APPENDIX 12: KEY PROBLEMS – QUALITATIVE REVIEW MATRIX FOR EACH GUIDELINE

ALCOHOL DEPENDENCE AND HARMFUL ALCOHOL USE

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 in crisis**	**Hospital care**	**Discharge/ transfer of care**	
Involvement in decisions & respect for preferences							
Clear, comprehensible information & support for self-care			**Facilitators to community care, information**: The majority of service users in one study expressed that they had inadequate information about the medication they were taking and the potential side effects.[1]				
Emotional support, empathy & respect	**Barriers to access, professionals**: Two studies described the experience of women when accessing services and found that when they sought help from	**Facilitators to assessment, professionals:** A quarter of service users in one study expressed the therapeutic relationship to be	Facilitators to community care, **professionals:** Service users wanted professionals treating their alcohol problem to be supportive and to treat them with		**Facilitators in inpatient care, professionals**: The most important aspect of inpatient treatment noted by service users was the therapeutic relations in particular		

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[1] "Nearly all participants were apprehensive about the transmission of information about medication between the staff and themselves; they felt they had inadequate information about what medication they were taking, why they were taking it and the effects it may have on them: *I didn't know what they were, what they were going to do to me … they didn't tell me why I was taking them."*

	professionals they were denied access, treated poorly or silenced.[2]	the most important factor in assessment. These factors included the professional to 'genuinely care' and have an understanding of the individual.[3] **Barriers to assessment, time**: some service users in one study criticised the assessment process for not having enough feedback and time to talk.[4]	dignity, respect and genuine concern.[5]		staff attitude (non-judgemental and empathetic) and support.[6]		

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[2] "Once the women sought help from a healthcare professional, several felt angry and frustrated after repeated clinic visits resulted in being turned away, treated poorly, or silenced by comments from healthcare professionals. Some women would go in needing to be treated for a physical health problem, and the practitioner would address the alcohol problem while ignoring the primary physical complaint."

[3] "Hyams and colleagues (1996) interviewed service users about their experience and satisfaction with the assessment interview prior to engagement in alcohol treatment. The study had both a quantitative and qualitative aspect to it. The qualitative component assessed the best and worst aspects of the assessment interview. Thirty-three of the 131 participants said that the therapeutic relationship with the interviewer was most beneficial (as assessed by 'The interviewer's understanding of the real me', 'Friendliness of the interviewer' and 'A feeling of genuine care about my problems'). Twenty participants appreciated the ability to talk generally and therapeutically to the interviewer about their problems."

[4] "Hyams and colleagues (1996) interviewed service users about their experience and satisfaction with the assessment interview prior to engagement in alcohol treatment. …Although participants identified few drawbacks regarding the interview, they did cite general nervousness particularly about starting the interview. Some criticised the interviewer for not giving enough feedback or not having enough time to talk. Several participants felt that it was distressing to have to reveal so much information about their drinking problems and to come to a state of painful awareness about their problem."

[5] "Nelson-Zlupko and colleagues (1996) found that individual counselling might be important in determining whether a woman is retained or drops out of treatment. Many women felt that what they wanted from treatment was someone to 'be there for them' and lend support. A therapist's ability to treat their patients with dignity, respect and

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genuine concern was evaluated as more important than individual therapist characteristics (such as ethnicity or age). Some women mentioned that good counsellors were those who: *…view you as a person and a woman, not just an addict. They see you have a lot of needs and they try to come up with some kind of a plan.”*

[6] “Bacchus (1999) carried out a study about opinions of inpatient treatment for drug and alcohol dependence...One of the most positive aspects of treatment noted by participants was the quality of the therapeutic relationships. Staff attitudes, support, and being non-judgemental and empathetic were all mentioned as crucial components of a positive experience in treatment.”

Fast access to reliable health advice	**Preferred access to services: GPs** Service users in one study identified GPs as the preferred professional to access services and discuss alcohol-related problems (and to deliver brief interventions) but referral to a specialist when the problem could not be treated in primary care.[7]			**Improvements to referral, waiting times**: Over one third of service users with alcohol problems reported that they wanted quicker referral to treatment in order to maintain treatment motivation and to receive medical care.[8]			
Effective treatment delivered by trusted professionals		**Improvement**: holistic approach					**Barriers to effective treatment, cultural:** Service users with substance misuse problems (including alcohol) from minority groups in one study found it difficult to discuss their emotional problems with

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[7] "Lock (2004) conducted a focus group study with patients registered with general practices in England. Participants were classified as 'sensible' or 'heavy/binge drinkers'. Participants responded positively to advice delivered in an appropriate context and by a healthcare professional with whom they had developed a rapport. Overall, the GP was deemed to be the preferred healthcare professional with whom to discuss alcohol issues and deliver brief alcohol interventions. Practice nurses were also preferred due to the perception that they were more understanding and more approachable than other healthcare workers. Most said they would rather go straight to their GP with any concern about alcohol, either because the GP had a sense of the patient's history, had known them for a long time or because they were traditionally who the person would go to see. It was assumed that the GP would have the training and experience to deal with the problem, and refer to a specialist if necessary."

[8] "Bacchus (1999) carried out a study about opinions of inpatient treatment for drug and alcohol dependence. Over one third of participants reported that they would have preferred to enter treatment sooner because there was an urgent need to maintain treatment motivation and receive acute medical care:
When you make that decision to ask for help, you need it straight away. If you have to wait a long time to get in you just lose your motivation and you might just give up."

								professionals due to cultural factors, such as cultural honour and respect. The lack of ethno-cultural peers in treatment made it difficult for service users to complete treatment.[9]
Attention to physical & environmental needs								
Involvement of, & support for, family & carers			Improvement to community care, **childcare services**: Women service users with alcohol problems expressed in two studies that they want outpatient services to be flexible to their needs by providing childcare and be available in the evening or weekends for treatment.[10] **Improvement: involvement of family, carers and peer support:** Service users in one study noted the					

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[9] "Vandevelde and colleagues' (2003) study of treatment for substance misuse looked at cultural responsiveness from professionals and clients' perspectives in Belgium. People from minority groups found it difficult to openly discuss their emotional problems due to cultural factors, such as cultural honour and respect. Participants stressed the absence of ethno-cultural peers in substance misuse treatment facilities, and how this made it hard to maintain the motivation to complete treatment."

[10] Both Nelson-Zlupko and colleagues (1996), and Copeland (1997), highlighted that childcare was a particular need for women as it was not widely available in treatment. When childcare was available, this was perceived to be among one of the most helpful services in improving attendance and use of treatment and drug/alcohol services. In addition, women felt strongly about the availability and structure of outpatient services offered and felt there should be more flexible outpatient programmes taking place in, for example in the evenings or at weekends.

			influence of family and friends in helping promoting change in alcohol consumption. In particular, the support from peers in treatment programmes such as AA and the 12-step programme.[11]				
Continuity of care & smooth transitions					**Facilitators in inpatient care, information on continued care:** In general service users in inpatient care were positive about the arrangements received about their aftercare treatment, however, patients wanted more information about the next phase in their continuity of care.[12]		
Stigma	**Barriers to access, stigma of services**: Service users in one study expressed that there is a stigma associated with receiving treatment						

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[11] Orford and colleagues (2005) also found that the influence of family and friends helped in promoting change in alcohol consumption. Treatment seemed to assist participants in finding non-drink related activities and friends, and seeking out more support from their social networks to deal with problematic situations involving alcohol. Supportive networks provided by AA and the 12-step programme facilitated recovery for participants in the Dyson (2007) study as well, because they were able to be with others who genuinely understood their experiences and fostered a sense of acceptance: *'Here was a bunch of people who really understood where I was coming from'.*

[12] "Bacchus (1999) carried out a study about opinions of inpatient treatment for drug and alcohol dependence...Sixty-two per cent of patients had made prior arrangements with staff for aftercare treatment and expressed satisfaction with the arrangements. The only exception was that patients wished for more detailed information about the next phase of their treatment."

	by specialists as it was perceived that you had a severe alcohol problem.[13] **Barriers to access, stigma of diagnosis**: Two studies described how the majority of service users viewed alcohol disorder to be stigmatising. As a result service users mask their dependence and women in particular feel that they are judged, which impacts on their willingness to seek treatment.[14]						

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[13] Lock (2004) conducted a focus group study with patients registered with general practices in England. Participants were classified as 'sensible' or 'heavy/binge drinkers'… Alcohol workers were perceived by many as the person to go to with more severe alcohol misuse because they were experts, but this also carried the stigma of being perceived to have a severe alcohol problem. Seeing a counsellor was also perceived as negative in some ways, as there would be a stigma surrounding mental health problems and going to therapy."

[14] "Dyson (2007) found that all participants used strategies to hide their alcohol dependence, including covering up the extent of their alcohol consumption. This was primarily due to the fear of being judged or stigmatised: *'I knew that I was ill but was too worried about how other people would react. I felt I would be judged'*." "Copeland's (1997) Australian study was of women who self-managed change in their alcohol dependence and the barriers that they faced in accessing treatment. One of the central themes of the study was the social stigma that women felt as being drug or alcohol dependent. Seventy-eight per cent of participants felt that women were more 'looked down upon' as a result of their drinking, and the additional burden of an alcohol or drug problem only increased the stigma. Some women reported that the feeling of being stigmatised impacted on their willingness to seek treatment: *There is the whole societal thing that women shouldn't show themselves to be so out of control … that stigma thing was part of the reason for not seeking treatment."*

ANTISOCIAL PERSONALITY DISORDER

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	
Involvement in decisions & respect for preferences		**Barriers in assessment, transparency**: People diagnosed with personality disorder, 16% found out about their diagnosis from their records (half found out from a psychiatrist) which increased their feelings of stigma associated with the diagnosis.[15]	**Facilitators to community care, more choice**: Two studies found that service users with personality disorder wanted more choice in treatment with less reliance on pharmacological medication and more 'talking therapies'.[16] **Facilitators to**				

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[15] "In a study by Castillo (2000) people diagnosed with personality disorder interviewed others to ascertain what it felt like to have the diagnosis, the problems people experience, and what they have found helpful in dealing with these problems. When asked about the diagnosis, of the 50 people in the sample (14 of whom—11 men and 3 women—had dissocial personality disorder), 22% said that it was '*a label you get when "they" don't know what else to do*', and 10% regarded having personality disorder as something 'bad' or 'evil' and a '*life sentence – untreatable – no hope*' (Castillo, 2000). Over 50% were told their diagnosis by their psychiatrist, but 16% found out accidentally from their records, which may have exacerbated their feelings of stigma, shame and exclusion: '*After I was discharged I opened a letter from my psychiatrist to the GP. It said it there. I was a bit stumped – shocked. I'd heard about people that had been diagnosed with personality disorder being the black sheep of the community. It made me feel I didn't belong anywhere*' (Castillo, 2000)."

			community care, service user involvement in decisions: service users in one study emphasised that they had important views on treatment on what was worked or not worked for them in the past which professionals should listen to when deciding on treatment options.[17]				
Clear, comprehensible information & support for self-care							**Facilitators to community care, more information**: Two studies found that service users with personality disorder expressed wanting more high quality information. In one study this was information specifically about personality disorder and in the other study, the type of information was not specified but was expressed that it would improve services.[18]

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[16] "In the Castillo survey (2000), 34% said that they wanted improved services. The themes that emerged included: being listened to; being treated with respect; healthcare professionals having a greater understanding of the condition; being given more information; being offered less medication and more 'talking therapies'." "The participants in the Haigh (2002) study felt that being offered options for treatment was helpful, and that there was an over-reliance on drug treatment."

[17] They emphasised that they had important views on treatment (that is, what helped them and did not help them) and that staff should listen to them when deciding on interventions (Haigh,2002)."

[18] "[(Haigh, 2002)] It was strongly stated by the participants that they required high-quality printed information about personality disorders, and that they should not be actively discouraged from seeking information by professionals"
In the Castillo survey (2000), 34% said that they wanted improved services. The themes that emerged included: being listened to; being treated with respect; healthcare professionals having a greater understanding of the condition; being given more information..."

Emotional support, empathy & respect							**Barriers in services, professionals**: Men with personality disorder from one study found professionals rude and dismissive.[19] **Facilitators to community care, professional training**: Across three studies, service users with personality disorder suggested the need for training professionals. The areas of training highlighted were in understanding their condition in order to improve services and to help build upon their empathy. The need for staff's attention o interpersonal interactions was also highlighted[20] **Facilitators to community care, professionals**: A third of service users with personality disorder found in one study wanted to improve services and identified being listened to and being treated with respect by professionals as a means to this.[21]

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[19] "Sometimes the staff were 'rude' and 'dismissive', and participants suggested that training and attention to interpersonal interactions were required [(Links *et al.*, 2007)]."

[20] "It was suggested that service users should help train healthcare professionals in managing people with personality disorder, particularly in terms of developing empathy and understanding (Haigh, 2002)."
"In the Castillo survey (2000), 34% said that they wanted improved services. The themes that emerged included: being listened to; being treated with respect; healthcare professionals having a greater understanding of the condition..."
"Sometimes the staff were 'rude' and 'dismissive', and participants suggested that training and attention to interpersonal interactions were required [(Links *et al.*, 2007)]."

Fast access to reliable health advice	**Improvements to access: physical:** Male service users from one qualitative study expressed that access to A&E would be improved if there was a separate psychiatric emergency service.[22]						
Effective treatment delivered by trusted professionals		**Validity of diagnosis:** one study found that service users questioned the legitimacy of the diagnosis of personality disorder as they suffered from other primary, co-morbid problems. However, one participant in another study found it to accurately describe his condition.[23]	**Barriers to effective treatment, stigma by professionals:** Service users from one study felt that a diagnosis of personality disorder was viewed by professionals as being untreatable.[24]		Improvements to care, reduce waiting time & improved support after treatment : The majority of the service users in one study had positive experience of psycho-education but thought it could be improved by reducing the waiting time between assessment and		

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[21] "In the Castillo survey (2000), 34% said that they wanted improved services. The themes that emerged included: being listened to; being treated with respect"

[22] It was also suggested that one way of improving access to emergency psychiatric treatment would be having separate psychiatric emergency services or triage points [(Links *et al.*, 2007).

[23] "In a study by Stalker and colleagues (2005), which elicited the views of ten people with a diagnosis of personality disorder, half felt that the term 'personality disorder' was disparaging. However one male participant thought that it accurately described his problems: '*It doesn't particularly disturb me. I don't see any problem because that is exactly what I suffer from – a disorder of the personality*' (Stalker *et al.*, 2005)." "The participants in Castillo (2000) questioned the category of 'personality disorder' when they said that they thought their primary problems were depression, abuse, stress or not coping, and substance misuse. In the survey by Stalker and colleagues (2005), participants said that the main problem in their lives was in making and keeping relationships, often because they felt unable to trust other people."

					feedback and to receive support after the intervention.[25] Improvements to care, more frequent reviews: the majority of men in one study found social problem solving "generally useful" but wanted more frequent reviews on how well the treatment is going and more consistency in how it is delivered.[26]		
Attention to physical & environmental needs							
Involvement of, & support for, family & carers							
Continuity of care & smooth transitions							

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[24] "The participants of a focus group convened by Haigh (2002) thought that the term 'personality disorder' was associated with stigma and that healthcare professionals viewed people with the condition as untreatable."

[25] "In a survey of 12 male patients of a highly specialist personality disorder hospital treatment unit (McMurran & Wilmington, 2007), nine of whom had antisocial personality disorder, both psychoeducation and social problem-solving therapies were thought to be 'useful' by this group. The majority found psychoeducation '*informative, interesting and helpful*', social problem-solving therapy was thought to be '*generally helpful*' and the group work was viewed as '*enriching the problem-solving process*'. However, the patients also suggested ways of improving the interventions. For psychoeducation this included reducing the waiting time between being assessed and being given feedback and receiving support afterwards for any distress caused by learning more about their condition."

[26] "For social problem-solving therapy, suggested improvements involved more frequent reviews of how well the therapy was working, more consistency in how the treatment was delivered, helping patients to draw out problems, supporting them during group therapy, and developing an advanced form of the intervention."

Stigma							

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**	
Involvement in decisions & respect for preferences		**Barriers to compulsory treatment, treatment options**: Service users with personality disorder across two studies expressed wanting more treatment options including more 'in-depth' and 'imaginative' treatments. In one study a preference was made for individual therapy.[27]	
Clear, comprehensible information & support for self-care			
Emotional support, empathy & respect		**Facilitators, professionals**: in an interview with 61 service users detained in forensic secure units found the qualities needed in professionals to facilitate effective services are caring and understanding with experience with people with personality disorders.[28]	
Fast access to reliable health advice			
Effective treatment delivered by trusted		**Barriers to compulsory treatment, prolonged detention**: Three studies expressed service users concern of prolonged detention in forensic secure units where they are detained and service users in one study viewed	

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[27] "The most favoured treatment by 66% was individual therapy, however this was influenced by gender and by type of disorder. A greater proportion of the men favoured this treatment, as did people with a mental illness in addition to personality disorder. The vast majority could name one treatment that had been helpful. Only one person said that no treatment had been beneficial. Just over 50% said they wanted improved access to treatment, and '*more in-depth groups, which don't skirt around the issues*' because '*personality disordered people need to be confronted*'." "During the Fallon Inquiry (Fallon *et al.*, 1999) eight patients treated in the Personality Disorders Unit of Ashworth Special Hospital were interviewed...Patient E had attended several different groups, including anger management and a sex offenders' group. The sex offenders' group had forced him to face what he had done as he had previously not thought of himself as a sex offender, and it had also addressed the causes behind his offences. However, he was critical of the lack of 'imaginative' treatments that enable patients to move forward"

[28] "In a study by Ryan and colleagues (2002), which aimed to capture the voice of people with personality disorders detained in Broadmoor about treatment and services, 61 people were interviewed. The aim was to feedback these views to the government's advisers developing the DSPD programme... When questioned about qualities of staff, the most important quality by some margin was being caring and understanding. Almost 50% felt that staff should be experienced in working with people with personality disorder."

professionals		prison to have earlier released dates.[29]	
Attention to physical & environmental needs			
Involvement of, & support for, family & carers			
Continuity of care & smooth transitions		**Barriers to compulsory treatment, continuity of care**: Service users detained in secure criminal justice settings expressed a lack of continuity of care which they expressed resulted in prolonged length of stay in higher secure units.[30]	
Other themes			

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[29] During the Fallon Inquiry (Fallon *et al.*, 1999) eight patients treated in the Personality Disorders Unit of Ashworth Special Hospital were interviewed. The themes identified included length of stay in the hospital, the mix of patients in the Personality Disorders Unit, access to treatment, and a comparison of hospital versus prison...One concern was continued detention." "In a study by Ryan and colleagues (2002), which aimed to capture the voice of people with personality disorders detained in Broadmoor about treatment and services, 61 people were interviewed... When compared with Broadmoor, people felt that the positive aspects about prison were having an earliest date of release." "In an evaluation of the assessment procedure for the DSPD programme (IMPALOX Group, 2007), just over 50% of the 40 prisoners interviewed from HMP Whitemoor and the Westgate Unit and HMP Frankland... Personal safety and prolonged detention were issues that were a source of 'fear' for the patients entering the unit"

[30] "Some of the other patients were also critical of the length of time it took before being reviewed for a medium security unit. Some felt that if they had been in prison they would not have spent as long being detained: *'That is the worst part of being a special hospital patient. You are sentenced to natural life imprisonment in a mental institution and from there . . . it is down to a lottery whether you ever get out: whether your doctor is competent, whether the RSU [regional secure unit] doctor likes you and is competent, whether the RSU wants you considering the pressures on RSU beds'.* (Patient H)."

BIPOLAR DISORDER

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 & referral to inpatient care**	**Inpatient care**	**Discharge/ transfer of care**	
Involvement in decisions & respect for preferences			**Facilitators to community care, service user involvement:** Service users want their preferences to be taken into account in treatment and to be treated as equal partners to their professionals.[31] **Barriers to community care, lack of treatment options:** Service users described a lack of treatment				

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[31] The testimonies and surveys (Morselli & Elgie, 2003) also emphasise the importance of a trusting, open and respectful working relationship between themselves and the professional. What is valued in a professional is someone who will ... clearly explain the treatment options and the risks and benefits. Patients nowadays expect to be treated as an equal partner, no longer the passive recipients of treatment, but as experts in their own condition (Morselli & Elgie, 2003), unlike the individual who felt that '*my psychiatrist and other professionals tend to decide what is best for me, rather than listening to my thoughts and feelings*'. (MDF The BiPolar Organisation survey). This will necessitate that patients are fully involved in decisions about their treatment and care, and that their preferences for a particular treatment, or their decision not to have an intervention, is taken into consideration by the professional when the treatment plan is prepared.

			options whereby mainly medication was offered.[32]				
Clear, comprehensible information & support for self-care			**Facilitators to community care, information:** Service users stated that there is a need for full discussion about dose and side effects of treatment which is not being provided.[33] They also want information about their condition and preferred this to be provided in booklets, newsletters, videos that are sensitive to social, cultural and educational backgrounds.[34]				
Emotional support, empathy & respect		**Facilitators to assessment, professionals:** Service users want professionals that provide thorough					

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[32] “Highet and colleagues (2004) report that patients experience a restricted range of treatment, both in primary and secondary care, mostly limited to medication. MDF The BiPolar Organisation also report that ‘a very high number of people still do not have access to a psychologist’ (MDF The BiPolar Organisation survey, 2004).”

[33] (MDF The BiPolar Organisation survey, 2004). Regarding medication, patients highlight the need for full discussion about dose and side effects. Sally (aged 51), a university lecturer, says that her psychiatrist ‘*listens to me and takes my view into account. I told him how my last psychiatrist put me on 20 mg olanzapine and turned me into a zombie.”*

[34] “The testimonies and surveys (Morselli & Elgie, 2003) demonstrate that people with bipolar disorder require healthcare professionals to provide full and clear information about the condition and about the treatment options, ideally in written form (for example, booklets or newsletters) or video (Kupfer *et al.*, 2002). In providing this information, the social, cultural and educational background of the patient (and carer) need to be taken into consideration.“

		assessment and listen attentively.[35]					
Fast access to reliable health advice		**Barriers to assessment, diagnostic delays.** Service users described their experience of severe diagnostic and treatment delay for their bipolar disorder.[36]	**Improvements to community care, access:** One study suggested that prompt and improved access to crisis care in early phases of acute relapse is needed in the community to avoid admission to hospital. One service user benefited from intensive CPN home support and a relapse prevention plan.[37]				

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[35] "The testimonies and surveys (Morselli & Elgie, 2003) also emphasise the importance of a trusting, open and respectful working relationship between themselves and the professional. What is valued in a professional is someone who will undertake a thorough assessment, listen attentively to the patient's description of his or her symptoms, and to their carers, and who will clearly explain the treatment options and the risks and benefits."

[36] People with bipolar disorder have reported that it has taken them years, sometimes decades to get a formal diagnosis of bipolar disorder and consequently to receive appropriate care (occurs in both primary care and specialist mental health services). This problem is one that occurs in both primary care and specialist mental health services (Highet *et al.*, 2004). It may be the case that symptoms of depression – for which patients are much more likely to seek treatment – will be recognised, but symptoms of hypomania may be missed or not initially detected by healthcare professionals when taking a patient's history. "*Over the next 27 years, they all treated me for depression, prescribing me more than a dozen different antidepressants. As far as I can tell they did nothing to stabilise my mood swings. None of the GPs ever recognised that my high moods in between the lows were symptomatic of bipolar disorder.*"
"The cyclical nature of the illness illness, whereby symptoms – and consequently the patient's judgement – changes from day to day, week to week and month to month, makes diagnosis much more difficult. For example, a patient who makes an appointment to see a psychiatrist when depressed and desperate for treatment may feel very different when attending the appointment several weeks later. People with bipolar disorder can labour under the illusion that they are 'just moody' for years."

			Barriers to community care, access to professionals: Very high number of service users reported that they had little access to psychologists.[38]				
Effective treatment delivered by trusted professionals							
Attention to physical & environmental needs							
Involvement of, & support for, family & carers							
Continuity of care & smooth transitions							
Stigma	**Barrier to access, stigma of diagnosis:** Service users described how the						

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[37] "Highet and colleagues (2004) reported that 'current crisis management practices were considered to contribute to negative perceptions and stigma' and they identified a need for 'prompt and improved access to crisis care during the early phases of acute relapse'. Sally has a crisis team but on one occasion could not access anybody to come out and assess her: '*the result was that I left home in my car in a manic state and had a fortunately minor accident some hours later, 100 miles away*' (extract from testimony). On another occasion she made four telephone calls to her team but was nevertheless sectioned the next day. She feels that '*everything should be done to avoid hospital: the staff there are generally not interested and offer virtually no psychological support. The experience is traumatic and one's stay tends to be prolonged."*

[38] "The BiPolar Organisation also report that very high number of people still do not have access to a psychologist'. After a psychotic episode, Linda (aged 34) '*pushed for some counselling but was made to feel like I was asking for a pot of gold by the hospital psychiatrist*'."

	stigma associated with mental illness was a barrier to them accessing services and ultimately receiving a diagnosis and treatment for their condition.[39]						

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[39] "(Highet *et al.*, 2004). For some people, getting a diagnosis and treatment can be made more difficult by the stigma associated with mental illness. It took Eileen, now aged 50, more than 20 years to get a diagnosis of bipolar disorder: *'I was 42 before I was diagnosed. I first became aware I was suffering severe mood swings as a young child. I can only ever remember being either very happy Service user and carer experience of bipolar disorder or very sad. When low I wished I'd never been born. My dad had also always suffered severe mood swings throughout my childhood and spent long spells in hospital, but I was told it was for treatment for a 'heart attack'. My parents felt such shame about his mental illness they never told me about it, and they never told me their suspicions about my illness. It was only when I broke the news about my diagnosis more than 20 years later that they said they 'had always known'. I felt quite angry really that they'd never said something earlier. If I had been diagnosed earlier I would have got the right treatment earlier'*. (Interview)"

BORDERLINE PERSONALITY DISORDER

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

Dimensions of person-centred care	**Guidelines: Borderline Personality Disorder**						**Themes that apply to all points on the pathway**
	Access	**Assessment**	**Community care**	**Assessment & referral to inpatient care**	**Inpatient care**	**Discharge/ Transfer of care**	
Involvement in decisions & respect for preferences							**Facilitators to community care, service user involvement:** Service users described wanting to make their own choices regarding services to increase engagement[40] and to be involved in clinicians' training.[41] **Facilitators to community care, more treatment options:** Service users stated that they would benefit from information on treatment options and deciding for

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[40] Haigh (2002) Service users preferred to make their own choice about services and treatments as this was felt to increase cooperation and engagement. It was stated that where there was a lack of choice and the service user opted not to engage with the treatment, this led to service users being labelled 'non-compliant'

[41] Haigh (2002) Service users also valued input from staff who had experienced mental health difficulties, as it was felt they had more insight. All service users thought it was important to have respect from staff, to be perceived as an individual and with intelligence, to be accepting but also challenging, and to view the therapeutic relationship as a collaboration. Problems arose for service users, however, when boundaries broke down and the staff began to share their own problems with service users, and when staff failed to show respect or were disinterested in the client. It was also felt that service users could provide a useful input to clinicians' training.

							themselves what would best meet their need[42]; others expressed wanting more choice as the only treatment offered to them was DBT.[43]
Clear, comprehensible information & support for self-care		**Barriers to assessment, information:** Some service users felt they had little information, negative information, unclear information or in some instances, were not disclosed the diagnosis[44]; or did not know what the term BPD meant.[45]	**Facilitators to community care: information:** Coping with rules and boundaries in a community-based service for people with personality disorder was easier when they were made explicit and transparent, and were able to be negotiated.[46]				**Facilitators to community care, information:** Service users in specialist community care valued clear, written information, particularly where it differed from mainstream services.[47]

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[42] Haigh (2002) Service users preferred to make their own choice about services and treatments as this was felt to increase cooperation and engagement. It was stated that where there was a lack of choice and the service user opted not to engage with the treatment, this led to service users being labelled 'non-compliant'

[43] In a study by Hodgetts and colleagues (2007) of five people (3 women and 2 men) with borderline personality disorder being treated in an NHS DBT service in the south west of England, the participants reported that DBT was presented to them as the only treatment for personality disorder, which may raise anxieties about what is expected of them. While some valued the sense of structure to the treatment, others would have preferred a more tailored and flexible approach.

[44] for others, who had been given little information or explanation about the diagnosis (and what information they were given tended to be negative), the diagnosis represented knowledge withheld and the viewing of others as experts. Haigh (2002), There was a feeling that many professionals did not really understand the diagnosis, instead equating it with untreatability. Other professionals did not disclose the diagnosis to the service user.

[45] Ramon and colleagues (2001) The majority felt that they did not really know what the term meant (26%) where as 22% described it as 'a label you get when they don't know what else to do' and 18% referred to the meaning 'as being labelled as bad'.

[46] (Crawford *et al.*, 2007) Rules and boundaries were a contentious issue in many of the pilot sites. People coped with these better when they were made explicit and transparent, and were able to be negotiated, rather than being implicit and/or forced upon them.

Emotional support, empathy & respect		**Facilitators to assessment, professionals:** Assessment was often considered difficult because of the focus on painful past experiences. Support and information by staff made the process easier.[48] Professionals can	**Barriers to self-care, support:** A barrier to self-care was not having the support needed; in times of crisis service users want support and not to be pushed towards self-care.[49]				**Facilitators to** community care**, professionals:** Service users expressed that the most productive relationship with professionals was when it was collaborative, when staff were non-judgmental, caring, respectful, amongst other characteristics[50] [51].

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[47] (Crawford *et al.*, 2007) Service users valued receiving clear, written information about the service, particularly where it differed from mainstream services.

[48] (Crawford *et al.*, 2007) Those interviewed tended to find assessment difficult, traumatic and upsetting, due largely to the focus on painful past experiences and the emotions these raised. Some service users felt that this process was over-long as they had to undertake tests and questionnaires over several weeks. The availability of staff to answer questions and offer support made the process easier, especially as support was often not felt to be available outside the service.
Explanation about the process, clear, written information about a service, and the opportunity to ask questions were all welcomed and valued.

[49] Nehls (1999) When in crisis, a dialogue with someone who cares was desired by service users. The push by some services towards ‘self-care' and ‘helping yourself' was felt to divert attention away from what matters to people with borderline personality disorder, that is a caring response.

[50] For some these relationships led to a position where they felt able to question the diagnosis. They want - respect from staff, to be perceived as a person with intelligence, to be accepting but challenging, and to view the relationship as a collaboration. Dialogue with someone who ‘cares' was desired in crisis situations.
It was felt that the most productive relationships were with staff who were non-judgmental, helpful, supportive, caring, genuine and ‘real', positive, flexible, accessible, responsive, skilled, and knowledgeable. Other valuable attributes were treating service users as whole people rather than as a collection of symptoms, being unshockable, being honest about themselves to some degree while maintaining boundaries, treating the service user as an equal, believing in the service user's capacity for change and consequently encouraging and supporting them to achieve their goals. It was also reported that services improved service users' relationships and interactions with others, particularly as a result of improved communication skills.

[51] Haigh (2002) Service users also valued input from staff who had experienced mental health difficulties, as it was felt they had more insight. All service users thought it was important to have respect from staff, to be perceived as an individual and with intelligence, to be accepting but also challenging, and to view the therapeutic relationship as a collaboration. Problems arose for service users, however, when boundaries broke down and the staff began to share their own problems with service users, and when staff failed to show respect or were disinterested in the client. It was also felt that service users could provide a useful input to clinicians' training.

		facilitate this process through having a more positive attitude towards the diagnosis and as such the people who have the diagnosis – this was something that was picked out in a number of the qualitative studies included in the BPD guideline – (Haigh, 2002; Horn et al, 2007; Nehls, 2009; etc					
Fast access to reliable health advice	**Improvements to access, phone or crisis teams:** Immediate support best provided by telephone service or (ideally) 24-hour crisis intervention teams focused on personality disorders). The ability to self-refer was seen as a big plus. [52]	**Barriers to assessment, time:** Some service users felt that the assessment process was too long (often several weeks).[54]					**Improvements to** community care**, alternatives:** Service users described improvements to services as an out-of-hours service and a safe house and an advocate service and helpline.[55]

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[52] Service users interviewed by Haigh (2002) believed that self-referral may prevent further negative and unhelpful experiences. It was also felt that immediate support, which is often needed, could be provided by a telephone service, but ideally 24-hour crisis intervention teams who had knowledge of and training in personality disorders should be available as this would reduce the need for inpatient care.

[54] (Crawford *et al.*, 2007) Those interviewed tended to find assessment difficult, traumatic and upsetting, due largely to the focus on painful past experiences and the emotions these raised. Some service users felt that this process was over-long as they had to undertake tests and questionnaires over several weeks. The availability of staff to answer questions and offer support made the process easier, especially as support was often not felt to be available outside the service.

	Improvements to access, phone or crisis teams: Service users also valued having a range of options to choose from and access at different times such as one-to-one sessions, out-of-hours support, crisis beds and an open clinic.[53] **Barrier**: Long waiting lists and being passed from one service to another before getting the right intervention (Nehls, 1999).						
Effective treatment delivered by trusted professionals		**Barriers to assessment, validity of the diagnosis:** Some received many diagnoses in the past and were therefore sceptical about the diagnosis[56]; others	**Facilitators to community care, choice of modality:** For those users undergoing group psychotherapy, the treatment was considered a good	**Barriers to assessment, validity of the diagnosis:** Some received many diagnoses in the past and were therefore sceptical about the diagnosis[67]; others	**Barriers to care, access to professionals:** Service users found services intentionally limiting with little access to mental health professionals.		**[Reasons for non-adherence[73]]**

Explanation about the process, clear, written information about a service, and the opportunity to ask questions were all welcomed and valued.

[55] In the study by Ramon and colleagues (2001) based on semi-structured interviews and a questionnaire,... Service users felt that the ideal services should be those that advocated a more humane, caring response, an out-of-hours service and a safe house, an advocate service and helpline.

[53] (Crawford *et al.*, 2007) The need for out-of-hours support was a common theme raised by service users. Crises usually happened outside the hours of 9am-5pm, and if people did have to access a service during a crisis outside of this time the staff often responded inappropriately. Service users felt that they needed a person-centred and responsive out-of-hours service.

		were unsure whether they were ill or troublemakers.[57] **Barriers to care, stigma by professionals:** Service users expressed how being told that their diagnosis was untreatable by professionals, which led to a loss of hope.[58]	opportunity to share experiences and they valued the peer support. This sentiment was not shared by those who preferred individual therapy.[62] **Facilitators to community care, therapeutic relationship:** Service users described	were unsure whether they were ill or troublemakers.[68] **Barriers to care, stigma by professionals:** Service users expressed how being told that their diagnosis was untreatable by professionals, which led to a loss of	Lack of access to inpatient care is a problem – psychiatrists not wishing to admit people with BPD as not viewed as mental illness and seen as not being the right environment for treatment – but it can be useful and at times a well needed		

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[56] Crawford and colleagues (2007) Others felt quite skeptical about the diagnosis having received a number of different diagnoses during their history of accessing services.

[67] Crawford and colleagues (2007) Others felt quite skeptical about the diagnosis having received a number of different diagnoses during their history of accessing services.

[73] Hummelen and colleagues (2007) interviewed eight people with borderline personality disorder who dropped out of long-term group psychotherapy following intensive day treatment. The main reasons for dropping out were finding: the transition too difficult from day treatment to outpatient group therapy and bad experiences of the previous day treatment; that group therapy was too distressing—service users reported having strong negative feelings evoked in therapy and feeling that these could not be adequately contained in an outpatient setting; that outpatient group therapy was not sufficient as too much time elapsed between sessions; that service users were unable to make use of the group or were unsure of how the group was meant to work; that service users experienced a complicated relationship with the group and felt that they did not belong; and that there were various aspects of the patient-therapist relationship that were negative (such as therapists not explaining adequately how the group worked, not dealing effectively with criticism and acknowledging the patients' distress). Other service users found it too difficult combining work, study, or parenting responsibilities with therapy. Other reasons stated included a desire to escape from therapy and no interest in further long-term group therapy.

[57] Horn and colleagues (2007) for others it was not useful and too simplistic. It did not appear to match their understanding of their difficulties, and service users were left feeling unsure whether they were ill or just a troublemaker.

[58] Inevitably if they were told that they were untreatable this led to a loss of hope and a negative outlook.

		[Barriers to assessment, experience of receiving a diagnosis. The qualitative review evidence seems to suggest overall that if the diagnosis is handled in a positive way (often by a specialist service) and in a correctly informed way then people can make better use of the diagnosis – it is when it is used inappropriately or used in conjunction with stigma or as a barrier to accessing interventions then it is viewed more negatively – it's the stigma that causes the main difficulties with receiving the label..[59] [60] [61]]	facilitators to the therapeutic relationship as building a relationship with the therapist who was viewed as non-judgmental, where they were considered an equal and where the therapist pushed and challenged them.[63] [64] **Facilitators to community care, support:** For those undergoing DBT therapy, 24-hour telephone skills coaching was valuable.[65] **Facilitators to care, therapeutic relationship**: Service users described specialist services as building a sense of belonging due to sharing	hope.[69]	safe place.[70] **Facilitators to care, specialist services:** Access to specialists improved users' perceptions of service provision.[71] **Facilitators to care, therapeutic relationship**: Service users described specialist services as building a sense of belonging due to sharing experiences with other users and building relationships with professionals.[72]		

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[62] Crawford and colleagues (2007): group psychotherapy was experienced by some service users as a good opportunity to share experiences with others and they valued the peer support. However, others, who would have preferred individual therapy, struggled where group therapy was the only option, particularly in understanding the way the group operated and its 'rules'.

[68] Horn and colleagues (2007) for others it was not useful and too simplistic. It did not appear to match their understanding of their difficulties, and service users were left feeling unsure whether they were ill or just a troublemaker.

[59] Horn and colleagues (2007) Knowledge of the diagnosis and professional opinions was experienced as power, both for the service user and for others. For some the diagnosis provided a focus and sense of control, for example the 'label' could provide some clarity and organisation of the 'chaos' experienced by the service user.

[60] receiving the label was a useful experience, giving some legitimacy to their experience and helping them begin to understand themselves.
People have reported that being diagnosed with borderline personality disorder can be both a positive and negative experience. For some it can provide a focus, a sense of control, a feeling of relief, and a degree of legitimacy to their experience.

[61] Haigh (2002), receiving the label was a useful experience, giving some legitimacy to their experience and helping them begin to understand themselves.
[63] (Cunningham *et al*., 2004). Participants reported that DBT allowed them to see the disorder as a controllable part of themselves rather than something that controlled them, providing them with tools to help them deal with the illness. They reported that the individual therapy played an important part, particularly when the relationship with the therapist was viewed as non-judgemental and validating and the therapist pushed and challenged them. However, where the client felt that the therapist did not push enough or too much, the therapy seemed to become less effective. Another key component in the relationship is equality, with the client feeling that they were operating on the same level as the therapists and working towards the same goal. This equality seems to empower people to take more responsibility in their own therapy.

[64] (Cunningham *et al*., 2004). DBT therapy. The skills trainers needed to have a strong understanding of the skills themselves rather than just use the manual—the latter proved to be less effective for service users . Service users found some skills more helpful than others. ‘Self-soothe’, ‘distract’ and ‘one mindfulness’ were the skills reported as useful most commonly. The skills most used also corresponded to the skills most easily understood. The support that service users received in the skills group also proved to be valuable.

[65] The 24-hour telephone skills coaching were valued by the service users as a means of supporting them through their crises (Cunningham *et al*., 2004).

[69] Inevitably if they were told that they were untreatable this led to a loss of hope and a negative outlook.

[70] People interviewed by Nehls (1999) experienced services as intentionally limited, in that some of them were on a programme that only allowed them to use hospital for 2 days a month, and that the opportunities for a dialogue with mental health professionals was also limited. provide a reliable time commitment to a service and the people they were treating.

[71] I have also been one of the lucky few who was in the first instant referred to my local hospital, which has very good specialist services such as dual diagnosis, an eating disorders unit, a crisis unit and specialist psychotherapy services for borderline personality disorder. But I was plagued by long waiting lists and being passed from one health professional to another until I was given the right treatment.
Specialist services (and long-term treatment) were viewed by the service users interviewed by Haigh (2002) as the most effective way of treating personality disorders.

[72] An evaluation of 11 community-based pilot sites with dedicated services for people with a personality disorder (Crawford *et al*., 2007)…Specialist services for personality disorder can lead to a strong sense of belonging for many service users due to sharing experiences with other service users and building relationships with staff. Service users also reported that these services tended to have a more positive focus, with staff having more optimistic beliefs about an individual’s capacity for change and more discussions with service users about recovery.

			experiences with other users and building relationships with professionals and more discussions with service users around recovery.[66]				
Attention to physical & environmental needs							
Involvement of, & support for, family & carers							
Continuity of care & smooth transitions						**Barriers to being discharged, change in structure:** Most service users in one study felt that leaving a therapeutic community was difficult. Particularly adjusting from a 24-hour structure to independent living or being required to leave before being ready. The conclusion of the qualitative review also makes an	

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[66] An evaluation of 11 community-based pilot sites with dedicated services for people with a personality disorder (Crawford *et al.*, 2007)…Specialist services for personality disorder can lead to a strong sense of belonging for many service users due to sharing experiences with other service users and building relationships with staff. Service users also reported that these services tended to have a more positive focus, with staff having more optimistic beliefs about an individual's capacity for change and more discussions with service users about recovery.

						important point about endings (of any kind including transfers)….'Leaving a treatment or service is often difficult for people with BPD and can evoke strong emotions as they may feel rejected. It has recognized that a more structured approach to 'endings' is needed. People also felt they would like reassurance that they could access the service again in a crisis.' This conclusion came from the recognition that abrupt, unmanaged endings/transfers a really problematic and work better if they planned in advance, structured and have opportunities for follow and easier re-entry if needed.[74] [75] [76] [77]	

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[74] Morant and King (2003) Some service users returned to dysfunctional patterns of behaviour, struggled to manage relationships with family and friends, and had difficulties in managing the practical issues such as housing and contact with mental health services. Problems reported included depression and anxiety, feelings of isolation and loneliness, and lack of structure - this is from people leaving thereputic care. Service users felt that a more structured approach to 'endings' was needed, and that there should

Stigma	**Improvements to access, education:** It was felt by service users that more education about mental health difficulties should be provided in schools to reduce stigma, to educate	**Barriers in assessment, stigma of diagnosis:** Many users felt stigma was attached to the diagnosis in the form of stereotyping and negative judgment by services and society. [79]		**Barriers in assessment, stigma of diagnosis:** Many users felt stigma was attached to the diagnosis in the form of stereotyping and negative judgment by services and society. [80]			**Barriers to access, stigma of diagnosis:** Some service users felt diagnosis as a way for services to reject them or, in other cases, a way to fix them into categories or labels. [81] [82] [83]

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be some way of retaining a link with the service and/or service users. It was also felt that reassurance was needed that they had the opportunity to restart in a service if a crisis developed. Most service users felt strongly that abrupt endings were unhelpful as they gave little opportunity to prepare and to work through any issues that arose out of it.

[75] Morant and King (2003) Those interviewed also struggled making the move back to a CMHT due to the passive and dependent role CMHTs encourage, in contrast with the responsibility people take for their own care in the therapeutic communities.

[76] Morant and King (2003) Three people were admitted as inpatients during the period covered by the study. However, service users also reported a gradual structuring of daily life and establishing a network of resources. They also reported that the outpatient service helped them to make the transition to independent living.

[77] Hummelen and colleagues (2007) interviewed eight people with borderline personality disorder who dropped out of long-term group psychotherapy following intensive day treatment. The main reasons for dropping out were finding: the transition too difficult from day treatment to outpatient group therapy and bad experiences of the previous day treatment; that group therapy was too distressing—service users reported having strong negative feelings evoked in therapy and feeling that these could not be adequately contained in an outpatient setting; that outpatient group therapy was not sufficient as too much time elapsed between sessions; that service users were unable to make use of the group or were unsure of how the group was meant to work; that service users experienced a complicated relationship with the group and felt that they did not belong; and that there were various aspects of the patient-therapist relationship that were negative (such as therapists not explaining adequately how the group worked, not dealing effectively with criticism and acknowledging the patients' distress). Other service users found it too difficult combining work, study, or parenting responsibilities with therapy. Other reasons stated included a desire to escape from therapy and no interest in further long-term group therapy.

[79] Crawford and colleagues (2007) Some felt that the terminology used was negative (having a 'disordered personality'), that stigma was attached to the diagnosis, and that they were stereotyped and judged by doctors. A proportion of service users also felt it would be helpful if the terminology 'borderline personality disorder' were changed.

	about vulnerability and to teach students how to seek appropriate help if they are experiencing difficulties themselves.[78]						However, one participant in a study said the terminology was an accurate description of his problems.[84]

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[80] Crawford and colleagues (2007) Some felt that the terminology used was negative (having a 'disordered personality'), that stigma was attached to the diagnosis, and that they were stereotyped and judged by doctors. A proportion of service users also felt it would be helpful if the terminology 'borderline personality disorder' were changed.

[81] This judgement was accepted and internalised by some service users, which led to service users in turn rejecting services if they were offered at a later stage. Labels of diagnosis was considered a 'dustbin-label' . Once the diagnosis was recorded, service users felt that the 'label' remained indefinitely and often felt excluded from services as a result. Felt they were being labeled rather than diagnosed.

[82] Service users preferred not to use the term personality disorder and found that the diagnosis led to negative attitudes by staff across a range of agencies and a refusal of treatment.

[83] Crawford and colleagues (2007) Many service users reported being denied services due to the diagnosis.

[78] It was felt by service users that more education about mental health difficulties should be provided in schools to reduce stigma, to educate about vulnerability and to teach students how to seek appropriate help if they are experiencing difficulties themselves.

[84] 'It doesn't particularly disturb me. I don't see any problem because that is exactly what I suffer from—a disorder of the personality

DEPRESSION UPDATE

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 & referral to inpatient care**	**Inpatient care**	**Discharge/ Transfer of care**	
Involvement in decisions & respect for preferences	**Barriers to access, information**: One primary study found a mismatch between how information is offered and how people with depression prefered to seek information. [85]		**Service improvement, more treatment options:** One systematic review found that the majority of service users did not receive information about psychological interventions and different treatment options. One participant commented that the only option given was pharmacology[86] and wanting				

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[85] "Saver and colleagues (2007) described four barriers to accessing help by people with depression. These were characterised as: (1) a lack of motivation because of their depression; (2) stigma associated with depression and/or denial of their diagnosis; (3) healthcare professionals seeming unresponsive; and (4) a mismatch between how information is offered and how people with depression prefer to seek information, for example: "*I would never sit down and read something about medicine. It has never interested me. I learned more from watching that commercial on television."*

[86] "Saver and colleagues (2007) found that less than half of the people with depression reported receiving information about psychological interventions. One participant commented that the only 'option' was a pharmacological treatment: *They just handed me a drug and said go on it right now . . . I felt rushed along, given a prescription, told this will fix it."*

			more psychological interventions.[87]				
Clear, comprehensible information & support for self-care							
Emotional support, empathy & respect	**Barriers to access, professionals:** One study found that professionals were a barrier to accessing help as they were perceived as unresponsive. [88]						
Fast access to reliable health advice							
Effective treatment delivered by trusted professionals			**Effective treatment**, people needed to understand a language and framework of longer-term recovery to tell their own story of improvement; that getting better meant different things				

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[87] "Ridge and Ziebland (2006) in their analysis of interview transcripts collected by Health talkonline found that people with deep-seated and complex problems needed longer-term psychological therapy... The main findings of the study were that people needed to understand a language and framework of longer-term recovery to tell their own story of improvement; that getting better meant different things to different people; and that people needed to assume responsibility for their own recovery. The majority of the interviewees had used and valued talking therapies as a means of gaining insight into their thoughts and feelings."

[88] "Saver and colleagues (2007) described four barriers to accessing help by people with depression. These were characterised as: (1) a lack of motivation because of their depression; (2) stigma associated with depression and/or denial of their diagnosis; (3)healthcare professionals seeming unresponsive; and (4) a mismatch between how information is offered and how people with depression prefer to seek information"

			to different people; and that people needed to assume responsibility for their own recovery[13]				
Attention to physical & environmental needs							
Involvement of, & support for, family & carers							
Continuity of care & smooth transitions							
Stigma	**Barriers to access, stigma of diagnosis:** One systematic review and one primary study found that the stigma of their diagnosis was perceived by service users as a barrier to accessing help.[89]		**Barriers to effective treatment, stigma of medication:** One systematic review found that service users had mixed feelings about taking medication which included a sense of relief because it helped them cope better but they also felt a lack of control and that there was stigma associated with taking medication.[90]				

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[89] "Saver and colleagues (2007) described four barriers to accessing help by people with depression. These were characterised as: (1) a lack of motivation because of their depression; (2) stigma associated with depression and/or denial of their diagnosis; (3) healthcare professionals seeming unresponsive; and (4) a mismatch between how information is offered and how people with depression prefer to seek information"
"Because of feelings of shame and 'lack of legitimacy', people may not have presented their problems in an open manner. There was a possibility that seeking help would 'threaten an already weakened sense of self'"

[90] "Khan and colleagues (2007) found that taking medication could lead to ambivalent feelings: on the one hand, people felt relief because medication helped them cope with difficulties in their day-to-day life; on the other hand, they felt a lack of control. There was also a moral component regarding personal responsibility and the fear of not being able to function in daily life. When the GP or others (family or friends) offered advice to relieve this ambiguity, people

Other themes	**Barriers to access, attitudes:** A lack of motivation characteristic of the depression itself was perceived by service users to be a barrier to accessing help.[91]						

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were more willing to accept medication as a possible treatment, but only on the understanding that it would be for short-term use. People were cautious about telling other people that they were taking medication because of perceived stigma. There was a feeling among the people in the studies that they were in some way 'deficient' because they needed to take antidepressants"

[91] "Saver and colleagues (2007) described four barriers to accessing help by people with depression. These were characterised as: (1) a lack of motivation because of their depression; (2) stigma associated with depression and/or denial of their diagnosis; (3)healthcare professionals seeming unresponsive; and (4) a mismatch between how information is offered and how people with depression prefer to seek information"

DRUG MISUSE: PSYCHOSOCIAL INTERVENTIONS

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 & referral to inpatient care**	**Inpatient care**	**Discharge/ Transfer of care**	
Involvement in decisions & respect for preferences							
Clear, comprehensible information & support for self-care							
Emotional support, empathy & respect					**Facilitators to inpatient care, professionals**: Service users in inpatient treatment reported that building a rapport with key workers motivated them to remain abstinent.[92]		
Fast access to				**Improvements to**			

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[92] (Bacchus *et al.,1999):* Most were able to develop a rapport with their keyworker, which motivated service users to achieve or maintain abstinence for fear of letting him or her down. Befriending and supporting other new service users was also conducive to abstinence maintenance and increased self-esteem, and the independent thinking involved in this role often operated as a marker of self-improvement."

reliable health advice				**referral, waiting times:** Service users in one study reported that the long waiting time to receive inpatient treatment was a barrier to accessing treatment because their motivation to change decreased over time.[93] However, in some cases, users were aware of the high demand in services and were satisfied with the waiting times.[94]			
Effective treatment delivered by trusted professionals							
Attention to							

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[93] "Through semi-structured interviews with 42 people who misuse drugs in receipt of inpatient treatment, Bacchus and colleagues (1999) found that service users acknowledged the high demand for the service and were therefore generally satisfied with pre-admittance waiting times. However, some reported that, during the waiting period, their motivation to cease drug misuse decreased, and continued exposure to drug-misusing friends increased social pressure to maintain use."

[94] (Bacchus *et al.,1999): "*Through semi-structured interviews with 42 people who misuse drugs in receipt of inpatient treatment, Bacchus and colleagues (1999) found that service users acknowledged the high demand for the service and were therefore generally satisfied with pre-admittance waiting times. However, participants perceived the long waiting times to be an obstacle in accessing treatment: *'I'd go with all the intentions to get off it…but the longer you have to wait, the more and more trouble you get in. Eight months is a long time; you don't know what is going to happen to you."'*

physical & environmental needs							
Involvement of, & support for, family & carers			**Service improvement, involvement of families and carers**: A quarter of service users felt that professionals did not offer families and carers enough support.[95]		**Barriers to family support in inpatient care, physical**: Service users with drug misuse problems expressed wanting more support and visits from family, especially for those drug users who were parents. However, in some cases there was an acknowledgement that the inpatient environment was not appropriate for young children.[96]		
Continuity of care & smooth transitions							

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[95] "There is an increasing recognition that drug misuse affects the entire family and the communities in which these families live. The NTA user satisfaction survey found that 25% of respondents felt that staff did not offer families and carers enough support (Best *et al.*, 2006)."

[96] (Bacchus *et al.,1999):* "Service users – and especially parents who misuse drugs – wished to receive more support and visits from family, though some felt the treatment environment was not appropriate for their young children."

Other themes	**Barriers to effective treatment, attitudes:** Some individuals were aware that they needed to be ready and motivated to access treatment and services for treatment to be effective.[97]		**Barriers to effective treatment, process issues**: Service users described methadone scripts to be time-consuming (must be collected daily). This restricted their job opportunities.[98]		**Facilitators to inpatient care, support from peers**: Befriending and supporting other service users was viewed by service users ho misuse drugs to be conducive to achieving and maintaining abstinence. It also increased self-esteem.[99]		

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[97] "Some individuals were aware that they needed to be ready and motivated to access treatment in order for it to be effective: *'You have to actually seek treatment. It's up to them if they want to start…If a person's not ready, they're not ready.' 'My true feeling is that you have to do it for yourself.'"*
Salter and colleagues (2005)*: 'You have to actually seek treatment. It's up to them if they want to start…If a person's not ready, they're not ready.'; 'My true feeling is that you have to do it for yourself.'*

[98] Neal, 1998: "Another common criticism was that being on methadone scripts is very time-consuming, as the script must be collected on a daily basis. For many, this restricts the opportunity to perform a regular job."

[99] Salter and colleagues (2005)*:* "Most were able to develop a rapport with their keyworker, which motivated service users to achieve or maintain abstinence for fear of letting him or her down. Befriending and supporting other new service users was also conducive to abstinence maintenance and increased self-esteem, and the independent thinking involved in this role often operated as a marker of self-improvement."

PSYCHOSIS AND SUBSTANCE MISUSE

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 & referral to inpatient care**	**Inpatient care**	**Discharge/ Transfer of care**	
Involvement in decisions & respect for preferences			**Service improvement, more treatment options:** Service users described the lack of individual talking therapies in treatment to deal with their multiple problems.[100]				
Clear, comprehensible information & support for self-care							
Emotional support, empathy & respect			**Facilitators in services, professionals**: Female service users with co-existing mental health problems and				

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[100] "Once service users were in treatment, many were frustrated at the lack of individual 'talk' therapy to help discuss and heal the trauma incurred from having a mental illness, having a substance problem, and living on the streets."

			substance misuse described the traits of empathy, honesty, encouraging and direct as important aspects for effective treatment.[101]				
Fast access to reliable health advice							
Effective treatment delivered by trusted professionals	**Barriers to access, physical**: Female service users with co-existing mental health problems and substance misuse problems described reduced access to services when there was no available child care.[102]		**Experience of peer support**: Service users in two studies described the importance of peer support in effective treatment; to have someone who can understand them.[103] **Facilitators to effective treatment, key workers:**			**Facilitators to the transfer of care, physical:** Service users in one study described their reasons for adherence to aftercare programmes owing to flexible timing of services and the facilitation of social	**Barriers to effective treatment, cultural**: Service users from minority groups expressed that professionals did not take into account the cultural context of their substance

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[101] "Penn and colleagues (2002) examined treatment concerns for women with coexisting mental illness and substance misuse. The women interviewed emphasised how a person-centred approach facilitates treatment, especially when the clinician embodies traits such as empathy, honesty, and being encouraging and direct. All participants identified that negative staff attitudes"

[102] "Penn and colleagues (2002) examined treatment concerns for women with coexisting mental illness and substance misuse...Childcare services were mentioned as necessary for women accessing treatment, as was support that specifically accounted for women's needs."

[103] "Other participants highlighted the need for support and having contact with others who have experienced similar mental health and substance problems (Turton *et al.*, 2009): *'most of the counsellors there were ex-addicts themselves and I could relate to them, and the things they said because they've been through it'*."
"Many participants interviewed by Vogel and colleagues (1998) mentioned that a mutual support programme was extremely beneficial in enabling people with psychosis and coexisting substance misuse to share similar experiences and providing a non-judgemental atmosphere in which they could discuss problems. The support group increased participants' optimism, brought them comfort and changed their attitudes towards taking their mediation (Vogel *et al.*, 1998). "

			Service users in one study described their key worker as an important part of effective treatment as they allowed access to local counselling services or alternative treatment options.[104]			activities.[105]	use and that there was an inconsistent cultural awareness among professionals.[106]
Attention to physical & environmental needs							
Involvement of, & support for, family & carers							
Continuity of care & smooth			**Barriers to effective treatment, service**				

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[104] "When participants were asked about their most positive experience of services in the UK, they highlighted having a key worker (for example, a social worker) with whom they have a good relationship, in addition to accessing local counselling services or alternative treatment options (for example, spiritual services or specific cultural support groups) (Warfa *et al.*, 2006). These services and options were seen as integral to their progress in treatment."

[105] Pollack and colleagues (1998) interviewed inpatients with psychosis and coexisting substance misuse about the factors that affected their attendance in an aftercare programme. Self-help meetings (for example, Alcoholics Anonymous [AA]) were easier to attend because of the flexible timing and the fact that they facilitated social activities: *'Just being around the other people, you know, I've pretty much alienated everyone due to my drug addiction and alcohol…so it provides me the opportunity to…generate a new relationship'. 'I found that it was a joy to go and share my daily achievements with a group of people that knew my condition because their own condition was so similar'.*

[106] "One UK study (Warfa *et al.*, 2006) looked at drug use (specifically cannabis and khat[106]) in black and minority ethnic (BME) groups. Whereas East African communities showed that use of khat was linked to their culture, cannabis was seen as entangled with religious uses for black Caribbean populations. Participants in the study stated that the cultural context of their substance use was not taken into account by healthcare professionals. Some participants in the study mentioned that their clinics or clinicians exhibited cultural awareness, while others felt that there needed to be increased cultural and religious sensitivity within services in the UK (Warfa *et al.*, 2006)."

transitions			**organisation**: Staff turnover and a lack of co-ordination between services was judged to be a barrier to effective treatment progress.[107]				
Stigma	**Barriers to access, stigma of diagnosis**: People with psychosis and substance misuse problems described the stigma associated with their problems which hindered their recovery and was a barrier to access and engagement. A minority expressed the positive aspects of their diagnosis.[108]		**Barriers to effective treatment, stigma of medication:** Three studies described reasons for service-users' non-adherence to medication which included service users expressing that they did not need medication in the first place or that they did not have a mental illness, the side effects of				

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[107] "Penn and colleagues (2002) examined treatment concerns for women with coexisting mental illness and substance misuse. The women interviewed emphasised how a person-centred approach facilitates treatment, especially when the clinician embodies traits such as empathy, honesty, and being encouraging and direct. All participants identified that negative staff attitudes or changes in the service significantly hindered their treatment progress (for example high staff turnover, lack of coordination between services, feeling judged)."

[108] "Dinos and colleagues (2004) interviewed service users in community and day mental health services in London in an attempt to describe the relationship of stigma to mental illness and the consequences of stigma for the individual. One significant theme that emerged for participants with a psychosis and coexisting substance misuse was anxiety surrounding managing information regarding both their illnesses, and issues of disclosure (whether to disclose to friends, family and prospective employers). Overt discrimination from others was experienced by most of the participants in this study, typically in the form of verbal or physical harassment, or through actions such as damage to property. Those with a coexisting mental illness and substance misuse reported having been verbally abused and patronised more frequently than those with other diagnoses. People with psychotic disorders experienced physical violence, as well as reduced contact with others. They also felt that they had been discriminated against in that they had not been selected by educational

			medication, the stigma associated with medication and the concern that the medication would not allow them to have control over their symptoms.[109]				

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institutions or employers due to their diagnosis. As a result, most participants felt fearful, anxious, angry, and depressed, as well as isolated, guilty and embarrassed. These feelings resulting from stigma were a significant hindrance to recovery and a barrier to seeking help: *'It makes you feel bad.. it makes you feel even worse… when people don't trust you and think you're going to do something to someone.'* On the other hand, many participants reported positive aspects to having a mental illness, expressing relief that they had a proper diagnosis and appreciating their treatment: *'I feel that if I survive it I've been through a very privileged experience and that I can actually make something of it…'*"

[109] "Service users in the study by Warfa and colleagues (2006) found that medication for their psychosis works for them and generally improved their mental health. However, antipsychotic medication typically is associated with negative perceptions and, consistent with this view, the Wagstaff (2007) study found that the most common reason for participants to cease taking their psychotropic medication was that they did not perceive themselves as requiring medication in the first place. Costain (2008) found that many participants had side effects from their antipsychotic medication, and when participants also had anxiety symptoms, they stopped taking their medication and increased their cannabis use. The reasons for non-adherence to medication were varied. Many felt that adherence to medication would not enable them to have control over their symptoms (for example, delusions). Others did not perceive they had a mental illness and therefore the medications were irrelevant (Costain, 2008). "
"Pollack and colleagues (1998) found that participants cited symptom improvement as the bigger driver for adhering to their medication, however the side effects and potential to be stigmatised because of the need for medication were a concern."

SELF-HARM

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**	
Involvement in decisions & respect for preferences		**Barriers to assessment, time & involvement:** Service users expressed their disappointment when the assessor did not give them sufficient time to talk during the assessment and involve them in the process.[110]	**Service improvement, service user involvement:** Service users said they were not able to play an active role in treatment. Some felt treatments were forced upon them and were not listened to when they expressed that certain treatments were not helpful for them. Service users want more			**Facilitators to the transfer of care, service user involvement:** Service users acknowledged that it was important that they were included in the planning of their aftercare.[113]	

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[110] Whitehead, 2002: "assessment was experienced negatively when the participant felt devalued by the assessor, was treated in a judgemental manner or they felt they were not understood. Similarly, patients who reported being disappointed with their psychosocial management found fault primarily with their lack of involvement in decisions or when the assessor did not give them sufficient time to talk during the assessment (Whitehead, 2002).
'O.K. The first interview was just "so tell us what happened" and he wrote it up and said "um hm, um hm" and wrote notes and he didn't look at me but he was nodding and looking at the other guy. And they looked at each other and exchanged nods. It was very factual like "So what did you take?" and "What happened at the house?" Um, you know I felt like saying "I can understand English, doctor". It was just very factual. They filled out their little form and that was it (p.8).'"

			responsibility to manage their care.[111] This hindered the relationship between them and the professional.[112]				
Clear, comprehensible information & support for self-care		**Facilitators to assessment, information:** Service users expressed that having information led to a more positive view of assessment for many.[114]	**Barriers to community care, information:** Service users wished they knew about types of support services before they self-harmed.[115] Users recommend				**Barriers to services, information:** Service users viewed inadequate sharing of information by professionals with

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[113] "However, not all participants welcomed the opportunity. Similar to adults, the need for their inclusion in planning their treatment was highlighted as an important issue for aftercare (Bolger *et al.*, 2004). Over half of the participants could think of other types of help they would like to have received but had not. These included admission to hospital, individual rather than family appointments and specific help with school problems."

[111] Harris and colleagues (2000): ". Many said they were not given the opportunity to play an active role in their treatment. In particular, patients perceived that treatments had often been given or forced upon them without any information as to why this was being done."
" Huband & Tantam (2007) the women reported 'being taught relaxation techniques' was experienced as the least helpful. Indeed, many reported that relaxation actually had the potential to make their self-injury worse, but they had been unable to convince staff that this was so."
"Patients said they wanted staff to give them more responsibility for themselves and their management (Bywaters & Rolfe, 2002; Whitehead, 2002)."

[112] Fish and Duperouzel, 2008: "Clients also identified a lack of control over their treatment as a negative aspect of the relationship.
'...I wanted to go to a meeting that's discussing my future or what possibly could happen in my future. And they said no., clients are not allowed. I think that's badly wrong...' (Fish and Duperouzel, 2008, p. 14) Conversely, service users reported that when staff spent time with them one-to-one and they demonstrated a caring attitude and most importantly recognised their individuality, this has a positive effect."

[114] "Participants had a more positive experience of assessment when they were given information about it beforehand (Crockwell & Burford, 1995)."

			information be available on self-harm.[116]				them as a significant problem. [117] **Barriers to self-care, support:** Service users were often provided with contact numbers for organisations in place of, or in addition to, a referral. Service users felt uncomfortable initiating their own self-care.[118]

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[115] For instance, many study participants were unaware of local services that provide support to individuals who self-harm (Bywaters & Rolfe, 2002). Adolescents wished that prior to taking the overdose they had access to the type of professional help that they had subsequently received (Burgess *et al.*, 1998).

[116] Common suggestions for service improvement included enhanced continuity of care and specialised training and education on self-harm, along with the provision of better information about self harm for service users and carers (Arnold, 1995; Bywaters & Rolfe, 2002; Carrigan *et al.*, 1994; Dower *et al.*, 2000; Horrocks *et al.*, 2005; Whitehead, 2002).

[117] Carrigan and colleagues (1994): "Carrigan and colleagues (1994) revealed many problematic issues with regard to communication with professionals. Specifically, inadequate sharing of information by medical staff with patients was perceived as an important problem."

[118] "In another study (Hume & Platt, 2007) participants were often provided with contact numbers to helping organisations in place of, or in addition to, a referral. Although the majority of participants made use of these numbers, some explained they felt uncomfortable initiating their own aftercare by dialling these organizations. Although the majority of participants made use of these numbers, some explained they felt uncomfortable initiating their own aftercare by dialling these organizations. Moreover, several patients from this study were anxious to impress on their friends, family and, in some cases, professionals the importance of managing self-harm rather than its prevention."

Emotional support, empathy & respect	**Barriers to access, attitudes towards professionals:** Service users' who did not self help described in one study how confidence and trust were important in order to seek help but how they would not ask strangers for help or support including professionals[119]. **Barriers to access, stigma:** Service users in one study described a barrier to seeking help is disclosing to others about self-harm; there is a fear that others would not understand and for fear of being labelled.[120]	**Facilitators to assessment, professional:** Service users described assessment to be a positive experience when there was engagement with the professional and when it involved restoration of hope/circumstance.[121] **Barriers to assessment, professionals:** This was experienced when participants felt devalued by the assessor, was treated in a judgemental manner, felt they were not understood, were not involved in the process.[122]	**Barriers to community care, stigma by professionals:** Mental health services were characterized as judgmental and lacking understanding of service users' problems.[123] Professionals who see beyond diagnostic labels were specifically valued by some service users.[124] **Barriers to services, professional:** Service users reported on barriers that hindered their relationship with the professional including: when		**Barriers to inpatient care, professionals**: Service users felt a lack of rapport with staff.[130] In some cases, patients felt they needed to act in exaggerated ways to get the attention of professionals.[131]	**Barriers to the transfer of care, professionals**: Service users stated in two studies that aftercare was often not arranged or acknowledged by service staff which led to feelings of abandonment.[132]	

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[119] "Confidence and trust are also important conditions for seeking and accepting help (Schoppmann *et al.*, 2007). The participants described that they would not ask strangers for help or support, for example, an unknown nurse during a night/weekend shift, because for them strangers are an equivalent to someone who cannot do anything, someone from whom help is not to be expected." "In a German study (Schoppmann *et al.*, 2007) participants conveyed the importance of personal relationships and confidence in the intervening person, especially if physical contact is involved: *'If there would be someone with whom I have no trusting relation I would of course not allow a touch, I would not say a word, I would not show a feeling. Nothing! Only someone I trust.'* (Schoppmann *et al.*, 2007, p. 594)"

[120] "Stigma also emerged as an important barrier to seeking help and disclosing to others about their self-harm (Ray, 2007). While all women reported trying to hide the fact of their self-injury, some alluded to the hidden wish that others would acknowledge their distress and care enough to reach out to them in a

supportive and accepting manner. The women appeared quite inhibited in their ability to reach out to others for fear that others would not understand and for fear that they would be labelled as attention seekers."

[121] "Participants experienced assessment positively when it involved a beneficial, hopeful engagement with the staff member and when it involved the restoration of hope or the possibility of change in the individual's circumstances (Hunter & Cooper, unpublished; Whitehead, 2002)."

[122] Whitehead, 2002: *'O.K. The first interview was just "so tell us what happened" and he wrote it up and said "um hm, um hm" and wrote notes and he didn't look at me but he was nodding and looking at the other guy. And they looked at each other and exchanged nods. It was very factual like "So what did you take?" and "What happened at the house?" Um, you know I felt like saying "I can understand English, doctor". It was just very factual. They filled out their little form and that was it (p.8).'* Similarly, Hunter and colleagues (unpublished) found that another negative aspect of assessment seemed to be the experience of not being understood, or when staff did not seem interested or genuinely engaged in trying to understand the individual reasons behind their self-harm. . Hunter and colleagues (unpublished): ssessment as invalidating and when assessment seemed to lead nowhere and offer no hope for change, it was experienced negatively and could compound the participant's initial feelings of hopelessness, powerlessness and low self-worth. "Whitehead, 2002: "assessment was experienced negatively when the participant felt devalued by the assessor, was treated in a judgemental manner or they felt they were not understood. Similarly, patients who reported being disappointed with their psychosocial management found fault primarily with their lack of involvement in decisions or when the assessor did not give them sufficient time to talk during the assessment (Whitehead, 2002).

[123] Baker and Fortune (2008): "In a study carried out by Baker and Fortune (2008), family, friends and wider society, including medical and mental health services, were often explicitly characterised as judgmental and lacking understanding."

[124] Shaw, 2006: "In a US study conducted on female college students (Shaw, 2006), core aspects of treatment women described as helpful in their passage toward stopping self-injury include an empathic relationship with a professional who sees strengths beyond diagnostic labels and provides an opportunity to discuss self-injuring behaviour."

[130] Arnold, 1995. One participant described a psychiatrist as *'cold, clinical, [and] impersonal'* (Arnold, 1995 p.18). In as study carried out by Taylor (2003) several of the male participants had experienced negative incidences with psychiatrists. Comments included *'I don't see them unless I absolutely have to'* and *'I made a firm decision not to ever see him again'*. The only positive assessment of support from a psychiatrist I encountered was a man who said of his second psychiatrist:

[131] "Patients also explained that, while on a psychiatric ward, they sometimes felt the need to act in exaggerated ways, and even self-harm, in order to get the attention of staff (Bywaters & Rolfe, 2002)."

[132] "Harris and colleagues (2000)... Finally, some people felt that their need for help was not acknowledged, particularly after no aftercare was arranged."

			professionals could make them feel that they did not care about their distress; were slow to respond; were dismissive of personal problems or were perceived; as uncaring[125] [126] **Facilitators to community care, professional:** Service users reported that they wanted professionals that spent time with them one to one; demonstrated a caring attitude; and				

"Horrocks and colleagues (2005) found that many service users experienced long delays before receiving any aftercare treatment and this led to many feeling disoriented or abandoned"

[125] Fish and Duperouzel (2008) examined the experiences of people with mild-moderate learning disabilities who self-harm. The key theme throughout the interviews was staff-client relationships (both negative and positive aspects), and the way they affect individual ability to cope with stress, emotion and urges to self-harm. Clients reported that staff could make them feel that they did not care about their distress when they were slow to respond to their distress, were dismissive of their personal problems or were perceived to be uncaring. *'I feel that nobody cares, and when you talk to them, it's "Oh, wait a minute". And when the minute comes it's, like, "I've not got a minute now, I'm doing this now" or "I'm doing that now". In the end you just go in your room and do [self-injure], instead of saying I feel like doing it...'* (Fish and Duperouzel, 2008, p. 13)
"Patients often felt a lack of rapport between themselves and staff members and a general lack of continual support (Horrocks *et al.*, 2005)."

[126] "The importance of staff tact and respect for patient's individuality was another aspect of care that patients expressed as necessary for service improvement (Carrigan *et al.*, 1994; Whitehead, 2002)."

			recognised their individuality[127]; were direct, proactive, and genuine[128] and did not focus on the physical disfigurements as a result of the self-harm.[129]				
Fast access to reliable health	**Improvements to access,** accessibility :						

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[127] Fish and Duperouzel, 2008; Many of the participants noted that simply talking during sessions was helpful - (Craigen and Foster, 2009). Craigen and Foster, 2009: most of the women emphasised that it was important for the counsellor to be nonjudgmental. Where people felt positive and satisfied with services, this was usually due to the compassionate support offered by individuals (Arnold, 1995). Likewise, Bywaters & Rolfe, (2002) found that overall, service users were more satisfied with their treatment when they felt that the professional was genuinely concerned about them, respected them and did not try to belittle them. Similar to women, many men prioritized the opportunity to talk about their self-harm and to feel understood by staff (Taylor, 2003). In contrast, some service users explained that the lack of opportunity to become involved in discussions about their care made them feel disrespected. Furthermore, respect for the young person and the opportunity to build trusting relationships with professionals were important aspects identified as a major factor in their receptiveness of an intervention (Crockwell & Burford, 1995; Sinclair & Green, 2005

[128] Ray, 2007: Similar to women, many men prioritized the opportunity to talk about their self-harm and to feel understood by staff (Taylor, 2003). In contrast, some service users explained that the lack of opportunity to become involved in discussions about their care made them feel disrespected. One man in particular, commented that his team worker had: *'never asked questions like you've asked me…[s/he] never asks me about self-harm, even after times I've done it'*. This had left him feeling that his self-harm was *'not taken seriously'*, which increased his anger and propensity to self-harm again (Taylor, 2003).
In a study carried out by Ray (2007) the importance of professionals taking self-injury seriously and acknowledging the depths of the self-injurer's pain was highlighted. In particular, the women expressed a preference for practitioners who were direct, proactive, and genuine. For most women, negative experiences with therapy appeared to stem from perceptions of therapists as judgmental, unable to relate, and lacking in knowledge about self-injury (Ray, 2007).

[129] *'Look at the individual, not the harm. Look at the person beyond the scars. Scars aren't important. It's the person that did them that's important'* (Bywaters & Rolfe, 2002, p. 41)

advice	Across two studies service users described how service could be more accessible. Suggestions included 24-hour staff, walk-in services, minimal waiting times, central location and telephone access.[133]						
Effective treatment delivered by trusted professionals		**Experience of lack of assessment:** Four studies found that not all service users received a psychosocial assessment while in hospital. And for those service users that did, they had varied experiences across studies.[134]	**Barriers to the therapeutic relationship**: For service users receiving psychological therapy they found that a therapist who failed to demonstrate understanding and who forced uninvited ideas upon them were		**Barriers to inpatient care: constant observation:** Service users in two studies described their negative views on constant observation to be distressing and intolerable (while others felt safe and a reduction of risk)[140] Service users in the study felt they were merely being		**Service improvement, professional training: Across several studies it was recommended that professionals gained more training in self-harm and in how to deal with patients who had self- harmed.[142]** **[Experience of**

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[133] "Several participants felt it was essential that services be as accessible as possible by being staffed 24 hours a day, providing walk-in services and minimal waiting times for appointments (Bywaters & Rolfe, 2002).""Adolescents, in particular, had a variety of suggestions about how services could be made more accessible for young self harmers. It was suggested that services be centrally located. Walk-in services and telephone access as well as decreased wait time for appointments were recommended."

[134] "Four studies investigated the views of service users with regard to psychosocial assessment (Crockwell & Burford, 1995; Horrocks *et al.*, 2005; Hunter & Cooper, unpublished; Whitehead, 2002). From these four studies, it was clear that not all patients received a psychosocial assessment while in hospital. And for those service users that did receive an assessment after a self harm episode their experience varied across studies."

			viewed negatively.[135] **Facilitators in the therapeutic relationship:** For service users receiving psychological treatment, facilitators included professionals who were respectful listened and were understanding.[136]		watched when in inpatient care rather than receiving any therapy for self-harm.[141]		**websites for peer-support:** Websites that offered a source of peer-support were valued by service users and were viewed as an important coping strategy.[143]]

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[140] "Only two studies looked at the experience of constant observation whilst on a psychiatric ward, both from the US and both in adult populations (Cardell & Pitula, 1999; Pitula *et al.*, 1996). In the study carried out by Pitula and colleagues (1996) on suicidal inpatients, service users' initial responses to constant observation ranged from discomfort to surprise or anger. On the other hand, study participants reported feeling safe because of the physical presence of observers who could prevent them from responding to self-destructive impulses. Participants reported that the lack of personal privacy was the most distressing aspect of constant observation. In fact, patients said that constant observation became almost intolerable after 30 – 36 hours."
"Cardell & Pitula, (1999) Moreover, a significant proportion of patients reported that their dysphoria, anxiety, and suicidal thoughts were decreased by observers who were optimistic, who provided distraction with activities and conversation, and who gave emotional support."

[142] "Common suggestions for service improvement included enhanced continuity of care and specialised training and education on self-harm, along with the provision of better information about self harm for service users and carers (Arnold, 1995; Bywaters & Rolfe, 2002; Carrigan *et al.*, 1994; Dower *et al.*, 2000; Horrocks *et al.*, 2005; Whitehead, 2002)."
"Several service users felt that hospital staff failed to address the underlying issues and did not have sufficient knowledge about DSH, or training in how to deal with patients who had self- harmed (Arnold, 1995)."

[135] "Craigen and Foster (2009) examined the counselling experiences of 10 young adult women with a history of self-injurious behaviour. For those interviewed, the most helpful counsellor behaviours were respectful listening, understanding, and acting as a friend. Furthermore, the women also discussed behaviours that they viewed to be unhelpful which included such things as counsellors who failed to demonstrate understanding and counsellors who forced uninvited ideas upon them."

			Barriers to effective treatment, undue focus on self-harm: No-harm contracts and the rigid focus of some therapies on stopping self harm were viewed by service users as ineffective. Rather than focusing on harm, they valued treatment that targeted underlying issues.[137]				

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[136] Craigen and Foster (2009); Hood, 2006, p. 89 - Other participants explained that their relationship with their therapist made them feel '*acknowledged*', '*heard*', '*cared for*', '*reassured*', '*supported*' and '*understood*'. A positive relationship between patient and therapist was often associated with perceived positive outcomes by the patient. Reece (2005) expressed a need to be accepted and to be listened to. In particular, they articulated a desire for staff to *'reach out'* to them as individuals and give them an opportunity to express their *'inner torment'* and pain.

[141] Bywaters & Rolfe, 2002

[143] Baker & Fortune, 2008. - Interacting with fellow users was reported as a preferable alternative to self-harming and suicidal behaviours. Participants also wrote about the sites as contributing to their recovery. One reported that the sites had facilitated change *'better than any therapy.'*
"In a US study (Adler & Adler, 2007) the majority of people who had self-injured for a long period had no intention of ever stopping. Others wanted to quit, but recognised its benefits as a coping mechanism and a means of self-expression. Yet, for a small minority their self-harm subsided after many years, either through therapy or with the help of online peer support and education. Many of these people remained in online communications, helping others, as a way of maintaining their abstinence."

[137] "Almost without exception, the participants considered no-harm contracts ineffective (Craigen and Foster, 2009). *'I won't make a promise unless I can keep it. Or, I try not to. I need to feel a deep sense of obligation to that person and that particular cause to make that promise. So that wouldn't have worked for me.'* (Craigen and Foster, 2009, p. 84). Another alluded to the potential dangers of using no-harm contracts. She suggested that counsellors need to provide their clients with new improved coping skills before making them stop using their old coping skills. In terms of the focus of treatment, participants did not like counsellors putting too much emphasis on the self-injurious behaviour. Rather, they reflected about the value of counselling that targeted the underlying issues. Asked what they would tell counsellors working with college-aged women who self-injure, most of the women emphasised that it was important for the counsellor

			Facilitators to effective treatment, consistent key workers: Having a long-term relationship with one key worker was seen as a facilitator for effective treatment.[138] **Barriers to effective treatment, attitude towards medication:** Service users in four studies reported their views n medication and found medication to be helpful to cope with their underlying problems.[139]				

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to be nonjudgmental. One said, *'I think the bottom line is to just try not to alienate them further. Because there is already the knowledge that what you are doing is very bizarre and not normal, and you need to be careful of inadvertently stigmatizing them further.'* p. 87" "Shaw (2006) on female college students in the US, opinions of psychological treatment varied dramatically with respect to the level of structure they found helpful. Some favoured more directive treatment programmes such as DBT as it provided structure and support, whilst others favoured more client-centred approaches which were unstructured and did not put excessive pressure on individuals to stop self-harming."

[138] Huband & Tantam (2007): "Similarly, in a study carried out by Huband & Tantam (2007) the women reported on a number of management strategies and their helpfulness. 'Having a long-term relationship with one key worker' and 'expressing feelings about the past' were rated overall as the most helpful methods of managing their self-wounding."

[139] Four studies examined service user experience of medication (Hood, 2006; Kool *et al.*, 2009; Shaw, 2006; Smith, 2002). Hood (2006) examined the perspective of several adolescents recruited from community mental health centres in New Zealand with regard to their feelings regarding medication and established that views were mixed. The majority (n =6; 60%) of adolescents interviewed were prescribed antidepressants as part of their management. On the

Attention to physical & environmental needs			**Barriers to services, lack of privacy:** Some service users felt that the lack of privacy in treatment rooms, particularly in waiting rooms, was a barrier to treatment.[144]		**Barriers to inpatient care, physical:** Some female service users feared being on a mixed ward and some older, adolescent patients had negative experiences of being placed on adult wards.[145]		
Involvement of, & support for, family & carers							
Continuity of care & smooth transitions						**Service improvement, continuity of care:** Six studies discussed service users	

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one hand, service users reported that medication helped them cope with their underlying problems; however, not all participants had a positive attitude towards medication especially at the beginning. ‘*I absolutely hated taking my medication when I first started a couple of years ago. Then it became part of my life and a part of being able to live so I just don't get all down about things… I don't know how it works but I mean I know the medication's always an option for me now so if things start to get bad and stay bad then it's here.* (p.98)’ Some adolescents felt that the medication did not work for them and had many undesirable side effects. ‘*[B]eing on medication I didn't deal with things or just had trouble with my memory for a while. I didn't know what day of the week it was…I just had no idea where I was or what was happening…* (Hood, 2006, p.99)’. In another study carried out on adults (Smith, 2002) in the UK a more negative view of medication was observed with service users reporting that they felt that medication was seen as a means of shutting them up. Similarly, in a study carried out in the Netherlands (Kool *et al.*, 2009), many participants felt that their emotions were subdued by the medication and as a result they lost their sense of connection with themselves and others. On the other hand, some participants found medications effective in addressing symptoms such as anxiety (Kool *et al.*, 2009; Shaw, 2006).

[144] “Other important barriers to treatment were highlighted by a study conducted by Harris and colleagues (2000). Firstly, some service users said treatment rooms did not provide privacy, either due to the location of treatment, for example in a waiting room, or lack of respect given by medical staff, for example showing patient off to other members of staff.”

[145] Hood, 2006: However, this was a very small sample size of only ten participants of which only five were female.

						wanting more enhanced continued care and the lack of currently available continued care. The lack of continuity of care impacted negatively on their attitudes towards future help-seeking and towards themselves. [146]	
Stigma	Barriers to access, attitudes: Two studies described service users' views on seeking help which acted as a barrier to accessing services. Seeking help was viewed by a minority in one study as unacceptable; service users viewed themselves as strong enough to handle the problem on their own; that the problem would		**Barriers to effective treatment, stigma of psychological therapy:** Stigma associated with psychological therapy caused some service users to miss appointments.[148]				

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[146] "Other adolescents reported that psychiatrists were often unavailable for continued care because they were too busy, or had left the service during the adolescent's treatment period (Hood, 2006).""Hunter and colleagues (unpublished), participants lack of continuity of aftercare impacted negatively on their attitudes towards future help-seeking and towards themselves." "Common suggestions for service improvement included enhanced continuity of care and specialised training and education on self-harm, along with the provision of better information about self harm for service users and carers (Arnold, 1995; Bywaters & Rolfe, 2002; Carrigan *et al.,* 1994; Dower *et al.,* 2000; Horrocks *et al.,* 2005; Whitehead, 2002)."

	resolve itself; that no one could help.[147]						
Other themes			**[Experience of peer support:** Peer support was valued by service users as it put them in touch with other people like them.[149] The sharing of experiences emerged as a valued aspect of group-membership by service users.[150]]				

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[148] *'I hated it. Couldn't stand the psychiatrist... Just thought "I must be crazy" that's all that came into my head. That's what I thought "if you see one of them, you're crazy".* (p.10)' Crockwell & Burford (1995)

[147] "Chowdhury, 1973; Nada-Raja *et al.*, 2003; Ray, 2007; Schoppmann *et al.*, 2007). Kreitman & Chowdhury (1973) recruited individuals attending hospital for the first time after a suicide attempt in Edinburgh and carried out individual semi-structured, face-to-face interviews to investigate attitudes to help seeking after completion of formal psychiatric examination. Most of the participants were in favour of seeking help with the most 'acceptable' form of help being specialized services followed by anyone available, no-one and lastly relatives. However, a quarter maintained that seeking help for personal problems was not an acceptable form of behaviour. It must be noted however, that as this study was carried out in the 1970's and therefore the attitudes towards help seeking and services may have changed substantially since, placing limitations on the generalisability of the findings reported."
"...for those who did not seek help attitudinal barriers such as thinking they should be strong enough to handle the problem on their own; thinking the problem would resolve itself; thinking that no-one could help or being too embarrassed to discuss it with anyone (Schoppmann *et al.*, 2007)."

[149] *'The fact that you talk to other people and there were other people who felt exactly the same as you, no matter what state they were in, no matter what part of life they came from, there were people that felt like you. It felt good to feel that you weren't on your own* (Bywaters *et al.*, 2002, p. 33)'

[150] Corcoran *et al.*(2007): involved a sense of *'genuine empathy'* derived from all participants having self-injury in common. Participants often realised that, contrary to previously held beliefs, their experiences were shared by many others, which increased feelings of self-acceptance, thereby reducing feelings of isolation and subsequent desire to self-injure arising from such feelings. Despite this, many participants felt that the depth of sharing could be compromised

			[**Experience of Dialectic behaviour therapy (DBT):** Positive experiences of DBT were reported by service users in two studies including the cognitive and behavioural skills learned. Others favoured more client-centred approaches that were less unstructured. [151]] **Preference for community care:** Service users expressed a preference for specialist community-based				

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by the low frequency and time restraints of meetings, sometimes preventing deeper exploration of issues. ‘Autonomy’ emerged as important, primarily in the group being ‘led and run by the participants themselves’. Positive feeling’ emerged as a common experience and led to improved mood and light-heartedness, particularly in relation to their self-injury.

[151] “Two studies in particular (Perseius *et al.,* 2003; Shaw, 2006) examined people’s satisfaction with dialectical behaviour therapy (DBT). Specifically, it was revealed that the majority of participants reported positive experiences of DBT. The patients believed the cognitive and behavioural skills they learned in the therapy to be crucial tools in conquering suicidal and self-harm impulses (Perseius *et al.,* 2003). When asked about the effective components of the therapy a number of elements were found useful such as the confirmation and respect received, the level of focus on specific problems, responsibility, challenge and group therapy among others. Many participants expressed that DBT gave them the opportunity to take responsibility for their behaviour and be involved in their treatment (Perseius *et al.,* 2003). In the second study carried out by Shaw (2006) on female college students in the US, opinions of psychological treatment varied dramatically with respect to the level of structure they found helpful. Some favoured more directive treatment programmes such as DBT as it provided structure and support, whilst others favoured more client-centred approaches which were unstructured and did not put excessive pressure on individuals to stop self-harming.”

			intervention that had immediate aftercare and acknowledged that self-harm may not necessarily involve its prevention.[152]				

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[152] "Hume and Platt (2007) found that patient's experiences of therapeutic interventions were strikingly diverse. There was a clear preference for specialist community based interventions, which focus on the provision of immediate aftercare and an acknowledgement that the management of self-harm may not necessarily involve its prevention.""Several adolescents who presented at hospital after a self harm episode (Hood, 2006) said they experienced a sense of relief upon being provided with aftercare at a community mental health service."