Patient Choice
in out-patient mental health care

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Foreword by Rt Hon Norman Lamb MP

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About the publishers

OCD Action is a registered charity that provides support and information to anybody affected by Obsessive Compulsive Disorder, works to raise awareness of the disorder amongst the public and front-line healthcare workers, and strives to secure a better deal for people with OCD. It was formed by a group of volunteers and leading professionals in 1994, and has the volunteers, trustees and staff to turn its vision into reality.

The BDD Foundation is a registered charity that provides support and information to anyone affected by Body Dysmorphic Disorder (a condition thought to be related to OCD). It also works to raise awareness and to secure a better deal for people with BDD. It was formed in 2013.

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Foreword by the Rt Hon Norman Lamb MP

As a Health Minister in the Coalition Government, my priority was to tackle the institutional bias between physical and mental health services in the NHS. Central to this mission was extending the 'legal right of choice' to patients with mental ill health, giving them the same right to choose where to be treated that was already enjoyed by people with physical health conditions.

My determination to fight this battle was informed by my own family's experiences. At the age of 16, our oldest son was diagnosed with obsessive compulsive disorder (OCD). Later on, we were told that he would have to wait up to six months to start cognitive behavioural therapy in Norwich.

When we asked if he could be referred to the expert service at the Maudsley Hospital in London, we were refused. We were told that the 'legal right of choice' for patients only applied to physical illnesses. Mental health was exempt. My reaction was one of anger and disbelief that society could tolerate such blatant discrimination from a publicly-funded service.

In April 2014, we introduced the legal right of choice for mental health patients for the first time to tackle this disadvantage. It was an important step towards true 'parity of esteem' between physical and mental health services. Nearly four years after it came into force, however, it is clear that Patient Choice is not working in practice.

This important report reveals that only one-third of CCGs comply with 'Patient Choice' for outpatients with Obsessive Compulsive Disorder (OCD) and Body Dysmorphic Disorder (BDD). The result is a postcode lottery where around two-thirds of people are denied their right to be treated at a provider of their choice. For all the rhetoric within government and the NHS, this is evidence of yet another failure to deliver on the promise of Equality for Mental Health.

Equally worrying is that some CCGs still appear to be uncertain about how to interpret this legal right. There remains a belief in some areas that Patient Choice applies only to secondary care and not to psychological treatments delivered in the community.

Patient Choice remains one of the best kept secrets in the NHS. We know that there is a dreadful lack of awareness among patients and GPs, even in areas that do have policies in place for referrals to out-of-area providers. As this report points out, giving people more control over their own care is especially important when quality of care is so variable across the country.

The authors rightly argue that the patchy implementation of Patient Choice should be investigated by NHS Improvement. A full public awareness campaign is also needed to ensure that people are made aware of their rights. Formal rights in the NHS Constitution are not enough – genuine Equality for Mental Health demands that we support people to exercise those rights effectively.

Summary

Patient Choice is a process introduced in 2014 allowing people with mental health problems to choose the provider of their outpatient care in the same way as a patient with a physical illness was already able to do. NHS Improvement have provided helpful guidance on implementation of the policy.

However, the experience of patients, advocates and NHS providers is that Clinical Commissioning Groups (CCGs) do not always follow the guidance. We therefore conducted a Freedom of Information (FOI) request to identify local policies governing referral of a patient with Obsessive Compulsive Disorder (OCD)/ Body Dysmorphic Disorder (BDD) who wished to be seen outside their local area.

We found that nearly two thirds of CCGs had policies that were judged to be not compliant with Patient Choice because such patients were not able to choose a provider of their choice. We are calling on the regulator, NHS Improvement, to investigate the policies of these CCGs. There appears to be a greater variation in the quality of services for mental ill health than those designed for most areas of physical healthcare, so Patient Choice becomes even more important for mental health service users. Yet many find their needs continue to be treated as a lower priority or disregarded altogether.

Background

Parity of esteem is the principle by which mental health must be given equal priority to physical health. A key component of achieving parity of esteem is to ensure that patients with a mental disorder can access care in the same way as a patient with a physical illness can. In most cases, patients with a physical illness have had the right to choose which hospital in England they go to for their first outpatient appointment and which team is in charge of their treatment. Choice of provider might be based a number of factors such as location (e.g. closeness to work); reputation or speciality of the service; or ease of car parking at the hospital.

Treatment for physical health care is routinely funded by the patient's local Clinical Commissioning Group (CCG). The same however was not true of mental health services until the Rt. Hon Norman Lamb and the Coalition Government (2010 -2015) introduced the legal right for NHS patients in England to choose their mental health care provider for out-patient treatment1[1]. This legal right came into force on the 1st April 2014 and will be referred to throughout this document as Patient Choice.

The way the change in law is interpreted is outlined in the document "Choice in Mental Health" published by NHS Improvement, the body responsible for the regulation of Patient Choice [2]. NHS England has also published some helpful documents and guides on Patient Choice [3] [4] [5]. Patient Choice guidance refers to out-patient treatment at a service that has a standard NHS contract. This can be at two levels of stepped care:

1 Primary Care

(Improving Access to Psychological Therapies - IAPT)

This consists of a psychological therapy with no consultant psychiatrist involvement. It is relevant for adults and young people with a wide variety of mental disorders who are seeking a NICE approved psychological therapy. Under Patient Choice, a patient can choose to go to any IAPT provider in the country even if their local CCG has a contract with a specific IAPT service.

2 Secondary Care - consultant led service

This applies where a patient with moderate to severe symptoms or complexity requires a more experienced therapist and perhaps medication advice in a consultant led service. Again, under Patient Choice, the fact that a CCG already has a block contract in place for a local CMHT or Psychological Therapy service is irrelevant if the patient and their GP wish to go to a different provider in the country and there are no reasons to exclude the patient.

Examples of where Patient Choice would be relevant include:

An individual is being referred by their GP for an assessment at either IAPT or a secondary care psychiatric service to determine a diagnosis and treatment plan.

An individual is being referred by their GP to IAPT/a secondary care psychiatric service for mental health treatment e.g. Cognitive Behaviour Therapy (CBT) for Obsessive Compulsive disorder (OCD)/Body Dysmorphic Disorder (BDD).

NHS England [5] stipulates that there are certain situations in which Patient Choice would not be applicable, which include where:

1) The patient's needs cannot be addressed either by a typical package of care (for example within National Institute of Clinical and Health Excellence - NICE - guidance) or such care is not routinely commissioned on an ongoing basis through a NHS standard contract. An example for which choice of provider does not exist might be deep brain stimulation for OCD because it is not routinely commissioned. Such requests would therefore have to be considered by a Specialist Commissioning panel.

2) The patient's needs mean that a non-local referral is not clinically appropriate as they require input from local CMHT and/or social services. This could be due to acute risk issues (such as urgent care for a patient at high risk of suicide) or because the patient needs integrated health and social services care.

3) Patients cannot choose their level of care, for example if a GP refers a patient to a primary care IAPT service, the patient cannot choose a secondary care service or inpatient care.

4) The Patient is already receiving care and treatment locally for the condition they are being referred for.

The principles developed by NHS Improvement and NHS England [4 5] are in our view sensible, but parity of care between physical and mental health is not working in practice [6]. Patient Choice may be less of a priority in physical health care [7]. When surveyed, people with physical illness most value proximity, a short wait list, and ease of transport to healthcare. This is perhaps because the quality of physical health care is more uniform across providers compared to say a delivery of a protocol in CBT for a particular disorder. It may not at first glance seem like an important issue, but it really matters for a significant number of people with mental health disorders.

There are a number of conditions, for example OCD, BDD, Post-Traumatic Stress Disorder (PTSD), dissociative disorders, chronic fatigue or Attention Deficit Hyperactivity Disorder (ADHD), where local services are not well developed and patients want to travel to an out-patient clinic of their choice that has greater or more concentrated expertise than a local service. The authors were aware of this situation both from the reports of the Advocacy services of relevant charities and their own clinical experience of the frustration of patients, especially those who know their rights and still cannot access a more specialist service.

We concluded that some of these practices must have occurred because of the policies

and care pathways followed by some CCGs. We therefore decided to conduct a Freedom of Information request to all CCGs in England in an attempt to improve our understanding of the reasons why people with OCD/BDD may not be able to access services through Patient Choice.

Method

We emailed a Freedom of Information (FOI) request to all CCGs in England in June 2017, with some follow up during July to September 2017.

We proposed the following scenario: a person with OCD/BDD wishes to be referred by their GP to a specific provider which is not one already commissioned by the local service (full letter text at Appendix A), and then asked these questions:

1) Can the GP refer the patient direct to an out of area provider?

2) If not, what is the pathway for such referrals? For example, must such referrals go to a clinical triage service to determine if it would be appropriate to refer to another provider? Does the commissioning group insist that the referral first go to a panel to establish exceptionality before the patient can be treated outside the locality? (NB This is not in keeping with Patient Choice)

3) If the GP is permitted to refer out of area, what criteria are used for the patient to be referred out of area? When does the CCG consider that the "exceptionality" issue applies for a referral out of area? For example, must the patient first have tried treatment in local services and/or exhausted that avenue? (NB If so, this again would not be in keeping with Patient Choice.)

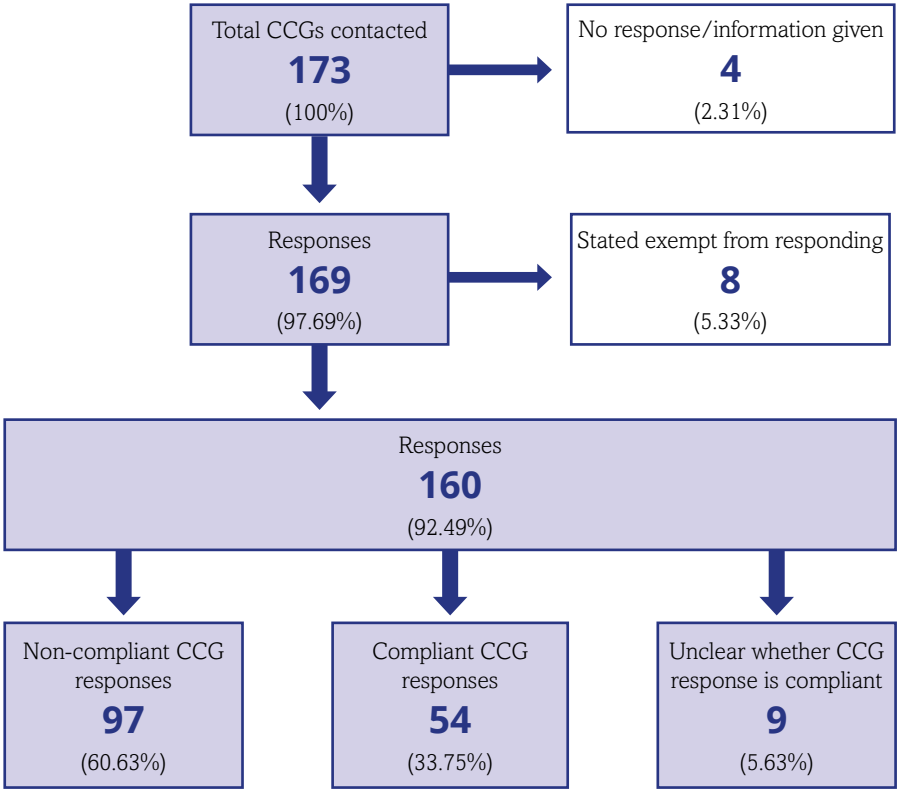
4) If the patient can be referred direct for an assessment to another provider and the provider seeks authorization for funding, what is the pathway for such referrals – for example is the request taken to a special panel or dealt with by a commissioner? As in question (1) does the panel or commissioner use any specific criteria to agree to fund the assessment of the patient?

5) If a patient is assessed by another provider and found suitable for treatment, would a further application for funding be made for treatment? As in question (1) does the panel or commissioner use any specific criteria to agree to fund the patient's treatment or suggest that they are treated locally?

The responses of each CCG were collated and then reviewed individually by two of the authors to assess if they met the Patient Choice criteria and identify any patterns within the responses (Please see appendix B - E for a full list of the CCGs and their response).

Results

A flowchart of the responses is shown below.



Analysis of responses

All the original responses and policy documents from CCGs that we analysed can be found here: https://tinyurl.com/y8n4xfzj.

A total of 173 CCG's were contacted and four (2%) did not send a response/sent an inadequate response (Barking and Dagenham; Havering; Redbridge; West Cheshire who stated they did not hold the information).

Of the remaining 169 that did reply, 9 (5%) stated that they were exempt from responding (please see Appendix B). Of these, seven referred to the NHS Choice Framework: "this information is exempt from disclosure under the Freedom of Information Act 2000, Section 21 (Reasonably Accessible), which provides an exemption from the duty to disclose information which is accessible to the applicant by other means. Information about patient choice is available in The NHS Choice Framework" and included a link to this document. We did not have the time to pursue this small number of CCGs to appeal the ruling and determine how the policy was implemented locally.

Eastbourne, Hailsham and Seaford CCG and Hastings and Rother CCG stated they were exempt from responding as "*The Panel will not consider requests for Specialist Mental Health, which will be dealt with by the Specialist Mental Health Panel at Sussex Partnership Foundation (NHS) Trust.*" It appears therefore that such referrals are treated as if they were tertiary referrals and assessed by a specialist panel. If that is indeed the case, these CCGs are unlikely to be complying with Patient Choice.

The remaining results were categorized by the authors into 3 different groups – compliant, non-compliant and unsure.

1. CCGs judged to be compliant

We deemed 54 (34%) CCGs (Appendix C) to be compliant with Patient Choice, though the clarity with which they described the processes they used and the amount of detail they gave both for the referrals themselves and for the funding arrangements varied greatly.

A number of CCGs gave succinct and unambiguous answers regarding both assessment and treatment under Patient Choice. For example:

- Sheffield stated: "*patient choice would apply in this context and therefore the provider would not need to seek authorisation*".
- Surrey Heath stated: "*The choice rights cover assessment and treatment in accordance with the national guidance.*"
- Camden stated: "*Once the assessment has been carried out and a treatment plan developed, the provider will send a further funding request outlining the cost of the proposed course of treatment. This is more a formality to aid financial planning, rather than a barrier to service access*".

- Guilford and Waverley stated: "*The CCG would expect the provider to invoice under the non-contracted activity route and not need to seek prior approval*".
- East and North Hertfordshire CCGs response initially did not appear compliant: "*NHS East and North Hertfordshire does allow GPs to refer to a provider, with whom we do not have a contract … Requests for off-contract referrals need to be approved before they are made.*" However, they also included a further document as a reference in their reply which highlighted that for Patient Choice GPs have to fill out a form and submit it to the CCG but this is only to demonstrate the patient meets the Patient Choice eligibility criteria and otherwise does not require any further justification.

Other organizations stated they would follow Patient Choice but did not clarify how this works in practice. For example:

- High Weald Lewes and Haven CCG "*recognizes the importance of patient choice; therefore referrals can be made to other providers.*" But additionally, "*The commissioner will review any requests, seeking clinical input as required, to determine that such a referral is clinically appropriate and that costs are reasonable.*" The clinical appropriateness can be viewed as still in keeping with Patient Choice as a patient does have to meet eligibility criteria, but it is unclear how affordability would influence the CCG's implementation of Patient Choice.
- Central London stated that "*when it came to treatment being required a further individual funding application would be required*". It did not clarify how funding is agreed for such referrals.
- Oxford stated, "*the provider needs to send a treatment plan to the commissioner. The decision to fund the treatment will be made after discussion with the local provider to determine if it could also be provided locally; and if this is the case the CCG will ask the GP to discuss with the patient to consider this option.*" We are not sure how much pressure there may be for patients to accept a local alternative as the same process would not occur for other physical health care.

2. CCGs judged to be non-compliant

97 (61%) CCGs were classed by the authors as non-compliant with Patient Choice (Appendix D). CCGs gave a number of reasons why referrals for treatment/assessment would not be funded in the scenario given, the two most common being (i) that local services must have been tried first and (ii) that clinical exceptionality is applied, e.g. "*the patient or their circumstances are significantly different from the general population of patients with the condition in question and the patient is likely to gain significantly more benefit from the intervention than might normally be expected for patients with that condition.*" In other words, these CCGs are following the same criteria as they were 4 years ago when Patient Choice was first introduced.

A number of non-compliant CCGs recognised that the scenario being presented was a matter of Patient Choice but, despite this, stated that they would not refer to an out of area service as a matter of course within this scenario.

- Hammersmith and Fulham stated, "*A GP cannot refer to an out of area provider if there is a commissioned service which clinically meets their needs. In the scenario, the request for a referral to another provider is purely on patient choice and therefore, if there is already a service commissioned it would not be agreed.*"

There was evidently some confusion about what the legislation meant. For example:

- The Vale of York replied that "*NHS England have confirmed that patient choice will apply to treatment of mental health disorders. There is however a distinction between treatments such as psychological treatments delivered in the community and treatments delivered in a formal hospital setting. Where treatments are delivered in the community the CCG commission a service to deliver the treatment and patient choice does not apply to these treatments … The CCG commission a community CBT in this way and therefore would not offer choice of provider in this case and a GP 'could not refer out of area'.*" This appears to be an erroneous interpretation of Patient Choice.

A number of replies from CCGs neither mentioned patient choice directly nor alluded to it, and, in the absence of a set policy or pathway, had a number of other mechanisms for making these types of decisions including Individual Funding Requests (IFR) and applying exceptionality criteria. Examples include:

- "*NHS Barnet CCG can confirm that there is no set pathway for patient requests of this nature. Requests for funding are considered taking into account the following factors: Clinical recommendations available to the responsible commissioner/head of service. Any indicated assessment risks of not funding the required treatment. Affordability and value in the use of public funds for individual treatments by the CCG outside of commissioned services.*"
- Hull CCG stated, "*There is no specific policy/criteria for this other than the overarching NHS Hull CCG IFR policy … any requests would be reviewed in line with the definition of clinical exceptionality.*"
- "*Sandwell and West Birmingham CCG do not hold a policy or care pathway for the scenarios described above.*"
- Wiltshire CCG "*does not have a mechanism for a GP to refer directly to an out of area provider. (NB: if the patient is a staff member at the local provider, there is a reciprocal agreement with out of area providers and a referral may be made directly.) A GP (or clinician) looking to refer to an out of area provider would need to apply to the Exceptions Panel of the CCG. Criteria for the Panel's assessment is not written in policy as each case will be assessed on its own exceptionality and the benefits to be achieved for that patient.*"

A third group stated they did not have locally commissioned services for BDD/ OCD and concluded they therefore did not need to follow Patient Choice legislation within this scenario. For example,

- Warwickshire North: "*in local cases of Body Dysmorphic Disorder, patient choice would not apply … The CCG do not commission a local service for Body Dysmorphic Disorder.*" And

"*our local process is managed by the CSU on behalf of the CCGs, and considers cases on an individual case-by-case basis. The process requires a recommendation by a GP to request an assessment for their patient. The CSU will review the clinical appropriateness and, if approved, the patient will access an out of area provider (with whom we may have a spot purchase contract in place) and the CSU await the outcome of an assessment into the clinical needs of the patient.*" The authors' understanding is that Patient Choice does not depend on existing spot purchase contracts.

- In Wakefield: "*In the scenario provided, the GP would refer direct to an out of area provider, however we do not have a local service specifically commissioned to address BDD so the GP would need to make an individual funding request.*" The individual funding request is then judged on clinical exceptionality.

There seems to be significant misunderstanding about OCD/BDD. NICE guidelines (CG31)[8] state that patients with moderate functional impairment should be offered either CBT or SSRI medication and patients with severe impairment should be offered a combination of the two. CBT for BDD may be offered by an IAPT service where many patients are treated with CBT. Alternatively, patients may be treated by a psychological service as part of a secondary care mental health team. A CCG does not need specific care pathways for every ICD10 mental health disorder and under Patient Choice may be referred to a different provider so long as it is clinically appropriate for the individual patient.

- In one case, the organisations belonging within the wider umbrella of Basildon and Brentwood CCG (Basildon & Brentwood, Castle Point & Rochford, Southend, Thurrock, Mid Essex, North East Essex and West Essex) included a standard phrase: "*The scenario as presented would not be a barrier to the patient exercising choice. The person could be referred to a suitable provider, which is appointed by the NHS directly by their GP, for their first appointment and subsequent treatment if needed… However, for referrals for out of area psychological interventions, such as those in your scenario for someone with BDD/OCD, the GP cannot refer directly to an out of area provider. Instead, the referral request would go initially to the Essex CCG's mental health Individual Placements Team (IPT) who would assess any risk and discuss the requirements with local mental health commissioners to determine an appropriate way forward. Patient choice will be taken into account during this process.*"

It is not entirely clear from this response whether Basildon and Brentwood CCG does indeed meet Patient Choice and they could have been categorised within the unsure groups. The authors have experience of a patient who met the criteria for a Patient Choice referral being assessed at a service under Patient Choice yet being refused funding by Northeast Essex CCG. In reality a patient is often entitled to self-refer to a local IAPT service and risk is rarely an issue.

3. Unsure response

A total of 9 (6%) of responses were classified within the unsure group as it was unclear whether the CCGs concerned were compliant (see Appendix E).

- Airedale, Wharfedale and Craven, Bradford City and Bradford Districts all replied: "*The CCG has no prior approval process in place for the named conditions. The CCG do not have any referral restrictions in place for BDD/OCD to services for an assessment holding an NHS standard contract.*" There is not enough detail in this reply and no mention of Patient Choice, but they do state they have no referral restrictions.
- Chiltern and Aylesbury Vale stated, "*The CCG would ordinarily recommend that patients are seen by local services in the first instance especially with regards to OCD treatment as there is a clear evidence based pathway in place with links to NHS England. If however this request is of a 'choice' nature the GP will need to make a referral to the MH funding panel for consideration.*" The authors were unable to access the referral form for further information so cannot tell whether the process was to exercise specific exceptionality criteria or just to clarify that the referral met Patient Choice criteria.
- Bassetlaw treated the scenario as if it comprised 4 separate components instead of being one whole, as well as responding to the actual questions posed. It was therefore unclear what they would do in a Patient Choice scenario though they did state, "*The patient is generally granted funding for any other provider with a contract within the NHS.*"

Discussion

Patient Choice of outpatient mental health provider came into effect four years ago but there is a systemic bias which limits people with a mental health problem exercising their rights. This is evident from CCG policies provided in response to a Freedom of Information request. We conclude that there is a postcode lottery which deprives around two thirds of people of their rights. This seems to arise from a failure in many CCGs and to a certain extent NHS Providers to update their policies and procedures following the introduction of Patient Choice.

Although we make a FOI request on the care of a person with OCD/BDD, this systemic bias is just as likely to apply to people with other mental health disorders that are treated as outpatients.

A common theme is the assumption that any referral outside a CCG's local contract must take the form of a specialist referral, which requires exceptionality criteria or a very good reason why a patient cannot be treated under a local contract. Such policies have not been updated for mental health. If a GP refers to a non-local NHS provider for outpatient treatment then the recommended route for invoicing by the provider is "Non-Contracted Activity" (NCA). This would not require prior commissioner or panel approval. NHS England[9] state "No prior commissioner approval is required for consultant-led elective care where the patient has exercised choice of provider under the legal rights set out in the NHS Constitution. A GP, dentist or optometrist referral is required in such cases, however." However, the fault is partly with providers who have persisted in applying for pre-authorisation at specialist panels for routine out-patient care.

Only the most persistent individuals, who are knowledgeable about the legislation and have the support of their GP, and sometimes an advocate, or who appeal to the regulator, NHS Improvement, have managed to overcome these obstacles. The CCGs who were judged to be non-compliant appear to be either unaware of Patient Choice or have a flawed understanding of what the legislation means in practice. Sometimes, CCGs appeared to believe they were compliant when they clearly were not.

We will be asking the regulator for Patient Choice, NHS Improvement, to investigate our findings for the non-compliant CCGs. We do not believe that nearly 2/3rds of CCGs are correctly interpreting the policy on Patient Choice and they are not in line with NHS policy and objectives. We will request the regulator to ask the CCGs to update their policies to make them consistent with physical health care in Patient Choice. A number of CCGs explicitly and unambiguously follow Patient Choice and demonstrate that awareness and implementation of this legislation is possible and already happening.

NHS England and some CCGs recommended funding by "Non-Contracted Activity" (NCAs). We will be asking NHS Improvement to encourage NHS Providers and CCGs to use this route as it is the same for physical care and does not require pre-authorisation. Over time it will become clear which providers have higher volumes of referrals and a CGG may then negotiate a cost for volume contract, just as in physical health care.

Footnotes

1 Department of Health (13th December 2012) Press release: *More choice in mental health* https://www.gov.uk/government/news/more-choice-in-mental-health

2 NHS Improvement (April 2016) *Choice in mental health: advice to commissioners* https://improvement.nhs.uk/documents/59/choice_in_mh_services_commissioners_2.pdf

3 NHS England Patient Choice team (19 December 2014). *Legal rights to choice in mental health: clinical scenarios* https://www.england.nhs.uk/2014/12/mh-choice-guidance/

4 NHS England (19 December 2014) *Choice in Mental Health Care* https://www.england.nhs.uk/2014/12/mh-choice-guidance/

5 NHS Improvement (April 2016). *Choice in Mental Health: how it can work for you.* https://improvement.nhs.uk/resources/choice-mental-health/

6 Veale, D. (2018). *Choice of out-patient provider is not working*. Psychiatric Bulletin. https://www.cambridge.org/core/journals/bjpsych-bulletin/firstview (after March 2018).

7 David Oliver (2017) *Choosing to be honest about patient choice.* BMJ 2017; 357:j1829 doi: https://doi.org/10.1136/bmj.j1829

8 National Institute of Clinical Excellence (November 2005). *Obsessive-compulsive disorder and body dysmorphic disorder: treatment.* https://www.nice.org.uk/guidance/cg31

9 NHS England (2013) *Who pays? Determining responsibility for payments to providers.* https://www.england.nhs.uk/wp-content/uploads/2014/05/who-pays.pdf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