Bringing meaning to user involvement in mental health care planning: a qualitative exploration of service user perspectives

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Keywords: patient experience, qualitative methodology, user involvement

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Accepted for publication: 14 September 2015
doi: 10.1111/jpm.12275

Abstract

Background: Service users wish to be involved in care planning but typically feel marginalized in this process. Qualitative explorations of the barriers and enablers of user involvement in mental health care planning are limited. Question: How is user involvement in care planning conceptualized by service users and how can meaningful involvement be instilled in the care planning process? Methods: In 2013, we conducted five focus groups (n = 27) and 23 individual interviews with current or recent adult users of secondary care mental health services (n = 27) in England. Eight users participated in both. Data were analysed using Framework Analysis. Results: Ten themes emerged from the data: these themes encompassed procedural elements (connection; contribution; currency; care consolidation; and consequence), service user characteristics (capacity and confidence) and professional enablers (consultation; choice; and clarity of expression). Procedural elements were discussed most frequently in service user discourse. Discussion: The process of care planning, centred on the user-clinician relationship, is key to user involvement. Implications for Practice: Users describe a common model of meaningful involvement in care planning. Their requests, summarized through a 10C framework of care planning involvement, provide a clear structure for practice improvement.

Accessible summary

What is known on the subject?

• UK mental health policy dictates user involvement in mental health care planning.
• Service users report feeling marginalized in the care planning process.
• Ongoing dissatisfaction with care planning involvement suggests a failure to translate policy into practice over time.

What this paper adds to existing knowledge?

• Service user involvement should no longer be regarded as a nebulous concept.
• Ten key criteria underpin service user satisfaction with care planning involvement.
• Five criteria characterizing the process of care planning involvement are prioritized by service users.

What are the implications for practice?

• Service users can conceptualize and describe meaningful user involvement. Service user requests, summarized through a 10C framework of care planning involvement, provide a clear structure for practice improvement.
Background

Mental health care planning can be defined as an iterative five-step process incorporating needs assessment, formulation, outcome and intervention planning, implementation and evaluation in light of the care received (Hall & Callaghan 2008). User involvement in care planning dictates that this process becomes a collaborative one, demanding patient and professional buy-in, adequate information exchange, participatory deliberation and decision-making (Bee et al. 2015b). Yet, despite the inherent rationality of these two definitions, national and international evidence syntheses show that users consistently report inadequate involvement in the care planning process (Bee et al. 2015b). Lack of collaboration has previously been reported across different service settings, care trajectories and professional roles (Bee et al. 2008, Goss et al. 2008).

In England, the consolidation of the user choice agenda has most recently been reflected in a new personalization agenda advocated by adult social care (Department of Health 2007). Contemporary mental health policy documents emphasize the importance of involving users in care planning and treatment decisions in order to (1) improve the culture and responsiveness of services; (2) enhance the quality of care users receive and (3) facilitate their recovery (Healthcare Commission 2008, Department of Health 2011). Current health service guidelines state that the outcome of any assessment within secondary care mental health services will be a care plan developed in conjunction with the user, a mental health professional and other appropriate parties such as informal carers (Department of Health 2008).

Research studies evaluating interventions to improve user involvement report multiple benefits. These benefits include enhanced service development, improved staff attitudes and increased user esteem (Crawford et al. 2002). As is the case with many health care innovations however, such evidence has been slow to permeate practice. National surveys and consultation documents consistently report user dissatisfaction with care planning involvement, suggesting that a political and moral acceptance of user participation has not been matched by its frontline implementation (Department of Health 2011). Recent evidence synthesis suggests that many users still want and need to be involved in the care planning process (Bee et al. 2015b); and that there persists an urgent and growing need to address this important translational gap.

The successful implementation of any new health initiative necessitates that all stakeholders share and can reach consensus on a common set of ideas regarding its role, scope, purpose and meaning (Pitt et al. 2007). Concepts of user involvement at the systems level have become synonymous with concepts of shared decision-making and patient empowerment, but user-led definitions of care planning involvement remain sparse. Where users’ views have been explored these have tended to be via small scale, qualitative studies focused on a single facet of the decision-making process (Goss et al. 2008, Rogers & Dunne 2013). There thus persists an important knowledge gap between the more nebulous ‘top-down’ concepts advocated by mental health policy and the power and influence of individual stakeholders in determining exactly what user-involved care planning should entail. The work presented herein seeks to address this gap.

The study reported here was undertaken as part of a bigger programme of research seeking to develop and evaluate new methods of facilitating and quantifying user involvement in mental health care planning. The current paper reports findings from focus groups and interviews with mental health service users. Exploration of professional (Bee et al. 2015a) and carer (Cree et al. 2015) perspectives are published elsewhere.

Study aim and objectives

The primary aim of the current study was to qualitatively explore user concepts of meaningful involvement in mental health care planning process, with a view to shaping and accelerating its frontline implementation. The objectives of the study were to:

1. Conceptualize care planning involvement from the user perspective
2. Examine how meaningful involvement can be instilled in the care planning process
3. Explore the role and influence of individuals, teams and organizational factors in achieving high quality user-involved care planning.

Method

Study design

Given the exploratory nature of our research study, we utilized a qualitative approach incorporating two different
data collection methods (focus groups and individual interviews). Themes identified in the focus groups were explored in more depth with participants via in-depth one-to-one interviews. The use of focus groups as a sole method of data collection is discouraged in some contexts, due to the potential for researchers to miss important or sensitive issues that participants will not discuss in front of others (Michel, 1999). Once the focus groups were complete, semi-structured interview schedules were adapted in line with data collected from focus groups.

Participant recruitment

Participants were recruited via purposive sampling from two large NHS Mental Health Trusts in North West (focus groups and interviews) and Central England (interviews only). Recruitment strategies comprised advertising on Trust websites, displaying posters within Trust premises, via Trust newsletters, press releases or via local user/carer networks and forums.

Inclusion criteria comprised service users who were aged 18 or over with current or recent involvement with secondary care mental health services within the host Trusts. Study exclusion criteria prevented the recruitment of any users already acting as consultants on the research study (e.g. as members of the research programme’s Service User and Carer Advisory Group).

Ethical considerations

Ethical approvals were obtained from the North West – Greater Manchester North and Dyfed Powys Research Ethics Committees (ref: 13/NW/0047 and ref: 13/WA/0074). Potential participants who responded to a study invitation were contacted by researchers in order to ascertain eligibility, discuss availability and provide more detailed information on the data collection process. In line with ethical guidelines, participants were sent a written participant information sheet before attending for a focus group or interview, which gave assurances around issues such as protection of current care provision and anonymity. They were also contacted by a researcher 48 hours beforehand to provide them with an opportunity to ask questions. Before the start of each focus group or interview, participants were given a second opportunity to ask questions prior to giving written consent.

A distress protocol was in place in case any participant showed signs of distress and at the end of the focus group or interview participants were given a debriefing sheet which gave contact details of the research team should any subsequent issues arise. Each participant was given a £25 gift voucher in recognition of the time they had spent participating.

Data collection

The research team, made up of health academics, service users and a carer, met to produce the focus group and interview topic guides. These co-produced topic guides provided a flexible focus group and interview framework which covered the participant’s understanding and experiences of care planning, user involvement in care planning, and views on the potential barriers or enablers of successful user involvement.

Five focus groups were carried out with users and carers (with a total of 27 user participants) on Trust and University premises between June and September 2013. The last of these focus groups contained mental health professionals in addition to users and carers. Each group was managed by a team of two to three researchers covering the roles of lead facilitator, co-facilitator and participant welfare support. Wherever possible, this team included a trained user/carer researcher. Focus groups lasted between 60 and 97 min (mean 82.4 min); this paper reports only on service user data alone.

Twenty-three individual interviews were completed between June and October 2013. Interviews were held on University premises, Trust premises, or in the participants’ homes or workplace according to the individual user’s choice and convenience. Interviews were conducted by academic and user/carer researchers. With the exception of one interview that took place on the telephone, all were conducted face to face and lasted between 34 and 91 min (mean 67 min). Eight users participated in both a focus group and an interview, meaning that we obtained data from a total of 42 different users.

All focus groups and interviews were digitally audio-recorded, transcribed verbatim and anonymized prior to data analysis.

Data analysis

Analysis followed a qualitative framework approach (Richie & Spencer 1994), a popular way of analysing primary qualitative data pertaining to health care practices with policy relevance (Dixon-Woods 2011). The analysis team consisted of five researchers, two of whom were service users and one a carer. Each researcher familiarized themselves with the data by reading several transcripts independently before the team met to discuss and agree an initial coding framework. Authors met regularly to discuss emergent codes and to develop a provisional coding framework. Word spreadsheets were developed which
incorporated framework codes as column headings and unique participant reference numbers in rows. Cells were populated with excerpts of data relevant to each participant and the emerging codes.

During the constant comparison of new data, the provisional framework was amended and reshaped to enable the introduction of new codes and allowed for the removal of other codes that became superfluous over the course of the analysis process. Previous iterations of the coding framework were stored for purposes of transparency. The research team agreed as a whole when data saturation had occurred (defined as the point at which no new themes emerged from the data) and no further data collection was warranted.

Results

Analysis revealed a clear distinction between user concepts of a care plan as a tangible, written document and care planning as the operational process through which this documentation is typically achieved. Rather than solely conceptualizing their own role in this process, users delineated an optimal model of user-involved care planning that comprised both procedural, and agent-centred (i.e. user- and professional) elements. Table 1 illustrates the final thematic framework, highlighting ten key criteria that users advocated as mandatory features this process. These features have been termed by the research team the 10Cs of user-involved care planning.

Procedural elements

The procedural elements of good care planning were discussed most frequently within service user discourse, reflecting their saliency to users. Five key categories of response emerged from our data set suggesting five distinct process-centred elements that were critical to care planning success. From the user perspective, successful user-involved care planning necessitated: (1) an emotional connection between users and clinicians; (2) a demonstrable contribution to care planning content; and evidence of (3) care planning currency; (4) care consolidation and (5) care planning consequence.

Establishing a connection

For the vast majority of users, successful user involvement was conceptualized predominantly in terms of the alliance that was established between themselves and their clinicians. User involvement was, for many participants, an objective that could only be realized within the context of a collaborative relationship developed over time and characterized by trust, respect and communication. The predominant message here was that user involvement necessitated regular and meaningful engagement, initiated from the outset and sustained throughout a person’s journey with mental health services:

[Good user involvement is] being listened to every step of the way really and being taken seriously about suggestions and issues from the very start. (ID15.F.IV)

Current practice was often deemed to fall short of this ideal with a user’s role typically limited to the retrospective endorsement of professional care decisions. This superficial approach was believed to lack the level of human interaction necessary for effective user-centred care planning, rendering user involvement a misnomer and transforming the process into an administrative, task-orientated exercise:

I feel the care component has been taken out quite a bit and it’s more paperwork, more… let’s not talk to him, let’s fill in the forms about him. (ID17.M.IV)

For some individuals, the value placed on a collaborative relationship was two-fold, facilitating involvement in the present but also determining attitudes and experiences in the future. As such, an early and demonstrable commitment to user involvement was critical; a commitment that could easily be conveyed through the enactment of basic activities:

If somebody was actually there going through a care plan and… really taking me seriously in terms of what I do then obviously… I would start to respond in a different way and feel differently about that person doing the review. (ID3.M.IV)

Demonstrating the users’ contribution

Central to user discourse was the desire to be recognized as an active agent in care planning decisions. The ability to influence care planning direction and generate a sense of ownership over the resulting documentation was deemed integral and necessary features of user involvement. In this way, participants conceptualized effective care planning as a process demanding a specific role for the user, explicitly facilitated by professional and organizational support:

…The involvement is the important thing, isn’t it? It’s about the person, it’s not about the clinician… the ownership is not on the clinician, it’s on the service user and the service user needs to be aware that they can take meaningful steps to have a good care plan. (ID21.M.IV)

…Many care plans, they’re disgraceful. They’re all about what the provider feels you need, not the user. (ID12.M.IV)
For some individuals, this active contribution was defined purely in physical terms i.e. the opportunity to create and write a care plan in their own words, while for others, it was much more about the equity by which the content of this document was shaped and agreed:

### Table 1

**The 10Cs of user involved care planning**

<table>
<thead>
<tr>
<th>Procedural elements</th>
<th>SU involvement in CPs</th>
<th>Meaningful consultation with SU</th>
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<tbody>
<tr>
<td></td>
<td>Quality of relationship between SU &amp; Care Co-ordinator</td>
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<td></td>
<td>Quality/continuity of relationship</td>
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<td></td>
<td>Dignity and respect towards SU</td>
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<td></td>
<td>High staff workload – impact on patient care</td>
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<tr>
<td>Problems with CPs</td>
<td>Not used as a working document/not followed through</td>
<td>Written without consultation with SU</td>
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</table>

<table>
<thead>
<tr>
<th>Demonstrating the users’ contribution</th>
<th>What should CPs include?</th>
<th>Needs of SU</th>
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<tbody>
<tr>
<td></td>
<td>Things that SU wants to include</td>
<td>Ownership of CP/responsibility</td>
</tr>
<tr>
<td>Problems with CPs</td>
<td>Meaningless/useless</td>
<td>Involvement possible without SU writing CP</td>
</tr>
<tr>
<td>Language of CPs</td>
<td>Ignores wishes/concerns of SU</td>
<td></td>
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<tr>
<td></td>
<td>Use SUs own words</td>
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<td></td>
<td>Tailored to the individual</td>
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<tr>
<td>Meaning of Care Programme Approach (CPA)</td>
<td>CPA is about people’s lives and feelings</td>
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<thead>
<tr>
<th>Ensuring care planning currency</th>
<th>Problems with CPs</th>
<th>Meaningless/useless</th>
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<tr>
<td></td>
<td>Out of date</td>
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<td></td>
<td>Not used as a working document</td>
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<td>Not seen</td>
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<td>Too brief</td>
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<td></td>
<td>Omissions</td>
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<tr>
<td>What should CPs include?</td>
<td>Diary/calendar</td>
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<td></td>
<td>Dealing with crises</td>
<td></td>
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<td></td>
<td>History/background of SU</td>
<td></td>
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<td></td>
<td>Flag up key issues to stop insensitive questions</td>
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<tr>
<td>Purpose of CPs</td>
<td>Medication and changes</td>
<td></td>
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<tr>
<td>Language of CPs</td>
<td>Communications</td>
<td>Tailored to the individual</td>
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<td>Shared document</td>
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<td>Working document</td>
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<td>Flexible document</td>
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<td>No CP</td>
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<tr>
<th>Achieving consolidation</th>
<th>Purpose of CPs</th>
<th>Holistic approach</th>
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<td>Aid to recovery</td>
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<td>Staff attitudes to SUs</td>
<td>Patient centeredness</td>
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<tr>
<td>Problems with CPs</td>
<td>Omissions</td>
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<th>Instilling consequence</th>
<th>Language of CPs</th>
<th>Review of progress</th>
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<tr>
<td></td>
<td>Specific goals</td>
<td>Individual and SMART goals</td>
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<tr>
<td>Problems with CPs</td>
<td>Misrepresents discussion at care planning meetings</td>
<td>Vague terminology</td>
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<tr>
<th>Agent-centred elements</th>
<th>Acknowledging service user capacity</th>
<th>Staff attitudes to SUs</th>
<th>Staff perceptions of SUs</th>
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<td>SU involvement in CPs</td>
<td>SU may not wish/be able to be involved</td>
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<tr>
<td>Nurturing service user confidence</td>
<td>SU involvement in CPs</td>
<td>SU may not wish/be able to be involved</td>
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<td>Facilitating professional consultation</td>
<td>SU involvement in CPs</td>
<td>Meaningful consultation with SU</td>
<td>Importance of SU attending meetings</td>
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<tr>
<td>Barriers to SU involvement</td>
<td>Attitude of psychiatrists</td>
<td></td>
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<tr>
<td>What should CPs include?</td>
<td>Unmet needs of SU</td>
<td></td>
<td></td>
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<tr>
<td>Making SU involvement easier</td>
<td>Include all relevant people at meetings</td>
<td></td>
<td></td>
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<tr>
<td>Enabling choice</td>
<td>Barriers to SU involvement</td>
<td>Don’t know what’s available</td>
<td>Know your rights</td>
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<tr>
<td>Making SU involvement easier</td>
<td>Ask for information</td>
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<tr>
<th>Advocating clarity of expression</th>
<th>Problems with CPs</th>
<th>Vague terminology</th>
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<tbody>
<tr>
<td>Barriers to SU involvement</td>
<td>Lack of understanding/jargon</td>
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I think it would make the patient think in a very precise way, if you’re asked to write something down you think how to put it into words and it makes you think about what exactly you want, I think this is a good idea. (ID15.F.IV)

I still feel like you could be a co-writer of your care plan in conjunction with somebody else… if somebody sat down with me and just had a discussion and said about things that I’ve enjoyed in the past and says, can we write these things down…? (ID17.M.IV)

Ensuring care planning currency
Alongside the opportunity to contribute to care planning content, users delineated a need for content that was both relevant and current. A lack of currency in care planning documentation was perceived to impact negatively on user involvement with care plans repeatedly being described as brief, vague and out of date:

Some have not been up-to-date for many years and are totally not applicable anymore. (ID3.M.FG)

The shared perception that care plans were rarely temporally or personally relevant meant that users did not regard current care planning processes as useful, either for themselves or the professionals involved in their care. Indeed, the perceived futility of the exercise led to some users disengaging completely from the care planning process:

…Some of it is a bit repetitive, and unless there is more information it’s not gonna be helpful to anyone. (ID2.F.IV)

Notably, users had clear and shared ideas of how care planning documentation could and should address their needs. Minimum requirements for a written care plan included (1) a summary statement of a user’s personal history, (2) a flagging system to prevent insensitive questions from repeatedly being asked, (3) up-to-date contact information including out-of-hours and emergency information and (4) coherent reminders of prior care consultations and decisions. In delineating these four key features, participants effectively shifted concepts of care planning away from a task-orientated or clinician-led process towards the development of a valuable user-centred support tool:

The patient should be given a handheld care plan which can act as a diary, a memory jerker, because when you’re in a distressed situation you can’t always… remember dates when you saw the psychiatrist, you can’t remember all the drugs that you’ve been put on, you can’t remember the doses. (ID8.F.IV)

The importance of care plans being individualized and person-centred was consolidated by discourse that emphasized the need for care planning discussions to remain dynamic and responsive to change. As such, the contextual and temporal relevance of the decision-making process was conceived both as an outcome and a facilitator of meaningful user exchange:

I’ve been at different stages and you need different things at different times… It’s got to be tailored to assessing what the person’s situation is. (ID5.M.IV)

Consolidating care
Common among user perspectives, was the belief that user-involved care planning would be greatly enhanced by promoting an integrated, recovery focused approach to care. To this end, participants advocated that care plans should uphold a holistic philosophy, reflected by multiple, personally tailored components related to employment, benefits, education and physical health alongside more traditional accounts of people’s mental health concerns:

[Care planning] should be about… your recovery. So it shouldn’t just be about the symptom, the dose, it should be about… what is gonna improve this person’s quality of life, the patient and also the carer’s as well. (ID14.F.FG)

Physical health needs were a particularly salient point for users, and provided a ready example of current limitations in care planning practices:

Under physical health and disability…the only thing that is under physical health… is the fact that my weight has increased over the last 2 years and I’m seeing a dietician. Well I’ve got Crohn’s disease, and this isn’t even written on here. (ID2.F.IV)

Instilling consequence
Users were unanimous in agreeing that effective care planning should extend to and encompass care implementation, and that their involvement in care decisions should translate wherever possible into tangible outcomes. Within this context, users frequently described their experiences of services which had failed to act; the futile repetition of the care planning process became a key focus of both individual and shared dialogues:

…Even when they do give you some hope and try and involve you, and try and move forward and… have new ideas, it’s then almost a slap in the face really because it doesn’t happen. (ID23.F.IV)

Lack of professional accountability for care planning implementation generated feelings of hurt, frustration and disappointment among users, leading in some instances to a negative spiral of disengagement and an increased sense of tokenistic involvement:
I wouldn’t pay a great deal of attention to it, because… it seemed like something so vague – there’s never any later evidence that it’s been stuck to. (ID11.M.IV).

**Agent-centred elements**

Less prevalent in user dialogue but nonetheless still evident were agent-centred elements of user-involved care planning. Five key categories emerged from the data, suggesting that two user-centred characteristics (capacity and confidence) and three professional behaviours (propensity for consultation, choice and clarity of expression) were essential for successful user involvement.

**Acknowledging user capacity**

Service users acknowledged the temporality and individuality of their mental health difficulties, accepting that individuals might not want to, or might not always be at an appropriate stage in their recovery, to engage fully in care planning. As such, user involvement was conceived as a bounded activity, the relevance and applicability of which would vary in accordance with internal and external circumstance.

Notably, from the user perspective, capacity for involvement was not an all or nothing phenomenon. Rather it was a continuum requiring different levels and types of interaction over time. Key to user satisfaction then was a sense that this variability had been fully recognized by mental health services, not only as a potential barrier to involvement but also as a reason to adapt professional behaviours and respond to user needs more effectively:

> People, when they first come into services are not necessarily going to be well, …you’re not going to understand all of this jargon and everything else that’s going on…I was disconnected, didn’t know what was going on. (ID21.M.IV)

**Nurturing user confidence**

Aligned with user capacity, was the notion that user confidence was critical to effective involvement. Acknowledgement of a potential power differential between users and professionals, and/or perceived differences in their respective areas of expertise left all but the most assertive of participants ill-equipped to participate fully in decisions about their care:

> Not everybody’s gonna have the confidence or feel well enough to do that. (ID14.F.IV)

Many participants saw this barrier as one that could be overcome. Emphasis here was placed less upon individual personalities so much as on the prevailing organizational ethos and support. Consensus among user participants was that the meaningful translation of user involvement into practice relied primarily upon a service level commitment that both validated independent advocacy and instigated longer term adjustments to care planning cultures. In particular, a symbiotic relationship was emphasized between the propensity of clinicians to listen to users, and users’ own motivations and confidence in engaging in discussions about their care:

> If they’re listening to what we’re saying, it will make a big difference to people’s lives and they will feel more comfortable about what they’re going… to be able to say to the psychiatrist or the psychologist and feel more at ease and not feel uncomfortable. (ID21.F.IV)

**Facilitating professional consultation**

Users clearly wanted to work collaboratively with clinicians in care planning. For the most part however, a complex mix of professional identities and personal attitudes were perceived to negate these longstanding principles of user involvement in mental health care:

> …Sometimes when I see a psychiatrist, I feel that they inhabit a world where they know about things and if…you mention things to them they seem slightly put out that you’ve actually looked at this yourself… as though they’ve got the golden chalice and you’re trying to… put your spoke in. (ID17.M.IV)

Participants advocated a fundamental need for professionals to acknowledge that, by virtue of their own health or circumstance, services users and carers would naturally assume a position of vulnerability and that, consequently, proactive steps would be required to raise awareness of and facilitate user involvement in the care planning process:

> I think, first of all, that users need to be aware that they should be involved in their care, because I’ve never been told that. (ID23.F.IV)

Pertinently, involvement defined from the user perspective did not dictate that decision-making would fall to them but simply that they would be afforded an opportunity to contribute contrasting and complementary expertise:

> If the professionals listen to the patient, on what’s best and it is not necessarily negotiation between the two, because one’s obviously got expertise by profession, and the other one by lived experience, but if they work collaboratively, if they work together, I believe that they can come up with the best care plan. (ID22.M.IV)

Some users similarly recognized the importance of a family member, or carer as a key agent in the care planning process. Within this context, the instigation of a top-down commitment to collaboration was once again advo-
cated as a pre-requisite to effective care planning involvement:

I think someone higher up needs to be questioning why there might be Care Programme Approach reviews going on where a carer hasn’t attended and asking why, because I think most of the time they’ve probably not received an invitation or don’t know anything about it. (ID4.F.IV)

**Enabling choice**

Transcending users’ requests for greater involvement were clear requests for greater and improved education regarding treatment options. Irrespective of whether users were discussing their mental, social or physical health needs, two key factors were consistently identified as essential prerequisites of effective involvement: (1) users’ awareness of their legal rights and (2) a working knowledge of the range and scope of services available to them. Where such information was lacking, meaningful user involvement was barred. Users believed that effective involvement relied heavily upon services providing meaningful treatment options and that the responsibility for recounting these different treatment options lay firmly with the service provider:

...I certainly didn’t have the knowledge of what was available...so you’ve got to know what’s available to engage in your care planning. So it’s the wrong way round really, you should be exposed to what the Community Mental Health Team can deliver or the Mental Health Trust can deliver and then we’re in a position to make choices. (ID8.F.IV)

**Advocating clarity of expression**

Synonymous with the request for greater information provision was the user’s need for open and transparent communication, with care planning choices, care expectations and consequences explained to users in a way that they could easily understand. To fully succeed in this objective, mental health services should ensure that the need to lay information provision was balanced with the risk of portraying care planning involvement in an overly simplistic or patronizing way:

...Things have to be done in a simplified manner, definitely, not like you’re talking to somebody who’s not very bright but in a simple easy way to understand. The easier it is to understand and the quicker people get it the more comfortable they are with it. (ID18.M.IV)

**Discussion**

This paper reports on a qualitative analysis of focus groups and interviews with service users recruited from UK secondary care services. Although user dissatisfaction with care planning has long been acknowledged, this study is one of the first to provide a clear framework for service quality improvement. Through in-depth qualitative data analysis we have identified ten key criteria (termed the 10Cs of care planning) that users perceive to be minimum requirements for meaningful user involvement.

Our data has confirmed that users attribute high worth to the quality of the care planning process. Whilst the emergence of a theme relating to the clinician-user relationship corroborates existing knowledge regarding the importance of a working alliance the saliency of other process features including the need for a stronger system of accountability is critically important to note.

Historically, mental health service users have reported that their role has fallen short of genuine involvement with a user’s role typically limited to the retrospective endorsement of professional care decisions (McDermott 1998). A recent systematic review of the international evidence base confirms that user and service-centred models of care planning and care planning involvement fundamentally conflict, with inevitable implications for service quality and user satisfaction (Bee et al. 2015b). Empirical evidence is nevertheless accumulating to suggest that across both community and inpatient settings, a combination of team, individual and organizational influences may be serving to replace meaningful user-centred interactions with more ritualized, task-oriented approaches.

Our study has demonstrated that users have some clear and as yet unmet needs in relation to their care planning documentation. Viewing a care plan as a memory jogger or diary for the user is very different to the usual concept of a care plan as a record of clinical decisions. Previous research has shown that users want care planning documentation to be meaningful to them (Webb et al. 2000, Alexander et al. 2002) and that in particular, that they want it to contain keyworker contacts (Healthcare Commission 2007) and dates of reviews (Healthcare Commission 2004). Our data moves beyond these more concrete recommendations, suggesting a more fundamental difference between users’ expectations of care planning ownership and meaning and the limited utility of the documents that they have received in practice.

Our data shows that users remain consistent in their desire for increased personalization in care planning processes so that care remains tailored to their goals and health needs. Temporal relevance and care consolidation emerge as critical features of a good care planning consultation. Consistent with previous research, users identify that there is a lack of focus on recovery in the care plan-
ning process (Henderson et al. 2010) and an ongoing need for more individualized, holistic and recovery-based care (Faulkner & Williams 2005).

Our study is somewhat unusual in identifying user-centred limitations to care planning alongside deficits in the care planning process. We have seen that users are looking to professionals and services to help them navigate well-known issues around perceived capacity and insight (Rogers & Dunne 2013, Shields et al. 2013), which have been used to suppress people’s involvement previously (Chinman et al. 1999, Hamann et al. 2006) and that even the most ‘unwell’ or ‘vulnerable’ people should be encouraged towards making their own choices for care provision. Crisis planning and the use of advance directives have an important role here (Antoniou et al. 2006).

The detail provided in our qualitative analysis highlights an urgent need to embed more contextual and temporal relevance into contemporary and future guidelines and policy requesting increased user involvement. We know that users feel that the current systems of consultation or involvement are often tokenistic (Antoniou et al. 2006) and that these processes often neglect or ignore users’ own expertise in their illness (Tee et al. 2007). In line with previous research, we have found that in order to achieve user-involved care more routinely, staff may need to engage more intensively and consistently with users (Tee et al. 2007, Woltmann & Whitley 2010). Our data suggests that fundamental changes to professional behaviours and communication styles are expected and importantly may still be required. This observation confirms the need to develop and consolidate explicit and transparent communication protocols at individual, team and organizational levels, in order to facilitate more meaningful user involvement.

Strengths and limitations of the study

Strength of the current study lies in its use of qualitative research methods with a wide range of service users. The size of our sample across two sites, the collection of data via two distinct means (focus groups and interviews), and the length of the individual interviews, provide depth to people’s experiences of care planning and their preferences for involvement.

By adopting this approach we allowed issues raised in focus groups to be explored in more depth in one-to-one interviews. Additionally, the combination of approaches had two advantages. On the one hand, it allowed discussion in groups which may have derived findings that would not have arisen from one-to-one interviews alone. Concomitantly, it engaged users on a one-to-one basis to ensure issues that participants may not have felt able to discuss in a group setting could also be explored.

The current study was undertaken as part of a larger programme of work (called EQUIP: enhancing the quality of user-involved care planning). This programme benefits from advanced patient and public involvement, including the full integration of trained users and carers as equal members of the research team. Having user researchers involved in recruitment, data collection and analysis brings different but complementary expertise to the multidisciplinary team. The findings provide practical recommendations how services can be improved, grounded in users’ current experience. (Gillard et al. 2010, Ennis & Wykes 2013).

It should be acknowledged that only the views of interested and consenting service users were collected in the current paper. We did not interview anyone from Black and Minority Ethnic communities and it was not possible to compare and contrast findings with data from carers and health professionals.

Implications for practice

Service users have clear and concrete ideas as to how they want to be involved in care planning. To implement these ideas staff need to take the initiative to involve users according to their preferences. Key messages for professionals are that they need to engage with, explain to, and involve users across the whole process of care planning. It is hoped that the 10Cs framework for care planning involvement will enhance understanding of user-involved care planning from the user perspective and provide an accessible means by which to expedite much needed improvements to current practice.

Acknowledgments

This paper summarizes independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (grant reference number RP-PG-1210-12007). The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.
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