Defining and naming themes                                                                                                                            |
| 6                 | Writing the report, including selecting extracts to demonstrate themes and discussing themes in relation to the research aims and existing literature |

Table 1. Table showing summary of key stages in process of thematic analysis adapted from Braun & Clarke (2006)

Though the data was largely analysed according to the stages detailed in the above table, the process was recursive rather than linear. For example, there were several instances when reviewing the themes that it was necessary to revisit the initial codes.

The analysis was undertaken within a largely realist approach as this seemed appropriate to capture the views of the service users. Initially, the data was approached in an inductive way, meaning that the analysis was focussed on drawing observations from the information that was present in the data rather than seeking to see if it confirmed existing theory. Following an inductive analysis, the data was revisited with a more deductive approach, noting any codes or themes that general principles that coincide within the existing literature and existing clinical knowledge of the researcher.

In addition to the thematic analysis, quantitative data produced by several scaled questions was analysed using descriptive statistics.

Several values were removed from the analysis after noticing that they did not correspond with that participant's qualitative report of how they felt. The values were removed as it appeared in these instances that that participant had not understood the question, and so the value they gave was not representative of how they felt. Both the 'trimmed' data and the whole data set are discussed in the results.

### **Ethical Considerations**

As the project was a service evaluation, full REC approval was not required. The details of the project were approved by Leeds and Yorkshire NHS Foundation Trust Research and Innovation department (Appendix 3).

### **Reflective statement**

I was interested in undertaking this project because as a clinician I am quite ambivalent about using routine outcome measures. I often wonder what the service users make of them; whether they see them as useful, as an irrelevant inconvenience, or as an anxiety provoking obstacle. However, as a researcher and an NHS worker, I know that measuring outcomes is essential both for developing the field, and to ensure funding for services. By undertaking this project, I hoped to uncover the often unheard opinion of the service user, in order to help inform best practice regarding how to use measures which are now a ubiquitous dimension of service provision.

During data collection and initial analysis phases I attempted to stay as close to the data as possible, keeping an open mind aside from my own assumptions and opinions. This was enabled by keeping a reflective journal to record my personal thoughts, keeping a space between them and the data, to be referred back to later. During the latter phases of analysis and when considering recommendations for best practice I referred back to my journal, and considered my clinical experiences in order to view the data with a different lens and place it into some context.

## **Results**

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## Acceptability of Measures

The mean average acceptability rating given for the booklet of measures as a whole, on a scale of 0-10, was 8 (trimmed value) or 7.6 (non-trimmed value). This indicates that the booklet of measures overall showed good service user acceptability (See Fig 1.) The acceptability rating for each individual measure is discussed below with reference to explanations from participants regarding their views of the measures. Discussion regarding what participants did and did not like about the booklet as a whole is given in the latter section outlining the key findings of the thematic analysis.

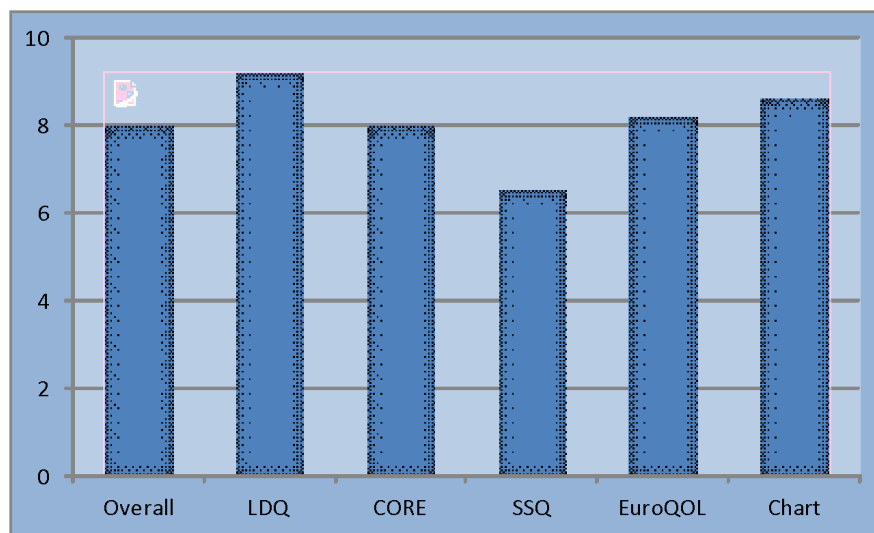


Fig 1. Graph showing trimmed mean score for each measure and booklet as a whole

### *Leeds Dependency Questionnaire (LDQ)*

The mean average acceptability rating for the LDQ, on a scale of 0-10, was 9.2 (trimmed value) or 8.2 (non-trimmed value). As can be seen in Fig. 1 above, the LDQ had the highest acceptability of all the questionnaires. This was supported by several participants noting that completing it was therapeutic in itself. It was noted that this was because it helped to raise awareness/combat denial of the problems with alcohol that they were facing.

*“I didn’t realise that’s what I did, until I actually read it and when I put down my answer, you sort of click and then think actually yeh I am planning my days around”*

*Participant 5*

*Clinical Outcomes in Routine Evaluation (CORE-OM)*

The mean average acceptability rating for the CORE-OM, on a scale of 0-10, was 8.0 (trimmed value) or 7.3 (non-trimmed value), showing that participants were largely happy with this measure. The majority of participants noted that it was important for gauging any problems with depression or anxiety they may have had either as a result of or as a contributory factor to their drinking. It was noted by some that it was a bit intimidating to complete the first time as they had not expected to be asked questions about their mental health. Several participants noted they felt that the information they disclosed on this measure was not actively used and wished for more discussion or support in this area once they had completed it.

*“You could say I am feeling like that so you put it down and they could say right - Why, what is going on?”*

*Participant 9*

*Social Satisfaction Questionnaire (SSQ)*

The mean average acceptability rating for the SSQ, on a scale of 0-10, was 6.6 both for the trimmed and non-trimmed values. As seen on Fig. 1., this is the lowest score of all of the measures, though is still at a level which indicates that participants were relatively happy with the measure. The most common reason for liking this measure less than others was that they felt the information that they gave on this measure was not informing their treatment, noting that it raised their awareness of how bad their situation was, but offered no hope that it would improve.

*“What you need, is you get the option, how satisfied are you? Dissatisfied. Then maybe speak to someone who can do something about it for you, you know, I had problems with housing and rent arrears and thinks like that but nobody offered to help me with that.”*

*Participant 5*

Other participants noted that progress as measured on this measure would be much slower than on the others which could be discouraging when completing it at follow up and discussing progress.

*“Or sometimes I probably wouldn’t have liked the fact that a lot of other areas in my life hadn’t changed. You know, my financial situation didn’t change, I didn’t get a house, I didn’t get all these other things. All these other things didn’t follow suit; so if they were supposed to, I failed.”*

*Participant 2*

Other participants were more positive about the SSQ as a way of gathering information that formed part of the formulation of why they drank and so could inform their care.

*“They can see like you living position, your money out goings, if you are satisfied or not and if all these are not satisfied or fairly satisfied then they know why you are going into that state. So that is just as important as the last. So for me the two are bolted together.”*

*Participant 9*

### *EuroQOL*

The mean average acceptability rating for the EuroQOL, on a scale of 0-10, was 7.9 (trimmed value) or 8.2 ( non-trimmed value). This indicates that participants found this measure quite acceptable. It was discussed by participants more as a way to gather information initially rather than to track progress. A topic that was raised by several participants was that they felt they would not have raised the issue of health problems if not asked, and so completing the EuroQOL gave them a chance to raise these issues.

*“And you know, some people would be embarrassed, and you know talking about these problems, but as I say if you are actually asked these questions it is giving you a chance to talk them through.”*

*Participant 7*

### *Substance use Chart*

The mean average acceptability rating for the substance use chart, on a scale of 0-10, was 8.6 both for the trimmed and non-trimmed values. This shows that participants saw value in this measure. Nearly all participants noted that this was an essential and very

relevant measure to be included in the battery. Many explicitly noted that the only reason they did not score it higher was issues they had had with the completion of it. The primary issue that was reported was that initially when engaging with the service they did not know what a 'unit' of alcohol was and so could not calculate a total accurately.

*"The problem I have is they do everything by units. You get like a chart of how many units are in a tin of cider and that. To be honest when you're completely out of your tree the last thing you can do is add up and multiply and work things out what you've drunk, and you can't remember what you've drunk coz you don't count it."*

*Participant 5*

Many also noted that there was no such thing as a 'typical day' which they were asked to describe. They offered suggestions in overcoming this such as writing what they would drink in terms of volume and type of drink, or type of drink and money spent. Most participants noted that the completion of this chart would be facilitated by a larger space in order to explain their substance use. It was noted by most participants that asking how many days they had used in the past 28 days was a pertinent and useful snapshot of their substance use. This is supported by Tober (2000) who reported that frequency data is more reliable and accurate than quantity data, and may be enough to use as outcome data in itself.

*"So it's useful to know, if you were to put 10 days down there, that's kind of normal. Kind of average isn't it, so it's going to be indicative that I don't have a problem, but if I put 28 days in there, then you know, so that's ok as it is. I think that's a waste of time (points to column of amount used in typical day)."*

*Participant 3*

## **Result from thematic analysis**

A map of the themes from the thematic analysis of the transcripts was developed representing the opinions and experiences that the service users expressed, which is shown overleaf.

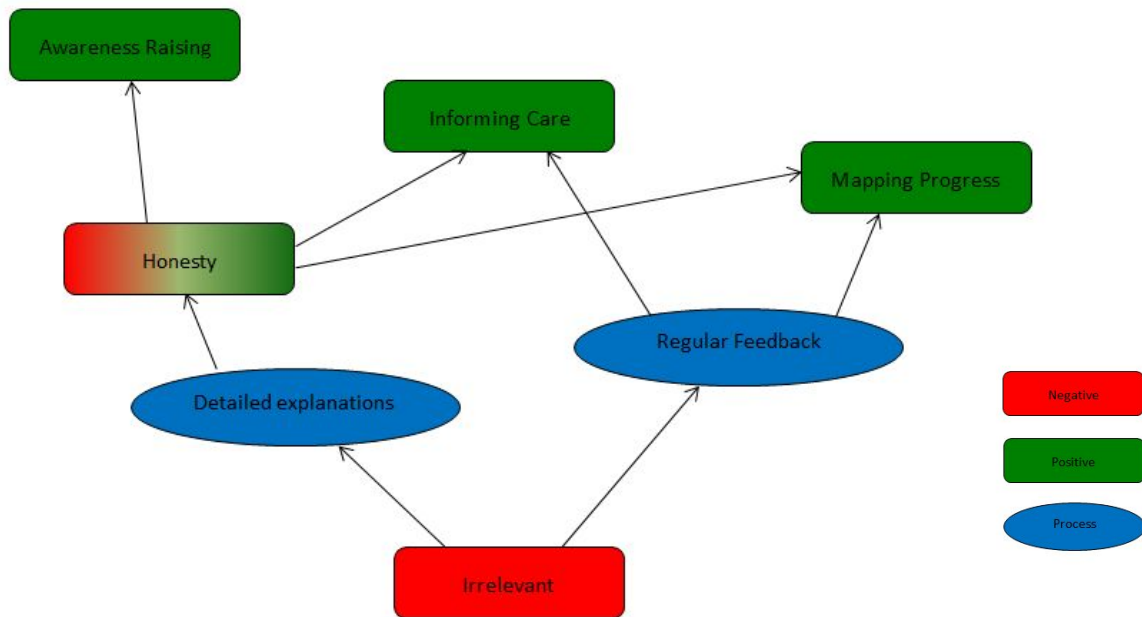


Fig. 2. Map showing interplay between themes identified through thematic analysis

Service users identified several positive aspects of the outcome measures, as well as noting that at times they could feel irrelevant especially when they found it would hard to be honest. Processes were identified which made the outcome measures meaningful, with some participants noting they had experienced those processes, and some suggesting that these processes could be used more to increase the positive aspects and decrease the feeling of irrelevance. The interlinking of these core themes are shown in Fig. 2. above. Below, these themes are explained in more detail with extracts of service user talk to represent their meaning.

#### *Battery of measures is irrelevant*

Several participants noted that they felt the measures were irrelevant for them noting they did not see the use in filling long forms in. It was mentioned by several people that their state of mind when first engaging also prevented them from finding them meaningful.

*“I may have found them “what are they asking this for?” “What are they going to be used for?”  
Erm why do I need to do it? Because for me it wouldn’t have been the relevant part of my  
treatment.”*

*Participant 2*

However, although seven of the respondents did note them to be inconvenient or irrelevant at times, most did note they were useful when given more thought, or could be useful if the processes were changed slightly (which will be discussed later in the report).

*“It is such a 50:50 thing. It is very important but it is so bloody annoying when they say fill in  
this huge 8000 page thing in for us please! Again...Oh but it is important.”*

*Participant 8*

#### *Gathers information to inform care*

One of the reasons that the service users reported that the measures were useful was that they gathered a lot of information relatively quickly and easily which could be then discussed in more detail and used in informing their treatment.

*“So by people filling these in, it’s giving people insight into the problems that this particular  
person is facing.”*

*Participant 7*

#### *Issues with honesty*

Eight of the participants noted that they struggled to be honest when completing the initial booklets. It was noted that part of the reason for this dishonesty was a dishonesty to themselves similar to the “denial” that is often conceptualised as an early stage of addiction recovery (e.g. Howard, McMillen, Nower, Elze, Edmond, & Bricout, 2002). With regards to this form of dishonesty, participants spoke positively about the process of completing the measures as they helped to overcome the “denial.”

*“It made me think and I thought I am not a good person. Why am I lying? When they are there  
to help me... I am only lying to myself, nobody else. So it is fetching the truth out in your  
own head. You know it is wrong while you are doing it. So it is fetching the truth home  
you could say.”*

*Participant 9*

It seemed to some participants that the switch from not telling the truth on the forms, to telling them was a distinct landmark in their recovery, and that being able to write down on paper the overcoming of this denial was motivating in itself.

*“So when I did it and was being truthful about it, I felt really chuffed coz I’d been truthful and I’d told them.”*

*Participant 5*

In addition to the issue of “denial”, participants also noted not telling the truth for fear of being judged. They noted that they were able to complete the measures more truthfully when they had built a relationship with their keyworker, and come to realise that they would not be judged for telling the truth. They reported a process whereby they realised that the questionnaires were meaningless as well as some other aspects of therapy unless they did tell the truth, and so they disclosed more openly as soon as they felt comfortable to do so.

*“I think it is time. And it’s usually when people get to know people…… It’s when I got to know the person I went to see.”*

*Participant 10*

#### *Completion as awareness raising*

This theme has already been discussed with regards to service users particularly liking the LDQ as it raised their awareness. Also, with regards to some aspects of honesty, it has been discussed that by writing down things that were not true, it raised their awareness of what they were telling themselves and the “denial” they might have been in. Several participants noted that the process of answering these questions made them consider things they had avoided thinking about before, and the process of writing it down on paper made this even more powerful.

*“I think it’s a good idea, because it gets your mind going. And it gets your thoughts on paper, sort of, and it makes you think about yourself.”*

*Participant 4*

### *Importance of detailed explanations*

The process of introducing the booklets was raised as something which could possibly be improved upon. For reasons closely linked with the discussion above with regards to honesty, participants felt that if they were given more detailed explanations of how the booklets were used they might have found it easier to have been more honest, which in turn would have made them more meaningful to themselves and the service. Currently LAU sends the first booklet out for completion prior to the first appointment, and several participants noted they would like to meet with the keyworker first to get to know them a little and understand the context of why they were filling in the booklets.

*“I think if there was more of a speech thing before hand, somebody sitting down and saying, “Right, feel free, don’t hold back... I am not going to be judged and it is not going to go away and be brought up at every occasion. Just feel free to say what you want, be honest because no one is going to judge you” Because I don’t think you feel that although you know it is confidential you still hold back.”*

*Participant 8*

### *Mapping progress*

Several participants noted that they valued the measures, as they showed the progress they had made thus far since engaging with the service. This was noted as something that was motivating and helped them to continue working towards their goals.

*“When I was discharged, my keyworker was able to show me the one I’d written when I started to be honest, not the initial one, and the one at the end, and the difference, and that was a huge boost, so I think for that reason alone, it is good.”*

*Participant 1*

### *Importance of feedback*

Relating to the value of mapping progress, several participants suggested they would like to get more feedback from the booklets they complete in order to facilitate the conversations regarding their care and their progress. It appeared that some of the sample they had received this feedback and these tended to be more positive about mapping

progress. Other participants reported they had filled the form in and heard nothing more about it. Several expressed that they would really value more feedback and discussions regarding the measures in order to monitor their progress.

*“I think that it would be good to look back at the first one that you filled in and see how you felt now. I think that would be really, **really** useful.”*

*Participant 8*

#### *Other*

Another noteworthy topic that emerged was the idea of completing the questionnaires online, and receiving feedback in the form of a score which can be compared with other populations.

*“The easiest way I can think is to do it online and have some sort of online score check, so at the end of it, it gives you a result – there and then that you can see.”*

*Participant 5*

Another service user recounted his difficulties with reading and writing, and noted that filling a booklet out in the corridor was stressful for him.

*“She said, “I have got you this form. Will you fill it in in the corridor?” Well with me learning difficulties I was shy with other people around me, so you know what I mean... I am taking my time and watching me, you know what I mean so that way I was not comfortable.”*

*Participant 9*

A few of the participants mentioned the motivational scales that were included in the initial booklet. Feedback was given that they felt they were not reliable, and the answers of how motivated you were would depend on how ill one was feeling on that day. It was also noted that being in the initial booklet was quite intimidating as they felt they could not say they were not motivated, or that they felt confident in case they were refused from the service. Therefore they noted that they wrote down answers that they felt the keyworker would want in order to let them access the service.

#### *Quality check of thematic analysis*

A quality check to ensure that themes are robust and consistent across a number of participants was carried out by tabulating which themes each participant identified (Table 2). This prevented the identification of themes that resonate with the researcher but do not appear consistently within the data set.

| Participant | Irrelevant | Information to inform care | Issues with Honesty | Mapping progress | Awareness raising | More feedback | More detailed explanations |
|-------------|------------|----------------------------|---------------------|------------------|-------------------|---------------|----------------------------|
| 1           | X          | X                          | X                   | X                | X                 | X             | X                          |
| 2           | X          |                            | X                   | X                | X                 |               |                            |
| 3           | X          | X                          | X                   | X                | X                 |               | X                          |
| 4           |            | X                          |                     | X                | X                 |               |                            |
| 5           | X          | X                          | X                   | X                | X                 | X             |                            |
| 6           |            | X                          |                     | X                |                   |               |                            |
| 7           | X          | X                          | X                   |                  |                   | X             |                            |
| 8           | X          | X                          | X                   | X                |                   |               | X                          |
| 9           | X          |                            | X                   | X                | X                 |               | X                          |
| 10          |            |                            | X                   | X                | X                 | X             | X                          |

Table 2. Table showing themes mentioned by each participant

## Discussion and Conclusions

### Recommendations to the service

From the analysis of service user accounts, the following recommendations have been made to the service with the aim of making the booklets more meaningful to service users and thus the service itself.

- Given that service users appear relatively happy to complete the measures, clinicians can feel more confident in actively incorporating them into the treatment process
- To explain the rationale of the measures comprehensively and in person
- To give more detailed and immediate feedback to prompt discussions regarding progress
- To consider giving a shorter version of the battery more regularly to track progress as part of the treatment process
- To discuss information given on the measures within the treatment sessions

- To consider giving time to fill them out at the unit rather than at home
- To consider separating the motivational scales from the booklet to be used independently as a treatment tool

### *Dissemination*

The conclusions and recommendations of this study have been fed back to the commissioner who is a senior researcher at LAU. This information will also be fed back to the mentors of the post treatment support group both for their information, and in order for them to cascade this to the participants who took part. It is also intended that the information will be fed back to clinical staff in order to inform best practise with regards to the use of the outcome measures in their future clinical work.

### **Limitations of the study**

The conclusions from this study are limited by the relatively small sample. To draw firm conclusions on the acceptability of the measures, a larger sample would be required to give power to the quantitative data. Whilst the sample size was appropriate for a qualitative study looking for a snapshot of service user opinion and experiences, the opportunity sampling limited the conclusions that can be drawn. Firstly, as all participants were drawn from a post treatment support group, no service users who dropped out of treatment or chose not to continue to engage were approached to take part. Also, as participants volunteered to take part, they may have chosen to because they had a strong or particular opinion, and so it cannot be assumed that these views are representative of all service users who have accessed treatment at LAU.

### **Conclusion**

The feedback from service users regarding the booklet of measure was overall positive with all standardised measures showed good acceptability. There are several easily accommodated recommendations that emerged, which could make the measures more meaningful to service users and, in consequence, to the service. In addition there are several more suggestions for development which would require further exploration in order to decide whether they are viable to implement.

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## Appendices

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Appendix 1: Interview Schedule

Appendix 2: Participant Information Sheet and Informed Consent form

Appendix 3: Letter confirming ethical approval for the project



## Appendix 1: Interview Schedule

### Introduction:

Thank you for offering to take part in this study. I would like to tell you a little more about this study and run through the information sheet with you, before you make the decision about whether you wish to participate. (run through information sheet and get consent form signed if participant agrees to participate)

I'm going to ask you some questions now about your experiences of the LAU questionnaires that you have recently completed. I am interested in your personal experiences and opinions so there are no right or wrong answers

### Interview:

- 1) I wonder if we could start by you telling me your general thoughts/feelings about completing the booklet of LAU questionnaires.
  - i) Initial reaction/ understanding of what they were all about
  - ii) How they were explained by staff/letter in post
  - iii) Time they take to complete
  - iv) Thoughts when completing them
- 2) I'm interested in finding out about the pros and cons of the questionnaires.
  - a) Overall how useful on a scale of 0-10.
  - b) Please can you tell me about what you feel the purpose or benefits of completing the questionnaires are.
    - i) To you
    - ii) To the service
    - iii) To other service users
  - c) And what isn't useful about completing the questionnaires.
    - i) To you
    - ii) To the service
    - iii) To other service users
- 3) I'm going to go through the booklet, and I'd like to get some of your thoughts on each questionnaire.
  - a) Leeds Dependency Questionnaire (LDQ)

This questionnaire is designed to look at the importance of alcohol or other drugs in your life

    - (i) How important do you think it is to look at that area?
    - (ii) How can using this measure make a difference to you?
    - (iii) How comfortable were you answering the questions in this questionnaire?
    - (iv) How understandable were the instructions/questions in this questionnaire?
      - Please note anything you particularly did not understand
    - (v) Overall can you rate how happy you were with this questionnaire (0 = not at all, 10 = really happy)
  - b) CORE-10

This questionnaire is designed to look at your psychological wellbeing  
(5 questions to be asked as above)
  - c) Social Satisfaction Questionnaire (SSQ)

This questionnaire is designed to look at your satisfaction with your social circumstances  
(5 questions to be asked as above)
  - d) EuroQoL (EQ-5D)

This questionnaire is designed to look at your level of general health  
(5 questions to be asked as above)
  - e) What do you currently use...?

Asks you what you have used and how much in the last 28 days

(5 questions to be asked as above)

- 4) Having gone through the questionnaires one by one, what do you make of the use of them?
  - (a) Pros/cons
  - (b) How useful on scale 0-10
  
- 5) What do you feel would improve your experience of completing the questionnaires?
  - a) Booklet /explanation/other
    - i) Improve understanding
    - ii) Increase meaning/usefulness
  
- 6) Is there anything that you would like me to know about your experiences or opinions on the questionnaires used by LAU?

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## Appendix 2: Participant Information Sheet for service evaluation

### ***What is the purpose of the service evaluation?***

This service evaluation aims to help the staff at Leeds Addictions Unit better understand the experiences and views that service users have of completing the booklet of questionnaires that are given routinely. It is hoping that knowing how service users feel, the staff can think of the best way to use these questionnaires so that they benefit the service user and the service. The service evaluation will also form part of a Doctorate degree in Clinical Psychology at Leeds University for the primary researcher.

### ***Why have I been chosen?***

You have been selected to potentially take part because you are or have been a service user at Leeds Addictions Unit, and you have recently completed a booklet of questionnaires.

### ***Do I have to take part?***

It is up to you to decide whether to take part or not. If you decide to participate you will be given this information sheet to keep and asked to sign a consent form. If you decide to take part you are free to withdraw at any time and without giving a reason. A decision to withdraw or not to take part will not affect your health care in any way. If you are interested in taking part I will answer any questions you may have.

### ***What will I have to do if I take part?***

After you have completed a booklet of routine questionnaires by your clinician, you will be asked a series of questions by a researcher about your views and experiences of completing the questionnaires. The questions should take around 20-30 minutes to answer. The researcher will be working independently from the person who gives you the questionnaires, and will not find out the answers that you put down on the questionnaires.

### ***What happens to the information about me?***

The information provided from all the service users who have taken part will be written up into a report. All information you provide is kept anonymous meaning that no one will be able to tell who you are or identify any of the responses you have given.

### ***What are the possible benefits of taking part?***

We hope to improve the way in which questionnaires are used within the service by being more aware of your views and experiences of completing booklets of questionnaires. In addition you will receive a £5 high street voucher to compensate for the time you give in taking part.

### ***What are the possible disadvantages or risks of taking part?***

Service Evaluation Project

There are no real risks to taking part in the study. If at any time you do feel distressed by the topic, then the interviewer will support you with this. You will not be obliged to discuss anything that you do not wish to and you are free to stop the interview at any time.

If you require any further information or wish to withdraw from the service evaluation, please contact the primary researcher at:

Hannah Capon  
Clinical Psychology Programme  
Leeds Institute of Health Sciences  
Charles Thackrah Building  
101 Clarendon Road  
Leeds LS2 9LJ  
(Tel: 0113 233 2732)



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***Participant Consent Form for service evaluation***

Please initial:

I have read the participant information sheet. ....

I have had the opportunity to ask any questions I have about the service evaluation. ....

I am satisfied with the answers to my questions. ....

I understand that my responses will be kept anonymous and confidential ....

I understand that I am free to withdraw from the service evaluation at any stage without giving a reason. ....

I understand that taking part in this service evaluation will not have any effect upon the healthcare I receive. ....

I agree to take part in this service evaluation. ....

Participant signature..... Investigator  
signature.....

Participant name..... Investigator  
name.....

Date.....

Appendix 3: Letter confirming ethical approval for the project



Leeds and York Partnership NHS Foundation Trust

Our Ref: 2012/356/L

Research & Innovation  
North Wing, St Mary's House,  
St Mary's Road  
Leeds LS7 3JX

E-mail: james.hughes4@nhs.net  
Direct Line: 0113 295 2387  
FAX: 0113 2954466

26.04.12

Hannah Capon  
Leeds Institute of Health Sciences  
University of Leeds  
Charles Thackrah Building  
101 Claredon road  
Leeds, LS2 9LJ

Dear Hannah,

**RE: Evaluation of services users experiences of completing outcome measures at Leeds Addictions Unit (LAU)**

Following the recent review of the above project I am pleased to inform you that the above project has been granted permission to be undertaken. As such your project may now begin within the Trust.

This approval is granted subject to the following conditions:

- You must comply with the terms of your approval. Failure to do this will lead to permission to carry out this project being withdrawn. If you make any substantive changes to your protocol you must inform us immediately.
- You must comply with the Trust's policy on project monitoring and audit.
- You must comply with any other relevant guidelines including the Data Protection Act, The Health and Safety Act and local Trust Policies and Guidelines.
- If you encounter any problems during your research you must inform your Sponsor and us immediately to seek appropriate advice or assistance.

Please note that suspected misconduct or fraud should be reported, in the first instance, to local Counter Fraud Specialists for your Trust. R&I staff are also mandated to do this in line with requirements of the RGF.

Adverse incidents relating to the project should be reported using Trust incident reporting procedures in the first instance. They should also be reported to:

- this department
- the study chief investigator
- other related regulatory bodies as appropriate (if applicable)

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the



Leeds and York Partnership   
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requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf> ) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

We will require a copy of your final report/peer reviewed papers or any other publications relating to this research. Finally we may also request that you provide us with written information relating to your work for dissemination to a variety of audiences including service users and carers, members of staff and members of the general public.

If you have any queries during your research please contact us at any time. May I take this opportunity to wish you well with the project.

Yours sincerely

A handwritten signature in black ink, appearing to read 'James Hughes', written over a light blue horizontal line.

James Hughes  
Research Management and Governance Manager

CC Duncan Raistrick  
Carol Martin