

A large, stylized graphic in the background. It features a teal house icon with a white circle for a window, centered within a large purple circle. The top-left corner of the page is a teal triangle, and the bottom-right corner is a teal triangle pointing upwards.

OUT-OF-AREA PLACEMENTS FOR PEOPLE WITH A PERSONALITY DISORDER DIAGNOSIS IN ENGLAND

FINDINGS FROM A FREEDOM OF INFORMATION REQUEST
AND REVIEW OF PUBLICLY AVAILABLE DATA

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CONFLICT OF INTERESTS

JZ is a consultant psychiatrist working in a specialist NHS personality disorder unit (Springbank Ward). KH is the clinical lead for Beam Consultancy that helps organisations avoid the use of long-term private hospital placements.

DISCLAIMER

‘Personality disorder’ is a diagnosis attracting criticism, with associated stigma. For the purposes of this report, we use the term ‘personality disorder’, to reflect the current use of the diagnostic term, not as an endorsement of it. We will use the wording ‘people with a personality disorder diagnosis’ (or words to that effect) to reflect this.

In the same way, we use the term ‘patient’ as we are referring to people who are admitted to hospital as ‘in-patients’. We are aware that other terms can be preferred, such as service user, client, or survivor.

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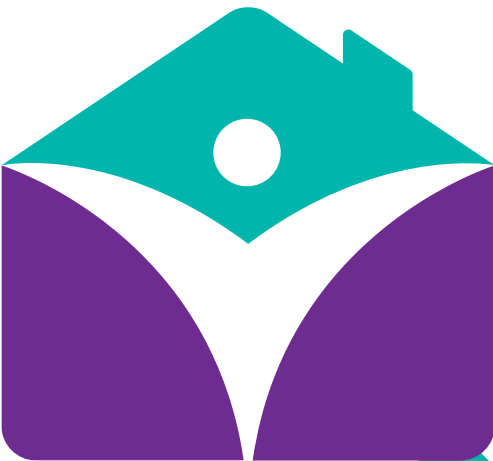
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HOW THIS REPORT WAS CONSTRUCTED

This report was based on a small grant project funded by BIGSPD and completed by Dr Vanessa Jones. Once the project was completed members of the BIGSPD executive were asked to volunteer to co-author a report to share the findings. The authors combined a mix of academic, clinical and lived experience of studying, providing and receiving both inpatient and community services for this client group. People who had received inpatient services centred around 'personality disorder' from NHS and private providers were invited to share their experiences. It is possible that there are people with very positive experiences of private services whose voices were not captured in this report.



FOREWORD

This report provides a welcome and important insight into an intolerable practice which must now be confronted by Government and NHS England. The idea that it is acceptable to send someone often long distances away from home to a locked institution for often nothing more than containment has to be challenged. Many people who are given the diagnosis of personality disorder end up being placed in these institutions – and too often get stuck there for long periods of time, sometimes years. It is a hidden scandal.

There is, at least, some sort of focus now on those who are placed out of area in acute wards, with targets set for bringing the numbers down, albeit that those targets have been missed. But there is no real focus at all on those placed in so called locked rehabilitation facilities sometimes far away from home. We know very little about the numbers of people in these facilities or their length of stay or the reasons why they are there. The truth is that we are spending vast sums of public money on private institutions which have a clear incentive to keep the beds occupied. This amounts to an enduring and unacceptable breach of people's human rights.

People with the diagnosis of personality disorder are amongst those most neglected by public services. They are routinely failed by the system – and yet the cost of this neglect is vast. This report seeks to shine a light on one aspect of such neglect. This is a case of 'funded and forgotten'. Yet it doesn't have to be like this. With the right support, it is possible for most of those who are locked up and hidden away from public view to live better lives in the community.

Time for action is long overdue. To achieve change, we need data on the numbers and categories of people in locked rehabilitation wards, and the cost of these placements. There has to be a clear commitment to end the inappropriate placement of people in such facilities with targets set achieve this reform. It must be seen as a moral imperative. We must use this report as a call to action, demanding change.

Norman Lamb



EXECUTIVE SUMMARY

The government has set a national ambition to eliminate the use of inappropriate out of area placements due to concerns about the quality of care provided; the disruption to individuals and their families; and the high cost of such care (1,2).

An out of area placement (OAP) is a unit that does not form part of the usual local network of services where a patient lives. The use of such placements for patients with diagnoses of schizophrenia, autism, and learning disabilities has attracted recent attention. Despite people with a diagnosis of personality disorder experiencing similar treatment, there is a lack of evidence describing the scale of the use of such placements.

OAPs often involve being treated in restrictive environments under a section of the Mental Health Act for long periods of time. Anecdotal reports have raised concerns about the oversight of the care provided, the expertise of the units accepting these patients and the inadequacy of pathways of care back to people's local communities.

This report looks at three sources of information:

- 1) Data from previous reports by the Care Quality Commission (CQC) on rehabilitation out of area placements.
- 2) Published data by NHS Digital on acute out of area placements at different time-points (acute OAP data)
- 3) Data gathered from a freedom of information request to clinical commissioning groups (CCGs) with additional information that is not in the public domain (FOI data).

MAIN FINDINGS

The main findings of the report include:

- 1) Despite government ambitions to end inappropriate acute out of area placements by 2021, these placements continue to occur at great frequency and at a significant cost to the taxpayer. The latest acute OAP data (February 2020 – February 2021) shows an annual spend of £112 million on 7,145 placements.
- 2) There is no consistent recording of relevant information on the use of placements and most CCGs (67%) were unable to provide even basic information.
- 3) The FOI data shows that at least 11% of placements are for people with a diagnosis of personality disorder and the acute OAP data shows at least 22% within this diagnostic category. The data presented here indicates that this is a likely underestimate, with the upper range potentially being as high as 46% of acute placements.
- 4) The average duration of an OAP for someone with a personality disorder diagnosis in the FOI data was 71 days (range 1 – 833 days. Median 42 days. SD 103). The low 'median' suggests that we received information on predominantly acute OAPs. People in rehabilitation OAPs have much longer durations of stay (median up to 952 days).
- 5) The FOI data shows that the private sector provides 99% of OAPs for people with a personality disorder diagnosis. 71% of placements are provided by 2 companies (The Priory Group and Cygnet).
- 6) The FOI data indicates that there is no consistent agreement between CCGs and providers on OAP duration prior to placements starting.
- 7) The FOI data shows that 67% of people with a personality disorder diagnosis in OAPs are detained under a section of the Mental Health Act.
- 8) The FOI data shows that people with a personality disorder diagnosis are not provided with specialist community treatment on discharge but are referred to generic community mental health teams or discharged back to their GP.

RECOMMENDATIONS

- 1) Data should consistently be collected and published on the use of rehabilitation OAPs, as recommended by the Care Quality Commission.
- 2) Data collection should use a consistent method for categorizing the reasons justifying placements.
- 3) A review of capacity and demand on specialist NHS in-patient services for people with a personality disorder diagnosis should be considered in line with the establishment of a service specification for Tier 4 specialist inpatient personality disorder services.
- 4) There should be accreditation schemes established and regular evaluation of specialist personality disorder placements against a nationally agreed service specification with clear outcome measures. The experience of patients or service users should be considered in these evaluations.
- 5) In line with the Community Mental Health Framework and RCPsych guidance on Services for People Diagnosable with Personality Disorder, we recommend that local specialist community provision should be developed in order to minimise the use of OAPs and to ensure a clear pathway of care into and out of such services.



LIVED EXPERIENCE TESTIMONY

The experiences below are told by people who received acute and rehabilitation inpatient treatment out of area within the private sector. Karina, Josie, and Sarah were subsequently transferred to an NHS specialist unit for a period of 1 year due to a lack of progress in the private out of area placements they were in. During their NHS admission, their detentions under the Mental Health Act were rescinded and they were never restrained.

KARINA

Throughout my time as an inpatient, I was transferred numerous times to different hospitals, and, more often than not, these units would be miles away from my home and family.

One of the units that I got sent to was 2 and ½ hours away from home and during the time I spent there I was treated horrendously. I was restrained daily and could be injected with sedative medication up to 3x a day, usually without being given the option of oral PRN, or even the chance to discuss why I was feeling so distressed with a staff member.

I had a similar experience, when I was once again transferred out of area to another unit 2 hours away from my home.

I had to wear an anti-ligature dress and was denied access to my underwear. This meant I had to wrap a blanket around my waist whenever I sat down, despite there being an option of a two-piece garment.

I was also restrained and injected regularly without being offered time to talk or oral medication. I remember a few specific memories from this unit which include a time when a nurse decided to inject me, (despite me saying I will take oral medication) just because I was crying.

Another traumatic memory I have is of me sitting in the corner of my bedroom very upset, and the staff member on my 1-1 decided to pull me across the floor by my anti-ligature suit so that she could apparently watch me better, instead of talking to me about what was upsetting me and asking me if I could move.

Neither of these units offered a reliable form of therapy and it was very hard to build up a trusting relationship with the staff. The impression I now get of these two units is the staff genuinely cared more about their liability as a hospital than caring and giving quality time to their patients.

JOSIE

'In 2019 I was placed in a private rehab near XXX.

I knew from the very beginning that I wouldn't see the outside world for a very long time. In the 18 months I was there I didn't even feel like a human being, just another statistic shut away from the world with all of my hope stripped away from me. It was a completely restricted practise, I left that ward for 6 hours in total in the year and half I was there. I was offered therapy, but as soon as I stopped engaging due to being too unwell they stopped it completely. I felt like the whole ward had completely given up on me. As well as only leaving the ward for 6 hours, I hardly ever saw my family. If I had an incident they'd stop my visits for 3 weeks. My family was my biggest support network and it was so obvious the positive impact they had on me. Yet they still stopped the visits.

They would hardly do obs properly and consequently this led to serious incidents happening and patients feeling completely abandoned and uncared for.

I felt so lost, scared and lonely and my MH declined rapidly yet the rehab refused to admit this was at least partly their fault if not fully their fault.

Being quite far away from my family also played a massive part in my health worsening. It meant when they were allowed to visit, it could only be for short periods of time as they needed to travel back. It was heart-breaking knowing my mum wasn't just down the road. I know that if I was receiving positive and unrestricted care then it wouldn't have been such an issue as I would have felt cared for and a lot less lonely.

I was also on 1:1 on and off pretty constantly for the time I was at this rehab and that just strips you of any dignity and definitely doesn't aid your recovery as there's no responsibility on oneself to keep safe.

All in all, private MH units aren't always what they say on the tin. I have had much more positive and pleasant experiences with NHS wards over the 5 years I was in hospital, and if it wasn't for the NHS unit I left hospital for good from, I'd still be locked away with no hope."

SARAH

Being sent out of area to XXX (around 100 miles away) was not great.

Being so far away meant I hardly got visitors, and when I did, they had to pay to stay overnight in a hotel close by. So it was really hard. Home leave was also hard because trains cost a lot of money and so I couldn't afford to go often.

One good thing was that once a month you were allowed to have staff drive you home for home leave, but you had to book it in well in advance to have a slot free for when you wanted to go, and it often came to it and they said they couldn't take you because of being short staffed. If it actually happened each month then that would be a good thing. However they'd only take you to family, so if you wanted to see a friend it was hard. I was lucky that I had a few friends drive up to see me, but most people didn't have that.

They did groups to get you use to the local area that weren't helpful for me because it wasn't my local area. So I didn't need to learn the bus routes etc. Whilst I was there I was able to access schema therapy which was helpful, and something I wouldn't have gotten otherwise because it isn't a thing my local area does.

Personally I think my views should have been taken into account more, because I just had an assessment from someone from (private sector provider) and from that one assessment, they decided where I would be sent. I asked to go to the place in my county and was told I couldn't because they didn't have a psychologist.

As I was in a private place, I believe I was kept far longer than needed. I had to go around 5 months incident free before I was discharged, which wouldn't have been the case if I was in an NHS placement.

I only had my care co visit me twice in the 13 months I was there, and my social worker once. But I do get that covid played a part in that.

Doing a staggered discharge was hard, and I ended up using savings I had to pay for trains. Most people don't have access to savings like that so I was lucky.



LIVED EXPERIENCE TESTIMONY CONTINUED

NATASHA

From the age of 13 I was placed in multiple out of area placements around the country for a period of 11 years. I'll never forget my first out of area placement at 13, it was 90 minutes away from home and I should never have gone there in the first place if CAMHs had accepted me at the right time! But that's a story for another time! Driving to this big scary mansion, a private clinic, somewhere the and famous get treated, I had heard! Well the grand hallway and dining room looked fancy and welcoming – I wish the same could be said about the rest of it! My room was bare and clinical, the staff were distant and cold. My parents weren't allowed to stay and just like that the grand door was shut and I was left, no phone not knowing when I'd see their faces or hear their voices again. I sat on my bed and just felt terrified. I got shown around the place, there was a lounge, therapy room and just old shabby seating areas in the corridors and a small kitchenette. I got the 'lowdown' of what to expect and my only question was 'when can I see my family?' I really didn't like the answer I was given! In two weeks you can talk to them on the phone! Two weeks, what! I was 13, a twin, hours away from home! I'll never forgot that, the tantrums I had because all I wanted to do was talk to my Mum, I'd scream 'I want my mum'. Those screams were met with restraints, medication, seclusion and injections.

My first night in this place, I was greeted with medication, sleeping tablets I found them out to be. Boy did I pass out from them! Ever seen the film girl interrupted with Winona Ryder – well that basically sums up the beginning. Can I go outside I asked? "No, not today". I basically spent my 13th summer of life shut away in a little ward, no air, no sunlight, no space, no contact with my familiars, just full of tears, restraints, screaming and seeing peers my age engage in destructive behaviours that I would later engage in! So just a little back story of me, a flourishing athlete, a twin I was born to go far in life in regards to sports. I was winning everything, me and my twin were known as the sporty twins, we'd rock up to gala's and competitions in various sports and people instantly new us! However we had a coach, and this coach mental hurt us and compared us so so much that it knocked out confidence. I began to restrict to look slimmer like my twin, I also began to break my arm to get out of sports, due to the pressure. Well to cut a long story short I ended up having my appendix out for no reason as I saw it as a get out, and to hide my restrictive habits. But CAMHs didn't see me as ill enough, so I wasn't accepted for any help. Fast forward six months, I started doing little chicken scratches on my arms, lost a bunch of weight and well ultimately became so low I tried to kill myself. CAMHs by this point thought I was too ill for the service so I ended up being placed in an out of area placement.

So yeah back to the story, well I got put on 1-1 as one of the patients beat me up. Yeah I was terrified by this point and absconded from the building and tried to get back home! I was unsuccessful and was brought back to the unit, still unable to speak to my family, I cried so hard for them. So much so that when I was restrained for trying to leave the site a male agency staff slammed my head into the ground put all his weight on me and continued to hit my head into the ground after each word and told me "you.... will..... not..... do..... thatagain.....". The only word that comes to my mind when I think of that day is Traumatic! So thanks NHS for paying £6000 plus a week for me to require probably £6000 worth of therapy that I'm still receiving to this day due to the trauma of out of area placements and the lack of (restriction) of family support! Its funny because the Maudsley model of therapy for ED is centred around the family, yet in private hospitals the family are kept so far out of the loop, it really does baffle me!

As days went on, more restraints, more medication, lack of family contact (I mean no family contact) as they wouldn't let me! This dark hole I was in became a lot darker, funny that, because surely these places are supposed to be 'therapeutic' and help! So my arms when I went into hospital had pretty little freckles on them, I'm

*pale in complexion so they looked really bright on my arms, well flip my arms over I had a few little red scratches, like my cat had scratched me. There's actual tears in my eyes as I write this next sentence, I can't really blame anyone but myself, but I can't help but think – would I have done this if I was at home with my family, my security? So I was feeling pretty chaotic, I was seeing chaotic things around me and girls cutting themselves, one girl gave me a razor and I wanted to cut to feel something, I mean with all the medication I was on I couldn't feel or think about anything, also I was denied that phone call home and ward round said I needed to stay at least 6 months and I wasn't allowed outside in that fresh crisp air, and that man restrained me so hard and hit my head I was feeling pretty scared, so yeah f*** it! For the next six months I sank razor blades so deep into my arms I needed surgery, stitched up over 100 times. My arms don't look like those pretty pale freckly arms anymore, and I can't help but blame that place for that!*

Do you know how much agency staff is used in these places too? I spent most of my days on 1-1 with some person who didn't even speak proper English, they sat on their phones talking to each other. What they did for me I'm unsure of to this day, they certainly didn't save my pretty arms! As or therapy what do you define as a 'specialist placement' because if I'm honest I see no difference between an out of area placement to your local NHS?! Also, medication I can honestly say I've had the whole BNF shoved down by throat, NG tube and bum! I've had over 10 different diagnoses, why? And why does no one from your NHS team stay in contact when you're out of area? Why don't they come to CPA's? Why is it that a Dr can determine how long you stay in hospital and keep extending it with no discharge date in site?! Why are they allowed to just make up new illnesses, practice so restrictively and keep you locked away, medicated, restrained and hidden from the world?!





INTRODUCTION

THE OUT OF AREA ISSUE

Psychiatric inpatient services should ideally be provided close to where the patient lives. This allows for the ongoing input of community support networks, such as family, friends, and community services, during the admission. When an appropriate inpatient bed is not available, either through lack of capacity or a lack of a specific service, a patient will often be sent ‘out-of-area’. An out of area placement (OAP) is a unit that does not form part of the usual local network of services where the patient lives. This can be an NHS unit or an ‘independent service provider’ in the private sector (3).

There have been multiple reports raising concerns about the quality of treatment provided by OAPs, the poor patient experience they provide, and their possible contribution to an increase in suicide risk (4-7).

When considering OAPs, it is important to be aware that the term refers to a variety of different types of placements. An understanding of adult inpatient psychiatric service provision is helpful here.

OVERVIEW OF ADULT INPATIENT PSYCHIATRIC SERVICES

Mental health inpatient services can be broadly divided into ‘acute’ and ‘rehabilitation’ services (8). In addition, there are ‘forensic’ and ‘Tier 4’ specialist services funded directly by NHS England.

Acute inpatient services include acute wards; where people with sudden deteriorations in mental health are treated, and psychiatric intensive care units (PICUs); where more intense 1:1 support is required due to the level of risk posed to self or others. The expectation is that acute inpatient services should be used for people needing relatively short periods of treatment, usually less than 90 days and only a few days to weeks in the case of PICUs (8).

Rehabilitation inpatient services provide ongoing care for people with complex mental health problems that persist beyond the usual treatment duration of acute services. The template for rehabilitation services was first described by the Royal College of Psychiatrists (RCPsych) (9) and specific guidelines for commissioners of these services were produced by the Joint Commissioning Panel for Mental Health (10).

There are different types of inpatient rehabilitation units described in these documents (see Table 1). These units are meant to be used predominantly for people suffering with chronic psychotic illnesses, such as schizophrenia, or people with a ‘dual diagnosis’ (psychotic illnesses with co-morbid substance abuse). The evidence cited for their effectiveness refers to studies of people with chronic psychosis. The use of these units for “severe personality disorders” is only reserved for ‘Highly Specialist’ units, along with other conditions such as acquired brain injury and autistic spectrum disorders (see p.31 in (9)). The resource recommended (1 unit per several million people) suggests that people with a personality disorder should only be treated in these units in extraordinary circumstances.

Tier 4 specialist services are regional or national specialist services funded directly by NHS England for specific patient groups. The need for Tier 4 specialist personality disorder units is estimated to be 4 beds per 100,000 people, or about 2,120 beds in England. Although officially there are 55 beds currently available (11), we believe the actual number to be 39¹. Secure or forensic services are reserved for people with mental health problems who need additional physical and relational security (12), who may have committed offences, and are also commissioned directly by NHS England.

¹The Cassel Hospital, 13 beds; New Dawn Ward, Cygnet Hospital in Becton, 17 beds; New Dawn Ward, Cygnet Hospital in Ealing, 9 beds.

UNIT TYPE	LENGTH OF STAY	SITE	RISK MANAGEMENT	RESOURCE SUGGESTED AS PER POPULATION SIZE	FUNDING
HIGH DEPENDENCY	1 - 3 YEARS	HOSPITAL	LOCKED	1 UNIT PER 600,000 - 1 MILLION	CCG
LONG-TERM COMPLEX	“SEVERAL YEARS”	HOSPITAL	LOCKED	1 UNIT PER 600,000 - 1 MILLION	CCG
COMMUNITY	UP TO 1 YEAR	COMMUNITY	OPEN	1 UNIT PER 300,000	CCG
SECURE	>2 YEARS	HOSPITAL	LOCKED	LOW SECURE: 1 PER MILLION. HIGH SECURE: 1 PER 15 MILLION MEDIUM SECURE: SOMEWHERE IN BETWEEN	NHS ENGLAND
HIGHLY SPECIALIST	1-3 YEARS	HOSPITAL	VARIES WITH RISK PROFILE	1 PER “SEVERAL MILLION”	CCG
TIER 4	VARIES	HOSPITAL	VARIES WITH RISK PROFILE	1 UNIT PER 300,000 - 600,000	NHS ENGLAND

Table 1. Different types of mental health rehabilitation units in the UK.

Despite the seemingly clear delineation between unit types, concerns that many units are trying to span a variety of functions have been there from the start of this classification (9). In addition, there is an inconsistent use of the terminology with some units being described as ‘locked rehabilitation units’, which is a category that is not yet defined (13) and could potentially refer to a variety of non-secure services (acute and rehabilitation).

CURRENT POLICY

In 2016, the government set a national ambition to eliminate inappropriate OAPs in mental health services for adults in acute inpatient care by 2020 to 2021 (1,2). ‘Inappropriate’ is defined as patients being sent out of area because no bed is available for them locally. As a result, NHS Digital publishes national statistics of acute OAPs on a monthly basis (14,15). Their latest report shows that in the period between February 2020 – February 2021 there were 6500 OAPs started. Of these 6,280 (97%) were classified as inappropriate (15). 58% of patients were detained under a section of the MHA. This contrasts the detention rate in local acute placements, which is around 37% (16).

There is no similar ambition to eliminate OAPs in any of the other service categories. However, the Care Quality Commission (CQC) had similar concerns about rehabilitation OAPs (17) and conducted a freedom of information request regarding “Mental Health Rehabilitation Inpatient Services” in 2017 (18), which was updated in 2019 (19). Their reports identified 2,125 patients in rehabilitation OAPs in 2017 and 1,641 patients in 2019. The small reduction in numbers was suspected to be due to a re-classification of placements rather than a true reduction. 78% of these patients were detained under the MHA. Patients in private provider placements were more likely to be out of area and their admissions lasted twice as long and costed twice as much as NHS placements. The CQC made several recommendations to NHS England, including the reduction of rehabilitation OAPs and the monitoring of these placement numbers, in a similar way to acute OAPs. This is not currently happening, however estimates of current use and cost are understood to be considerable (Table 2).

	ACUTE OAPs	REHABILITATION OAPs
PLACEMENTS PER YEAR	6000-7000	1600 - 2000
COSTS PER YEAR	~£112 MILLION	~£535 MILLION

Table 2. Out of area placement numbers and costs by placement type (7,15)



PERSONALITY DISORDER AND OUT OF AREA PLACEMENTS

ACUTE OAPS

The latest data on acute OAPs available from NHS digital shows that in the period between February 2020 and February 2021 there were 625 OAPs (OAPs ended plus OAPs active) where the 'primary diagnosis' was 'personality disorder'. This corresponds to 9% of the total number of acute OAPs during this period (7,145). The average (median) daily cost for these placements was £575/day. The total spent on placements for those diagnosed with personality disorder was £12,056,850 or 11% of the total costs (£112,335,340) (14).

The duration of acute OAPs for personality disorder placements that ended during this period (n = 550) is shown below. The distribution suggests that most placements are of an 'acute' nature or less than 90 days (see Figure 1).

NIGHTS IN HOSPITAL

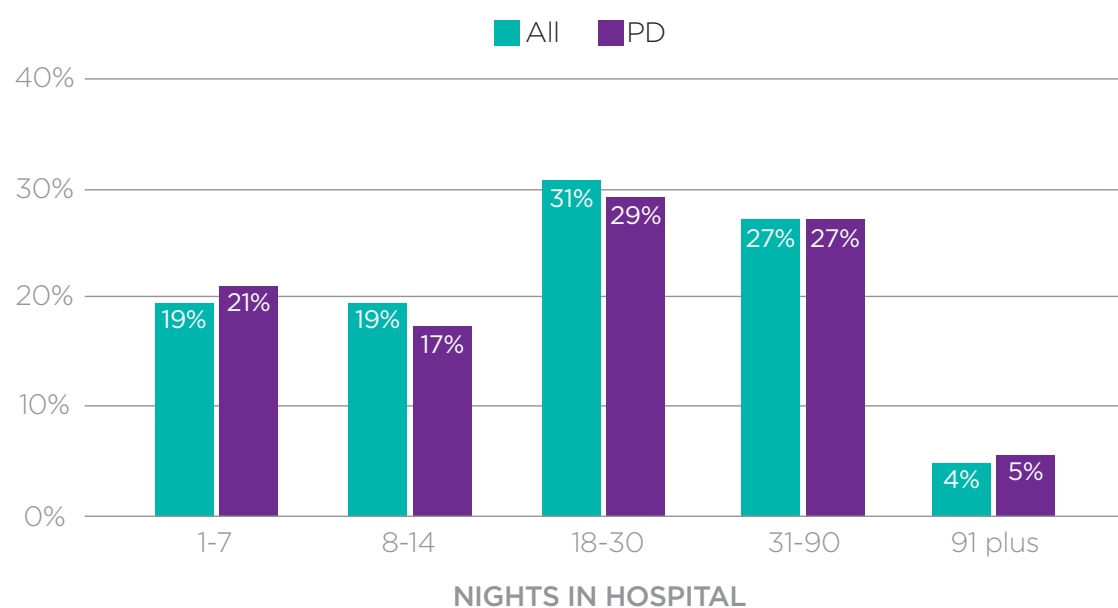


FIGURE 1. ACUTE OUT OF AREA PLACEMENT DURATION (FEB 2020 - FEB 2021)

It is important to note that this only provides a partial picture of the situation with acute OAPs in relation to patients with a personality disorder diagnosis. The prevalence of patients diagnosed with a personality disorder in acute inpatient services is known to be over 26% (20), so it is likely that the actual costs and number of acute OAP placements are much higher. There are other 'primary diagnosis' categories in the data published that are likely to include people with an undiagnosed personality disorder, such as 'self-harm', 'in-crisis', 'anxiety', 'depression', 'drug and alcohol difficulties', 'post-traumatic stress disorder', 'eating disorders', 'conduct disorders', 'relationship difficulties', 'gender discomfort issues', and 'attachment difficulties'. These categories bring the total number of OAPs to 3,345 and the cost to over £47 million. We believe, therefore, that the number of patients who could meet the criteria for a personality disorder diagnosis is as high as 46% of all acute OAPs.

REHABILITATION OAPS

The CQC reports that the median length of stay in rehabilitation OAPs is of 683 days. When broken down by provider, the private sector's median length of stay is 952 days and 492 days in the NHS. The total cost of rehabilitation inpatient services (local and out of area) is approximately £535 million/year (18). 78% of these patients are detained under the MHA and the most common type of ward is defined as 'locked-rehabilitation' (19).

There is no publicly available data about the number of people in rehabilitation OAPs with a personality disorder diagnosis. The report by the CQC on rehabilitation services does not have a breakdown of the data by diagnosis, but the wording of the reports clearly assumes that these services are for people with psychotic illnesses (18,19). We know from clinical experience that many people diagnosed with a personality disorder are treated in rehabilitation OAPs, predominantly in the private sector². These units are advertised as 'locked rehabilitation units' or 'specialist services', but are registered as locked rehabilitation services (21) as there is no agreed definition for a 'locked rehabilitation' unit (13) or a 'specialist personality disorder unit'. As a result, the description of 'specialist' is bestowed by the unit themselves.

TIER 4 OAPS

There are only 3 units in the UK that are funded by NHS England for the treatment of personality disorder (1 NHS and 2 private units). There are 39 beds available. The estimated funding available at Tier 4 level for personality disorder is £6 million/year. There is no agreed service specification for a Tier 4 personality disorder unit, unlike other specialised mental health services (22).

FREEDOM OF INFORMATION REQUEST OBJECTIVES

The available data does not provide a clear picture on the use of OAPs, how they are planned, what co-morbidities people present with, how restrictive the treatment provided is, and what the outcomes post-discharge are. Given the absence of data we developed an FOI approach to explore these questions.

² There is only 1 rehabilitation unit that specialises in the treatment of personality disorder capable of accepting patients detained under the mental health act within the NHS (Springbank Ward in Cambridgeshire. 12 beds). This unit does not receive Tier 4 funding.





METHODS

DATA COLLECTION

The data on out of area placements was collected by a series of requests to Clinical Commissioning Groups (CCGs)³ under the Freedom of Information Act 2000 (23). The questions chosen for the request were constructed by a small steering group containing researchers, clinical practitioners, and people with lived experience. In total, 191 CCGs in England, as per the list published (24), were contacted for general information for the period between 1st January 2017 to 31st October 2019.

Clinical Commissioning Groups (CCGs) were asked to answer the following questions:

- 1. For the period 1st January 2017 to 31st October 2019, how many Out of Area Mental Health placements did you make?⁴

For each of these placements, please state anonymized detail as to: _____
- 2. How long was the placement initially contracted for?
- 3. How many days the placement actually lasted (or length of stay until 31st October 2019 if ongoing)?
- 4. How much the placement cost (costs to 31st October 2019 if ongoing)?
- 5. What was the primary diagnosis of the service user who was placed?
- 6. What were the other diagnoses of the service user who was placed?
- 7. Which organisation provided the placement?
- 8. Was the status of the service user informal or detained under the Mental Health Act?
- 9. On discharge from placement, which local service was the service user referred to (if any)?

³ Clinical Commissioning Groups (CCGs) commission most of the hospital and community NHS services in the local areas for which they are responsible. Commissioning involves deciding what services are needed for diverse local populations and ensuring that they are provided. CCGs are assured by NHS England, which retains responsibility for commissioning primary care services such as GP and dental services, as well as some specialised hospital services.

⁴ The expectation was to receive information on acute and rehabilitation OAPs.

DATA ANALYSIS

This report refers to and makes comparisons between 3 data sources:

- 1) The data resulting from the freedom of information enquiry (FOI data).
- 2) The published data for acute OAPs for the same period of time (15).
- 3) The latest published data for acute OAPs at the time of this writing (February 2020 – February 2021).

Data obtained from 1 and 2 was divided by 2.8 years (the period spanning the FOI request) to provide an annual estimate of costs and referrals that could be compared to 3 (see Figure 2).

Placement numbers in the published data were taken to be the number of OAPs ended plus the number of active placements at the end of the period. Statistical methods for comparisons between different data categories were not possible, as the data is provided by CCGs as totals, rather than as individual records. Only simple calculations were possible.

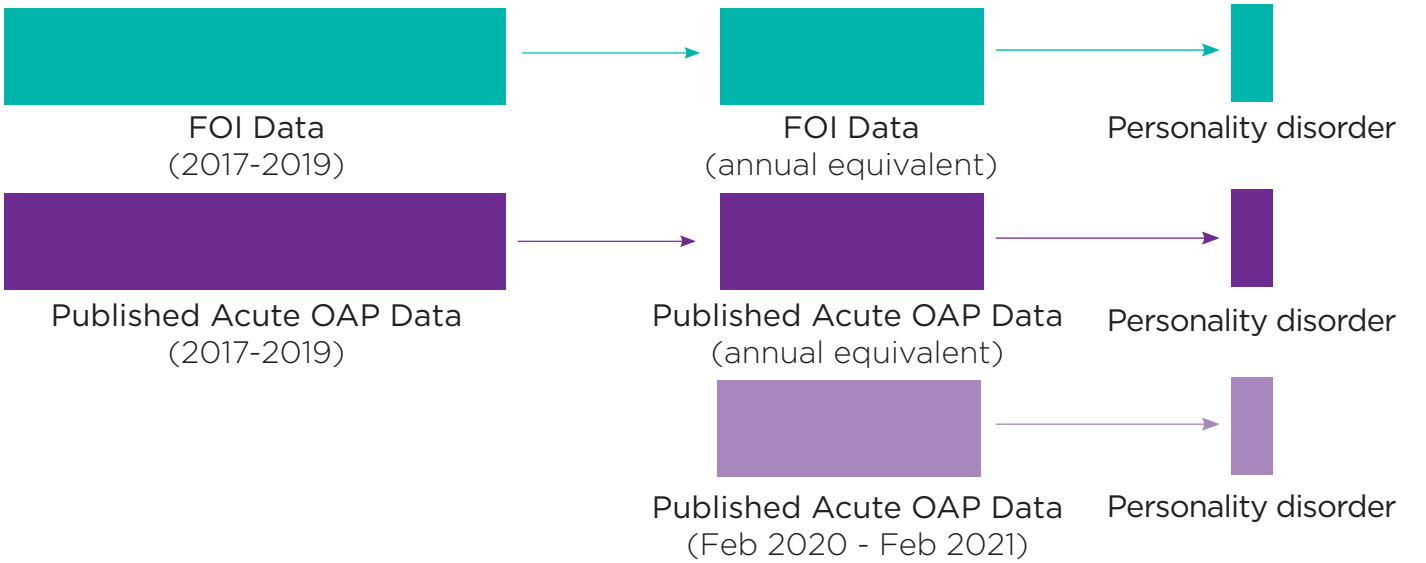


FIGURE 2. DATA SOURCES FOR THIS REPORT. FOI AND PUBLISHED DATA WERE CONVERTED TO ANNUAL EQUIVALENTS TO FACILITATE COMPARISONS WITH THE LATEST PUBLISHED INFORMATION.



RESULTS

RESPONSE RATE

129/191 CCGs (67%) did not to provide any information.

The reasons given by CCGs for refusing to provide data included:

- Section 17(1) of the FOIA (Freedom of Information Act), stating that the data would take more than 18 hours to provide. These were all sent a re-request asking for simpler data (but including the request for diagnosis information). All refused, giving the same reason.
- Section 40(2) of the FOIA stating disclosure could lead to patient identification.
- The data being ‘commercially sensitive information’ (regarding placement provider data).
- Information was not recorded or not available.

Table 3 shows the response rate from CCGs to our FOI request, broken down by question number.

DATA REQUESTED	NUMBER OF CCGS PROVIDING DATA
1. NUMBER OF PLACEMENTS	62 (32%)
2. CONTRACT PERIOD FOR PLACEMENT	11 (6%)
3. DURATION OF PLACEMENTS	45 (24%)
4. COST OF PLACEMENTS	45 (24%)
5. PRIMARY DIAGNOSIS	22 (12%)
6. OTHER DIAGNOSES	5 (3%)
7. PLACEMENT PROVIDER	38 (20%)
8. MHA STATUS	35 (18%)
9. FOLLOW-UP ON DISCHARGE	14 (7%)

Table 3. Number of CCGs (out of 191) responding to our freedom of information request by data category

Our primary interest was to understand OAPs in relation to personality disorder, hence we focus on the 22 CCGs that provided diagnostic information in the sections below. This corresponds to 11% of all CCGs.

PLACEMENT NUMBERS BY DIAGNOSIS

The FOI data reported 3,541 placements during the study period, which are equivalent to 1,251 placements per year. Table 4 shows the breakdown by primary diagnosis, or the reason given for the OAP. There were 383 placements for people with personality disorders (11% of placements with a diagnosis). This is equivalent to 135 placements/year.

OOA PLACEMENT REASON / DIAGNOSIS	N	% OF TOTAL
PSYCHOTIC & DELUSIONAL DISORDERS	1,266	36%
NOT PROVIDED	809	23%
PERSONALITY DISORDERS	383	11%
DEPRESSIVE EPISODE/DISORDER	195	6%
BIPOLAR	184	5%
IN CRISIS	139	4%
DEMENTIA	99	3%
SELF-HARM	92	3%
ASD/LD	84	2%
PHYSICAL	76	2%
ANXIETY DISORDERS	71	2%
DRUG AND ALCOHOL DIFFICULTIES	70	2%
PERINATAL	23	1%
OTHER	16	0%
PTSD	15	0%
CAMHS	6	0%
EATING DISORDERS	6	0%
TOTAL	3,541	100%

Table 4. Number of out of area placements by reason or diagnosis provided.

There were 24,540 placements during the same period in the published acute OAP data, equivalent to 8669 placements per year. There were 5,460 placements classified as ‘personality disorder’ (22%), which is equivalent to 1,929 placements per year.

INFORMATION SOURCE		TOTAL PLACEMENTS	PERSONALITY DISORDER PLACEMENTS	PERSONALITY DISORDER PLACEMENTS (%)
FOI DATA				
	TOTAL PERIOD (2.8 Y)	3541	383	10.8%
	ANNUAL EQUIVALENT	1251	135	10.8%
ACUTE OAP DATA BY NHS DIGITAL				
	FOI PERIOD (2017 - 2019)	24540	5460	22.25%
	FOI PERIOD ANNUAL EQUIVALENT	8669	1929	22.25%
	FEBRUARY 2020 - FEBRUARY 2021	7145	625	9%

Table 5. Personality disorder placements by information source. FOI: freedom of information; OAP: out of area placement.



OAP PLANNING

No CCGs specified the initial length contracted for the OAP prior to admission. One CCG ‘reviewed annually’ the length of stay, five stated they had spot contracts, the rest said they were open-ended or that they did not collect that data.

PLACEMENT DURATION

The FOI data showed that the average duration of an OAP was 90 days (range 1 - 1,244 days. SD 154). The average duration of an OAP for someone with a personality disorder diagnosis was 71 days (range 1 – 833 days. Median 42 days. SD 103). Figure 2 shows the distribution of OAP duration in the FOI data.

DURATION OF OAPs FROM FOI DATA

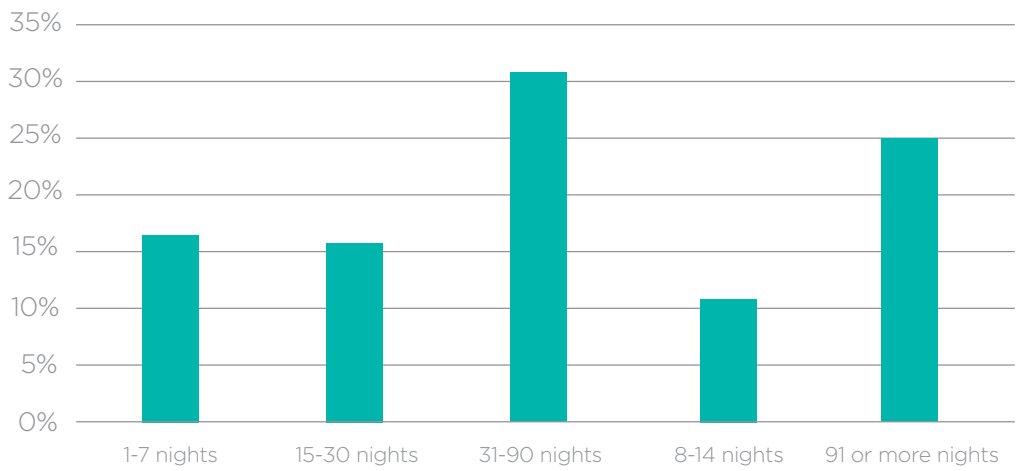


Figure 2. Out of area placement duration (FOI data)

The published data does not allow for the calculation of means and medians, as it only publishes the number of placements within a certain duration range, rather than the exact duration for each placement. Figure 3 shows the distribution of OAP duration during the FOI period in the published data.

DURATION OF OAPs FROM PUBLISHED DATA

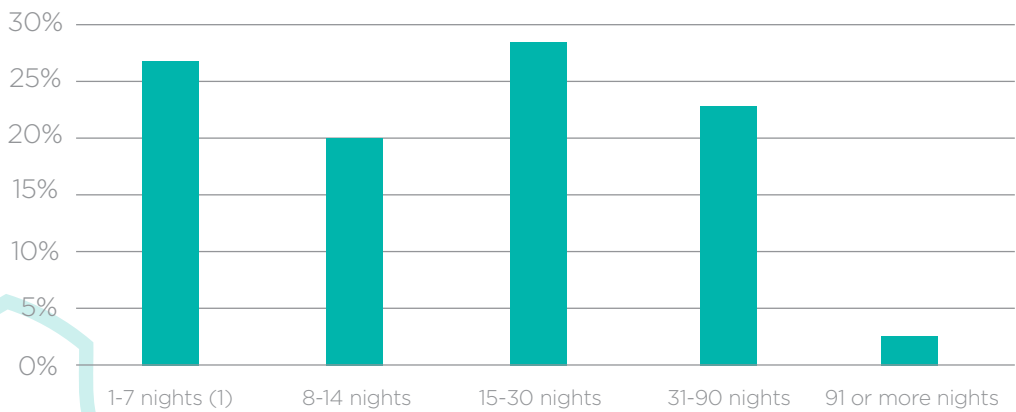


Figure 3. Acute out of area placement duration (published data during FOI period)

CCGs reported nearly 169,000 days out of area during the FOI period. This is equivalent to nearly 60,000 days per year. People with a personality disorder accounted for 16% of OOA days or the equivalent of nearly 10,000 days/year. Table 6 summarises this information.

	PLACEMENT DAYS	%
PSYCHOTIC & DELUSIONAL DISORDERS	73267	43%
IN CRISIS	6123.5	4%
PERSONALITY DISORDERS	27170	16%
BIPOLAR	8490.5	5%
DEPRESSIVE EPISODE/DISORDER	7551	4%
SELF-HARM	4087	2%
DRUG AND ALCOHOL DIFFICULTIES	2998.5	2%
PHYSICAL	7653.5	5%
ANXIETY DISORDERS	2659	2%
DEMENTIA	15696	9%
PTSD	552.5	0%
OTHER	11517	7%
EATING DISORDERS	306	0%
PERINATAL	893.5	1%
TOTAL	168965	100%

Table 6. Acute out of area placement days by diagnosis (published data during FOI period)

There were 661,060 OAP days in the published data, equivalent to 233,513 days/year. 150,010 days were for people with a personality disorder diagnosis, equivalent to 52,990 days per year (23% of the total number of days).

Our FOI request captured 18% of the OAP days for personality disorder during this period.





OTHER DIAGNOSES

The FOI data showed that the average duration of an OAP was 90 days (range 1 - 1,244 days. SD 154). The average duration of an OAP for someone with a personality disorder diagnosis was 71 days (range 1 - 833 days. Median 42 days. SD 103). Figure 2 shows the distribution of OAP duration in the FOI data.

PROVIDERS

The FOI data shows that the distribution of OAPs is concentrated in two main private providers (Table 8).

PROVIDER	NO. OF PLACEMENTS	%	COST
PRIORY GROUP	503	29%	£3,606,044
CYGNET GROUP	472	27%	£3,044,709
OTHER NON-NHS	251	14%	£7,806,895
NURSING HOME	128	7%	£2,781,722
ST ANDREWS HEALTHCARE	67	4%	£434,964
BRIEF THERAPY SUPPORT SERVICES	55	3%	£49,250
NHS	41	2%	£771,253
ELLINGHAM FARM	29	2%	NOT GIVEN
MHC UK - NEWTON HOUSE	25	1%	£1,443,880
VICTORIA HOUSE INDEPENDENT HOSPITALS	23	1%	£2,200
KNEESWORTH HOUSE HOSPITAL	22	1%	NOT GIVEN
POTENS	22	1%	£261,710
SIGNHEALTH	21	1%	£51,730
ALTERNATIVE FUTURES GROUP	15	1%	£238,583
CAMBIAN GROUP	15	1%	£784,858
CODE ONLY	15	1%	NOT GIVEN
BLUE RIBBON HEALTHCARE LIMITED	13	1%	£606,736
LAKESIDE VIEW	10	1%	NOT GIVEN
NEXT STAGE - A WAY FORWARD	10	1%	£183,035
ELYSIUM HEALTHCARE	9	1%	£1,115,256
PARTNERSHIPS IN CARE	9	1%	£52,914
TOTAL	1755	100%	£23,235,739

Table 8. Number of placements and costs by provider in the FOI data (all diagnoses)

This distribution for patients with a personality disorder diagnosis recorded is below (Table 9). The FOI data shows that only 1% of placements for people with a diagnosis of Personality Disorder were provided by the NHS. The Priory Group provided 50% of the placements and the Cygnet Group 21%.

PROVIDER	NO. OF PLACEMENTS	%	TOTAL COST
PRIORY GROUP	96	50%	£492,943
CYGNET GROUP	41	21%	£293,898
OTHER NON-NHS	24	12%	£1,070,274
ALTERNATIVE FUTURES GROUP	6	3%	£54,530
CAMBIAN GROUP	6	3%	£495,430
KNEESWORTH HOUSE HOSPITAL	4	2%	NOT GIVEN
ST ANDREWS HEALTHCARE	4	2%	NOT GIVEN
ELLINGHAM FARM	3	2%	NOT GIVEN
NEXT STAGE - A WAY FORWARD	2	1%	£19,421
POTENS	2	1%	£16,920
BRIEF THERAPY SUPPORT SERVICES	1	1%	£900
ELYSIUM HEALTHCARE	1	1%	741,000
LAKESIDE VIEW	1	1%	NOT GIVEN
NHS	1	1%	-
VICTORIA HOUSE INDEPENDENT HOSPITALS	1	1%	NOT GIVEN
TOTAL	193	100%	7,204,761

Table 9. Number of placements and costs by provider in the FOI data (personality disorder)

MHA

The FOI data shows that, on average, 77% of people in OAPs were detained under the Mental Health Act (MHA). There was considerable variation with 13 CCGs reporting 100% of their patients being detained and the lowest being 39%. 67% of patients with a personality disorder diagnosis were detained (see Table 10). There was no data on MHA status recorded or provided for 40% of OAPs in the FOI data.

DIAGNOSIS	INFORMAL	%	MHA DETAINED	%	TOTAL
ANXIETY DISORDERS	19	59%	13	41%	32
ASD/LD	0	0%	84	100%	84
BIPOLAR	33	30%	77	70%	110
CAMHS	0	0%	6	100%	6
DEMENTIA	2	2%	97	98%	99
DEPRESSIVE EPISODE/DISORDER	75	57%	57	43%	132
DRUG AND ALCOHOL DIFFICULTIES	14	40%	21	60%	35
EATING DISORDERS	1	100%	0	0%	1
IN CRISIS	8	73%	3	27%	11
PERINATAL	1	50%	1	50%	2
PERSONALITY DISORDERS	88	33%	179	67%	267
PHYSICAL	3	5%	57	95%	60
PSYCHOTIC & DELUSIONAL DISORDERS	203	23%	682	77%	885
PTSD	3	75%	1	25%	4
SELF HARM	9	69%	4	31%	13
OTHER	8	53%	7	47%	15
NOT PROVIDED/UNKNOWN	9	3%	342	97%	351
TOTAL	476	23%	1631	77%	2107

Table 10. Detention by diagnosis in the FOI data

The published data on acute OAPs for the same period shows that 60% of patients were detained under the MHA. The data does not allow for a breakdown of detention rates by diagnosis.

OUTCOMES

The outcomes of people ending an OAP are not publicly available. We looked at the outcomes of people with a personality disorder following discharge in the FOI data. None of the CCGs reported a referral to specialist community personality disorder services. We found 4 placements where no further treatment was given, with the remainder being discharged to Community Mental Health Teams.



DISCUSSION

FREEDOM OF INFORMATION REQUEST RESPONSE RATE AND TYPE OF DATA RECEIVED

With 67% of CCGs refusing to provide any information following our Freedom of Information request and a lack of centrally collected data, the scale of the challenge remains obscured. This is especially problematic for rehabilitation and long stay placements.

The distribution and average length of stay in the FOI data suggests that CCGs responding to the FOI request provided mostly data from acute OAPs (compare Figure 1 with Figure 2). Therefore, we estimate that our FOI enquiry captured approximately 7% of people in acute OAPs diagnosed with a personality disorder. These placements accounted for 18% of the out of area days and costs in this group.

Despite the significant cost and number of placements in rehabilitation OAPs identified by CQC (18,19), there is no data collected on the number of patients diagnosed with a personality disorder.

PERSONALITY DISORDER ACUTE OUT OF AREA PLACEMENTS IN 2021

The published data on acute OAPs during the FOI period (2017 – 2019) showed that at least 22% of placements were for people with a personality disorder (see 6.2). The published data from February 2020 - February 2021 classified only 9% of placements as such (14). This suggests a 68% reduction in acute OAPs for people with a personality disorder diagnosis, however, the increase in total spend and the moderate reductions in total number of placements puts this into question (see Table 11).

	TOTAL PLACEMENTS	PERSONALITY DISORDER PLACEMENTS	TOTAL SPEND	PERSONALITY DISORDER SPEND
FOI PERIOD (2017 – 2019) ANNUAL AVERAGE	8669	1929	£106,960,892	£27,271,255
LATEST PUBLISHED DATA: FEBRUARY 2020 -2021	7145	625	£112,335,340	£12,056,850
CHANGE	-18%	-68%	+5%	-56%

Table 11. Acute out of area placement trends over time (published data).

The reductions in acute OAPs for people with a diagnosis of personality disorder could be explained by either a reclassification of ‘personality disorder’ OAPs under a different category (such as ‘in crisis’ or ‘self-harm’), or with a reclassification of acute out-of-area units to ‘locked rehab’ facilities. These units are not included in the acute OAP published data, so these placements would not be accounted for. The reduction could be a combination of both issues.

From the FOI request, approximately 67% of people with a personality disorder diagnosis are treated under the MHA. This figure is an estimate as 47% of the data is missing (Table 10) and the published spreadsheets do not allow for the breakdown of the data by diagnosis and detention status.

The median duration of personality disorder OAPs (42 days) in the FOI data is very likely to be a gross underestimate, as the duration distribution (Figure 2) suggests that the information is predominantly from acute OAPs. We have no information about people with a personality disorder diagnosis in rehabilitation OAPs, which can have a median duration of up to 952 days in the private sector (7). NICE guidelines

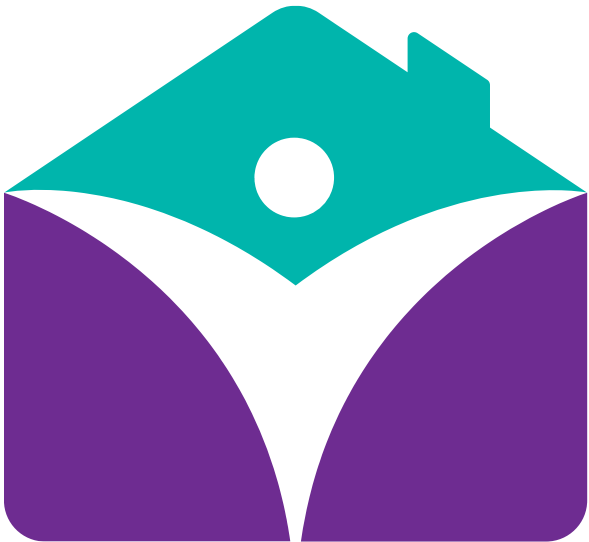
stipulate that compulsory treatment is only advised for short term use. Furthermore, we know from anecdotal evidence that patients are frequently moved between OAPs (see lived experience perspectives above). For example, children in OAPs turning 18 are often transferred to an adult OAP. Each time that a patient is moved, the duration of that placement starts from zero, which confounds the data.

The FOI data suggests that the planning for OAPs is insufficient with no specific timeframe in mind when referring a patient out of area or planning for step down to assist early discharge.

A small number of providers from the private sector provide most of these placements. The lack of competition and the clear financial incentive to maintain these beds occupied is concerning, as is the absence of specialist personality disorder inpatient care in the NHS. Commissioners require an understanding of evidence-based practice in this area to ensure it is not the providers deciding the type and length of service provision.

The FOI data also shows insufficient aftercare, as people with a diagnosis of personality disorder completing an OAP did not receive specialist treatment in the community at the point of discharge. This raises the question as to whether the absence of specialist community service in their locality contributed to the need to send them out of area, and whether any potential gains made during the OAP are lost due to a lack of access to community specialist treatment.

The latest published acute OAP data (15) shows that personality disorders are costing a minimum of £12 million/ year, with the actual figure potentially being much higher due to the prevalence of personality disorder in other categories. This is money being spent in non-specialist settings that may not be providing evidence-based care for this group of people. The cost of rehabilitation OAPs for personality disorder is unknown, but likely to be much higher, given the total spend of £535 million/year in these placements (18). The King’s Fund estimates that service costs by people diagnosed with a personality disorder in 2007 amounted to £700 million and are projected to reach £1.13 billion by 2026 (25). They based their service use estimates on a study that followed people with a personality disorder diagnosis, who had been in contact with their GP, for 1 year (26). They estimate that inpatient admissions represent 9% of service costs. Based on this report, the present annual cost of inpatient treatment for people diagnosed with a personality disorder should be between £63 - £117 million. This is in stark contrast with the figure of £6 million/year currently available for specialist personality disorder inpatient services at Tier 4 level. With no public discussion on the matter, it seems that inpatient treatment for those given a diagnosis of personality disorder has been outsourced to the private sector.





RECOMMENDATIONS

1. COLLECT AND PUBLISH INFORMATION ON ALL TYPES OF OUT OF AREA PLACEMENTS

We recommend that a minimum data set is devised, collected and published routinely on rehabilitation OAPs, as recommended by the Care Quality Commission.

2. CLASSIFY OUT OF AREA PLACEMENTS IN A WAY THAT INDICATES THE TYPE OF TREATMENT REQUIRED

An agreed method of categorizing the reasons for placements needs to be in place. The simplest approach would be to link the reason for the OAP to established diagnostic classification systems. Co-morbidities should also be recorded and data published should allow for the analysis of detention status by diagnosis.

3. DEMAND AND CAPACITY OF SPECIALIST NHS IN-PATIENT SERVICES FOR PEOPLE WITH A PERSONALITY DISORDER DIAGNOSIS SHOULD BE REVIEWED

There is a clear need for higher levels of specialised mental health commissioning for personality disorder in-patient treatment. Tier 4 specialist service provision would be improved through the development of a defined service specification alongside the development of clear commissioning intentions to address the current shortfall.

4. ESTABLISH ACCREDITATION SYSTEMS FOR OUT OF AREA PLACEMENTS

Commissioning of placements should be contingent upon services demonstrating adequate expertise through independent accreditation schemes. There should be a regular evaluation of specialist personality disorder placements against a nationally agreed service specification with clear outcome measures. The experience of patients or service users should be considered in these evaluations.

5. COMMISSION SPECIALIST PERSONALITY DISORDER COMMUNITY SERVICES

In line with the Community Mental Health Framework and RCPsych guidance on Services for People Diagnosable with Personality Disorder, we recommend that local specialist community provision should be developed in order to minimise the use of OAPs and to ensure a clear pathway of care into and out of such services.

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