

Centre for  
Mental Health



# **Report on the Key Themes from the Mental Health Act Survey**

## **Independent Mental Health Act Review**

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## Introduction

In October 2017, the Prime Minister commissioned an independent review of the Mental Health Act (1983). An Independent Review Panel was tasked with appraising existing practice and evidence, and formulating recommendations to improve legislation and/or practice in the future.

An important part of the review has been the gathering of evidence from those who had direct experience of the Act, i.e. those who had been detained, those who were currently detained and those who were a carer for a person detained. This evidence was gathered in a number of ways, including focus groups, but this report gives the analysis for a survey that was facilitated by the Department of Health. The survey collected data both online and through hard paper copies.

The survey responses have provided important evidence that has helped the review make informed decisions about the priorities for the next phase. The survey is critical in demonstrating that the

review has considered the experience and views of people with lived experience of being detained and those who care for them.

Centre for Mental Health, an independent charity, was commissioned to analyse the survey results.

This report presents key themes that have emerged from over 2,000 responses to the survey. The focus of this report is the desired changes and reforms that respondents expressed a view on, but it also features some the experiences of the Mental Health Act and being detained under section or caring for someone detained under section.

The report is in two main parts:

- **Part 1** details some of the facts and figures of those completing the survey, for example their socio-demographics.
- **Part 2** describes the main themes that are emerging from the analysis.

As has been stated there have been over 2,000 responses; the bulk of the survey was semi-structured and qualitative. Most survey forms were completed online but there were also handwritten survey forms submitted. There have also been different formats of survey form, for example:

- Lived experience forms;
- Carer forms;
- Easy-read lived experience forms;
- Easy-read carer forms
- British Sign Language forms.

## **Analysis of the survey data**

The data was provided to Centre for Mental Health in a Microsoft Excel spreadsheet, with some data being received in hard copy and then transcribed to the spreadsheet. The 'find', 'search' and 'count' features of Excel were used for the analysis. The data was subjected to inductive thematic analysis, where initial scans of smaller samples of the respondents have found commonly used words and phrases; these have been explored in more depth within the sub-samples, then these emerging apparent themes have been tested within larger groups (e.g. carers, those with lived experience) and across all the survey respondents.

The themes were relatively easily uncovered in these responses as, although qualitative, most responses are relatively short. In addition, respondents have often repeated the answer given to one survey question, and/or given more detail, in the response they have given to others.

### **Limitations of the survey analysis**

The survey had been designed with predominantly open questions (alongside questions about demographics, detention type, etc.) and therefore, the analysis of the survey is largely qualitative, seeking themes that emerge from the responses.

Whilst the report does cite numbers and percentages in places, it is important to note that that these cannot be seen as representative of all people with lived experience or carer experience. Those who completed the survey have made an important contribution and helped the review understand service user and carer perspectives, but they are a self-selected sample and we have no way of knowing if their views are representative of service users or carers overall.

An additional point on the number and percentages given in the report is that these are only an approximate guide to how many people gave a particular type of response as, for example, there were quite a variety of ways in which either a positive or a negative response could be given, and it is possible that the analysis may have missed some responses given on a particular theme. However, on the whole the responses given were short and therefore relatively easy to analyse.

People responding to the survey with lived experience sometimes had multiple experiences of mental health services, being detained under the Act but also as voluntary patients. Some respondents commented on both experiences, i.e. they do not limit themselves to the experience of detention. And in some cases, it is not clear if a respondent is referring to their experience of being detained or more generally as being a service user of mental health services.

Some of the printed copies of the survey are different from the online survey, in that pages with questions or individual questions were either missed when these were being reproduced or have gone missing after completion. However, the vast majority of survey forms were intact. Easy-read hard copy versions of the survey were also completed and inevitably the responses on these were shorter. Where these had been completed by a current inpatient, some had some supplementary answers (mostly socio-demographic) given by a health care professional. The easy-read survey forms usually did not ask for permission to contact the respondent after survey completion and so the survey team has not been able to seek permission to use quotes from their responses.

## Part 1: Who completed the survey?

The survey received a total of 2,060 responses, most of these online (1,815) but 245 were handwritten surveys. Only 9 of the latter could not be included (these were incomplete and/or too difficult to decipher), leaving 2,051 online and handwritten responses that could be analysed.

### Male and female respondents

Table 1: Males and females

	Lived experience	Carers	Other
<b>Males</b>	266	155	139
<b>Females</b>	458	547	248
<b>Not stated</b>	61	46	131
<b>Total</b>	<b>785</b>	<b>748</b>	<b>518</b>

A third of the lived experience respondents described themselves as males, and just over 20% of carers were male.

The 'other' respondents are described a little later but were people who did not report having been detained under section or having cared for someone who was. They either completed a carer or a lived experience version of the survey online.

### Age of respondents

Table 2: Age range for people with lived experience

Age <sup>1</sup>	Number	% (rounded)
Blanks	93	12%
Under 18	9	1%
18-24	80	10%
25-34	166	21%
35-44	147	19%
45-54	160	20%
55-64	96	12%
65 or above	33	4%
Don't know	1	0%

Table 3: Age range of carers

Age <sup>2</sup>	Number	% (rounded)
Blanks	124	17%
Under 18	1	0%
18-24	23	3%
25-34	54	7%

<sup>1</sup> Some versions of the questionnaire did not include all the 'age bands', therefore, 'under 18', '18-24' and '65 or above' may be underrepresented.

<sup>2</sup> As per footnote 1.

35-44	85	11%
45-54	143	19%
55-64	202	27%
65 or above	115	15%
Don't know	2	0%

Table 4: Age range of other people completing the survey

Age	Number	% (rounded)
Blanks	86	17%
Under 18	6	1%
18-24	27	5%
25-34	55	11%
35-44	76	15%
45-54	101	19%
55-64	92	18%
65 or above	75	14%
Don't know	0	0%

For the 518 'other' respondents, some gave some further information on their backgrounds and interest in the Mental Health Act; 101 said they had lived experience of poor mental health but had not been detained/sectioned under the Act; 52 were carers of someone with poor mental health who had not been detained/sectioned; and another 55 had some form of professional role around the Mental Health Act, largely mental health professionals. The remaining 310 did not give more detail.

#### Where in the UK did respondents come from?

Table 5: Where did those with lived experience come from?

Region	Number	% (rounded)
Blanks	87	11%
East Midlands	46	6%
East of England	35	4%
London	88	11%
North East of England	54	7%
North West of England	113	14%
Northern Ireland	3	0%
Scotland	11	1%
South East of England	110	14%
South West of England	67	9%
Wales	25	3%
West Midlands	69	9%
Yorkshire and Humber	77	10%



<b>Region</b>	<b>Number</b>	<b>% (rounded)</b>
Blanks	87	11%
East Midlands	46	6%
East of England	35	4%
London	88	11%
North East of England	54	7%
North West of England	113	14%
Northern Ireland	3	0%
Scotland	11	1%
South East of England	110	14%
South West of England	67	9%
Wales	25	3%
West Midlands	69	9%
Yorkshire and Humber	77	10%

Table 6: Where did carers come from?

<b>Region</b>	<b>Number</b>	<b>% (rounded)</b>
Blanks	79	11%
East Midlands	34	5%
East of England	53	7%
London	97	13%
North East of England	35	5%
North West of England	88	12%
Northern Ireland	2	0%
Scotland	5	1%
South East of England	124	17%
South West of England	80	11%
Wales	24	3%
West Midlands	68	9%
Yorkshire and Humber	59	8%

Table 7: Where did 'other' respondents come from?

<b>Region</b>	<b>Number</b>	<b>% (rounded)</b>
Blanks	57	11%
East Midlands	31	6%
East of England	43	8%
London	56	11%
North East of England	22	4%
North West of England	60	12%
Northern Ireland	4	1%
Scotland	17	3%
South East of England	70	14%
South West of England	57	11%

Wales	27	5%
West Midlands	40	8%
Yorkshire and Humber	34	7%

## Ethnicity of respondents

Table 8: Ethnicity of those with lived experience

<b>White</b>	<b>Number</b>	<b>%</b>
English/Welsh/Scottish/Northern Irish/British	623	79.4
Irish	8	1.0
Any other white background	3	0.4
<b>All</b>		<b>81%</b>
<b>Mixed/multiple ethnic groups</b>		
White and Asian	8	1.0
White and Black Caribbean	12	1.5
White and Black African	2	0.3
White and Somali/Arab	2	0.3
Any other mixed/multiple ethnic background	14	1.8
<b>All</b>		<b>5%</b>
<b>Asian/Asian British</b>		
Bangladeshi	2	0.3
Chinese	1	0.1
Indian	8	1.0
Pakistani	6	0.8
Any other Asian background	10	1.3
<b>All</b>		<b>4%</b>
<b>Black/African/Caribbean/Black British</b>		
African	6	0.8
Caribbean	14	1.8
Any other Black/African/Caribbean background	5	0.6
<b>All</b>		<b>3%</b>
<b>Prefer not to say/Blank</b>	61	<b>8%</b>

12% of those with experience of being detained under section were from Black and Minority Ethnic communities.

Table 9: Ethnicity of carers

<b>White</b>	<b>Number</b>	<b>%</b>
English/Welsh/Scottish/Northern Irish/British	631	84.0
Irish	9	1.2
Any other white background	32	4.3
<b>All</b>		<b>90%</b>
<b>Mixed/multiple ethnic groups</b>		

White and Asian	5	0.7
White and Black Caribbean	10	1.3
Any other mixed/multiple ethnic background	13	1.7
All		<b>4%</b>
<b>Asian/Asian British</b>		
Any other Asian background	2	0.3
Bangladeshi	1	0.1
Chinese	1	0.1
Indian	7	0.9
Pakistani	5	0.7
All		<b>2%</b>
<b>Black/African/Caribbean/Black British</b>		
African	2	0.3
Caribbean	10	1.3
Any other Black/African/Caribbean background	2	0.3
All		<b>2%</b>
<b>Prefer not to say/Blank</b>	18	<b>2%</b>

Table 10: Ethnicity of other respondents completing the survey

<b>White</b>	<b>Number<sup>3</sup></b>	<b>%<sup>4</sup></b>
English/Welsh/Scottish/Northern Irish/British	446	83%
Irish	4	1%
Any other white background	19	4%
All		<b>87%</b>
<b>Mixed/multiple ethnic groups</b>		
White and Asian	3	1%
White and Black Caribbean	7	1%
Any other mixed/multiple ethnic background	11	2%
All		<b>4%</b>
<b>Asian/Asian British</b>		
Any other Asian background	5	1%
Bangladeshi	1	0%
Chinese	1	0%
Indian	11	2%
Pakistani	1	0%
All		<b>4%</b>
<b>Black/African/Caribbean/Black British</b>		
African	3	1%
Caribbean	3	1%
Any other Black/African/Caribbean background	4	1%

<sup>3</sup> Some people ticked more than one category

<sup>4</sup> % in the bold cells in this column are rounded and based on 537, as some people ticked multiple boxes.

All		2%
<b>Prefer not to say/Blank</b>	18	3%
<i>Note: some people ticked multiple boxes</i>		

The carer and 'other' respondents also overwhelmingly came from 'White' and 'White UK' backgrounds.

**Diagnosis**

The question on diagnosis in the survey was open text rather than fixed choice and consequently there were a great variety of ways that people described their diagnosis, indeed there were 537 respondents who described their diagnosis/diagnoses in a unique way. These unique descriptions were often of multiple diagnoses. Most people gave two or more diagnoses. Some respondents gave quite a bit of descriptive text with their diagnoses. Therefore, gauging the proportion of people with a particular diagnosis was not easy and the percentages below are approximate only.

In the region of 43% of the sample stated they had a diagnosis of a psychotic illness and/or BiPolar Disorder, over 20% of the respondents reported a diagnosis that included one or more personality disorders. About 6% reported they had learning disability and/or an Autistic Spectrum Disorder, sometimes combined with a psychosis diagnosis and sometimes with a personality disorder. In the region of 13% of the sample reported a range of other diagnoses, prominent amongst which were Post Traumatic Stress Disorder, Depression, Anxiety and Anorexia Nervosa. Often these 'other' diagnoses were a combination of several diagnoses. In the region of 10% of respondents left this section blank and a further 8% either declined, did not know or gave accounts from which a diagnosis was difficult to discern.

**What Section of the Mental Health Act (the Act) did respondents have experience of?**

One of the survey questions asked which sections of the Act respondents had experience of. Approximately half of both those with lived experience and carers had experience with Section 2 of the Act. Over a quarter of carers had experience of Section 3 and just under 10% of people with lived experience reported having been detained under this section.

Between under 1% and 6% of people with lived experience and carers stated they had experience of the following sections when answering this question: Section 4, Section 5.4, Section 5.2, Section 6, Section 7, Section 20, Section 17, Section 37, Section 37/41, Section 42, Section 45a, Section 52, Section 117, Section 135 and Section 136.

## **Part 2 of findings: Emerging themes**

This section looks at the responses of those with lived experience, carers and other respondents to the 10 substantive questions that the survey asked and has drawn out the key themes that emerged from these. There is much repetition across the responses to the questions. Respondents often repeated previously given answers or further clarified their response to another question.

People with lived experience and carers were asked more or less identical questions (differing only to reflect the experience of the respondent). The questions asked of those with lived experience of being detained under the Mental Health Act are listed below.

There is also considerable overlap between both the views of those with lived experience and those of carers, for example, just for the survey's second question on what might prevent/have prevented further detention under the Act, one of the most common responses concerned 'improved mental health services in the community/better community support/earlier intervention'. At least 180 carers (24%+) expressed this view, and similarly at least 120 people (15%+) with lived experience expressed such a view.

### **What is a theme?**

In this section of the report the themes have emerged from commonly occurring answers, i.e. answers where several respondents appear to be saying very similar things. There are no fixed rules applied about how many respondents giving a similar response equals 'a theme'. In this report, the themes have emerged from similar responses, generally having been given by at least 20 (but often many more) respondents. However, as the primary concern of the survey and indeed of the independent review is what reform to legislation and guidance might be required, ideas on such reform are included when smaller groups of respondents have suggested them.

Where quotes are given, those with lived experience have a 'LEX' before the number (e.g. 'LEX599'); similarly, carers have a 'CAR' before the number; and other people who completed the questionnaire, where quoted, have an 'OTH' before the number.

Not all respondents gave permission for the Department of Health and Social Care to contact them to seek permission to use quotes from their responses, and so it has not always been possible to use the quotes that might best illustrate a theme.

### **A brief overview**

The survey's questions were specific and based on the current Mental Health Act, and respondents were asked about their experience of the Act and various parts of it (e.g. detention in hospital,

Community Treatment Orders and Section 117 Aftercare). Respondents were also asked about what they would change about this Act.

There were some suggestions given by respondents on reforms and changes to the Act and potentially its guidance. However, it does not necessarily follow that because a person has direct experience of being detained under section or having a loved one detained under section, they understand or are well-versed in the legislation. Several respondents made this very comment. Therefore, it may be difficult for many respondents to suggest changes to the Act.

There were a group of respondents, primarily those with lived experience (at least 10 or 1%+), who wished for the repeal of the Act (or a part of it) and the abolishment of compulsory treatment in both hospitals and the community. There were also those, both carers (in the region of 60 or 8%+) and those with lived experience (19 or 2%) who stated a clear 'nothing' when asked what they would change about the Act, that wanted to see no change and thought the Act was as it should be. Examples of such statements made by those with lived experience when asked about reforms to the Act they wished to see, or what could have been done to prevent them being sectioned included:

*"...Nothing could have been done different really. I was in a bad place, mentally, physically and spiritually..." (LEX694)*

*"...Nothing and I did not view the act of sectioning in my case as something that should be avoided, if you are physically exceptionally unwell you are placed in intensive care - the same arrangement applies to your mental health when in crisis..." (LEX443)*

*"...I'm unsure if anything could have happened differently at the time as I was extremely uncooperative, and I believe it was the only option at the time..." (LEX157)*

Of the 38 easy-read survey respondents with lived experience who completed hand written surveys, exactly half (19) were satisfied that they had been sectioned and largely content with the care they were receiving. Some of the responses from these suggested that they were mostly current patients, some of whom had experienced many years of detention under the Act.

Most of those responses which concerned changes that respondents would like to see, from all types of respondents, could be considered as falling outside the areas that the Independent Review has been asked to address, i.e. they do not generally concern changes to legislation or its guidance. Whilst respondents to the survey did have much to say about their treatment under the Act in hospitals and in the community, when it came to reforms these largely concerned matters that might prevent or at least reduce the need for use of the Act, such as reforms to mental health

services, seeking better resourced and more responsive community services, better support before and during a crisis, early intervention and more holistic provision of mental health care (whether sectioned or not).

The themes in this section are grouped under two headings:

- Reform themes (where a reform or change is suggested);
- Experience themes (themes where the experience of the Act is expressed).

### **The survey questions for those with lived experience**

- Based on your experience, do you agree or disagree that being sectioned has been the best approach for your mental health needs?
- What could have happened differently that could have prevented you from being sectioned?
- How would you describe the care you received while sectioned? This could be either in hospital or on a Community Treatment Order.
- In your experience, what are the most important things that can help people stay well following discharge, and reduce the need to be sectioned again in future?
- Do you feel you have been treated with dignity and respect?
- Where relevant, do you feel your carers (e.g. family or friends supporting you while you were sectioned) were treated with dignity and respect?
- What rights do you think a person sectioned under the Mental Health Act should have?
- What rights do you think a carer (e.g. family or friend) should have when supporting someone sectioned under the Mental Health Act?
- If you could change one aspect of the Mental Health Act, what would you change?
- Is there anything else you would like to tell us?

As stated, the questions asked of carers were nearly identical to the above but were directed at the carer experience.

It is important to note that not everyone who took part in the survey expressed a view on change and reform and that some respondents, both carers and those with lived experience of being detained under section<sup>5</sup>, did not want to see any changes.

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<sup>5</sup> In this report 'lived experience' refers to and is shorthand for 'people with lived experience of being detained under section of the Mental Health Act'.

Not all of those with lived experience and carers had a negative view of their experience, indeed a minority expressed a largely positive view of their treatment, for example:

*"...Overall most of my experiences in inpatient care have been largely positive... Most staff have a passion for their chosen vocation and this shines through in their practice professionalism and quality of care..."(LEX1445)*

*"...The care I received in hospital was excellent and included a controlled medication regime and intensive group and one to one therapy..."(LEX1128)*

*"...The last time my daughter was sectioned was in my view was correct as it was a safe place for her at the time..."(CARBS4)"*

## **Wider reform themes**

### **Early intervention, prevention, and a better crisis response**

Respondents talked about the need for early intervention (at least 58 carers (8%) and 28 people (4%) with lived experience used the phrase 'early or earlier intervention'), a better crisis response and more availability of beds so that they could be admitted on a voluntary basis at an earlier stage. It should be noted that 'early intervention' and 'crisis responses' are not the same thing: the former might prevent the need for the latter, for example. However, they are merged in many respondent accounts. 'Early intervention', sometimes means exactly that, or it can mean 'earlier intervention' (i.e. at the point of a crisis or when 'trigger' signs first present themselves) in other accounts. Specific references to 'crisis teams' were made by 60 respondents (8%) with lived experience and 58 carers (8%).

*"...I have mixed feelings. In a crisis situation I would say that detentions can be necessary, but crises can sometimes be avoided. I have been sectioned during two different episodes of illness. Both times I think the use of the Mental Health Act could have been avoided..." (LEX3)*

People wanted a system that responded to early warning signs of a decline in mental wellbeing:

*"...Earlier intervention could have prevented me from being sectioned ..." (LEX489)*

*"...My parents battled with GPs and psychiatrists to try and access the right support but all they did was keep upping the dosage of the very anti-depressants that were causing me to be ill. Nobody helped and then it spiraled until I was so ill I couldn't speak or do anything for myself, so they resorted to sectioning..." (LEX597)*



*"...The illness could have been caught earlier on and treated sooner to avoid getting to this point..."*  
(LEX743)

*"...Early intervention and better monitoring by health professionals is key to keeping someone with my diagnosis well...this would also include adherence to the law ... in Wales..."*(LEX143)

The end of the last quote is a specific reference to the Welsh Mental Health Measure<sup>6</sup>, and the right of a former patient to request a mental health assessment. This respondent went on to add that the law had not been adhered to in their case and that they had found it very difficult to access an assessment by the local mental health service.

*"...I have said it many times, adult services need to be like children's early help assessments and use an 'observe, plan, do', review approach and have more regular meetings, checks and conversations etc..."* (CAR1322)

The role and knowledge of family and friends in risk and crisis planning is also important.

*"...Family and friends' involvement is crucial, to ensure that care and risk plans are actually do-able and realistic in the context of the service user's daily life..."* (CAR31)

### Home treatment to prevent a crisis

Respondents expressed the potential of home treatment services to support someone in a crisis and prevent the need for admission. Specific references to home treatment services were made by 33 (4%) people with lived experience and 26 (4%) carers. Some people reported a very poor experience of home treatment:

*"...The intensive home treatment team were awful. Multiple times I was told to 'get a job' 'stop wasting their time'. They were emotionally abusive and due to that I struggled to work with them. Had there been appropriate community support I could have managed in the community much better..."*(LEX1627)

*"...If there was more funding for the crisis and home treatment teams so that they can better support at home treatment. Another option less costly if there could be a day treatment centre for patients so they can be looked after by staff in the day and then family can take on the responsibility at the evening and night..."* (LEX137)

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<sup>6</sup> More details at: <http://www.mentalhealthwales.net/mental-health-measure/>

There were positive accounts of home treatment, and presumably these were better planned and resourced than the first account above, for example:

*"...and the person I care [for] was placed at home with her parents, under home treatment, and with the proviso that she stayed at home and followed whatever medication and therapy programme the home treatment team prescribed. The message the service user took away was "Go home, stay at home, engage with services or we will have to section you." It worked. There were 6 weeks of intensive home treatment, but no section..." (CAR31)*

### Missed opportunities

Whilst not strictly speaking a 'reform theme', the many missed opportunities described can illustrate the changes required. Several examples were given of how some earlier intervention might have prevented the need for use of the Mental Health Act:

*"...For the week preceding our relative's sectioning, we had repeatedly taken her to A&E, the unit from which she had been discharged having failed to provide us with a "protocol" for contacting them. Despite many hours in hospital and our distress and pleas for assistance, staff repeatedly sent her home with us. She finally managed to "escape" our house and made her way to the busy road at the end of the drive. By pure chance one of our family spotted her and saved her from being killed. It was this and only this that convinced her consultant she should be obliged to return to hospital via a section..." (CAR 182)*

*"...I contacted the mental health team on the Monday to say that my husband was experiencing symptoms of psychosis. I was told that I could have an appointment for him the following week! I asked them what I was supposed to do if he deteriorated further. They told me to take him to A&E and ask for the Crisis team!...It would have been better if someone from the mental health team could have come to the house before his psychosis really took hold. He could then have had medication prescribed that could have prevented this total breakdown..." (CAR258)*

*"...Responsiveness and understanding and access to appropriate support and follow up when I first contacted my GP about the situation I was in. Had I...had this then management of the situation may have meant that the illness did not develop..." (LEX62)*

*"...I have been sectioned many times since I was a teenager. Every single time, I had asked for help previously and found that there were insufficient community resources to prevent a crisis occurring..." (LEX63)*

However, for this same respondent a more recent episode had been more positive:

*"...Last summer, my mental health was deteriorating rapidly and instead of being admitted to hospital, I was treated by an Intensive Home Treatment Team who visited me at home or spoke to me 2-3 times a day for 6-7 weeks until the really rough patch was over. I avoided an admission completely and felt empowered by the whole experience. Service[s] like these need..." (LEX63)*

One respondent talked about the need for mental health services to deliver the care plans they had already agreed:

*"...Following through with what they say like when they say we will ring or come see you or something make sure it happens as a lot of the time it doesn't ..." (LEX506)*

### Improved community services

This theme overlaps with those above and others but goes beyond a desire for better crisis responses. It encompasses a desire to see better resourced and more reactive mental health services in the community.

*"...Better community care which was more flexible and more supportive, and perhaps raised the alarm before situations have become dangerous..." (LEX1016)*

*"...Good community services of which there are very few in [respondent's home town]. Also easy access to a crisis team again which is absent in [respondent's home town]..." (LEX A24)*

*"...In our case it would require very assertive community mental health outreach. Someone would need to be very persistent and build his trust in order to provide regular support and help him access other services. Needless to say this has not happened..." (CAR53)*

*"...Treatment/therapy in the community could have been offered to me to help me deal with the repercussions of lifelong trauma. Having been under secondary mental health care for over 7 years I am now on the waiting list to be seen by a psychologist in the community mental health team. Had this been available sooner my life could have been saved..." (LEX110)*

*"...To reduce the chance of readmission, the care from community teams need to be ready and timely. This was not our experience and we continue to struggle to avoid readmission..." (CAR152)*

*"... Early input from the community teams before I was admitted. I was left in crisis with little support in the community and I spiraled. We tried to contact the crisis team but living on a county border meant no-one would speak to me. ..." (LEX659)*

The importance of the availability and accessibility of services is stressed by several respondents and particularly the access of out of hours services:

*"...Out of hours services also have a direct knock on effect on people's readmission chances..."*  
(LEX1445)

One service user highlighted that office hours services are all well and good, but if a crisis occurs at night those services are unable to help.

Consistency in the mental health team was also deemed important, with over 20 people (3%+) with lived experience and over 40 carers (5%+) specifically mentioning it and the need for and/or the lack of consistency in some aspect of care.

*"...Comprehensive community care that is responsive to changing and fluctuating needs... A consistent team that gets to know the individual and can help recognise and respond to deterioration..."* (LEX534)

*"...Better community support from a consistent team of practitioners, not different people coming each day, staying 5 minutes then leaving..."* (LEX U40)

#### Informal admission and alternative forms of support and respite

There was a perception amongst some respondents that voluntary admission to hospital was difficult, but that if a bed had been available earlier, they would have been willing to be admitted, and a crisis and longer stay could have been avoided:

*"...not being turned away from A&E with the words "it's not our job to stop you from killing yourself" by mental health staff when an informal inpatient stay was withdrawn due to lack of beds..."*

*"...There are no respite beds anymore. This is such a shame..."* (LEX612)

*"...I've noticed that care has deteriorated over the years, fewer beds mean that only the very unwell are admitted. There are no respite stays any more. There is no care, only containment..."* (CAR1194)

#### Continuity

Comments were made about failings in providing continuity when a person was transferred from one ward or hospital to another, and even more so when leaving hospital and returning to the community. Obviously, there are a variety of ways of expressing continuity of care, but over 20 carers (3%+) gave accounts of issues with continuity using the phrase 'continuity of care' and similarly 14 people (2%) with lived experience described issues with continuity of care/treatment.

There was a desire for a 'planned discharge', with the implication and direct statements that some people leaving hospital have little or nothing in the way of aftercare or a plan for ongoing support:

*"...Make sure the care is there and a proper discharge route is in place because I was left with no medication or aftercare after spending 18 months in hospital. I ended up in a homeless hostel and had to get an emergency appointment with a GP for meds and urgent aftercare..." (LEX140)*

Having something meaningful to do with one's time when discharged was also cited as important:

*"...I found coping strategies such as counselling, exercise, journal writing, mindfulness and voluntary work very helpful in keeping me well. I also found setting out a routine with different things to do helped motivate me to focus my mind in more helpful ways..." (LEX1291)*

Some respondents suggested that there ought to be a planned transitional period from hospital to the community, and one suggested that some contact with the community mental health team that would be supporting them following discharge, whilst still under hospital care, would have been beneficial. Quite a number of respondents suggested that funding of community services (issues around funding featured in the accounts of nearly 90 carers (12%) and nearly 40 people (5%) with lived experience), particularly the perceived lack of it, was an obstacle to care that might otherwise prevent the need for 'sectioning':

*"...A decent care plan, high levels of supervision from Community Psychiatric Nurses and consultants in the community, work on improving drug compliance and work on identifying warning signs and symptoms – but ultimately more funding to allow all of this to happen..." (LEX241)*

Continuity in mental health staffing was also deemed important by some:

*"...Since his discharge my son has been in supported housing - this helps but I have honestly lost count of the number of care coordinators who have been assigned to his case and as a consequence they do not know him or when his mental health needs change. He has also had several different psychiatrists... Continuity and the development of a therapeutic relationship would have helped..." (CAR940)*

Respondents stated that regular (and even daily) contact from mental health professionals was required. In the region of 50 people (6%) with lived experience and 45 carers (6%), talking about the support following discharge from hospital (and section), stated there should be much more regular and frequent 'follow-up'. This would be proactive in nature and would help the recipient to access the required services in the community, rather than leaving them to find their own way.

*"...Often you are waiting months and months to access the CMHT and the resources they have... Creating an action plan for the first few days out of hospital so that they do not simply slip back into old habits... work with people to find a group or sessions they are interested in..." (LEX380)*

Several respondents talked about practical support (for example 22 carers (3%) talked about the need for 'holistic care'), such as with accommodation (at least 25 people (3%) with lived experience described the need for support around 'housing'), finances and accessing benefits, but within these were respondents seeking recovery-orientated approaches, i.e. seeing social recovery as of equal importance to managing clinical symptoms:

*"... It is important that there is an actual life waiting for you when you leave hospital. Often the situation you were in before detention is drastically different when you leave. For example, you may have lost your job, lost contact with friends and family, you may have lost your home etc. The hospital needs to make sure you do not completely sever all ties with your life in the community, otherwise what do you have to lose by going back to hospital? The more positive things you have in your life, the more incentive you have to work on recovery and staying well. Why bother on being well if your life in the community is difficult, lonely and has no direction? This requires proper support in the community from CMHTs, a multidisciplinary approach which focuses not only on medication compliance but also therapeutic support, help with employment..." (LEX390)*

### Training and awareness

Police, GPs, paramedics and schools were identified amongst others as needing either specialist training and/or their mental health awareness raising.

*"... Mostly the problem is the police. I'm a man, I'm crazy, it's late [at] night and because I'm crazy my behaviour is aberrant - arresting me is so much easier than trying to understand. And if you arrest me, I retaliate and pretty soon the locked ward is the inevitable outcome. This inevitability is not inevitable and could readily be pre-empted by police with better training. ..." (LEX69)*

*"...There is an urgent need for training in such crises, with the police, those that work on A&E wards, in schools and with the families supporting those with Autistic Spectrum Disorder..." (CAR356)*

*"...train paramedics in mental health and train paramedics to deal with crisis situations..." (LEX212)*

*"...better training for professionals who work with families, health visitors, GPs etc, they can spot signs of mental illness ..." (LEX221)*

### Peer support workers

Those with lived experience saw a role for peer support workers (over 40 or 5% mentioned peer support workers in their accounts) and for increasing their numbers, seeing them as having a role in better mental health care both in hospital and the community.

*"...Peer support groups in the community which are not run by professionals... perhaps using the word 'survivors'..."(LEX95)*

*"...Good peer support from a user led peer support project..."(LEX1430)*

*"...peer support and good after care..."(CAR1186)*

#### A limited care offer

*"...A change of paradigm, so that eradication of symptoms isn't the goal of treatment ... but finding a life worth living is..." (LEX1595)*

There were a great many comments on the quality of care (there are of course a variety of ways of expressing this, for example, around 50 people (6%+) with lived experience and 60 carers (8%+) described the care they experienced as 'poor') and just how limited the treatment offer could be. This in most cases referred to hospital care, but it also was applied to community provision. It was widely perceived that treatment was largely about medication, medical model orientated, clinical symptom focused and lacking in social recovery approaches. Hospital wards were seen as offering little in the way of meaningful activity, and sometimes little attention was given to the quality of life of people living in the community.

One comment specifically on a Community Treatment Order (CTO) concerned the focus on medication and not on the person's broader recovery. Their "*quality of life*" did not seem to matter to the mental health professionals involved in their case:

*"...On a Community Treatment Order care is unhelpful and inadequate. It does not allow me to recover as I am forced to continue taking medications, which make me physically and emotionally unwell. It needs to be addressing my issues and helping me to reduce and stop the medications in an appropriate manner. My quality of life is extremely poor, but unfortunately psychiatrists are not interested in it..." (LEX1706)<sup>7</sup>*

And on the inpatient experience:

*"...I wouldn't say there was much active care. I was put on medicine which helped, but due to staff shortage I was unable to receive psychology which I think would have been really helpful... I found the nurses had no time at all and were never available. When I was first sectioned I was told about how I would be worked with, given a recovery pack, told about 2 x daily short chats with nurse and a couple of 45 min chats a week. None of these ever took place. There was very little occupational*

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<sup>7</sup> Repeated quote.

*therapy. In fact, most time was just sat on the ward watching the TV...there seemed very little active treatment...*"(LEX1609)

*"...A shortage of staff who spent most of their time catching up on notes, let us in and out of the ward and administer meds. There were barely any therapeutic activities on the ward, although there were some in the unit. We were generally left to ourselves most of the time - stuck in front of shit telly ..."* (LEX1704)

*"...please make it [mental health care] trauma-informed rather than dominated by psychiatrists and the psychiatric medical model. Please introduce much more choice in terms of available treatments, to include peer support, psychological therapies, complementary therapies, art therapy, music therapy etc..."* (CAR538)

*"...What care? Just left wandering around a ward begging for staff to open the office door so I could have shower gel or something while they sat around doing nothing or breaking up fights or restraining people. 4 staff to 19 patients! ..."* (LEX599)

One respondent noted that in addition to the limited therapeutic offer, a shortage of beds meant being discharged before they were ready for this:

*"...During any of the times I have been sectioned I have received no other treatment than having my medication dispensed to me and the odd available activity, staff have been so limited that getting 1 to 1 discussion with them is pretty much impossible, with 4-5 staff running a 13 bed ward it's understandable why. No therapy treatment has been available on any of the wards I have been admitted to, and when it was claimed to have been available the psychologist was on a few months leave with no replacement. Also limited bed spaces have always ensured that us service users are made to feel like we need to be rushed out the ward because our particular bed is in high demand, therefore resulting in patients like myself being discharged as quickly as possible despite still expressing suicidal thoughts..."* (LEX1649)

*...[medication] it has been the smallest part of my recovery journey ...and so much has revolved around understanding my experiences and finding ways of living with them ... these approaches were not really touched in the ward, except for a few conversations with some good staff members every now and then. Such useful interventions were much more ad hoc and seen as an additional rather than the crux of the work..."* (LEX1595)

One person commented that if forcibly detained in hospital, the care offer should be comprehensive and intensive.



*"...It was ok. The treatment during section is no different to informal really except you are unable to leave of your own choice unless agreed. It could have been better. I believe people who require a section should instantly receive intensive therapies or care..." (LEX727)*

### Appropriateness of inpatient settings

This theme concerned how the inpatient setting in which a person was placed was not designed around a particular group's needs, including that of:

- Women (and a desire for a choice over single sex wards);
- People with autistic spectrum disorders (sometimes stating staff having little apparent knowledge of these conditions);
- Children placed on adult wards (relating to safeguarding and lack of peers).

There were a number of comments on the need for leave when sectioned (and Section 17 in particular<sup>8</sup>). Respondents commenting wanted greater flexibility in its application, stressed its importance in maintaining links with the family, or more staff available to enable it. There was a small number of comments on the Ministry of Justice role and the delays involved in decision on Section 17 Leave.

### The experience of those from Black and Minority Ethnic (BAME) communities

The views expressed by those from BAME backgrounds were very similar to the general sample. For example, when exploring whether being detained under a section of the Act had been the best approach for those with lived experience, BAME people with lived experience stated (like other respondents) that better support in the community might have prevented the need for a section. They wanted proactive care, greater availability of care, and access out of hours. A small group of respondents made the observation that people from BAME communities were overrepresented in mental health services:

*"...A much more creative and trauma informed approach to mental health services may deliver better outcomes; particularly for BME people who are over represented in MH services..." (CAR1652)*

Racism, racial discrimination and racial bias (in diagnosis or otherwise) did not feature in many accounts. The need for greater cultural awareness training amongst mental health professionals was also mentioned by a very small number of respondents. Those mentioning it did not describe what this might look like. One respondent suggested that people from BAME communities should have a right to culturally responsive services:

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<sup>8</sup> In a small number of cases, comments on Section 17 may have been referring to Section 117 Aftercare.

*"...the right to services responsive to BAME communities if requested as part of the aftercare plan..."*  
(CAR1458)

Another thought that people from BAME groups should be cared by other BAME people, who would understand their needs better.

BAME respondents wanted what other respondents wanted – and this was improved mental health services in the community that might prevent the need for detention and or help a person on leaving hospital; better crisis support and more intensive and holistic offers from community mental health services:

*"...Close monitoring and support...Respite care/services...Access to crisis emergency care with an individual care plan for relapse if the patient wishes. I have access to a respite/crisis accommodation which is the best thing I've ever had..."* (LEX298)

*"...Having appropriate support when requested in the local community, in our home..."* (CAR100)

*"...Monitoring and high level of support in the community... 24-hour access to therapy if possible. A place to call home and prompt and good talking therapy. I was not given this. I was homeless and not told what I could do about this..."* (LEX527)

*"...A well planned holistic person-centered care assessment and care plan with a higher level of support from trained staff that have lower caseloads and quicker access to funding..."* (CAR1321)

*"...Availability of properly funded support/therapeutic services without the ridiculous 6 months to 2 years limit that seems to apply nowadays. If you are recovering from an abusive & traumatic childhood, it can take much longer than that and repeatedly feeling 'abandoned' prolongs the time needed for recovery. There are some really good services in the community, but being denied access to them because your 2 years is up is detrimental..."* (LEX1215)

*"...By having a community service that is not based on getting people discharged back to GPs as soon as possible. There is no care like there used to be..."* (LEX1628)

*"...Community Services have become so stretched due to cuts and lack of funding that the chance of you seeing a CPN or Support Worker in the community is almost non-existent unless you are in Crisis and even then, it's hit and miss..."* (LEX1648)

*"...I was discharged September 2016 and am still awaiting a CPN or Support Worker in the Community..."* (LEX1648)

One person contrasted the care received by a community mental health team with the proactive, accessible and 'wrap-around' support they had received from a charity when leaving a prison.

### Reforms to the Mental Health Act and its guidance

There are a group of themes that emerged from the questions asked both to those with lived experience and carers about what change they would make to the Mental Health Act. Quite a number of rights, changes and reforms were proposed and the most prominent are listed below:

"...[I want] *the same as everyone else...that's what the Human Rights Act is all about surely?...*" (LEX1506)

### Community Treatment Orders (CTO)

A 'health warning' on the themes in this section is that relatively few people commented directly on the CTO experience, even though quite a few people reported having been on a CTO (15%), or having cared for someone on a CTO (28%).

Just over half of both those with lived experience (51%) and carers (54%) reported that being detained under the Act had been the best approach at the time, and a little short of a third of both those with lived experience (31%) and carers (28%) thought it was a largely negative experience. However, the vast majority did not appear to be referring to their experience under a CTO, but rather detention in hospital.

Table 11: Experience of being under a CTO

<b>Yes</b>	<b>115</b>	<b>14.6%</b>
No	453	57.7%
I don't know	142	18.1%
Missing	75	9.6%

Table 12: Experience of caring for someone on a CTO

<b>Yes</b>	<b>211</b>	<b>28.2%</b>
No	230	30.7%
I don't know	160	21.4%
Missing	147	19.7%

### A punitive measure

"...*The CTO seemed punitive. I don't think it was necessary and I was only in hospital so long because the depot (injection) they put me on made me even more psychotic and I was on that for 5 months and hospitalised on and off during that time...*" (LEX203)

*"...My experience is the individual wants to be off the section or CTO as soon as possible - even when the individual wants to engage with their treatment and be proactive, sometimes they feel that the section or the CTO is punishing them..." (CAR123)*

#### No end date

A carer saw the CTO as having "stolen her son's autonomy":

*"...We are both unhappy that the CTO seems to be without an end date and plan to discuss this at the next meeting with his psychiatrist. I feel strongly that they should not be in place for more than 12 months and should automatically come to an end. It should then be up to mental health professionals to make a case as to why it should continue for a further limited period..." (CAR1652)*

#### Medication-focused approach and not addressing other issues

The concern that mental health treatment was often not holistic and mainly concerned with medication was a consistent theme across the survey.

*"...It [the CTO] does not allow me to recover as I am forced to continue taking medications, which make me physically and emotionally unwell. It needs to be addressing my issues and helping me to reduce and stop the medications in an appropriate manner. My quality of life is extremely poor, but unfortunately psychiatrists are not interested in it. They turn a blind eye and deaf ear to my sufferings..." (LEX203)*

The above quote alludes to a perceived paucity of care, non-holistic care, and/or care that is purely symptom-focused and that does not embrace 'recovery' in its fullest sense.

#### A route to accessing care

Several respondents commented on a perceived lack of beds and difficulty in obtaining inpatient care, and a CTO was seen as a means of guaranteeing access to a bed (and other treatment) if needed:

*"...I have been both sectioned and on a CTO. With the lack of mental health beds in the country it is the norm today for most in patients to be sectioned. As it is the norm the care you receive is universal. The system is badly broken, and I have noticed that people on the wards have acuter symptoms than they have [had] in the past. This means that their decline is not being picked up and treated in the community sooner. When on CTO I have been able to access in patient care quicker..." (LEX1199)*

*"...As the daughter and more latterly nearest relative for my mother, I can say that without detention and CTOs it would have been almost impossible to manage my mother's health and as a*

*family. Being able to draw on the support and authority of the NHS and social services under the Mental Health Act has been invaluable..." (CAR1656)*

The combination of a CTO with Section 117 aftercare was seen as a powerful tool, and one respondent stated:

*"...He...was able to return to his home after his medication was increased, and additional support was provided following his discharge, this would not have happened unless he had been Sectioned and discharged under S117 with a CTO..." (CAR1058)*

#### Not being listened to

This is a theme throughout carer responses, and to several of the survey questions. Many carers felt their knowledge of the person they cared for, years of experience with them, and experience of what has worked and what has not in the past was not sufficiently taken into account.

*"...On the CTO I felt isolated and ignored most of the time and patronised other times. I gave clear advice on what I felt would work and whilst this was noted, no action was taken so my dependent's chance of recovery was non-existent. If you keep doing what you've always done, you'll keep getting the same outcome..." (CAR1458)*

*"...I, as a carer, always have a far better experience of communication in the hospital. Under the CTO communication with me, as a carer is negligible...I recognise that the individual doesn't actively ask for involvement of their carer. But the CMHT should recognise and understand his history and utilise the knowledge and support system of the carer for the benefit of their patient..." (CAR1461)*

#### CTOs incentivise recovery

Interestingly the 'threat' of admission when on a CTO was seen by some carers as a positive, partially as a motivator to the person to stick to their treatment regime, but also because the CTO allows rapid access, as previously stated, to more intensive inpatient care if someone is unwell:

*"...We know from our daughter that the CTO and fear of hospitalisation did serve to restrict the extent of her relapse and weight loss..." (CAR1179)*

*"...On CTO, it's really important to know that, if needed, the Doctor can send her to hospital relatively easily.... (CAR462)*

*"...the best process once we got it in place. Enabled a very clear model to be established with [individual under section] that demonstrated everyone was working to their best interest to keep them home. The risk of 'being called back' was a massive supporting incentive to help recovery..." (CAR386)*

Another carer spoke in a similar vein, stating that the patient was clear on the consequences if they did not follow the treatment plan.

### Tribunals

There were 41 carers (6%) and 44 people (6%) with lived experience that made mention of tribunals. Some of those were concerned that the tribunal process is biased against the patient. A few had experienced a tribunal where they felt they had been treated very unfairly. A desire for more regular tribunals and free legal advice on tribunals featured in the responses. There was a perception amongst a small number that hospital staff had refrained from telling patients they have the right to a tribunal. There were few comments that were positive about tribunals.

Some carers said that they weren't made aware of the rights of appeal procedures, and/or they perceived the tribunal process as daunting and it added pressure and stress to the patient and wider family. Some carers thought their views were not taken seriously at the tribunal, because they were not mental health professionals. There were accounts of feeling lost/overwhelmed by the tribunal process, and those who took it on reported dedicating a vast amount of time and energy to support their family member's/friend's case.

### Changes to 'nearest relative'

There was a perceived rigidity in the current guidance and legislation with regards the 'nearest relative' under the Act. Around 22 carers (3%) and 28 people (4%) with lived experience talked about specific reforms to the 'nearest relative' under the Act; some wanted the right to greater information for the nearest relative, but most wanted the patient to have the right to choose their own 'nearest relative' and for the current rules to be relaxed around this.

*"...The system of nearest relative is too inflexible. Right now there is a strict pecking order of who can serve as nearest relative. In my case my mother used to perform this role but she now has Alzheimer's and she lacks capacity. Under the current system I cannot specify who I wish to serve as my nearest relative. The responsibility would automatically go to my oldest sister - a sister I do not get on with..." (LEX3)*

*"...The determination of the nearest relative, the current legislation does not allow for more than one and has outdated hierarchy. The patient should be able to have more than one or a group and the decision on who that person(s) should be is an agreed position..."(CAR67)*

*"...The person or people who have regular contact with and provide support should be consulted in a section tribunal, not a relative who may have a poor or non-existent relationship with the patient. It is archaic to make it the oldest family member..." (CAR1511)*

### People are being discharged just before their tribunals

*"...I have also often seen consultants discharging patients the day before the tribunal as they knew they would be released. People should be discharged/made informal when they are no longer detainable. It shouldn't only happen if there is a tribunal..." (LEX82)*

### Involve people with lived experience of poor mental health to improve tribunals

*"...Perhaps former service users being involved in manager's reviews and tribunals in a similar way that people with lived experience are involved in learning disability Care and Treatment Reviews would be an idea..." (LEX94)*

### Fighting/struggling to get a tribunal

*"...Having worked with the MHA I was already aware of my rights; however, no one issued my rights to me until I had already been on the ward for over a week. I had to fight to get a tribunal as no one was forthcoming with the information on doing so, and even when I tried to arrange this off my own back, I was pushed back, saying I had to wait for the nurses to enact it. I was devastated. My wife was stopped from visiting me as I had to be placed out of area due to working for the trust. The communication was beyond poor..." (LEX186)*

*"...I was finally released on the condition that I dropped my tribunal and ceased contact with the lawyer the independent MH advocate got for me...No one is informed of their rights etc or that they can apply for a tribunal and solicitor. The advocate saved my life by helping me get out of that hell hole..." (LEX305)*

*"...We pondered whether to appeal xxxx's section but in any event, we thought the 14 day allowance was far too short. It took us many months and many telephone calls to understand the system, the agencies involved, and the roles they play. The mental health advocate could not advise us so we calculated that the tribunal would not agree to allowing xxxx's release into our care until he had been assessed by the medics...and found out later that few appeals are indeed allowed... We had no time for legal advice as events moved so quickly..." (CAR539)*

### Perception that tribunals are unfair

There was a perception amongst a small number of respondents (for example 6 people (1%) with lived experience indicated this) that there were more rights and safeguards in a criminal court case than in a tribunal. One person with lived experience wanted tribunals to be more court-like, with more cross examination of mental health professionals and recording of the proceedings.

### Carers' voices should be heard more at the tribunal

'Carers not being heard' is a recurrent theme in responses to most of the survey questions; in some cases, the patient's family/carers was not informed about the tribunal:

*"...When our daughter appealed against her section, we were not informed until close to the date of her tribunal - which came as a huge shock and was a cause for massive anxiety for us. I would like parents/carers to be kept fully informed in this kind of situation..." (CAR1020)*

### Tribunal process is distressing, especially for children. Not enough support for them and parents' voices should be respected more

This quote reveals more than just the challenges posed by the tribunal process, but also the decision to section a child and the apparent lack of parental engagement in this process:

*"...Parents must be involved during assessment. How can two AMHP doctors assess a child that they have never met, I knew my child's needs and could articulate my concerns through a tribunal. Coincidentally, my twelve-year-old child had to instigate this tribunal and appoint her own solicitor all while in a state of disassociation and whilst in emotional mind, how can this be right? As I've mentioned before my child's diagnosis states that the sectioning, the way it was delivered, and the subsequent treatment was a factor in her illness..." (CAR71)*

### Hospital Managers

There was a total of 15 comments (<2%) made related to hospital managers, and these were largely from carers. Understandably, not all the comments were necessarily referring to the definition of the 'Hospital Manager' under the Act, but instead to those managers running the hospital, or in some cases it was unclear which they were referring to.

### Bias

One comment from a person with lived experience stated they felt that Hospital Managers were largely biased towards the clinical team and less likely to take on the concerns of the patient.

### A concern over hospital manager powers

*"...I would abolish the right of appeal to the "Hospital Managers" as this is a duplication of procedure when the Mental Health Tribunal appeals system is available. In my experience the composition of it and the expertise required is far below what is required to decide on complex mental health conditions..." (CAR957)*

*"...In my son's case being subjected to a Community Treatment Order with a regular depot injection has worked well until recently. He appealed to the Hospital Managers to be discharged from the CTO; and against professional advice they granted it...we are awaiting the outcome with trepidation as he is no longer receiving medication after 20 years and numerous incidents etc..." (CAR957)*

### Section 117 Aftercare

24 people with lived experience (3%) had experience of Section 117, but there were relatively few comments by them. There were a few from carers. There was a perception amongst some that even



when 'on' Section 117, the entitlement had to be pushed for. A few more carers (22 or 3% made at least some mention) felt that Section 117 was extremely helpful, but that one had to argue for it, and even discover its existence by oneself:

*"...The Section 117 aftercare was not pointed out to us and we found out through my research that he was entitled to support such as free prescriptions. We have had to push for this and were not made aware of the aftercare when he left hospital..."* (CAR271)

Several carers made comments to the effect that Mental Health Trusts were failing in their duties to provide Section 117 Aftercare where there was an entitlement.

### Representation immediately on being sectioned under the Act & second opinions

This was very commonly stated by those with lived experience and was a significant theme. Views on the type of representation differed but lawyers, family, friends and mental health advocates were all mentioned, with in the region of 60 people (8%) with lived experience mentioning the latter.

*"...A mental health lawyer representing the patient should be appointed to represent the patient's views and needs..."* (LEX840)

*"...[I want] the right to see friends and family. The rights to an advocate..."* (LEX127)

*"...Apart from 136 there should be a statutory requirement for both an advocate to be present and for the Mental Health Act assessment to be recorded. You're taking away someone's liberty and yet there are less rights than in the criminal justice system...That I am not afforded basic rights speaks volumes..."* (LEX10)

Related to this was the right to a second opinion, which was mentioned both by those with lived experience and carers, many stating explicitly that this should be a right on being detained under section:

*"...I had to fight tooth and nail for a second opinion outside the Trust and our daughter was then transferred to the [name of hospital] where she was diagnosed with paranoid schizophrenia..."* (CAR395)

### Changes to appeal process

There was a desire for a right to immediate and/or more frequent review:

*"...To go to a tribunal first and then have a discussion regarding length of time in hospital. Much like a normal court that gives a sentence to someone..."* (LEX170)

### A right to information

There was a related issue about being given information both for carers and those with lived experience:

*"...They should be told on being sectioned that they have the right to appeal the decision..."*  
(CAR14)

Several respondents stated that getting information about the current rights of appeal was often difficult.

*"...The right to appeal...to have it explained as many times as necessary..."* (CAR159)

### The right to refuse treatments

Quite a number of those with lived experience had concerns over their medication and wanted to have more of a say on it; several wanted the right to refuse medication:

*"...right to refuse medication, ECT and other invasive treatment..."* (LEX83)

*"...The right to refuse medication...after all they are already being detained in a safe place..."*  
(LEX1651)

*"...The person should have a right to refuse medication if they feel it is not right for them and request the treatment they want to receive..."* (CAR436)

At least 20 people with lived experience talked about having choice over their care/treatment:

*"...To be able to choose which professionals you deal with. To be able to decide what sort of treatment you have without having to have meetings with people who know nothing about you and don't care to learn..."* (LEX AK34)

### A right to smoke

There were in the region of 20 comments on smoking (i.e. 3% of those with lived experience), mostly referring to the smoking ban and desiring a right to be able to smoke in open spaces.

### A right to carer input

This saw carers as having a role in the multidisciplinary team. This might include a right to 24/7 contact with a carer, but also that they should be informed in a timely way on the support of the person they care for. Some respondents wanted them to have increased powers to challenge decisions by the care team:

*"...Maybe the second time when I was being sectioned this could have been discussed with me and my husband as to whether this was the best course of action before someone else decided this was the best course of action..." (LEX197)*

*"...My husband...He was treated as a conflict to my care rather than included and asked his opinion..." (LEX237)*

### **A right to carer support**

Both those with lived experience and carers thought that there should always be an offer made to provide some support, advice, and advocacy for carers.

### **A right to advocacy**

This was cited by a significant group of respondents, sometimes expressing it as a general right and sometimes specifying times when an advocate might be most needed:

*"...I think that everyone going through a section should be afforded an independent advocate (mandatory), like having your own counsel when going through court..." (CAR234)*

*"...They should have the right to an advocate at the beginning of their Section if there is no competent relative who knows how the system works. They should also have the right to be able to access legal information (through an advocate if necessary) so that they are aware of their rights...It isn't enough to tell them they are incarcerated for a certain period without knowing what that means. My experience is that patients often think they won't be able to leave or will be in hospital for far longer than they will actually be there..." (CAR1001)*

*"...Rights to an advocate at assessment time..." (CAR56)*

*"...The patient should have the right to ask to see anyone they like, nominate anyone as a advocate..." (LEX 60)*

## **Experience themes**

### **It saved my/their life**

There was a large group of people both with lived experience and carers who saw the necessity of compulsory treatment under the Act. They often did not have an entirely positive experience of their treatment under the Act, but nevertheless at the very least saw this as "*a necessary evil*" (LEX632).

Around 40 respondents (5% approximately) who had experienced being sectioned who said that this had saved their life. Typical statements from those with lived experience and carers included:

*"...In hindsight absolutely yes. It saved my life. At the time I would have argued there was nothing wrong with me..." (LEX459)*

*"...It has at times been the best approach, it kept me alive when I would have definitely died without it..." (LEX926)*

*"...Being detained saved their lives..." (CAR47)*

*"...at the time my wife was at a high risk of suicide so the section probably saved her life..." (CAR1336)*

*"...It was very important that I was sectioned ... I was prevented from committing suicide by a Police Sergeant and taken to a police station where I was sectioned..." (LEX1218)*

### **A loss of self-agency**

For those who saw being sectioned as a negative experience (and even for some who thought it was the right decision for them) there were a range of descriptions, but rough or inhumane treatment, restraint and being forced to take medication are reported by many respondents. Several respondents reported that there were other possible options that were not considered. The loss of rights and the loss of a say in one's own life featured prominently in respondents' accounts:

*"...At a time when you are vulnerable and seriously ill you find yourself losing your rights and any say in anything. This isn't healthy for anyone. I felt as though I was being judged and ordered around. An advocate helped me more than once and made complaints too. My views and feelings were dismissed by [psychiatrists] ..." (LEX1704)*

### **A traumatic experience in its own right**

Some respondents described the experience of being detained under the Act as being traumatising, this in most cases referred to their treatment under section and being treated against their will, and the incidence of restraint is mentioned in particular.

*"...Being sectioned has been an incredibly stressful and traumatic experience for me and has increased my mental distress and state of confusion. What is needed are more crisis houses and places of safe sanctuary where people can go in states of need. Also, the use of the police to transport people is awful and very distressing..." (LEX59)*

*"...at other times and for other people it has been an unhelpful, traumatising and horrendous experience, which has led to/ created/ exacerbated a range of mental health triggers and experiences..." (CAR6)*

*"...Being sectioned was one of the most traumatic experiences of my life. Sadly, as a result of being sectioned I developed PTSD as the direct result of the way I was treated..." (LEX1091)*

Some respondents such as the one quoted above felt the experience added to their mental health problems, and some likewise saw the experience as compounding existing distress:

*"...being held in hospital against my will was a deeply distressing, painful and at times humiliating experience that only compounded the trauma I was already living with at that time in my life..." (LEX1650)*

### Use of restraint

There was concern over the use of restraint (in the region of 80 people or 10% with lived experience mentioned being restrained) and accounts that described what could have been serious assaults carried out by staff on patients. These included accounts of limbs being broken. There were accounts of restraint where the person with lived experience felt excessive force had been used.

*"...I was held down and injected and although I needed it I ended up covered in bruises. They could have been more gentle. Also, I was kept in de-escalation and after saying I needed the toilet they wouldn't let me. I couldn't hold it in and ended up going in a plastic cup. That never should have happened..." (LEX1438)*

*"...Being restrained by 5 men and taken into a fellow patient's bedroom, thrown on to a bed. Having my skirt pulled up, underwear pulled down and injected with heavy tranquilisers is not care..." (LEX483)*

### Coercion: the threat of section

From a few carers perspectives the 'threat' of a section has been useful in motivating the person they care for to comply with treatment. But it was more commonly perceived negatively. Around 20 of the 'other respondents' (4%), those who described themselves as having mental health problems or as caring for someone with a mental health problem, described experiences of such coercion.

*"...my son was not sectioned but threatened with section if he did not agree to be admitted on a voluntary basis. I later learned that this was not best practice was not allowed but nonetheless it happened..." (OTH1328)*

### Treated with dignity and respect?

Both those with lived experience and carers were asked if they were treated with dignity and respect. A number of experience themes emerged from these two questions:

*"...During my first experience of being sectioned I was treated with no dignity or respect and will never recover from that terrifying, degrading experience..." (LEX1178)*

Many people had a mixed experience. Some periods in hospital under section were more positive than others, and others found that this varied depending on the staff who were there with them on a particular day.

*"...Sometimes, maybe even most of the time. This was too dependent on an individual staff member's personal feelings, though. Some would make an action that was supposed to be keeping me safe feel very intrusive, whilst others showed more understanding of the loss of dignity that comes with being closely monitored 24 hours a day..." (LEX1215)*

*"...there are some amazing people working in mental health but there are also quite a few that really shouldn't be! So yes and no depending who was looking after me..." (LEX1248)*

*"...Yes, even though I was told to give my phone, clothes ...to the nurses it was all explained to me the reason why. They were respectful to me and very empathetic and they were also caring and made sure I had something to eat and that I was as calm as I could be..." (LEX1496)*

Quite a number of people with lived experience were positive about how their carers had been treated.

*"...Yes, when visiting, they had good and welcoming treatment from staff and patients..." (LEX496)*

*"...They were, yes. They were eventually notified of my whereabouts and they were then kept in the loop..." (LEX576)*

But a "yes" was not always a ringing endorsement and some of those with lived experience felt their carers had a mixed experience.

*"...Yes on the first occasion and they were blatantly lied to on the second..." (LEX880)*

There were several comments to the following effect:

*"...Yes, more so than me..." (LEX1280)*

The key themes that emerged concerning carers were:

### **Carers not being listened to & not being informed**

A significant theme in the accounts of carers (and those with lived experience) is that carers' views were often not listened to or taken seriously. In the region of 75 carers (10%+) described feeling ignored by the clinical team.

*"...If I had been listened to before the hospital admission then this might have been a better outcome for her. To this day I have to fight for professional to listen to the carers. Professionals forget that it is the carers that have lived and have known this person for most of their life whilst doctors/consultants only ever see them for short periods. This needs to change and carers should be listened to..." (CAR A53)*

*"...You become quite the expert in monitoring the signs of deterioration but as a carer are often ignored or marginalised by MHS staff..." (CAR725)*

*"...I was devalued, and my advice not listened to. Yet the assessment reports produced were based on the information I provided...I was asked not to phone the ward for information, even when he was seriously ill with [a physical illness] because they were 'too busy'..." (CAR12)*

*"...They also did not inform them [my carers] when they discharged me even though they had visited every day and would have taken me home themselves..." (LEX101)*

*"...My family were never updated on me and never called back when they tried to contact the hospital. The hospital only contacted them when they wanted to discharge me back to my family..." (LEX177)*

*"...My parents complained on several occasions, however my parents' complaints were ignored. When my parents came to visit, they were left languishing in the airlock whilst staff went searching for keys. I feel that parents were deliberately kept out in order to disguise the abuse that was going on..." (LEX1091)*

*"...Not at all! They weren't given any support or guidance throughout the experience and were treated awfully when they tried to make suggestions regarding my care..." (LEX597)*

### Being treated with disrespect

Some respondents stated that their carer was treated disrespectfully:

*"...my family told me that when they came to visit or had something to ask they were sometimes greeted with a moody response..." (LEX235)*

*"...My friend visited me whilst I was sectioned and he was spoken to rudely and treated with the same contempt I was..." (LEX8)*

*"...they would often be ignored and treated rudely..." (LEX390)*

### Lack of privacy for family contact

*"...I wasn't able to have private time with my family..." (LEX1124)*

### Carer/patient dynamic

Several respondents pointed out that the question being asked in the survey did not account for particular dynamics with families or carers, where there was a strained relationship for a variety of reasons and where, for example, a patient may be concerned that their carer's account was given more credence than theirs.

*"...I made a conscious effort to exclude family members from my in-patient experience as they had been a contributory factor in my illness..." (LEX AJ30)*

### The experience of those with Learning Disability and or Autistic Spectrum Disorder

This subsection is not a theme as such, but a brief commentary on whether the responses given by those people with lived experience who had a diagnosis of Learning Disability and/or Autistic Spectrum Disorder were discernably different to other respondents.

Approximately 6% of the sample (47) had either diagnosis and the vast majority of those with Autistic Spectrum Disorder also had a Learning Disability diagnosis. Most of those with these diagnoses completed the easy-read survey forms and had not given permission for their responses to be quoted.

It was also apparent that most of those with Learning Disabilities and/or Autistic Spectrum Disorder were likely to be current inpatients and currently detained, as a proportion of Easy-Read and other hard-copy forms had been distributed to inpatients units including mental health secure units. And the survey forms of these respondents were often completed with the assistance of a mental health professional, who had often added the diagnosis and other demographic data.

Understandably the responses given were much shorter than many other respondents', but there was no real difference in the responses of those with Learning Disabilities and/or Autistic Spectrum Disorder to other respondents.



## Conclusion

Whilst it is not possible to say if the 1,533 people (of the 2,060 in total) with lived experience and carer experience of the Mental Health Act who contributed to the survey were representative of all those with such experience, the views they gave and the experiences they shared struck a chord with other consultations and surveys Centre for Mental Health has conducted with both service users and carers.

There was, overall, an acceptance of the necessity of compulsory detention and assessment and treatment under the Mental Health Act, indeed both those with lived experience and carers talked about it having on occasion saved lives. However, there were concerns that in some cases that little or no treatment was available unless one was detained under the Act. It was also apparent in some cases that Community Treatment Orders were perceived as being the only reliable guarantee of quick access to a bed when inpatient treatment was required, and likewise was compulsory admission to hospital.

Some of those who responded to the survey described the 'paucity' of care offered when detained in hospital and stated that beyond medication and its review, much of a patient's time could be devoid of meaningful occupation or other forms of therapy.

There were comments both from service users and carers about the lack of appropriate community care and that often in their experience a person had to become seriously unwell, i.e. meeting the criteria for detention under the Act, before they would receive a service. Therefore, some of the commentary and requests for change did not concern the Mental Health Act itself and the remit of the Independent Review, but a broader reform of mental health care and especially a desire for earlier intervention in the community.

Being detained under the Mental Health Act does mean necessarily that the person detained understands the Act and its current provisions and for that reason some people with lived experience and carers did not feel able to suggest reforms to the Act. However, reforms were suggested. Several respondents expressed frustration at how the 'nearest relative' is currently defined and interpreted and wanted this to become more flexible. There were also concerns and desired changes to the tribunal set-up and role of the 'Hospital Manager', both were perceived by some as biased (in favour of the clinical team) and the former being quite intimidating. Some respondents felt they had had to fight to get a tribunal and that the information on this and other rights of a detained persons was not always given to them.

Tribunals were one area where some respondents saw a role for peer support workers and their advocacy. Having the support of someone with similar experiences and understanding, such as a peer support worker was seen as important.

Some service users, carers and other respondents all stated that at times they had felt coerced by clinicians with the threat of detention under the Act if they did not follow the clinician's view of care and sometimes simply when they felt they were stating alternatives rather than rejecting treatment; this was deemed unacceptable and an abuse by respondents.

Carers sometimes did not feel informed or taken seriously and this was echoed in the accounts of some of those with lived experience when recounting the experience of their own carers.

Some accounts revealed respondents' feelings that being detained had psychologically traumatised them, or perhaps given what we now know about the common experience of trauma in the lives of many people in with mental illness (e.g. Adverse Childhood Experiences), had retraumatised them. This was associated with physical restraint and accounts of mistreatment and even serious assaults (including sexual), but also due to the loss of agency and the ability to make decision for themselves. Psychiatric inpatient settings can be distressing and frightening places, and all the more so if one is unwell and vulnerable. Enforced treatment, especially medication was distressing to some people, and made more so when other treatments and particularly counselling and psychological intervention was not on offer. At a recent focus group for another project with Centre for Mental Health, one service user participant made a comment that they wanted putting forward to the Review. This concerned the witnessing of traumatic events and that both staff and patients *"...can be negatively impacted upon, and traumatised by some of the daily events in an acute psychiatric ward..."* and that patients as well as staff should be debriefed and *"checked to see their ok"*. It was the policy of this service user's mental health trust to offer this to patients, but she had never witnessed this happening and felt it was due to the *"pressure on inpatient staff"*.

The contributions of the respondents to the independent review's survey have been extremely valuable in shaping the outcome of the review. They have helped ensure that the voice of those with current and previous experience of being detained under the Act, and those that care for them, has made a significant contribution to the thinking of the Independent Review Panel in shaping its recommendations to the Government.