Introduction

Access to accurate, timely data is a crucial step in developing a robust response to inequalities in access, experience and outcomes. It is an essential part of understanding how best to provide services that meet the needs of marginalised groups including ethnic minorities, deprived communities, people with learning disabilities and autism, and people living with long-term conditions, homelessness or mental ill health.

NHS England (NHSE) has identified ensuring datasets are complete and timely as one of its five key priorities for reducing healthcare inequalities. This is necessary to ensure action on health inequalities and prevention is based on the best possible understanding of the inequalities faced by local populations – and requires mechanisms to be in place to gather the data. A strong evidence base is also essential to other priorities on health inequalities set by NHSE, including strengthening accountability, and restoring NHS services inclusively.

Despite this, many trusts say that a lack of access to the right insights is a barrier to mounting an effective response to health inequalities. This briefing sets out some of the key challenges, and offers some points for trust leaders to consider when looking to address these common issues. Including:

- strengthening their processes for collecting, storing, sharing and analysing data about health inequalities across sectors, so that it can be used to drive action at board level as well as in services
- recognising that data about health inequalities may contain gaps, in particular about people who struggle to access services, and addressing them so that work to tackle health inequalities does not miss those who experience the greatest inequity
- building capacity among informatics teams, business analytics functions and among clinical staff to interrogate data about health inequalities and embed it into conversations across the trust.
Dealing with incomplete and imperfect data

In an ideal world, trust leaders and clinicians would have access to a wealth of complete and accurate data about the inequalities people face in accessing care and experiencing equitable outcomes.

However, incomplete datasets due to differences in how information is collected, analysed or interpreted, weaknesses in data collection methods, and information governance barriers to sharing data between organisations, are common issues leading to an incomplete picture of how health inequalities manifest for the local population. For example, elective recovery guidance asks trusts to cut their waiting list data by ethnicity and deprivation, but some trust leaders say they have faced challenges in gathering complete data on ethnicity, and in linking deprivation data to patient records. They also cite concerns that patients are often asked multiple times for the same information because systems for storing this information are not joined up.

Trust leaders also say that data about patient characteristics such as ethnicity and deprivation in the Core20PLUS groups only offers a meaningful insight into inequalities when combined with other sources, including geographical data about service use across a variety of services including primary care, social care, and ambulance services. Looking at individual services in isolation means that the impact of systemic barriers to accessing care, particularly for people with multiple or complex health needs, cannot be fully appreciated.

Trust leaders may wish to consider the following:

- How they are building buy-in among the clinical workforce, who are often at the frontline of collecting accurate data about the communities they serve, to enable analysis of complete and reliable data.
- How they are simplifying the process of collecting, sharing and recording relevant patients’ characteristics, including ethnicity, deprivation, learning disabilities and other priorities identified by Core20PLUS5, so that information can be collected once rather than many times.
- What gaps may exist in their current understanding of health inequalities for the local population, and whether there are any ‘hidden’ populations whose poorer access, experience or outcomes are not being surfaced in the current data collection methods.
- How they are gaining a holistic view of inequalities across a range of services, pathways and places, in order to identify any patterns and share learning across the trust.
Enriching quantitative insights

Analysis of waiting list data and population health data can help trusts identify how services are meeting the needs of the population, who is being left behind, and where in the system those left-behind communities are. This can enable trust leaders to allocate resource to where it is needed most.

However, large-scale datasets cannot give a full insight into the ‘why’ of health inequalities – including the broad range of factors which influence someone’s health outcomes or ability to access services in a timely way. Trust leaders need to look beyond the numerical data to understand how best to address the issues which can drive inequalities in access, experience and outcomes. Engaging with communities that experience inequalities can then support a greater understanding of how to design services around their needs.

Trust leaders should consider the following

● How the trust is working with local communities to understand the social determinants of health and build a more detailed understanding of how health inequalities arise, and communicating what has been learned so that they know their feedback is being acted upon.

● Ensuring discussions of quantitative data about health inequalities are accompanied by lived experience insights at all levels, including through public and patient engagement groups, engagement events, local Healthwatch and voluntary sector forums.

● Identifying any structural biases that exist in current datasets which may disguise inequalities or fail to capture ‘hidden’ populations who need care but are not visible in existing data because they have not accessed services.

● How best to increase connections with local communities, including through working with faith leaders, voluntary sector partners, or other leaders who know and are trusted by the local community.

● Their understanding of the practical challenges communities face in accessing health services, and what concerns, beliefs and perceptions people have about the experience they have of services.
Maximising the expertise of local colleagues

While many trusts are doing the groundwork of strengthening the quality of their datasets as they navigate the backlog recovery, some have identified a lack of expertise in population health management and public health as a barrier to fully realising the benefits of this improved data.

Understanding and addressing health inequalities through data and evidence is a multi-faceted process involving many partners. Many organisations across systems hold insights on how health inequalities manifest for local communities, with local government, the voluntary sector, educators and emergency services all sharing unique perspectives on local populations.

Within the NHS, different parts of the system offer different insights into people’s needs. For example, the urgent and emergency care pathway including ambulance services, act as a first port of call for many marginalised groups, and collect clinical and demographic information about large numbers of patients every year that can be shared to provide insight about unmet needs and inequalities in health outcomes.

Similarly, primary care services are a vital support network for local communities with strong insights at place and neighbourhood level, particularly for those who find secondary care services less accessible. System working therefore offers an opportunity for these partners to come together to develop a shared view of how inequalities affect the health of their shared populations, providing trust leaders with an important context for their work to reduce healthcare inequalities. Some trusts are working with local GP practices to combine analytical capacity to support local primary care to do more with their data, which simultaneously offers greater insight into local populations for their own work on health inequalities.

Alongside this, trusts can develop their own capacity to understand and address inequalities in their services. Some trusts have developed partnerships with local council directors of public health to strengthen their analytical capacity, while others have worked with commissioning support units and academic health sciences networks to access additional analytical resource. In-house public health consultants can also support trust-wide data analysis on health inequalities, and some trusts have embedded a health inequalities approach to improvement work to involve a larger number of staff in reviewing evidence.

Trust leaders may wish to consider the following

- Are analytical capabilities fully utilised across business intelligence functions in local authority, public health, and the voluntary sector, and are there effective mechanisms in place for sharing analysis?
- How is the trust engaging with and building relationships with local informatics teams and data scientists to understand the data and identify any trends or patterns of systematic inequalities?
- How is the trust ensuring it engages with staff who may be leaders in their local community, and harnessing their expertise when designing a response to health inequalities challenges?
Understanding shared populations

Across systems, a range of partners will hold information about the local population on the situations and circumstances which influence their health. For example, local government holds data on people’s access to statutory services, such as housing, benefits, work, education and social services, all of which contribute to population health. Police and fire services will also gain insights from their work with the local community. Ambulance services are often the first port of call in a crisis and therefore witness the impact of inequalities on people’s lives. Primary care partnerships play a pivotal role in identifying and managing long term conditions close to people’s homes, and so have an important part to play in understanding how inequalities affect people’s health.

In some systems, organisations are coming together to identify their ‘shared cohorts’ – people who are coming into contact with a variety of services, and are in need of support, but whose needs are not being holistically met by any one service or in a joined-up way by the wider system. This work often takes place in partnership with local health and wellbeing boards, or as joint audits of clinical pathways between NHS partners.

Trust leaders may wish to consider the following

- How collaboration with system partners may be able to support an improved understanding of these gaps – for example by triangulating data from primary care, other local trusts with different patient cohorts, local public health teams and other social services.

- Is there a shared system-wide understanding of the most significant healthcare inequalities, with agreed-upon objectives for action on these health challenges faced by the local population?

- What information governance agreements are in place to enable the sharing of data and information across boundaries, and are there any practical or cultural barriers that need to be addressed?
Uncovering who is ‘missing’ from the data on health inequalities

Trusts’ role in health inequalities is often considered to be largely focused on the inequalities in access, experience and outcomes for patients already within their services. However, access barriers go beyond just waiting times for treatment, and exist throughout the health and care system. Health inequalities impact how people access services at multiple stages in their journey through the health and care system, with compounding effects.

This can lead to people not being under the care of services they may need, with their health needs and outcomes not recorded in elective care data. Trusts may therefore have gaps in their understanding of how health inequalities affect whole communities if they only look at those who are already on waiting lists, as this can exclude those who have experienced barriers at earlier stages in their journey.

In order to tackle this issue it is important for analysis of inequalities in existing datasets to be accompanied by an assessment of whether there are any unexpected gaps in a trust’s patient population compared to the demographics of the local population. For example, an analysis of cardiology services may reveal that the proportion of patients under the care of the service from an ethnic minority background is lower than expected when higher rates of heart disease in certain ethnic groups is taken into account.

Reducing these gaps involves understanding where they exist, working to reduce them by building trust, ensuring services are accessible to people from all backgrounds, and monitoring progress carefully.

Trust leaders may wish to consider the following

- How expected rates of conditions in population health data compare with the rates seen among trust services, recognising that prevalence and severity may be different in certain communities.
- How the trust is working to reduce access barriers, including through partnership across the system, to ensure that people with health needs are able to come forward to receive timely care.
- How piecemeal approaches to analysing data and assessing inequalities as part of single services or improvement projects are being converted into a systematic and holistic approach to embedding equity across the trust, and as part of system-wide conversations.
About our health inequalities support offer

Health inequalities have worsened over the past 10 years, and we have seen evidence of wide inequalities in how people access healthcare, and the outcomes they experience as a result.

Trusts have a vital role to play in addressing the systemic challenge of health inequalities, embedding a focus on equitable access to and outcomes from care alongside work to reduce waiting lists and transform services.

Our support offer for trust boards aims to help trust leaders make sense of health inequalities, and embed it as part of ‘core business’, with resources informed by our research and engagement with trust leaders over the past year, through webinars, briefings and peer learning forums.