APPENDIX 13: KEY PROBLEMS – QUALITATIVE ANALYSES MATRIX FOR EACH GUIDELINE AND HEALTHTALKONLINE

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DEPRESSION

A matrix of service user experience (not under the Mental Health Act)

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
The relationship between individual service users and professionals	*Involvement in decisions and respect for preferences*	-	-		-	-	-	-
	Clear, comprehensible information and support for self-care	-	-	-	-	-	-	-
	Emotional support, empathy and respect	-	-	-	-	-	-	-
The way that services and systems work	*Fast access to reliable health advice*	Issues regarding referral, waiting lists and getting into NHS services were raised. Some service users said that they waited too long to be referred to a psychiatrist or receive psychotherapy.	-	-	-	-	-	-

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
		One person said that while she was on a waiting list she was barely coping with her depression. *[I was referred to the psychiatric hospital for assessment. Although I think it probably took about two months I believe between the initial sort of GP's referring letter and getting an appointment. Which again in retrospect was, was way, way too long, way too long. I was really, really ill and barely coping.]* (NCCMH, 2010a) Another person described how she felt that she had to be violent in her GP's surgery in order to be referred to NHS services.						

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
		[It's very difficult to get a hospital bed for quite severe mental illness. You've got to be suicidal … I was feeling suicidal. I was also quite violent at times. I mean in my own doctor's surgery, I swept all the things off his desk you know … there was a part of me, kind of watching what I was doing … saying, 'Right, well make it really dramatic.' I wasn't pretending exactly, but I knew I had to make a song and dance to get heard.] (NCCMH, 2010a)						
	Effective treatment delivered by trusted professionals	-	-	Nurses: service users did not feel that nurses understood the sensitive nature of their depression, that nurses in the NHS were too busy to talk to their	-	Service users also had negative experiences of mental health services provided by the NHS, including not feeling cared for.	-	-

Dimensions of person-centred care		Key points on the pathway of care						Themes that apply to all points on the pathway
		Access	Assessment	Community care	Assessment and referral to inpatient care	Hospital care	Discharge/ Transfer of care	
				patients and that their attitudes may be because of inadequate training. *[There's an awful lot there who … you felt as though it was people saying to you, 'Oh, for goodness sake pull yourself out of it', and, 'Get yourself together', which you don't want, it's the last thing at the end of the day. I just don't think that there is enough, in regards to, against private and NHS, there is just not enough funding to be able to … I don't know, train the nurses in a certain way.]* (NCCMH, 2010a) Psychiatrists: service users had mixed experience of psychiatrists. Some did not like how psychiatrists tried to illicit information about their				

<table>
<tr><th colspan="2" rowspan="2">Dimensions of person-centred care</th><th colspan="6">Key points on the pathway of care</th><th rowspan="2">Themes that apply to all points on the pathway</th></tr>
<tr><th>Access</th><th>Assessment</th><th>Community care</th><th>Assessment and referral to inpatient care</th><th>Hospital care</th><th>Discharge/ Transfer of care</th></tr>
<tr><td></td><td></td><td></td><td></td><td>childhood experiences, describing the method as a ‘text book’ approach that instantly created a barrier. Others did not like to discuss feelings in general.

[I felt my psychiatrist was a very … oh … wet individual. Again, I think because I’d been quite a numerate, factual, organised person, to have someone to talking about feelings and what about this and what about that? And it was … nothing could ever be pin-pointed or … I just found it annoying.] (NCCMH, 2010a)

People with depression also had mixed opinions about how their psychiatrist dealt with their medication. The</td><td></td><td></td><td></td><td></td></tr>
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Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
				majority had positive experiences. Some people were concerned about taking tablets; they did not think pills solved the problem, or they had a cynical view of drug companies. Others who tried medication and did not have positive experiences said they felt that it 'robbed' them of feelings. [*Note*. Many people described positive experiences with medication] *[I've been prescribed antidepressants in the past but I've always felt reluctant and apprehensive about taking it, largely because a) I feel that the effects are probably short-term, they're not going to actually resolve the*				

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
				depression, b) because they do have side-effects and, c) I didn't feel comfortable, myself, with taking some tablets.] (NCCMH, 2010a) Many people with depression reported side effects from taking medication, notably dry mouth, hair loss, increased sweating, weight gain and problems ejaculating. A minority also reported experiencing suicidal thoughts as a consequence of their medication. [*Note*. Some people with depression said that the benefits of medication outweighed the potential side effects] *[For many years I hadn't had any suicide thoughts at*				

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
				all, and I had certainly never thought of cutting myself, but while I was on Seroxat, I did start to get sudden images in my head of you know, cutting long gashes in myself.] (NCCMH, 2010a) Four service users recounted their experience of ECT; the majority had negative experiences because of the frightening nature of the intervention and loss of memory post-treatment.				
	Attention to physical and environmental needs	-	-	-	-	-	-	-
	Involvement of, and support for, family and carers	-	-	-	-	-	-	People with depression described the impact that their condition had on families and carers. Some stated that it

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
								was harder for their family and carers than it was for the person who had depression. Others described the impact that it had on their partner, often resulting in a change in roles.
	Continuity of care and smooth transitions	-	-	-	-	-	-	-
Other themes	*Stigma*	-	-	Stigma around receiving treatment for depression for both psychological and pharmacological interventions. *[It took a hell of a lot for me to go to therapy. You know A: nutters go to therapy, B: therapy makes you a nutter. These were the kind of things that I grew up with. And it doesn't help. You know, so hostile kind of lower middle class*	-	Once in mental health services, people with depression described a mixture of positive and negative experiences. One person said that a psychiatric intensive care unit was 'a place of safety'. Others described a mental health service as a place where they had no responsibil-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
				sort of feeling about that sort of thing.] (NCCMH, 2010a)		ities, where they could 'hand yourself over' to the care of the service. Accompanying this, however, was the feeling of being institutionalised. *[In eight weeks, I very quickly became institutionalised myself. I was scared to come out because I was in this enclosed world where I knew what was going to happen. There were routines, mealtimes, getting up times, medication times, OT [occupational therapy] times. There were routines and I had no responsibilities … I was in a place where I didn't have to think about anything, and nobody could touch*		

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
						me.] (NCCMH, 2010a)		

DRUG MISUSE: PSYCHOSOCIAL INTERVENTIONS

A matrix of service user experience (not under the Mental Health Act)

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
The relationship between individual service users and professionals	*Involvement in decisions and respect for preferences*	-	-		-	-	-	-
	Clear, comprehensible information and support for self-care	It was not uncommon for service users to report being unaware of treatment facilities available to them.	-	-	-	-	-	-
	Emotional support, empathy and respect	-	-	-	-	-	-	-
The way that services and systems work	*Fast access to reliable health advice*	Due to the strain on resources and limited spaces available in different treatment settings, some service users experienced being turned away from services.	-	-	-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
		['I really thought I was going to get off it, but I was told that I was going to have to wait a month for an appointment. When I went for that appointment they said I wasn't on it too badly so there wasn't a rush for me to be seen; it was going to take over 6 months'.] (NCCMH, 2008) Service users expressed concern over the delay in accessing treatment and how this can lead to criminal behaviour, return to drug misuse and can have a negative impact on seeking further treatment.						
	Effective treatment delivered by trusted professionals	-	-		-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
	Attention to physical and environmental needs	-	-	-	-	-	-	-
	Involvement of, and support for, family and carers	-	-	-	-	-	-	-
	Continuity of care and smooth transitions	-	-	-	-	-	-	-
Other themes	*Stigma*	For some service users the obstacle to accessing treatment was fear of involving social services with regard to their children. *['I used to work around the children so that I could pick them up from school and make dinner and things like that … I was worried what would happen to the children if I went to get help … so I just stayed on it, so I could get up in the morning and get the kids to school'.]* (NCCMH,	-	-	-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
		2008) Some service users reported that they did not receive adequate help when trying to access services. *['I went to every doctor's … everywhere. But we're smack heads, "See the door, close it on the way out, fuck off". That's all we got … them days … I was asking for methadone, that was all. I wasn't asking for valies [valium] or temazies [temazepam] or anything… You get sick of asking for help and not getting any'.]* (NCCMH, 2008)						

PSYCHOSIS WITH COEXISTING SUBSTANCE MISUSE

A matrix of service user experience (not under the Mental Health Act)

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
The relationship between individual service users and professionals	*Involvement in decisions and respect for preferences*	-	-	There was a feeling among service users of having to conceal certain issues or disclose specific aspects of their illness to comply with their healthcare professional. *['….make it clear that you believe what they say, very clearly that you believe what they say because if you show or hint that you don't believe what they say then that's, then you've undermined your own authority in their eyes and therefore that makes the repair process a lot, a lot more difficult and a lot more long term.']*	-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
				(NCCMH, 2011c)				
	Clear, comprehensible information and support for self-care	-	-	-	-	-	-	-
	Emotional support, empathy and respect	-	-	-	-	-	-	-
The way that services and systems work	*Fast access to reliable health advice*	-	-	-	-	-	-	-
	Effective treatment delivered by trusted professionals	-	-	There were many reports within the online accounts of interactions with healthcare professionals. Some service users lacked confidence and trust in their healthcare professional. *['I would get very frustrated with what I felt was incompetence and ineptitude by my doctors. I did not feel that they were listening to me nor were they willing to make medication*	-	-	-	Many felt that they were or would be treated differently by mental health professionals as a result of their ethnicity or cultural background. *['…it wasn't so much racist it was more institutionalised racist. It's embedded within the system.']* (NCCMH, 2011c)

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
				changes when my current mix of medications did not seem to be stopping my cycling. I had three doctors within that year, until I found my current doctor, who I am finally comfortable with.’] (NCCMH, 2011c) *[‘I’ve seen different psychiatrists but to me they always feel, they, it’s always felt like they’re sitting on a pedestal… and I’m just there as part of their job really’.]* (NCCMH, 2011c) One of the most prominent themes that emerged from all of the online accounts was a strong opinion about medication regimes for psychosis. Feelings towards medication were typically ambivalent, and				

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
				side effects often outweighed the positive aspects of medication in managing symptoms. In some cases, medication had a debilitating effect and was not allowing the service user to engage in other activities in their daily life (for example, holding down a job or staying awake). Some online accounts highlighted the problematic nature of increasing and changing doses, and how this resulted in them stopping their medication altogether or relapsing. *[‘I was seeing a psychiatrist once a week and slowly I felt like my life was getting better. However the*				

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
				medication did not continue to work. So my doctors just put the dose up each time they saw me. I was incredibly frustrated with this and decided that I would take myself off all the medication and do it my own way.’] (NCCMH, 2011c). Others were concerned about the side effects of their medication. *[‘Well, lithium turned me into an emotionless zombie. I think they just had me on too high of a dose, but I wasn’t about to live my life that way, so I stopped taking it. Of course, I went back on a manic high right away.’]* (NCCMH, 2011c)				
	Attention to physical and environmental needs	-	-	-	-	-	-	-
	Involvement of,	-	-	-	-	-	-	-

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
	and support for, family and carers							
	Continuity of care and smooth transitions	-	-	Another theme that emerged from the online accounts was the link between mental health services and the criminal justice system and the police. Several accounts compared how, in the UK, there needs to be more coordination between the police and mental health services in order to make the most effective referrals for people with psychosis and coexisting substance misuse. In addition, information regarding mental illness was mentioned as necessary to circulate to the police. *['…if you're*	-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
				struggling with a substance misuse problem you'd be better off in, in the criminal justice system. People say that their lives have been saved by being put in the criminal justice system being forced to come off the drugs and then given help to stay off. And I have to tell you that at the moment there's no, no plan to, to give that kind of care to, to people in my trust [NHS].'] (NCCMH, 2011c)				
Other themes	*Stigma*	Many online accounts, from both service users and carers, highlighted the experience of interacting with others in the community and the stigma that their dual diagnoses carried. The experience of stigma often elicited feelings of	Participants also described how they would hide their symptoms from others. *['You can't lump everybody in together, you know, to say oh this is, these people are manic depressives, so their behaviour would be blah, blah, blah. Everybody is different … I might act different to the next manic depressive or whatever and,*	-	-	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
		shame, embarrassment, and frustration. *['When we go out there in the community people might know you have got a mental health problem, you might not look different to the, but they know you have got that. There is a stigma against it and a discrimination taboo…because of the label, and because of what it stands for. Which is people don't understand.']* (NCCMH, 2011c) One theme that emerged in several testimonies was that access to care was more difficult for those coming from a black and minority ethnic group or a	*you know, perhaps I might not show my symptoms because there's one thing about manic depression, depressives you really are clever at hiding your symptoms and very good at manipulating people.']* (NCCMH, 2011c)					

Dimensions of person-centred care		Key points on the pathway of care						Themes that apply to all points on the pathway
		Access	Assessment	Community care	Assessment and referral to inpatient care	Hospital care	Discharge/ Transfer of care	
		different cultural background. Factors that affected access to care for black and minority ethnic groups were a fear of accessing treatment due to the conceptualisation of mental illness in their home country or native culture, or fear of stigma. *['Well people look at you differently if you say you've got a mental health problem back home. They don't treat you the same. I think now it's changed but that, when I was there it was different…']* (NCCMH, 2011c) A significant number of factors affected accessing services, including fear of						

Dimensions of person-centred care		Key points on the pathway of care						Themes that apply to all points on the pathway
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
		contacting a healthcare professional about substance misuse, and uncertainty about how to begin accessing treatment or who to contact. *['And I did ask somebody from my mental health team if it was possible to have like a social worker and she said no, she didn't know how I would access that. I asked my doctor the same thing she didn't know how I would access anything like that so it just leaves you vulnerable.']* (NCCMH, 2011c) Many participants described how their social networks facilitated or impinged on accessing care or treatment.						

HEALTHTALKONLINE – EXPERIENCES OF PSYCHOSIS

A matrix of service user experience (not under the Mental Health Act)

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
The relationship between individual service users and professionals	*Involvement in decisions and respect for preferences*	Having more time to speak about problems was important. [*He [the GP] asked me what was going on in my head, and I said, 'I had thoughts in the third person, like voices in my head telling me stuff.' And he said, 'Had I been taking drugs and stuff?' I said, 'Just smoking weed.' And he said, I hadn't been… I can't remember what he said now. He said something else as well. And then he prescribed me some anti-psychotic medications, as well as a sleeping pill,*	Service users were of the opinion that an improvement to their experience of care would be the provision of information, with a clear explanation of what they were going through, especially on first contact with mental health services.	-	-	Service users recognised that while the situation on wards was sometimes chaotic and difficult, they still wanted as many rights as they could realistically expect to have in a hospital context: [*I think the ones, the nurses I've had the most problem with have been the ones that are ultra controlling, and I think it's because, when I get ill, my head is not in my control. Then if I end up in a situation, say on a section in hospital, and somebody tries*	-	-

Dimensions of person-centred care		**Key points on the pathway of care**						**Themes that apply to all points on the pathway**
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
		and anti-anxiety pills as well. *I: So what was this first doctor like?* *R: He was all right, but I don't think he actually had that much time. Compared to doctor I've got now, because the surgery I went to before, obviously had like more people to cover. And they seemed like in a rush, they weren't, like, as bothered in my opinion as the ones that I see now.* (Healthtalkonline, 2011)]				*to take away all the other controls I've got, then it can be really difficult.* *You see the doctor once a week, for like five minutes, when the doctor does the rounds. But there's like ten of them in a room. You go in. You're like Whoa, who are these people, and then they start talking to you. They, [smacks table] they make a decision about you. They obviously are quite knowledgeable, but to you, it seems like what the hell? And they make a decision right you're staying. Stay on the same drugs. Go and that's it.* (Healthtalkonline, 2011)]		
	Clear, comprehensible information and support for self-	-	-	-	-	Several service users mentioned how difficult it was to research	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
	care					their condition or the services that were available in hospital: [*And like, when I was in the hospital I was like, 'Can you give me some literature about what's going on?' and stuff like that. But there was nothing. Yeah. That was horrible too. [...]* *No one sits down and says right this is what's happened. You're experiencing this, and blah, blah, blah. No one was there to reassure you. [...]* *And later on I found out there's a gym. You're entitled to benefits. You can get a freedom pass, and no one told me any of that. Do you know what I mean.*		

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
						No one sat me down and helped me? I was just living, I was just living there. (Healthtalkonline, 2011)]		
	Emotional support, empathy and respect	Many service users expressed how difficult it was to access help when they were very distressed and described the role of the healthcare professional to facilitate and improve experience of care. [*For example, one service users described the 'courage' it took to see his GP when he had cut his wrists. Not able to speak, he was taken by reception staff to the doctor who was 'very warm'* (Healthtalkonline, 2011)]	Some people described how the experience of having someone try to make sense of their problems was helpful and aided their recovery: [*...my psychiatric nurse told me that I was [um] once I was diagnosed with schizophrenia...* *I: And how did you react to being told….?* *R: [um] I was sort of shocked. I was sort of relieved that I could put a name to what I was going through. [um] When I sort of researched schizophrenia I could simply recognise all the symptoms, all the symptoms, and so I sort of, you know, I could recognise this was schizophrenia, so I was sort of relieved to have a diagnosis, it felt I had something to work with.* (Healthtalkonline, 2011)]	-	-	Many people found that they received greater support from other inpatients than professionals: [*...the only kind of really support I have to say I got was from the other patients. So you know, there was many a time I was crying on the ward and no nurse came to comfort me. It was you know, for the patient. And there was one lady, I'll never forget this, she went, she saw that I was crying, she went out, to the kind of drinks machine and she bought me back a*	Many people felt abandoned by services: [*I was never allowed a, a CPN, I was never allowed a Social Worker, because I, I used to ask for them, and they had said, 'No you can make your way to the centre.' But sometimes I would be so bombarded with voices and paranoid to go out that I might go missing for six to eight weeks and nobody would ever come and see if I was okay, well me parents would obviously but this, the services just abandoned me at*	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
						can of Cola to cheer me up. (Healthtalkonline, 2011)] Professionals showing kindness even in difficult situations, such as being on observation, helped: [*And there was one nurse, there was one nurse I remember very clearly. She had a polka dot dress on and she was just so warm. She was always there in this empathetic close way, where you felt she wanted to look after me and she was going to be nice.* (Healthtalkonline, 2011)]	*that point.* (Healthtalkonline, 2011)] Other people felt monitored by services in what they thought was a punitive manner: [*I mean if you take the medication, okay if you don’t take it and there’s a problem, like I don’t know, you might violent, throw a glass of wine in someone’s face. [...] If someone contacts Social Services they also have to get involved, and they have to come and meet you, they have to make an assessment. Is he okay? Is he not okay? What happened? What didn’t happen? With an ordinary member of the public you don’t*	

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
							have that hanging over you. (Healthtalkonline, 2011)] Some service users were supported on coming out of hospital to access courses and support groups. Others had regular contact with community teams who supported them to stay out of hospital.	
The way that services and systems work	*Fast access to reliable health advice*	Prescriptions not being available at the right time was a barrier to accessing medication. One person was discouraged by primary care staff from seeing a mental health professional.	-	-	In a crisis, lack of instant help in A&E departments was mentioned by service users as a problem: [*I actually thought my heart was going to stop when... I was just so terrified. So I flee to A&E and I was getting a commentary and they were telling me all about psychiatric drugs. […] And nobody came to help me in A&E. They just put*	-	-	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
					me in a room and left me there and I was so distressed that I thought, right I've got to get up to [name of place]. (Healthtalkonline, 2011)]			
	Effective treatment delivered by trusted professionals	Service users described not being given help when it was needed during the first stages of being assessed for severe mental illness: [*I was about 27, [um] I realised something was going drastically wrong and I picked up the phone to my then GP and said, 'I think I need to be in hospital. A psychiatric hospital.' It's quite a renowned psychiatric hospital in this area. And her response to that was, 'Well what do you want to go there for?' And that*	Many people said they had received different diagnoses over time, had more than one diagnosis at a particular time or felt that schizophrenia was not a valid diagnosis and preferred other descriptions such as 'voice hearers'. A negative experience of the assessment process was being told by professionals that they were not mentally ill when they felt distressed: *[I went to the doctor, and then I got my Mum involved, and she said, 'Oh he wants to see a psychiatrist.' And, and, you know, I was told all these things. 'Do you want to be viewed as mad?' And all that. 'Do you want to go to the mental hospital?' And*	-	-	Service users found that access to specialist services improved their perceptions of service provision, and built a sense of belonging due to sharing experiences with other users and having stronger relationships with professionals. A few people had access to group therapy in hospital which they found useful: *[I was getting to actually talk about some stuff, you know, which was good and it was group therapy as*	-	-

Dimensions of person-centred care		Key points on the pathway of care						Themes that apply to all points on the pathway
		Access	**Assessment**	**Community care**	**Assessment and referral to inpatient care**	**Hospital care**	**Discharge/ Transfer of care**	
		was the limit of the help I got from the GP at that time. (Healthtalkonline, 2011)]	*you know, it was all like real negative. And the GP really, he just gave me some pills to take, and said, 'You know, you don't want to see psychiatrist. It's meant for people that are mentally ill.* (Healthtalkonline, 2011)] Some service users felt that they were not listened to when they discussed the side effects of medication, or were misinformed about what the likely side effects would be. One service user felt that they were left to get too unwell before mental health professionals intervened, while another service user felt that professionals were reluctant to reduce their medication.			*well so it was kind of quite helpful to be with other people and kind of be like sort of in a way helping each other like you know, yes so that was good.* (Healthtalkonline, 2011)] Many service users felt that there was little to do in hospital, that there was hardly any contact with staff and that they were too medicated to be able to interact with anyone properly. Others felt that they could not recuperate in hospital: [*...well I used to always think it was a bit strange because when you're being detained the last person you see is the*		

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
						Social Worker who normally - [the] rationale for you going into the hospital is you need to go in to have a rest. There's no way you can rest on an acute unit in Britain, that, that is a sort of silly idea. (Healthtalkonline, 2011)] One woman was not given any details about her diagnosis of schizophrenia while in hospital. Another man felt that he was not told in sufficient depth about the possible side effects of his medication. The few people who had experienced constant observation found it humiliating:		

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
						[*Horrible. You can imagine somebody following you about constantly. It's, it really isn't nice to be on. it's … I don't like it at all. [...]Can you imagine your partner constantly watching you? 24 hours a day. Going to toilet and watching you do a toilet. Going to a shower and watching you do a shower. Eating. it's not nice.* (Healthtalkonline, 2011)]		
	Attention to physical and environmental needs	-	A few people found day centres helpful, but one woman was of the opinion that the local day centre was depressing and boring for her son.	-	-	Many service users were shocked by the physical environment on the wards. [*And [my Dad] took me to the local Psychiatric Unit and it was a real eye-opening experience. It was absolutely filthy there was people*	Many service users stressed the difficulties of dealing with housing, benefits, finances and employment when they came out of hospital and would have liked more support to help deal with this: *[Yeah. It was very*	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
						laid on the corridors, there was double mattresses on single beds, it was really, really frightening as well. (Healthtalkonline, 2011)]	*difficult, because like life, there's no like, no one's standing there handing it to you on a plate. So you have to be quite resourceful, so I read a lot of websites. I went to book shops and read some books. And recently I've joined a group. Like a help group, which will help, and obviously I had my nurse and my doctor which helped me once, once I came out. So that was good. I had a lot of support with getting the areas of my life fixed up. So finances. Career. That kind of thing. Like a lot of professional support.* (Healthtalkonline, 2011)]	

Dimensions of person-centred care		*Key points on the pathway of care*						*Themes that apply to all points on the pathway*
		Access	*Assessment*	*Community care*	*Assessment and referral to inpatient care*	*Hospital care*	*Discharge/ Transfer of care*	
	Involvement of, and support for, family and carers	-	-	-	-	Some service users felt that their families were told little about what had happened to them or the support that was available: [*So when I got on ward round me parents and me wife were there and they said, you know, 'What's wrong with [name]?' And they said, 'It's confidential, ask him.' Well I couldn't explain anything because nobody had said anything to me.* (Healthtalkonline, 2011)]	-	-
	Continuity of care and smooth transitions	-	Poor continuity of care was a prevalent theme. One service user saw different psychologists each time they had an appointment; another person had to repeatedly recount their personal history; and another was seen by different services	-	-	-	One service user described the lack of support available after he left hospital: [*I got very bored and asked if I could leave, and they said, 'Well we'd really*	-

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
			and given different diagnoses. One service user was seen by different services and given different diagnoses.				*like to keep you a bit longer, but you know, as you're not on a section…' Yes. I could leave whenever I wanted to. I'm looking back on it, I think I wish I stayed a bit longer, because I came home and I got a job, but I couldn't do the job, you know. It was quite a simple job but I couldn't get the hang of it. And I went on the sick and I was just wandering, I just remember wandering around the streets, and because there wasn't any day centres or anything like that to go to.* (Healthtalkonline, 2011)] A few service users described being without their medication after discharge, which had	

<table>
<tr><th colspan="2" rowspan="2">Dimensions of person-centred care</th><th colspan="6">Key points on the pathway of care</th><th rowspan="2">Themes that apply to all points on the pathway</th></tr>
<tr><th>Access</th><th>Assessment</th><th>Community care</th><th>Assessment and referral to inpatient care</th><th>Hospital care</th><th>Discharge/ Transfer of care</th></tr>
<tr><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td>upsetting consequences:
[<i>I’ve been discharged or sent home on weekend leave without any medication. And become physically quite ill, and that, and you know, had to ferry myself back in and that to get something back in my system.</i> (Healthtalkonline, 2011)]
While some service users described difficult challenges and situations they had to face on coming out of hospital, others talked about the support they received:
<i>[And from being discharged from hospital, I was taken to the care of the local community</i></td><td></td></tr>
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Dimensions of person-centred care		**Key points on the pathway of care**						**Themes that apply to all points on the pathway**
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
							mental health team. And had a very, very good psychologist, who I used to see every week and just discuss things with. And work things through. (Healthtalkonline, 2011)] [*...so she [key worker] was very keen to have me go to [name of clinic] because she thought that that would be you know be helpful. So I went there straightaway as like an inpatient for a week but they sort of said you don't need to stay here as an inpatient you can come back to the CBT, into the therapy so I kind of did that quite regularly for at least a couple of months [...] and it was really helpful in a lot of ways, it was a*	

Dimensions of person-centred care		***Key points on the pathway of care***						***Themes that apply to all points on the pathway***
		Access	***Assessment***	***Community care***	***Assessment and referral to inpatient care***	***Hospital care***	***Discharge/ Transfer of care***	
							bit stressful, still a bit weird but it was helpful and I was getting to actually talk about some stuff. (Healthtalkonline, 2011)]	
Other themes		The first time people accessed mental health services or spoke about their mental health often had an influence on their engagement with services after that.	Service users described a number of other issues that they considered to be barriers, including always being considered a mental health 'patient', being encouraged to take a 'dead end' job, and the relative lack of professionals from black and minority ethnic groups.	-	-	-	-	-

A matrix of service user experience (under the Mental Health Act)

Dimensions of person-centred care		***Key points on the pathway of care***		***Themes that apply to all points on the pathway***
		Assessment/ admission under the Mental Health Act	***Receiving compulsory treatment***	
The relationship between individual service users and professionals	*Involvement in decisions and respect for preferences*	-	Service users not only spoke about medication and forcible detention but also about the smaller freedoms they were or were not permitted in hospital: [*It took me two or three years of being the good girl and obeying everything to my suddenly saying bollocks, I'm not doing this any more. I'll do what I want to do, and you're not going make me do anything I don't want to do. Which made life a lot easier. And there's these petty rules, like you must draw your curtains all the way back in the daytime. Why? Exactly?* (Healthtalkonline, 2011)]	-
	Clear, comprehensible information and support for self-care	-	Many service users were unaware that they had been detained, or only told they were detained if they tried to leave an inpatient ward: [*Yeah. It was awful. Because I was like, who are they? How do they have the right to do this? They've got no right to do this. It must be the most awful thing. Like I hadn't heard much about that kind of thing happening before, but, so that's why it was very frightening. Because I was like, what the hell?* (Healthtalkonline, 2011)] Some people felt they had not been given enough information about the side effects of medication or did not have any control over which drug they were given: *[...the last time I was in hospital, they were trying me on different medications then and you had very little choice then, because you know, you're under section and you can't really refuse medication. So I was getting a lot of, quite a few side effects from the medication I had in hospital. Like tremors were again quite, tremors and also I was biting on my teeth a lot, to the point where I cracked my own teeth, because I was biting that hard down. I couldn't control when that happened.* (Healthtalkonline, 2011)]	-

	Emotional support, empathy and respect	The experience of being detained was for many people highly traumatic. People were unsure on being admitted to hospital what their rights were and what was happening. Having to have injections of antipsychotics was specifically mentioned by some people as being an unpleasant experience: *[And I know in particular the injections, you tend to lose your dignity to, I mean you do to an extent in a psychiatric ward anyway, although it's not going to be as bad as prison. But yes, the injections, sometimes you know, you do tend to feel that you're not in control at all.* *And I was sort of wandering up to the ward with sort of blood dripping down and this nurse came up and she was wonderful. And she just said, 'Oh [name], where have you been?' And I said, 'Look what I've done.' And she said, 'Oh silly person. Come to me.' And then I got to the nursing station. I didn't want to be touched. I refused to let them touch me, and the doctor was really angry with me. I don't know why he was so angry. But he was. And he took me away to be stitched up and he made a point of saying he wasn't giving me an anaesthetic when he was going to stitch me up. Which may be you don't need it if you're on high does Largactil. I was on a 1000mgs of Largactil by then, which is a very high dose, so I didn't feel much anyway, but it felt quite humiliating when he said it.* (Healthtalkonline, 2011)]	-	-
The way that services and systems work	*Fast access to reliable health advice*	-	-	-
	Effective treatment delivered by trusted professionals	-	For some people antipsychotic medication had a dramatic impact on improving their quality of life, but for others it did not take away the symptoms and had serious psychological and physical side effects: *[...it's a very kind of difficult subject area. Because I can see how it helps so many people, medication. But I also can see it, it might not be the thing for other people, and it might be doing them more damage actually. That's what I said to, when I first was in hospital, I said, 'Why are you giving me medication, you know, I need help with my diet. I need...taking medication doesn't stop me being abused and getting distressed from the abuse. It's*	-

			just putting the distress on pause. It doesn't tackle anything really.' (Healthtalkonline, 2011)] One service user talked about their experiences of being detained and having to take antipsychotic medication: [*Oh it was awful. It set me back. It was like, frightening. I thought they had no right to do that. I, I think that it's a very brutal approach. I know why they do it. Because they know that if you go on the medicine for a month, you'll be better. And then after that you progressively get better, the more you take the medicine.* *And, it was a never ending cycle of in and out of hospital and they always tried to blame me, they said that, you know, I was non-compliant but the drugs didn't work and I didn't see how the drugs not working made me non-compliant I think it made the drugs not work.* (Healthtalkonline, 2011)] Another service user spoke about the side effects of antipsychotic drugs: *[I was very tired all the time, very drowsy, very zonked out, you know, very medicated sedated. And also strangely enough, my throat constricted. The muscles in my throat constricted so it made it very difficult to speak. [...]* *Things did get better [after changing his medication] but that problem with my speech which, you know, which I had no help from the psychiatrist [who] refused to believe it was a recognisable [side effect].* (Healthtalkonline, 2011)]	
	Attention to physical and environmental needs	-	Many people found the hospital environment frightening at worst and boring at best. Physical health often suffered in this environment: [*And they tried me on different drugs every week, Risperidone, what else? Haloperidol, Olanzapine. I went through the book, and I was putting on more and more weight, because of hospital food and they wouldn't take me out to do any exercise, because it was winter and they didn't want to go out. And you're not allowed out on your own if you're under Section, particularly not if you're blind. And then they put me on Clozapine, but they didn't warn me, what could happen. And I went up to about*	-

			seventeen stone. Not because I was a piglet, just because I was on Clozapine and eating hospital food, and not getting any exercise. (Healthtalkonline, 2011)] A few people described the hospital environment as disorientating and distressing: [*I think it's a well-established fact that you have less rights in hospital than the prisoners do in prison. So you have, there's a loss of freedom. You know, isolation or disorientation, all those things really and [er] it's quite hard to, it's quite hard to live with. I think you have to be a very strong type to have those many admissions and then come back, and you know, do the things I've managed to do with my life really.* (Healthtalkonline, 2011)]	
	Involvement of, and support for, family and carers	**-**	-	-
	Continuity of care and smooth transitions	**-**	-	-
Other themes		**-**	The shock that people felt when they discovered they could be detained and treated against their will was something that people often spoke about in great depth: [*I woke up in the middle of the night, and I think, I thought to myself, no they've made a mistake. So when I went to the office where the night nurse were. She was there and like that sleeping and I saw her, and I said, 'Excuse me love. Excuse … I think you've made a mistake. Have you got my clothes? I need to go. I think you've made a wrong mistake.' And I remember she buzzed. She pressed a buzzer underneath the desk. I saw four big blokes run down the corridor. They got hold of me and held me down on the floor, and injected me with tranquillizer and it knocked me out for four days.* (Healthtalkonline, 2011)]	-