The Denny Review

A review of health inequalities in Bedfordshire, Luton and Milton Keynes

September 2023

Contents

Foreword	P3
Executive summary	P5
Introduction	P8
Terms of reference	P11
What we heard	P13
Published evidence	P14
Listening to residents	P20
Gypsy, Roma, Traveller community	P21
Women from migrant backgrounds	P22
LGBT+ people	P25
People who have experienced homelessness	P27
People with a physical or learning disability	P28
Insights and themes	P30
Recommendations	P34
Short-term change	P34
Long-term change	P37
Embedding the recommendations	P39
Conclusion	P40
Steering Group members	P42
Participant organisations	P43

Commissioned by







Foreword by Reverend Lloyd Denny DL

As a local pastor working in the heart of Luton, I listen to people's stories each day.

Often people tell me about their health problems. These stem from a range of issues, such as poverty, poor housing and unhealthy lifestyle choices.

When some residents try to get help from our local health and care system, they tell me about the barriers they face. The system, plainly, is not designed for them. I hear very clearly that this experience can be frustrating and often demeaning.

The truth is that some people do much better out of the health and care system than others. And it has hugely significant real-life consequences.

Life expectancy across Bedfordshire, Luton and Milton Keynes varies widely. A typical woman living in a deprived area of Luton, such as Bury Park where I am a Minister, has a life expectancy around six years lower than a woman living in a more affluent part of town. For men, the difference is an even more shocking nine years.

These issues have long been with us. This year marks both 75 years since the NHS was founded, and 75 years since the Empire Windrush brought men and women from the Caribbean to help get Britain back on its feet after the Second World War. It is still people from migrant backgrounds who often face the greatest health inequalities.

I have seen diseases like diabetes become a fact of life for too many people, particularly from our Caribbean and south Asian communities, for lack of education and support about healthy lifestyles. I have seen people not getting the care they need because they don't understand how the health system works. I have seen people die before their time because they cannot afford to travel out of our area to access treatment.

Experiences like this will be familiar to many. Health inequalities are common not just for people from migrant backgrounds, but also people experiencing homelessness, the LGBT+ community, the Gypsy, Roma and Traveller communities, people living in deprived neighbourhoods, and people with learning and physical disabilities. But these experiences, while common, are rarely heard.

This three-year study was triggered by the COVID-19 pandemic, when the data told us that people from ethnic minorities were much more likely to be infected and die from the disease. These people were often on the frontline, supporting us all through the crisis. That is an injustice we cannot let slide.

I was not the only one observing this. A group called the Legacy of Windrush Descendants (LOWD), based in Bedford, called on the NHS in Bedfordshire, Luton and Milton Keynes and their partners to do something about the inequalities people face.

This prompted the study which I was asked to lead, to get to the root cause of health inequalities in our area, and to work with those most affected to tackle the issues head-on.

This report is the culmination of that work. I have no doubt that it will take time to rebuild residents' trust, as will responding to this report in full in a way that delivers the radical change required. However, I am confident that if the recommendations in this report are acted upon, we will be much closer to getting the fair and equal health and care system we all need.



Executive Summary

The Denny Review investigated health-related inequalities in Bedfordshire, Luton and Milton Keynes (BLMK). We have sought to understand where health inequalities are greatest and what can be done to improve the situation for those affected.

A review of the published evidence both in the local area and nationally was commissioned from the University of Sheffield to establish what is known about health inequalities. Local voluntary, community and social enterprises (VCSE), including the four local Healthwatch organisations, engaged directly with local residents, particularly those from underrepresented groups.

Our recommendations reflect the evidence gathered, particularly residents' experience.

The factors driving health inequalities

The published evidence explains why some people face much worse health outcomes than others. These are:



These factors often combine to mean that a person facing health inequality is more likely to be in poor health. The following groups are more likely to be affected by health inequalities:

- People living in deprived neighbourhoods
- People from ethnic minorities
- LGBT+ people
- Gypsy, Roma and Traveller people
- People with physical or learning disabilities
- People who have experienced homelessness.

A better, more personalised service needed

Following in-depth engagement work with residents from these groups and beyond, four themes emerged:

- 1. Cultural competency
- 2. Communication
- 3. Access
- 4. Representation.

Cultural competency

The majority of residents we spoke with felt an understanding of their cultural background was often lacking in healthcare staff.

Examples include:

- Migrant women feeling that their condition was not being taken seriously
- An LGBT+ person being spoken to with the wrong pronouns, even after repeatedly explaining what the correct ones were
- A member of the Gypsy, Roma and Traveller community being treated differently as soon as they said what their background was
- A person with autism being expected to wear a face mask even though the healthcare staff member was told it would make them distressed.

Communication

Linked to cultural competency, many issues with communication were raised by residents.

Issues raised include:

 A lack of interpreters to help migrants access healthcare services

- Communication materials with images and text perceived to exclude LGBT+ people
- The body language of a GP receptionist making a resident feel unwelcome
- Hearing loops not being made available to a deaf person
- A person experiencing homelessness being sent letters which they cannot receive.

Access

Access to services plays a big role in someone either feeling that a service is for them, or if they are excluded from it.

Issues around access include:

- Having services in a location that a person cannot afford to get to
- Having GP appointments at times when a resident cannot attend
- Long waiting times for referrals to specialists
- Not having female-only clinics, which would make it easier for some women, such as victims of male violence, to openly discuss their health.

Representation

The need for residents to feel represented in the services they use is a critical part of those services truly serving all residents.

We know that working with patient participation groups from the beginning of a healthcare project increases its chance of success by 20%. Therefore, we need to make sure that the ability for residents to give their views is clearly available and can be fed into decisions made about services where they live.

Evidence-based recommendations

The evidence we present strongly indicates that large-scale change is needed in how health and care is delivered in Bedfordshire, Luton and Milton Keynes to help rebuild trust with residents that healthcare services are truly for them.

The Denny Review Steering Group has worked together to design a series of recommendations based on the published evidence and the views of residents. These are presented in full from page 38.

Recommendations are broken into:

- Short-term solutions that can be implemented quickly, which will help to make an immediate difference to the experience of residents over the next one to two years.
- Larger changes to how healthcare is delivered, which residents will see the effect of over the next three to five years.

These recommendations are for the Bedfordshire, Luton and Milton Keynes Health and Care Board, working with the Integrated Care Partnership and local residents, to take forward. Regular updates should be shared on the Partnership's website and social media. A comprehensive update will be published each year so that residents can see that change is happening.

Why the Denny Review is different

The Denny Review comes from the people of Bedfordshire, Luton and Milton Keynes. It is the result of intense engagement with residents, much of which has taken place inside communities that feel forgotten, underrepresented, and left behind. The true test in assessing the success of the

response to the Report will be whether those individuals to whom we listened begin, over time, to feel like health and care services are for them, and that the barriers to access are tackled with pace and determination. The Report calls for a bold and radical response from system leaders with a real focus on action, not words.

The Denny Review provides a timely focus to help drive positive change. The introduction of the Integrated Care Board (ICB) sees a fundamental shift to a community-led approach to responding to residents' healthcare needs and a greater focus on stopping health problems from appearing in the first place, rather than just treating them when they do.

In addition, the BLMK ICB has used inequalities funding to invest in VCSE organisations. It has recruited community connectors to work with the communities highlighted in the Denny Review and develop equal partnerships with them. Since the pandemic, discrete programmes to tackle health inequalities have been established in all four unitary authority areas of BLMK.

The Denny Review plays a vital role in holding up a mirror to health and care organisations, showing leaders the reality for many minority groups, and acting as a lightning rod for change.

By bringing all insights and recommendations together and learning from existing best practice, we have the opportunity to ensure that insights from residents reach all areas of health and care. This should lead to more residents consistently experiencing improved care.

Introduction

The Bedfordshire, Luton and Milton Keynes Health Inequalities Review, also known as the Denny Review, was commissioned during the early part of the COVID-19 pandemic.

During 2020, evidence showed that while the effects of the virus were felt by all, people from ethnic minorities were disproportionately affected.

The Government ordered a rapid review to look at the facts, determine causes and make recommendations. That **review**, called Disparities in the Risk and Outcomes of COVID-19, was conducted by Public Health England and published in August 2020.

The purpose of this review is not to go over what already is known nor to look solely at the impact of COVID-19 on different communities. Instead it investigates health inequalities in Bedfordshire, Luton and Milton Keynes (BLMK) in their wider sense.

Wider determinants of health, such as housing, poverty and education, have a considerable and measurable impact on health, and are considered as part of this review.

In partnership with the four local Healthwatch organisations which cover the BLMK area, and a range of other organisations, we listened in depth to communities often described as 'seldom heard'. These include people from ethnic minorities, people with physical and learning disabilities, LGBT+ people, and those living in areas of deprivation.

The BLMK Integrated Care System (BLMK ICS) has developed five strategic priorities to improve the health of the local population. Reducing inequalities is one of these priorities, described as: In everything we do, we promote equalities in the health and wellbeing of our population. Reducing health inequalities is also woven through the other four priorities.

But what is clear from the evidence in the pages that follow is that health inequalities are real, and exist due to multiple factors, each of which needs to be tackled. Areas of deprivation tend to have poor housing, fewer green spaces, and poorer levels of education, all of which have an impact on health outcomes.

With the advent of the new Integrated Care System (ICS), there is an opportunity to work together in a more collaborative, integrated and impactful way. And, in doing so, to truly deal with longstanding and deeply entrenched issues.

This Review brings together what is known, and gathers new evidence from people directly experiencing health inequalities.

This allows us to make clear, actionable, time-specific recommendations, which can both start to make changes in the short-term, but also make the longer term, more systemic changes which will make a lasting difference.

The recommendations form part of the ways in which the NHS in Bedfordshire, Luton and Milton Keynes can meet its obligations to the Equality Delivery System (EDS) 2022. The main purpose of the EDS is to help local NHS systems and organisations, in discussion with local partners and residents, review and improve their performance for people with protected characteristics.

This means that a person is legally protected from discrimination due to characteristics such as disability, sex, or race.

Those changes will only happen by working together as a health and care system. That includes NHS organisations, local authorities, VCSE organisations, the faith sector and, of course, residents.

About Bedfordshire, Luton and Milton Keynes residents and their health

Bedfordshire, Luton and Milton Keynes (BLMK) is home to about 1 million people. Its population is projected to grow strongly over the coming years.

There are four Places, each covered by local councils:

Bedford Borough

Central Bedfordshire

Luton

Milton Keynes

Health in the area is covered by the BLMK Integrated Care System, an Integrated Care Board, and an Integrated Care Partnership.



Integrated Care System (ICS)

– a partnership of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in the area. In BLMK this is called the BLMK Health and Care Partnership, and it has a website which you can find here.



Integrated Care Partnership (ICP)

- A statutory committee jointly formed between the NHS integrated care board and local authorities. It brings together partners, including voluntary, charity and social enterprises (VCSE) concerned with improving the care, health and wellbeing of the population.



Integrated Care Board (ICB)

 A statutory NHS organisation responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services.

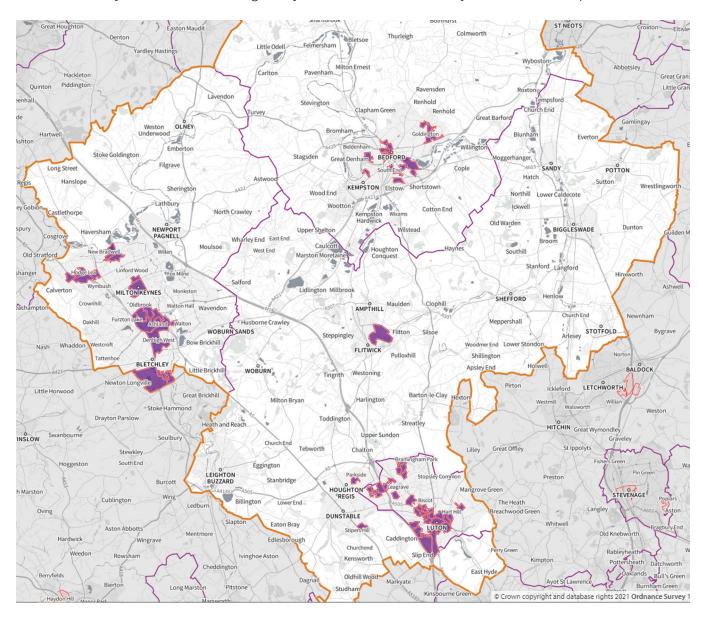
Where are the most deprived areas in BLMK?

There are 64 small areas, highlighted on the map below, within Bedfordshire, Luton and Milton Keynes which are among the 20% most deprived in England. These areas have populations of between 1,000 and 3,000.

Of these areas there are:



Health inequalities can be found throughout BLMK, but these areas are where residents are most likely to be disadvantaged by the health and care system as it is at present.



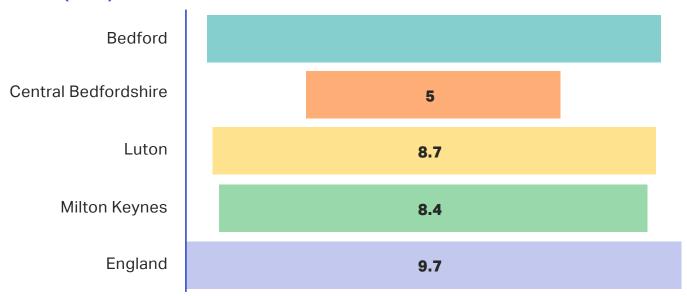
Differences in life expectancy

There are significant differences in life expectancy between people living in the most and least deprived areas of BLMK.

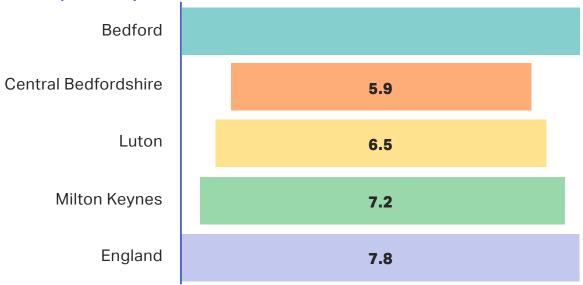
As the chart below shows, a woman living in an affluent part of Central Bedfordshire can expect to live around six years longer than a woman in a deprived area. This difference rises to almost eight years in Bedford.

For men, the difference is even greater. There is a difference of more than eight years between the life expectancy of the least and most deprived areas of Bedford, Luton and Milton Keynes. The differences are, on average, slightly less than the national average, but nevertheless unacceptable.

Difference in life expectancy 2018-20 between most and least deprived areas (Men)



Difference in life expectancy 2018-20 between most and least deprived areas (Women)



Context and terms of reference

In June 2020, the Legacy of Windrush Descendants wrote to the BLMK Clinical Commissioning Group asking that health inequalities be addressed urgently. The charity was responding to emerging evidence that people from black Caribbean and African backgrounds were more adversely affected by the COVID pandemic because of existing inequalities. The Reverend Lloyd Denny was invited to lead a review the following year, when the relaxing of regulations allowed for access to the communities most affected.

A Steering Group was established in the winter of 2020 to agree the methodology for the review and first met in September 2021.

Governance

The Bedfordshire, Luton and Milton Keynes Clinical Commissioning Group (from July 2022 the BLMK ICS) leadership commissioned this review to ensure that all inequalities work across the system is informed by an up-to-date evidence base.

This review was led by a dedicated Steering Group. It reported through the BLMK ICS inequalities group, and through that to the ICS Partnership Board.

Remit

The review was led by Reverend Lloyd Denny, former lay board member for patient and public involvement at Luton Clinical Commissioning Group and a respected member of the community.

The review posed the following questions as a starting point to help identify recommendations for the BLMK healthcare system to address:

- 1. How were members of different communities affected by COVID-19? What impacts has the pandemic had on health, housing, poverty and education for different groups in BLMK?
- 2. Has the system in the BLMK area done anything to mitigate these inequalities? What are the highest priorities for the system to address based on the evidence?
- 3. What should BLMK ICS do to help address these inequalities, with the maximum impact for residents? What should be done at neighbourhood, place, Care Alliance and system levels?

This review was based on lived experience and sought evidence from a wide section of our population, paying particular attention to the often-overlooked sections of our population.

Furthermore, the review endeavoured to be transparent and accountable. It was focused on enabling the right actions to be taken to reduce inequalities.

A <u>virtual library</u> has been set up to help manage the multiple documents and enable the review to clearly reference the evidence base.



A summary of the evidence gathered in the literature review commissioned from the University of Sheffield.

Health inequalities is not a new concept. In commissioning this review, it was important to first review the literature on the health inequalities from different social groups and communities in Bedfordshire, Luton, and Milton Keynes, to ensure that the review had a solid evidence base and took account of the population health data from public health. The review, conducted by the University of Sheffield, also looked at national data on health inequalities, as well as studies of specific groups in different parts of England.

The review set out to address the following research questions:

What information is available on health inequalities in BLMK?

What good practices are there to reduce health inequalities, and what can be learnt from them?

What are the connections between what we know about health inequalities in our area, what are the key themes, and what gaps in our knowledge?

What work does the ICS need to do in collaboration with the communities to improve understanding of people's experiences of inequalities and how to reduce them?



Case study: Mr and Mrs W – experience of accessing care for son with complex needs

Mr and Mrs W live in a deprived part of Central Bedfordshire with their son, who has mental health issues, obsessive compulsive disorder (OCD), autism and severe learning disabilities.

The couple feel that they have been "badly let down" by the Community Mental Health Team, who have not provided consistent support for their son. Mrs W said: "No one takes responsibility, you are just shoved from one person to another."

Their son was prescribed medication but only after he was admitted to a psychiatric ward. Mr W said: "There's no follow-up, no monitoring, no checking on whether the patient is taking the medication, or whether the medication is working."

Mr and Mrs W both feel that healthcare professionals need to find a better way of communicating with him because their son lacks social skills and is very difficult to interact with.

Both parents would like to see a change in the way emergency situations are dealt with. Also, they feel healthcare professionals should be trained to identify people who are under enormous stress, and are not getting the support they need, so they can get help.

More recently, having finally achieved support from the Community Mental Health Team, a support worker visits their son once a week to try to identify their son's needs and how they can help him. Mr W said their son can be responsive to people he feels are 'nice' or who are trying to help him, and he appears to be responding to the weekly visits.

Mr and Mrs W do not feel involved in decisions regarding their son. When they have complained about a service, they either feel that their complaint is 'dismissed' or they are told changes will be made but nothing ever happens. Mrs W said: "In the end I just get fed up because the system doesn't work."

The evidence base

The literature review looked at local evidence identified by the Bedfordshire, Luton and Milton Keynes ICS, including searches of data from the four Healthwatch organisations within the area. Data was also gathered from a range of sources, including health research databases and data from across the NHS, the King's Fund, and the Department of Health and Social Care. For the full list of data sources, go to the literature review document here.

Eighty-eight relevant reports were identified, including 71 academic studies or other reports. Seventeen documents were from local health data sources, mostly small studies engaging with specific groups of residents. Nine studies looked at research about the COVID-19 pandemic, and eight papers presented good practice examples.

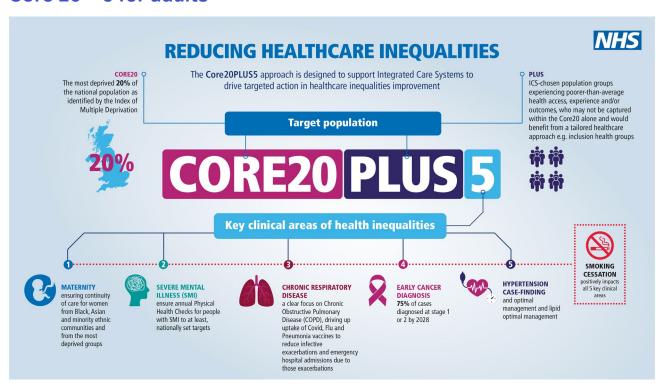
The review looked at evidence across a person's whole life. These include protective factors, which aid good health, such as a good diet, exercise, good housing, and clean air.

Risk factors, which have a negative effect on a person's health outcomes, include smoking, poor diet, physical inactivity, and harmful alcohol use can lead to preventable diseases and premature deaths.

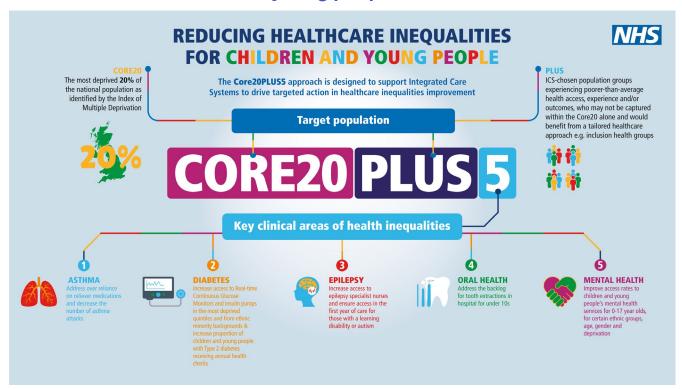
Looking at these wider determinants of health will help draw out specific ways to improve the conditions into which people are born, live and work.

The literature review paid attention to NHS England and NHS Improvement's approach, Core20PLUS5, to reduce health inequalities (see tables below). It focuses on the most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD) and five priority areas. It targets the most vulnerable groups and communities identified through population data for addressing health inequalities (NHS England, 2021).

Core 20 + 5 for adults



Core 20 + 5 for children and young people



What the evidence showed

The findings from our commissioned review of health inequalities research were clear.

A person's health behaviours, their physical environment, and socioeconomic factors, affect their health and wellbeing throughout their life. These factors – such as poor housing, pollution, poor diet, smoking, and lack of exercise –can combine to have a bigger effect on an individual, family, social group, or community. They lead to higher rates of a range of health conditions and, ultimately, lower life expectancy. Below we explore the various themes which help to explain health inequalities.

Ethnic minority groups have generally poorer health

Ethnic minority groups generally live in the most deprived areas of the UK. This is also true of people living with two or more health conditions, people with a disability, those experiencing homelessness, and those with drug or alcohol dependence.

Research by the Centre for Ageing Better shows that people reporting that they have poor health has been higher for ethnic minority groups than the white British population. For example, black Caribbean people and those from Pakistan and Bangladesh report poor health between 1.5 times and double the rate of white British people.

Cultural factors can influence health outcomes

The literature review looked at several studies focusing on how cultural factors can have an impact on an individual's health outcomes.

On the positive side, cultural factors, such as family support, sense of community, and religion, were shown to have a positive effect on the mental wellbeing of people from ethnic minority backgrounds.

However, cultural factors for ethnic minority groups can have an impact on health outcomes or be a barrier to accessing health and social care. Cultural or religious beliefs can lead to the misplaced use of traditional remedies. Differences in the presentation of symptoms can lead to misunderstandings, misdiagnosis, or incorrect referrals. Cultural differences may lead to a person not wanting to seek help if they have symptoms of cancer or a sexually transmitted infection¹.

In addition, a limited understanding of the English language may mean people do not understand health promotion materials and how to access the related services if translations or interpreters are not provided.

The role of the environment in a person's health

Environmental factors play an important role in a person's health outcomes.

A report² showed that Luton lacks green space – and the most deprived wards have less access to green spaces than wealthier parts of town.

A Friends of the Earth study on England's green spaces found a strong link between ethnicity and green space deprivation. It suggested that people from ethnic minorities are twice as likely as white people to live within areas with few green spaces.

In Milton Keynes, it has been identified³ that 5.8% of deaths in adults over 30 are estimated to be due to poor air quality.

People who struggle to afford heating bills – those said to be in fuel poverty – are lower than the regional and national numbers in Milton Keynes but are increasing. This can make health conditions worse in the winter for people living in cold homes. People living in poverty may also be less likely to access the care they need or access it only when their condition has worsened.

¹ Goff et al. 2020; Ehiwe et al. 2012

² Joint Strategic Needs Assessment, Luton (2015)

³ Health Impact Assessment, Milton Keynes (2021)

Living and working conditions

Poor living and working conditions have a significant impact on a person's health outcomes. They are recognised as a critical problem within BLMK health reports.

The pandemic highlighted poor working conditions leading to health inequalities. The Race and Health Observatory 2022 review suggested ethnic minority healthcare workers had less access to personal protective equipment (PPE), with the pandemic having a more negative effect on their mental health.

Housing can play a very important role in widening inequalities. Many low-income families live in poor quality or overcrowded housing – some in temporary accommodation, disrupting children's well-being.

Children who live in poor housing⁴ are more likely to suffer from poor health, have a longstanding illness or disability, dislike the area they live in, run away from home, be excluded from school, and leave school with no GCSEs. Poor housing leads to health risks such as respiratory illnesses, poor nutrition, depression, and anxiety.

Homelessness is a key driver of severe health inequalities. According to estimated data from Shelter, one in 66 people in Luton are classed as homeless, the worst figure for the entire UK outside of London. Milton Keynes was also ranked in the top 10 list of local highest rates areas for homelessness and rough sleeping.

There is a direct link between homelessness and access to health and social care services and management of long-term conditions. The Government's figure on the prevention and relief of homelessness in England shows that people from ethnic minority backgrounds are disproportionately affected by homelessness.

Health behaviours

Health behaviours, including physical activity, healthy food and social connections, can make a big difference to a person's overall health.

We know that access to affordable food is strongly influenced by income, so people living in poverty are estimated to need to use 45% of their available resources to afford healthy food, clearly not an option when there are so many competing demands. Whilst some physical activity opportunities are free to access there are barriers, such as transport and equipment, so inequalities exist here too.

A study⁵ with Pakistani, Bangladeshi and white British mothers in Luton revealed that very few women consumed folic acid before conception, nor understood its benefits in preventing health problems from birth.

A different report found that African and South Asian women were more likely to endorse "using traditional remedies" for cancer and were more likely to report that they "pray about a symptom" than white British women. This may lead to accessing the NHS when their condition was at a later, harder to treat, stage.

⁴ Finney, & Harries (2013). Understanding ethnic inequalities in housing

⁵ Garcia (2018). Understanding the consumption of folic acid during preconception in Luton

A study⁶ showed that COVID-19 had a significant impact on the health behaviours of ethnic minority groups especially during the lockdowns as they reported changes to behaviour such as low levels of physical activities. Hence, it is important to promote health awareness among ethnic minority groups to encourage healthy living.

Access to and uptake of health services

People affected by health inequalities had many barriers to accessing health services.

The biggest barrier for migrants to general practice registration is the inability to provide paperwork, with two out of five (39%) of registration refusals due to lack of ID.

Evidence shows that ethnic minority groups, including Gypsy, Roma and Traveller communities, and LGBT+ people face prejudice from GP surgery staff, including refusal to book an appointment. Several local studies also highlighted that patients were not always clear how to access urgent care services.

Inequalities in access to healthcare were experienced by the deaf community. According to Healthwatch Bedford Borough and Healthwatch Central Bedfordshire's 2021 Seen and Heard report, most study participants representing the deaf community found it challenging to access a GP appointment.

Social networks

Family and community networks were shown to be positive forces for ethnic minority groups. One study from the north of England showed participants preferred to live in neighbourhoods with people of the same ethnicity, even if it was a deprived area.

Another study showed that participants' spiritual and religious beliefs directly influenced their behaviour to maintain health and wellbeing.

A study⁷ exploring relationships and faith argued that faith-based affiliations were significantly relevant for ethnic minority groups to pursue health and wellbeing.

Randhawa (2023) The impact of COVID-19 on the changes in health behaviours among Black, Asian and Minority Ethnic (BAME) communities in the United Kingdom (UK)

⁷ Ochieng, B. (2010). Spirituality as a mediating factor in black families' beliefs and experiences of health and wellbeing.

The pandemic and health inequalities

The COVID-19 pandemic disproportionally affected people from ethnic minority backgrounds.

Several studies showed that people from these groups have been at a much greater risk of contracting, being hospitalised, and dying from COVID-19.

Two studies, one for Bedford Borough and Central Bedfordshire⁸, and another for Luton⁹, revealed that participants acknowledged that inequalities experienced by different communities contributed to a more severe impact of COVID-19. Participants discussed how poor living conditions and overcrowded homes contributed to the transmission of the virus.

They said there was a great deal of community suspicion surrounding how ethnic minority groups were treated, compounded by a lack of confidence to complain.

A recent paper on vaccine hesitancy¹⁰ among Luton's ethnic minority groups found a significant association between educational attainment and vaccine hesitancy. The most common reasons for low vaccine uptake among ethnic minority groups included lack of trust in the Government and vaccines, and concerns about vaccine side-effects. Public Health England statistics from 2021 showed that Luton had the third-lowest uptake of COVID-19 vaccine outside London in the UK.

¹⁰ Cook, et al (2022). Vaccination against COVID-19.



⁸ Community Engagement & COVID-19 (2023), National Centre for Social Research

⁹ Ali, N., et al, (2021). Talk, Listen, Change (TLC) COVID-19.

Listening to residents

The Denny Review commissioned studies by Healthwatch Bedford Borough, Healthwatch Central Bedfordshire, Healthwatch Luton and Healthwatch Milton Keynes, working in partnership with grassroots VCSE organisations where trusted relationships were held.

The lived experiences part of the review ensured that the voices of more than 2,000 local people who experienced health inequalities were heard through a range of surveys, case studies and detailed discovery interviews.

Gypsy, Roma and Traveller community

Despite growing evidence that Gypsies and Travellers are particularly disadvantaged in access to health care, there are very few studies to explore the reasons for this. Healthwatch Bedford Borough investigated the nature of the social disadvantage that the group experience. Nineteen members of this community were interviewed to explore both attitudes and structural reasons behind this health inequality.

People from the Gypsy, Roma and Traveller community told us:

- Almost all described literacy as a barrier to meaningful communication about their health or social care. About half said it was the most important barrier. One person described their feeling of shame in not being able to read or write.
- Only two or three people out of 19 interviewed felt literacy was not a barrier for them. The majority said they can't read text messages. Consequently, they often take these to the Gypsy and Traveller Liaison Officer for help.
- For some, the challenges regarding health literacy are so overwhelming that they feel lost in the system. Gypsies and Travellers say that they have described their issues to the NHS, and yet see nothing changing to address or improve these. One said: "All of those forms, stupid asking."
- The move to online services has resulted in more isolation and, as a result, the elderly and sick were unable to get help.
- The need for videos and voice
 messages was mentioned as a way of
 overcoming communication barriers.
 However, the lack of secure Wi-Fi on
 either of Bedford's local authority-run
 sites was an issue.

- The need to be understood was mentioned by people in the Gypsy and Traveller communities when asked that they wanted from the NHS.
- Cultural understanding was also mentioned by the majority of the Gypsies and Travellers who talked about communication barriers. They felt people were "clueless" at best and "scared of them" at worst.

Voices of Gypsy, Roma and Traveller people

One woman said:

"Female doctors for pregnancy, smear tests. It's against Traveller ways for men to be involved."

When asked about the impact of being a Gypsy or Traveller on the treatment they receive, all but two felt that their cultural identity had a negative impact.

One said:

"Every time they think I'm a Traveller I get treated real bad."

Another said:

"They don't understand what I'm on about, I hate talking to them."

Women from migrant backgrounds

Women from migrant backgrounds have been found to be particularly at risk of health inequalities due to a combination of different factors, such as language skills and cultural differences. Healthwatch Bedford Borough spoke with women from West Africa, Bangladesh and Bulgaria.

Women from West Africa

A consistent theme was women's experiences of negative interactions, stereotyping, disrespect and cultural insensitivity. Interviews also explored the issue of female genital mutilation (FGM), a traditional cultural practice undertaken in some countries in West Africa. This is the partial or total removal of the female external genitalia or other injury to the female genital organs for non-medical reasons. Interviewers spoke with 15 black women from West Africa and women who have undergone FGM.

Women from West Africa said:

- There is a concern that the stereotype of the strong black woman may lead health professionals to discount expressions of pain, anxiety and vulnerability.
- Migrant women from Africa asked for greater sensitivity by healthcare providers. Half of this group said that being a black African woman had a negative impact on their care. They said they wanted to be spoken to nicely by healthcare professionals.

- FGM is a significant issue for this community. Women who had undergone FGM spoke of being subjected to hurtful comments, being asked questions such as "how did you get pregnant?" or "did your husband do this to you?"
- Negative experiences have meant that some women have avoided going to see their GPs, putting these women's health at further risk.
- Language issues and accent can become a barrier.

Voices of West African women

One woman said:

"I hate how non-inclusive some services are. They will tell you what works for the average white female without even taking into consideration who you are [African]."

In contrast, one participant described a positive GP relationship:

"My doctor and I have the same native language and it is great.

It makes me feel heard and respected since we have the same cultural background."

Bangladeshi women

The Bangladeshi population in Bedford is a complex network of people who are the first, second and third generation of migrant families. Language skills, attitudes towards health, and attitudes about how to 'fit in' to mainstream society vary widely. Nine out of 10 Bangladeshi women could not read or write in either English or Bengali.

People from a Bangladeshi background are most likely not to speak English well, with Bangladeshi women five times more likely to speak no English at all.

Bangladeshi women said:

- They had a high level of frustration, because they are seen as being time-wasters with trivial reasons for approaching healthcare.
- All felt that they would get better treatment if they were white. They felt it was easy for them to be overlooked and not listened to.
- They were concerned about having to jump through hoops and described being talked down to by staff which, they say, results in unfair treatment.
- Some said they relied on a relative to help them access health services.
- All said they needed support from an interpreter.

Voices of Bangladeshi women

"Give us an appointment when needed not when about to die."

"The receptionist was very rude - she didn't listen and talked down to me."

"Sometimes it doesn't make sense. I have waited over 12 months to see someone. I had to do a blood test before the appointment. I had to book online and the next slot available was two weeks later. Waiting time in waiting room for completing blood tests is quick at the hospital. What was the point of me doing a blood test 12 months before I see someone at the hospital?"

Bulgarian women

Bulgarian people were part of a more recent pattern of migration following entry into the European Union in 2014. Bulgarians have high levels of cardiovascular disease, but cancer is below the European average. Mental health is generally not discussed in Bulgaria. Excess alcohol consumption and smoking are higher than the UK national average. Only one Bulgarian woman we spoke with could speak, read or write in English.

Bulgarian women said:

- Their health priorities included advice on stopping smoking, reducing alcohol intake, healthy eating and where to go to participate in activities.
- They were keen not to criticise, but they found accessing care difficult.
- All needed help from an interpreter.
 Seven out of the eight Bulgarian women were unaware of NHS messages, attributing this to the language barrier.
- Several Bulgarian women described negative experiences due to language difficulties. One spoke of a GP who refused to book an interpreter. Another had the phone put down on her.
- Three women mentioned poor communication, feeling stuck between departments and organisations that were not communicating with one another.
- Misunderstandings can arise from cultural differences. The women try to anticipate what would get a negative reaction from healthcare professionals.

- They thought that an understanding of the different culture and background of clients or patients should be a requirement for healthcare professionals.
- They were concerned about understanding English etiquette and would like to have group classes so that they can blend in.

Voices of Bulgarian women

"It can be interpreted wrongly, and you can have your child taken away.

It is a difference in culture."

"Would not know where to go if there was an emergency."

LGBT+ people

Healthwatch Luton listened to 52 LGBT+ people, through survey, interview, email or phone call. LGBT stands for lesbian, gay, bisexual or transgender, and the plus sign stands for a range of other descriptions people may choose to use, such as queer or questioning, intersex or asexual.

LGBT+ people told us:

- Over half of respondents said staff and **staffing attitudes** were **more favourable** than in the past. They said staff were, caring, respectful, empathetic and responsive.
- The use of inclusive language was praised. This had the effect of a more honest dialogue between health and care clinicians and patients, with trusting relationships developed for ongoing care.
- Luton Sexual Health services/ iCaSH was praised as having knowledgeable staff and providing relevant information. Hospital support was 'great' according to a few respondents.
- General health prevention messages were clear but could be advertised more in more appropriate places, such as on digital forums and apps.
- Digital access to clinicians where available worked best for a lot of responders, to support anonymity, when important, and allowed more flexible appointment times.
- For under-18s, information on gender identity was lacking, and waiting times for gender identity psychoanalysis were raised as concerns.
- Many felt they did **not have enough time with GPs**, particularly face-to-face, to discuss issues. Not seeing the same GP made it harder to have an open conversation. They felt there was a lack of support in referrals and hospital discharges.
- Residents said there was a lack of follow-ups or referrals from Children and Adult Mental Health Services (CAMHS), which resulted in increased hospital admissions.
- Some said health and care **staff continually got their gender wrong**, despite being corrected by the resident on more than one occasion. Residents said there was a lack of culturally or age appropriate LGBT+ groups.
- Some respondents had completely **stopped engaging** with health and care services, due to previous, distressing experiences. Sexual health information could be more widely available, for people of different age groups and cultures.
- A lack of cultural competency both in terms of race and gender was felt by some respondents, along with a lack of standardised sexual orientation and gender identity data collection.

Voices of LGBT+ people

"Being from the culture I am, being how I am is viewed so differently to how British people view it. But if you want to really understand how it makes us feel, then change how you present the world to us. My mental health has not ever been in crisis state, but I could have appreciated some more **culturally relevant support**.

"Telling my doctor from a different culture to mine, who has his own views on what I am and what I do – just makes for a very un-honest approach. I would never go to him for health advice and would only use online."

Male, Black Caribbean, bisexual

"I have had **many positive experiences** of health and care
over the years and have to say I
have felt limited stigmatisation in
general health settings. Most I have
encountered have accepted and not
perceptibly judged or changed their
level of care, from what I can tell.

"It is hard to discuss openly with my GP – so I tend to revert to the sexual health clinic for all manner of support, as I trust them. Training on **sensitivities of language** would be good – if you get the language right or try, you're half-way there. Some people just show disrespect with not even attempting to find the right words."

Male, white British, gay

"If you grow up seeing white women who don't reflect yourself, in every textbook or media image, you learn to disengage very early on...More culturally appropriate images have been seen on health messages more recently, but I wouldn't say it's the norm.

"We are constantly told Luton has more Asian people than other towns, and yet everything I still encounter is white – white, heteronormative messaging – nothing that ever speaks to me as a young, questioning Pakistani."

Young Pakistani female, who identifies as queer / questioning

"There is more information than before – and that is great – but it's like it is all written by people who don't really understand what it is like to be LGBTQIA+. There is a lot even in the NHS guidelines that refer to all questioning or queer young people as 'transient' as though it's not for all of us something sustainable, or real.

"The support for young people with their mental wellbeing is so old-school and face-to-face – we need the online anonymous digital support to really support us... through what we are feeling."

Female, Catholic teenager, identifies as questioning

People who have experienced homelessness

YMCA Milton Keynes spoke with 47 young adults who live at its accommodation in the city centre. All the young people interviewed felt comfortable to share their information and views with a trusted professional in a familiar setting. YMCA staff clearly explained why they were collecting the information, and how the information would be used.

The residents interviewed were aged 18-35. 47% identified as female, 47% as male, while 6% identified as 'other' including three transgender men.

The most common ethnicity was white British. Other ethnicities included black African, black British and Asian British. One in three interviewees (34%) identified as LGBT+ while two out of three did not.

Nearly half of respondents (49%) identified as having a disability, including mental health conditions. 13% declined to answer the question.

People who have experienced homelessness said:

- They had **difficulties getting GP appointments**, and some found receptionists to be rude in GP practices. Others said that GP appointments were often not long enough to deal with their issues.
- There was a varied experience of A&E services at hospital. Some said it was positive, while others said they had to wait a long time whilst experiencing significant pain.
- Mental health services are insufficient with long wait times experienced. One respondent said services were inaccessible due to their location. Others said they did not feel like they were being treated seriously.
- Those with mental health concerns said that the NHS often takes a 'medication-first' approach, rather than addressing the root cause.
- Those accessing social services said they felt social workers were sometimes not listening to them properly, or had acted against their interests or those of their family.



Voices of people who have experienced homelessness

"It's been eighteen months since I've been involved with my kids. I was deemed unfit because of my mental health. The social worker asked my partner questions about my mental health, but they never asked me. I feel I was written off because of it and I've been completely pushed out the picture. No effort to speak to me or to try and help me with my kids so I can have a relationship with them."

Male aged 31

"I've experienced a lot of racism [accessing the NHS]. One time, I said I had food poisoning and the paramedic said, "have you eaten chicken curry?" I think to myself, why is that? Is it because I'm Asian? He then asked me if I eat ham and I thought why are you [the paramedic] asking me this?"

British Asian female, aged 25

"You wait for ages, and then at the end of the wait, they say there's nothing they can do. It's the same across all the services. They make referrals to seem like they're doing something and it never goes anywhere."

Male, aged 19

People with a physical or learning disability, living in deprived areas

A survey was created and widely distributed by Healthwatch Central Bedfordshire which generated 1298 responses in October and November 2022. The questions sought to understand what specific services work well for individuals and which ones do not, and how those services could be improved.

People were asked what was most important to them in the way they are treated by healthcare professionals, and what the barriers are to accessing healthcare services. They were also asked how communications could be improved to access services more easily, and if they knew which preventative services were available to them.

People with a physical or learning disability said:

- The most common services which did not work well were GP services (29%), Children and Adolescent Mental Health Service (CAMHS) on 21%, and hospital on 18%.
- When asked what could be improved, residents particularly highlighted easier access
 to appointments and staff to be more helpful. The same improvements were desired for
 hospital services.
- A need for interpreters in hospitals was highlighted by 26% of respondents. A similar proportion said more appointments with a Disability Champion would be beneficial. This suggests **disability awareness is an issue** within hospital services.
- The way residents with disabilities are listened to was highlighted as a key issue. Three
 out of 10 respondents said they wanted to be listened to, and a quarter wanted to be
 involved in decision-making. Being treated equally was highlighted by one in every five
 survey respondents.
- Respondents viewed the biggest barriers to accessing services as the difficulty in getting appointments, waiting lists, staff shortages, no disabled access and a lack of interpreters.
- **Communication** was a key area for improvement. A majority wanted hearing loops installed, longer appointments and interpreter services. They also wanted their individual needs to be understood.
- Many survey respondents were positive about participating in activities to prevent health problems. Exercise and active lifestyle choices were desired by people with disabilities, as well as screening services.

Voices of residents experiencing physical or learning disabilities

"My GP seems to rely on 111 to screen patients and arrange appointments. Also, I am deaf and they don't seem to understand that a phone appointment is useless, I need face to face but cannot get this."

"My husband and I have repeatedly been let down by social services. Hospital communication needs significant improvement for those with dementia. There needs to be closer communication between professionals, for people who live in Central Beds but whose GP is in Buckinghamshire and whose nearest hospital is Luton & Dunstable, or other cross-county issues."





Case study: A mother's experience of accessing healthcare with her autistic son

Mrs C, from Luton, is a care-giver to her teenage son who has autism and learning disabilities.

Mrs C told us that getting appointments with a GP for her son was usually difficult. She often found that they had to wait for a long time in the surgery for an appointment to begin, which her son, who is sensitive to loud noises, beeping sounds or unexpected movement, finds stressful. She also said that healthcare workers were often not well-informed about her son's medical history, and might be unfamiliar with the variety of behaviour autistic people can display.

For example, when Mrs C visited a doctor's surgery with her son, the receptionist insisted he wore a mask, even when she explained this was difficult for her son. She then put it on her son, only for him to rip it off.

She said: "For this reason I do not go to appointments alone with my son, I go with one of his brothers or anyone I can find. He is such a body builder and things can go horribly wrong."

Mrs C and her son have had positive experiences, such as when a healthcare worker took time with her son, going at his pace when taking measurements. She also praised the annual health checks to which her son is entitled.

Mrs C cited a major challenge as the lack of joined-up care, where her son is passed between different people, rather than a more consistent co-ordinated approach being taken.

In addition, she said that simple changes can make a big difference. Providing photos of the healthcare setting her son will attend can help him to prepare and result in him being more calm and comfortable.

Mrs C was dissatisfied with information from healthcare providers about the guidelines for her son's health needs. She thinks information could be more tailored, such as for non-verbal individuals. She emphasised the importance of training for parents, who can play a critical role in supporting their child's health needs – with people sharing their lived experience of providing care particularly beneficial.

Insights and themes

In the many conversations and responses from residents, common insights and themes were raised. Here we summarise the key areas which were consistently brought up by residents. Some of the insights are linked, or can combine, to create a greater, negative impact for those who experience health inequalities.

Accessing services

Gaining access to services – whether that is with a GP, a hospital, or a different healthcare setting – was consistently raised as an issue by residents, such as in Healthwatch Milton Keynes' inequalities survey and interviews.

For GP services, simply getting an appointment was found to be difficult by many. When residents managed to get an appointment, this was sometimes not face-to-face when that was a clear, and sometimes necessary, preference. In addition, the length of appointments was felt to be too short by many to get to the heart of the matter.

At each stage, residents spoke of difficulties convincing someone that they needed help, or that their need was sufficiently serious. For example, people spoke of having to convince a receptionist they needed to see a GP, or convincing a GP that they needed a referral.

"I can't get an appointment, when I do get through on the phone, they say you have to access the online portal. When I say I can't, they hang up on me." Some residents said that appointment times were not available at the times when they could attend, creating a barrier to health services.

People with physical disabilities found that having to attend A&E or urgent care was particularly difficult because the long wait times could be physically impossible for them. This was also noted as an issue for people with mental ill health or neurodiverse conditions.

Some felt doubly penalised because they tended to avoid contacting the GP due to worries about staff attitudes towards their particular characteristic, and so their needs were more acute by the time they were seen.

"I always feel rushed which makes me nervous and forget what I want to say...long waits and impatient staff over the years also increase my nervousness and inability to approach health and care services in a relaxed manner." Digital methods of accessing services caused barriers for a range of different people. This includes those with low levels of literacy, people who aren't fluent in English, and people who can't afford an internet connection, or don't have a smartphone.

Finally, while there are many VCSE groups offering support, there is no single place to find this information, or it is inaccessible. This means there is often a disconnect between those offering support and people who need it most.

Literacy and interpreters

Literacy was raised as an issue for some people, both from migrant backgrounds, and members of the Gypsy, Roma and Traveller community, for whom literacy is not a traditional part of their culture.

Migrant women are more likely to be illiterate than their male counterparts. They therefore find it difficult to access health information and successfully navigate the health and care system. This language and literacy barrier is a significant driver of health inequality.

Residents spoke of the need to access services to reduce the barriers they face. There is a need for resident to know about what is available to help them.

The need for **interpreters** was a consistent theme from people from migrant backgrounds. Most migrant women we spoke with could not speak English, which presented a barrier to them getting the help they needed. Some said they asked friends or family to help them, but again they tried not to do this too often because they did not want to be a burden. This in turn could lead to a delay in getting help, and their condition getting worse.

Those who needed an interpreter struggled to find one. And if they did, this greatly reduced the appointments they could attend with an interpreter, due to their availability. However, even with interpreters some said they didn't understand what was being explained to them – suggesting that a visual approach using photos, diagrams or pictures could help.

For members of the Gypsy, Roma and Traveller community, audio messages would be welcome.

"If English isn't your first language, you may have a male family member take you to the appointment but how can you feel comfortable if the appointment was to talk about a female thing, a personal female issue?"

Cultural understanding and personalisation

The residents we spoke with often felt that there was a simple lack of understanding of their culture, background or characteristics. While this might be unintentional, it can make a person feel that a service is not for them – and that racism, sexism or homophobia might be the root cause. This can lead to them being much more reluctant to access health and care services.

This can play out in a range of different ways. It could mean that a person is judged by stereotypes, rather than who they are as an individual, or their symptoms downplayed or disregarded. It could mean that the way in which a person speaks is misinterpreted, due to cultural difference. Or it could be that parts of a person's religious or cultural backgrounds which are a vital part of their understanding and approach to health matters are not taken into account.

For LGBT+ people, a common issue was referring to them by the wrong name, gender, or pronouns, which leads to a sense that they are not being treated fairly or equally.

This lack of understanding can have a damaging impact for the people affected – but if an understanding is demonstrated, or a willing to adjust, this is welcomed.

Seeing the whole person

The need to be seen as an individual was regularly cited by residents as something they wanted to see from healthcare professionals. People felt that services were not linked together, so that they had to repeat the same facts again and again.

In addition, residents felt that services were not 'person-centred'. In essence, this comes down to services being delivered in a way that makes sense to organisations, but not to the individual. This often meant that services feel inflexible, and could send a person down a path which was not right for them.

People from ethnic minority groups said they often felt health professionals didn't see them as a whole person. They also had a strong sense that they weren't being cared for because appointments were so rushed.

Those with strong religious beliefs said they felt there was no place for their faith to be part of discussions around care and treatment. Whether discussions were around lifestyle or around medication, they felt that their particular belief system was seen as separate to themselves, their illness or their recovery. They felt their beliefs should be integrated into the conversation to support more appropriate clinical care.

People with mental ill health felt that a lot of the care or treatment they received was done to them, not with them, and that they were not involved in discussions about the benefits, or side effects, of available treatments. They shared that they often felt 'fobbed off' with pills on the first attempt to talk about their mental health. Those who had an existing diagnosis said they were worried that if they talked about what they were experiencing, they would be sectioned.

Appropriate communication

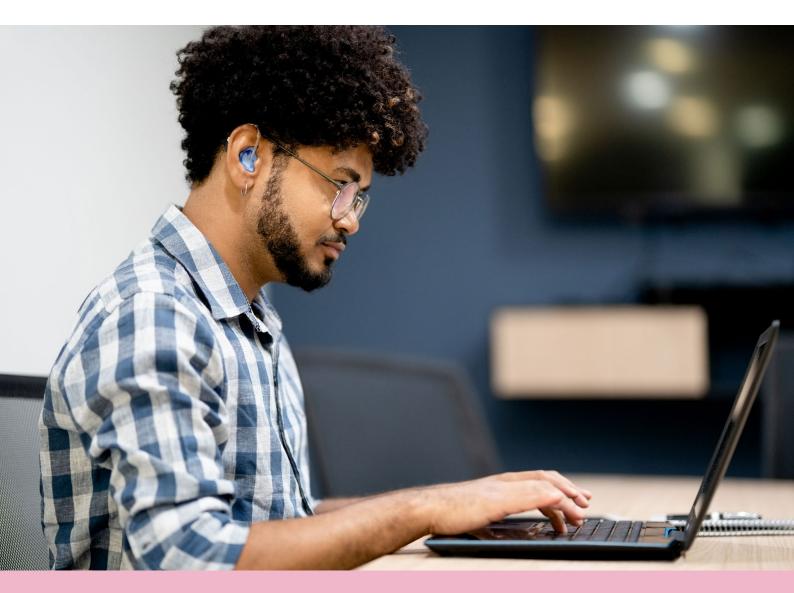
Issues with communication were many and varied – and almost all respondents had some sense that they were not being communicated with properly.

For example, one deaf person said they were spoken to by a healthcare professional wearing a mask, which made it impossible for them to understand what was being said. More generally, it was often felt that front-line staff made presumptions about a person based on their individual characteristics, such as skin colour, accent, or how they dressed.

Communication by healthcare professionals was often too technical or full or jargon to be understood. This could leave a patient feeling overwhelmed with information, and unable to make informed choices.

Information produced by NHS organisations was often off-putting for people from some groups, such as LGBT+ people. The information might be written in a way that suggested the author did not understand their perspective, or the images were not inclusive.

Sometimes the type of communication was not right, with a reliance on more traditional forms of communication, like letters, when text messages, audio messages, or better use of video might open up access to people from a range of different backgrounds.





Ms F (using pronouns they/them) has, in general, had a positive experience of using healthcare services. They did not say what their specific needs were, but said healthcare professionals adapted to suit those needs.

Ms F said, however, that there is a lack of flexibility in scheduling appointment times. They said the "ability to reschedule is very difficult and rigid" and the next appointment "can be weeks away."

Furthermore, they sometimes need additional support to access the venue of the service they are using, which isn't always offered.

However, within the service, adjustments are usually made in an appropriate way, and staff are mostly friendly and helpful.

Ms F welcomed text messages with information about appointments but said this was inconsistent across different services. In addition, they said that their patient records were shared across the GP and hospital, but this was not the case for other, smaller services.

Overall, Ms F was happy with the services, but felt that the health service could be more joined up, with better customer service, and improved flexibility on appointment times.

Recommendations

Our recommendations fit within four groups. These are access, communication, representation and cultural competency. They are grouped in two time-frames. The first is short-term changes which can be actioned over the next one to two years.

These changes will allow residents to see that things are changing for the better. The second category of recommendations are longer-term and will change how the health and care system operates in a deeper and more fundamental way. It's important to note that some work has already taken place in some of the areas outlined in the recommendations – but greater focus and momentum is essential.

How we developed the recommendations

Overall it is the clear ambition of this report to make recommendations which, when taken together, spur system leaders to respond radically in designing and delivering their approach to health inequalities.

The recommendations have been developed by the Denny Review Steering Group based on the published evidence and the views of residents.

Further work is required with community pharmacists, dentists, optometrists, NHS Trusts and local authorities and the VCSE sector to determine how the recommendations can be implemented and performance monitored, and to define the crucial role provider collaboratives can play. These organisations will need to come together to determine whether the recommendations are delivering the impact called for by residents and healthcare professionals.

Short-term change

Recommendations that can be implemented in the shorter term, which will help to make an immediate difference to the experience of residents over the next one to two years.

Insight area	Recommendation
Access	Contracts for new products and services should rigorously apply the Accessible Information Standards and the Equality Act so that they meet the needs of all residents and staff members, for example when purchasing personal protective equipment (PPE).
	This includes ensuring that residents are asked about or offered information in a format or language that they can understand. Consideration should be made to help prevent residents being excluded from services due to barriers which include a lack of access to digital technology.
	An urgent review of all health and care premises should be undertaken to ensure disability access is always available.
	Hearing loops should be installed across all healthcare establishments and staff should be provided with training to ensure they are always functional.
	Hospital trusts and primary care should undertake a review of what, if any, interpreter and translation services are available and accessible to ensure patient needs are being met.
	GP practices should review their procedures to stop residents being wrongly stopped from registering, potentially denying them access to essential health services. Practices must ensure they meet Primary Medical Care Policy and Guidance, and that national policy is uniformly and rigorously applied.

Insight area	Recommendation
Communications	Residents and partners to come together to co-develop a communications campaign to support people to explain how the health and care system works, and how to navigate it, with a particular focus on supporting minority groups. This campaign should include regular updates on the implementation of the Denny Review, and, where relevant, have a gender focus too for specific men's/women's issues highlighted.
	Urgent review of all communications and marketing materials to ensure that imagery and language is culturally appropriate and reflects the different communities in BLMK.
	Collaborate to implement a universal translation service for BLMK that provides consistency across all NHS provider organisations.
	This should be achieved by undertaking an urgent review of all translation services provided in BLMK's health and care sector to ensure it complies with Accessible Information Standards.
	This should mean that interpreters are always available, that there is consistency across primary and secondary care services, and that British Sign Language (BSL) interpreters are included in the list of available languages.

Insight area	Recommendation
Representation	Support GP practices to ensure that Patient Participation Groups, as required within contracts, are in place and receive sufficient investment.
	BLMK Integrated Care System should set out how its future engagement work is shared, to avoid duplication of effort and maximise impact.
	Training for health and care professionals and those people involved in community connector roles in Quality Improvement (QI) and co-production. This will help to embed a more person-centred approach, so that residents' needs are at the heart of any solution.
	Support the healthcare system to be more resilient for future pandemics. Consider the impact they can have on the workforce, specifically people from ethnic minority backgrounds. Within this, look at how PPE is distributed to meet the needs of a diverse health and care workforce.
	Senior leadership mentoring scheme introduced within NHS organisations for people from ethnic minority backgrounds to help improve diversity management across the ICS. Encourage greater diversity within management, and greater diversity on interview panels.
Cultural competency	Training rolled out to all health and care settings to support with language, and understanding the needs of residents, including different ethnicities, those with physical and learning disabilities, and LGBT+ people. This will help to address perceptions of cultural bias / racism which was a consistent theme within community engagement and can build on current patient participation.
	Greater investment in services that are working well, such as local sexual health services.

Long-term change

Recommendations which make larger, more fundamental changes to how healthcare is delivered, which residents will see the effect of over the next three to five years.

Insight area	Recommendation
Access	Consider extending the service hours available in primary care to evenings and weekends for those unable to attend day-time appointments. Also include access to female-only clinics to support people from different faiths and cultures, and victims of male violence.
	Ensure that residents who would prefer to access some healthcare services anonymously are able to do so. This could be done, for example, through more services, or a greater proportion of them, being provided digitally.
	Work with the VCSE to fund Access Champions to support people who are unsure how to navigate health and care services or have additional needs to access appointments, or other services to support their health and wellbeing.
	Establish an end-to-end service for long COVID.
Communication	Based on the findings of the review of interpretation services, ensure that there is a consistent service across health and care and that translated materials are available in line with legal duties.
Representation	Improve integration of housing, hospitals and mental health support in homeless shelters.
	1 in 4 black men will get prostate cancer in their lifetime. Black men are more likely to get prostate cancer than other men, who have a 1 in 8 chance of getting prostate cancer, according to Prostate Cancer UK. The ICB should work with researchers to better understand the extent of this issue in BLMK and the reasons behind it. Furthermore, that the ICB develop a programme of engagement with men in general regarding their personal health and co-produce with residents communications activity focused on specific support available for male health.

Insight area	Recommendation
Cultural competency	Develop an Asset Based Community Development (ABCD) approach to engaging with local communities to drive grassroots change and represent their views in service development. ABCD is a way of local people taking the lead, and developing solutions for themselves, supported by statutory organisations, such as local councils.
	This would be achieved by ring-fenced investment being provided to VCSE and Healthwatch organisations to continue to build on the dialogue and trusted relationships developed in this review and lead to continuous improvements. Funding these organisations would enable them to proactively co-produce solutions with residents.
	Co-produce solutions with people from different backgrounds, including people with learning disabilities, young people affected by mental ill health and autism, and refugees, to adjust health services and the spaces in which they are delivered to make them more appropriate and inclusive.
	Co-produce services and training resources with transgender people, people from different ethnic minorities and cultures or faiths to increase awareness of individual needs, so that health and care professionals feel confident and empowered to better support patients. This will better support people when receiving diagnoses or delivering care for their specific needs.
	Develop an education programme for refugees to develop skills and independence to support them in understanding the health system and navigating it. This should also educate refugees on rights available to them, such as taking time off work to support family members and access to health and care.
	Undertake further research to understand the barriers that ethnic minorities including Gypsy, Roma, Travellers, face. Work with residents as part of an Asset Based Community Development approach to develop solutions for greater equality.
	Develop more service offers that involve going into communities, where people are most comfortable, such as pop-up centres, building on the successful approaches adopted through the COVID vaccination programme.
	Encourage health and care professionals to add a 'listening to patients' section to every training event to ensure lived experiences of local people are shared and professionals are given the opportunity to identify solutions to improve the quality of services / experiences.
	Review what is currently in place to provide healthcare advice, guidance and signposting information to residents. Develop a consistent approach so that people can get access to information about the services they need.

Embedding the recommendations through Quality Improvement

Our recommendations aim to tackle deep, longstanding issues, which are often complex.

To succeed, this requires a Quality Improvement (QI) approach, which involves staff and service users to explore the issues, unpick them, and develop services in a more person-centred way.

This means giving residents a much stronger voice, and thinking about what the ultimate goal is, rather than how organisations are currently run. Ultimately, residents need to feel that services have taken into account what they want, how they feel, and what is logical for them. It necessarily means being more flexible, and not rushing to judgement about what a person does or does not need.

By focusing on what residents and staff who work within services areas think, this should help to make inclusion something that is inherent within health and care services, part of their DNA.



Equality Delivery System (2022)

While much of the focus of our review has been on residents, we cannot forget staff members, who often live in the communities they serve.

The Equality Delivery System (EDS) helps NHS systems and organisations improve the services they provide while supporting better working environments, free of discrimination.

The main purpose of the EDS is to help the NHS, in discussion with local partners and local populations, review and improve their performance for people with characteristics protected by the Equality Act 2010, such as sex, disability or race.

Therefore, part of the way we can reduce health inequalities is through ensuring the EDS is rigorously applied and appropriately scrutinised. There is an opportunity to apply the EDS when health and care providers procure new products and services, to create a more fair and equal health service for all, including NHS staff.

Accessible Information Standard

A big theme from residents was around accessibility. One of the ways better accessibility can be delivered is through the Accessible Information Standard. All organisations that provide NHS care or publicly-funded adult social care are legally required to follow the Standard. It sets out a specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss.

Financial investment

This review has not put a price tag on its findings and recommendations. However, to deliver the generational change required to level the playing field, significant investment will be required to support the delivery of the above recommendations.

While it is recognised that considerable investment is needed across BLMK in its entirety, the Denny Review recommends that funding be prioritised in areas where there is a greater prevalence of known health inequalities.

Prioritisation of funding would support the Integrated Care System's prevention agenda. This is because data shows that areas with large populations of black and south Asian residents have greater numbers of people who contract diseases including type 2 diabetes, sickle cell anaemia, thalassaemia, long COVID, heart disease, cancer, as well as higher levels of infant and maternal mortality.

The quality of services is unequal in terms of availability and delivery. Therefore, spending needs to be prioritised to address historical inequalities so the past is not carried into the future. For example, more needs to be spent on preventing type 2 diabetes because this preventable disease significantly disproportionately affects Black and Asian people.

Conclusion

by Reverend Lloyd Denny

COVID-19 as a global emergency is now over. However, the long-term effects of the pandemic cast an uncertain shadow into the future. The inequalities identified in this report in terms of the disease and death and take-up of the COVID-19 vaccine were exacerbated due to a lack of trust in officialdom and in "the system".

To build trust, the challenge is to demystify decision-making processes, so they can be better understood. Furthermore, we need to make sure that there is cultural competency and diversity at senior levels of organisations. This is particularly important in the public sector.

Building trust will take time. Bedfordshire, Luton and Milton Keynes ICB, and all its system partners, need to acknowledge this and find ways to ensure that health inequalities for people from different communities or with different personal characteristics are mitigated against. Reducing health inequalities needs to become part of everyday business.

Leadership is the key to change. This review was commissioned to draw out recommendations and support system leaders to make evidence-based decisions. I have participated in NHS-wide events, discussions and meetings in connection with this review and have been assured that the review has national interest.

This report has focused on the experiences of the public as recipients of NHS services and care. The evidence shows there is clear disparity in the quality of care received and outcome.

I have seen for myself the benefits of good health and social care. The relief, joy and gratitude patients and their families have when a baby is successfully delivered at a hospital. The tears of joy when a life-saving medical procedure goes well. Sadly, good outcomes are not universal across the system. Sometimes this disparity is only a postcode away.

I hope that those in leadership positions in the health and social care system will recognise the scale of the change needed, rise to the challenge for the public wants it, and work with communities to bring about equality for all in the most basic of human need. A failure of leadership created some of the health inequalities faced by the Windrush generation. Therefore, we need to show, 75 years on, that we have learned.

These recommendations must be acted upon to help improve the healthcare system and to build residents' trust in it. If implementation of specific recommendations doesn't happen, the reasons why need to be clearly communicated.

Conclusion continued

Health inequality and inequity

There are many kinds of health inequality and several ways in which the term is used. Various definitions exist¹¹ but broadly speaking, health inequalities can be defined as:

- The avoidable and unfair differences in health across different groups of people
- Differences and biases in the access, quality and experiences of care
- The wider determinants of health, such as housing and income.

A further definition of health inequality by Lord Victor Adebowale, Chair, NHS Confederation: "Inequality is the way of the world; inequity is what we do with the way of the world."

Also from Lord Adebowale: "The NHS was not designed for inequality or inequity; it was designed to eradicate it. It should shame us that we are heading in the wrong direction. We have to make this core business. There isn't a plan B for the NHS."

We must heed these words, and those of residents and NHS staff, to make the changes we need, and demonstrate that serious action is being taken.

11 King's Fund (2020): What are health inequalities?



Steering Group Members

Reverend Lloyd Denny DL

Chair

Diana Blackmun

Chief Executive, Healthwatch Central Bedfordshire

Emma Freda

Deputy Chief Executive, Healthwatch Bedford Borough

Lucy Nicholson

Chief Executive, Healthwatch Luton

Maxine Taffetani

Chief Executive, Healthwatch Milton Keynes

Paul Calaminus

Chief Executive, East London NHS Foundation Trust

Sally Cartwright

Director of Public Health, Luton Council

Liz Cox

Associate Director of Finance -Strategy, Planning and Performance at BLMK ICB

Chimeme Egtubah

Service Manager, Health Inequalities and Communities, Luton Council

Colin Moone

Director, Housing, Luton Council

Elizabeth Learoyd

Managing Director, Engaging Communities Solutions

Nicola Kay

ICS Programme Director, BLMK ICB (until July 2022)

Laura MacSweeney

Business Support Manager, BLMK ICB

Michael Keating

Project Manager, East London NHS Foundation Trust

Steering Group Members continued

Gurch Randhawa

Professor of Diversity in Public Health at the University of Bedfordshire and Director, Institute for Health Research

Julia Robson

Inequalities Programme Lead for BLMK, East London NHS Foundation Trust

Celia Shohet

Assistant Director – Public Health for Central Bedfordshire, Bedford Borough and Milton Keynes

Michelle Summers

Associate Director – Communications, BLMK ICB

Helen Terry

Chief Executive, Healthwatch Bedford Borough (until December 2022) – Elizabeth Learoyd and Emma Freda have represented Healthwatch Bedford Borough since the beginning of 2023.



Thank you

We would like to thank all of the residents from across Bedfordshire, Luton and Milton Keynes people who gave their views to the Denny Review.

We also want to thank all of the organisations who have contributed to the Denny Review:

Healthwatch Bedford Borough

Healthwatch Central Bedfordshire

Healthwatch Luton

Healthwatch Milton Keynes

YMCA Milton Keynes

Community Action: MK

Disability Resource Centre

ACCM (UK)

Queen's Park Community Organisation (QPCO)

Bedford Borough Council's Gypsy and Traveller Liaison Officer, Sharon Wilson

Community Dental Services

Penrose Synergy Ambassadors

Pride in Luton

All others who participated and contributed.