NHS England

Toolkit for reducing health inequalities & improving equity in Highly Specialised Services

What are Highly Specialised Services?

Within the specialised commissioning portfolio, there are around 80 services that are designated as 'highly' specialised. In general, these services:

- Are delivered in a small number of expert centres, usually no more than three, which have been commissioned by NHS England.
- Have small caseloads of patients, usually no more than 500 and therefore considered rare disorders.
- Are clinically distinct.
- Benefit from national coordination.

Policy background

The Triple Aim set out in the Health and Care Act 2022 sets out the requirement for all health bodies to cooperatively pursue:

- The health and wellbeing of the people of England (including inequalities in health and wellbeing).
- The quality of services provided or arranged by both themselves and other relevant bodies (including inequalities in benefits from those services).
- The sustainable and efficient use of resources by both themselves and other relevant bodies.

Reducing health inequalities is a key priority within the NHS Long Term Plan, the UK Rare Diseases Framework, and England Rare Diseases Action Plan. This toolkit aims to support Highly Specialised Services (HSS) to reduce health inequalities and improve equity in their everyday service delivery. It provides a step-by-step guide and prompts to help teams to find out whether health inequalities exist within their services and, if so, develop actions to address them.

What are health and healthcare inequalities?

Health inequalities are unfair and avoidable differences in health across the population, and between different groups within society. They arise because of the conditions in which we are born, grow, live, work and age. These conditions influence how we think, feel and act and can impact both our physical and mental health and wellbeing.

This toolkit will focus on healthcare inequalities, which are about the access people have to health services and their experiences and outcomes.

NHS England's Healthcare Inequalities Improvement Programme works with other programmes and policy areas across NHS England, as well as with partners in the wider

system, patients and communities, to deliver exceptional quality healthcare for all; ensuring equitable access, excellent experience and optimal outcomes.

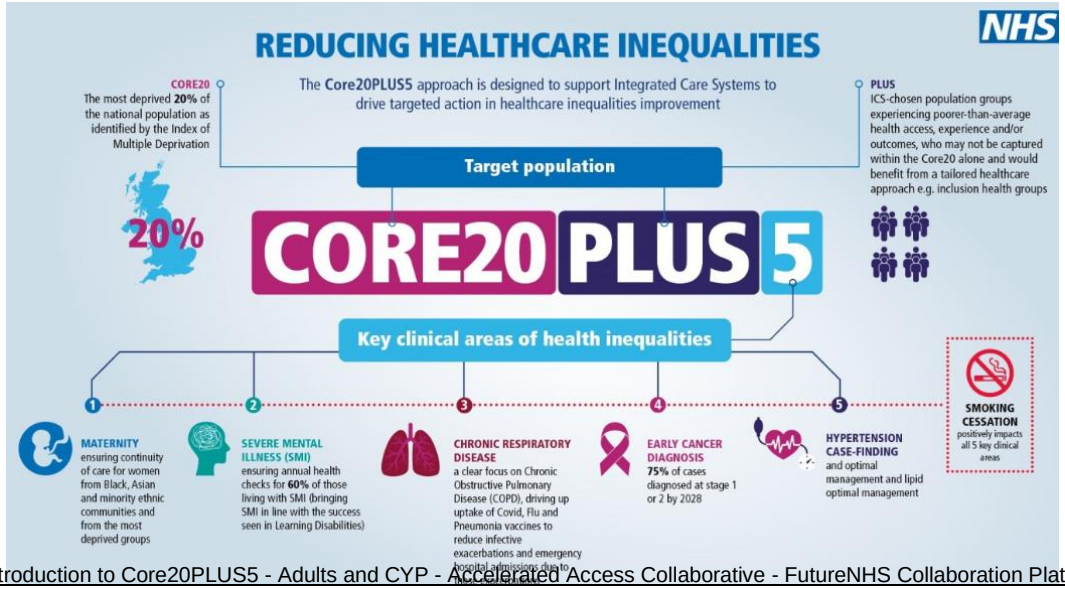
The Programme uses a quality improvement approach to tackling healthcare inequalities by adopting the following methodologies:

i) Data for Improvement – Dis-aggregate data to surface inequalities, generate actionable insights, use those insights to implement tangible interventions and drive improvement, generate intelligence about what works

ii) Experience Based Co-Design – Co-design the interventions with people and communities affected by the health inequalities surfaced through data dis-aggregation

iii) Appreciative Inquiry (Strengths Based Approaches) – Inquire into what is already strong and the assets, within the area requiring improvement, and leverage it to drive improvement

Core20PLUS5 is NHS England's approach aimed at supporting Integrated Care Systems (ICSs) to implement change in order to tackle healthcare inequalities.



Source: Introduction to Core20PLUS5 - Adults and CYP - Accelerated Access Collaborative - FutureNHS Collaboration Platform

The 'Core20' refers to "the most deprived 20% of the national population as identified by the index of multiple deprivation" (2)

The 'PLUS' refers to "ICS chosen population groups experiencing poorer-than-average healthcare access, experience and/or outcomes, who may not be captured within the core20 group alone and would benefit from a tailored healthcare approach e.g. inclusion health groups" (2)

The '5' stands for key clinical areas of health inequalities [2]

- Maternity
- Severe mental illness (SMI)
- Chronic Respiratory Disease
- Early cancer diagnosis
- Hypertension case finding

What are the health inequalities in healthcare?

As well as the inequalities already described, there are groups of patients who are experiencing differences in access to services, speed of diagnosis, the quality and experience of care and clinical outcomes, compared to others using the same services.

Inequalities in healthcare may be driven by:

- Inequitable access to healthcare. This could be due to a range of factors including physical barriers, such as availability of the service in certain areas, access to transport for patients, service opening times, childcare etc. In addition, patients may face real or anticipated discrimination, challenges around language (whereby they are unable to understand the services available to them) and literacy or cultural sensitivity.
- For patients with rare disorders attending Highly Specialised Services, inequalities may arise as a result of lack of awareness of the condition by healthcare professional and associated delay in referral and diagnosis.
- Systematically different experiences within the service between different population groups in terms of the quality of care and whether they are treated with dignity and respect.

How can we tackle inequalities in healthcare?

Health inequalities can be tackled. HSS are well established clinical services and service staff know their populations well. Inequalities can be investigated using existing data, systems and processes. Some inequalities can be mitigated through individual actions as clinical team members as well as thinking about how the HSS is designed and accessed. Your team are in the best position to identify areas of inequality and come up with creative, time and cost-effective means of reducing them.

Five strategic priorities for tackling healthcare inequalities

The Healthcare Inequalities Improvement Programme has in place five strategic priorities for tackling healthcare inequalities. They are:

1. **Restoring NHS services inclusively:**
    - Ensuring services are restored whilst continuously addressing healthcare inequalities.

2. **Mitigate against 'digital exclusion':**
    - Improve the inclusiveness of services or offerings that have a digital element.

3. **Ensure datasets are complete and timely:**
    - Make it easier for people to identify and access indicators to monitor progress on health inequalities.
    - Improve the quality of data about patient ethnicity to reveal ethnic inequalities in access, experience and outcome.

4. **Accelerate preventative programmes including Core20PLUS5 approach:**
    - Ensuring that work which helps to prevent further healthcare inequalities is advanced.

5. **Strengthen Leadership and Accountability:**
    - Ensuring healthcare inequalities is everyone's business and ownership for tackling is taken at all levels.

Specialised services often involve treatments provided to patients with rare cancers, genetic disorders or complex medical or surgical conditions. They deliver cutting-edge care and are a catalyst for innovation, supporting pioneering clinical practice in the NHS. The complex nature of many specialised services provides multiple opportunities for inequalities to arise and become embedded for the people and populations that use them.

How can you find out if health inequalities exist within your services?

HSS are in a strong position to mitigate health inequalities as they know their patient populations well, have regular interactions with them and already work in partnership with patient groups. Liaising with patients and understanding their opinions can help you to identify health inequalities and will enable you to work with your patient populations to help tackle them. Patient groups and patient generated data e.g. feedback questionnaires, QOL measures etc. can be important and provide good resources to highlight potential areas for investigation. Patients and patient groups may also be useful in generating data and co-creating solutions. Where possible, they should be included from the outset.

HSS already collect large amounts of data to monitor quality, activity and experience as well as for research. Although this data may have gaps it could be a useful starting point to start investigating the impact of demographics, protected characteristics and diagnoses on a patients' experience and outcomes. A deep dive into this information can also help with future planning and may identify groups who aren't currently accessing services.

The three stages of the process are Scoping, Assessment and Actions/Monitoring (please see below). Some services may have already undertaken this work as part of other projects. Assessment of health inequalities should be discussed within your teams and key areas

Stage 1: Scoping

Decide which area you would like to assess to improve equity

Are there any specific areas of interest/concern where clinicians, patients or patient groups think that some patient groups may be experiencing the service in a different way to others?

Examples may include:

- Patient feedback and experience
- Compliance with medication
- DNA rates
- Time to diagnosis or intervention
- Clinical outcomes
- Participation in research

Think about the characteristics of your patient population

What are the population characteristics (e.g. age, ethnicity, geography, deprivation, patients with a learning disability*) that might influence the area selected above?

Which one will you focus on for this project?

*See Box 1

Identify data & information you already have that could be used to assess inequalities

Examples of data & information include:

- Registry data/outcomes data
- Patient satisfaction survey (service/patient group)
- Audit data
- Incident reports
- Service activity data

Can you analyse these data for the population characteristic you selected?

No

The action could be to consider another data source and/or improve the quality of recording of population characteristics (for example developing a minimum data set or using lived experience)

Yes

Go to stage 2

BOX 1: Deprivation

The Index of Multiple Deprivation (IMD) is the official measure of relative deprivation in England. The IMD has seven domains with indicators accounting for a wide range of social determinants of health. The IMD relatively ranks each small area in England from most deprived to least deprived.

How to measure deprivation for your patient:

You can use postcode information to identify IMD for a patient. For more details on how to do this, see Appendix 1.

Your Trust's data team may also be able to assist you in deriving the IMD for your patient groups.

Stage 2: Assessment

Now look at the outcome of your interest. Is the population characteristic you have chosen over or under represented?

For example, if you chose DNA rates and found that a specific age group is over represented in this group

Yes

No

BOX 2: Using patient feedback/survey data – considering potential bias

If you are using data such as patient feedback or a patient survey, you may want to consider if the dataset is representative of your patient population or is there a selection bias? Some patients may find it more difficult to respond to surveys for various reasons. Some aspects of survey administration that can affect response rates include:

- Mode of survey (e.g. online, postal, telephone, face to face)
- Language/accessibility (are other language options available?)
- Clear, short questions that are easy to understand
- Who in the team is best placed to deliver the questionnaire?

What are the potential drivers for these differences in your service?

Are there any potential barriers in your service that might prevent certain population groups from fully engaging with your service (e.g. digital inequality, language, cultural barriers) ?

Which health behaviours might play a role?

Continue working on delivering an equitable service

Continue periodic monitoring of health inequalities

Consider different outcomes or a focus on different population groups in a future review

Go to Stage 3

You can avoid bias and overinterpretation by validating your assessment using simple statistics, such as comparing proportions for 2 or more groups to evaluate the frequency of event occurrence. Please see the following link for an example: Basics > Proportions > Compare proportions (radiant-rstats.github.io). Please use this link to help you calculate proportions MedCalc's Comparison of proportions calculator

Stage 3: Action and Monitoring

Develop an action plan

What are the most important issues to address? You don't need to address all the issues at once. It's important to focus on what's practical and achievable in a given time frame.

How will you address these issues? What are the steps involved? How can you improve care for a sub-group without changing outcomes for other patients? What are your SMART objectives and how will achievement against them be measured ? For more complex issues, using quality improvement tools (see tools below) may help you plan manageable steps that can contribute to the overarching aim over time. Do you have the resources to address these issues?

As a minimum the data used to identify the inequality should be reassessed to see if there is any improvement

Who is going to be working on these actions? Are there any colleagues you work with e.g. local clinicians, GPs who can also contribute? How can changes become sustainable? How will you share good practice as well as what didn't work?

Where appropriate, co-design with patients to ensure patient voices are reflected in your plan. Clinical NHS services cannot address all issues, particularly social inequalities e.g. housing, but liaising with patients to find out more about those wider determinants could help shape new approaches to care.

Monitoring

Establish a framework for monitoring progress & feeding back to contributors especially patient groups (see tools below)

Plan how you measure the impact of your activities.

Link this into existing HI governance and monitoring systems and processes within your trust

Tools that may help developing action plan and monitoring progress

There are a range of tools that can support the sustainability of your initiative by helping to create more manageable steps that can contribute to the overarching aim over time and help you to always keep the bigger picture in mind. Some examples may include:

- *Logic Model*: is a graphic depiction (road map) that presents relationships between your programme's activities and its intended outcomes.
- *Driver Diagrams*: a driver diagram is a tool that can be used to help plan improvement project activities.

- *Plan, Do, Study, Act (PDSA) cycles and the model for improvement:* the model for improvement provides a framework for developing, testing and implementing changes leading to improvement. Using PDSA cycles enables you to test out changes on a small scale and building on the learning from these test cycles in a structured way before implementation at larger scale
- *Reducing health inequalities in your local area: a toolkit for clinicians (bma.org.uk)*
- *NICE and health inequalities | What we do | About | NICE*
- *Health Equity Assessment Tool (HEAT) - GOV.UK (www.gov.uk) i*s used to address health inequalities related to work and helps to establish ways to reduce inequalities and strive for equality and inclusion

Appendix 1: How to measure deprivation for your patient population

The Index of Multiple Deprivation (IMD) is the official measure of relative deprivation in England. The IMD has seven domains with indicators accounting for a wide range of social determinants of health. The IMD relatively ranks each small area called Lower Super Output Area (LSOA) in England from most deprived to least deprived.

You can derive the IMD scores for your patient data based on patients' postcode.

1. Make sure your patient dataset has full postcode of their residence/GP.
2. Go to this website and follow the instruction; English indices of deprivation 2019: Postcode Lookup (opendatacommunities.org)

This tool provides access to the latest IMD dataset for up to 100,000 postcode at a time.

3. Once deprivation data is extracted, download and open the excel file. The column you need is the "Index of Multiple Deprivation Decile", where 1 = the most deprived decile in England and 10 = the least deprived decile.
4. "Index of Multiple Deprivation Decile" of 1 and 2 together makes up the 20% most deprived population in England. You may consider analysing your patient data by five deprivation group (Decile 1&2 = the most deprived 20%, Decile 3&4, Decile 5&6, Decile 7&8, Decile 9&10 = the least deprived 20%).

Health inequalities resources and references

There are many resources available to help you learn more about health inequalities. This section will signpost you to a few resources which may be of benefit and interest to you.

NHS England » Inclusive digital healthcare: a framework for NHS action on digital inclusion
A resource regarding digital inclusion has been released which includes a framework for NHS action on digital inclusion. It explains the digital exclusions and how to address them.

NHS England » A national framework for NHS – action on inclusion health
A framework for the NHS to action on inclusion health. It explains what inclusion health is and how to action on inclusion health.

There are a range of resources to help understand health inequalities, listed below:

Introducing a framework to support the identification and tackling of health inequalities within specialised services | BMJ Leader
This paper describes the opportunities to identify and address inequalities in specialised services.

Health Inequalities - elearning for healthcare (e-lfh.org.uk)

- Narrowing health inequalities in sickle cell disease
- Narrowing health inequalities in hypertension
- Narrowing health inequalities in early cancer diagnosis
- Narrowing health inequalities in chronic respiratory disease
- Narrowing health inequalities in maternity
- Narrowing health inequalities in severe mental illness (SMI)

The latter five eLearning courses are part of the Core20Plus5 approach.

NICE and health inequalities | What we do | About | NICE
This website is created by NICE and includes a range of information about inequalities to help provide the fundamental knowledge to properly understanding health inequalities.

Course: An introduction to inclusion health (rcgp.org.uk)
This is a course created by the Royal College of General Practitioners that provides an introduction to inclusion health, the factors that cause exclusion, as well as steps that can be taken to help overcome these issues.

A brief introduction to inclusion health (fairhealth.org.uk)
This is another course which provides information about inclusion health. It looks into population groups within the migrant, LGBTQ, homelessness, sex workers and travellers community.

Morbidity and mortality in homeless individuals, prisoners, sex workers, and individuals with substance use disorders in high-income countries: a systematic review and meta-analysis - The Lancet

This is an article containing information about the morbidity and mortality of the population groups who experience social exclusion e.g. homeless populations, sex workers etc.

Reducing health inequalities in your local area: a toolkit for clinicians (bma.org.uk)
The BMA produced a toolkit aimed at clinicians to aid in tackling health inequalities. It is split into three different tiers, based on how much time and how many resources are required. It also provides some case studies of some projects.

https://www.england.nhs.uk/publication/virtual-clinics-in-highly-specialised-services-guidance-for-services-supporting-patients-with-rare-and-complex-and-multi-system-disorders/
This NHSE guidance includes guiding principles for establishing digital/virtual and phone clinics that can be applied to other services.

The Dahlgren-Whitehead rainbow - Economic and Social Research Council (nationalarchives.gov.uk)

Introduction to Core20PLUS5 - Adults and CYP - Accelerated Access Collaborative - FutureNHS Collaboration Platform

Health disparities and health inequalities: applying All Our Health - GOV.UK (www.gov.uk)

Inclusive and sustainable economies: leaving no one behind (executive summary) - GOV.UK (www.gov.uk)

https://www.gov.uk/government/publications/uk-rare-diseases-framework/the-uk-rare-diseases-framework