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

DEPRESSION UPDATE

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 & referral to inpatient care	Inpatient care	Discharge/ transfer of care	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences							
	Clear, comprehensible information & support for self-care							
	Emotional support, empathy & 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 people said that that they waited too long to be referred to a psychiatrist or receive psychotherapy. One person said that while she was on a waiting list she was unable to cope 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.] 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. *[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.]*						

	Effective treatment delivered by trusted professionals			**Nurses** People said that they did not feel that nurses understood the sensitive nature of their depression, that nurses in the NHS were too busy to talk to their 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*		People also had negative experiences of mental health services provided by the NHS, including not feeling cared for.		

				nurses in a certain way.] **Psychiatrists** People had mixed experience of psychiatrists. Some did not like how psychiatrists tried to illicit information about their 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.] People also had mixed opinions about how their psychiatrist dealt with their medication. The 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 who 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 depression, b) because they do have side-effects and, c) I didn't feel comfortable, myself, with taking some tablets.]* 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 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.]* 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 & environmental needs							
	Involvement of, & support for, family & carers							People with depression described the impact that their condition had on families and carers. Some stated that it was harder for the family and carers than it was for the person who had depression. Others described the impact that it had on the partner, often resulting in a change in roles.
	Continuity of care & smooth transitions							

Other themes			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 sort of feeling about that sort of thing.]*		Once in mental health services, people 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 responsibilities, 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 me.]		

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 & referral to inpatient care**	**Inpatient care**	**Discharge/ transfer of care**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences							
	Clear, comprehensible information & support for self-care	It was not uncommon for service users to report being unaware of treatment facilities open to them.						
	Emotional support, empathy & 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 patients experienced being turned away from services. *['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'.]* 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							
	Attention to physical & environmental needs							
	Involvement of, & support for, family & carers							

	Continuity of care & smooth transitions							
Other themes		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’.]* 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, f*** 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’.]*						

PSYCHOSIS AND 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 & referral to inpatient care**	**Inpatient care**	**Discharge/ transfer of care**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences			There was a feeling among service users of having to conceal certain issues or disclose specific aspects of their illness in order 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.']*				
	Clear, comprehensible information &							

	support for self-care							
	Emotional support, empathy & respect							
The way that	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 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.']* *['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'.]*				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.']*

				One of the most prominent themes that emerged from all the online accounts was a strong opinion about medication regimes for psychosis. Feelings towards medication were typically ambivalent, and 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, 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 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.’] 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. ‘]*				
	Attention to physical &							

	environmental needs							
	Involvement of, & support for, family & carers							
	Continuity of care & smooth transitions			Another theme which 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 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].']				

Other themes	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 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*	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, 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.’]*					

	because of what it stands for. Which is people don't understand.'] One theme that emerged in several testimonies was that access to care was more difficult for those coming from a BME group or a different cultural background. Factors that affected access to care for BME 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…'] A significant number of factors affected accessing services, including fear of 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.'] 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		**Guidelines**						**Themes that apply to all points on the pathway**
		Access	**Assessment**	**Community care**	**Assessment and referral in crisis**	**Hospital care**	**Discharge/ Transfer of care**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences							
	Clear, comprehensible information & support for self-care							
	Emotional support, empathy & respect							
The way that services and systems work	Fast access to reliable health advice							
	Effective treatment delivered by trusted professionals							
	Attention to physical & environmental needs							
	Involvement of, & support for, family & carers							
	Continuity of care & smooth transitions							
Stigma								
Other themes								

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 MH Act	**Receiving compulsory treatment**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences			
	Clear, comprehensible information & support for self-care			
	Emotional support, empathy & respect			
The way that services and systems work	Fast access to reliable health advice			
	Effective treatment delivered by trusted professionals			
	Attention to physical & environmental needs			
	Involvement of, & support for, family & carers			
	Continuity of care & smooth transitions			
Other themes				