This guide is based upon the Patient Choice chapter in NHS Law and Practice written by David Lock QC and Hannah Gibbs, published by the Legal Action Group. Thank you to David Lock QC for agreeing to check our guide for accuracy[1].

Right to choice in mental health - Neurodevelopmental Conditions

NHS England and Improvement confirmed in September 2020 that Patient Choice, also referred to as Right to Choose (RTC), DOES apply to Neurodevelopmental diagnostic assessments and have informed all Clinical Commissioning Groups (CCGs) accordingly.

This is S4Nds guide to Patient Choice regulations.

History

Patient choice rules were established for physical conditions in the **National Health Service Commissioning Board and Clinical Commissioning Group (Responsibilities and Standing Rules) Regulations 2012**, hereafter referred to as the regulations. Mental Health services were originally excluded from patient choice rights when the 2012 Regulations were originally made. Since 2013 the NHS Constitution for England has contained a commitment "to improve, diagnose and treat both physical and mental health problems with equal regard". Amendments made to the regulations in 2013 sought to enable equal access to people needing to access mental health

[1] David Lock has done this pro bono and on the basis of not assuming any liability to anyone who relies on the Guidance.

services by giving patients, in consultation with their GP, the right to choose the service they are referred to. The changes came into effect on 1 April 2014. Despite this change, guidance issued by NHS England in 2014 (updated in 2018) appeared to attempt to curtail the rights of patients in England to exercise patient choice rights in mental health. Those restrictions were that:

1. The referral must be for treatment which is of a type which the patient's own CCG routinely commissions; and

2. The "commissioning contract" held by the provider must be in the form of an NHS Standard Contract and not any other form of contract.

3. GPs making choice referrals, should comply with commissioner's requirements to make individual funding requests (IFR) for treatments that are not routinely commissioned, rather than making a direct referral to a provider.

Updated guidance removing the restrictions has now been published on the NHS England website. However, there is a danger that some GPs or CCGs may still be working under the former Guidance which we believe to be incorrect.

The duty on Clinical Commissioning Groups

The Regulations sets up the system of legal rights of patients to make their own choices about which provider should provide 'treatment' to them. Patients have a legal right to choose the secondary care provider to whom they are referred for a first appointment by their GP where the GP decides that the patient requires an "elective referral."

A legal duty is imposed on each CCG to "make arrangements" to give effect to the right of patients to exercise their patient choice rights. However, the Regulations mean that the CCG must operate a patient choice system which ensures that patients can access first appointments in accordance with the Regulations which give effect to patient choice rights.

When making decisions as to whether to fund medical treatment for an NHS patient, regulation 39(1) requires both CCGs and NHS England to put in place a decision-making process, which asks four questions, namely:

1. Is this patient a person for whom the CCG has commissioning responsibility?
   The relevant CCG will be identified by the location of the patient's GP (or by where a person lives if they have no GP at the moment).

2. Is this patient a person who requires an "elective referral"?
   "Elective referral" means referral by a general medical practitioner to a health service provider for treatment. The only general exemption to this right relates to treatment that is "immediately required" at the time of referral, namely emergency medical treatment.

3. Do the patient's circumstances come within Regulation 39(2)?
   Patient choice does not apply to cancer services which are subject to the two-week maximum waiting time or maternity services. The person seeking to exercise patient choice rights must also not be serving as a member of the armed forces or detained under the Mental Health Act 1983 or detained or on temporary release from prison.

4. **Is the patient entitled to exercise patient choice rights for this particular episode of treatment?**

   "Treatment" means an intervention that is intended to manage a person's disease, condition or injury and includes prevention, examination and diagnosis.

Each CCG and NHS England must have policies which provide that, if the answer to all four questions is "yes," the CCG or NHS England must decide to fund the initial consultation with the healthcare provider nominated by the patient. An appointment with that provider must be funded because the patient has a "legal right" to have NHS funded treatment with that provider (at least to the extent of a first appointment). Where these conditions are satisfied, CCGs or NHS England must fund the first appointment as part of NHS funded care.

GPs

The Regulations require that the decision as to whether the referral is clinically appropriate for the assessment or treatment which is the subject of the referral is exclusively a matter for the person making the referral, namely your GP. This is not a decision for the CCG.

Patient choice is generally concerned with elective procedures as opposed to emergency procedures and the role of the GP in this system is essential. Therefore, a patient cannot "self-refer" for secondary NHS care and claim to exercise patient choice rights in respect of that referral. The person making the referral must be a GP (or another NHS clinical professional with referring rights for that procedure such as a dentist). Further, the rules about choice for elective referrals do not apply to

emergency procedures and so a referral by a GP for treatment that is "immediately required" does not give rise to patient choice rights.

Giving effect to patient choice for secondary care is not, in reality, giving effect to a choice for the patient alone. It is giving effect to joint decision-making between a GP and the patient. The GP makes the decision to offer a referral and if the patient agrees to be referral, and then the patient alone has the right to be referred to any clinically appropriate provider who contracts with the NHS.

Making choices beyond a first appointment

Under the NHS Choice Framework (also known as "Patient Choice"), there is a right to choose a new provider for an entire course of treatment when:

1. A GP in consultation with the patient, decides to refer a person for assessment or treatment.

2. The wait time for a service exceeds 18 weeks or the patient has been waiting at least 18 weeks.

3. The patient was not offered choice by the GP in the initial referral.

The referral can be made to:

1. The locally commissioned NHS service.

2. Any "health service provider" that that has a "commissioning contract" with a CCG or NHS England for any NHS service (whether of the same type as now being requested or not). In the case of physical health, the service must be led by a consultant. In the case of mental health, the service must be led by a consultant or a healthcare professional.

The service must be registered with CQC as required. However, some diagnostic services that do not offer treatment for disease do not need to be registered with the CQC. Service Providers that prescribe medication for the treatment of symptoms should be registered as they are carrying out a regulated activity. CQC registration mainly applies to ADHD services. It is worth checking with the service provider.

Potential CCG Responses

Some CCGs actively promote patient choice rights, some do not understand them and others seek to put obstacles in the way of patients exercising rights because they impose costs on CCGs outside normal contracts (which are almost all block contracts where the amount the CCG pays is the same regardless of the number of referrals).

We are aware that the following are the type of reasons CCGs have used in the past to decline a patient choice referral. Our view is that these responses are not lawful and cannot lawfully be used to decline a referral. We provide them here to enable patients and their GPs to refute them and challenge CCGs decision-making:

"A diagnostic assessment is not considered to be a treatment"

This is incorrect because the legal definition of "treatment" includes diagnostic assessments.

"A provider must be commissioned by the CCG"

This is wrong. Legally, patients may choose a provider that has a contract with any CCG or NHS England, not just the CCG which has responsibility for this patient.

"A referral cannot be made due to cost"

This would be an unlawful objection. The Regulations do not specify any right to restrict the choices agreed between the patient and the patient's referring GP based on the cost of the assessment or treatment.

"A provider must have an NHS Standard Contract"

This is incorrect. The patient choice right applies if any CCG has previously entered in a contract for this form of treatment with any CCG. That includes where another CCG had entered into a "spot contract" in the past with a provider to treat a specific patient. Once that contract is placed, that contract can be relied upon by other patients to establish a right to be referred to that provider.

"Requirements for GPs to make Individual Funding Requests (IFR)"

Imposing this additional requirement is unlawful. The Regulations apply to a first out-patient appointment and do not specify any right to restrict the choices agreed between the patient and the patient's referring GP to a prior approval under an IFR process.

"The service provider is not on the e-Referral System"

This is not part of the statutory scheme. A request cannot lawfully be denied on the basis that a provider is not on the e-Referral system.

"The CCG does not commission a diagnostic service"

A service does not need to be presently commissioned by a CCG in order for a patient to exercise the right to choose a first appointment.

"The provider has not accepted the referral"

A healthcare provider must accept any clinically appropriate referral for any service of an individual to exercise their legal right to choice as set out in the NHS Choice Framework.

"Your referral will be sent to the First Point of Access (FPoC) or a Single Point of Access (SPA)"

This would be unlawful. Patients have a legal right of choice at point of referral, which means that a GP does not need to seek commissioner approval. The guidance states that healthcare providers must accept all clinically appropriate referrals and where they consider the referral clinically inappropriate, they should consult with the patient's GP. Hence, the decision-making processes cannot allow the commissioner to reach their own view as to whether the referral is appropriate.

"Patient Choice only applies to the first outpatient appointment; it does not entitle you to treatment"

While this is correct when that part of the Regulations is relied upon, different rules apply where waiting time limits are breached. *See the note below for information about ADHD assessments and treatment.*

"The service must be NICE compliant"

Not being NICE compliant would not be a lawful reason to refuse to fund the service. It is not mandatory for every NHS provider to apply recommendations in NICE guidelines and they do not override the responsibility of professionals and practitioners to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

If the CCG declines a Patient Choice request for any of the reasons above, please email patientchoice@s4nd.org so we can help you.

Additional Information

Patient choice only applies to people living in England.

The legal right of choice of provider currently applies at the point of referral from primary care practitioners for first outpatient appointments for a physical or mental health condition to clinically appropriate providers which have a commissioning contract for the service required, that is, which have been commissioned by a CCG or by NHS England (host commissioner) to provide that service.

At the point of referral, patients have the legal right to choose any clinically appropriate provider in England which has been commissioned by at least one NHS commissioning body, to provide the particular service required. In this context, "the particular service" must be taken to mean the service as described in a written commissioning contract, including where and how that service is to be delivered.

NHS-funded services delivered to a patient by a provider which does not, at the point at which those services are delivered, have a written contract in place with that patient's responsible commissioner, but which does have a written contract for the

delivery of that service in place with at least one other NHS commissioner is undertaken by the provider on the terms of the NHS Standard Contract in place between that provider and its host commissioner(s). A contract on those terms will be implied as between the patient's responsible commissioner and the provider.

Services will be delivered in accordance with the service specifications and other terms and conditions of the provider's contract with its host commissioner

Healthcare service providers can choose to focus their activities within, for example, specific geographies and not actively seek referrals from outside these areas. This does not enable providers to refuse referrals from outside their core area.

Information for ADHD Referrals

If you require an assessment for ADHD unless you are 100% sure that you will never try medication to improve focus and reduce impairments in Executive Functioning, then we urge you to choose a healthcare provider that prescribes medication. If you receive a positive diagnosis from a non-prescribing service, then afterwards, ask to be referred for medication, the service receiving the referral may reassess you. We are aware that for some people this has led to a diagnosis being removed. The NHS has scarce resources and it is everyone's responsibility to ensure that money isn't being wasted.

If you are in a situation where something in your life is at imminent risk e.g., education, employment or relationships and you consider you have no option but to ask for a private assessment, please note that the Society for Neurodiversity may be able to help you to access the reasonable adjustments you need. Using the guidelines, we have provided, you should be able to access a diagnostic assessment through your legal right to choose service provider.

If you decide that you have no option but to self-fund an assessment and you decide to try the medication, it is expensive, with private prescriptions costing between £75 and £115. Titrating medication can be a lengthy process while the prescriber attempts to ensure you are on the correct medication at the right dose for you. As previously mentioned, if you decide following a self-funded assessment that you now want an NHS referral to try medication you could be re-assessed. Unfortunately, it is the case that self-funded assessments are not always accepted by the NHS and you may have your diagnosis removed.

For both NHS and self-funded referrals where you intend to try the medication, ensure you ask your GP prior to the referral being made, if they are willing to continue to prescribe your medication once titration is complete on a Shared Care Agreement. If a GP is uncertain about their competence to take responsibility for the patient's continuing care, they should seek further information or advice from the clinician with whom the patient's care is shared or from another experienced colleague. If possible, speak to another GP about the referral and the potential for a Shared Care Agreement, if treatment is successful.

Important Note:

The information provided by the Society for Neurodiversity (CIO), known as S4Nd, is for advisory purposes only. All information is provided in good faith. However, we make no representation or warranty of any kind, express or implied, regarding the accuracy, adequacy, validity, reliability, availability or completeness of any information provided.

It is incumbent on the intended recipients to pursue the necessary official clarification and formal confirmation that they are fully compliant with the statutory Regulations for the execution of their legal duties and responsibilities.

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Glossary

Care Quality Commission

The Care Quality Commission (CQC) regulates all health and social care services in England. The commission ensures the quality and safety of care in hospitals, dentists, ambulances, and care homes, and the care given in people's own homes.

Clinical Commissioning Group

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. Many GP services are now co-commissioned with CCGs.

Commissioning Contract

Means a contract, other than a primary care contract, entered into by a relevant body in the exercise of its commissioning functions.

E-Referral System

The NHS e-Referral Service (e-RS) is a national digital platform used to refer patients from primary care into elective care services.

Host Commissioner

The host commissioner will be the CCG who contracts the service. Please note that the service does not need to be located within the geographical area of the CCG.

Health Service Provider

Means a person who has entered into a commissioning contract.

Healthcare Services

Means one or more services consisting of the provision of treatment for the purposes of the health service.

Individual Funding Request

An individual funding request can be made by the clinician treating you if they believe that because your clinical circumstances are exceptional, you may receive benefit from a treatment or service that isn't routinely offered by the NHS.

Medication Titration

Is the process of adjusting the dose of a medication for the maximum benefit without adverse effects.

NHS Standard Contract

The contract is for use when commissioning healthcare services.

NICE Compliant

Clinicians are able to offer their patients access to clinically appropriate NICE recommended medicines and treatments within the given time frames and in accordance with the NHS Constitution.

Responsible Commissioner

The responsible commissioner is the CCG of which the patient's GP practice is a member.

Secondary Care

Secondary healthcare is the specialist treatment and support provided by doctors and other health professionals for patients who have been referred to them for specific expert care, most often provided in hospitals. Usually, patients are referred from primary healthcare when the patient requires an assessment or treatment from specialists. Secondary healthcare includes a wide range of specialists.

Self-funded Assessment

Paying for your own assessment – using a private provider.

Spot Contracts

Are contracts between a commissioner and a provider on a one-off basis for the treatment of a specific patient.

References

Lock, D and Gibbs, H. (2018). NHS Law and Practice. LAG Education and Service Trust Limited

Draft chapter (Patient Choice) can be found at Landmark Chambers

National Health Service Commissioning Board and Clinical Commissioning Groups (responsibilities and Standing Rules) Regulations 2012

Part 1 section 2, Part 8 section 38, 39, 40, 41, 43, Part 9 Section 45.

Choice in mental healthcare Guidance April 2021

Contains sections for Patients, GP, CCGs and Service Providers

Who Pays? Guidance

Section 5.10 Non-Contract activity and patient choice provider.

NHS Standard Contract Technical Guidance 2021/22

Section 25 Non-contract activity. Relevant parts 25.1, 25.4, 25.5a, 25.5b, 25.5e, 25.11, 25.12, 25.16 and 25.20.

NHS Standard Contract Service Conditions 2021/22 (Full Length)

Section SC6 Choice and Referral and SC29 Managing Activity and Referrals specifically 29.2, 29.17 and 29.23.

Non-contract activity as set out in the NHS Standard Contract Guidance apply to SC6.8.2 and SC6.8.3.

Important note: The Service Conditions are part of the Contract, which NHS England updates from time to time (typically every year). In most cases, contracts let locally cover only a single year. So, for a contract which covered only the financial year 2020/21, the 2020/21 version of the Service Conditions would apply, whereas, for a

contract which covered only the financial year of 2021/22, the 2021/22 version of the Service Conditions would apply. Where a commissioner and provider agree a contract covering multiple financial years, they are required to implement a National Variation to their contract at the start of each new financial year, amending the national terms of the contract so that they reflect the most recent published version. So, in that case, if a commissioner and provider agree a three-year contract covering 2019/20, 2020/21 and 2021/22, then the relevant version of the Service Conditions would apply in each year.

NHS Standard Contract 2021/22Guidance on National Variations to existing 2016/17, 2017-19 (November 2016 edition), 2017-19 (January 2018 edition), 2017-19 (May 2018 edition),2019/20 and 2020/21 Full Length and Shorter Form

For information as it applies to NHS Standard Contracts Service Conditions.

NICE guidelines CG128 (autism spectrum disorder in under 19s: recognition, referral and diagnosis)

Relevant sections 1.2 Recognising Children and Young People and 1.3 Referring children and young people.

NICE guidelines CG142 (autism spectrum disorder in adults: diagnosis and management).

Relevant section 1.2 Identification and Assessment.

1.2.1 Adaptations, 1.2.2 can aid the GP in making a clinically appropriate referral, 1.2.3 NICE approved self-administered test, 1.2.5 outlines a comprehensive assessment.

NICE Guidance Statement

"The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services and considering their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties."

The NHS Constitution for England guidance updated January 2021

Relevant section – Patients and the public: your rights and the NHS pledges to you.

The NHS Choice Framework: what choices are available to me in the NHS?

Section 3 – Choosing where to go for your first appointment as an outpatient.

If you have any ideas, questions, comments or feedback about our guide then please email feedback@s4nd.org