User-Focused Monitoring
of
Community Treatment Orders
in Westminster and Kensington and Chelsea

Report February 2016
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CHAPTER ONE – INTRODUCTION

Background
User Focused Monitoring (UFM) is a user-led programme set up by a diverse team of local mental health service users in Kensington & Chelsea and Westminster to monitor and evaluate mental health services. UFM was established in 1996 by Professor Diana Rose* at the Sainsbury Centre for Mental Health. It has been commissioned by NHS Central London Clinical Commissioning Group and NHS West London Clinical Commissioning Group (and predecessor organisations) for the past nineteen years to monitor and evaluate their mental health services. The UFM team comprises 10 mental health service users trained and supported to be peer interviewers, a project worker and a project manager.

Aims
User Focused Monitoring has four essential aims:

- To give a **voice** to patients and service users
- To ensure patients and service users **actively influence** service planning and delivery
- To provide **ongoing, user-led monitoring** of mental health services
- To promote **positive changes** in mental health services

Principles of UFM
User control is a defining tenet of User Focused Monitoring. All of our team members are involved throughout the evaluation process and in the implementation programme. All major decisions, the parameters of the project and its strategic direction must be decided and agreed by the team as a whole.

- All UFM interviewees and interviewers are service users
- Service users guide each stage of the evaluation process
- UFM operates with independence and objectivity
- UFM follows good standards of research methodology
- UFM enables a wide range of service users to contribute their views and experiences

*Prof. Diana Rose now co-directs the Service User Research Enterprise (SURE) in the Health Service and Population Research Department at the Institute of Psychiatry*
Making a Difference
Each UFM report presents findings and recommendations based on the views and experiences of the service users interviewed. The findings are presented in both quantitative and qualitative format in the UFM Report and fed back formally through the steering group to senior managers from the services evaluated. UFM interviewers are key players throughout the research cycle: devising the questionnaires, conducting the interviews, collating data, developing reports and recommendations. UFM members present the findings and meet service managers to follow up action plans for change and improvement.

The UFM Team
A diverse team of interviewers conducted all interviews and co-developed this report and recommendations. All of the interviewers have used or continue to use local mental health services in Kensington & Chelsea and Westminster and bring valuable knowledge and experience to their work. The UFM Project Manager conducts regular UFM Interviewer Skills training and provides ongoing support to all interviewers.

Current Report
This survey collected the views of service users about their experience of Community Treatment Orders (CTO). All interviews were conducted in the community at the preferred location chosen by the interviewee.

‘A CTO is the legislative power by which patients with mental health difficulties who are treated involuntarily in hospital can be discharged into the community but still remain subject to compulsory treatment. The CTO thus extends the setting for involuntary treatment from being exclusively confined to the hospital ward to the community.’ (Stroud, J., Doughty, K., and Banks, L., School of Applied Social Science, University of Brighton May 2013)
CHAPTER TWO - METHOD

Selection of participants
UFM targeted key mental health professionals across Westminster and K&C with promotional material about the CTO evaluation and a request to pass this on to people with whom they work who are currently or were previously on CTO.

Mental health professionals asked for consent from potential participants for UFM to contact them. In addition, UFM called mental health hostels to see if they had any people who might be willing to participate in the evaluation, and visited three hostels to conduct interviews on site. A total of seventeen people were interviewed. Thirteen of the participants were on CTO at the time of the interview, four were not on CTO but had been on one in the previous twelve months.

Interview Schedule
UFM interviewers devised the questions for the survey. These were piloted with the UFM service user team, as well as one to one with a service user. The questions were adapted accordingly and the service user was re-interviewed with the adapted interview schedule.

Procedure
Each of the seventeen participants was read a brief information sheet explaining the nature of the evaluation, and then answered the interview questions. All interviews took place either in people’s homes, at The Advocacy Project meeting room or in a community location selected by the interviewee. All interviews were conducted by two UFM interviewers. Using two interviewers increased inter-rater reliability.

Each interview took approximately 20-30 minutes and a one-off payment of £5 was given to interviewees.
Demographics

The majority of interviewees were male (82% n=14) and a minority were female (18% n=3)

Most respondents were aged between 36-45 (47% n=8) four (23%) were aged 46-55, three (18%) were in the 26-35 year age bracket and one (6%) was in each of the 18-25 and 56-65 year age brackets.
Two of the interviewees were carers (12%). Seven (41%) of the interviewees had a physical health condition. Ten (59%) stated they have a disability.

Which borough?
Fourteen people (82%) we interviewed were from Westminster and three (18%) from Kensington and Chelsea.
CHAPTER THREE – FINDINGS

1. Are you currently on a CTO? Thirteen people (76%) said yes, four (24%) said no.

2. Is it your first time on a CTO?

More than half the people interviewed had previous experience of Community Treatment Orders (53% n=9).

For 41% (n=7) of interviewees this was the first time. This question was not answered by one person (6%).

3. How long have you been on a Community Treatment Order?

<table>
<thead>
<tr>
<th>Duration</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than a year</td>
<td>11</td>
</tr>
<tr>
<td>Between six months and a year</td>
<td>3</td>
</tr>
<tr>
<td>Between one and three months</td>
<td>2</td>
</tr>
<tr>
<td>Was not sure</td>
<td>1</td>
</tr>
<tr>
<td>Did not answer</td>
<td>1</td>
</tr>
</tbody>
</table>

4. Were you told what a community treatment order is?

<table>
<thead>
<tr>
<th>Information</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>The majority of interviewees were told what a CTO is</td>
<td>15</td>
</tr>
<tr>
<td>Was not told what a CTO is but commented (see below)</td>
<td>1</td>
</tr>
<tr>
<td>Did not understand what it was because of limited English</td>
<td>1</td>
</tr>
</tbody>
</table>

Comment:
- “…didn’t need an explanation as I had been on one before.”
5. Was the reason you were put on a CTO explained to you?

| (88% n=15) | The majority of interviewees had the reason explained  |
| (6% n=1)   | Did not have the reason explained                     |
| (6% n=1)   | Did not answer the question                           |

Comments:
- "I did not think it was a very good or strong reason".
- "I didn't understand because I am not good at reading and it came by letter".

When asked who explained the reason the following were mentioned:

| (53% n=9) | Stated the psychiatrist explained the reason for the CTO |
| (29% n=5) | Stated it was the doctor (although we may presume some people meant psychiatrist by that term) |
| (6% n=1)  | A combination of doctors and nurses                   |
| (12% n=2) | No answer                                             |

Comments:
- "It was not fully explained and [it was] justified that coercion was necessary and indeed later a tribunal decided a CTO was not necessary and discharged me".

6. Were you given the information in a way you could understand?

| (76% n=13) | Were given information in a way they could understand. |
| (6% n=1)   | Could not understand the letter                       |
| (6% n=1)   | Had insufficient English to understand the information |
| (6% n=1)   | No answer                                             |

The people who were not given the information in a way they could understand commented:
- "They did explain but I don't understand a lot. I forget sometimes".
- "No, because I am not good at reading and it came by letter".
- "No, not given information".

Comments when people could understand the information included:
- "Jargon but I could understand"
- "It was explained clearly without too much waffle".
- "Talked and in writing".
7. Were you told how long the CTO would last?

Most people (59% n=10) were not told how long a CTO would last. Six (35%) said yes, and one person (6%) did not answer

- “They said six months. When I was on a CTO before they said they had a right to keep me on it for longer”.
- “For six months”.
- “In hospital they said 6-12 months, in the hostel they said 2 years. They keep on renewing it”.
- “I was told it would be renewed every 6 months, they tell me why they are keeping me on it”.
- “Not bothered by CTO as it is not restrictive and it monitors my sickness”.
- “It would be nice to be told. Prison is not a nice place”.
- “Want to know how long it would last, I’m compliant with medication”.
- “I don’t know why extension is as long as a year, it should be 6 months”.
- “I go from year to year. I get an assessment each year”.
- “[I was told] that it would be reviewed every six months”.
- “I’d like [it to] end soon, the CTO”.
- “Would like to come off - fully compliant”.

One of the people who had not been told how long exactly, had been told:

- “It’s not going to last that long.”

One person was told how long it would last:

- “… but equally it was implied that it could be renewed and go on indefinitely which I think constitutes an overriding of human rights and the requirement to impose treatment with 'minimum interference to personal liberty' which CTO's disrespect”.
8. Were you told about the advocacy service and how to contact an advocate?

Nine people (53%) were told about the advocacy service and how to contact an advocate, seven (41%) were not and one person (6%) did not answer this question.

9. What are the conditions attached to your CTO?

Note: Some people mentioned more than one condition.

Out of the 17 people interviewed:

<table>
<thead>
<tr>
<th>Condition</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mentioned medication</td>
<td>88%</td>
<td>15</td>
</tr>
<tr>
<td>Mentioned meetings/appointments</td>
<td>41%</td>
<td>7</td>
</tr>
<tr>
<td>Mentioned specific accommodation</td>
<td>18%</td>
<td>3</td>
</tr>
<tr>
<td>Mentioned not allowed to go abroad</td>
<td>6%</td>
<td>1</td>
</tr>
<tr>
<td>Mentioned refraining from illegal drug use</td>
<td>6%</td>
<td>1</td>
</tr>
</tbody>
</table>
Medication;
• "That I take my medication".
• "Keep taking medication".
• "One of the conditions is to maintain medication - oral now - previously it was injections".
• "I have to take an injection once every two weeks".
• "I have to take medication by injection".
• "I have to have a depot injection every three weeks".
• "To take medication".
• "Comply with medication".
• "I have to take medication. Every four weeks I have to go to St Charles to get medication".
• "I had injections monthly. If I became unwell I could go to hospital".
• "Drug by injection".
• "I had to take clozapine".
• "Take medication every two weeks".

Accommodation;
• "Remain at abode".
• "Live in a hostel until transfer approved to flat".
• "I have to live at the hostel".
• "To live at xxxxx".

Meetings/appointments;
• "That I stay contacted to my mental health services".
• "I must see the nurse and doctor once a month".
• "Section 17. Attending appointments to prove I am well. More restriction with section 17"
• "Maintain contact with care coordinator-I see my care coordinator every week and sometimes she phones me".
• "Attend all appointments".
• "I have to see my doctor and social worker".
• "See GP and nurse".
• "Meetings with the shrink".
• "I see the doctor once a month".

Other conditions;
• "Stay off cannabis".
• "Not to go abroad".
10. How did you find the conditions?

Nine people (53%) said the conditions were fine, 5 people (29%) stated they found it a bit difficult, 1 person (6%) found it very difficult, 2 people (12%) did not answer.

Comments:
- "I find the medication a bit excessive”.
- "I don’t enjoy taking the injections. They make me drowsy”.
- “Staying off cannabis is difficult”
- "It would be better to have the freedom to take medication”.
- "I’m not free to decide”.
- “[What I find hard is] the restriction of it”
- "I do not find it difficult”.
- "It’s ok taking meds”.
- "I kept the first two conditions but broke the third and was discharged by the tribunal”.

11. Has there been a change in the conditions of your CTO?

| (82% n=14) | Most people had not experienced any changes in the conditions of their CTO |
| (18% n=3)  | Stated there had been a change to medication |

Comments:
- "Gone from injection to tablets, I like this better”
- "I take less medicine”
- "They have reduced the medication”
12. Did you have a say in these changes?

Of the three people who had a change in the conditions, two had had a say and one had not.

13. Which mental health professionals did you see during your CTO?

*Please note, people often put more than one response to this question.*

<table>
<thead>
<tr>
<th>n</th>
<th>Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>Psychiatrist</td>
</tr>
<tr>
<td>5</td>
<td>CPN</td>
</tr>
<tr>
<td>2</td>
<td>Care coordinator</td>
</tr>
<tr>
<td>2</td>
<td>Social worker</td>
</tr>
<tr>
<td>3</td>
<td>MH Team</td>
</tr>
<tr>
<td>1</td>
<td>GP, nurse and social worker</td>
</tr>
<tr>
<td>1</td>
<td>I don’t know</td>
</tr>
<tr>
<td>2</td>
<td>No answer</td>
</tr>
</tbody>
</table>

Comment:
- "A lot of them".

14. Who do you see most often?

<table>
<thead>
<tr>
<th>n</th>
<th>Professional</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>CPN</td>
</tr>
<tr>
<td>2</td>
<td>Care coordinator (who could be their CPN, social worker or OT)</td>
</tr>
<tr>
<td>2</td>
<td>Social worker</td>
</tr>
<tr>
<td>1</td>
<td>MH Team</td>
</tr>
<tr>
<td>1</td>
<td>Occupational therapist</td>
</tr>
<tr>
<td>1</td>
<td>GP, nurse and social worker</td>
</tr>
<tr>
<td>1</td>
<td>I am not sure</td>
</tr>
<tr>
<td>4</td>
<td>no answer</td>
</tr>
</tbody>
</table>

Comments:
- "Nurse and social worker every two weeks”.
- "Social worker is not regular”.

15. How often do you see them?

| (18% n=3) | Once a week or more |
| (24% n=4) | Between once a week and once a fortnight |
| (29% n=5) | Between once a fortnight and once a month |
| (24% n=4) | Less than once a month |
| (5% n=1)  | No answer (note percentage point downward rounded to make 100) |

Comments:
- "Only at CPA’s I wrote to my MP and said that it would be an infringement of my personal liberty if as the social worker said services were to threaten to visit me any time of every day”.
- "Right for my needs (less than once a month)”.

14
Does this meet your needs?

Figure 8: Does this meet your needs?

- "I’m not sure what my needs are, I want a break from my medication, I have liver and kidney failure. I feel as though I am in a coma”.
- “I see my CPN every 5 weeks, I am happy with these arrangements”.

16. Did your relationship with your mental health worker change when you went on a community treatment order?

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
<th>No answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>(29% n=5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(59% n=10)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(12% n=2)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Of the people who said yes the relationship changed, these comments were made:
- "It got worse. Care coordinator is new and not helpful”.
- "It became very cynical, doubtful and critical. Reports were lies, I was not happy about what was written in reports”.
- "It’s better - I get on well with the nurse, I don’t find it helpful speaking to the doctor”.
- "It improved, it got better, as did my mental health”.

Of the people who said no there was no change in the relationship these comments were made:
- "Care in hospital was lacking and I wanted help. There was an individual I did not get on with. I came out after six months and relapsed”.
- "I have had three mental health coordinators in the last three years and they all give the same service”.
- "I’ve only just got the social worker. The doctor hasn’t changed”.
17. Were you informed about CTO reviews?

Thirteen people (76%) were informed about reviews, three (18%) did not answer and one (6%) said no.

Comments:

Timing:
- "Every 3 months”.
- "At the Tribunal only”.
- "No, it hasn’t”.
- "On a yearly basis. Its hard to come off it. I can ask for a solicitor but I don’t”.
- "Yes, 6 months ago - it gets reviewed every 6 months”.
- "6 months review and kept on for another 6 months. No restriction”
- "Yes recently”.

18. Has your CTO been reviewed?

Thirteen people (76%) said yes, three people (18%) said no. One person (6%) did not answer.

Comments:
- "Yes. But I did not participate. I didn't want to. I just spoke to psychiatrist”.
- "I’m not getting discharged and not getting out of this place. I want a house with stairs and a balcony”.
- "Reviewed every six months, it was explained to me that I can bring along a family member, advocate etc”.
- "Would like them to be every 6 months. Its so one sided at the tribunal. The doctor pays in with notes which I don’t think are fairly painted. I had an advocate last time who helped”.
- "Nothing changed. I wanted the injections changed. It slows me down”.
- "It was reviewed when I was on one in the past. The doctor agreed under pressure that I should come off it”.
19. Has your care plan changed as a result of going on a CTO?

![Has your Care Plan changed as a result of going on a CTO?](chart1)

Eight people (47%) said no, four people (24%) said yes, two (12%) people did not know what a care plan is and did not have one, 3 (18%) gave no answer

- "I didn’t know I had one”.
- "I don’t know what a care plan is, I don’t have a copy of a care plan”.
- "I don’t agree with my care plan it is full of lies. They say I cannot look after myself but my flat is spotless”.
- “They relax once I am out of hospital. I had to change psychiatrist because the last one was not very good for me”.
- "My care plan changed after I changed doctor, it hasn’t changed much except moving on to get a job”.
- "It changed with the new social worker”.

20. Have you appealed against your CTO?

![Have you appealed against your CTO?](chart2)

Nine people said (53%) yes, five (29%) said no, three (18%) gave no answer
• “About 4 to 5 times”
• “I feel I have missed out on life. Contemporaries have families and jobs, want to be a barrister. Want to sue”.
• “It was made fairly easy to appeal but I had to wait a long time”.
• “I agree with what the doctor says mainly but I want to come off the injection, it makes me too drowsy”.
• “Nothing changed”
• “Negative, I was not discharged from CTO”
• “How can I have a personality disorder if my personality has not been disrupted, a senior forensic psychologist contradicts the view that I have a personality disorder”.
• “For the CTO to be renewed”.
• “The outcome was I have to stay on it”.
• “It was declined”.
• “Nothing happened”.
• “Negative”.
• “No change”.

21. What was the outcome of your appeal?
Out of the nine people who had appealed, none were successful in their appeal.

• “Nothing changed”.
• “Negative, I was not discharged from CTO”.
• “For the CTO to be renewed”.
• “The outcome was I have to stay on it”.
• “Nothing happened”.
• “Negative”.
• “It was declined”.
• “No change”.

22. Have you been recalled to hospital when under a CTO?

![Bar chart showing the number of times recalled to hospital]

<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>9</td>
</tr>
</tbody>
</table>
Nine people (53%) said no, 8 (47%) said yes

- “I haven’t been recalled but they say that if I come off the injection I will be taken to hospital”.
- “For threatening behaviour - once only”.

23. Did you go back to the assessment ward or to the ward you left when you were put on your community treatment order?

Out of the 8 people who had been recalled;
4 people (50%) went back to the treatment ward
2 people (25%) went back to the assessment ward

The other two people stated:
- “A locked ward for 3 days then transferred to an assessment ward”.
- “I went back to the Gordon and also St Charles a few years ago but can’t remember if I was on CTO then. It was the Court team at the Gordon.”

24. What were your experiences of going back into hospital?

Out of 8 people who had been recalled all recounted negative experiences.
The following statements were made:

- "I was disappointed I felt I didn’t need to go back to hospital the first time. Second time my state was so bad I didn't realise I had been sectioned”.
- “I was rational, reasonable, competent and coherent, composs mentis of sound mind”.
- "Frightening, I felt claustrophobic in hospital. I felt unfairly treated. There was someone smoking drugs next to me and I flipped out. I feel they should have looked after me a lot better”.
- "Did not like being in hospital”.
- "It wasn't very nice. I was there three and a half months. They told me I'm not mentally ill”.
- "Hell”.
- "Negative”.
- "It was not very pleasant, against my wishes. They put me on a ward because I didn’t want to take my meds”.


25. If you were recalled to hospital would you prefer to be reviewed by your known consultant or go via the assessment ward and be reviewed by a different consultant?

![Bar chart showing responses to the question]

<table>
<thead>
<tr>
<th>Option</th>
<th>Count (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Via known consultant</td>
<td>7</td>
</tr>
<tr>
<td>Via the assessment ward and with a different consultant</td>
<td>3</td>
</tr>
<tr>
<td>I don't mind</td>
<td>2</td>
</tr>
<tr>
<td>I don't know</td>
<td>1</td>
</tr>
<tr>
<td>No answer</td>
<td>4</td>
</tr>
</tbody>
</table>

*(41% n=7)* Via known consultant
*(18% n=3)* Via the assessment ward and with a different consultant
*(12% n=2)* I don't mind
*(6% n=1)* I don't know
*(23% n=4)* no answer (note: percentage point downward rounded to make 100)

**Added comment**

- "Because I know the doctor”.
- "By my regular doctor”.
- "She knows me quite well now”.
- "I hated it in the Gordon Hospital. It was like a jungle. St Charles is much better. There was a lot of shouting in the Gordon. The staff just chat with each other. They lost my belongings”.
- "Same team but different hospital”.
26. What was/is your personal experience of Community Treatment Orders

![Bar chart showing the distribution of experiences.]

<table>
<thead>
<tr>
<th>Experience</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very poor</td>
<td>6% (n=1)</td>
<td></td>
</tr>
<tr>
<td>Poor</td>
<td>12% (n=2)</td>
<td></td>
</tr>
<tr>
<td>Fair</td>
<td>35% (n=6)</td>
<td></td>
</tr>
<tr>
<td>Good</td>
<td>18% (n=3)</td>
<td></td>
</tr>
<tr>
<td>Very good</td>
<td>12% (n=2)</td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>12% (n=2)</td>
<td></td>
</tr>
<tr>
<td>Comment only</td>
<td>*5% (n=1)</td>
<td></td>
</tr>
</tbody>
</table>

*Note: Percentage point downward rounded to make 100%

**Comments:**

Negative:
- "I don’t think they’ve done me much good in the long run”.
- "I’d like to come off it so I’m always quite peeved when they keep me on it. I’ve been on it three years now”.
- "I feel uncomfortable about just being one letter away from being back in hospital”.

Positive:
- "Sometimes I see it as a safety net, I get on well with my care coordinator”.
- "I know now I need it”.
- "Not too bad”.
27. Have you any suggestions for improving community treatment orders?

- "Don’t know”.
- "I want to come off CTO completely, it is unnecessary”.
- "More care treatment like art therapy”.
- "I’m ok but would rather be on tablets than injections and I am now on tablets.”
- "[Make them] less official. Be nice if I could go in there, give my view and come off the medication”.
- "I don't think people should be put on injections on a quick assessment”.
- "Give us freedom to decide how much medication to take and for how long”.
- "Don’t dish them out as readily, give people the benefit of the doubt”.
- "Scrap them. They endanger a breakdown of doctor-patient relations”.
- "Mental health staff should listen to the patient more”
- "CTOs are crap and shouldn't exist. I didn't get any help”.

28. Any other comment

- "Why do I have to do something wrong before I am taken into hospital? Listen more”
- "I want to detach myself from psychiatry, would like to get married and have a family. Want to be in the community and lead a normal life... with my art. Write poetry, painting and portraits”.
- "I would like some work to do”.
CHAPTER FOUR – DISCUSSION

In the period 2013/2014 a total of 150 uses were made of Community Treatment Orders by the Central and North West London NHS Foundation Trust: (http://www.hscic.gov.uk/searchcatalogue?productid=16329&q=title%3a%22Inpatients+Formally+Detained+in+Hospitals+Under+the+Mental+Health+Act+1983+and+Patients+Subject+to+Supervised+Community+Treatment%22&sort=Relevance&size=10&page=1#top)

UFM interviewed 17 people in Kensington and Chelsea and Westminster about their experiences of being subject to a community Treatment Order. This was not a new experience for more than half of the people we interviewed (53%). The majority had been on a Community Treatment Order for more than a year (65%).

In interpreting the findings it is important to place this in the context that in terms of the demographic data there were significantly more men who were interviewed (87%). The largest age group was 36-45 (47%) and the largest ethnic group represented in the sample was white British (41%).

It was interesting to note that a recent study by the National Institute for health Research (NIHR) School for Social Care Research at the University of Brighton in their ‘Exploration of service User and practitioner Experiences of Community Treatment Orders’ in 2012 explored some similar questions to our evaluation. Where appropriate these will be referred to in the discussion.

Communication:

Nearly everyone was told what a Community Treatment Order is and the reason they were given one (88%). Positive feedback indicated the information was given in a way that they could understand. However in the cases where there was a barrier to understanding (such as literacy or interpreting) this was not always addressed sufficiently in order for the person to fully understand.

Most people (59%) were not told how long a CTO would last. People reported being communicated different things by different people. There was a sense that the limitation to their personal freedom was not always taken seriously enough by professionals. An example of this was that although people were told about reviews, they were not getting clear dates for review (leaving some people feeling like the CTO could go on ‘forever’ and feeling as if they were in ‘prison’).

People were very clear about the conditions of their CTO which were usually related to the taking of medication and keeping to appointments with mental health professionals. The conditions were perceived to be ‘fine’ by just over half the people we interviewed. Where it was considered a bit difficult or very difficult this was usually related to medication, either the type of medication or the process in which it was administered (people preferred not to have the injection). Communication around what would happen if someone broke the conditions was in some cases considered heavy handed.

"I feel uncomfortable about just being one letter away from being back in hospital". (interviewee)
The NIHR School for Social Care research found in their study in the Sussex Partnership Trust area that

"...often Service Users were under the impression that if they did not keep to the conditions of the CTO they would be automatically returned to hospital, which constitutes an implied threat. It did not seem to be generally explained to Service Users that they should only be recalled if there was a significant deterioration in their mental health. There is an ethical question about whether increased honesty would negate the effectiveness of the CTO in relation to this implied threat of recall."

Source: https://www.brighton.ac.uk/_pdf/research/ssparc/ctos-report.pdf

Involvement:

The NIHR study noted that;

‘The service user’s consent to the making of a CTO is not a requirement in law. Clearly the conceptualization of CTO’s is at odds with the precepts of person centred care...in the contradictory policy context of promoting autonomy and choice on one hand, and enforcing compulsion and control on the other’

Source: https://www.brighton.ac.uk/_pdf/research/ssparc/ctos-report.pdf

In our evaluation there were a small number of service users who had their care plan changed since their CTO was put in place. Many (46%) however had not experienced any change in their care plan since the start of the CTO (a long time considering most people interviewed had been on a CTO for more than a year) or even knew they had a care plan at all. Support to write a care plan with the service user is the responsibility of the care coordinator. They should do this through the Care Programme Approach.

Advice from Rethink states ‘You should get a care plan that suits you and your needs’: http://www.rethink.org/search?s=CTO.

This is also backed up by CNWL’s Care Programme Approach information:

- Working with service users and carers to build an assessment, establishing care and support needs
- Developing a care plan in partnership with the service user and carers, setting out what will be done and who is involved - including plans for supporting recovery goals; treatment; activity, training or employment; safety; a personal budget if there is one; and support for carers
- Identifying who is responsible for making sure the action agreed in the care plan is carried out (for people on CPA, this is a care co-ordinator; for people on LPC, a lead professional)
- Making sure the care plan is reviewed regularly to take account of any changes (excerpt taken from: http://www.cnwl.nhs.uk/service-users-carers/mental-health-care-treatment/care-programme-approach-cpa/)
Relationship with professionals:

In terms of the relationship with mental health professionals it was usually the psychiatrist who informed the person of the CTO and the conditions initially. People tended to see their CPN in the course of the CTO most often. Frequency of mental health appointments varied between interviewees. Most people expressed that the frequency was fine for their needs.

Being on a CTO did not usually change the relationship between the person and their mental health professional they saw most often. In instances where it did change there was no consistency in terms of this being better or worse (there were cases of both). What people said they valued was someone who really listened. This was also reflected in their preference if they had to be recalled to hospital. If they had a good relationship with the psychiatrist they would prefer to go via their known psychiatrist and the ward they came from rather then back to the triage/assessment ward. They preferred to go via triage assessment ward with a different psychiatrist if they were not happy with their psychiatrist.

“When the therapeutic relationship is able to progress without being overshadowed by the authority of the CTO, but nonetheless the CTO can help contain and encourage engagement, this can work very well. However, when the element of compulsion is overshadowing all other therapeutic work and the Service User becomes resentful of the CTO, there can be a breakdown in the relationship with the Care Coordinator. Sometimes it was seen as helpful that the Care Coordinator was not the one who made the decision about the CTO (unless they were also the AMHP, but added another layer of complexity to the relationship) and in a sense the ‘blame’ could be shifted onto the psychiatrist”

Source: https://www.brighton.ac.uk/_pdf/research/ssparc/ctos-report.pdf

Independent Mental Health Advocacy;

Access to an Independent Mental Health Advocate (IMHA) is a statutory right for people on a CTO.


It is a statutory duty for mental health providers to ensure their patients understand they have the right to an IMHA and explain how they can access the advocacy service. IMHAs are independent from mental health services. IMHAs support patients to access their legal rights and speak up for themselves, facilitating them to be more involved in the decision making processes.

Source: http://www.advocacyproject.org.uk/service/%ef%bf%bcadvocacy-for-hospital-patients/.

Despite the fact that it is a statutory duty, seven people (41%) were not told about the advocacy service or how to access an Independent Mental Health Advocate. In the NIHR School for Social Care Research study they also found that there was a lack of referrals to IMHA services.
CHAPTER FIVE – RECOMMENDATIONS

1. Make sure that people know what a Community Treatment Order is and understand why they have one, bearing in mind that some people cannot read well and that some people do not have English as a first language.

2. Inform people early on about their legal right to an IMHA. (And support people to access the IMHA service at any time under their section).

3. Explain at the outset how often and when the CTO will be reviewed. Inform the person of review dates well in advance and explain that the CTO might be renewed after the review (and how long this could be renewed for).

4. Give people the option to have their CTO reviewed more than once a year, (should they prefer).

5. Ensure that people are told about their legal right to appeal the CTO and have the process and time frame explained to them.

6. Make sure everyone has an updated Care Plan that is reviewed regularly and that they have been involved in creating so that it meets their needs and goals.

The comments we received from people who had been readmitted to hospital while on a CTO were all negative. This is an area that needs further exploration.

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