

Patients' experience of dangerous and severe personality disorder (DSPD) services: qualitative interview study

Table DS1 Sample characteristics compared with the full IDEA sample

Socio-demographic characteristics	Full IDEA sample N=168		Qualitative IDEA sample N= 60	
Mean age at IDEA Index Date (s.d)	37.6	(8.9)	36.9	(8.1)
Country of birth UK	159/167	(95.2%)	57	(95%)
Ethnic group White	151/167	(90.4%)	55/60	(91.7%)
Received special education	73/154	(47.4%)	20/54	(37%)
Referring location <i>Prison</i>	148	(90.8%)	51	(86.4%)
<i>High secure hospital</i>	11	(6.7%)	5	(8.5%)
<i>Other</i>	4	(2.4%)	3	(5.1%)
Mean age at first psychiatric contact (s.d)	20.2	(9.6)	19.7	(8.9)
Mean age at first psychiatric admission (s.d)	24.5	(9.1)	27.3	(10.5)
Mean age at first MHA* detention (s.d)	28.6	(10.7)	31.1	(12.4)
No. of psychiatric hospital admissions (%)	(n = 157)		(n = 60)	
None	78	(49.7)	29	(48.3)
One or more	79	(50.3)	31	(51.7)
Mean years in psychiatric hospital care (s.d)	2.5	(5.3)	2.3	(4.8)
Current legal status <i>Mental Health Act</i>	67	(40.1%)	29	(48.3%)
<i>Life sentence</i>	76	(45.5%)	25	(41.7%)
<i>Indeterminate</i>	3	(1.8%)	0	0
<i>Determinate</i>	21	(12.6%)	6	(10%)
Mean no years tariff (s.d)	10.6	(5.6)	11.9	(5.8)
Current index offence	(n = 167)		(n = 60)	
<i>Homicide</i>	42	(25.1%)	16	(26.7%)
<i>Other violent</i>	69	(41.3%)	21	(35%)
<i>Sexual</i>	47	(28.1%)	20	(33.3%)
<i>Other</i>	9	(5.4%)	3	(5%)
Age at first conviction (s.d)	15.0	(3.4)	15.0	(3.2)
Age at first custodial offence (s.d)	18.5	(4.6)	18.5	(4.0)
Mean no. of convictions (inc. index offence) (s.d)	14.2	(11.0)	13.9	(11.4)
Total years duration in custody (s.d)	12.7	(7.9)	12.4	(7.5)
Mean PCL-r Score (s.d)	28.1	(4.6)	28.4	(4.5)
IPDE: mean no. of PD diagnoses per patient (s.d)	(n = 144)		(n = 52)	
	2.2	(1.4)	2.4	(1.4)
Mean IQ Score (s.d)	(n = 119)		(n = 49)	
	94.2	(17.0)	98.9	(16.5)
DSM III diagnoses of learning disability	(n = 116)		(n = 42)	
	8	(6.5%)	2	(4.8%)

Online supplement 1 Summary analysis of main participant concerns and impact on engagement with the programme

Waiting for something to happen

The majority of participants talked of spending time waiting for time to pass or waiting for something to occupy them. The daily routine across the four sites differed including whether time was spent on their own or in communal areas, but the sense of time spent waiting for something to happen, and the negative impact that had, was pervasive across the interviews.

"One group's taken up in the morning, one group's in the same afternoon, one-to-ones the following one. There's three sessions out of ten. You've got seven sessions you're doing nothing.... They need more stuff to alleviate the boredom." (Whitemoor)

"It has an impact on us cos if you're having any kind of problems or you're in a situation that you don't think you can deal with yourself and you can't talk to one of your peers about it, and the staff ain't there. Or the staff are busy, so what you gonna do? You're just gonna sit on it, you're gonna vegetate on it all day. One problem's gonna go up to another problem, to another problem." (Broadmoor)

"You seem to be constantly waiting for something, there's a lot of idle time where you're sitting around all day doing very, very little and this leads, I believe, to a lot of problems that we're getting..." (Rampton)

"any environment like this where you're sitting about and doing nowt,... eventually what'll happen is the anxiety will build up, and eventually they'll just want to kick off" – Rampton

"It's always the same thing. You're waiting to go on something. And, you're motivation just goes out of the window. I'm waiting and waiting and waiting. I ain't going anywhere. Forget it. Forget it. Just pull out of it, don't do it." - Broadmoor

"The inmates are here for 7 days a week, 52 weeks in a year and it's the same old thing, there's nothing to do. Like today I emptied my bin liners and that's it, that's my day done." - Whitemoor

Being Occupied

All participants spent the vast majority of their time outside formal treatment sessions, and gave full accounts of the activities they used to occupy this time. The most common were unstructured solitary entertainments included watching TV or videos, playing computers,

various hobbies and letter writing. Depending on the unit regime these occurred whilst locked in their room/cell or participants chose to stay there despite being able to access communal areas. Activities linking them with the outside world, such as visits or telephone calls were much less frequently mentioned (in only 12% of participants).

"In my free time? Very little to be honest with you because we're very restricted in what we could do, what hobbies I have I can't do them so most of my free time is taken up by playing on the PlayStation, watching TV or you know I'd be listening to some music in my room or doing my homework really. That's what my free time's taken up with." - Rampton

"I like sometimes being in the creativity areas of the occupational room. Erm I'm not dissatisfied. I mean happiness is not in places, you know, it's in us or it's not at all. You know I can pick up a good book, you know really if you can read and you read well you can lead as many lives as you want in some ways." – Whitemoor

"Um... put the, radio will go on, everyone will sit there bored out of their skull doing absolutely nothing unless you get, erm, psychologists coming to see you, they'll be here for an hour, but the rest of the day you're basically sitting around doing nothing... it's ridiculous." - Rampton

"Yeah I go to workshop seven.... It's good, because it keeps me occupied during the day. It keeps me motivated, erm it just passes the time because it just gives me something to do. Or otherwise I'm just sitting in me cell doing nothing." - Whitemoor

Structured activities as an integrated part of the programme viewed as developing and practicing what had been learnt, was most frequently discussed by patients in Whitemoor and Broadmoor (N=12), but rarely by those in Frankland or Rampton (N=4).

"Even the staff have said you know, every time you come back you've got a big smile across your face. I enjoy it because... all right I'm trying to learn a bit about electronics and we have problems and I mean it's teaching me to think problems through...I'm putting together some of the things I'm taught here on how to work with them, I'm using the skills, I'm learning here to use with them." - Broadmoor

Unstructured communal entertainments included spending time chatting, playing cards or snooker, or cooking with others. Structured activities were discussed by 75% of the participants and the opportunity to attend structured off ward/wing activities (e.g. workshops, gym, swimming, cooking, gardening and education) was highly valued.

"So the only two places where you get any freedom is the gym and the education, they're the only two really therapeutic type of things because you go to the gym and you can work off any frustrations you've got, you go to education and you can just be left alone and get on with your own thing." – Frankland

Procedural and Relational Security

From the participants perspective a key determinant of how positively or fully their days were spent was the number and experience of staff on duty, and the impact this had on procedural security. It was clear from the interviews that many participants were well aware of the unit policies about staffing levels, and considered there to be insufficient staff to deliver them, owing to staff training needs, or other duties or illness that staff needed to cover. Increases in numbers admitted to the units, as they reached capacity, and the consequent relative staff shortages, meant that participants could see but not always use facilities.

"So much stuff gets cancelled 'oh no sorry we can't do this we haven't got staff'. One member of staff goes off sick that screws the whole shift up. They're supposed to have eight members of staff on per shift, we're lucky if we've got five which is huge." – Broadmoor

"He told us that we'd be starting a schema group, because he's going to be a part of it, that was actually supposed to start about a month and a half ago, and they just couldn't get the staff. That's because of all the staff taking sick leave and then they had the problem of what day do they were going to run it on? And it's all them problems that make you feel 'what's the point in staying on this unit'? So we are just waiting to find out now." - Whitemoor

"It just comes down to the same thing. Short staffed...It's happened quite regular. Cos you used to have erm, bingo once a month in the forum. We used to have film club every Sunday in the forum. That's stopped. No staff." - Broadmoor

More participants in hospital (44%) compared than in prison units (7%), talked of how they considered aspects of procedural security as curtailing their autonomy and restricting access to activities. Some felt that they had additional restrictions within the secure perimeter of the ward, whereas those in the prison units were allowed greater freedom within the spur they were on.

Several patients talked about the how they perceived that security policies dominated therapeutic aims. The initial procedures following admission were perceived as punitive by some of those who had been transferred in from the prison system. They saw the loss of

privileges and curtailment of activities arising from procedural security as difficult to understand or justify. These included not being allowed their own razor, a two-person escort, no personal items allowed in their room, being secluded for swearing, and being subjected to rub downs, being stripped and showered. Thirteen participants (twelve in the hospital system) described these procedures as engendering feelings of annoyance and frustration through to resentment, hate, and alienation.

“In prisons you can get china plates, cups and bowls, knife, fork, spoon, as many spare razor blades within reason as you want all in your room. You know you can have four or five people sat in your room and you won’t see an officer until they lock you up at night. So you get treated as an adult in prison, here you kind of get treated a bit like a child.” (Broadmoor)

“They’ve told me that it’s done for security reasons, whilst I can appreciate that, I don’t think that stripping a man bare of everything literally for two weeks and not really explaining why this is being done sets you off on a good footing.. There’s a lot of anger, a lot of resentment ..., the majority have asked to come here, some haven’t but the majority at the moment have asked, so we’d actually get treated better if we were in a prison segregation unit than we would here for the initial two weeks” - Rampton

Interestingly the participant above talks of being made to feel ‘back straight into the frame of mind of being a prisoner’. None of the prison sample considered the regime in these terms, indeed several described it in terms of being ‘safe’, ‘friendly’ and ‘relaxing’. Participants within the prison system, although critical of aspects of the regime, seemed more willing to accept that as a prisoner there was a reason why they were incarcerated, other than simply as a waiting area for therapy, but that the conflicting demands of security and therapy were difficult to balance. This participant articulates that tension within the system well.

“I think the purpose is good, I think the program is excellent. I just wish they would marry it up a bit more..., we know it’s a prison, we don’t have to keep on about it... they do the creativity but, it’s, it’s destroyed by the regime that they want. They can’t have it both ways. They should be more encouraging to people. There should be more participation. They should be more relaxed so that people are able to come out and discuss things and, you know, if you’re off work they lock you up. Well that’s no good.” – Whitemoor

Pathways into the DSPD programme

The sample of patients interviewed appeared to fall into three broad groups in terms of their pathways into a DSPD unit. This had a significant impact on their perception of many other aspects of the DSPD units and programme, although did not appear to

be associated with specific personal attributes, other than some associations with offence type. The groups were as follows:

1. Those who were brought to the units without either choice or warning.
2. Those who believed, or were persuaded, that the DSPD programme would offer the best chance of reaching their goals (primarily as the quickest or only route to release).
3. Those who actively chose or volunteered for the programme.

These groups were not mutually exclusive and over the course of the interview some patients would alter their characterisation of coming to the DSPD programme depending on what they were discussing. For example one patient in Broadmoor acknowledged that he had nowhere else to go in the system (Group 1), but later also talked of his need to do therapy to help understand his situation better (Group 2).

*“Because I’m a lifer, at the end of my tariff and I’m still an A Cat, and from day one I had a problem with doing any offence related coursework. No one would allow me to do any offence related coursework at all. They just said I was unsuitable for everything. And because I was being classed as unsuitable I couldn’t address my offending behaviour and so I couldn’t be taken off the book so I could never be considered for release or anything else. So it was a catch 22 situation. And this was - according to the hype for this place. It was literally the only avenue left for me to try and progress through the system because I wasn’t being allowed to progress through the system at all” - **Whitemoor***

*“I’ve been in the institution for 15 years and I opted for the DSPD and I was very dubious about what they had on offer and how long I would wait and I wasn’t sure about the roles here, because it was very different to the rest of this hospital” - **Broadmoor***

The patients who described themselves as having little choice or warning of coming to the programme formed the largest group in the sample. It was unequally divided between the hospital and prison systems, reflecting the different legal mechanisms for detention: seventeen patients in this group were within the hospital system (eleven of those in Rampton and six in Broadmoor) compared with four in the prison system

(three in Frankland and one in Whitemoor). They were more likely to have been in custody for longer periods of time, had exhausted other options, or were at or near the end of their sentence.

“I was at the end of my sentence, I only had I think about a week left to do on my sentence and I’d made all these plans with my girlfriend, and they just let me go on, go ahead and [plan]... and then I got brought here” - Rampton

“I’ve been in prison a considerable amount of time... Basically, I was looking forward to going home, I had prepared myself for it, I had job prospects, I’ve got family, I had everything waiting for me. And then to be brought here, and I believe erroneously, doesn’t please me. And the prospect of spending another three to five years here with no guarantee at the end, you know..., there is no way that I can cooperate in any way with what’s going on here; I’m here very much under protest” - Broadmoor

“It made me feel quite angry at the time because I’ve seen it happen to a lot of other people and friends where they’ve been doing well in prison and due to get out and where the next minute the DSPD sort of get hold of them and the next minute they are on the DSPD and then these use all these medical terms and stuff saying ‘oh no you are not fit to go out and blah, blah’. But that’s the law now” – Whitemoor

“I ain’t got a choice. What choice do I have? If I don’t, because I’m completing coursework here, they’ll section me at the end of it. And if I tell them to stick the coursework now, they’ll section me anyway” - Frankland

Those who appeared to have in some way been persuaded that the DSPD programme was the best option, were equally divided between the prison (N=10) and hospital (N=10) systems. They either acknowledged that they saw the DSPD programme as their only or quickest route to release, or suggested that they had been persuaded that it would be the best place for them to address their needs.

*“The way it’s put across, DSPD and all that...The public are probably thinking that we’re in some kind of f***ing shock therapy sessions 24 hours a day getting pure empathy drilled into us. It’s nothing like that....It’s nothing what I expected to be, no. I thought it would’ve been a bit more intense, you know, and a bit more productive*

*than it is.” - **Frankland***

*“I started to think and realise about the future and about sorting my life out and making plans for getting out and stuff like that, decided then to contact Whitemoor DSPD about coming back here, and erm doing the treatment that I missed out on when I was here the first time... I was coming up for parole and through experience when it comes to DSPD and mental health issues if you’ve not addressed them while you are in prison or sorted them out usually it can come back to haunt you when you come to the end of your sentence they can sort of stop you from getting out” - **Whitemoor***

Those who talked of choosing or volunteering for the DSPD programme were again equally spread between the two systems. The primary reason given was the wish to understand and deal with their personality disorder more constructively, and that there were limited opportunities to do so elsewhere in the system.

*“My understanding of it first of all was that, I was told, that it was going to be all day, all day therapy. That happened on assessment, you know what I mean, but it doesn’t happen on intervention” - **Whitemoor***

For some, transfer to the DSPD programme was talked about as being no more than a change of scene.

*“They gave information, but to be fair that didn’t help me at all. And I didn’t know what I was coming to, or as far as I was concerned I was just coming to another jail” - **Frankland***

Those who had been in custody for longest were more likely to volunteer or choose the DSPD programme, relative to those in the programme earlier on in their sentences. Those whose index offence was sexual were more likely to be in the groups 1 or 2 (i.e. coerced or persuaded into the DSPD programme), whereas those who had committed homicide or other violent offences were more likely to have chosen to enter the programme. There were no clear associations between which groups patients were in and their PCLR score, number of previous psychiatric admissions or type of sentence.

There were, however, significant links between the impact of how a participant had come to the unit and their emotional response to it, particularly in relation to unmet expectations. These were more frequently expressed by the hospital patients, who talked of feelings of injustice and anger as well as feeling apprehensive and frightened. No positive emotions were recorded in relation to arrival on the unit.

“And of course when you first come here I think it’s appalling that straight away you’re stripped of everything... why not have my property? If I was in a top security jail, if I move from one to another, the same day I moved there I’d have all my property and access to everything that I was allowed within those local rules” - Rampton

Pathways through the DSPD Programme

Whilst the criteria for DSPD are well defined with admission to the DSPD programme dependant upon them, exit pathways were more varied. From the individual participant perspective, expectations of pathways out of the units fell into **three broad groups**.

1. An expectation of a pathway out of the unit, with clear criteria for how to achieve this.
2. Feeling that there was a pathway out but with the exit route less fixed.
3. Little or no expectation of a pathway out of the DSPD unit.

How participants viewed their trajectory through the system appeared to be a key factor in how they related to other aspects of the programme.

For those who had opted to come to the units as a route to being released, the delays in progressing through the system were particularly frustrating and alienating.

"It's a case that you come here, you're feeding them as much information as you can, they're going away and coming back and saying 'right, we're going to put you on this course' 'okay, when?' 'oh, in a year's time' and you think well, what was the use of me coming here and sitting here for a year, 2 years and then I've got to wait for a course for a year, you know what I mean and it's the same as one of the courses that I've got to do that she mentioned today, it's not even been written yet, you know what I mean, it's not even been worked out how they're going to do it." (Frankland)

*"... your CPA, that's either three to six months and [then] they let you go to work areas. I had quite a bit of difficulty with that... I put in for work and everybody else was going down there for two weeks and three months later I'm still waiting... I just want to find out what's happening. I just kept persisting. I think another three months after that that's when I actually got down there, so it took a while." - **Broadmoor***

In the hospital system patients perceived that there was an additional wait for security assessments to be completed prior to being allowed to engage in therapy.

Over half of the patients interviewed at Rampton reported restrictions due to security incidents or other specific aspects of the regime, although there is no specific data available to qualify whether the number of actual incidents there differed from the other units.

Moving through the system

The majority of those in the hospital system (72%) described themselves as either having a transfer or release plan in place, or expressing the view that they would be transferred to a place of lower security in the foreseeable future. Despite the much greater perceived opportunity for positive progression within the hospital system participants from both systems raised equal levels of concern about the inconsistency and speed of progression. Perhaps, more surprisingly the expression of negative emotion in relation to pathways out was expressed by 40% of patients, compared with only 10% of prisoners. Prisoners in general appeared to be more accepting of the possibility of an extended period of detention. Only two prisoners talked of having some understanding of clear pathways through the unit, the remainder either choosing not to discuss the subject or actively questioning whether there was any real possibility of release.

*"They stopped the step-downs... I got quite uptight about that because it was a promise when I came here that there will be step-downs to go through the system. And that got stopped It's still a worry to me about what's going to happen in the future, you know, ... I've done... and I'm not proud of this next fact, I've done about twenty six years in prison" – **Whitemoor***

There were no clear associations between which of the 'pathways out' group participants perceived themselves to be in and their PCL-R score, number of previous psychiatric admissions or type of sentence.