North Central London Integrated Care System

NHS

Start Well

Opportunities for improvement in maternity, neonatal, children and young people's services in North Central London

Case for Change

Table of contents

Foreword

This document is being published at an important moment for health and care in North Central London (NCL), as we transition formally into an integrated care system (ICS) from 1 July 2022. This is a major step in increasing partnership and collaboration, which was accelerated with the response to the COVID-19 pandemic.

I believe that the way this case for change has been developed exemplifies how we want to work as an ICS. It has been a clinically led, collaborative process, which truly puts the needs of pregnant women and people, babies, children, and young people at its heart.

By taking a population health approach and examining services and outcomes through an equalities lens, particularly in understanding deprivation and ethnicity, we have highlighted the need for further work to ensure everyone gets the very best start in life.

Our workforce is our greatest asset and the maternity, neonatal and paediatric staff in NCL are dedicated to delivering the best care to patients and there are examples of great practice and world-leading services of which we are very proud. Through this process we have highlighted the need for long-term resilience in our workforce, recognising challenges in recruitment and retention, which put pressure on both staff and services. Working as an ICS provides an opportunity to think innovatively, so that we can look after our staff and ensure that they have the right infrastructure and support around them to provide the best possible care and have fulfilling careers.

Seeking out and listening to the views of patients and staff, working in partnership with the voluntary and community sector and local authorities, and co-creating solutions together is how we want to work as an ICS.

There are some significant challenges and opportunities identified in this document for our maternity, neonatal and paediatric services and it underlines the importance of getting these services right for local people. We now need to hear your feedback and insights on the opportunities identified through our review. I look forward to your response.

Frances O'Callaghan

Chief Executive (Designate)

North Central London Integrated Care Board

Introduction from NCL clinical leadership

As we work as an ICS to improve services and outcomes, it is important that that we hold a mirror up to really understand how we are serving local communities, and identify the areas that work well and those that could be improved.

This case for change has been clinically led from across the ICS and is based on extensive engagement, involvement and collaboration with maternity, neonatal and paediatric clinical teams across NCL.

We believe that as we come together as an ICS, now is the moment to be honest and transparent about where we need to do better to meet the needs of local communities. We also believe that the ICS needs to respond to these opportunities from a population health perspective.

The case for change set out in this document has been developed with invaluable input from the clinical and operational teams working across NCL's hospitals, all of whom have embraced the challenge of working together to honestly assess where we can be proud of the care we provide, and where there is opportunity to do better. We would like to thank all staff for their contributions to this review and for their ongoing hard work and commitment to delivering the best possible care for pregnant women and people, babies, children and young people.

Over the summer the next step will be to hear the views of patients, staff and wider stakeholders, and we really look forward to hearing your views and experiences as part of this wider period of engagement.

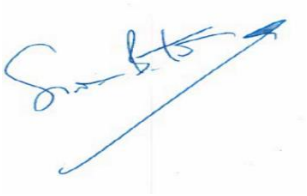
Dr Josephine Sauvage	Dr Emma Whicher
Chief Medical Officer (Designate)	NCL ICS Lead for Children, Young People, Maternity and Neonates (Joint Senior Responsible Officer for Start Well Programme)
NCL Integrated Care Board	*Medical Director – North Middlesex University Hospitals NHS Trust*

Introduction from regional clinical leadership

From the outset of this important review in NCL, it has been vital to align the analysis of clinical need with the design of services across London region. The development and success of Integrated Care Systems will depend on careful and skilled work to ensure the highest quality of care, with greatest access and reduction of inequality.

To achieve this, the value of clinical networks in developing pathways of care that best utilise the multidisciplinary workforce across NCL and more widely across North Thames has been essential, and by using population health metrics should enable clear quality improvement as well as maximal efficiency in the delivery of care for children and their families.

The Region fully supports this case for change and the need to further tune its impact by wider debate and detailed analysis.



Dr Simon Barton

Medical Director for NHS Commissioning in London

NHS England (London Region)

Executive summary

Across North Central London (NCL), we want to understand whether we are delivering the best services to meet the needs of children, young people, pregnant women and people, and babies. The healthcare organisations in NCL strive to deliver safe, high-quality and compassionate care. However, as a system we face challenges that mean that we may not always be able to provide care that best meets the needs of our population.

This case for change describes the current maternity, neonatal, and children and young people's services in NCL and highlights where we consider there are opportunities for improvement. It will be used to develop proposals for improvement and drive that improvement to ensure that our local populations have access to the services that best meet their needs. This document has been published by North Central London Clinical Commissioning Group (NCL CCG) and will be owned by the Integrated Care Board (ICB) from 1 July.

In November 2021, the partner organisations who make up NCL's integrated care system (ICS) formally launched a long-term programme looking at children and young people, maternity and neonatal services, called the Start Well programme. This case for change is the result of the first phase of work in the Start Well programme.

The areas of focus for the programme are elective and emergency services for children and young people, maternity and neonatal services at North Middlesex University Hospital NHS Trust, Royal Free London NHS Foundation Trust, University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust. The programme also considers services provided by specialist providers, including Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH), Royal National Orthopaedic Hospital NHS Trust (RNOH) and Moorfields Eye Hospital NHS Foundation Trust (Moorfields).

There were several drivers for starting this work:

- The clear calls to action set out in the NHS Long Term Plan and the initial Ockenden Report
- The learning from the temporary changes to local children and young people's services in NCL during the COVID-19 pandemic
- External reviews of services across our sites by the Care Quality Commission (CQC) and NHS England and NHS Improvement (NHSE/I)
- The health inequalities further highlighted through the pandemic and the urgent need to address them
- The opportunity to build on existing partnership working as we transition to a formal integrated care system

The Start Well programme has been a true piece of ICS system work, delivered through collaborative engagement between organisations and with clinical leaders from across NCL. A range of approaches have been used to ensure a variety of views and insights have been captured from across the system, as follows:

- **Staff interviews:** close to sixty clinical leaders from across NCL took part in one-to-one interviews with the Start Well programme team. The interviews were an

opportunity to explore the needs of NCL's population and to identify both strengths and challenges in how services are currently delivered.

- **Clinical workstream reference groups:** bringing together clinical and operational expertise, the clinical reference groups met to provide feedback and insights on the data analysis, identify interdependencies with other services and review best practice standards
- **Wider clinical workshops:** two half-day workshops, with around one hundred participants, were held to explore current patient care pathways in more depth and reflect on themes that had emerged through the workstreams, interviews and data analysis.
- **Surgical deep dives:** five focused sessions with surgical colleagues from NCL providers were undertaken to understand the current surgical services, pathways and areas of strengths and challenges.
- **Patient and public engagement:** recruitment of an online patient panel began in February 2022, with the aim of establishing a group of local representatives interested in, and with experience of, using services for children and young people, maternity and neonatal services in NCL. Eight individuals from the online panel have been involved in smaller focus groups, where they have shared their experiences.

Understanding the health and care needs of children, young people and pregnant women and people helps us to plan for the future and understand if our services are meeting the current needs of our populations.

NCL covers five London boroughs: Barnet, Camden, Enfield, Haringey, and Islington, with a resident population of around 1.5m people. Around 1 in 5 of NCL's 1.5m residents are children and young people, defined as those aged 0-18. The children and young people population is projected to decline by almost 10% by 2041. Children and young people population in NCL is diverse, with just over a quarter identifying as white British, a quarter as white other and 10% as black African. Some of our local children and young people are living in some of the most deprived areas in London. Almost one in five children and young people in NCL that are under the age of 16 years are living in poverty.

We also know there are lots of children and young people across NCL living with long-term health conditions. Many long-term conditions, like asthma and diabetes, can be well managed and improved with the right support. However, we know that there are social factors, such as income deprivation, that can influence the prevalence of long-term conditions. For example, the prevalence of asthma is almost double in the most deprived areas in NCL.

The number of women and people living in NCL giving birth has been declining. There are around 1,000 fewer births a year now compared to 2018. Birth rates also vary between the different areas. There were three times more births in the most deprived areas than the least deprived.

For pregnant women and people, we know there are variance in the prevalence of long-term conditions in pregnant women and people in NCL. For example, twice as many Black pregnant women had diabetes in 2020/21 compared to white women during the same period (24% vs. 12%), and more than twice as many Asian pregnant women had diabetes compared to white women during the same period (21% vs. 9%). Similar differences are

seen for other long-term conditions that impact during pregnancy, with the percentage of Black women in NCL who are obese being significantly higher than the NCL average.

Deprivation and ethnicity are strongly associated with health inequalities, which impact on all areas of people's lives and health outcomes – from conception through to death. Understanding the different characteristics and underlying health needs of our local communities, and where there are differences between them, is critical in ensuring we plan and deliver services to meet the population needs.

Maternity and neonatal services – opportunities for improvement

Ensuring excellent experience, equitable access and optimal outcomes for pregnant women and people

Currently there is variation in maternal outcomes in NCL and there is also some variation in the quality of maternity services provided. This means that not all pregnant women and people have the same outcomes and experience of services.

Between 2018 and 2020, there were 238 stillbirths in NCL, with varying levels between the boroughs. Haringey had the highest stillbirth rate in England, according to the ONS data for this period. Although there are indications that this has reduced in recent years, which may be as a result of concerted efforts to reduce stillbirth rates, the differential between NCL boroughs is stark and there will need to be a determined focus as a system to investigate the reason for this high rate and address the root causes of it.

Currently, the number of women accessing perinatal mental health care in all boroughs is below the Long Term Plan ambition and, with the exception of Camden, also below the NCL 2020/21 ambition. Access to perinatal mental health services is a national priority and currently only half of pregnant women and people in NCL requiring support are able to access the care they need.

We need to focus on supporting those that use maternity services to have access to the right services. This means taking into account the diversity of our population and ensuring that maternity services are designed around women and pregnant people.

Better utilisation of the range of maternity capacity offered in NCL

Pregnant women and people can choose to deliver their baby in a range of different settings and as a result, the number of deliveries varies between each of the units within the system.

Currently, the units in NCL are not utilised in an equal way, with many pregnant women and people either choosing to deliver, or being recommended to deliver, in an obstetric-led setting. Data shows that for some sites in NCL, the utilisation of their midwifery-led units was around 30% or under, whilst obstetric-led units were dealing with significant pressures. This means that currently, pregnant women and people giving birth in NCL are either not electing to give birth in midwifery-led settings in large numbers, or their level of complexity means this would not be recommended.

During times of high demand or low staffing levels, obstetric-led maternity units are sometimes forced to close to ensure the safe care of pregnant women and people they are

looking after. This suggests we are not able to utilise our current capacity in the best way possible to meet the needs of pregnant women and people.

Ensuring pregnant women and people are able to make informed choices and their care is fundamental. We know that there is an opportunity to explore whether the current maternity capacity is best aligned with the needs of the NCL and non-NCL populations that use the services.

Supporting maternity workforce sustainability

Maternity workforce sustainability is a national challenge and the recent Ockenden Report has further highlighted the impact that unsafe staffing can have on the care and quality of maternity services.

We know that across our maternity sites in NCL there are challenges in recruiting and retaining maternity staff. For our units to comply with the new staffing standards we need to recruit an additional 27 midwives across the system. To help fill in these gaps, collaborative work is ongoing and further work is needed to recruit into the funded posts to ensure that vacancies do not impact upon patient care and the experiences of staff working in maternity services. Midwifery recruitment is, and will continue to be, an ongoing challenge and focus in NCL.

Matching neonatal intensive care capacity and need

The NHS has defined different classifications of neonatal units, which range between a special care unit (level 1), a local neonatal unit (level 2) and a neonatal intensive care unit (level 3). SCUs are able to look after babies with the least complex conditions requiring neonatal care, and NICUs look after the most premature or unwell babies. Those likely to have a very premature or unwell baby should give birth on a site with a co-located NICU. In NCL, The Royal Free Hospital is designated as an SCU, whilst at the other end of complexity, UCLH and GOSH both have a NICU. All the other units in our system are LNUs.

Evidence highlights that some neonatal units in NCL looking after the smallest and sickest babies do not have sufficient cot capacity. The UCLH NICU between 2018-20 was on average 85% occupied, which is higher than the maximum threshold set out in the NHS neonatal service specification.

Not having enough cots for these babies can also make it difficult for neighbouring hospitals to secure a cot for labouring pregnant women and people who require a transfer to UCLH. In many cases this means either delays in transfer, or that a pregnant woman or person must be transferred to a unit outside NCL. These situations can be extremely stressful for both families and staff. Evidence shows that in 2020/21 over-stretched capacity at UCLH meant that 40 babies from NCL LNUs were transferred to a NICU outside NCL.

Consider the sustainability of the Royal Free Hospital Special Care Unit

The Royal Free Hospital is the only hospital in NCL that has a SCU (level 1) and is therefore unable to look after very small or very sick babies. We know from other areas that the location of this type of unit in an urban area is unusual, particularly with other units so close by. In general, SCUs (level 1) are found in rural areas to enable babies to be discharged closer to home. Data shows that the Royal Free Hospital unit looks after a very low number of babies compared to the other units in NCL and the number of admissions to the unit has

been declining by 12% every year since 2018/19. The occupancy of the unit is also low at 42%, meaning over half of its cots were not occupied on any given day.

This level of activity means that the unit falls below the upper threshold suggested by standards set out by the British Association of Perinatal Medicine (BAPM). These standards are in place to ensure that staff caring for babies needing respiratory support have the required experience and competencies to do so.

The low number of admissions creates a challenge for our staff to maintain the required competencies to look after babies needing respiratory support. We have mitigating actions in place however, in the longer term, the clinical risk around the unit remains and it will continue to be difficult to staff the unit in a sustainable way as it is currently set up.

Minimising avoidable admissions to neonatal units

Maternity and neonatal services should be set up in a way that minimises separation of the woman or person that has given birth and their baby. The community outreach support available to neonatal teams at our hospitals can have an impact on whether a baby needs to be admitted to a neonatal unit and how long a baby stays in hospital.

Currently, access to neonatal outreach programmes depends on where you live in NCL. The existing provision is not consistent between our boroughs and does not represent equitable access. For example, in Islington, phototherapy (used for the treatment for jaundice) is available in the community whereas for babies living elsewhere, they would likely have to stay in hospital for treatment.

There is an opportunity to increase the provision of these very important community services to ensure babies and their families are able to access the same services, no matter where they live. This will help ensure babies are not staying longer in hospital than they need to.

Addressing workforce vacancies and variation in provision and access to allied health professionals across the units

There are currently high levels of staff vacancies in our neonatal nursing workforce. This places a strain on services and means that teams are heavily reliant on temporary staff to fill gaps. Vacancies also mean our neonatal nursing workforce are unable to be released to complete their qualification in neonatal service training – which is integral to the staffing of a safe neonatal unit. The staffing shortage means that some of our units are unable to open all their cots as they do not have safe staffing levels in place.

Across NCL there is a shortage in the number of allied health professionals (AHP) in the neonatal units. Compared to the staffing levels recommended by professional bodies, NCL is consistently below these levels for all disciplines. For example, units in NCL would need an additional four dietetic staff and three staff for physiotherapy.

Across NCL we need to think about how we can address the current staff vacancies. For example, hospitals could work in a more joined up manner to support with AHP staff shortages.

Having the right maternity and neonatal estate

For pregnant women, people and their families, hospital facilities should provide privacy, preferably labour rooms with en-suite bathrooms and space for the birth partner to join delivery when possible.

We are fortunate that there is some good estates within NCL; however, we know that current the maternity and neonatal estate at the Whittington Hospital does not meet agreed modern standards. For example, although there are en-suite facilities in the birth centre on the site, they do not currently have these in their labour ward rooms. For neonatal facilities, there are challenges around the space that is allocated for the unit and the number of cots that they have.

Across NCL we do not use some of our buildings as effectively as we could to allow parents to stay with their sick babies. Parents should still be the primary caregivers and should be supported by the clinical practice team to deliver as much cot-side care as is feasible.

There is an opportunity to improve maternity and neonatal facilities within NCL, ensuring that the estate does not detract from the care or birth experience.

Children and young people's services – opportunities for improvement

Increasing emergency demand

Across NCL sites our emergency departments provide emergency care for over 160,000 children and young people a year. The size of paediatric emergency departments across NCL varies. For example, North Middlesex University Hospital has the busiest paediatric emergency, with around 4,100 children and young people being seen every month.

Evidence shows that the number of children and young people accessing emergency services has been increasing and is now higher than before the COVID-19 pandemic. Between April and December 2021, NCL sites were treating an extra 73 children and young people every day compared to the same period in 2016.

Our staff have also reflected that the complexities of those accessing emergency services are changing. Data shows that there are increasing numbers of children and young people attending who could have potentially been treated elsewhere. Whilst some do require hospital treatment, many children and young people could be better looked after in the community. To ensure children and young people are accessing emergency care in the right place, more could be done to focus on joined up services between hospitals, GPs and community services. Work is underway in some areas in NCL to help support this.

We also know that the current organisation of emergency care means that in the north, sites such as North Middlesex University Hospital and Barnet Hospital, are providing emergency services for a large catchment population. In the south of the system there are three sites providing emergency care within close proximity of each other. With the pressures on emergency care, we need to think about how best to support our emergency departments to ensure there are sufficient resources to meet the needs of the local population.

Improving long-term conditions management

Often children and young people with long-term conditions do not get enough support to manage their health and wellbeing, and this can lead to unplanned time in hospital. Evidence also shows that children and young people with long-term conditions living in the most deprived areas are more likely to be admitted. For example, children and young people with asthma living in the most deprived areas were twice as likely to spend unplanned time in hospital as those living in the least deprived areas.

Addressing the variance in long-term conditions management and support will require a focus on whole system approaches across NCL.

Organisation of paediatric surgical care

In line with national guidance, our local hospitals should be able to provide low complexity paediatric surgical care for children over the age of three.

However, when it comes to emergency surgical care evidence shows that some children and young people in NCL are being transferred for some treatments which should be managed locally. From April 2020 to March 2021, 144 children and young people were transferred from an NCL provider to other hospitals for an emergency surgical procedure, with almost one in five moved to hospitals outside NCL. For our patients and their families, this can cause added stress at an already stressful time.

From speaking with our staff, we know that some children and young people in NCL are being transferred for some treatments which NCL should be able to manage locally. Across NCL there is a gap in paediatric anaesthetist provision at local sites, which is a main driver for children and young people being transferred.

Our staff have reflected that more needs to be done across NCL to address the current skills gap, ensuring that our surgical pathways provide the best experience for our patients. In doing so, it is important that the role of GOSH is fully defined in the pathways. We know from guidance and evidence elsewhere that a paediatric surgical network can improve access, support implementation of consistent models of care and improve quality of care. Organisations across NCL could consider this approach to help support paediatric surgery.

Reducing long waits for elective care

Elective care should be delivered within 18 weeks and across NCL we are not meeting this standard of care. Data shows that currently one in 46 children and young people in NCL are waiting for treatment. Of those waiting for care, over 330 have been waiting over a year, and 1,600 over 18 weeks. At best, the waiting time for treatment for children, young people and their families is stressful and frustrating, and at worst it can impact children and young people's health and their wider lives.

In NCL evidence shows that specialties have experienced different levels of backlog, and this means some children and young people are waiting longer for routine procedures than others. For example, ophthalmology, paediatric dentistry and ear, nose and throat (ENT) services have the largest number of children and young people waiting for treatment.

There are several factors that can contribute to growing waiting lists, including bed and staff capacity, theatre efficiencies and organisational productivity.

Within NCL there are existing areas of collaboration in terms of delivering elective surgical care, which has supported organisations in tackling the growing waiting list, however children and young people are waiting too long to be treated. There is an opportunity in NCL to consider how to work together and do more to better utilise the current resources within the system and optimise productivity to address the growing backlog.

Improving transition to adult services

The transition from adolescent to adult services is an important step, and a poor experience can be associated with a deterioration in health. Transition preparation should begin as early as possible, ideally starting around age 14.

Across NCL there is no consistent definition of the cut-off age for children and young people's services. This can mean that in one part of NCL a child will move into adult services at 17 years old, whereas at another they will not move until after their nineteenth birthday, or twenty fifth birthday for complex children.

Across all services, including community and mental health, there is an opportunity to consider how children and adult services could work collaboratively and in partnership with families to support their child through the transition. This may mean that our staff need further training and support to help manage effective transitions and expectations.

Recruitment and retention of the paediatric workforce

There is currently a high number of staff vacancies across the paediatric workforce, which is placing significant pressures on our staff. Vacancy rates are particularly high in paediatric nursing, with rates ranging from 13% - 36% across the NCL sites. Often our own staff are having to work to provide cover for shifts, which at a time where staff have been under extreme pressure, is leading to significant burn out.

We know that there are national challenges with respect to paediatric nursing staffing shortages and so it is important that NCL considers how to work collaboratively to develop innovative workforce solutions.

Conclusion

There are strong drivers for thinking about the way in which maternity, neonatal and children and young people's services in NCL can be improved.

This review presents an exciting opportunity for us to improve current services for our populations.

Section one: Introduction and vision

Vision for services in NCL

The foundations of lifelong health are built during pregnancy, at birth and in childhood. We want to ensure that patients and service users in NCL receive the best care and outcomes possible from their interaction with maternity, neonatal, children and young people's services. This is fundamentally important on an individual level for each pregnant woman or person, child or family, and also for the health and wellbeing of NCL as a community.

The experiences of being pregnant, giving birth, and the early days with a new baby, create memories that are likely to stay with a pregnant woman or person for a lifetime.

Maternity services should be considered as one alongside neonatal services if we are to achieve the best possible outcomes for both the pregnant woman or person and their baby. This should have at its heart the fundamental principle of keeping the pregnant woman or person and baby together as far as is safe and possible, and minimising avoidable admissions to neonatal units. When babies do need to be admitted, the neonatal care they receive is one of the most crucial phases in their survival and development. We must ensure that we have the right neonatal care available, and that babies are looked after in the best care setting for their level of need and as close to home as possible.

Interaction with paediatric NHS services is something that many families will experience as their child grows up. We want our paediatric services in NCL to be able to provide the best possible care for children and young people at their time of need – be that in an emergency, or when they need to see specialists in a planned way. Our services should be set up in a way that minimises the impact of receiving care on a child's development, so that they continue to grow and thrive.

Many families will experience the services described in this document from birth and as their child grows. Families should feel that our services are compassionate, family friendly and are able to take into account their choices and needs. They should have trust in services and feel assured that they will be looked after. Working as an integrated care system in NCL, our collective ambition is that we provide services that support the best start in life, both for our own residents and those from neighbouring boroughs and beyond who chose to use our specialist services.

In order to achieve this vision, we must have the right workforce and we are committed to enhancing the working lives of our workforce. By working together and cooperating beyond individual organisational footprints, we can resolve some of the workforce challenges faced. We should use the specialist knowledge and skills that exist in NCL to ensure that we continue to provide the best start in life for those who use our services.

Feedback on the case for change

We are asking patients and residents, providers, clinicians and other stakeholders to feedback on this case for change. The responses received during this period of engagement will provide important data to feed into the review by the Integrated Care Board and other commissioners of services and help to determine the next steps for the programme.

We hope to obtain as wide a range of responses as possible from members of the public, the voluntary sector, any interested providers, commissioners (both in NCL and neighbouring integrated care systems) and other stakeholders.

As set out in section two we have planned a programme of engagement activities during July, August and September 2022 and would welcome input from any interested organisation that would like to be included in the engagement programme.

To capture feedback we have designed a two-part questionnaire and will also run a wide range of engagement events. Feedback will be sought on two different areas using the questionnaire, engagement events and other written and verbal forms. The two areas are:

- Feedback on the case for change and the opportunities identified within it
- What is most important to them about maternity, neonatal and paediatric care when considering these services in the future

Purpose of this document

Formally initiated in November 2021 by NCL CCG, working on behalf of the NCL integrated care system, the first phase of the Start Well programme has sought to understand whether we are delivering the best services to meet the needs of children, young people, pregnant women and people, and babies. This process has been collaborative in nature, with insights from patients and excellent participation from partners, including clinicians, operational leads and system leaders. This document, called a case for change, reflects the findings from this initial assessment.

The document is intended to be read by a range of individuals and organisations who have an interest in and views on the delivery of these services. They include patients, staff, clinical leaders, voluntary sector organisations and local authority partners. Following publication there will be an intensive period of engagement with patients, staff and the public to understand if the content of the document, and opportunities for improvement identified, resonate with their experiences of services. Feedback received on the opportunities for improvement and what good services look like will help to inform the decisions that are taken at the end of the engagement process about the next steps for the Start Well programme.

The language used in this document

The audience for this document is broad. It has been written with the intention of being as easy to understand as possible for everyone that reads it. As far as possible, jargon-free, plain English has been used and medical constructs and terminology explained. A glossary has been included to support the understanding of abbreviations and terminology for those who may be less familiar with the terms used. This document will also be accompanied by some summary materials, which will set out the key points of the case for change. These will be made available and translated into community languages on request.

We want this document to be as inclusive of everyone's experiences of health care as possible and it therefore refers to 'pregnant women and people' when describing those that use maternity services. Services should be appropriate, inclusive and sensitive to the needs of those individuals whose gender identity does not align with the sex they were assigned at birth and in describing services in this document we hope to mirror that inclusivity and sensitivity.

How this document has been structured

The main purpose of this document is to describe opportunities to improve maternity, neonatal and children and young people's services in NCL. Before doing this, sections one, two and three will set the context within which the document has been drafted. They describe NCL as an area and the healthcare landscape – including a description of the hospitals and the organisations which manage them, in addition to the background information about the drivers for starting the Start Well programme.

Section two: Principles and process of the programme to date

In November 2021, through NCL CCG, the partner organisations who make up NCL's integrated care system formally launched the Start Well programme; a long-term programme looking at maternity, neonatal and children and young people's services. The governance of this programme is through the North Central London Children and Young People, Maternity and Neonatal (NCL CYPMN) Board, which has oversight of a wider range of CYPMN services than the Start Well programme considers.

Within Start Well the areas of focus are elective and emergency services for children and young people, and maternity and neonatal services at North Middlesex University Hospital NHS Trust, Royal Free London NHS Foundation Trust, University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust.

Great Ormond Street Hospital for Children NHS Foundation Trust, and the other specialist hospital sites in NCL (Moorfields Eye Hospital NHS Foundation Trust and the Royal National Orthopaedic Hospital NHS Trust), are key partners. The interface with specialist services and pathways, particularly with GOSH, are considered as part of the programme. Most specialist services are currently commissioned by NHSE/I through specialised commissioning, who are co-sponsors of this document.

Community and mental health services and primary care are not part of the programme, but interdependencies have been carefully considered.

The reasons for looking at these services now include:

- The opportunity to give babies, children, and young people the best possible start in life and to deliver the ICS priority action to start well
- The clear calls to action set out in the NHS Long Term Plan and the initial Ockenden Report
- The learnings from the temporary changes to local children and young people's services in NCL during the COVID-19 pandemic
- External reviews of services by the CQC, and NHS England and NHS Improvement
- The health inequalities further highlighted through the pandemic and the urgent need to address them
- The opportunity to build on existing partnership working as we move into becoming a formal integrated care system
- Wanting to ensure there is a resilient and sustainable maternity, neonatal and paediatric workforce

More recently, the publication of the final Ockenden Report has highlighted the even more urgent need to look at our maternity and neonatal services and ensure that they are set up in a way that allows them to deliver the best possible care to patients.

The Start Well programme currently reports into NCL's Children, Young People, Maternity and Neonatal Board, made up of all system partners including senior local authority

colleagues, (see below section on governance for further detail) and has followed several key principles in the development of the case for change. These include:

- Taking a clinically led, collaborative approach, with all participants clear about their roles and responsibilities
- Collaborating as system leaders to support the programme with key enablers such as finance, data, analytics, organisational development, and communications and engagement
- Working across organisational boundaries and outside NCL to identify and learn from innovation and best practice from around the UK and beyond
- Collaborating and looking for opportunities to work as a system and use our resources (people, places and money) in the best possible way to ensure the best outcomes for patients

The Children, Young People, Maternity and Neonatal Board also agreed to adopt communications and engagement specific principles for the Start Well programme and development of the case for change. We will:

- Work collaboratively, openly and transparently, involving residents from the very beginning
- Ensure the experiences and aspirations of local people directly influence the programme
- Make every effort to involve communities who experience poorer health outcomes and greater health inequalities
- Work to flexible timelines to allow time for meaningful, authentic engagement, balanced against the need to maintain momentum
- Use a variety of methods, tailoring our approach to be accessible to diverse communities and remove barriers to participation
- Be inclusive and ensure a wide and diverse range of stakeholders have an opportunity to meaningfully contribute to the programme
- Work in partnership with local voluntary, community and social enterprise sector (VCSE) and councils, and draw on their specialist engagement expertise and advice
- Tell staff, families and children and young people (CYP) how their feedback has helped to shape the programme and informed decision-making

Start Well programme timeline

Since November 2021 the Start Well programme has been in its first phase, which has been the development of the case for change. Baseline analysis, stakeholder interviews and clinical engagement have helped to shape the assessment of the current situation regarding children and young people, maternity and neonatal care in NCL. The outcome of this assessment has formed the foundations of this case for change document.

On 30 June 2022, the NCL CCG Governing Body, on behalf of the integrated care system will be asked to approve the case for change and begin a process of engagement on its findings. Over the summer, between July and September 2022, an engagement process will begin where patients, staff, and the public will be asked to comment on the case for change and feedback their views on the opportunities for improvement which have been identified.

This engagement process will run alongside and inform clinical workshops where clinicians will discuss best practice clinical care models. This process will lead to a decision point in autumn 2022 about the strength of the case for change and the next steps that are required to meet the challenges set out.

At the autumn decision point, there may be opportunities identified that could be realised through quality improvement initiatives which could be put in place by ICS partners working together collaboratively.

If there is a decision that the case for change requires consideration of options involving significant service reconfiguration, the Integrated Care Board (as the body taking on the commissioning responsibilities of the CCG from 1 July 2022) will complete an options appraisal (which would likely be carried out over the autumn and winter 2022) before the publication of a pre-consultation business case (PCBC) and public consultation, if required (potentially in spring 2023).

Depending on the feedback through the engagement phase, the timeline for any future steps will be formally confirmed at the autumn decision point. For transparency, an indicative timeline is set out below.

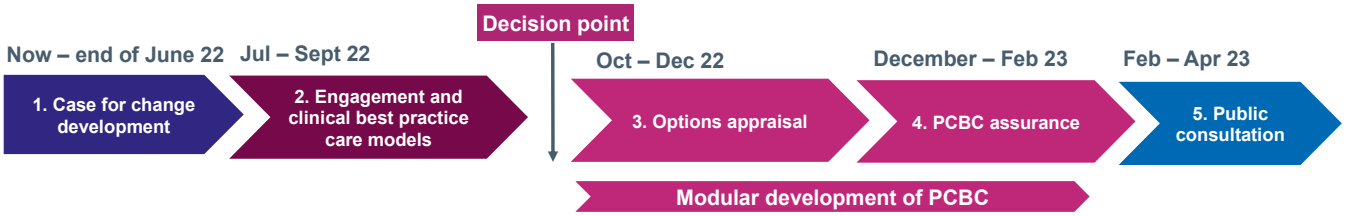


Figure 1: Start Well programme indicative timeline

Scope of the programme

The scope of the Start Well programme is focused on all maternity and neonatal services and children and young people's services that are delivered in an acute setting across the four secondary care provider Trusts in NCL. For the purposes of this review, a child or young person has been defied as anyone using services up to their nineteenth birthday.

Organisation	Maternity services	Neonatal services	Paediatric planned care	Paediatric emergency care
North Middlesex University Hospital NHS Trust	✓	✓	✓	✓
Royal Free London NHS Foundation Trust	✓	✓	✓	✓
University College London Hospitals NHS Foundation Trust	✓	✓	✓	✓
Whittington Health NHS Trust	✓	✓	✓	✓
Great Ormond Street Hospital For Children NHS Foundation Trust	N/A	✓	✓ *	✓ *
The Royal National Orthopaedic Hospital NHS Trust	N/A	N/A	✓ *	N/A
Moorfields Eye Hospital NHS Foundation Trust	N/A	N/A	✓ *	✓ *

Figure 2: Services in scope of the Start Well programme

* GOSH, RNOH and Moorfields are specialist hospitals and are key system partners in NCL. Some of their services have been included in the scope of the programme due to the strong links within the sector, agreed pathways of care and the interface between secondary and tertiary providers for some aspects of care. Throughout the document it will be made clear when data from these hospital sites is included as part of the analysis.

Services that are out of scope of the programme:

- Community and mental health services for children and young people, for example community dietetic services
- Specialist services for children and young people, including cancer services
- Primary care services for children and young people, for example general practice services

A more detailed summary of the scope of the programme can be found in Appendix A. Any interdependencies with this programme are highlighted throughout the document.

Clinical leadership and governance of the programme

The Start Well programme leadership

The Start Well programme has leadership from across NCL, with joint Senior Responsible Officers, Dr Emma Whicher and Sarah Mansuralli - as outlined below:

Name	Role	Organisation
Dr Emma Whicher	Integrated Care System lead for Children, Young People, Maternity and Neonates	NCL ICS and North Middlesex University Hospital NHS Trust
Sarah Mansuralli	Executive Director for Strategic Commissioning at NCL CCG and Chief Development and Population Health Officer (Designate)	NCL CCG and NCL ICB

Figure 3: Start Well programme leadership

The programme has three workstream Clinical Reference Groups, each with executive-level leadership from an NCL acute trust:

Name	Clinical Reference Group	Role	Organisation
Michelle Johnson	Maternity and neonatal services	Chief Nurse and Director of Allied Health Professionals	Whittington Health NHS Trust
Dr Mike Greenberg	Children and young people's planned care in an acute setting	Medical Director	Barnet Hospital (part of Royal Free London NHS Foundation Trust)
Dr Tim Hodgson	Children and young people's emergency care in an acute setting	Medical Director Specialist Hospitals Board	University College London Hospitals NHS Foundation Trust

Figure 4: Clinical workstream leads for the Start Well programme

A programme director and small programme team based in the CCG support the programme and they have worked alongside an independent management consultancy, Carnall Farrar (CF), to write this document. Colleagues from across the system have supported on key enablers such as finance, population health intelligence, workforce, and communications and engagement. Specifically, finance and analytics have had senior leadership from across the integrated care system:

Name	Role	Organisation	Workstream
Kevin Curnow	Chief Finance Officer	Whittington Health NHS Trust	Finance
Dr Sarah Dougan	Director of Population Health Intelligence	NCL ICS	Analytics

Figure 5: Finance and analytics leads for the Start Well programme

The North Central London Children and Young People, Maternity and Neonatal (NCL CYPMN) Board

Robust governance arrangements were established at the outset of the Start Well programme. The Start Well programme currently reports into the North Central London Children and Young People, Maternity and Neonatal (NCL CYPMN) Board. The Board's remit encompasses the reporting line for the Local Maternity and Neonatal System (LMNS) Board and the Children and Young People Regional Improvement Programme, as well as taking reports around children's community and mental health services. This ensures alignment between the Start Well programme and other key existing areas of work.

The NCL CYPMN Board is chaired by North Middlesex University Hospital Medical Director, Dr Emma Whicher, in her role as the Integrated Care System lead for Children, Young People, Maternity and Neonates. The NCL CYPMN Board also has representation from primary care, the paediatric and neonatal networks, local authority, public health, specialised commissioning and medical or nursing executive leads from each of the NCL acute Trusts.

The NCL CYPMN Board has further clinical representation, including from primary care, which have been outlined below:

Name	Role	Organisation
Dr Josephine Sauvage	Outgoing CCG Chair and Chief Medical Officer (Designate)	NCL CCG/NCL ICB
Dr Oliver Anglin	Clinical lead for the Children and Young People's Regional Improvement Programme	NCL ICS

Figure 6: Clinical representation on the NCL CYPMN board

Local authorities and Public Health in NCL are also represented, with representatives outlined below:

Name	Role	Organisation
Ian Davis	NCL Local Authorities chief executives representative	LB Enfield
Ann Graham	NCL Local Authorities director's of children's services representatives	LB Haringey
Kirsten Watters	NCL Directors of Public Health representative	LB Camden

Figure 7: Local authority and public health representation on the NCL CYPMN board

Specialist commissioning is also represented on the NCL CYPMN board:

Name	Role	Organisation
Simon Barton	Medical Director for NHS Commissioning in London	NHSE/I
Rachel Lundy/Sara Nelson	Programme of Care Lead for Women and Children (job-share)	NHSE/I

Figure 8: Specialist commissioning representation on the NCL CYPMN board

The full membership of the NCL CYPMN Board can be viewed in Appendix B.

Support for the case for change

The Start Well programme has been a truly collaborative programme of work that has meaningfully engaged ICS partner organisations and clinical leaders from across NCL in leading and developing this case for change. Having had so much engagement from system partners, it was fundamental to the programme that the content of this case for change reflects the views of those partners and to ensure that all organisations support the opportunities for improvement that are identified within it.

For this reason, partners have been involved and have had the opportunity to input into this document throughout drafting. It is being presented in this form following an extensive feedback process and has the endorsement of the Trust Boards which have a significant proportion of their services in scope: Great Ormond Street Hospital for Children NHS Foundation Trust, North Middlesex University Hospital NHS Trust, Royal Free London NHS Foundation Trust, University College London Hospitals NHS Foundation Trust and Whittington Health NHS Trust. It also has the approval of the Specialist Commissioning Regional Oversight Board and the NCL Children Young People Maternity and Neonatal Services Board.

Clinical feedback and insights

A range of approaches were used to ensure the knowledge, experience and insights of clinical leaders from across the local NHS directly informed the case for change.

Each of the three workstream clinical reference groups brought together a broad range of clinical and operational staff from NCL to support and guide the programme. Each group met four times between January and March 2022 and in total over 70 staff were involved in the meetings, bringing both operational and clinical expertise.

At the workstream clinical reference group meetings, members:

- Provided feedback on, interrogated and validated data analysis about in-scope services
- Identified interdependencies with other services
- Reviewed best practice standards in relation to care delivered in NCL

In addition to the workstream meetings, five surgical 'deep-dives' were also undertaken to gain a better understanding of some of the specific challenges facing the surgical specialties. These deep-dives covered: urology, dentistry, plastic surgery, ear nose and throat (ENT) and ophthalmology. These were one-off sessions that had attendance from surgical leads from across providers in the sector and have helped to inform the descriptions of opportunities and challenges later in the document.

Close to 60 clinical leaders from across NCL took part in one-to-one interviews with the Start Well programme team. The interviews were an opportunity to explore the needs of NCL's population and to identify both strengths and challenges in how services are currently delivered. Topics discussed included the population need for services and the capacity available to treat patients, workforce, recruitment and retention, training and skills, and best practice models of care. Outputs were analysed and the emerging themes were tested alongside the data analysis and further refined by the workstream clinical reference groups. An overview of those interviewed from each organisation can be found in Appendix C, and the themes that were identified in the interviews are set out in Appendix D.

An online form was promoted on Trust intranets, regular communications and e-bulletins to invite all staff to give their views of services. Questions on this form mirrored those used in stakeholder interviews, offering staff a structured way to engage with the process. 87 responses were received and covered themes including the consistency in quality of care across NCL and what are the areas of challenge both at the individual organisation and across the system. The themes identified from this questionnaire can be found in Appendix E.

In early March 2022 two half-day virtual workshops were held with around 100 workstream clinical reference group members and some wider clinical representatives – one on maternity and neonates, and another on planned and emergency care for children and young people. Staff worked together to explore current patient care pathways in more depth and reflected on themes that had emerged through the workstreams, interviews and data analysis. This included staff discussing strengths such as the high quality of many services and the commitment and resilience of staff, alongside challenges such as increasing emergency demand, potential gaps in service provision, and staff recruitment and retention.

The information and evidence gathered from the workstream clinical reference groups, clinical interviews, and workshops is represented throughout this report.

Engagement undertaken to date

The aim of engagement during the development of this document was to assist the team in obtaining a wide range of views and knowledge, as well as to initiate involvement with those groups who have historically engaged less with NHS programmes of this nature, in preparation for the more formal engagement phase of the programme following publication of this document. Initially, a review of existing patient insight and feedback was undertaken to collate existing knowledge. This can be seen in Appendix F. This existing insight was broad in scope and captured the experiences of a wide range of existing service users, including young people, those from different ethnic groups, condition-specific groups and those with pre-existing relationships with the partner Trusts working on the Start Well programme. The additional work outlined below was targeted to supplement this review of existing patient insight, and gain input from other groups, so as not to repeat work. Building on this, the following engagement was undertaken.

Online patient panel

The recruitment of an online patient panel started in February 2022. Recruitment used several different techniques, including social media advertising, engagement with community and voluntary sector groups and outreach to acute Trusts. The panel has 50 members so far, with ongoing recruitment to ensure it is representative. The panel exists as an online entity that engages via a web-based forum. Questions are posed using text or short films, inviting responses. These focused on:

- The environment in which they experienced care
- Experience of paediatric ED services
- Experience of paediatric surgery

Patient representatives

A group of around 6 - 8 local people with an interest in and experience of the services in the scope of the Start Well programme are being recruited from the patient panel, to stay with the programme through the engagement phase, and provide patient voice at workshops, input into the refreshed governance for the next phase of the programme, and wider engagement opportunities.

Patient focus groups

Two focus groups involving online patient panel members took place during early May 2022. Members of the panel were invited to attend sessions entitled: ‘Let's Talk about NHS Children and Young People’s services in NCL’ and ‘Let's Talk about NHS Maternity and Neo-natal services in NCL’ to discuss their experiences of these services.

Targeted engagement with identified groups

A number of groups were invited to take part in conversations with the Start Well programme team to ensure that the voices of those who may not normally participate or who may be disproportionately disadvantaged (as outlined in our population analysis) have been captured. Due to the vulnerability or communication barriers of some groups, community

and voluntary sector organisations were asked to undertake engagement on our behalf and insight was captured using a structured interview format. Examples include a group of young people who were previously in care, and a group of women with experience of domestic violence.

Youth summits and youth mentoring scheme

The establishment of a youth mentoring scheme was agreed to ensure that the voices of young people are at the centre of the programme. In partnership with a specialist youth engagement agency, Participation People, and starting over the summer of 2022, a group of young people will partner with the programme through a series of 'Youth Summits' where their input will be sought at key milestones in the programme. These are planned to coincide with school holidays to maximise participation.

In addition to the summits, several young people will act as 'Youth Mentors' to the programme clinical leadership team, working closely with leaders to ensure that the voice of young service users remains central to the programme.

Staff engagement

In addition to the clinical and operational insights gained from staff via the workstream clinical reference groups described above, one-to one interviews and workshops, all staff were given ongoing opportunities to give broad feedback during the development of the case for change. As set out above, an online form was promoted on Trust intranets, and in regular communications and e-bulletins.

Additionally, staff update sessions were offered by Trusts, delivered by their executive lead for the programme. These offered opportunities for two-way dialogue, for the programme to give information to staff and the staff to provide feedback to the programme. These were supported by regular internal staff communications that were developed after each workstream meeting, where meeting content and outcomes were shared with staff to support transparency.

Next steps for engagement

Future engagement on the themes and opportunities outlined in this document will build on engagement to date. The programme has established a list of almost 200 voluntary and statutory sector groups, relationships with Trust patient experience and engagement teams, local authority youth service leads and condition-specific groups in preparation for comprehensive engagement over the summer.

- For a 10-week period, as well as seeking views from staff, we will engage with patients, the public and wider stakeholders on the case for change through a diverse programme of structured engagement opportunities
- Opportunities to provide feedback will be available throughout the engagement period, with a significant degree of activity focused in the first three weeks of July before the school holidays begin
- We will seek a broad range of views and welcome and enable involvement from any stakeholders in NCL who wish to contribute, through a core engagement offer for all. We will seek deeper engagement with current and recent patients, carers/parents of patients and staff working in the relevant services, those identified through our population analysis with protected characteristics under the Equality Act, who are

more likely to experience inequalities, ill health or deprivation. We will also consider geographical mix. We are identifying and segmenting audiences through an updated stakeholder mapping and prioritisation exercise, which draws on data and equalities analysis conducted for the case for change

A broad range of engagement techniques will be used, tailored to each audience and their level of interest. Opportunities for involvement will be available both online and face-to-face.

- We will work closely with local VCSE and councils, and established networks and groups including Maternity Voices Partnerships (MVPs) and Birth Companions to reach our audiences
- Activities will be delivered at times and in places that are convenient and appropriate for each stakeholder group. Depending on the most appropriate approach for the specific audience, the engagement activity/content will be delivered by the Start Well programme team, a specialist provider, or a VCSE partner
- A range of materials will be produced to support audiences to engage with the content of the case for change. This will include a summary version of the document, presentation slides, website copy, maps, infographics, and case studies/patient stories. Wherever possible, we will test content with Healthwatch or another community partner. Staff materials will be produced with the input of Trust communication teams
- We will also seek to meet any specific format needs including translations, easy read, audio, braille etc. We will use the stakeholder prioritisation exercise to anticipate these needs in advance and will remain responsive to those that arise as the engagement phase progresses
- Mechanisms will be put in place to log feedback consistently and methodically from each form of engagement activity. This will include the appropriate level of demographic information for the engagement method

When engaging on the case for change we will seek to understand from stakeholders:

- What do they think about the ideas and opportunities in the case for change?
- Do the challenges set out in the case for change resonate with you or the group/community you represent?
- Are there any areas or themes not covered in the case for change that we need to explore?
- What does good care look and feel like, when considered in the context of the case for change conclusions, to inform future planning

We will ensure an open approach to capturing feedback to our proposals and will invite feedback in a number of ways:

- Response using a questionnaire (freepost return)
- Response using an online version of the same questionnaire
- Feedback captured at patient and carer groups and other in-person interactions
- Feedback captured at deliberative events
- Submissions via letter or email, not using the structured questionnaire mechanism

- Video or audio response would also be accepted and analysed alongside all other methods – for example, information captured at interactive workshops with young people using innovative engagement methods

It is suggested that in-person feedback is captured in a number of ways:

- Large forums and public meetings will be captured in detailed notes
- Smaller meetings will be captured by the person presenting or a note taker. If it is a meeting that is minuted by the organisation receiving the presentation, then meeting minutes can also be used. All notes should ideally be agreed by the chair of the meeting or similar
- An audio recording could also be used in some cases as an additional aid to check after a meeting. (The programme will follow best practice which suggests that people should be made aware of the use of recording equipment before any meeting is recorded and the reason why it is being used, ensuring some element of consent is sought)
- Receipt of written submissions to the postal address given

A focus group/meeting reporting template will be developed and agreed to ensure robust recording of feedback in face-to-face engagement events.

Section three: Background and context

3.1 Drivers for this work

This section of the document outlines the context within which the case for change has been developed, from both a national policy perspective, and covering the local context, such as learning from the pandemic. It will highlight why this programme of work is so important for NCL services and the future outcomes of pregnant women and people, babies, children, and young people that use them.

The NHS Long Term Plan (LTP)

The NHS LTP was published in January 2019, and it set out key ambitions for the NHS over the next 10 years. It outlines clear aims to improve services for pregnant women and people, babies, children, young people and their families. If achieved, these will make a material difference to the outcomes and lives of those that access these vital services. In writing the case for change, we are asking if services are on track to meet these aims, and what more we may need to do to ensure that we achieve them.

The LTP focuses on important clinical areas, which were chosen due to their impact on the population's health and where outcomes lag behind those of other similar advanced health systems. Of all the priorities, a particular need was identified in NCL around the maternity, neonatal and children's priorities, therefore these are the focus for this document.

One of the targets set out in the Long Term Plan is to halve the number of stillbirths, maternal and neonatal deaths and serious brain injury by 2025. There are a range of commitments that it is hoped will support the achievement of this target, such as continuity of care during pregnancy, birth and after birth, increased bed capacity in neonatal intensive care where it is needed, and improved mental health services for pregnant people and women.

The LTP also has an important focus on care for children and young people. It sets out the agenda for the creation of a children and young people's transformation programme, which aims to ensure that their complex and diverse needs are given a higher profile and more attention at a national level. It also highlights the need to improve the quality of care for children with long-term conditions, such as asthma, diabetes and epilepsy through the creation of clinical networks to support the integration of paediatric skills across services. There is also a focus on mental health for children and young people, which we now know to be even more important given the documented impact of the pandemic on the mental health of children and young people.

One key area of focus for the Long Term Plan that is particularly relevant for this case for change is around paediatric critical care and surgical services. The document highlights the need for these services to evolve to meet the changing needs of patients and to ensure that children and young people can access high-quality services as close to home as possible.

Focus on maternity and neonatal services nationally

Better Births was published in February 2016, and it set out a clear vision for maternity services to become safer, more personalised, kinder, more professional and more family friendly. It outlined how every pregnant woman and person should have access to

information enabling them to make decisions about their care, and where they and their baby can access support that is centred on their individual needs and circumstances.

It also called for all staff to be supported to deliver care which is person-centred, working in high-performing teams, in organisations which are well-led and in cultures which promote innovation, continuous learning and break down organisational and professional boundaries.

On a national basis, the work around Better Births has been supported by the National Maternity Transformation Programme and locally this has been delivered through the NCL Local Maternity and Neonatal System (LMNS). Nationally, data shows that there has been good progress made in reducing perinatal and maternal mortality, despite an overall increase in the complexity of care[1].

In England and Wales, the stillbirth rate has fallen by 29% in the ten years from 2010-2020[2] and there has also been a reduction in extended perinatal mortality by 18% over six years from 2013-2019[3]. Maternal deaths, which are a very rare occurrence, are also falling. There has also been improvement in the support for women experiencing mental ill health, with there now being a specialist perinatal mental health team in every local system across England.

We also know that there is so much more to be done to tackle inequalities in maternity care. Nationally, there is a disparity in maternal mortality rates between women from Black and Asian ethnic groups and White women. Research shows that in the United Kingdom, Black women are more than four times more likely than White women to die during pregnancy or up to six weeks after giving birth from causes associated with their pregnancy. This figure is two times higher for mixed ethnicity women and almost twice as high for Asian women[4]. Similarly, we know that rates of stillbirth and infant mortality have been found to be higher in those of Black ethnicity[5]. This is an unacceptable situation for maternity care in this country and action must continue to be taken to address it.

Taking a population health approach, in the Start Well programme, data has been looked at by ethnicity and deprivation, and where the data allows, other protected characteristics. However, it should be noted that data quality issues across the system have meant that not

[1] Better Births Four Years On. A review of progress: 2020. Available online: https://www.england.nhs.uk/wp-content/uploads/2020/03/better-births-four-years-on-progress-report.pdf
[2] Office for National Statistics. Births in England and Wales: 2020. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthsummarytablesenglandandwales/2020#:~:text=Stillbirths,-In%202020%2C%20the&text=For%20a%20fourth%20consecutive%20year,in%202019%20(Figure%203). [Accessed March 2022]
[3] MBRRACE-UK. UK Perinatal Deaths for Births from January to December 2019. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/perinatal-surveillance-report-2019/MBRRACE-UK_Perinatal_Surveillance_Report_2019_-_Final_v2.pdf [Accessed March 2022]
[4] MBRRACE- UK. Saving Lives, Improving Mothers' Care Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2017-19. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf [accessed March 2022]
[5] Office for National Statistics. Births and infant mortality by ethnicity in England and Wales: 2007 to 2019. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/childhealth/articles/birthsandinfantmortalitybyethnicityinenglandandwales/2007to2019 [accessed March 2022]

all outcomes can be viewed through an inequalities lens and has also highlighted the importance of collecting this data going forward.

The Ockenden Report

The Ockenden Report is an independent review of maternity services at Shrewsbury and Telford Hospital NHS Trust, commissioned by NHS England and NHS Improvement in the summer of 2017. It followed the collation of 23 cases of concern by the parents of two babies who died at the Trust in 2009 and 2016 respectively. It went on to review the maternity care received by 1,486 families in 1,592 separate clinical incidents. The size and scale of this review is unprecedented in NHS history. The review of these incidents found that 201 babies and nine mothers could or would have survived if they had received better care. The impact on the lives of the families and loved ones who experienced death or serious complications as a result of maternity care is profound and permanent. The goal of the review was to ensure that the families who had been impacted by the maternity services at the Trust were heard, and that lessons could be learned to ensure no other families have to go through what they did.

The report was published in two stages – the first in December 2020[6], followed by the final report in March 2022[7]. The first report covers a review of 250 cases, and it was published without finishing the full review of all incidents due to the urgency with which action was felt to be needed to improve the safety of maternity services at Shrewsbury and Telford NHS Trust, and to ensure learning was applied across services in England. The initial report identified seven immediate and essential actions to be implemented across all Trusts in England. The final report identified a further fifteen actions, some of which build on the initial actions in the first report.

The final report highlights failures including poor antenatal care for vulnerable pregnant women, repeated failures to correctly assess fetal growth, reluctance to refer women to tertiary centres to address fetal abnormalities, poor management of multiple pregnancies, poor management of gestational hypertension, failure to recognise sick or deteriorating women, failure to act on abnormal fetal heart patterns and failure to escalate concerns.

The report also identifies shortcomings in leadership and teamwork – which were also factors in the findings of a review into the maternity services in Furness General Hospital, Morecambe Bay[8]. In addition to this, the Ockenden Report highlights a culture of bullying and there was a failure identified of the Trust Board to understand the depth of the problems with the maternity service, and to learn from serious incidents.

---

[6] Ockenden Report. Emerging Findings and Recommendations from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust. December 2020. Available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/943011/Independent_review_of_maternity_services_at_Shrewsbury_and_Telford_Hospital_NHS_Trust.pdf [accessed March 2022]

[7] Ockenden Report. Findings, Conclusions and essential actions from the Independent Review of Maternity Services at The Shrewsbury And Telford Hospital NHS Trust. March 2020. Available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1064302/Final-Ockenden-Report-web-accessible.pdf [Accessed April 2022]

[8] The Report of the Morecambe Bay Investigation. March 2015. Available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/408480/47487_MBI_Accessible_v0.1.pdf [accessed April 2022]

Standalone midwifery-led birth centres are cited in a number of the cases of the final Ockenden Report. There are some immediate and essential safety actions for these standalone units to comply with as part of the learning from what was found to have happened at Shrewsbury and Telford NHS Trust.

The outcomes of the Ockenden Report are crucial when considering the purpose of this case for change. The report recognised that many of the issues highlighted are not unique to Shrewsbury and Telford NHS Trust, and that the learning from what happened there must be applied to all maternity services in England.

The report states an urgent, and sustainable, maternity-wide workforce plan is required without delay and this plan should continue into future years. It is essential that all Trusts implement this plan to address the current and future requirements of all staff in and around maternity services. Without a robustly funded, trained and well-staffed workforce, maternity services will be unable to provide high quality and safe care to pregnant women and people, and their families.

This case for change considers how maternity services in NCL comply with the actions set out in the initial Ockenden Report and where opportunities for improvement exist to ensure the achievement of the safest, most equitable and highest quality service possible.

The Neonatal Critical Care Review

Better Births highlighted several challenges facing neonatal medical and nurse staffing, nurse training, the provision of support staff and cot capacity at a national level. It recommended a dedicated review of neonatal services and in response NHS England commissioned the Neonatal Critical Care Review (NCCR)[9]. The resulting review set out the actions required by the local and regional NHS to improve the care of babies and enhance the experience of families. It was published in 2019 and highlighted seven key actions for neonatal care across the UK:

- Review and invest in neonatal capacity
- Develop transport pathways
- Develop the neonatal nursing workforce
- Optimise medical staffing
- Develop strategies for allied health professions
- Develop and invest in support for parents
- Develop local implementation plans

Following the publication of the NCCR, local neonatal operational delivery networks (explained in section 3.4) developed implementation plans to support achievement of the aims set out in the document. Implementation plans have been progressing since the NCCR was published, and significant steps have already been made towards implementation with long-term plan investment across NCL. The themes identified in the NCCR, and the London implementation plan which followed it, have helped to shape the themes in this document.

[9] NHS England and NHS Improvement. Implementing the Recommendations of the Neonatal Critical Care Transformation Review. 2019. Available online: https://www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the-Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf [accessed March 2022]

The impact of COVID-19

On pregnant women and people

Pregnant women and people have an increased risk of severe infection from COVID-19 which could result in more harmful outcomes.[10]

There were further indirect impacts of the pandemic on families who were having a baby. Across all maternity services, there were rapid changes or cancellations to appointments and in some instances restrictive visiting policies. These changes negatively impacted the experience of maternity care, causing uncertainty and distress at a time which can already be stressful.

"I gave birth at Christmas [during the pandemic] and was in hospital for two weeks. I felt that the service was possibly dangerous, and giving birth was delayed due to staff shortages." - Patient focus group, May 2022

Pregnant women and people also faced challenges with establishing social networks – with antenatal classes not being able to meet face-to-face. These types of networks are important for the emotional and mental health support for those having babies.

On children and young people

The full long-term impact of the pandemic on children and young people, and their experience of it at different ages, has not yet been fully established. However, we do know that the physical health impact of COVID-19 on children and young people is much less than on adult members of the population. However, children and young people were significantly impacted by the pandemic and the actions put in place to reduce the number of infections. These impacts include delays in development of early years, impact on speech and language through lack of interaction with peers, disruption to education as a result of school closures, living in overcrowded accommodation with a lack of green space during lockdowns and the impact of the pandemic on the mental health and resilience of children, young people and their families. Studies have found increased levels of distress, worry and anxiety among children and young people, with increased feelings of loneliness and worries about school and the future[11].

Children and young people are likely to be impacted unequally by the pandemic. More deprived children and young people are subject to poorer quality housing, lack of access to outdoor green space and reduced resources for home schooling, and those living in poorer households are already more likely to experience mental health problems[12]. The impact of the pandemic was to widen pre-existing health inequalities. These experiences during the

[10] Vousden N, Ramakrishnan R, Bunch K, et al. Management and implications of severe COVID-19 in pregnancy in the UK: data from the UK Obstetric Surveillance System national cohort. Acta Obstetricia et Gynecologica Scandinavica. February 2022. Available online: https://obgyn.onlinelibrary.wiley.com/doi/10.1111/aogs.14329 [accessed April 2022]

[11] Mental Health Foundation. Impacts of lockdown on the mental health of children and young people. Available online: https://www.mentalhealth.org.uk/publications/impacts-lockdown-mental-health-children-and-young-people [Accessed April 2022]

[12] Social Metrics Commission. Measuring Poverty 2020 A report of the Social Metrics Commission. July 2020. Available online: https://socialmetricscommission.org.uk/wp-content/uploads/2020/06/Measuring-Poverty-2020-Web.pdf [Accessed April 2022]

pandemic are likely to have unequal impacts on the future health outcomes in children and young people in NCL. Section four sets out a detailed description of the population in NCL.

On NHS services

In March 2020, the pandemic was declared a Level 4 incident, with national NHS command and control systems implemented. During 2020/21, NCL's health and care system worked together to oversee the response to the unprecedented challenges presented by the pandemic.

Recognising the challenge of continuing to deliver safe and effective care, several changes were rapidly implemented across NCL. For babies, children, young people, pregnant women and people, this meant some periods of temporary service changes, such as the temporary closure of the home birthing services, temporary closures of the Edgware midwifery-led birth centre and changes to visiting rules for antenatal appointments, for partners and family members during labour and postnatally and also for neonatal units.

The pandemic has also led to a significant challenge in waits for care across secondary and community services and mental health services – both adults' and children's services – due to the necessary pause in non-urgent elective care. Hospitals in NCL are working together in collaborative ways to ensure that children waiting for treatment receive the care that they need as quickly as possible and to tackle some of the long waits for elective care. The extent of these challenges has led to the COVID-19 pandemic being a key driver of the Start Well programme.

Temporary changes to paediatric hospital urgent and elective care services in response to COVID-19

The COVID-19 pandemic placed unprecedented demands on the NHS. In NCL this led to several local service delivery challenges, particularly in relation to maintaining and staffing five separate paediatric sites in highly pressurised and unpredictable circumstances.

The temporary changes occurred at pace and scale, at a uniquely demanding time for staff, and difficult choices were made to maintain safe, quality care. A partnership approach was adopted with NCL organisations working together as an integrated care system, across institutional boundaries.

Temporary changes were implemented at all hospital sites in NCL which deliver paediatric services. This was done to ensure that there was sufficient space for adult patients with COVID-19, to support the release of staff to adult areas to support the response to the pandemic and to create sustainable access to paediatric care, which was delivered through the consolidation of workforce.

The sites involved included, Barnet Hospital, the Royal Free Hospital, UCLH, Whittington Health, GOSH and North Middlesex University Hospital (North Mid). During the changes staff moved between organisations, with services and arrangements put in place at speed to enable staff to work in any of the NCL Trusts. There is an opportunity to utilise these staff sharing opportunities in the future both for service delivery and learning and development opportunities.

The changes took place in phases, consisting of modifications to service provision, including closures of some paediatric emergency departments. The only paediatric emergency

departments in NCL that remained open for the whole of the pandemic period were North Mid and Whittington Health, with UCLH closed for a full year and Barnet Hospital and the Royal Free Hospital both having temporary closures. Despite the closures of these departments there remained a small number of children who continued to access the services. There were clear protocols in place to manage these attendances when they occurred.

GOSH provided inpatient services to all hospitals in NCL at points during the pandemic and much of the inpatient orthopaedic trauma surgery across NCL was diverted to the RNOH.

All paediatric services reverted to their pre-pandemic configuration in April 2021. An overview of the temporary changes and timeline is outlined in Figure 9.

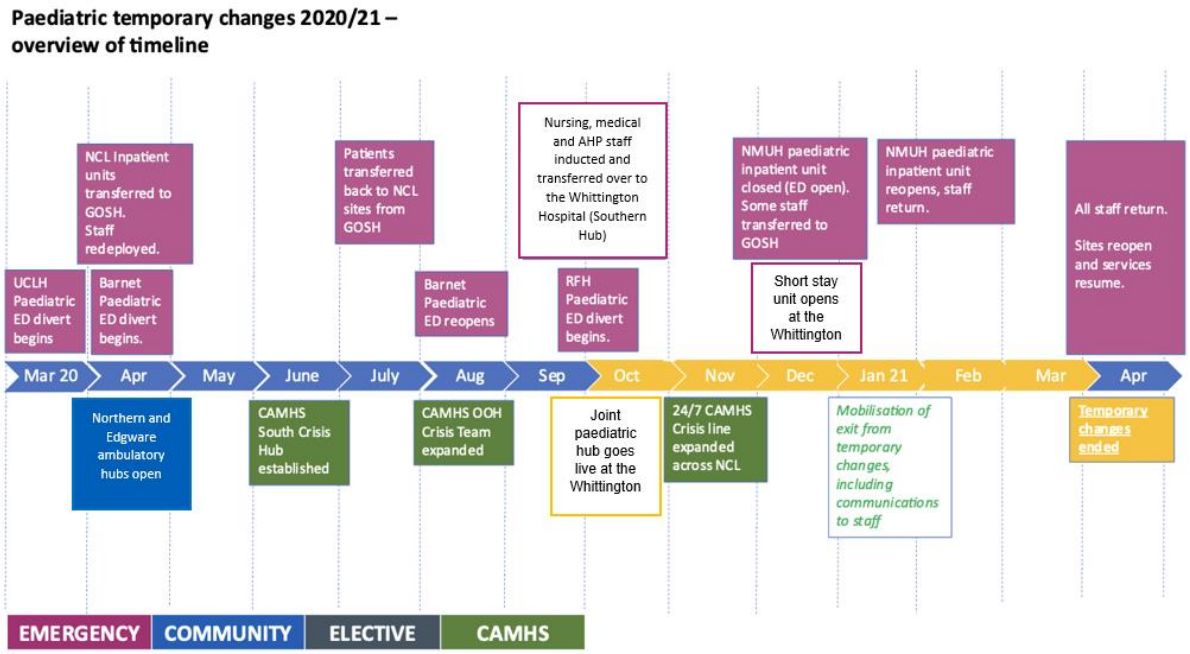


Figure 9: Paediatric temporary changes timeline overview

The impact of the pandemic on system working

An independent evaluation report covering the period October 2020 to March 2021 was published in July 2021 and summarised the changes to paediatric services and system learning, with a focus on the Delta wave of the pandemic[13]. The engagement process that supported the evaluation highlighted that for some clinicians, both individuals and teams, the changes elicited a very strong response and had a significant impact, both personally and professionally.

Learning from the process of the temporary changes was central to the development of the Start Well programme. The programme has drawn heavily on the recommendations from the evaluation about how long-term system change should be planned and managed,

[13] North London Partners. A review of the temporary changes to paediatric services within North Central London over autumn and winter 2020/21. July 2021. Available online: https://conversation.northlondonpartners.org.uk/wp-content/uploads/2021/07/NCL-Evaluation_finalfullv2.1.pdf [accessed March 2022]

including how staff need to be involved and supported to participate in the programme development. The insights from patients and residents gained through the evaluation have also been drawn on in the development of the case for change.

3.2 The North Central London (NCL) context

Working as an Integrated Care System (ICS)

On 1 July 2022, NCL will formalise working as an ICS. Commissioners, providers and local authority partners will work together to form a new statutory organisation, an Integrated Care Board (ICB).

The new organisation will be the culmination of years of partnership working and integration in NCL – through both the Sustainability and Transformation Partnership (STP) and single NCL CCG – which was accelerated through during COVID-19. This will mark the formal shift to an organisational framework which promotes cooperation between organisations at both an NCL and borough level.

The emerging principles informing the work of the NCL ICB are:

- **Taking a population health approach:** we need to continue to develop the way we plan services to reflect the needs of people and communities, acknowledging the wider determinants of health. This will support tackling health inequalities across and within the communities we serve
- **Evolving how we work with communities:** embedding co-design with partners and communities in planning and designing services and developing systematic approaches to communications and community engagement
- **Continued focus on boroughs:** partnership working within boroughs is essential to enable the integration of health and care, and to ensure provision of joined up, efficient and accessible services for residents
- **Learning as a system:** we have learnt a lot as a system over the past 18 months, both with our response to the pandemic and our efforts to recover. Capturing this learning across primary care, social care, community, mental health and hospital services will guide our next steps for both individual services and system approaches
- **Acting as a system to deliver a sustainable health and care system:** providing high quality services enabled by workforce, finance strategy, estates, digital and data

To start life well is one of the core aims of NCL's Integrated Care System; the way we deliver services for pregnant women and people, babies, children and young people can have a lasting impact on the rest of their lives both in the immediate future and for years to come.

The Start Well programme has provided an early opportunity to collaborate as an integrated care system and practically work in a way that is true to the ICB's principles. This document has support from across our Integrated Care System and has been shaped by clinical and operational leaders in our partner organisations, as well as those that use our services.

The local area

NCL covers five London boroughs: Barnet, Camden, Enfield, Haringey, and Islington, with a resident population of around 1.5m people. NCL is extremely diverse, with areas of both affluence and deprivation within each borough. As an ICS, North Central London has strong

place-based partnerships, which will work alongside the ICB as the new statutory arrangements are formalised.

About the Integrated Care System (ICS)

Integrated Care Boards (ICBs) are a key change in the Health and Care Act and will replace Clinical Commissioning Groups from 1 July 2022. The ICB will be the formal statutory organisation bringing the NHS together within North Central London.

The development of the ICS builds on strong foundations; NCL has a track record of close working between partners, NHS, and local authorities, through the Sustainability and Transformation Partnership (STP) and other collaborative programmes of work. In April 2020 the five Clinical Commissioning Groups in North Central London – Barnet, Camden, Enfield, Haringey, and Islington – merged to form one CCG.

NCL has strong partnerships already formed in each borough to support working at a 'place' level, with over 30 primary care networks. Over the last two years, system partners (the CCG, councils, NHS providers, general practices, and voluntary and community organisations) have worked closely together to respond to the COVID-19 pandemic. There has been continued progress towards a more strategic approach to health commissioning at NCL level, and within borough partnerships (explained below).

The geographical location of the hospitals in NCL means that many people who use our services live in areas outside NCL. This includes neighbouring areas such as Hertfordshire to the north, North East London, particularly Hackney and Waltham Forest, and North West London, particularly Brent, Harrow and Westminster. These flows are two-way and some NCL residents will look to access services from providers outside of NCL. Given the number of specialist providers and highly specialised services delivered in NCL, there are also many patients that are treated here from across London and the rest of the United Kingdom.

NCL borough partnerships

Working relationships across the NHS and local government in NCL have developed significantly over the past two years, particularly in terms of the joint work that has happened in response to the COVID-19 pandemic.

There is a shared commitment between NHS and local government to work together through the ICB and place-based partnerships to design integrated care arrangements to meet the needs of our residents and ensure collective focus on the challenges the NHS is facing around elective recovery, financial constraint, recovery from the pandemic, as well as a focus on wider population health issues. There is an opportunity for strengthening the existing partnerships at borough level and to build on the recognition that the wider determinants of health have a huge impact on health and wellbeing outcomes.

As part of the transition to the ICS and formal ICB arrangements, work is ongoing to co-design how borough partnership decision-making will work in practice and where decisions will be devolved to a borough level and where they need to remain within the remit of the ICB. This is an exciting opportunity to develop mature and lasting partnerships across the NHS, local authorities, social care and the voluntary sector that reflect each borough.

Figure 10 sets out the current partnership arrangements at a borough level, the population each borough partnership serves, the number of primary care networks (PCNs) and the number of organisations represented as part of the borough partnership governance arrangements.

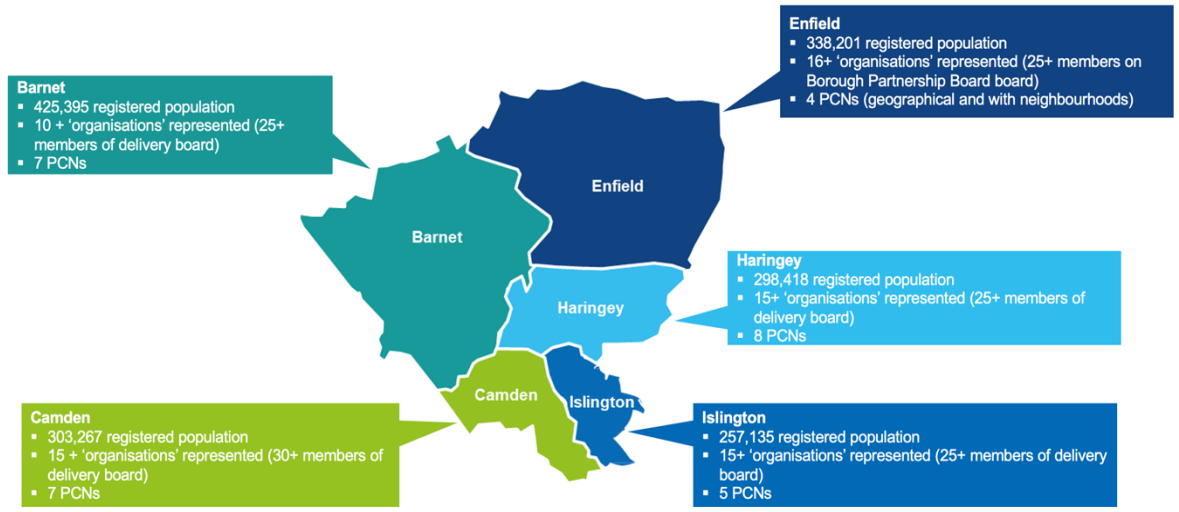


Figure 10: Current borough partnership arrangements in NCL

Priorities for the ICS

All partners within the ICS have come together to agree some overarching strategic aims, with a relentless focus on improving health outcomes and reducing health inequalities. These are split between four areas to enable NCL residents to start well, live well, age well and work well.

Aim- For the NCL population to live better, healthier and longer, to fulfil their potential over their entire life

Start Well	Live Well	Age Well	Work Well
• Every child has the best start in life • All children, adolescents and young people improve their mental health and emotional resilience	• Better prevention and management of long-term conditions • Reduced unemployment levels • Parity of importance between physical and mental health	• People over 65 are independent and live in the community for longer • People over 65 feel less isolated and more socially connected	• The NCL population work in good, inclusive and compassionate environments free from discrimination • The population has a greater wellbeing with an improved work-life balance

Figure 11: NCL ICS priorities

To support its priorities, NCL is committed to taking a population health approach. This is being supported by a population health strategy and outcomes framework to measure progress in our priority areas. NCL is also implementing a population health management digital platform to enable frontline health and care professionals and their care teams to identify gaps in care, unwarranted variation and reduce health inequalities to improve population health.

The ICB as a commissioner of services

Transfer of CCG commissioning responsibilities to the ICB

Commissioning involves deciding what services are needed and ensuring that they are provided to a high quality. The NHS North Central London ICB will be responsible for allocating NHS budget and commissioning services. The ICB will take over responsibility for the commissioned areas managed by the CCG, including most of the NHS hospital, community, and mental health services for our local area. The ICB will also be responsible for the commissioning of primary care and GP services, including responsibility for monitoring their quality and performance.

Devolution of specialised commissioning

With the formation of Integrated Care Boards covering services provided to populations of around 1.5 million or more, from April 2023 many services that were previously commissioned centrally by NHS England are due to the Integrated Care Board.
The intended benefit of devolution is to enable an increased focus on the end-to-end pathway from prevention and early intervention through to tertiary services, which would allow health and care systems to focus on providing seamless and equitable access to high quality services to improve health outcomes and reduce health inequalities.

Shadow arrangements will be put in place over the course of 2022/23 to oversee the transfer and to allow a period transition to the new arrangements. At the time of writing, the list of services to be devolved has just been published and is still subject to change. Devolution of specialised services is likely to include clinical areas such as neonatal and cancer services. Highly specialised services, which are used by a small number of patients each year, will remain centrally commissioned, although with a focus on greater collaboration between NHS England and local ICBs in their delivery. Additionally, aspects of delegated specialised services will remain nationally prescribed, such as the production of service specifications and agreeing performance standards, as this will ensure patients receive equitable care wherever they live.

As the roadmap for specialised services delegation and the services to become delegated become clearer, this process will be an important consideration for the Start Well programme, to enable integration of specialist secondary and specialist hospital services within end-to-end pathways of care.

NCL Green Plan 2022 - 2025

Sustainability is extremely important to the NHS, and the impact of emissions and climate change has a direct impact on the health of our population. It is estimated that the NHS is responsible for 4% of the England's carbon footprint; it is therefore imperative that the NHS works towards greater sustainability. A national target has been set for the NHS to become net-zero by 2040. NCL has implemented a 'Greener NCL' programme set out in a Green Plan, which details how the system will achieve the net-zero target. The Green Plan was co-produced with Trust teams and sustainability leads, and its objectives are to:

- Deliver better, more sustainable healthcare, improving health outcomes and reducing emissions
- Improve health and address reduce inequalities

- Prioritise activity which is having an impact on our communities and local environment, such as transport

As part of meeting these overall objectives, some specific targets have been set by the Greener NCL Programme Board, such as eliminating all carbon from heating and water use in NHS buildings by 2030, and carbon neutral staff, patient and visitor travel by 2028.

3.3 Providers of acute NHS services in NCL

The NHS currently delivers maternity, neonatal, and general and specialist paediatric care at 10 separate NHS sites within NCL. This section provides a broad overview of these providers and services.

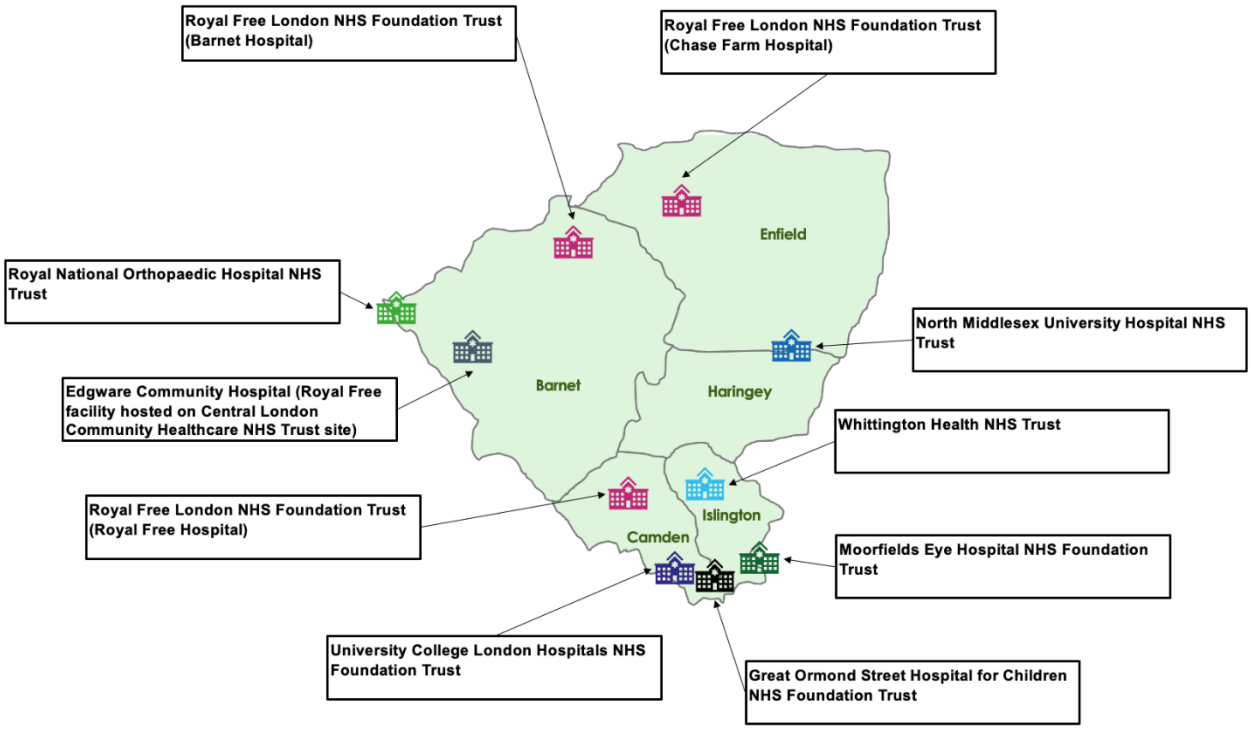


Figure 12: Acute providers in NCL

Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH)

Based in central London, close to Russell Square and Euston, GOSH is a specialist tertiary and quaternary centre providing local, regional, national, and international care for neonates, children, and young people. The hospital provides planned care and takes planned emergency transfers within its areas of specialism. It does not have a maternity unit, emergency department (ED), or ambulatory care unit.

GOSH has a strategic ambition to define more clearly how it can contribute to local care pathways for children and young people within NCL and how this aligns with its specialist practice. The Start Well programme will cover the intersection where GOSH services meet those provided by local NCL Trusts and where GOSH plays a key role in delivering local NCL paediatric care and pathways, especially for surgical and intensive care.

The GOSH neonatal intensive care unit has 10 cots and provides the most specialist support to babies with serious medical and surgical conditions that require intensive care support, such as bowel obstruction requiring surgery or persistent pulmonary hypertension. Given the specialist nature of their neonatal service, the GOSH unit looks after babies from across

London and the country, as well as NCL. GOSH works closely with UCLH, with some women and pregnant people giving birth at UCLH so that there can be a swift planned transfer after birth of a very sick baby to the team at GOSH.

GOSH has a 17 bedded, level three paediatric intensive care unit, which serves not only NCL, but London and beyond.

The geographical proximity to UCLH means that there is very close working between the two organisations for both neonatal and paediatric care. There are many clinicians who work across both sites, and situations where responsibility for care is shared between the two hospitals. Specialities for which there is a lot of joint work include oncology, rheumatology and endocrinology. For some specialties GOSH support the management of children up to the age of 13, and then the child may transition to the specialist teenage and adolescence service at UCLH.

Specialist regional, national and international services at GOSH, for example specialist cardiology, neurology and neurosurgery, are not within scope of the Start Well programme, and neither are cancer services.

North Middlesex University Hospital NHS Trust (North Mid)
Situated in Enfield and serving the most diverse and deprived catchment area in NCL, North Mid provides hospital care and community services for patients living predominantly in Enfield and northern Haringey.

The maternity services at the site deliver around 4,500 babies every year at both the obstetric unit and midwife-led birthing centre. The team also supports home births. The neonatal unit has 24 commissioned neonatal cots and is designated as a local neonatal unit (level two). The unit has strong links with East London, and the agreed pathway for babies requiring step-up care into a NICU (level three) is to be transferred to the Homerton Hospital in Hackney.

North Mid is the busiest emergency healthcare provider for children and young people in NCL. Its ambulatory care unit is a nine bedded short stay ward adjacent to the paediatric emergency department, looking after children for up to 48 hours. Within the ambulatory care unit, the North Mid also run a paediatric assessment unit (PAU), which is a 24/7 facility for the assessment and treatment of children who require care from home or need to stay longer after an emergency department visit.

There is one longer-stay children’s ward with 16 beds. The hospital has no commissioned dedicated high dependency unit (HDU) beds; however, provision can be flexed if required to provide high dependency care nursing levels on the ward.

Due to the high emergency flows within the Trust, it offers only a small number of planned surgical pathways, although it does carry out a larger number of emergency operations. Many children and young people in the North Mid catchment area will therefore be referred to other Trusts, such as UCLH or Barnet for ENT, for planned surgery.

Specialist paediatric medical services at the Trust include HIV, blood disorders, diabetes, sickle cell and thalassaemia, very much reflecting the population need within its catchment area. The Trust also provides dedicated community services for children and young people in Enfield, including health visitors and school nurses.

Moorfields Eye Hospital NHS Foundation Trust (Moorfields)
Moorfields is a leading provider of eye health services nationally, regionally and locally, for both children and adults. It is an international centre for ophthalmic research, education and advanced clinical practice.

The Richard Desmond Children's Eye Hospital at Moorfields Eye Hospital, based at the main Moorfields site on City Road in Islington, offers care for children and young people up to the age of 16, providing outpatient consulting rooms, a day care ward and a children's emergency department (open weekdays 9am to 4pm). Out of hours children and young people are seen in a dedicated area of the main emergency department on the City Road site.

There are close working relationships between Moorfields and GOSH ophthalmology teams, with some shared or joint appointments between the two organisations for several ophthalmology pathways. Discussions have started on how this relationship can be further strengthened for patient benefit, ensuring that we make the most of having two world-leading Trusts within our local system.

Virtually all Moorfields' surgery takes place on a day-case basis, meaning that the hospital has very few overnight beds and no beds for children and young people. Children requiring a planned overnight stay prior to surgery will normally be admitted overnight at GOSH and then be transferred to have their surgery at Moorfields, although this pathway is rarely used. If a child needs an unplanned stay post-operatively, a bed will be secured in liaison with neighbouring Trusts and a transfer will be arranged.

Following the outcome of a public consultation in 2019, Moorfields Eye Hospital (City Road site), including its paediatric services, will move to a new integrated hospital and national research facility in 2025/26 on the St Pancras site, just behind Kings Cross in Camden. Building for this £250m new development is scheduled to begin in autumn 2022.

Royal Free London NHS Foundation Trust (the Royal Free)
The Royal Free is a single Trust managing a group of hospitals, including four sites where maternity, neonatal, children and young people's services are delivered within NCL: Barnet Hospital, Chase Farm Hospital, Edgware Community Hospital and the Royal Free Hospital.

Barnet Hospital

Barnet Hospital is in the north of the borough of Barnet and was built just over twenty years ago. It has a wide catchment area and significant inflows of patients from neighbouring Hertfordshire, as well as serving the local population of Barnet and north Enfield.

Every year round 5,400 babies are born at Barnet Hospital, making it one of the busiest maternity units in NCL, with both a 13-room obstetric led delivery suite and a co-located birth centre with five suites and three birthing pools. The Starlight neonatal unit on the site has 30 cots and was one of the first units in the country to have special single rooms enabling parents and their babies to stay together 24 hours a day.

Barnet Hospital operates as a predominantly emergency hospital for both adults and children. It has one paediatric ward with 20 beds. An ambulatory care unit, open from 9am to 10pm, and linked to the paediatric emergency department provides assessment and

treatment of children who need to stay longer after an emergency department visit for observation or medications.

The hospital has no dedicated paediatric high dependency beds, however provision can be opened if required to provide high dependency care nursing levels on the paediatric ward.

Due to the high emergency flows, Barnet does not offer many planned surgical pathways. The exception to this is ENT and oral maxillofacial surgery in children, where Barnet Hospital is a major provider within NCL.

Barnet offers a range of paediatric medical specialities, with the highest volume clinics being general paediatrics and allergy, as well as offering medical specialities such as diabetes.

Chase Farm Hospital

Chase Farm Hospital in Enfield provides planned paediatric medical and surgical outpatient services, predominately to Barnet and Enfield.

Chase Farm Hospital hosts antenatal clinics on its site, run by the Royal Free London midwifery team. There are no neonatal services on site.

Day surgery is provided to young people over the age of 16 for a limited range of conditions with special arrangements made to meet safeguarding and other requirements for the care of teenagers and young adults. A typical example would be a 16-year-old with a sports related knee injury requiring specialist orthopaedic care.

Chase Farm also hosts a children and young people's urgent care centre for minor ailments and injuries, open from 8am to 9pm. Cases that cannot be managed at the urgent care centre because they are too complex are transferred or re-routed to Barnet Hospital paediatric emergency department or to the North Mid, depending on where the child or young person and their family live.

The Royal Free Hospital

The Royal Free Hospital, based in Belsize Park, Camden, offers both general and specialist tertiary care, with a particular focus on providing regional and national liver transplants, kidney and infectious disease care for adults alongside a teaching and research practice. Children and young people's services are predominately provided to a local catchment area in North Camden and South Barnet, however there are also inflows from neighbouring boroughs, such as Brent.

The Royal Free Hospital has both obstetric and midwifery-led units on its site and there are around 3,000 deliveries at the hospital every year. The hospital also has a neonatal unit, which is classified as a special care unit (level one). This unit looks after a relatively small number of babies every year (237 in 2020/21), with babies that need higher acuity care being transferred to other units in NCL when it is needed.

The hospital provides general and specialised paediatric medical and surgical services in both outpatient and inpatient settings. It has a dedicated, recently refurbished paediatric emergency department offering a range of different services. There is an ambulatory or short stay unit with 10 beds, however this is for planned care only and it does not take admissions

directly from the paediatric emergency department. There is also a longer stay inpatient ward of 20 beds. The hospital has no dedicated HDU beds, however provision can be flexed if required to provide high dependency care nursing levels on the main paediatric ward.

A particular area of specialism within the Trust is plastic or reconstructive surgery, for which the Royal Free Hospital is the specialist centre for both adults and children in North Central London. Children requiring plastic or reconstructive surgery, for example a lip laceration, will be referred by other hospitals in NCL. This is often an emergency pathway, with a child or young person treated for their immediate injury at their local hospital's paediatric emergency department and then asked to attend for surgery at the Royal Free Hospital the next day, often via the ambulatory care unit. If the injury requires immediate surgery, the child or young person will be admitted to the main paediatric ward, via the Royal Free Hospital paediatric emergency department.

Edgware Community Hospital

Edgware Community Hospital is a site in Barnet, managed by Central London Community Healthcare Trust, which hosts a range of services provided by different NHS organisations. The Royal Free London has some outpatient services there, in addition to a birth centre.

Royal Free London manages a standalone midwifery-led birth centre at Edgware Community Hospital. This has a relatively low annual number of births; in 2019/20 there were 73 deliveries in the birth centre. It is staffed by midwives from Royal Free London and is used as a centre for antenatal appointments for those booked to deliver their babies at Edgware Birth Centre or Barnet Hospital.

Royal National Hospital Orthopaedic Hospital NHS Trust (RNOH)
Based in Stanmore, the RNOH is a highly specialist orthopaedic hospital providing neuro-musculoskeletal care to both children and adults. It is recognised as a national centre of excellence for the treatment of acute and chronic neuro-musculoskeletal conditions in children and young people. Many of the patients using these services have profound physical, mental and syndromic disability.

The Trust provides planned care, in both medical and surgical services and therefore does not have an emergency department or ambulatory care unit. It does not provide any maternity or neonatal care.

Specialist regional, national, and international services such as paediatric spinal surgery and limb lengthening are out of scope of the Start Well programme. The RNOH provides a permanent level two paediatric HDU to support its specialist work. The Trust has several shared pathways and joint appointment to support its specialist work; with UCLH around cancer pathways and with GOSH around specialist orthopaedic pathways of care.

Although RNOH predominantly provides highly specialised care, some local pathways are in place for more routine orthopaedic care for children and young people and it is this intersection that is referenced within this document.

University College London Hospitals NHS Foundation Trust (UCLH)
UCLH is one of the largest NHS Trusts in the UK and provides local, regional and national acute and specialist services based across several hospitals in Central London. Maternity,

neonatal, and paediatric services are delivered from the University College Hospital site (UCLH) on the corner of the Euston Road and Tottenham Court Road in South Camden.

Over 6,000 babies are delivered each year at the Elizabeth Garrett Anderson Wing of UCLH, which is the maternity and neonatal centre for the Trust. The Wing has both an obstetric-led labour ward and a midwife-led birthing centre which includes two birthing pools. It also provides a home birth service. The co-located neonatal unit is a highly specialist neonatal intensive care (level three) unit with 33 cots, 21 of which provide high dependency care. In total over 700 of the sickest and most premature babies are treated in this unit every year.

UCLH is the lead provider for Maternal Medicine within NCL and provides many specialist maternal medicine services for pregnant women and people with cystic fibrosis, liver disease, and severe asthma. As a result of their specialist services, UCLH serve the local NCL population, alongside those from other parts of London and nationally. UCLH is a specialist fetal medicine centre and has one of the only fetal surgery services in the UK which offers treatment to some babies found to have spina bifida while still in the womb.

UCLH works closely with GOSH, with some pregnant women and people giving birth at UCLH so that there can be a swift planned transfer after birth of a very sick baby to the team at GOSH for surgery or other specialist medical interventions.

Compared to overall activity, UCLH has a relatively small paediatric emergency department and a six bedded, 24 hour 7 days a week, same day emergency care unit (SDEC) co-located on the ward, which allows timely treatment and investigation of short stay emergency presentations and speciality referrals. This protects flow through the emergency pathway, reduces admissions and length of hospital stay and minimises infection risk to staff and patients. Children and young people are admitted for both planned and emergency care to three wards in the main hospital tower with 41 beds.

The hospital provides a range of specialist and general services for children and young people, covering all ages, with a particular specialism in caring for teenagers and young adults. The trust has one of the largest adolescent services in the country, with a team of specially trained staff; as a result, it takes referrals not just from local NCL boroughs, but from London and beyond.

The close geographical proximity with GOSH means that there is very close working between the two organisations, with many joint or shared appointments; for a number of pathways – including oncology, endocrinology and rheumatology – GOSH will manage children up to 13 and they will then transition into the specialist teenage and adolescent services at UCLH.

The hospital also provides a range of specialist paediatric surgery for ENT, dentistry, urology and gynaecology.

Established level 2 paediatric HDU care is available to support the teenage and young adult practice (over 13 years old). The hospital currently has no dedicated HDU beds for children under 13 years of age, however provision can be flexed if required to provide high dependency care nursing levels.

Whittington Health NHS Trust (Whittington Health)
Based in Archway close to the boundary of Islington and Haringey, Whittington Health provides integrated hospital and community care services to people living in Islington and Haringey, including services for children and young people and some community services to other boroughs, including Barnet, Enfield, and Hackney.

The service provides care to a diverse population and has some specialist maternity services, such as for those who have been subject to female genital mutilation. Whittington Health has a fetal medicine service for high-risk pregnancies, specialist clinics for those with pre-existing health conditions and a bespoke twin clinic.

Every year around 3,500 babies are born at the Whittington Hospital, either in the obstetric-led delivery suite which has seven labour rooms, two of which offer birthing pools or in their five-room midwifery-led birthing centre, of which four rooms have birthing pools. The team also supports home births.

The hospital also has a neonatal critical care unit which is classified as a local neonatal unit (level two) with 23 cots. Whittington Health has a community outreach neonatal team who are able to deliver care to babies in the local area for conditions that may otherwise have required an admission, such as phototherapy for jaundice.

The children's emergency department is supported by an ambulatory care unit which aims to avoid unnecessary admissions by allowing children and young people to be observed for longer periods of time than is possible in the emergency department. It enables children to come back in a planned way for IV antibiotics, rather than waiting in hospital or being admitted. For longer stay admissions, children and young people are admitted to the main 23 bedded children and young people's ward. The hospital has no dedicated HDU beds; however, provision can be flexed if required to provide high dependency care nursing levels the ward.

Providers of other NHS services (community and mental health)

There are a number of providers of mental health services in NCL who deliver care across the geography. These are: Barnet Enfield and Haringey NHS Mental Health Trust, Camden and Islington NHS Foundation Trust and the Tavistock and Portman NHS Foundation Trust.

There are five providers of community care in NCL, these are Barnet Enfield and Haringey Mental Health Trust, Central London Community Healthcare NHS Trust, Central and North West London NHS Foundation Trust. Whittington Health NHS Trust has a large community service, and North Middlesex University Hospital NHS Trust provides some community services in Enfield.

There are also two standalone walk-in centres in Barnet, one in Finchley and one in Edgware. These are both managed by Central London Community Healthcare NHS Trust.

3.4 Regional Networks

North Thames Paediatric Network
The North Thames Paediatric Network (NTPN) is an NHS-funded group of operational delivery networks and strategic workstreams that focuses on improving and streamlining children and young people's services and pathways. The Network is hosted by GOSH and represents 25 hospitals across the North London area – from North East London, through North Central and into North West London – and includes all NCL organisations.

The Network has representation from across all organisations and has a clear vision to function as a virtual children's hospital, so that every child in any hospital gets access to the best high-level care possible. It currently covers a range of specialities including surgery, gastroenterology, dentistry, respiratory, cardiac, oncology and a focus on transition across all specialities.

Working collaboratively across organisational boundaries, the Network works to develop cost-effective, new models of paediatric specialist care that are planned around children and young people's care needs.

The Network supports patients, families, clinicians, and organisations by providing access to specialist resources, education, and expertise. It helps to deliver improvement programmes, co-ordinating patient pathways and providing objective data to support best practice reflective of national and international guidance. The Network has been key in driving new models of care.

The London Neonatal Operational Delivery Network
Neonatal services across England are organised into Operational Delivery Networks (ODNs). For London, there is a single ODN covering the whole capital, which is hosted by Guys and St Thomas' NHS Foundation Trust. The ODN brings together neonatal providers, NHS England, regional maternity leads, parent users and commissioners to improve outcomes and reduce variation in service delivery.

The aims of the Network are:

- For mothers and babies to receive the care they need, as close to home as possible
- To promote and share best practice
- To give families consistent and high-quality information and support, and involve them in the care they receive

The ODN has had a key role in developing, supporting, and having oversight of neonatal services in London, and has been leading on many aspects of the implementation of the NCCR, which is described in section 3.1.

Section four: Our population

NCL has a diverse population which is younger than the national average. There are high levels of deprivation in some areas, and of integrated care systems, NCL has the second most deprived population in London. Deprivation is associated with health inequalities, and some ethnic groups experience poorer health outcomes. The direct and indirect impacts of COVID-19 have starkly highlighted the disparities in health between different parts of the population. The diversity of our local communities and their different cultures means that they may have different health needs and may want to access services differently.

Understanding the different characteristics and underlying health needs of different communities, and where there are differences between them, is critical in ensuring we plan and deliver services to meet these needs, improve health outcomes, and reduce health inequalities. The following section outlines the population demographics, health needs and variation in needs of pregnant women and people, babies and children, and young people in NCL.

4.1 Pregnant women and people

Over a quarter of the NCL population is currently women of childbearing age, defined as those aged 14-49 (403,000). By 2041, this number is expected to increase to 412,000, is in line with the expected growth of the total population of NCL, which is expected to grow from 1.5 million to 1.7 million people.

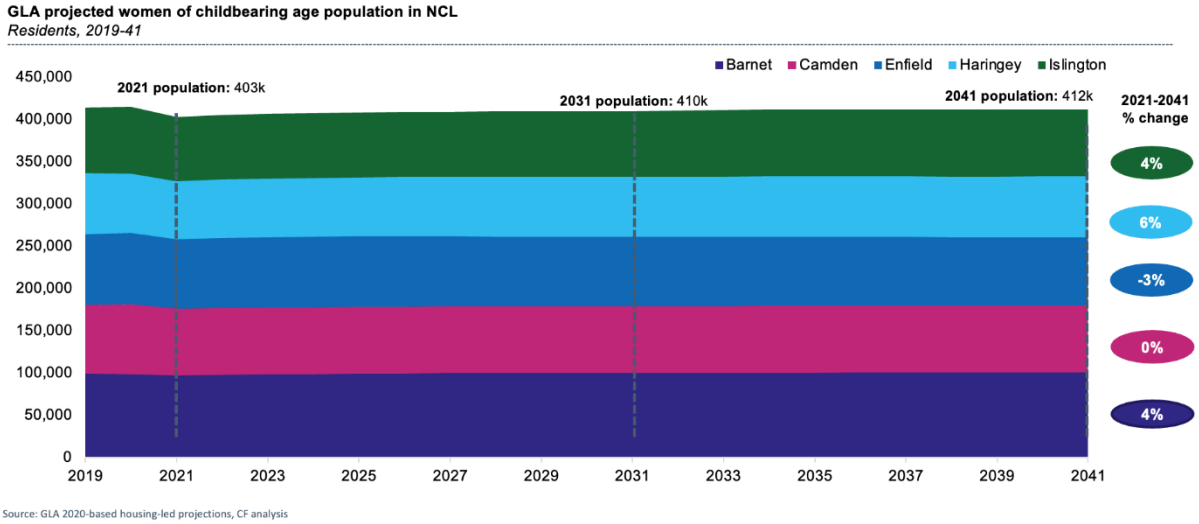
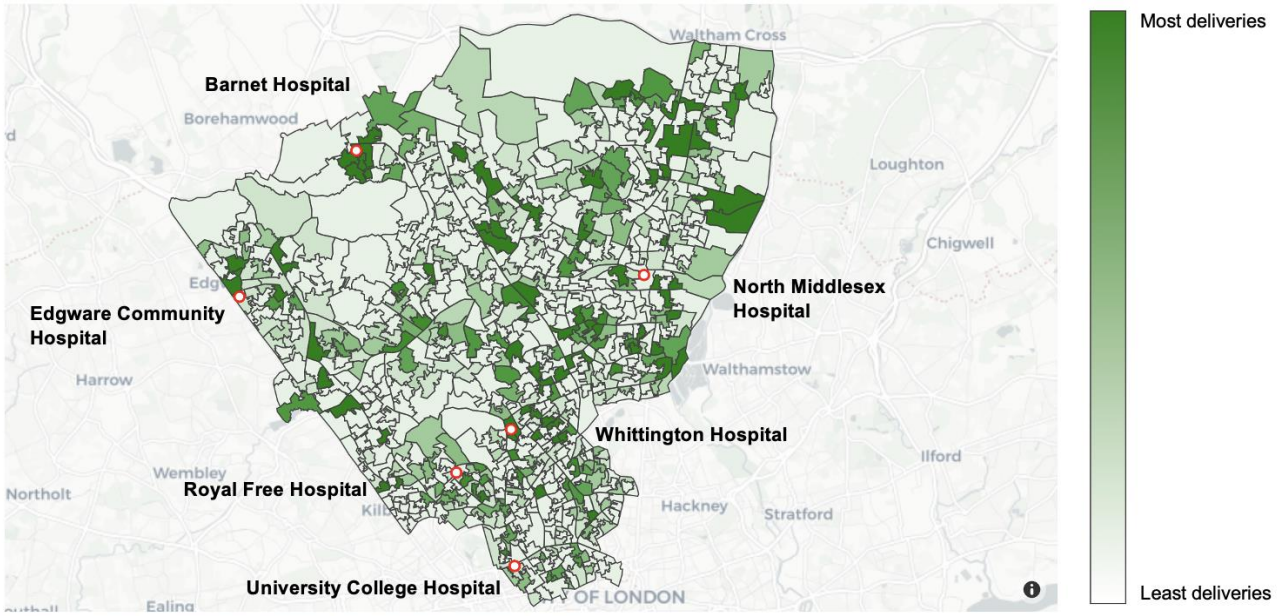


Figure 13: GLA projected women of child bearing age population in NCL (to be updated with more recent census results)

The number of live births in NCL has been declining across all boroughs. In 2020, there were 17,000 live births, compared to 18,800 in 2018. Since 2018, the number of live births has declined by 10% and this is projected to continue to decline. There are more children being born within the more deprived areas of NCL: between 2018 and 2020, there were more than three times as many births in the 20% most deprived areas compared to the 20% least deprived areas. Over half of all births in NCL in 2019/20 were in the 40% most deprived areas.

Deliveries in NCL

Total deliveries by LSOA in NCL, 2019/20



Source: HES data, GLA population estimates, ONS population estimates, CF analysis

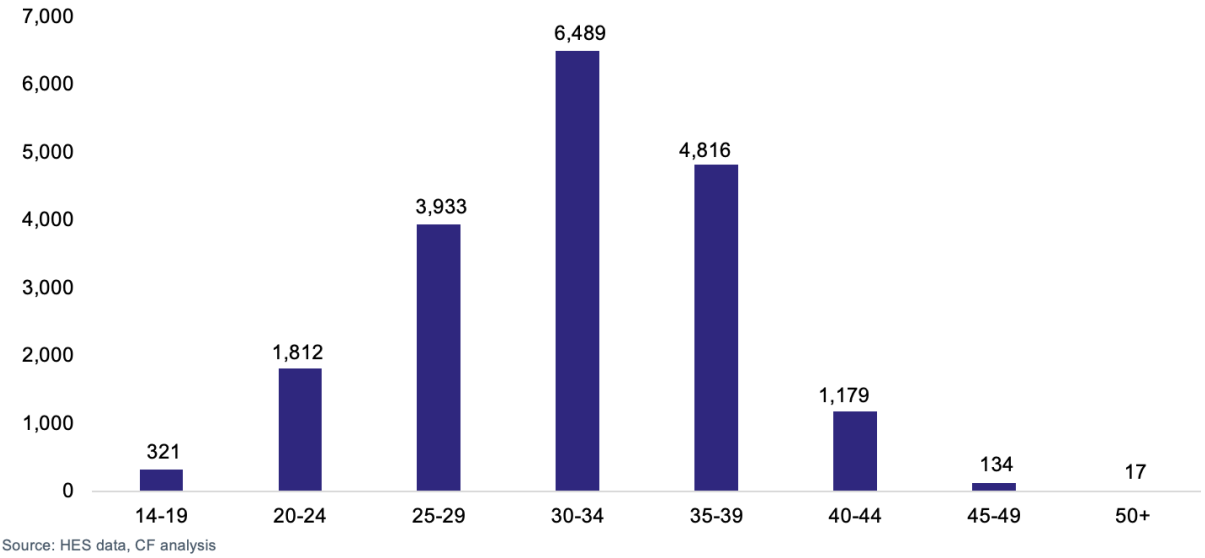
Figure 14: Map of deliveries in NCL

Despite total numbers of births being higher, birth rates are generally lower for the more deprived populations in NCL compared to the less deprived populations. This is because the more deprived areas have larger populations, which leads to a greater number of total births. Birth rates are also significantly lower, on average, in the inner London boroughs.

The teenage pregnancy rate in NCL is comparatively low compared to the England average. At the other end of the age spectrum, 7% of women and people who give birth are over the age of 40 (Figure 15).

NCL CCG commissioned deliveries by age band

Delivery episodes, 2018/19



Source: HES data, CF analysis

Figure 15: Deliveries by age band for NCL commissioned activity

There are differences in birth outcomes in different areas of NCL. The still birth rate in Enfield and Haringey is significantly higher than the London average, with Haringey having the highest still birth rate in England with 68 still births in 2018-2020. Rates of still birth are 55% higher in the 20% most deprived areas of NCL compared to the 20% least deprived. Furthermore, in 2020, 8.9% of babies born in Enfield weighed less than 2.5kg – a low birth weight – which is significantly higher than the England average of 6.9%.

Evidence suggests there is a strong relationship between social determinants of health and poor maternal outcomes, including an increased risk of maternal death. Women living in difficult social circumstances tend to have worse maternal health outcomes compared to the general population. This can be driven by several factors, including pre-existing health conditions such as obesity, use of substances such as alcohol and tobacco during pregnancy, deprivation, living in temporary accommodation and those at risk of abuse[14].

Complexity during pregnancy and increased risks to the baby can be caused by several factors, including the age of the mother, lifestyle factors and pre-existing health conditions such as diabetes and obesity. One in 20 pregnant women and people are smokers at the time of delivery in NCL. Enfield and Haringey have the highest percentage of mothers that are classed as smokers at the time of delivery, at 7.9% and 6.3% respectively. 7.8% of mothers in the 40% most deprived areas are smokers at the time of delivery, compared to 3% of mothers in who live in the 40% least deprived areas (Figure 16).

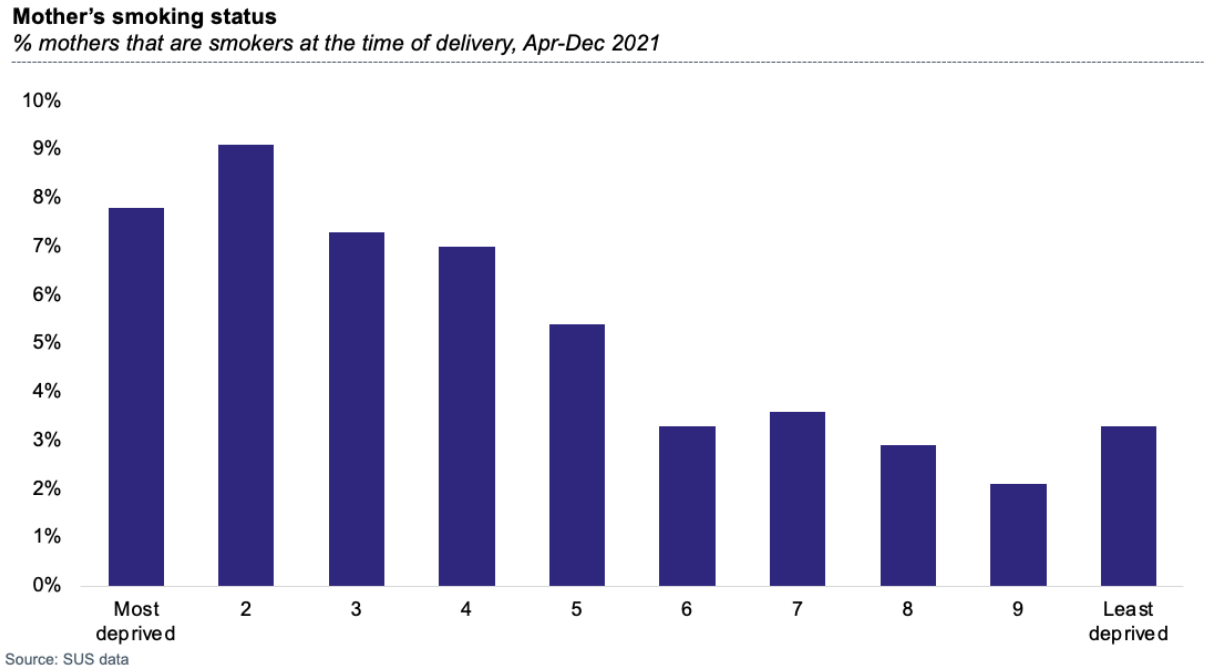


Figure 16: NCL Mother's smoking at the time of delivery

There are ethnic inequalities in the prevalence of long-term conditions in pregnant women and people in NCL. For example, twice as many Black pregnant women had obesity in 2020/21 compared to white women (24% vs. 12%). Black and Asian pregnant women are significantly more likely to have diabetes than the NCL average with more than twice as many Asian pregnant women having diabetes compared to white women (21% vs. 9%) (Figure 17).

[14] https://www.rcog.org.uk/sip67

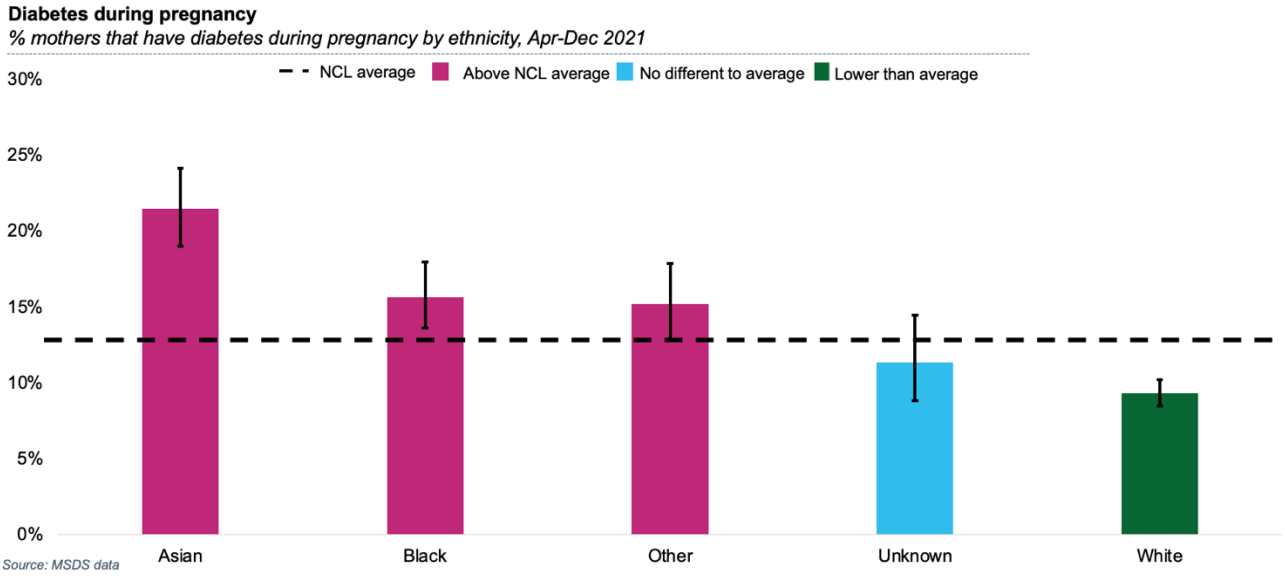


Figure 17: Diabetes during pregnancy by ethnicity

Similar differences are seen for other long-term conditions during pregnancy, with the percentage of Black women in NCL who are obese being significantly higher than the NCL average. Higher levels of deprivation are also strongly associated with obesity and diabetes. Pregnant women in the 20% most deprived areas have a higher prevalence of obesity (Figure 18) and diabetes compared to the NCL average.

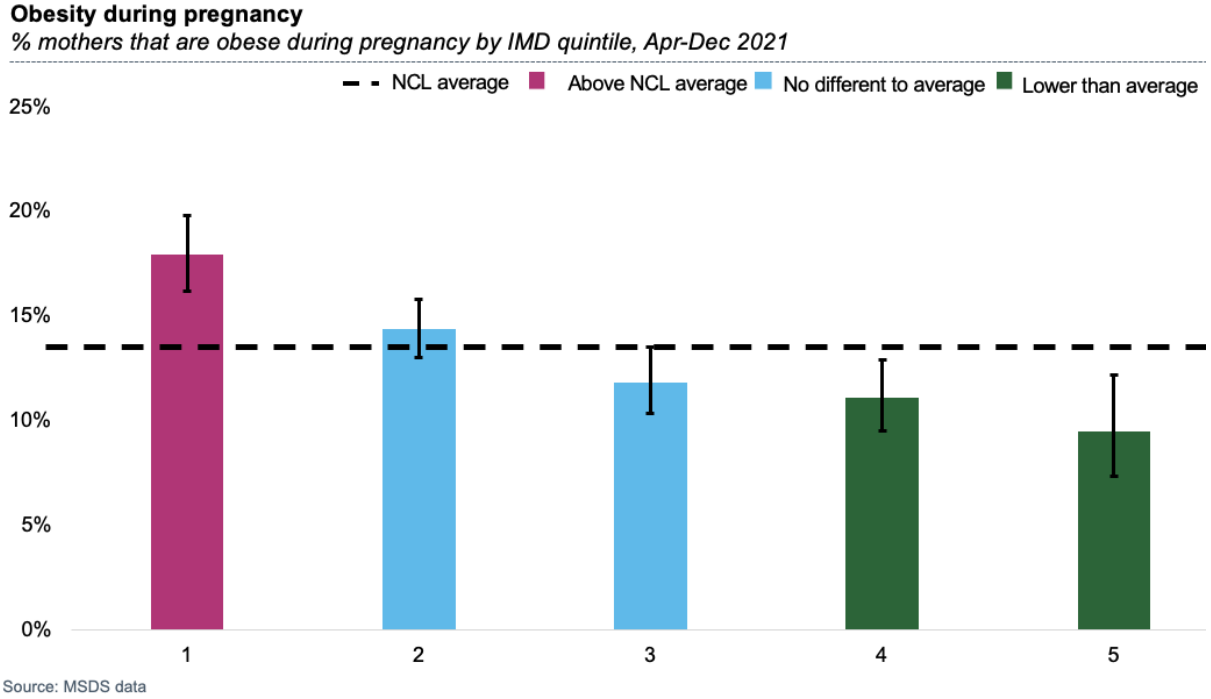


Figure 18: Obesity during pregnancy by deprivation

There is clear intersectionality between ethnicity and deprivation, with some ethnic groups more likely to be living in the most deprived areas. It is not possible to unpick the relative contributions of ethnicity or deprivation using these data, or to quantify any additional negative impacts on health from being from a minority ethnic group. This intersectionality is covered in more detail in section 8.2.

4.2 Children and young people

Around 21% of NCL's 1.5m residents are children and young people, defined as those aged 0-18 (317,600). By 2041, the population is projected to decline by 10%. Between 2018 and 2020, there were 90 deaths in children and young people in NCL, which is similar to the national death rate. Most of these deaths were from cancer.

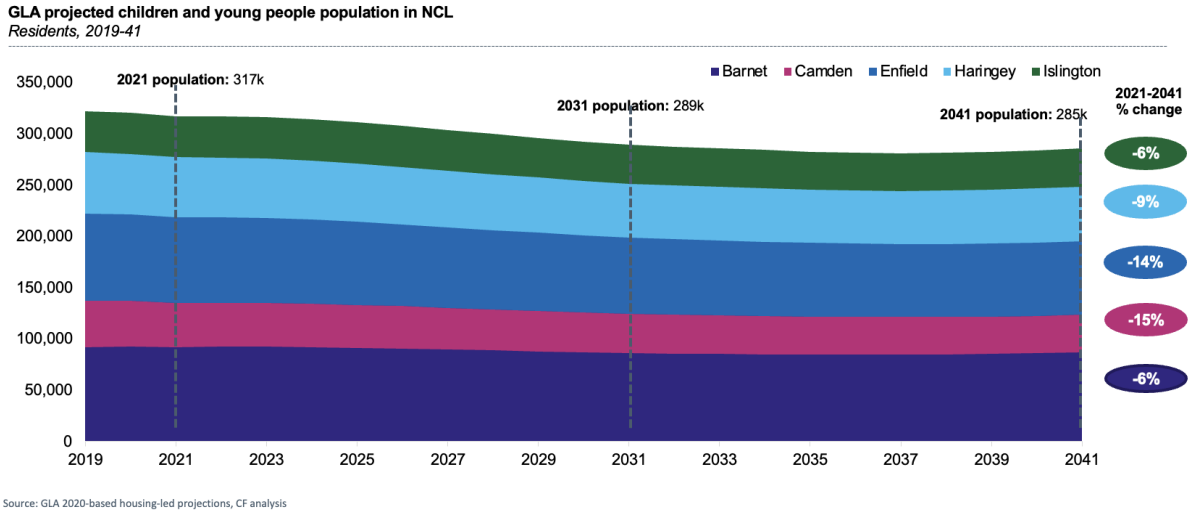
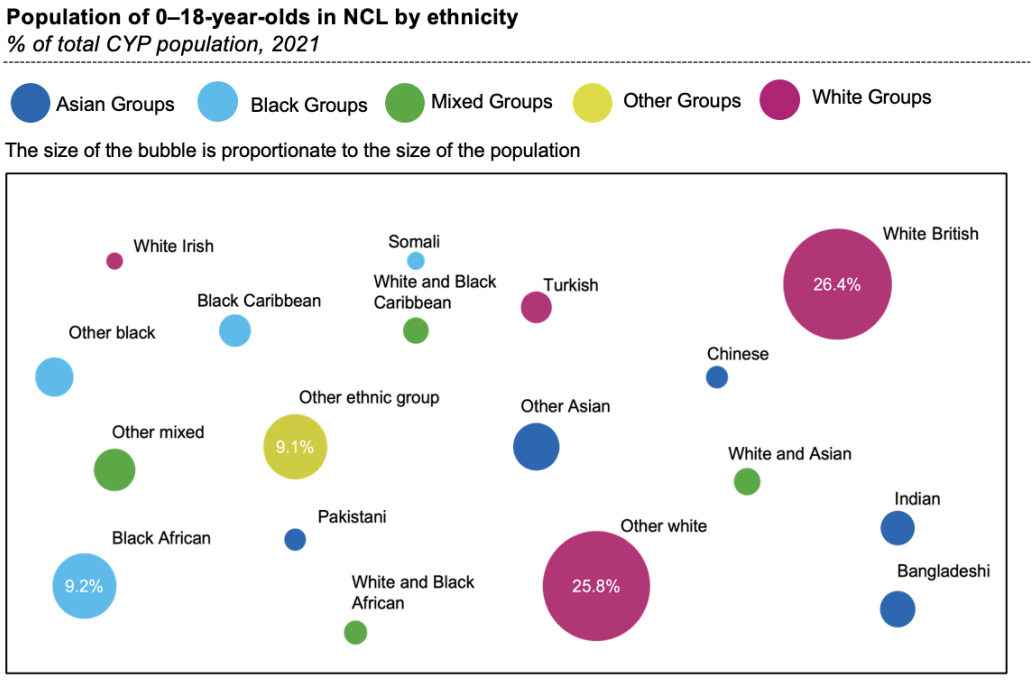


Figure 19: GLA projected children and young people population in NCL

Children and young people in NCL are particularly diverse; just over a quarter identify as white British, a quarter as white other and 10% as black African (Figure 20). One in five children do not speak English as their first language at home.



Source: Patients registered to NCL GP practices (Source PDS). Ethnicity data derived from local GP data flows, GPDPR and SUS , CF analysis

Figure 20: NCL children and young people population by ethnicity

An estimated 62,000 children and young people under 16 years in NCL are living in poverty. The eastern border of NCL in Enfield, Haringey and Islington generally has a high level of

deprivation, with the western areas of Barnet and Camden generally being the least deprived (Figure 21).

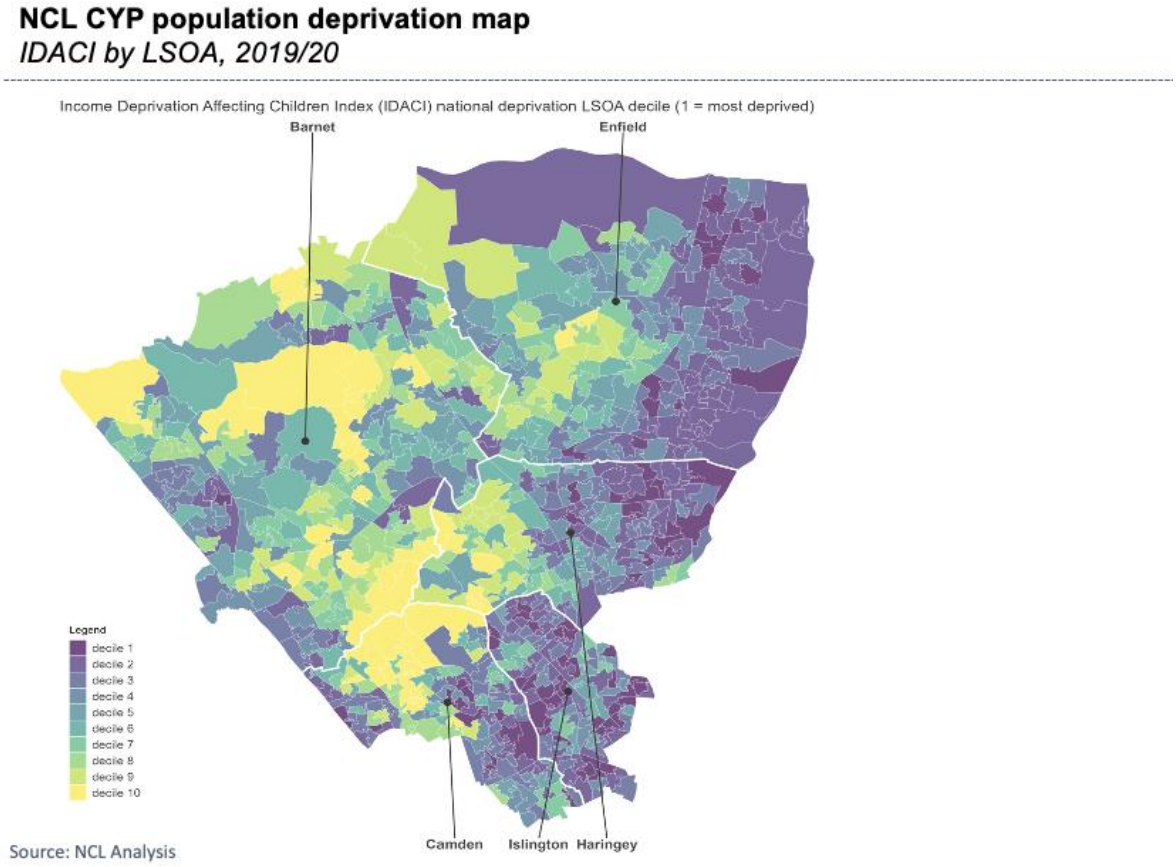


Figure 21: Map of income deprivation by IDACI decile

Islington has the highest percentage of children living in poverty in London, at 25%. Within certain pockets of Islington and Haringey, nearly half of the children live in an area that is income deprived. In Barnet, Camden and Enfield, there are small areas with nearly 40% of children living in poverty. Although Haringey and Islington have areas which have the highest proportion of children that are living in poverty, Enfield has greatest absolute number of children under 16 that are deprived in NCL. The borough averages however, mask the fact that in all NCL boroughs there are small areas where children and young people are growing up in poverty, which will have substantial implications for their life chances and their health.

There is a link between income deprivation and ethnicity in NCL, with children from some ethnicities being more deprived on average than others (Figure 22). Children and young people of Black ethnicity are generally more deprived than other communities with over 80% of Black African and Black Caribbean children living in areas which are in the 40% most deprived areas. The relationship is more complex for Asian communities; the Bangladeshi community are as deprived as the Black communities, with 79% of children and young people living in the 40% most deprived areas, whereas the Indian community is the least deprived of all communities in NCL.

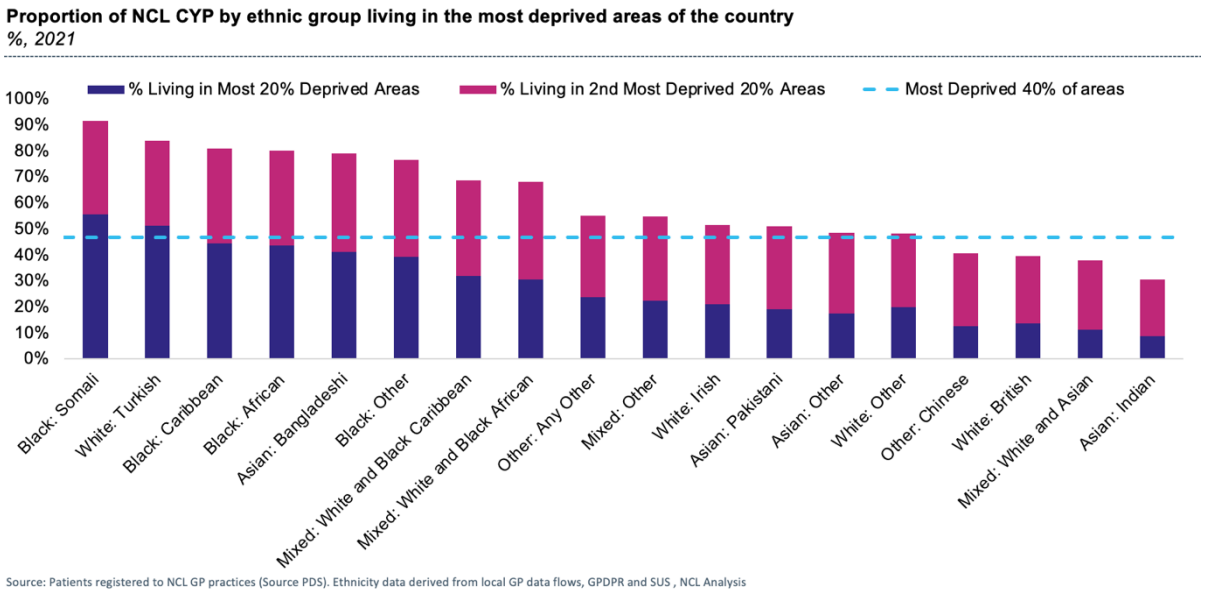


Figure 22: Proportion of children in NCL that live in the most deprived areas by ethnicity

The social determinants of health are important drivers of good health outcomes[15]. Education and employment are two of these. Only 70% of young children in Enfield achieve a good level of development at the end of reception, which is significantly lower than the national and London averages. A similar trend is seen in children and young people in Enfield at the end of Year 11. In Haringey, 7.9% of 16–17-year-olds are not in education, employment or training, which is the highest of all London boroughs. Local data are not available on the impact of health conditions on children and young people's education but given the importance of education as a social determinant of health, NHS services need to be designed to maximise children's education.

Income deprivation is associated with a higher prevalence of long-term conditions among children and young people in NCL. Over one in 10 children in NCL have asthma, making it the most prevalent long-term condition. However, there is an unequal asthma burden in NCL, with significantly higher prevalence in the 40% most deprived areas (Figure 23). This trend is also seen in other long-term conditions, including diabetes (Figure 24), epilepsy and learning disabilities, where children and young people in the 20% most deprived areas have a significantly higher prevalence.

[15] https://www.instituteofhealthequity.org/resources-reports/fair-society-healthy-lives-the-marmot-review

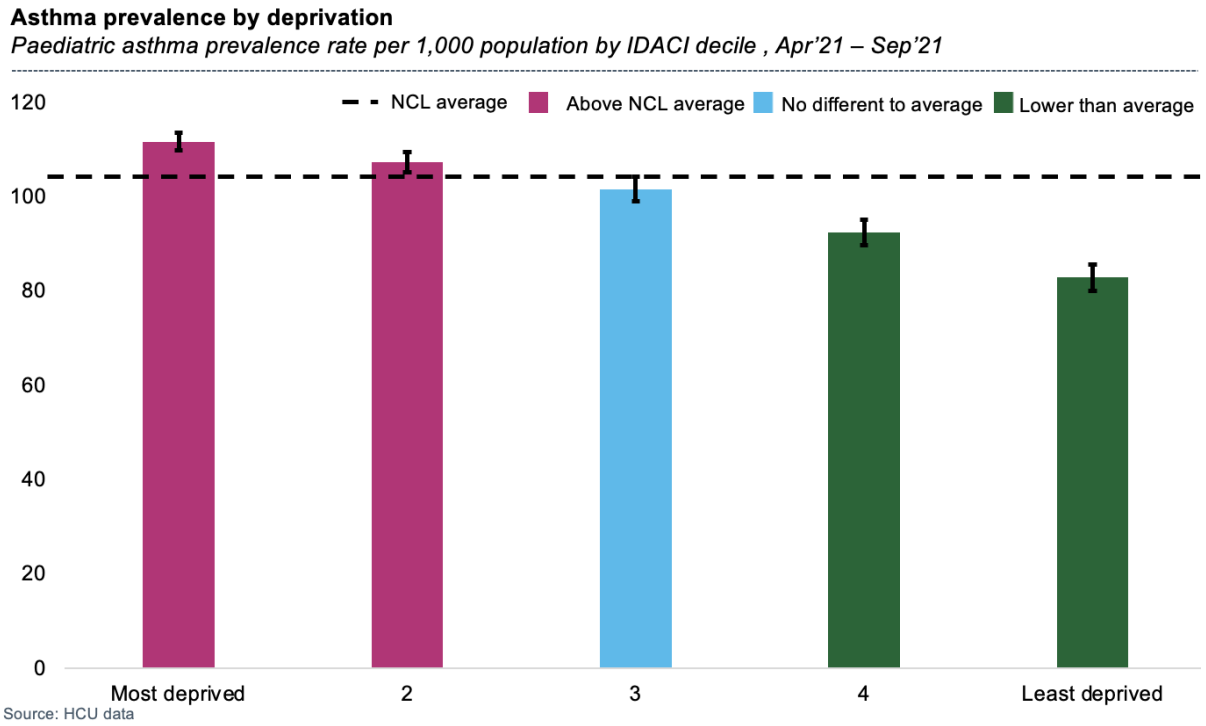


Figure 23: CYP asthma prevalence by deprivation

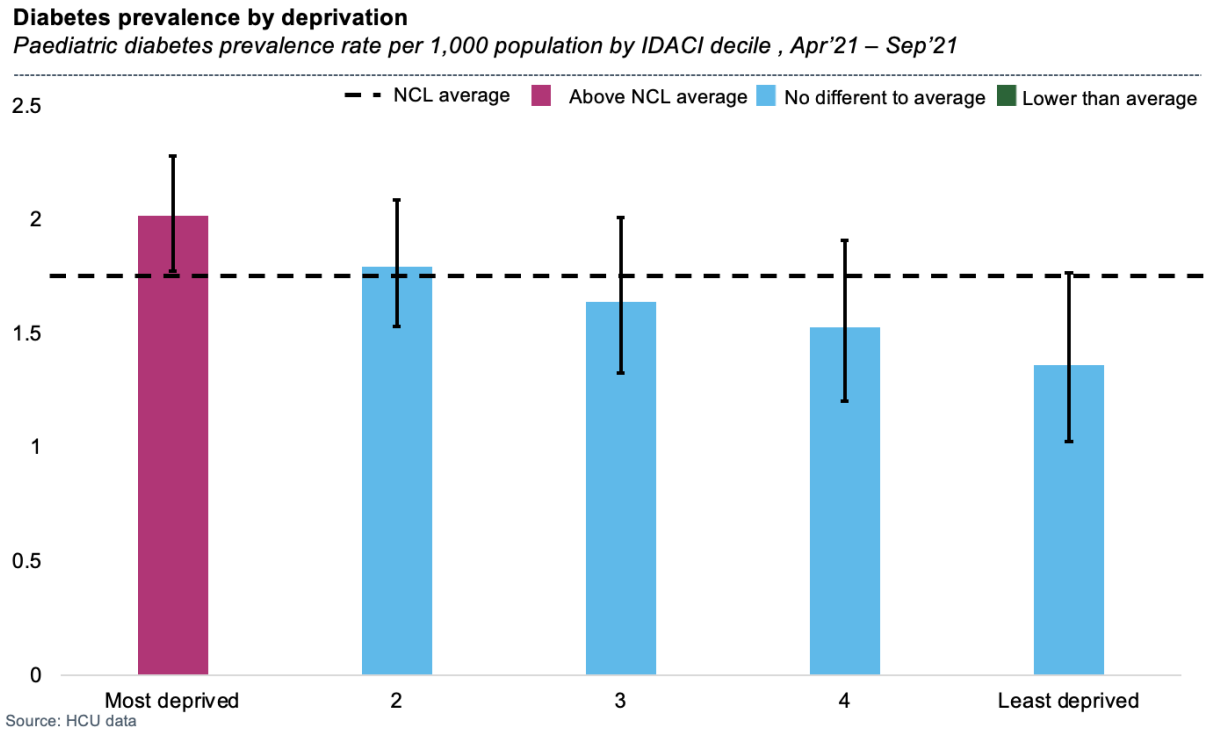


Figure 24: CYP diabetes prevalence by deprivation

There are also ethnic inequalities in the prevalence of long-term conditions in children and young people. Children from Black, Asian, Mixed White and Black, and White British communities have a significantly higher prevalence of asthma compared to the NCL average (Figure 25). Epilepsy prevalence is higher among Black and Bangladeshi children, and children from Bangladeshi, Black African, and Mixed White and Black backgrounds have a

significantly higher prevalence of learning disabilities (Figure 26). Again, the intersectionality between ethnicity and deprivation needs to be considered when interpreting these data.

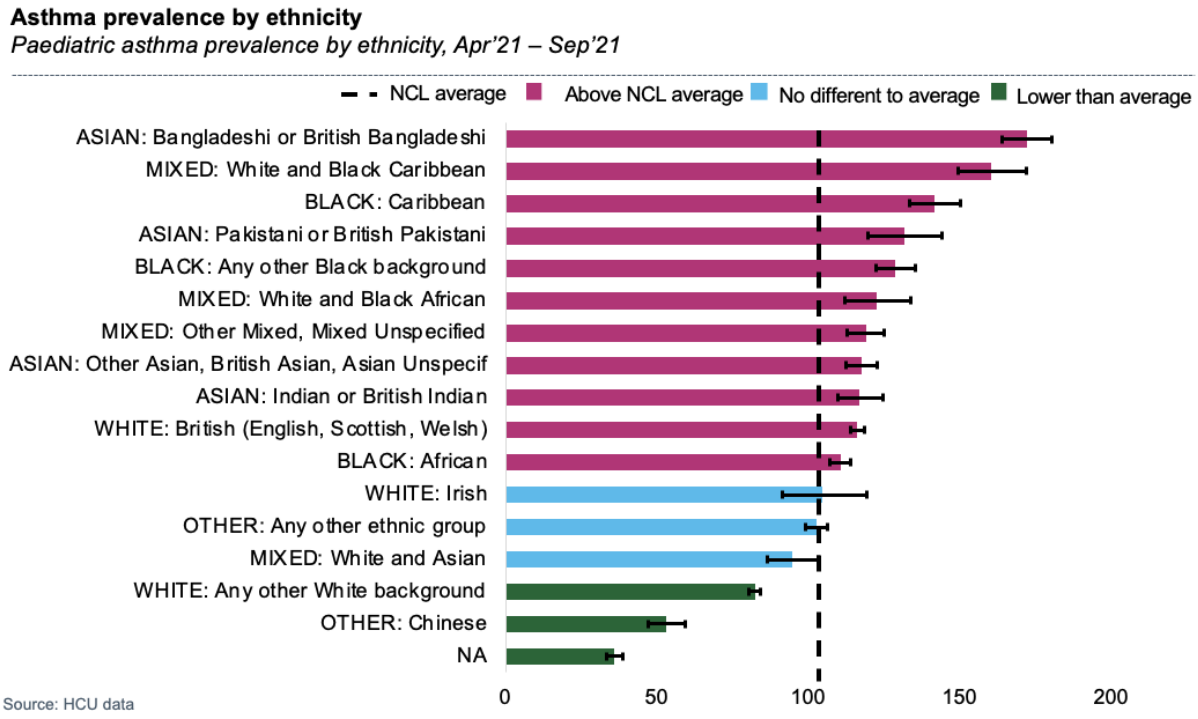


Figure 25: CYP asthma prevalence by ethnicity

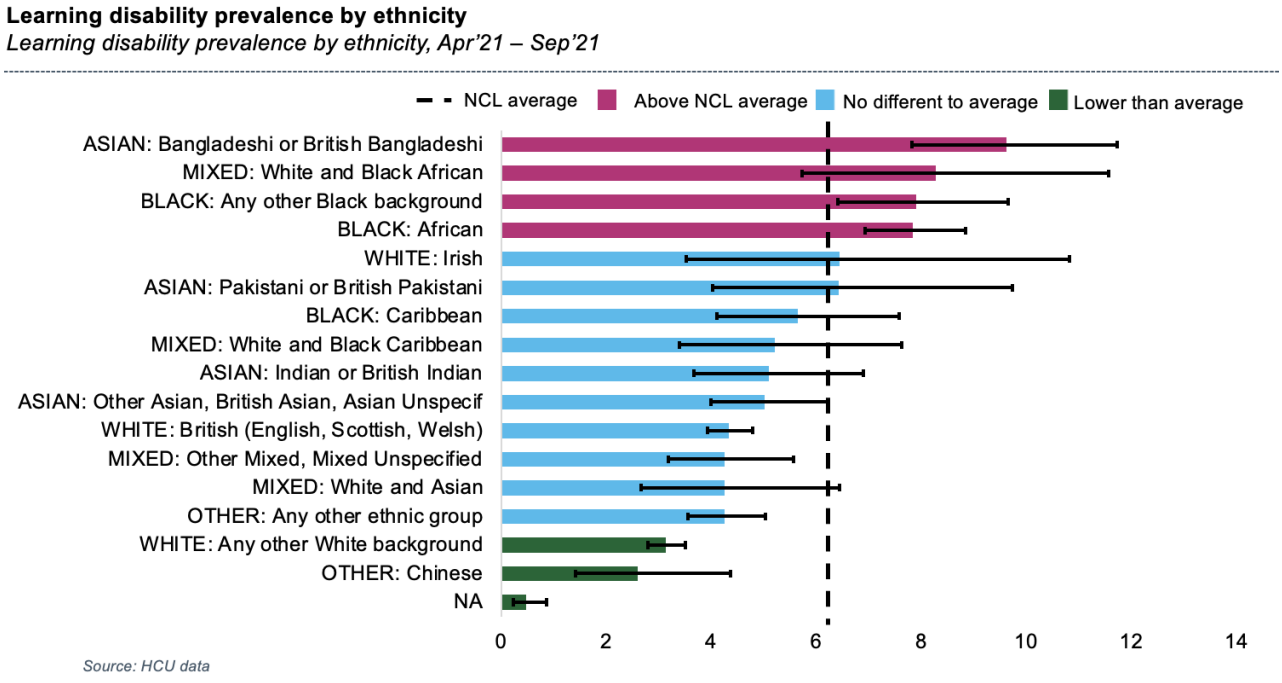


Figure 26: Learning disability prevalence by ethnicity

There are also inequalities in long-term condition prevalence by sex. For example, boys have a significantly higher prevalence of asthma, epilepsy and learning difficulties as compared to girls.

As we move forward, NCL is committed to taking a population needs-based approach. This means fully understanding the needs of our local population to ensure that we are delivering care and distributing our resources to those areas that need it most.

Section five: Maternity and neonatal services

5.1 Vision for maternity and neonatal services in NCL

The birth of a child is a life-changing experience for a woman or person and their family. The experience and outcomes of maternity and neonatal care can go on to have far reaching, life-long impacts for both the pregnant woman or person and their baby. If NCL is to achieve one of its core aims of 'starting well' then the experience of maternity and neonatal services is a key component of this.

Maternity services should be safe, compassionate, personalised and family-friendly. NCL has a diverse population with different needs and maternity services should be set up to empower pregnant women and people to make informed decisions about their maternity care. All pregnant women and people should have access to the same high-quality outcomes of maternity care, regardless of their background.

Having a baby in NCL, for most service users, is a positive experience. However, for some pregnant women and people there are complications and when these arise, services must be responsive and compassionate, and must learn from anything that could have led to a different outcome.

Sometimes complications can lead to a baby needing admission to a neonatal unit. When this happens, it can be one of the most stressful experiences a family can go through. Neonatal services must put the experience of a woman or person giving birth, the baby and family at the centre of service planning and delivery. Parents are key partners in neonatal care and involving the family and providing support to them is integral to the delivery of high-quality, personalised neonatal care. This enables the family to become part of the team looking after their baby, minimises separation, promotes attachment, helps families to understand their baby's needs and develops their confidence in caring for their baby[16].

This chapter will describe maternity and neonatal services in NCL and outline findings from a review of current service delivery. This includes highlighting some areas of success and also outlining where there may be opportunities to improve services further to better meet the needs of families that use services.

5.2 Introduction to maternity and neonatal services

Maternity care

Maternity care refers to care provided by health professionals during pregnancy, labour, birth and up to six weeks after birth. It also encompasses the monitoring of the health and wellbeing of the mother and baby, health education and any additional support required.

The NHS offers a choice to pregnant women and people on where they would like to give birth. This can be at home, in a unit run by midwives (midwifery unit or birth centre), or in a

[16] https://hubble-live-assets.s3.amazonaws.com/bapm/file_asset/file/793/BAPM_FICare_Framework_November_2021.pdf

unit run with 24/7 medical support from obstetricians and the other services a hospital provides (sometimes referred to as an obstetric-led unit). The choice of these options will depend on the needs of the pregnant woman or person, the risk factors in terms of their pregnancy and sometimes where they live.

Those that are healthy and have no complications during pregnancy are classed as low risk and could consider the full range of these birthing options. Those with either pre-existing medical conditions, or conditions linked to their pregnancy, may be advised to give birth in a hospital where specialists are available in case any further treatment is needed. Figure 27 describes the different birth settings available for women and people in NCL to choose.

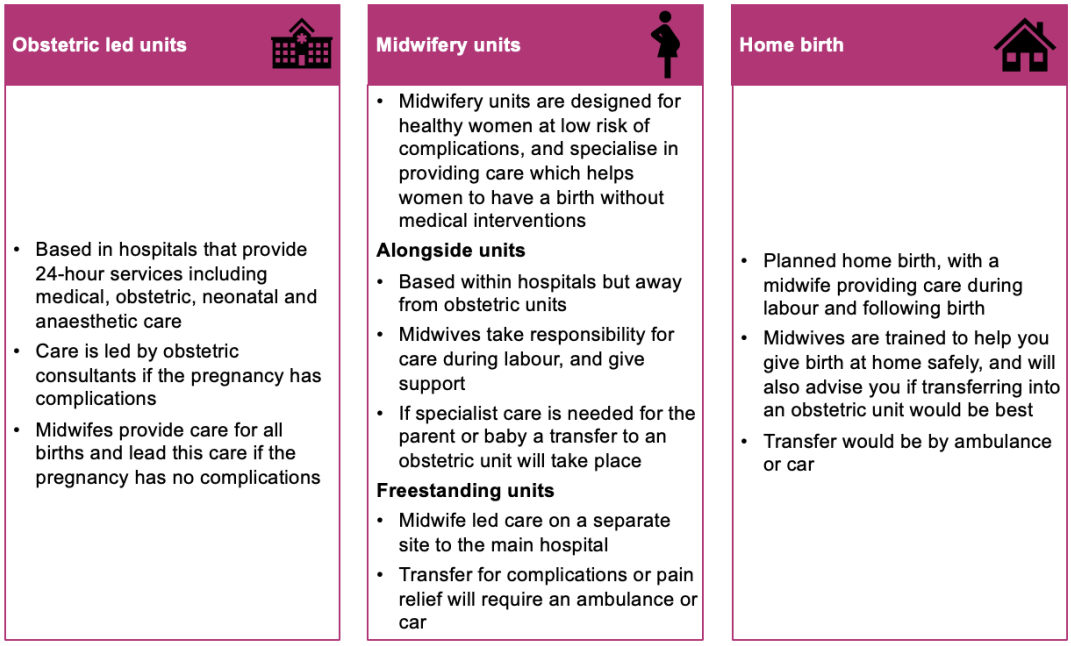


Figure 27: Different types of birth settings

In order to safely care for the needs of a pregnant woman or person during labour, it is important that obstetric-led units have a full range of support services available 24/7, in case of any complications. This typically includes the following services:

- Access to an emergency operating theatre, in case a pregnant woman or person needs an emergency caesarean section in order to safely deliver their baby
- High dependency or intensive care support should there be any complications during birth that lead to a pregnant woman or person becoming critically unwell and needing a higher level of medical care
- Specialist obstetric anaesthetists available at all times, to provide anaesthetic support for a pregnant woman or person who may need to have an emergency caesarean or provide other pain relief (such as an epidural)
- Timely access to interventional radiology services. These services treat pregnant women and people who may have a significant bleed (known as postpartum haemorrhage) after giving birth. The Royal College of Obstetricians and Gynaecologists (RCOG) has produced guidance to urge all obstetric units to consider

interventional radiology as an important tool in the prevention and management of postpartum haemorrhage[17]

Units leading in maternal medicine specialties (explained later in this document) would need to be able to provide timely access to specialists who are able to support the needs of pregnant women and people with complex health conditions and who may need additional support through their delivery.

Neonatal care

Neonatal care is provided to babies born prematurely (before 37 weeks' gestation), babies that are born unwell or with additional needs. The care is delivered in a neonatal unit, or by specialist neonatal doctors outside of a neonatal unit. Babies admitted to neonatal units need extra treatment to grow and thrive in the same way as a baby born at full term, or with no other health conditions.

The medical definition for the word 'neonatal' means newborn, or in the first 28 days of life. Babies that are admitted to neonatal units are usually admitted directly from birth or transferred from another neonatal unit or clinical environment. Some babies born early or with a low birth weight may spend a number of weeks, or even months, in a neonatal unit until they are ready to go home.

The NHS has defined three categories of neonatal unit in its Neonatal Critical Care Service Specification (E08/S/a)[18]. All of these provide different levels of neonatal care and are able to provide care to babies born at different gestational age, birth weight and with different conditions.

The British Association of Perinatal Medicine (BAPM) is the professional association that produces evidence-based standards for perinatal care in the UK. It has developed several frameworks for practice, that describe the optimum activity and staffing levels for neonatal units to maintain skills and experience of looking after neonates. Evidence demonstrates improved outcomes for extremely preterm babies delivered in larger units in the UK[19].

BAPM recommendations focus on number of admissions of low birth-weight babies and delivery of respiratory care days (RCDs). RCDs are defined as days during which the newborn receives either invasive ventilator support via an endotracheal tube or tracheostomy, or non-invasive respiratory support with continuous positive airway pressure mask or high-flow nasal cannula[20].

---

[17] Royal College of Obstetricians and Gynaecologists, The role of emergency and elective interventional radiology in postpartum haemorrhage. Available online: https://www.rcog.org.uk/media/4nbn0ffm/goodpractice6roleemergency2007.pdf [accessed May 2022]

[18] NHS England. Neonatal Critical Care Service Specification. Available online: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e08-serv-spec-neonatal-critical.pdf [accessed March 2022]

[19] Marlow N, Bennett C, Draper ES, Hennessey EM, Morgan AS, Kosteloe KL. Perinatal outcomes for extremely preterm babies in relation to place of birth in England: the EPICure 2 study 2014 May; 99(3): F181– F188

[20] BAPM. Optimal arrangements for Local Neonatal Units and Special Care Units in the UK including guidance on their staffing: A Framework for Practice. Page 2. November 2018. Available online: https://www.bapm.org/resources/2-optimal-arrangements-for-local-neonatal-units-and-special-care-units-in-the-uk-2018 [accessed March 2022]

The NHS service specification criteria and BAPM standards have been summarised in Figure 28. Neonatal services will be outlined using the unit's name and the equivalent international level classification.

Unit name	International level classification	Neonatal Critical Care Service Specification	BAPM standard
Special Care Unit (SCU)	Level one	• Special Care Units (SCU) provide local care for babies born at 32 weeks or more and >1,000g birthweight who require only special care or short-term high dependency care.	• SCUs should anticipate admitting up to 25 infants <1,500g or undertake up to 365 RCDs annually[14]
Local Neonatal Unit (LNU)	Level two	• Local Neonatal Units (LNU) provide care for all babies born at their hospital at 27 weeks of gestation or more, >800g birthweight or multiple pregnancies >28 weeks • They may receive babies 27-31 weeks who require high dependency care.	• LNUs should care for 25 or more infants with less than 1,500g admission weight and perform 365 or more RCDs annually[14]
Neonatal Intensive Care Unit (NICU)	Level three	• Neonatal Intensive Care Units (NICU) provide care for the whole range of neonatal care. • All women and their babies who are born <27 weeks of gestation or birthweight <800g, and multiple pregnancies <28 weeks of gestation, should receive perinatal and early neonatal care in a maternity service with a NICU facility	• NICUs should care for at least 100 new very low baby weight admissions per year (very low baby weight defined as less than 1,500g)[14] • NICUs should undertake at least 2,000 days of intensive care per annum • An intensive care day is defined in the BAPM Categories of Care
Neonatal Surgical Intensive Care	Level three	• There are also some specialist services such as neonatal surgery and cardiology which are provided by NICUs. • However, not all NICUs are designated as sites that deliver this complex neonatal surgery	

Figure 28: Neonatal unit types and specifications

Neonatal units are able to provide care not only at their maximum designation, but also at the lower acuity levels of care, as babies become more well. For example, a NICU will have cots that provide intensive care support to babies, but also high dependency care, and special care.

Organisation of maternity and neonatal care in NCL

In NCL, maternity care and neonatal is provided by the four secondary care hospital Trusts and GOSH as a specialist provider of neonatal care. Figure 29 shows the organisation and location of these services.

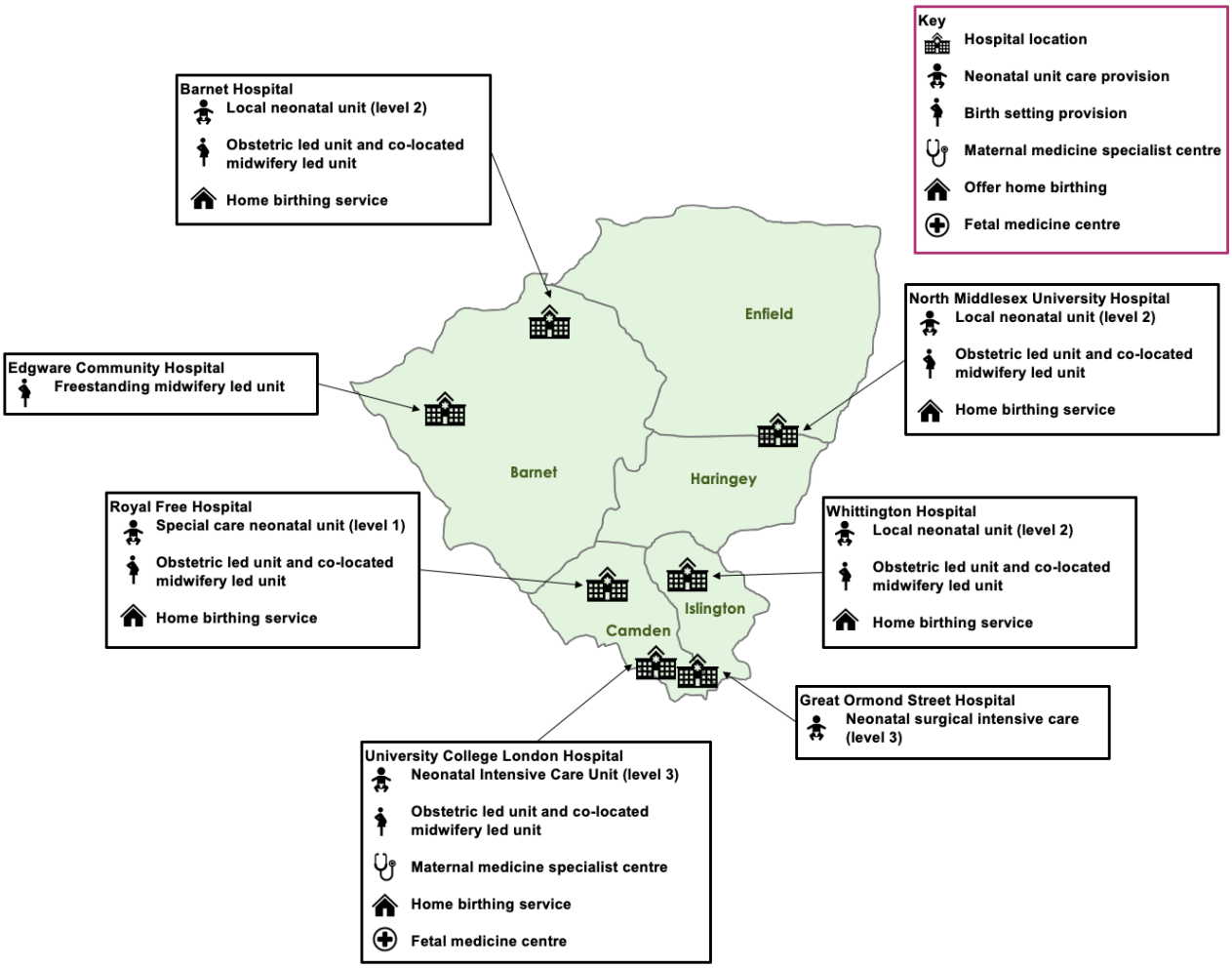


Figure 29: Neonatal units, birth settings, maternal and fetal medicine in NCL

Maternity departments in NCL have a strong history of working together to improve safety and to drive improvements across our sites. Through this approach we have developed a shared clinical safety dashboard; enabled staff to work more flexibly between sites and designed and implemented a new website for people having babies in North Central London[21]. The Local Maternity System (LMS) incorporates neonatal leadership and is now known as the Local Maternity and Neonatal System (LMNS). The Ockenden Review reinforced the importance of the LMNS's accountability for ensuring that the maternity services they represent provide safe services for all who access them; further guidance which sets out how to strengthen the LMNS models and function is expected from the national neonatal implementation board. The LMNS is the formal maternity 'arm' of our Integrated Care System.

[21] https://nclmaternity.nhs.uk/

Neonatal care pathways in NCL

NCL has defined care pathways for pregnant women and people and their babies that ensure they are able to access the level of care that they need, at the right time. In NCL this mostly falls within the ICS footprint, with UCLH and GOSH acting as the NICU (level three) and surgical NICU respectively, as well as serving a much wider footprint. There is one exception: the North Mid is part of the North East London Network and accesses the NICU (level three) at The Homerton Hospital in Hackney.

GOSH is a specialist tertiary and quaternary centre in NCL, providing specialist services such as complex neonatal surgery, cardiology and other paediatric subspecialty services. The unit does not have a co-located maternity service and therefore the NICU (level three) does not provide some of the more traditional care that would be delivered in a neonatal intensive care unit. The GOSH NICU treats babies with serious medical and surgical conditions such as those needing surgery for bowel obstruction and with persistent pulmonary hypertension of the newborn (PPHN).

Local care pathways and transfer of babies between neonatal units is supported by the London Neonatal Transfer Service (NTS). Transfers of neonates can either be for higher acuity care when a baby needs more specialist support, or when the baby's health has improved and they are able to be transferred to an LNU or SCU as they continue to become well enough to go home. The NTS is an integral part of the delivery of neonatal care in NCL and helps to ensure babies are transferred safely for care to be delivered in the best place for their level of need.

NCL maternal medicine network arrangements

Maternal medicine is the pre-pregnancy, antenatal and postnatal care for women and people who have significant medical problems that either arise during or predate their pregnancy. Ensuring the right knowledge, skills and expertise to manage those with complex conditions through their pregnancy is an integral part of safe maternity care.

Maternal medicine networks were established by the maternity transformation programme and identified as a priority in the Long Term Plan. Networks are designed to ensure that pregnant women and people are able to access specialist medical input for their condition. To support this model, some sites have been designated as maternal medicine specialist centres, or 'hubs', and other maternity units are designated as 'sub-hubs' or 'spokes'. The hub sites employ maternal medicine physicians, who are medical doctors and experts caring for pregnant women and people with other medical conditions. These clinicians provide outreach support and care at the 'spoke' sites through specialist clinics, which are normally delivered jointly with obstetricians from that site.

Across London, conditions have been grouped in into categories A, B or C based on their complexity (increasing in complexity). These categories require different input, ranging from being able to be managed locally to highly complex conditions requiring care to be led by the maternal medicine centre. A summary of what these categories mean for the care of pregnant women and people is summarised in Figure 30.

Category	How the condition should be managed	Example of a condition in this category
Category A	These are the least complex conditions and can be managed using local expertise of a maternity unit, without the need for input from the centre	Chronic Obstructive Airways Disease
Category B	These are complex medical conditions where a Maternal Medicine Centre provides clinical review and ongoing advice and guidance to a local maternity unit	Lung cancer
Category C	Highly complex medical conditions where care in pregnancy is led by the Maternal Medicine Centre during pregnancy and includes plans for delivery	Cystic fibrosis

Figure 30: Maternal medicine categories as defined by the London Maternal Medicine Network

In NCL, UCLH is designated as the specialist maternal medicine hub. As maternal medicine networks have only recently been formally commissioned and UCLH designated the lead, there is ongoing work to formalise pathways for the different conditions, making best use of the expertise in NCL.

Pathways are being developed and cross site multidisciplinary teams (MDTs) implemented to ensure that local expertise is maximised, and that pregnant women and people are looked after with minimal disruption to their pathway of care. In NCL, there is medical expertise of different specialties spread across all sites to manage some of the more complex (category C) conditions – for example, the Royal Free Hospital has expertise in managing those with kidney conditions and the Whittington those with sickle cell. For some conditions, these sites act as 'sub-hubs' to the centre (UCLH), although the numbers of category C conditions managed outside of UCLH is smaller than those managed by the centre.

In NCL, there are two obstetric physicians who provide outreach across all hospital sites and there is funding and plans in place to recruit an additional consultant to support the maternal medicine network. Once the third doctor is in post, there will be capacity to support all 'spoke' sites with one specialist maternal medicine clinic every week. However, this is not currently the case and some sites currently have a fortnightly clinic only. As the network develops and pathways embed resourcing for it, it will need to be reviewed on an ongoing basis to ensure that all pregnant women and people in NCL have the necessary input into their care to support them to stay well during pregnancy.

Fetal medicine

The NHS defines fetal medicine as the branch of medicine that provides care for the fetus (or fetuses) and mother[22]. In England, these services are centralised to certain sites due to the complexity of the investigations and treatment involved and to ensure there are enough cases to maintain skills in those who are delivering care.

In NCL, UCLH is the fetal medicine centre and is a regional, national and international referral centre for fetal medicine, caring for more than 7,000 patients each year. The close relationship with GOSH means that they are able to provide care for babies who may need specialist input once the baby is born.

[22] https://www.england.nhs.uk/wp-content/uploads/2013/06/e12-fetal-medi.pdf

Further work is required within fetal medicine to strengthen the networks and pathways across the levels of care for service users. NHS England has recently designated services for pregnant women and people with abnormally invasive placenta[23] (a condition that can cause significant blood loss in a pregnant woman or person at birth the placenta attaches too strongly or invades too deeply into the wall of the uterus, which may result in the placenta not separating following delivery). Pathways for this condition are still being operationalised. There will be a requirement for the LMNS to ensure that outcomes are evaluated and the number of at-risk pregnant women and people identified with this condition increases.

The link between maternity and neonatal services

Neonatal and maternity services work very closely together to ensure that any babies born prematurely, or requiring intensive care, are born in the most appropriate place for their anticipated care needs. The Getting It Right First Time[24] (GIRFT) neonatology report highlighted that relationships and joint working across neonatology, obstetrics and maternity needs to be effective for services to be delivering the best outcomes for babies[25].

Maternity sites that have an obstetric-led units, as well as having the additional services already identified (HDU, anaesthetics, access to interventional radiology), are typically co-located with a neonatal unit to ensure there are the staff and facilities to look after babies in case of complications. This is fundamentally important when considering the clinical safety of looking after both the pregnant woman or person and their baby, and is particularly important when looking after those who have more complex pregnancies.

5.3 Patient experience insight

Patient experience and insight into maternity and neonatal services was gathered from primary and secondary sources and is summarised in Appendix F.

These summaries and thematic reviews highlight what is most important to patients when using services, as well as priority areas for improvement from a patient perspective:

- Improving communication between hospitals and patients
- Improving one-to-one communication between individual staff members and individual patients
- Personalisation of care and continuity of care
- Equality and inclusion in relation to the experience of care
- The quality of the environment in which pregnant women and people and babies receive care

The patient voice will continue to be central to the next stage of the programme, as there is a strong call for improved communication from the services; this will be further explored in the detailed engagement planned over summer 2022.

[23] https://www.england.nhs.uk/publication/service-specification-specialised-maternity-care-for-patients-child-bearing-age-diagnosed-with-abnormally-invasive-placenta/

[24] Getting It Right First Time (GIRFT) is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change. https://www.gettingitrightfirsttime.co.uk/

[25] Neonatology, GIRFT Programme National Specialty Report, April 2022

"Communication was felt to be key. It is not only about the words that are used, but also the tone that is used, and the spaces provided for listening to women." - (NCL LMNS/Birth Companions, February 2020)

"Personalised care means that I am given all the different options, and that I can make my own informed decisions as to how, where and when I wish to give birth to my child. It means that those decisions are respected and supported" - NCL Better Births: A participatory action research project, Summer 2018

5.4 Local successes

There are many examples of local successes across NCL in respect of maternity and neonatal services. Our staff have reflected on the dedication of local teams and work being undertaken in NCL on 'leading the way with personalised care, aiming to give parents a central role in the care of their babies from as early as possible'[26].

Below we have shared a few examples of the excellent care being provided across NCL.

Example 1: Magnolia Midwives, North Middlesex University Hospital

The 'Magnolia Midwives' service at the North Mid was the first of its kind in the UK. The multidisciplinary model brings together midwifery care, obstetrics, psychiatry, psychology and social workers, to support women with moderate to severe mental health issues during their pregnancy.

Established in May 2019, the service provides continuity of care for women during their pregnancy and birth, and postnatally. In 2018, more than 600 women booking their pregnancy with North Mid needed the kind of joined-up service provided by the Magnolia Midwives team. The team has been publicly credited by the Nursing and Midwifery Council with leading the way in making mental health a priority.

For patients, the Magnolia Midwives service supported them to make informed choices without judgement.

"Just being able to talk and "let it all out" without judgement, felt amazing. It felt like almost immediately, they had a plan in place for support and I felt like I was suddenly enveloped in safety. I honestly cannot thank them enough; I love my life and my son and this is all as a result of my midwives." - Care Opinion, 2021

"My care was completely personalised, and I was able to make a decision for a Caesarean section delivery without judgment. I felt empowered (and still do) and that is all down to the care provided by my midwives" – Care Opinion, 2021

Example 2: NCL neurodevelopmental pathway for neonates

During engagement on the case for change, we heard how NCL neonatal units have been working together for a number of years to improve the outcomes for babies in their care.

In 2004, led by a neonatologist from UCLH and an occupational therapist from the Royal Free Hospital, the five neonatal units in the North Central London Neonatal Network came together with the community paediatricians and therapists, to design a consistent

[26] Start Well Staff interviews, 2021

neurodevelopmental follow-up pathway for high-risk infants. This resulted in a standardised follow-up at three months, six months, one year and two years for infants born under 30 weeks, or below 1,000g, and for term babies with neurological complications at, or soon after birth that had been admitted to a neonatal unit.

The implementation of this consistent follow-up with diagnostic tests, plus a standardised neurological exam at term and three months, created a consistent framework for reviewing neurodevelopmental progress of infants and has allowed for earlier diagnosis (and therefore intervention) for conditions such as cerebral palsy, cognitive delay and speech delay. Since it started, more than 3,000 premature babies and more than 500 term babies have been followed up in this way.

The work around neurodevelopmental follow-up has led to significant steps forward in neonatal practice, which has improved not only the follow-up care of babies and infants after discharge, but also the care delivered directly in the neonatal units across NCL. For example, it was found that babies who had been laying on their side whilst nursed in the unit, were less likely to have fine motor skills challenges at their two-year reviews, which led to changes in the way babies were positioned in their cots for all the units.

The results of the detailed assessments lead to significant improvements in developmentally appropriate neonatal care. As knowledge expanded, it became clear that participation of families in their infants' care in the unit, led to improved two-year outcomes. In the same way, improvements in NICU environmental challenges like noise and activity, seemed to lead to improved adaptive behaviour by two years of life. Following Scandinavian advice and with the findings from this follow-up, Barnet neonatal unit designed the Family Integrated Care individualised rooms.

This pathway was ahead of its time it was when first implemented: involving a multidisciplinary team working over multiple sites and across organisational boundaries to ensure that the outcomes of babies admitted to all units improved, shows the commitment of staff to serving babies and families over a number of years. Data continues to be collected from NCL neonatal units and findings are reviewed by clinical teams from across the sector. This facilitates shared learning and implementation of best practice in neonatal care in NCL, with many of the findings now being applied both nationally and internationally.

Example 3: family care rooms, Barnet Hospital

The UK's first care rooms allowing parents to stay close to their premature babies 24 hours a day, opened at the Starlight neonatal unit at Barnet Hospital in 2014.The rooms allow a newborn baby to receive treatment in a private, family-centred setting. By limiting extraneous light and noise, the family rooms can support a newborn baby's brain development.

The rooms have space for parents to stay with their newborns 24 hours a day, allowing them to play a central role in the care of their child. Each room is staffed according to the baby's needs, providing 24/7 support to parents. Allowing parents to stay enables them to learn a sense of parenting control, to provide prolonged episodes of skin-to-skin care and to get to know their baby within a calm, private setting.

For one family, whose baby was born at 25 weeks, the family care rooms provided an opportunity to be with the baby 24-hours a day.

"Before, I would come to the hospital in the morning and go home in the evening, but the unit enables me to be with my baby for 24-hours a day and to do everything for her, with the added bonus that a nurse is available outside for support. I think more hospitals should adopt it" [27]

This model is increasingly being adopted both in Europe and around the world, with the support of organisations such as the British Association of Perinatal Medicine (BAPM).

Example 4: Royal Free London 'Keeping Mothers and Baby Together Pathway'

The pathway started in 2017 in response to the national increase in neonatal admissions and as part of the Saving Babies Lives bundle[28]. A Clinical Practice Group (CPG) pathway team at the Royal Free London was formed to address this issue. The CPG team came together to review the reasons for the increase, and what could be done differently to ensure that as many babies as possible could stay out of a neonatal unit and with their family.

The criteria of what constitutes a baby at risk of a neonatal unit admission was identified and agreed – for example, those born to pregnant women or people with diabetes and high blood pressure, or babies that had restricted growth. Clinical guidelines across both Barnet Hospital and the Royal Free Hospital sites were reviewed and standardised, meaning that all babies would have initial observations at birth, then at one hour and two hours, for 12 hours. This meant that babies were having observations done on the labour ward and postnatal ward in a consistent way that aligned with best practice guidance.

The reasons for special care level neonatal admissions were reviewed, and it was identified that respiratory distress syndrome was the leading cause for admission soon after birth. The team then looked to prevent babies from developing this syndrome. Things like the temperature of the environment, the need to feed within the first hour, and receive skin-to-skin contact were identified as factors. Guidelines around all of these factors and others were then altered as a result. An orange hat was also introduced for these babies to wear, to remind busy staff that these babies were on the high-risk pathway, and they needed regular observations to be done.

The result of implementing this pathway has been a significant reduction in the rate of admission to the neonatal units at Barnet and the Royal Free – from 8.3% in 2016 to 6.5% in 2022, and in total 296 babies have been able to stay on the labour ward with their families instead of being admitted to a neonatal unit.

"…the midwives, everyone gave us that special care for the extra obs…anything really that we require…it [orange hat] made a world of a difference…" [29]

[27] https://www.royalfree.nhs.uk/news-media/press-releases/barnet-hospital-opens-the-uks-first-individualised-care-rooms-at-its-neonat/
[28] https://www.england.nhs.uk/mat-transformation/saving-babies/
[29] https://www.royalfree.nhs.uk/services/services-a-z/maternity-services/orange-hat-appeal

5.5 Opportunities for improvement

Some examples of the excellent care that is delivered across NCL maternity and neonatal units have been outlined in section 5.4. However, data analysis, engagement with clinicians and gaining an understanding of the experience of pregnant women and people and their families has also identified opportunities to improve the way services are delivered to better meet the needs of babies and families in NCL.

Good health and care in pregnancy significantly influences a baby's development in the womb, which in turn influences the long-term health, educational and life outcomes of the child. Given the interdependencies between neonatal and maternity services, this chapter will explore opportunities to improve and highlight the case for change for neonatal and maternity services in NCL.

1. Ensuring excellent experience, equitable access and optimal outcomes for pregnant women and people

Variation in the provision and quality of services means that not all pregnant women and people are able to access the same services and not all pregnant women and people have the same outcomes and experience. Delivering equitable maternity care means that all mothers and babies achieve the best health outcomes possible and have access to services to support their individual needs. There is evidence that currently in NCL there are areas of differential maternity outcomes. This section will explore the differences in quality and access to maternity services.

Ensuring equity in maternity service provision with a focus on improving outcomes means that our maternity services respond to our local population's individual needs. Care should be safe and personalised for all pregnant women and people.

Good health in pregnancy has a significant impact on the pregnant woman or person's health and the baby's development, which in turn can have an influence on the long-term health of both parent and child. Giving every child the best start in life is a key priority for the ICS and will help each individual in NCL fulfil their health and wellbeing potential. Safe and personalised maternity services are crucial in ensuring every mother and their baby achieves the best health outcomes.

In measuring the quality of maternity services, typically three domains of quality are explored – safety, clinical effectiveness, and patient experience. Across NCL there is variation in the quality of maternity services. This impacts on our ability to ensure optimal and equitable care for all pregnant women and people. Addressing inequities in access and tailoring maternity services to best meet the needs of the local population is a critical area for action and something that good services are prioritising.

Stillbirths

Reducing stillbirths and promoting safer maternity care is a key priority for the NHS. The Government's ambition is to halve the rate of stillbirths in England by 2025[30]. This would require the national rate to fall to 2.6 per 1,000 births in England. A still born child is defined as a child born after the 24th week of pregnancy that is not alive when it is born. Stillbirth can happen in any pregnancy however there are a number of risk factors that can increase the likelihood. Deprivation, maternal age, smoking during pregnancy and being overweight are all example risk factors[31].

Between 2018 and 2020, the Office for National Statistics (ONS) recorded 238 still births in NCL boroughs[32]. This is equivalent to a rate of 4.4 per 1,000 births. The rate varies between the boroughs, with Haringey and Enfield having the highest rates in NCL (Figure 31). The data for 2018-2020, available through the ONS, shows Haringey as having the highest stillbirth rate in England, at a rate of 6.3 still births per 1,000 births.

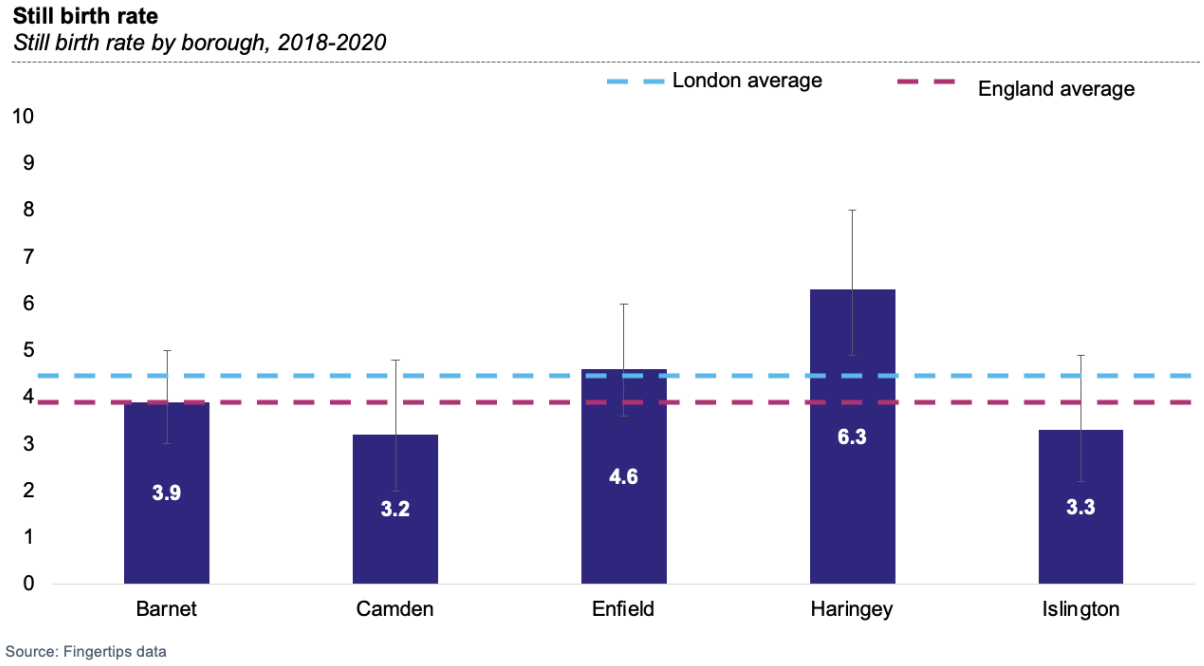


Figure 31: Still birth rate by NCL borough

A stillbirth is a devastating event for the pregnant woman or person and their family. Across NCL, all stillbirths are analysed by the Trust of birth using the Perinatal Mortality Review Tool[33], and if there are any instances where care has been found to be sub-standard, they will be treated as serious incidents by the hospital to understand what happened and what could be learned.

Since 2018, Trusts have implemented a range of interventions that are part of the 'saving babies' lives care bundle[34]', in order to reduce stillbirth rates and neonatal deaths. These include use of scanning and customised growth charts, training of staff, smoking cessation

[30] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1019109/E02666664_GovResp_to_HSC_Expert_Panel_CP_514_Web_Accessible_v2.pdf
[31] https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884-014-0404-0
[32] Child and Maternal Health - Data - OHID (phe.org.uk)
[33] https://www.npeu.ox.ac.uk/pmrt
[34] https://www.england.nhs.uk/mat-transformation/saving-babies/

services, fetal monitoring training and improvements in practice, and improved pathways for women who present with reduced fetal movements.

ONS data for stillbirths for 2021/22 is not yet available and it is therefore not possible to see whether this has resulted in improvements by borough. However, the LMNS regularly reviews hospital-level data and this shows that, for 2021/22, the stillbirth rate for Whittington Health and North Mid (the hospitals used by the majority of Haringey residents) were 3.3 and 3.07 respectively. This is an improvement on the 2018/19 position and represents a particular year on year improvement for North Mid.

Nevertheless, the differential stillbirth rate within NCL is stark, and there will need to be a determined focus as a system on investigating the reasons for the high rate in Haringey and addressing the root causes through prevention and early intervention (for example stop smoking and weight management support) to address this gap in life chances and experiences between our boroughs.

Admissions to neonatal units

As outlined in section 5.2, a baby is admitted to a neonatal unit when it is born premature or unwell. This could be as a result of complications during pregnancy or labour. NCL neonatal units provide excellent care to babies that are admitted to their unit. The National Neonatal Audit Programme Report for 2020 shows the north, central and east London hospitals had the lowest proportion of mortality from admission to discharge in babies born at less than 32 weeks of all the ODN areas in the country[35].

However, in NCL there is a differential rate of admission to neonatal units depending on ethnicity and level of deprivation. Analysis of admissions to neonatal units in 2020/21 shows that babies born to pregnant women and people of Black ethnicity have twice the rate of admission to a neonatal unit than babies born of White ethnicity, and those of Asian ethnicity have 1.5 times the rate of babies born to White women and people (Figure 32).

[35] https://www.rcpch.ac.uk/sites/default/files/2022-03/NNAP%20Annual%20Report%20on%202020%20data.pdf

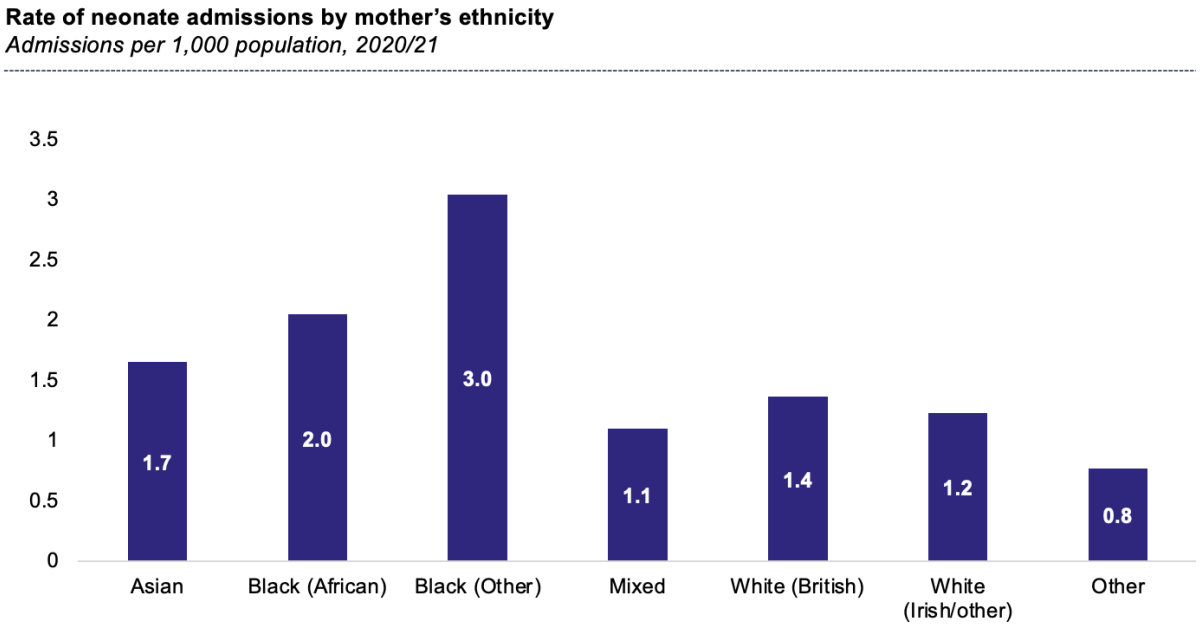


Figure 32: Rate of neonate admissions by mother's ethnicity

Analysis of the NCL registered population's use of neonatal units shows that 60% of neonatal admissions at NCL sites are for babies in the 40% most deprived quintiles of the population and there is a reducing rate of admission when looking at the other quintiles – with only 6% of admissions in 2020/21 being from the least deprived quintiles (Figure 33)

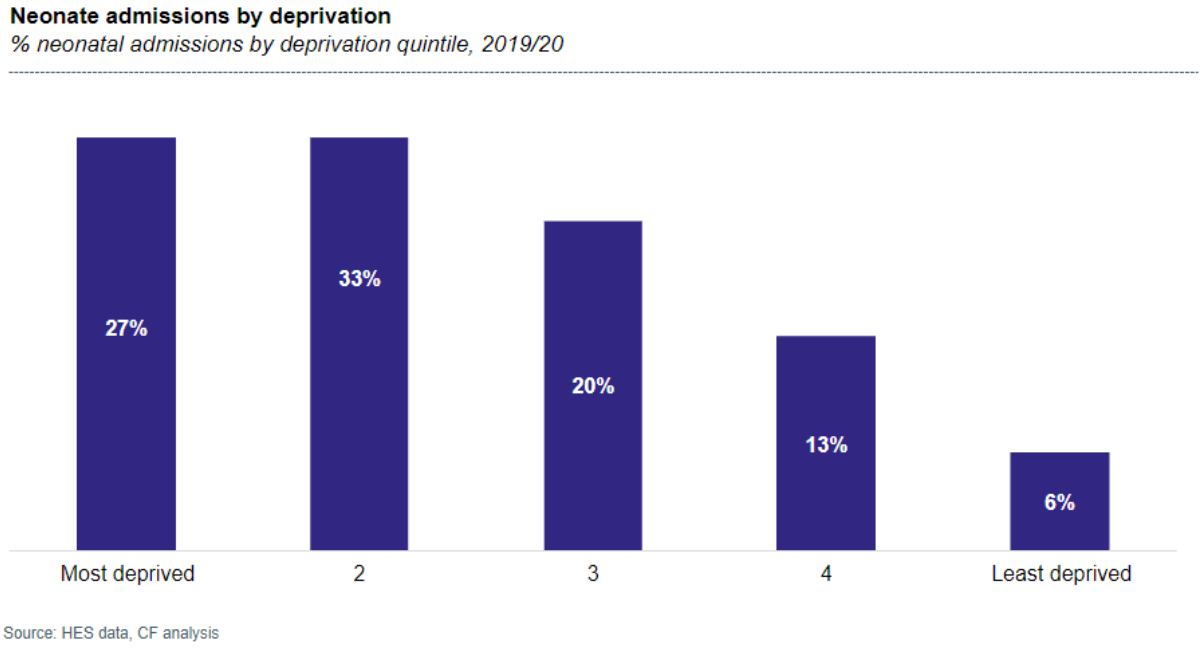


Figure 33: Neonatal admissions at NCL units by deprivation

Maternity serious incidents

In broad terms, serious incidents in healthcare are events where the consequences for patients, families and carers, staff or organisations were so significant they warrant using input to investigate and additional resources to develop a comprehensive response[36]. These

[36] https://www.england.nhs.uk/wp-content/uploads/201s5/04/serious-incidnt-framwrk-upd.pdf

incidents can extend beyond the patient and include incidents that could indirectly impact patients' safety or an organisation's ability to deliver ongoing healthcare.

Reporting and investigating incidents is a sign of a well-functioning organisation and should be promoted and encouraged. This includes organisations reporting cases of harm to regulators such as the Care Quality Commission (CQC) and referring cases to the Health Care Safety Investigation Branch (HSIB) who undertake an independent investigation into the care and incident.

Better Births highlighted that where things go wrong in maternity care, "a rapid investigation, and support for staff involved, openness and honesty with the family" should be in place. The Ockenden Report tragically highlighted the impact on the outcomes of pregnant women and people and babies of mistakes not being learned from and organisations not having a culture that encourages openness and transparency after mistakes occur.

In NCL the governance arrangements of how organisations manage serious incidents was reviewed and it was found to be robust. It included scrutiny at an organisation and NCL level to investigate, report on and learn from serious incidents

Serious incidents reported April 2019 – March 2022 were analysed by LSS, and the quality of reports and themes reviewed. In terms of the quality of SI reports undertaken by Trusts, the investigations were found to predominantly be undertaken by an appropriate multidisciplinary panel, with comprehensive Terms of Reference and case-specific key lines of enquiry that were robustly documented in the reports. Specific questions raised by the pregnant woman or person and family are increasingly noted to be embedded and answered in the reports and the investigations are also benchmarked against the relevant national and local guidelines with appropriate references and links to the documents included in reports.

In terms of themes that have been identified as the cause of the SIs reported in NCL – these vary from cognitive factors (characteristics of an individual professional that may affect performance – for example attention), communication factors between clinical professionals, knowledge and training issues, MDT working, documentation, lack of situational awareness, risk assessment and care planning and service factors (a broad term that covers hospital systems – like use of interpreters). Overall, increases in the themes of human factors elements (such as cognitive factors) were identified between 2019 and 2022. This may indicate an increase in the consistency in the recognition of these factors. Some elements such as knowledge and training may, however, reflect the difficulties encountered during the COVID-19 pandemic in relation to the completion of training and study days. There has also been an increase in the theme of deviation from guideline/policy.

There is evidence of learning across the hospitals within NCL in relation to clinical fetal monitoring with a gradual sustained downward trend in SIs reported. This corresponds with a sustained increase in focus of maternity services in NCL on this element of care, which is strongly linked to neonatal outcomes. All four providers in NCL have recruited into a role with the specific remit of supporting staff and raising standards in relation to foetal monitoring and subsequent management and care. Units have a rolling programme of training for obstetric medical and midwifery staff and conduct additional case reviews and learning sessions to review guidelines relating to fetal monitoring.

Continuity of carer pathway

Midwife Continuity of Carer (MCoC) is defined as receiving postnatal care from a midwife who has been involved in both labour and antenatal care. The care model has been highlighted as a way of ensuring safer care for pregnant women and people, based on a relationship of mutual trust and respect between them and their midwife[37].

This continuous relationship between caregiver and receiver has proven to lead to better outcomes and greater safety for the child and parent, whilst also offering a better and more personal healthcare experience for the pregnant woman or person[38]. Whilst all pregnant women and people will be positively impacted by continuity of carer, it is particularly significant for those who are from deprived and from ethnic minority backgrounds. Evidence has shown that a targeted approach in midwifery-led continuity of carer towards women from minority groups and those living in deprived areas, is linked to significant improvements in clinical outcomes and experience of services and care.

Core20PLUS5 is a national NHS England and NHS Improvement approach to support the reduction of health inequalities at both national and system level[39]. In November 2021, Core20PLUS5 programme set a target of ensuring continuity of carer for 75% of women from Black, Asian and minority ethnic communities and from the most deprived groups by the end of March 2024.

The current provision and delivery of MCoC in NCL is variable, and there are challenges with data collection, which means it is difficult to get a definitive position on current compliance against the NHSE standard. There are also different models of MCoC implemented across the sector, with some sites providing continuity pre- and postnatally, but not during labour, and others providing full continuity throughout the pathway.

Figure 34 gives the current MCoC provision in NCL and, where it is available, the coverage of this pathway for maternity bookings. The teams in place at all Trusts have been established following a review of local populations, ensuring that pregnant women and people from the target groups and most deprived areas were prioritised. Commissioners in NCL have agreed, as part of the quality performance standards in maternity contracts, a measure around the continuity of carer pathway to raise the profile of this work and the efforts to reduce health inequalities in both maternity care and the local community.

[37] https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf
[38] J Sandall et al. Midwife-led continuity models versus other models of care for childbearing women. 2016. Available online: https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004667.pub5/full [accessed May 2022]
[39] https://www.england.nhs.uk/about/equality/equality-hub/core20plus5/

Hospital Trust	Number of MCoC teams currently	Plans in place for provision	MCoC coverage May 2022
North Middlesex University Hospital	Two teams in place	Home birthing team by end of summer 2022	22%
Royal Free London NHS Foundation Trust	Nine teams in place (two safeguarding-based and seven geographically based teams covering high deprivation areas)	Two further teams roll out is paused until safe staffing levels are met	35%
University College London NHS Foundation Trust	One full team (geographically based) and five hybrid teams providing pre and post-natal care only	Further team roll out paused until safe staffing levels are met. Expect to implement by late summer 2022	18%
Whittington Health NHS Trust	Two full teams covering geographical areas of high deprivation and with higher percentage of Black, Asian and minority ethnicities population	Will condense to one team in June 2022 due to midwife vacancies	Coverage not available

Figure 34: MCoC provision in NCL

"We didn't have continuity of carer, and each time I attended appointments I had to retell my story. This was upsetting and had a negative impact on my mental health. The only continuity was at the end of my pregnancy, when had the same midwife who was lovely." - Participant in patient focus group, May 2022.

Whilst the benefits of a continuity of carer model are well documented, the final Ockenden Report has recommended that 'all Trusts must review and suspend the existing provision and further rollout of the midwifery continuity of carer model unless they can demonstrate staffing meets safe minimum requirements on all shifts'[40]. In April 2022, NHS England asked Trusts to review their delivery of continuity of carer models and presented three options for the rollout of the model[41]:

1. Trusts that can demonstrate staffing meets safe minimum requirements continue existing MCoC provision and continue to roll out
2. Trusts that cannot meet safe minimum staffing requirements for further rollout of MCoC, but can meet the safe minimum staffing requirements for existing MCoC provision, should cease further rollout and continue to support at the current level of provision
3. Trusts that cannot meet safe minimum staffing requirements for further rollout of MCoC and for existing MCoC provision, should immediately suspend existing MCoC provision

Following this guidance, all NCL Trusts are in position two and have ceased further rollout of continuity teams but are able to continue to provide their current level of continuity provision. Coverage at the Whittington Hospital will reduce slightly from June 2022, due to going from two to one continuity team.

Recruitment plans have been completed that cover the rollout of additional MCoC teams will be phased alongside the fulfilment of required staffing levels. Pregnant women and people from Black, Asian and ethnic minorities and from the most deprived areas, have been prioritised to receive MCoC.

[40] https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1064302/Final-Ockenden-Report-web-accessible.pdf
[41] https://www.england.nhs.uk/wp-content/uploads/2020/12/B1523-ockenden-final-report-letter-1-april-22.pdf

This pause in rollout of further continuity teams has given the NCL LMNS the opportunity to review the continuity model in the sector and it is currently undertaking a review of how services have implemented continuity teams. It is also reviewing those that use services to understand the populations that will most benefit from being booked on a continuity pathway. This work is ongoing, but once concluded will form the basis of agreeing a consistent approach across the sector to implementing the model, and agreement around who the target groups are. This will mean greater consistency of care across NCL for those booked on a continuity pathway.

Perinatal mental health

Perinatal mental health problems are those that occur during pregnancy, or in the first year following birth of a child. Across England, perinatal mental illness affects up to one in five new and expectant mothers and, if left untreated, can have a significant impact on pregnant women and people, their babies and wider family[42]. Perinatal mental health problems are the most common complication of having a child and are associated with considerable maternal and infant morbidity and mortality.

The data around the prevalence of mental health conditions in pregnant women and people in NCL is not readily available, however the prevalence of depression and severe mental illness for NCL as a whole suggests that there is a higher prevalence than the London average. In NCL 9.2% of the population was diagnosed with depression in 2019/20, compared to the London average of 8.2%, and 1.3% of the population was diagnosed with severe mental illness, compared with a 1.1% average in London.

Specialist perinatal mental health services provide care for pregnant women and people with complex mental health needs. Services support the development of relationships between parent and baby, as well as providing women and people with mental health needs advice for pregnancy planning. Timely access to good quality perinatal mental health services can provide a range of long-term benefits, including[43]:

- Improving recovery rates and outcomes for the woman or person and their children
- Reducing the risk of premature births and stillbirths
- Reducing the risk of obstetric complications and delayed physical growth in a developing baby
- Reducing the risk of behavioural and emotion problems for the child later in life

NCL's vision is that all women and people, and their families, in its five boroughs who experience mental health problems at preconception, during pregnancy or the postnatal period have access to appropriate, timely, consistent, high-quality and specialist health care. Perinatal Mental Health Services (PMHS) specialise in the assessment, diagnosis and short-term treatment of women in NCL who are affected by a moderate to severe perinatal mental health illness or who have complex needs during these periods. The service model is driven by evidential data and best practice, as detailed in NICE guidance, NICE quality standards and NHSE guidance, as well as local experts' knowledge of local need: experts by profession and experts by experience. The service is provided by Camden and Islington NHS Foundation Trust and delivered by a multi-professional team. Some hospital sites also have specialist staff working in their maternity units who support the mental health of

[42] https://www.england.nhs.uk/mental-health/perinatal/
[43] https://www.england.nhs.uk/wp-content/uploads/2018/05/perinatal-mental-health-care-pathway.pdf

pregnant women and people; for example, UCLH has a specialist perinatal mental health midwife.

NHS LTP set priorities for care quality and outcomes improvement for specialist perinatal mental health services. This included expectations for access, workforce, activity, expanded patient cohort, wider skills mix and ways of working and investment. Access to mental health services is measured as a percentage against 2016 ONS data. For NCL, this means 20,092 births. In 2021/22, the percentage of pregnant women and people accessing perinatal mental health services was 4.9%, falling significantly short of the LTP ambition of 8.6%.

Perinatal mental health

% perinatal mental health access by borough, 2020/21

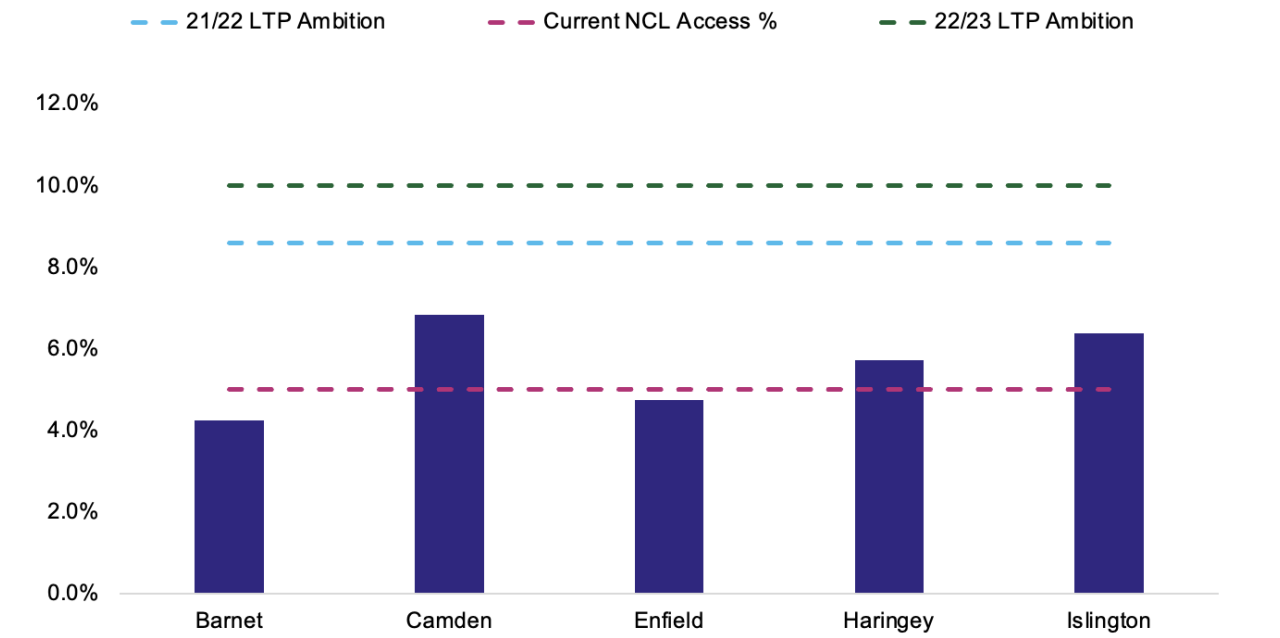


Figure 35: Perinatal mental health access by borough

In 2021/22, only Camden met the NCL year-end ambition, with Barnet and Enfield boroughs having the lowest access (Figure 35). We know that Enfield has some areas of high deprivation, which are strongly associated with mental health conditions during pregnancy[44]. The reduced access to perinatal mental health services will not only have negative impact on the health outcomes for these women, people, their families, but will also widen existing health inequalities. The access target for perinatal mental health services in 2022/23 increases to 10%, therefore NCL has significant steps forward to make in meeting this target.

Any form of mental ill health during pregnancy or early parenthood is a concern. Across NCL, all expectant and new mothers or people should be able to access mental health support and care in a timely manner, to ensure women and people are supported. We have

[44] Impact of socioeconomic deprivation on maternal perinatal mental illnesses presenting to UK general practice https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3459774/#:~:text=Results,more%20marked%20in%20older%20women

a role to play in ensuring everyone receives the help they need at the right time, ranging from prevention through to support for those with moderate or severe mental health needs.

The current access rates are below the LTP ambition and the variation between the boroughs for moderate and severe mental health needs suggests that the health and care system may not be meeting these needs. Perinatal services have been included as part of a recent review of mental health services in NCL and as part of this, NCL will be looking at opportunities to further support investment into specialist perinatal services to support meeting the LTP access target.

"Having a specialist team who knew how to deal with her mental health needs was really important. Once she got the help it was amazing, but she had to ask for it - it wasn't presented to her. There could be lots of other mums out there struggling, without getting the support they need." NCL Better Births: A participatory action research project, Summer 2018

Compliance against Ockenden Immediate and Essential Actions (IEAs)

The first Ockenden Report, published in December 2020, outlined seven IEAs. Nearly all sites in NCL have been found to be 100% compliant against these initial IEAs. The Royal Free Hospital was found to be at 90% compliant in one of the domains relating to guidelines used in maternity services being up to date. An audit indicated that a number had passed their review date. Since this was found to be the case, nearly all of the guidelines have been updated following the internal Trust process. At the time of writing there remains a small number of all guidelines that have been updated and are awaiting final sign-off by internal committees. Once signed off, the reported compliance against the IEAs will need to be assured by the regional NHSE maternity team.

IEA Total Compliance- Phase 2 audit (March 2022)				
IEA	Royal Free London NHS Foundation Trust	North Middlesex University Hospital NHS Trust	University College London Hospitals NHS Foundation Trust	The Whittington Health NHS Trust
IEA 1- Enhanced safety	100%	100%	100%	100%
IEA 2- Listening to women and families	100%	100%	100%	100%
IEA 3- Staff training and working together	100%	100%	100%	100%
IEA 4- Managing complex pregnancy	100%	100%	100%	100%
IEA 5- Risk assessment throughout pregnancy	100%	100%	100%	100%
IEA 6- Monitoring fetal wellbeing	100%	100%	100%	100%
IEA 7- Informed consent	100%	100%	100%	100%
Workforce total	90%	100%	100%	100%

Figure 36: NCL provider compliance with initial seven IEAs.

The final Ockenden Report, published in March 2022, outlined an additional 15 IEAs (Appendix G). It is expected that implementation of these IEAs will make a significant contribution to the delivery of safe maternity care. The NCL LMNS will be focused on delivering these and ensuring that all sites across NCL are compliant with the recommendations.

Care Quality Commission (CQC) ratings

The CQC regulates and inspects all health and social care services in England, including all maternity services. The inspections cover antenatal services, pregnancy units, maternity assessment centres, labour wards, postnatal services and neonatal services[45]. During inspections, five key questions are asked:

- Is the service safe?
- Is the service effective?
- Is the service caring?
- Is the service responsive to people's needs?
- Is the service well-led?

The ratings from inspections are on a four-point scale: outstanding, good, requires improvement and inadequate. The most recent maternity ratings for NCL units are outlined in Figure 37.

Hospital Site	Formal CQC inspection rating	Unannounced CQC inspection rating
Barnet Hospital	Good (August 2016)	Not re-rated (June 2021)
North Middlesex Hospital	Good (September 2021)	N/A
Royal Free Hospital	Inadequate (October 2020)	Requires improvement (May 2021)
University College Hospital	Good (December 2018)	N/A
Whittington Hospital	Good (July 2016)	N/A

Figure 37: NCL maternity units CQC ratings

The Royal Free Hospital's maternity service was rated inadequate by the CQC following an unannounced visit to the site in October 2020. The visit was in response to concerns related to the service's response to a serious incident. This was a focused inspection and the activities of inspection only considered the safe and well-led domains. Key lines of enquiry in each of the other areas (effective, caring, responsive) were not looked at. The Royal Free Hospital maternity service was rated inadequate in both the safe and the well-led domains. The hospital was issued with a warning notice and asked to take immediate actions to improve with regard to these domains.

An improvement plan was put in place with immediate effect and two other unannounced inspections were carried out at the Royal Free Hospital and Barnet Hospital, in May and June 2021 respectively. After these inspections, the Royal Free Hospital's rating improved from 'inadequate' to 'requires improvement', due to the significant improvements made since the inspection in October 2020. Barnet Hospital services were also reviewed, and they were found to have applied learning from the changes made at the Royal Free Hospital. Barnet Hospital's maternity services were not re-rated and retained their previous inspection rating from 2016 of 'good'.

[45] https://www.cqc.org.uk/help-advice/help-choosing-care-services/choosing-maternity-care

Data quality

This section outlines some important findings about maternity service provision in NCL, and the outcomes of those that use services. Although it has been possible to present some data around services, there are elements which have been more difficult to collect and interpret because of the quality of data in the sector. For example, the ethnicity of pregnant women and people who use services in NCL is not currently well recorded. The accuracy of this data is fundamentally important when considering some of the findings relating to the differential outcomes outlined in this section. This poor data quality makes getting a clear picture of performance and outcomes of services challenging.

In order for NCL to improve its maternity outcomes, work is needed to improve the maternity data set to ensure that the right data is more consistently collected, and that this feeds through at a system level to ensure appropriate oversight of services. The current arrangements around data recording rely to an extent on manual counting and returns, which is also not sustainable in an increasingly digital age and considering current pressures on staffing. There is a considerable opportunity to improve the maternity data set in NCL and automate data flows; the ICS will need to separately consider how best to resolve this at a system level.

Conclusion

There are many factors that may contribute to a pregnant woman or person's outcome and experience of maternity services. This section has explored the variance in outcomes of using maternity services in NCL and also the quality of those services. It has shown that there may be disparity in outcome of maternity care, based on your socio-economic status, ethnicity and where you live in NCL. It has also shown that in many respects, maternity services in NCL are high-quality and deliver a high standard of care compared to national targets and recommendations. There is however, an opportunity to do more to improve the outcome of those who use maternity services and to take into account more fully the diversity of our population and ensure that data around maternity bookings is improved.

2. Better utilisation of the range of maternity capacity offered in NCL

NCL offers a range of different settings for pregnant women and people to deliver their baby. Currently, these are not utilised in an equal way, with many pregnant women and people either choosing to deliver or being recommended to deliver in an obstetric-led setting. This can create pressure on this type of capacity, whilst it appears that the other options available to pregnant women are under-utilised. This section explores this variation in the use of current capacity and highlights that further work is needed to understand whether we have the right type of capacity to meet the needs of those that choose to give birth in NCL hospitals.

Maternity services should be set up to deliver safe and personalised care. This means taking account of the choices of pregnant women and people, and also ensuring their birth setting is appropriate for a person's level of clinical need.

As outlined in section 5.2, there are a range of birth settings available for pregnant women and people in NCL. Those who have more complicated pregnancies, for example those with pre-existing medical conditions or who have a high BMI will be recommended to deliver in

an obstetric-led unit. In NCL, all units use the same criteria to determine risk level for a pregnant woman or person, and what that means for where they are recommended to give birth.

Deliveries in NCL hospitals

As outlined in section 5.2 there are six sites where pregnant women and people can deliver their baby in NCL. Overall, in 2019/20 just over 22,500 babies were delivered at these sites. The distribution of these deliveries compared to the other sites in London can be seen in Figure 38.

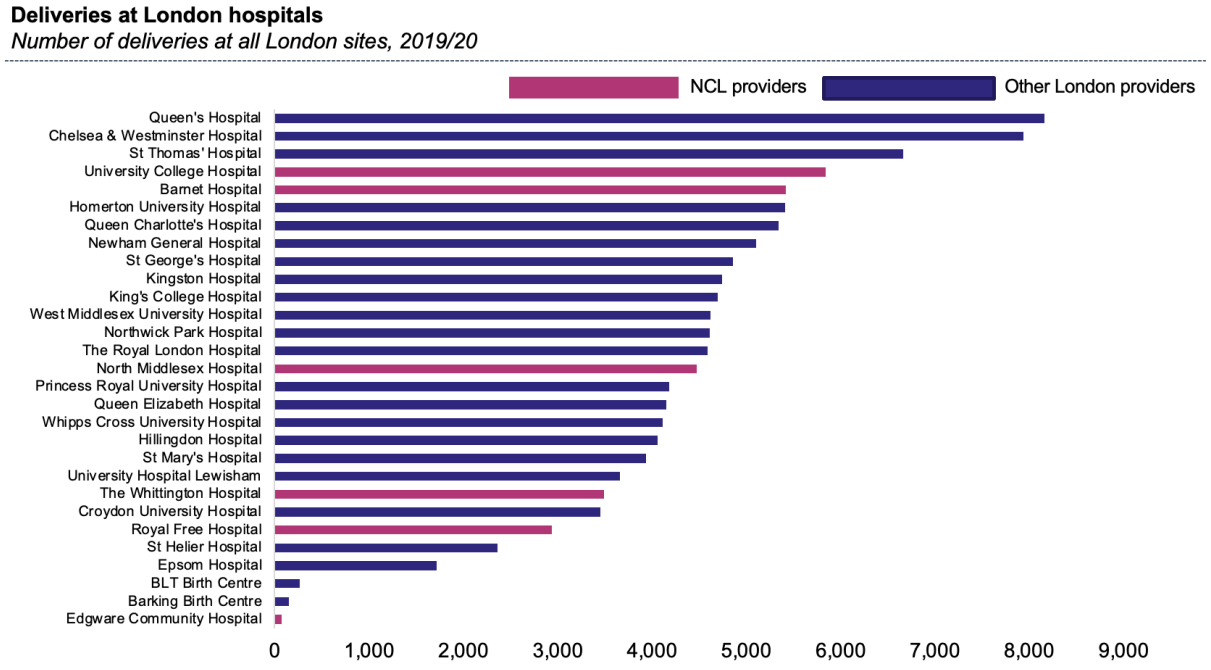


Figure 38: Number of deliveries by London hospitals

Overall, the numbers of births at NCL sites is slightly declining, figure 39 shows the number of deliveries over time at each of the NCL sites.

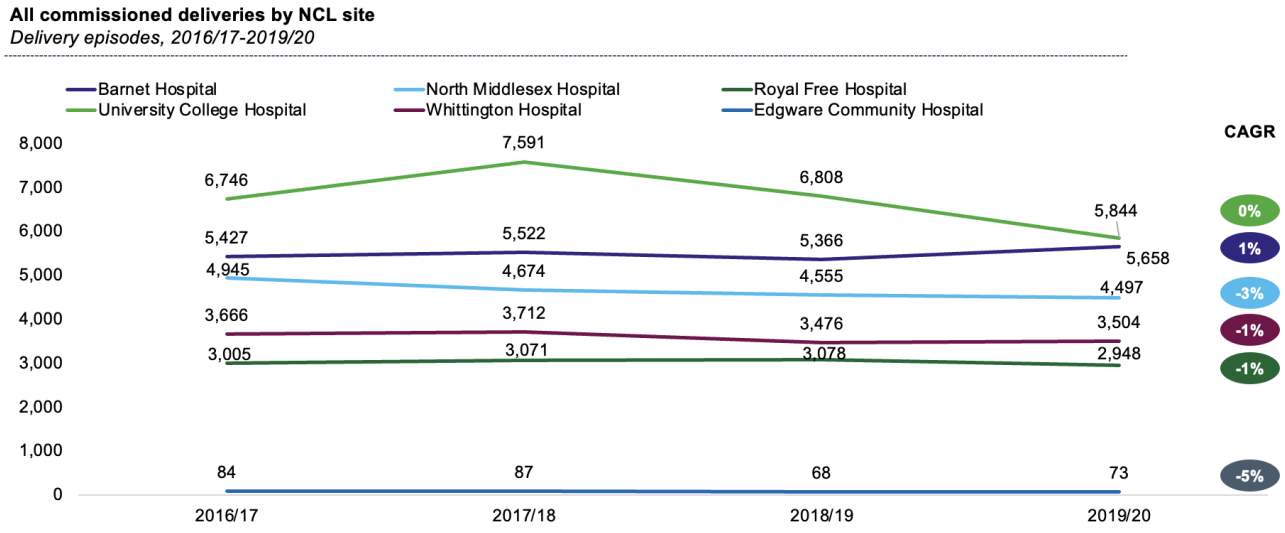


Figure 39: Number of deliveries by site

N.B UCLH data is incomplete for 2019/20 due to transfer to EPIC information systems

The demographic profile of women and people giving birth in NCL differs between each of the units. UCLH has the highest proportion of deliveries in women and people over the age of 40 (10%). In 2019/20, 72% of women and people who delivered at the North Mid live in the 40% most deprived areas, compared to only 26% of deliveries at Barnet Hospital (Figure 40). This difference is due to the catchment population, served by the North Mid in southern Enfield and northern Haringey, being more deprived.

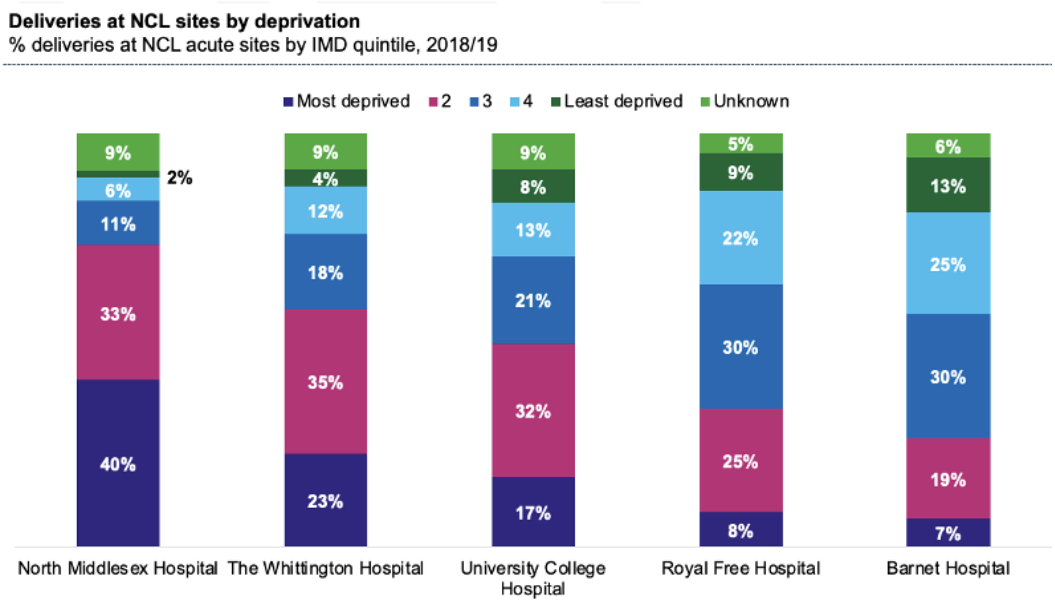


Figure 40: Deliveries at NCL sites by deprivation

The population health section outlines that the number of babies born to those registered in NCL has reduced by 10% since 2018. However, this decline of deliveries is not mirrored in births in NCL sites, and 25% of the deliveries in NCL hospitals for 2019/20 were for those registered outside of NCL. The demand for NCL maternity services is therefore partly driven by women and people coming into the sector for their maternity care. The proportion of deliveries for people resident outside NCL varies by Trust (Figure 41).

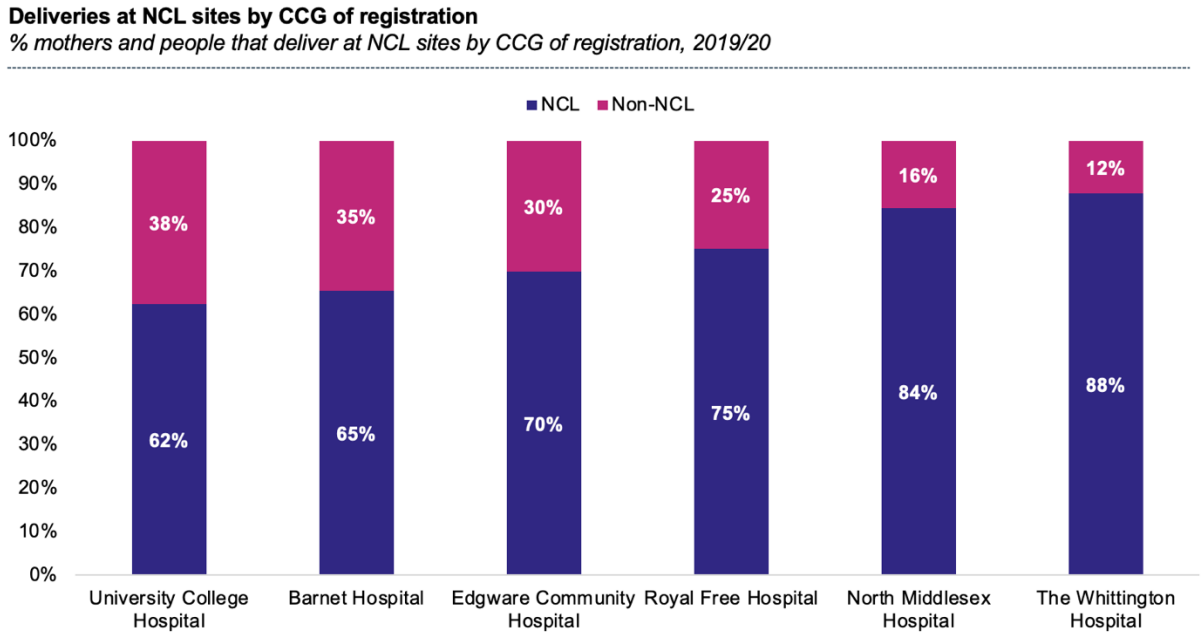


Figure 41: Deliveries at NCL sites by patients' registration

Figure 41 shows that there are some sites (UCLH and Barnet) that have a much higher proportion of non-NCL patients than the other sites. For Barnet, this may be reflective of its very close geographical location to Hertfordshire. For UCLH, this may be more reflective of patients who are accessing some of the more specialist services that they offer. The birth-rate in NCL is predicted to remain largely unchanged in future years; however the flows of patients across ICS footprints point towards the need to consider the impact of these flows into the sector for maternity care.

Choice of different birth settings

The high-level data about sites where pregnant women and people choose to give birth does not represent the full picture when it comes to their choices of birth setting and what this means for units in NCL. There is different utilisation of the birth settings available within units and of home births. The impact of these will be explored below.

Obstetric-led (labour ward) care

As outlined in section 5.2, obstetric-led maternity care is where pregnant women or people are supported by obstetric doctors to deliver their baby. This is delivered on sites with all of the co-located support services that may be needed in case of complications with a delivery (24-hour emergency theatre access, anaesthetic support etc.). For some units, the utilisation of this type of care is reported to be high and labour wards are, at times, running at high occupancy. During times of high demand or low staffing levels, maternity units are sometimes forced to temporarily close to ensure the safe care of pregnant women and people they are looking after. This only happens in the most extreme of circumstances and would be for the shortest time possible to minimise disruption to those giving birth.

Staff have reflected that the complexity of births in NCL may be increasing. There may be many factors contributing to this, such as the age of the pregnant woman or person at the time of birth and prevalence of conditions such as diabetes, obesity and hypertension at the

time of pregnancy. The prevalence of these conditions for those that gave birth between April and December 2021 registered with NCL GPs is shown in Figure 42.

Metric	NCL average
Obesity during pregnancy	13.7%
Diabetes during pregnancy	12.5%
Hypertension during pregnancy	3.2%
Smoking at time of delivery	5.8%

Figure 42: Prevalence of obesity, diabetes and hypertension during pregnancy and smoking status at the time of delivery in NCL April – December 2021

As outlined in the population health section (4.1), the prevalence of these conditions is not equally distributed across our population. The prevalence of obesity during pregnancy is higher for pregnant women of Black ethnicity, and Black and Asian pregnant women have a higher prevalence of diabetes compared to the NCL average (Figure 17). Those that are more deprived also have a higher prevalence of obesity while pregnant (Figure 18).

It is important to note that this data is for those registered with NCL GPs. Those not registered in NCL who are coming into the sector to access maternity care are also likely to be classified as 'complex' when they are risk stratified, given the specialist services available at sites like UCLH.

As a result of the numbers of pregnant women and people using obstetric-led units, these units can face challenges with capacity and patient flow. The NCL LMNS is supporting work around a framework for managing times of high demand, called the Operational Pressures Escalation Levels Maternity Framework (OPELMF), which will track staffing numbers and bed availability across NCL to support better planning and utilisation of mutual aid between maternity units. This will give the ICS greater oversight of the safety of each hospital in the area and will mean hospitals are better able to support each other to maintain safe staff and occupancy levels across NCL.

Midwifery-led birth centres (co-located with obstetric units)

All sites in NCL (apart from Edgware) have an obstetric-led unit, alongside a birth centre which provides midwifery-led care for 'lower' risk pregnancies. During engagement on the themes for the case for change, we heard that birth centre care capacity is not utilised to the same extent as the obstetric capacity. Some sites reported that the utilisation of their midwifery-led units was around 30% or under for 2019/20. This means that currently, pregnant women and people giving birth in NCL are not electing to give birth in these settings in large numbers.

Edgware birth centre utilisation

Edgware Community Hospital hosts the Edgware birth centre. The birth centre is a standalone midwifery-led unit managed by the Royal Free London NHS Foundation Trust. Only pregnant women or people who are deemed to be low risk and meet the criteria for midwifery-led care are recommended to deliver their baby at the Edgware birth centre. They will be under the care of the Edgware continuity of care midwifery team, part of the Royal Free London midwifery service, who will provide care throughout their pregnancy and be

called upon to support the delivery in the same way as for a home birth. If complications arise during delivery, they will be transferred to Barnet Hospital, by ambulance, with their midwife.

The current utilisation of the Edgware birthing unit is low and has been declining over the past three years. In 2019/20, 73 women elected to give birth at the centre, which represents a very small proportion of NCL's total deliveries. This is a trend that has been seen at the two other freestanding birth centres in London. Many pregnant women and people are not choosing to give birth in this setting.

In the final Ockenden Report, standalone birth centres are cited in a number of the cases reviewed. Ockenden recommends a number of immediate and essential safety actions for standalone midwifery-led units to complete, one of which is a detailed operational risk assessment, which should be undertaken yearly. This should be combined with a review of the workforce and bespoke training needs of teams.

Home births

Giving birth at home is something which all the sites in NCL are able to support, although the rate of pregnant women and people choosing this option is low – at around 1% of all births supported by NCL hospitals. This low number of home births can represent a problem for midwifery teams that deliver them. Being able to support a home birth requires a different skillset to those needed to support births in hospital settings. Low numbers of home births mean that it can be difficult for midwives to maintain their skills in supporting them. Many hospital sites staff their home birth services through their continuity of carer midwifery teams, but where there are challenges recruiting into these teams it is difficult to maintain a consistent home birthing service offer.

The North Mid is currently in the process of recruiting a specific team to support home birthing, which represents a different model of supporting pregnant women and people to give birth in their homes and this may be something from which other sites in NCL are able to learn. There may also be opportunities to explore how to provide a home birth service across boroughs in order to ensure that staff deliver at sufficient scale to maintain their skills and have resilience in their staffing.

Conclusion

Births of those that are registered in NCL have decreased by 10% since 2018, however the total number of births in NCL hospitals has not decreased at the same rate and there are significant flows of pregnant women and people who reside outside of NCL coming into the sector to give birth. For some, the choices of birth setting are limited by the risk stratification that takes place, which means that to ensure their clinical safety they are recommended to deliver in an obstetric-led setting. Those that give birth in NCL may be increasingly complex, which is leading to higher utilisation of this type of capacity compared with the others that are offered.

However, there is also the possibility that services in NCL could go further to provide even more personalised care, which would support pregnant women and people to make a choice within the widest range of options available for them. This is something that has come through clearly in patient engagement for the programme and in reviewing engagement done previously. In other parts of London there is a central maternity booking system, which

supports these very important conversations taking place in the right way from the first contact with the maternity service, and in looking at care models there may be an opportunity to explore lessons learned from these initiatives.

"All the information that parents need is there but for some reason it's not connected up ... which means you are stranded. Maybe you just need one key person ... it would definitely make it a lot easier for mums and dads." - NCL Better Births: A participatory action research project, Summer 2018

"[there are] too many sources of information, and uncertainty about which sources to trust, a reliance on written rather than verbal communication and assumption that women have the information they need, or know where to look for advice"

"It should be the patient that makes the decision not the consultant/midwife."- Patient Focus Group, May 2022

There is an opportunity to explore whether the current maternity capacity is best aligned with the needs of the NCL and non-NCL populations using the services. This would need to be done through complex demand and capacity modelling, taking into account flows of patients in and out of NCL, patient choice (and how this can be further supported) and also the complexity of the maternal population.

3. Supporting maternity workforce sustainability

NCL maternity units recently received an uplift in funding following the initial Ockenden Report. This means that their funded midwifery establishment is in line with the recommended Birthrate Plus level. However, there is further work to do to recruit into the funded posts to ensure that vacancies do not impact on patient care and the experiences of staff working in maternity services. Midwifery recruitment is, and will continue to be, an ongoing challenge and focus for the NCL LMNS.

Obstetric ward round arrangements are complaint with RCOG standards with the exception of one NCL hospital, however there are plans in place to address this through recruitment of additional obstetric staff.

Midwifery staffing

In determining safe staffing of maternity units, organisations nationally use the Birthrate Plus planning tool. Endorsed by NICE, the workforce planning tool assesses the needs of women and people for midwifery care throughout pregnancy, labour and the postnatal period, covering both hospital and community settings[46]. Data is then used to calculate the required number of midwives required for a particular unit.

Following the publication of the initial Ockenden Report and the concerns identified with the staffing of the maternity unit at Shrewsbury and Telford NHS Trust, the Department of Health granted hospitals additional recurrent funding to bring midwife establishments in line with the Birthrate Plus requirements. In NCL, this meant an uplift of over £1.5 million to contribute

[46] https://birthrateplus.co.uk/an-overview-of-methodology-and-its-development-within-the-uk/

directly to maternity services staffing distributed across each of the hospitals. This funding is to support both midwifery and obstetric uplifts and for NCL has meant a total of 27.1 additional WTE in the midwifery establishment. Figure 43 shows the previous and new establishments for midwifery staffing across NCL maternity units.

Provider	Establishment prior to Ockenden funding	Additional WTE funded via Ockenden	Current establishment	WTE Vacant	% Vacancy rate
North Middlesex University Hospital	211.88	6.2	218.08	5.79	2.65%
Royal Free London	338.98	4.4	343.38	5.34	1.56%
UCLH	267.87	11.5	279.37	34.86	12.50%
Whittington Health	165.38	5	170.38	29.09	17.00%

Figure 43: Previous and new midwifery staffing establishments at NCL units, March 2022

This funding was released in July 2021, and Trusts have been working to fill additional posts, as well as vacancies already within their previous establishment. The increase in establishment has meant that overall, vacancy rates across NCL Trusts have increased; however, there is lots of collaborative work ongoing to fill the vacancies with permanent staff, and in the short-medium term, to fill staffing gaps with bank and agency staff to meet the Birthrate Plus requirement. The vacancy rates for midwives across NCL units varies significantly, which is shown in figure 44.

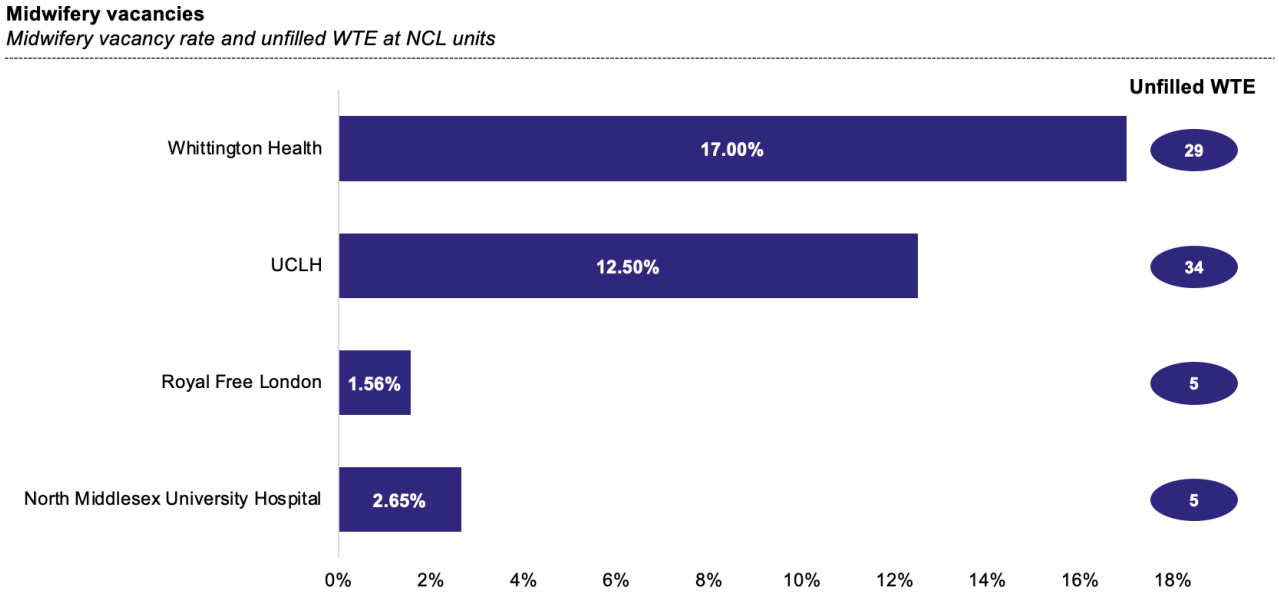


Figure 44: nursing and midwifery vacancies within the maternity services at NCL sites

Recruitment of midwives (as well as nurses and allied health professionals) has become increasingly difficult in London. Brexit has meant that there has been less migration from Europe, and the rising cost of living in the capital has contributed further to the challenges hospitals face to fill vacancies.

There are also challenges derived from the type of staff leaving posts. The midwife population is comparatively older than other NHS workforce groups and higher numbers are reaching retirement age. Finding staff who have the knowledge, skills and experience of these midwives is also a challenge.

Despite this, NCL units have found an innovative way to attract midwives into both temporary and permanent posts in the sector. This has been done through:

- The creation of a joint recruitment model with the temporary staffing provider, to offer a collaborative approach to the provision of bank midwifery opportunities. This will include an agreed recruitment and selection process and harmonised payment rates
- Successful midwives can work at any of the Trusts in NCL, rather than applying to multiple staff banks
- Once recruited, midwives can access in-house specialist mandatory training for free if they do a required minimum number of shifts
- Midwives then have fast tracked access to a substantive job should they want to join a Trust permanently
- Maternity units in NCL are part of the Capital Midwife consortium approach to the recruitment of internationally educated midwives. Forty candidates were requested during the initial phase. All Trusts in NCL have committed to supporting larger numbers throughout 2022

Consultant obstetrician presence on the labour ward

Consultant obstetricians are senior doctors with specialist qualifications in delivering babies and providing medical care to women and people while pregnant, during labour and after birth. They have extensive skills to manage complex and high-risk pregnancies and can perform interventions to assist the delivery of a baby, such as the use of forceps or a ventouse and carrying out a caesarean section.

The Royal College of Obstetricians and Gynaecologists (RCOG) previously published guidance around the number of hours of consultant cover per week, based on the number of births in a unit[47]. However, the new agreed standard is focused on the frequency of consultant-led ward rounds on a labour ward. The RCOG states that acute obstetric consultants need to conduct twice daily ward rounds as a minimum, one of which should be in the evening[48]. This RCOG standard is also reflected in the final Ockenden Report, which includes an essential action that states: 'Multidisciplinary training and working together must always include twice daily (day and night through the 7-day week) consultant-led and present multidisciplinary ward rounds on the labour ward.'[49] The RCOG are working with the Department of Health to create a standard equivalent to Birthrate Plus for obstetric staff, which is not yet published.

[47] https://www.rcm.org.uk/media/2359/safer-childbirth-minimum-standards-for-the-organisation-and-delivery-of-care-in-labour.pdf
[48] https://www.rcog.org.uk/media/igqfguvs/roles-and-responsibilities-of-the-consultant-workforce-report-june-2021.pdf
[49] https://www.ockendenmaternityreview.org.uk/wp-content/uploads/2022/03/FINAL_INDEPENDENT_MATERNITY_REVIEW_OF_MATERNITY_SERVICES_REPORT.pdf

All NCL obstetric-led units are compliant with the new Ockenden standard, with Whittington Health experiencing the greatest challenge with this, due to historic connections between their gynaecology and obstetrics on-call rotas. Whittington Health has plans to increase their consultant establishment. Until that point, Whittington Health is increasing the on-call commitment for the obstetric team, to facilitate twice-daily obstetric-led ward rounds whilst this recruitment in under way.

4. Matching neonatal intensive care capacity and need

The review of the current state of neonatal services in NCL has highlighted that at times the NICU (level three) sites in NCL (UCLH) do not have sufficient cot capacity to look after pregnant women or people who go into early labour and the sickest babies that require specialist care and support. This lack of capacity impacts on the care of these pregnant women and people, and babies. This section will explore the evidence for this, and the associated challenges for babies, their families and staff working in maternity and neonatal services.

Neonatal admissions

The NHS neonatal service specification suggests that neonatal units should be, on average, at less than 80% occupancy. This allows for the local neonatal network to flex during times of high demand, ensuring that there is space for all babies to be cared for within the network, at an appropriate unit for their level of need. Average occupancy levels above 80% have been found to be associated with increased mortality[50].

In NCL, the number of babies being admitted to neonatal units has declined slightly between 2018/19 and 2020/21 (by 4%). The reduction in overall need for care may be linked to the slight reduction in births at NCL hospitals in recent years, as well as the impact of the national ATAIN Programme, which is a national improvement programme focused on avoiding term admissions into neonatal units.

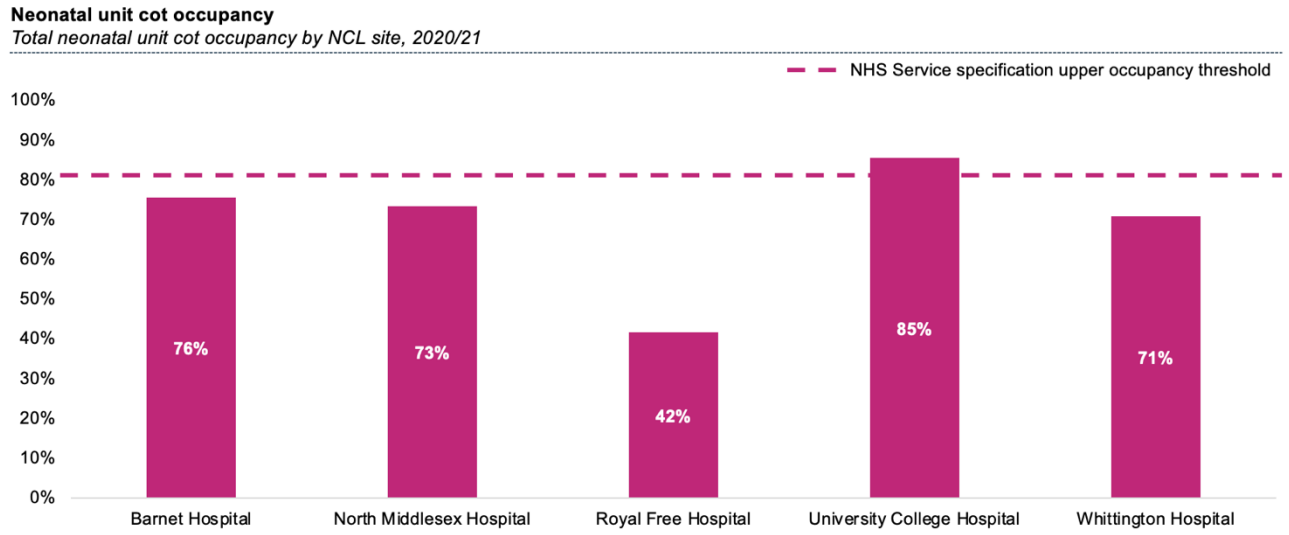


Figure 45: Neonatal unit cot occupancy at NCL units

[50] NHS England and NHS Improvement. Neonatal Critical Care Transformation Review, 2019. Available online: Implementing-the-Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf (england.nhs.uk) [accessed March 2022]

Whilst the overall admissions to neonatal units has seen a small decline, the usage of high and intensive care capacity has remained the same. This means that in NCL the neonatal unit at UCLH was on average 85% occupied, which is higher than the standard set out in the NHS neonatal service specification.

As UCLH is the designated NICU (level three unit) in NCL, high occupancy of this unit can have a significant impact on the critically unwell babies and labouring pregnant women or people in the rest of the sector. Many of these babies will be born to pregnant women and people who reside outside NCL, given that 38% of UCLH's deliveries are from those who live outside NCL.

There are also challenges with capacity at GOSH. As described in section 5.2, GOSH is the designated surgical NICU for NCL hospitals to refer babies to, for certain conditions that require surgical intervention soon after they are born. Babies are transferred there from sites with a co-located maternity unit. GOSH is also the centre for treatment of conditions at a London and national level. Analysis of admissions to the GOSH neonatal unit in 2020/21 shows that only 19% of their total neonatal activity was for babies whose family resided in NCL. Of all the babies admitted to GOSH in this year, 98% of the care days delivered were classified as either intensive, or high dependency care (38% of which was intensive care – the highest acuity of neonatal care).

Analysing the overall occupancy for GOSH in the way that has been done for other NCL units is challenging because there are multiple units within the hospital that a baby may be admitted to depending on their level of clinical need. Their NICU has 10 cots, however there are two other intensive care units on their site where a baby might be admitted, for instance the specialist cardiac intensive care.

During the clinical engagement for this programme, staff told us that LNUs (level two units) often find it difficult to secure a cot space for a baby, or labouring woman or person at 27 weeks or under who need to be transferred to UCLH. This can lead to either delays in transfer, or transfer to a different unit outside of NCL. These situations can be extremely stressful for both families and staff.

Figure 46 is an example of a situation we were told about during clinical engagement, of the impact that high occupancy of NCL's NICU (level three) can have on families and staff.

Threatened labour for a mother of 25-week gestation twins at Barnet Hospital – Barnet neonatologist

'I came onto the labour ward in the late afternoon and was told there was a pregnant woman with twins who was threatening labour. She was 25 weeks pregnant. The maternity team had contacted UCLH (our designated NICU) for an in-utero transfer but had been told there were no neonatal cots there. They had spoken to three other nearby units with NICUs, but there were no cots at any of those either.

I then tried to arrange a transfer by calling five other units – all outside London. They were all unable to accept the transfer. I finally tried a hospital as far as Devon, but they also had no available cots to accept the mother.

By this point, it was much later and I felt like there weren't many more options to try. I informed the mother that if we could not transfer her then her babies would be born at Barnet and transferred after birth.

Later in the night, after many more phone calls and discussions with many clinical teams, two cots were found at a West London hospital. The mother was eventually transferred at around midnight.'

Figure 46: Patient example of clinical services in NCL

The above example highlights the time and effort that clinical teams have to put into ensuring pregnant women and people and their babies are cared for in the right unit for their level of need – time and effort that takes them away from direct clinical care. There is an NHSE target for babies born at under 27 gestation to be delivered in a maternity service with an on-site NCIU. London does not regularly meet this target. As a result of this, the London Maternity Clinical Network and London neonatal ODN are in the process of updating the 2018 pan-London in utero transfer guidance. The aim of this is to improve the process for in utero transfers across the region, ensuring pregnant women and people give birth in a setting that is most appropriate for them and their babies' level of need, and also to reduce the burden on clinician time in securing an appropriate labour ward, bed and cot for the baby or babies.

In 2020/21 NTS data shows that 40 babies were transferred from LNUs or SCUs in NCL to NICUs (level three) outside of NCL. Some of these other units were as far as Chelsea and Westminster Hospital, and St George's Hospital in Tooting (both of which are surgical NICUs). This is an indication that the NICU capacity (both surgical and non-surgical) is not sufficient to care for babies along agreed ODN pathways. The capacity at GOSH may be particularly impacted by out of area referrals into their intensive care units.

The result of this is that families of critically unwell babies had to travel significantly further to see their baby in a neonatal unit. This is particularly impactful for families at a time of extreme stress and anxiety, especially in the context of the level of need for an unwell or premature baby requiring NICU (level three) support. Babies that need so much additional support when they are born can stay in NICUs for up to three months, so this increased

distance is likely to hugely impact on the ability of parents to see their baby, making it much more difficult to do so – both emotionally and financially.

Although UCLH is the designated NICU (level three unit) for NCL, it looks after babies across the spectrum of levels of acuity. Analysis of their occupancy across the different types of capacity shows that there is high occupancy at the lower levels of acuity. This may suggest that babies are not always able to be swiftly transferred back to a local neonatal unit (LNU) when they are ready to graduate from intensive care. This could be for a number of reasons, including LNU cot capacity (sometimes cots can be closed due to staffing challenges) and the availability of NTS to support the transfer.

In order to achieve timely transfers back to LNUs for babies that are ready to move out of intensive care, there also needs to be consistency in visiting protocols and facilities for parents within all units. Where receiving units do not have parenting facilities, or have restrictive visiting protocols, this presents a significant barrier to safe and effective neonatal patient flow across the region, as well as to the experience of parents and families.

This section has highlighted that there is an opportunity to optimise the use of neonatal intensive care capacity in NCL, which would mean more babies are able to be looked after along the agreed ODN pathways of care and ultimately the experience of neonatal care in NCL would be improved for families and babies. There is a need to model level three capacity available within NCL at GOSH and UCLH, to see if it is sufficient to meet the increasing demand for this type of care.

5. Consider the sustainability of the Royal Free Hospital Special Care Unit (SCU)

This section explores The Royal Free Hospital Special Care Neonatal Unit – which is a level one unit. It provides only the lowest acuity care of all the neonatal critical unit types.

The number of admissions to this unit in 2020/21 meant its cots were 42% occupied, making it difficult for staff to maintain their skills for looking after critically unwell babies.

There are restrictions on the admission criteria to the unit; it does not accept babies born under 34 weeks in gestation, meaning that the number of admissions requiring significant support is low. When babies are admitted over 34 weeks and require a high level of neonatal care, it represents a potential safety risk as staff do not have significant experience delivering this type of care. This risk is currently mitigated by employing additional fixed-term consultants with neonatal expertise.

The additional posts and other measures have provided short-term mitigation to the clinical risks caused by the low admissions to the unit. However, in the longer term, the clinical risk around the unit remains and it will continue to be difficult to staff the unit in a sustainable way as it is currently set up.

London context

The Royal Free Hospital neonatal unit is classified as a Special Care Unit (level one). This type of unit can only provide the lowest acuity care of all the neonatal critical unit types. SCUs (level one) are unable to provide extended periods of respiratory support to unwell and premature babies. Generally, these types of unit are used to transfer babies to a hospital

more local to a family when their baby is well enough to be looked after in a lower acuity setting.

There are very few of these types of units in London, the Royal Free Hospital being one of only three (West Middlesex Hospital and Epsom Hospital being the other two) in the London ODN footprint. The short distances between hospitals in London mean that the need for this type of unit is less compared with rural settings, where distances between hospitals is much greater and it is more appropriate to repatriate a baby to a more local hospital with an SCU to reduce the travel burden on parents to see their child in a unit. Following the publication of the NCCR, the London ODN is encouraging all ICS regions where there is a SCU to review the appropriateness of this in the context of their local system.

Activity

The Royal Free Hospital neonatal unit looks after a low number of babies compared to the other units in NCL. It does not accept babies born under 34 weeks' gestation, nor women or people labouring under 34 weeks. The number of admissions into this unit has been declining by 12% every year since 2018/19. The occupancy of the unit in 2020/21 was 42%, meaning over half of its cots were not occupied on any given day. The low numbers of babies being cared for in this unit meant that in 2020/21 just three babies of a birth weight below 1,500g were admitted and only 120 respiratory care days were delivered.

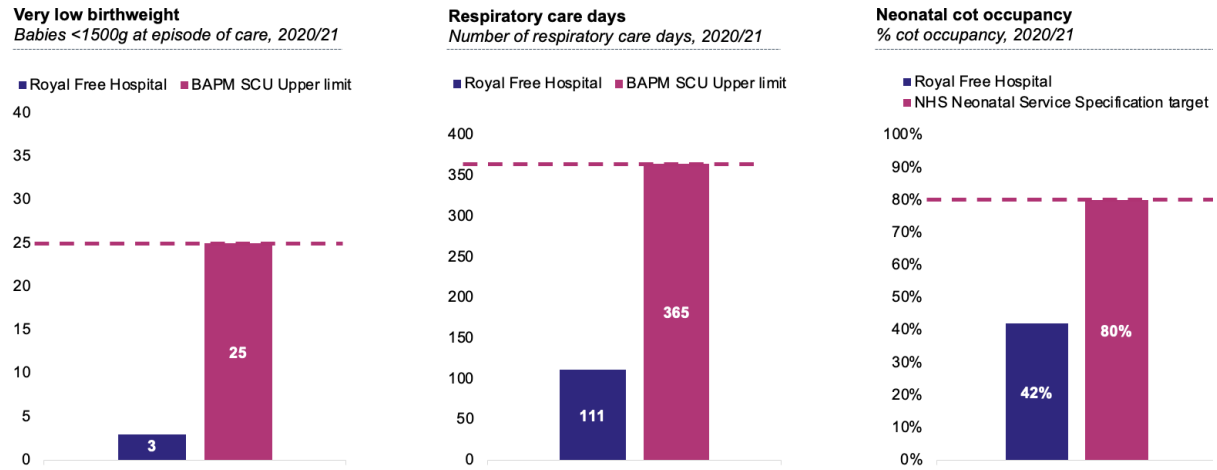


Figure 47: Number of admissions, respiratory care days and special care occupancy of the Royal Free neonatal unit in 2020/21 compared to national standards for a Special Care Unit (level 1)

This level of activity means that the unit falls below the upper threshold suggested in the BAPM standards for a Special Care Unit (level one). The BAPM standards are in place to ensure that staff caring for babies needing respiratory support have the required experience and competencies to do so. Being so far away from the upper threshold highlights that it is difficult for staff to effectively maintain their skills in looking after infants that need support with their breathing.

Staffing of the SCU

In term of medical staffing, The Royal Free Hospital's paediatric service, including the SCU, does not have any middle grade (ST3+) trainee paediatric doctors and is staffed by consultants and junior trainee doctors (foundation year, ST1/2) only. Out of hours coverage for the site is provided by resident on call consultant staff. This is unique for a paediatric service and means that the overall paediatric consultant workforce on the site is large.

The low number of admissions creates a challenge for the consultant and nursing staff to maintain the required competencies to look after babies needing respiratory support. There has also been consistent feedback from foundation year doctors that working in the unit does not represent a good training experience for them.

To mitigate the low numbers of admissions to the unit, the Trust has put in place actions to ensure it can be safely staffed:

- Recruitment of seven fixed-term paediatric consultants with neonatal expertise, who provide an additional level of non-resident out of hours support to the resident on call consultant paediatricians
- Consultants and junior trainee doctors rotate to the LNU (level two) at Barnet Hospital and the NICU (level three) at UCLH and have regular simulation training to maintain their competencies to care for babies who require respiratory support
- Rotation of nursing staff with both UCLH and Barnet Hospital neonatal units, to support training and maintenance of competencies

These actions have provided short-term mitigation to the clinical risks caused by the low admissions to the unit. However, in the longer term the clinical risk around the unit remains and the Trust believes it will continue to be difficult to staff the unit in a sustainable way. Over time, the skills and experience of the consultants with neonatal expertise who were recruited will wane and further interventions may be required to ensure the clinical safety of the unit.

Maintaining the clinical safety of the unit and funding the mitigations in place is also expensive and given the very low level of occupancy of the unit, there are inevitably questions about whether it provides good value for money.

Interdependency between maternity and neonatal services at the Royal Free Hospital

All hospital sites providing obstetric-led care need to have appropriate neonatal facilities on site that can support babies should there be complications with their birth. At the Royal Free Hospital this currently represents a challenge, as the neonatal unit is only able to look after babies who require level one care.

For those booking their maternity care at the Royal Free Hospital, if their babies are likely to need a higher level of neonatal care, a transfer to a higher-level neonatal unit can be arranged before the woman or person goes into labour.

This may be particularly relevant for pregnant women and people who have other complex medical (category B and C) conditions. All other obstetric-led sites in NCL have the capability to manage pregnant women and people with complex conditions, however the Royal Free Hospital is the only site that does not have a neonatal unit that can match this level of complexity when it comes to looking after premature or unwell babies.

In some instances, complications with a baby cannot be predicted and sometimes babies born at the Royal Free Hospital require urgent transfer to another hospital with an LNU (level two) or NICU (level three). Figure 48 shows the number of completed transfers to another neonatal unit. It highlights that 24% of the admissions to the Royal Free Hospital SCU were

transferred to another unit in 2020/21 – significantly higher than transfers from LNUs (level two) which can manage babies with a greater degree of complexity. This high transfer rate is also notable considering there are restrictions on those who can give birth at the unit (none under 34 weeks), and those known to have babies requiring complex care are transferred to other units before they go into labour.

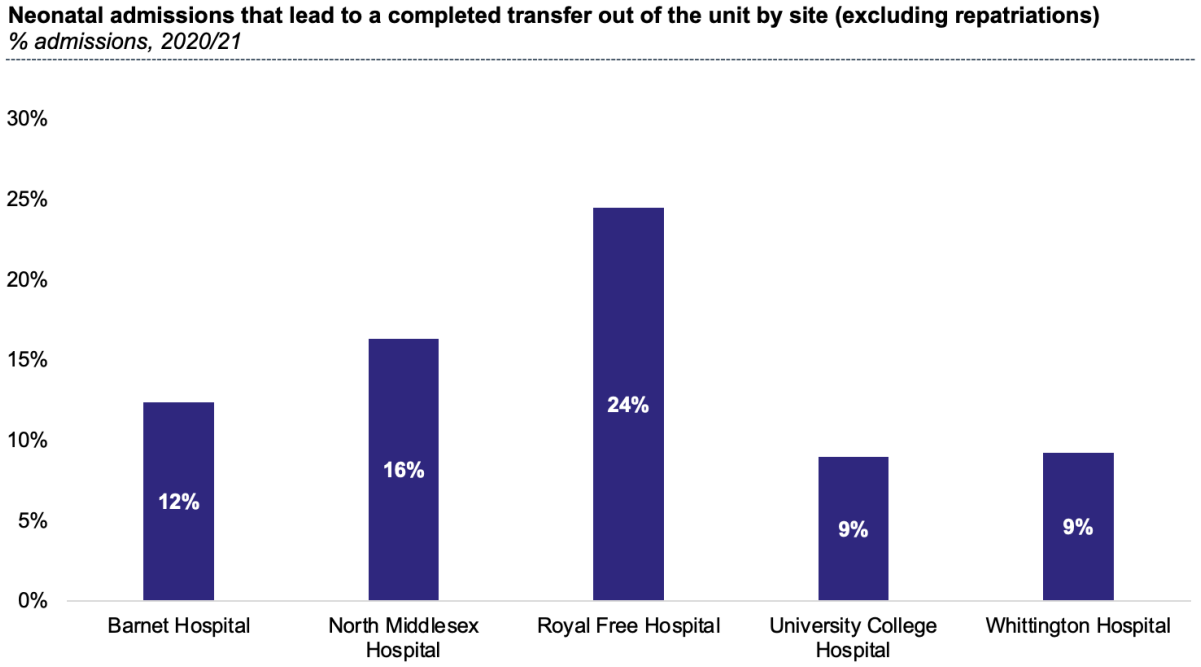


Figure 48: Percentage of completed neonatal transfers as a proportion the unit's total activity for 2020/21

The impact of late pre- or postnatal transfer

The impacts of the increased likelihood of transfer on pregnant women, people and their families are significant when this happens postnatally. It means the separation of the baby and the woman or person who has just given birth at a critically important time for the development of the bond between them. And although the impact may be slightly less if transferred to another hospital's care prenatally, the impact of late and unexpected changes on a pregnant woman or person's experience of care should not be underestimated. This is particularly important when you consider these pregnant women or people may already have a complex medical history, with a risk of complications, and so may be feeling particularly vulnerable.

6. Minimising avoidable admissions to neonatal units

Wherever possible, admissions to neonatal units should be avoided and as much care delivered outside of a neonatal unit as possible – be that on the labour ward, or in the community. This section will explore where there may be further opportunity to reduce the number of admissions to neonatal units, as well as the time a baby spends in a neonatal unit, except for in situations of compelling medical indications. In NCL, varying provision of community neonatal services means that there are unnecessary admissions into our units. This section will explore where there may be further opportunity to reduce the number of admissions, as well as the time babies spend on neonatal units.

The importance of reducing admissions to neonatal units

Maternity and neonatal services should be set up in a way that minimises separation of the woman or person that has given birth and their baby. This is vitally important for the experience of patients at a highly emotive and stressful time; there is also overwhelming evidence of the impact on the health outcomes that this has on the woman or person that has given birth and their baby[5152]. Being physically close to one another and having skin-to-skin care has been shown to reduce stress in newborns, help with the transition to postnatal life[53], reduce the risk of neonatal hypothermia[54] and help to facilitate reflexes of the baby which assist in the baby's positioning and latching to breastfeed.

Avoiding unnecessary separation of mothers and babies has been a focus nationally. Through the ATAIN Programme, there is an aim to reduce mother-baby separation by early preventative actions and improving transitional care arrangements[55]. Another important factor to consider when reducing unnecessary family and baby separation is improving discharge pathways to home. The Neonatology GIRFT report found significant variation in community outreach support available upon discharge[56].

"For the duration of my pregnancy care was fantastic. Unfortunately, after labour - an emergency caesarean at 33 weeks then being separated from my son (who was taken to neonatal) I was taken to the postnatal ward with other mothers with their newborns." - Care Opinion, UCLH patient 2018

NCL community neonatal provision

Although this case for change is primarily focused on care delivered in acute hospitals, it is important to recognise that the community outreach support available to neonatal teams has an impact on whether a baby needs to be admitted to a neonatal unit and how long a baby stays in hospital. Currently, where you live in NCL has an impact on the services that can be accessed for babies at home.

The differences in access to neonatal outreach care in the community are particularly relevant for the 'lower' acuity conditions that mean full-term babies being admitted to a neonatal unit, such as jaundice. As can be seen in Figure 49 in some parts of NCL, treatment for this – phototherapy - is available in the community, whereas in others, the baby would need to stay in hospital to receive this treatment.

[51] Crenshaw JT (2007) Care practice #6: No separation of mother and baby, with unlimited opportunities for breastfeeding. Journal of Perinatal Education Summer 16(3): 39–43
[52] Sobel HL, Silvestre MAA, Mantaring JBV, III, Oliveros YE, Nyunt US (2011) Immediate newborn care practices delay thermoregulation and breastfeeding initiation. Acta Paediatrica 100(8): 1127–1133
[53] Moore ER, Anderson GC, Bergman N, Dowswell T (2012) Early skin-to-skin contact for mothers and their healthy newborn infants. Cochrane Database of Systematic Reviews (5): CD003519
[54] Takahashi Y, Tamakoshi K, Matsushima M, Kawabe T (2011) Comparison of salivary cortisol, heart rate, and oxygen saturation between early skin-to-skin contact with different initiation and duration times in healthy, full-term infants. Early Human Development 87(3): 151–157
[55] https://www.england.nhs.uk/mat-transformation/reducing-admission-of-full-term-babies-to-neonatal-units/
[56] Neonatology: GIRFT Programme National Specialty Programme, April 2022

	Barnet	Enfield	Haringey	Camden	Islington
Phototherapy	Not available	Not available	Not available	Not available	Available
Administration of IV antibiotics	Not available	Not available	Not available	Not available	Available
Monitoring of weight and growth	Available	Available	Available	Available	Available
Monitoring and establishment of feeding plans	Available	Available	Available	Available	Available
Blood tests	Available	Available	Available	Available	Available
Naso-gastric tube management	Available	Available	Available	Available	Available

Figure 49: Community outreach neonatal services across NCL

The current provision of community neonatal outreach programmes is not consistent between our boroughs and does not represent equitable access. Although NCL services are serving many families very well and many admissions to neonatal units are avoided, there is an opportunity to increase the provision of these very important community services. This will help facilitate discharge of babies from hospitals and ensure families can remain together after birth, regardless of where they live.

7. Addressing workforce vacancies and variation in provision and access to allied health professionals across neonatal units

Delivering neonatal care requires a high level of specialist skills, experience, knowledge and training. Optimum staffing of a unit requires a specialist multidisciplinary team (MDT), bringing together their expertise to support not only extremely vulnerable babies, but also their families.

This section will explore some of the challenges with neonatal nursing staffing, in addition to exploring the opportunity around improving the provision of and access to allied health professionals in NCL neonatal units.

The final Ockenden Report states that neonatal providers must ensure sufficient numbers of appropriately trained consultants, tier two staff (middle grade doctors or advanced

neonatal nurse practitioners) and nurses are available in every type of neonatal unit (NICU, LNU and SCU) to deliver safe care 24/7 in line with national service specifications.

Neonatal nursing vacancies

Neonatal nurses provide the day-to-day care for babies in a neonatal unit. The type of care being delivered (special care, high dependency care, intensive care), will determine the numbers of nurses that are needed to support the safe care of sick and premature babies on a neonatal unit. For babies that require intensive care support, it is recommended that they are nursed on a 1:1 basis. Due to the specialist nature of the care given in neonatal unit, nurses working there also do some additional training that makes them Qualified in Specialty (QIS), meaning they have an additional qualification and are experts in delivering neonatal care (although this is not a prerequisite for a registered nurse to work in a neonatal unit).

Nationally, there are challenges in recruiting to the neonatal nursing workforce. This is reflected in some, but not all, areas of NCL. There are vacancy rates ranging between 0% - 23% (Figure 50).

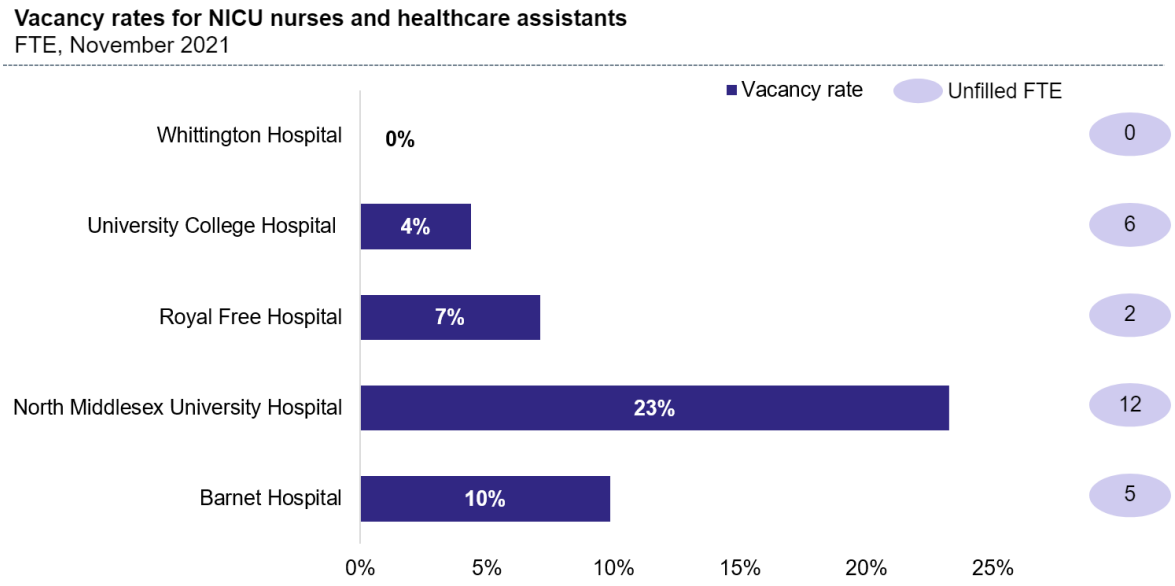


Figure 50: Vacancy rates for NICU nurses and healthcare assistants

High vacancy rates in neonatal nursing workforce place a strain on services and mean that teams heavily rely on bank and agency staff to fill gaps. Vacancies also put a particular stress on the neonatal nursing workforce, as they mean that fewer staff can be released to do their qualification in neonatal service training, which is integral to the staffing of a safe neonatal unit. The number of vacancies at the North Mid means that they cannot open their full establishment of cot spaces. By running at reduced occupancy levels, they are able to meet BAPM recommendations. The largest workforce gap is in the qualified in specialist band 6 nursing group and options such as international recruitment and development of current band 5 nurses are in progress to address this workforce need.

NCL neonatal units also require an overall uplift in nursing establishment to be compliant with Dinning/CRG workforce tool[57]. A London ODN review of the nursing workforce in July 2021 highlighted that an additional 26.1 WTE in the funded establishment were required across NCL neonatal units, with the majority of these gaps being at band 6 level. To support this increase in establishment, and on the back of the NCCR, NCL units will receive additional funding in 2022/23 of £431K to help bridge the gap in funding cot side nursing staffing.

The role of allied health professionals in a neonatal unit

To holistically care for the breadth of needs of a baby admitted to neonatal unit and to ensure the embedding of developmentally sensitive care in a unit, the provision of allied health professionals (AHPs) in units is essential. Working across the MDT, AHPs play a key role in reducing the need for support in the future, especially for the cohort of more complex babies, where some professions overlap. These disciplines comprise: dietitians, occupational therapists, physiotherapists, speech and language therapists (SLTs), pharmacists and psychologists, amongst others.

These members of staff have wide and varying input into the care of a neonate, which can go on to have an impact on the child's life in the long term; for example: SLTs have a role in the early identification of feeding and swallowing difficulties and facilitate positive feeding experiences; dietitians assess nutritional needs, develop eating programmes and monitor growth progress; and occupational therapists have a role in supporting families to provide developmentally appropriate care to their infants both in the unit and when they are discharged.

Inconsistent allied health professional provision and access in NCL neonatal units

The NCCR highlighted the need for joined-up workforce planning around the provision of AHPs within neonatal units. National recommendations have been published for the allied health professions on their professional association websites (Appendix H).

AHP provision has been identified as a national and regional priority, and as a result the London ODN has appointed a lead AHP for physiotherapy, occupational therapy (OT), dietetics, speech and SLT and psychology to help inform its strategy relating to allied health resourcing across London. The ODN have undertaken a benchmarking exercise to understand what the provision and access to AHPs is across London neonatal units.

This benchmarking exercise has found some common themes across NCL AHP provision:

- There are some areas of excellent practice – for example, UCLH provides consistent early intervention through a combined lactation and SLT role, Whittington Health, Barnet and Royal Free teams all have well-established, embedded occupational therapy services that have a lead role in infant family-centred care, and Whittington Health and Royal Free OTs are also the lead for the community services – providing seamless follow-up to the community for eligible babies
- There are some significant gaps in provision. For some disciplines at some sites, there is no access to AHP support, and it can be a challenge to recruit experienced

[57] Neonatal nurse staffing tool that provides an analysis of cot-side staffing nurse staffing based on a unit's care activity and nursing budget, identifying any shortfall against the national neonatal service specification

neonatal therapists into posts. For example, the North Mid currently does not have access to any occupational therapy support

- There is a need to increase AHP provision across all NCL units. AHP staffing has been compared with the recommended professional body levels and NCL is consistently under these levels for all disciplines. For example, there is a 3.8WTE deficit in the dietetic workforce and a 2.67 WTE uplift required for physiotherapy
- Apart from at UCLH (which has a dedicated 0.8WTE psychologist to support families and staff on the unit), the psychological support available to families may be insufficient. A review has found that psychologist cover varies and there is little or no provision for outpatient work as part of their roles. Posts are generally funded either by paediatrics or CAMHS, which means there is no ring-fenced neonatal time as part of their role. Some sites do not have access to a private room for a therapist to see families and staff
- For many sites, the AHP staffing model is fragile. In many units, AHP input is provided by therapists who provide support to the neonatal unit as part of their job plan covering a number of other areas, such as the paediatric inpatient wards and paediatric outpatients. This makes the model fragile and puts pressure on the therapists' time as they are managing a number of competing priorities
- Funding arrangements are unclear and complex. Many sites do not have dedicated budget for AHPs within their neonatal budget, and therapy posts sit within the wider paediatric budget. For this reason, it is difficult to unpick what funding is allocated to the neonatal unit specifically
- AHPs do not have a great deal of neonatal peer support. Given the small numbers of neonatal AHPs working across NCL services, there is not a great deal of educational or peer support for those working in NCL units. For example, over 70% of SLT staff reported no current access to a neonatal trained SLT for supervision – this may impact on staff skill development and retention

The areas above highlight that there is an opportunity to improve the access to AHPs within NCL neonatal units. Given what has been outlined around the challenges, and some of the difficulties recruiting into AHP posts, there may be an opportunity for hospitals in NCL to work in a more joined up way in terms of their allied health professional support, and this is something that should certainly be explored, with support of the London ODN, along with any other options.

8. Having the right maternity and neonatal estate

Well-designed, well-built and well-maintained estates are a critical component of a positive birth experience. The main objective for maternity and neonatal services is to provide safe care for both the mother or person giving birth, and their baby, in a comfortable, relaxing environment. Across NCL, pregnant women and people currently have differential access to estates that meet best practice. This section explores the current challenges with maternity facilities.

Hospital facilities should provide privacy, preferably labour rooms with en-suite bathrooms and space for the birth partner to join delivery when possible. Every pregnant woman and person should feel that they have choice and control over their labour and birth to the extent possible. Most babies receive care at their parent's bedside before going home with their family, but approximately 10% require some type of specialist support at birth. The hospital environment and facilities need to be supportive of the needs of the family, whether that is at the bedside, in a special care unit, local neonatal unit, or intensive care unit.

Currently, the maternity and neonatal estate at the Whittington Hospital does not meet agreed modern standards for maternity and neonatal facilities. For example, although there are en-suite facilities in the birth centre on the site, they do not currently have these in their labour ward rooms. This does not provide the optimum environment for those in labour, and does not comply with the Department of Heath Building Note[58].

In terms of the neonatal facilities, there are challenges around the space that is allocated for the unit, given the number of cots. This means that there is not the optimum amount of space between each of the cots that would be in place if the unit was built now. These risks are mitigated by excellent staff and clinical processes; however, this does create increased pressure on staff to safely deliver the service.

All our facilities could be better utilised to enable parents to stay with their sick babies when they must be admitted to a neonatal unit. Parents should still be the primary caregiver and should be supported by the clinical practice team to deliver as much cot-side care as feasible. The facilities at the Whittington in particular could better support this, as currently there is insufficient space for carers in the neonatal unit, which is overall not a parent-friendly environment.

"[Women spoke of] poor internal comfort conditions including lighting and temperature... lack of privacy on noisy wards [and] dirty or messy facilities." - NCL Better Births: A participatory action research project, Summer 2018

"I gave birth at Whittington hospital. It's really difficult to navigate as it's huge and sometimes some doors are locked and others are open (depending on the time of day). Being 8 months pregnant walking around in the dark trying to enter the hospital can be frustrating." - Patient Panel Member 2022

The focus of the case for change is on the clinical considerations around care, including how the estate impacts on clinical care and there is an opportunity to improve maternity and

[58] https://www.england.nhs.uk/wp-content/uploads/2021/05/HBN_09-02_Final.pdf

neonatal facilities within NCL, ensuring that the estate does not detract from the care or birth experience and meets best practice standards.

There is an ongoing process within the ICS to make best use of capital funding over the next few years and a collaborative process for prioritising the capital available against clinical priorities. In subsequent phases of the Start Well programme, we will need to consider the capital implications of delivery of best practice models of care and incorporate this into ICS prioritisation process for allocating capital funding.

5.6 Summary of findings

The challenges that NCL maternity and neonatal services face and the opportunities to improve these services have been outlined in this section.

For maternity services, there are areas of variation in terms of outcomes of care, and in some areas, varying quality. Poorer outcomes in maternity and neonatal care are associated with deprivation, and in some cases, ethnicity. It is difficult to disentangle to what extent deprivation and ethnicity each contribute, because of the intersectionality between them. There are many factors that contribute to maternity care outcomes. The evidence points to some clear opportunities for further work on prevention and early intervention with communities, including the social determinants of health. These elements are out of scope of the programme, but findings will be taken forward by the ICB and other system partners.

Further modelling is required to ensure that NCL has the right type of maternity and neonatal capacity for those that use the services. Current high occupancy and utilisation of the more complex maternity and neonatal capacity points to increasingly complex service users; the flow of patients from outside of NCL for the specialist services in the sector must also be considered.

The current low volumes of admissions to the Royal Free Hospital special care unit (level one) highlight a potential sustainability challenge. Effective mitigations are in place, but these are costly and may not represent a long-term solution to the staffing of the unit.

Challenges with workforce are also clear – in both the maintenance of specialist skills due to low volumes of activity (the Royal Free Hospital SCU and home birthing being examples) and also ensuring enough of the right staff to support the safe staffing of services. These issues point towards further joint working across NCL to mitigate some of the risks that they pose.

A review of patient experience of services highlights the need for services to communicate clearly and with compassion about maternity care and choices. Services in NCL may need to go further in offering greater personalisation and continuity in maternity care, which have been identified as important factors in patients' experience of care and outcomes.

Maternity and neonatal services are inextricably linked to one another and effective working between the two services is essential for both the outcome for the pregnant woman or person and the best possible start in life for a baby. They should be considered together when thinking about how NCL may capitalise on the opportunities to improve services for the future.

Section six: Children and young people's services

6.1 Vision for children and young people's services

The first few years of life have a profound effect on physical, cognitive and emotional development in childhood, likely influencing health and wellbeing outcomes in later life[59]. Health and wellbeing support and intervention spans a vast array of services provided by multiple cross-sector organisations such as education, the NHS, the voluntary sector, child and adolescent mental health services (CAMHS) and local authority services. When a child or young person is unwell, it can be a really worrying time for them, their families and carers. Accessing the right information, advice or treatment, at the right time is crucial.

Urgent and emergency care should be fully integrated, to ensure that any child or young person attending the ED is seen by the right people, at the right place and in the right setting. If an emergency operation is needed, perhaps for appendicitis, children and young people, their families and carers need to be confident every hospital is able to offer the same standard of care. If a child or young person needs more specialist care, transfer to another hospital needs to be timely and smooth, within defined pathways to prevent any delays to treatment.

Waiting for a diagnosis or an elective procedure can be stressful and all children and young people in NCL should receive prompt diagnosis and treatment. Children and young people, their families and carers should feel empowered and supported to manage health conditions. This means ensuring that the voice of children, young people and parents/carers is heard.

6.2 Introduction to children and young people services

Paediatric service provision and activity in NCL

The provision of paediatric services in NCL varies between sites. Five sites provide non-specialist paediatric care, each of which has a co-located ED. The specialist eye provider Moorfields has an emergency front door whist GOSH and RNOH, do not.

The majority of NCL providers have dedicated paediatric inpatient beds, with the exception of Moorfields and Chase Farm which only provide day case surgery for children at their sites (Figure 51).

[59] https://www.gov.uk/government/publications/health-profile-for-england-2018/chapter-4-health-of-children-in-the-early-years

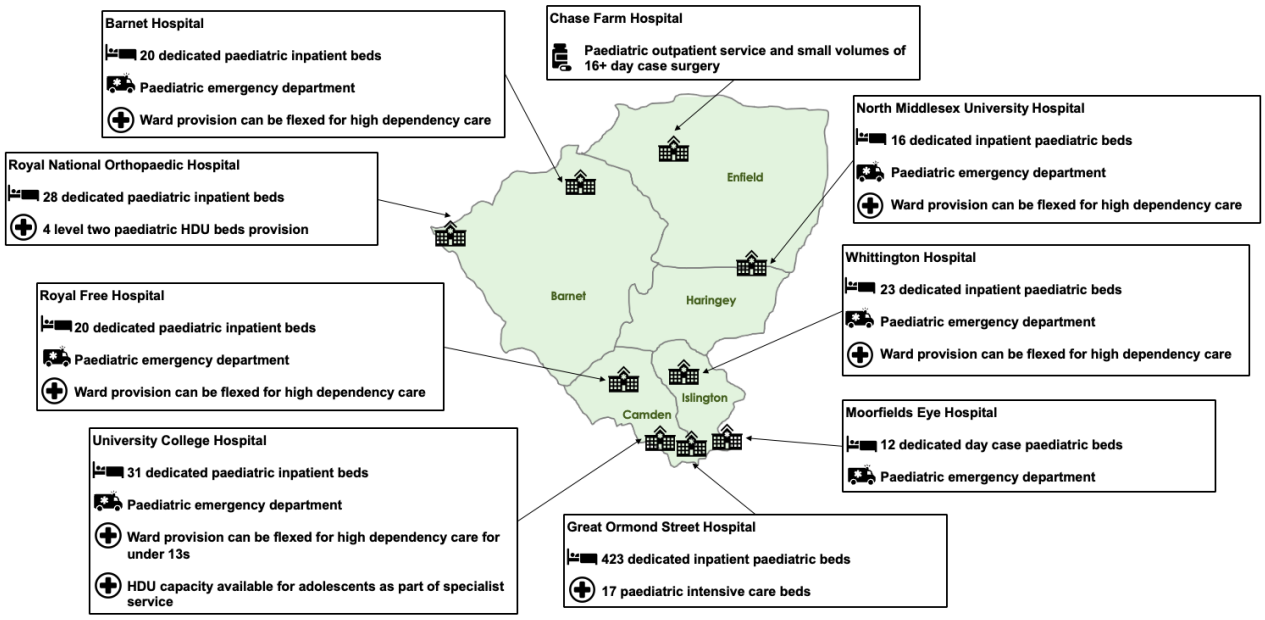


Figure 51: Paediatric service provision across NCL

The configuration of services in NCL also sees variation in the volume of activity at each site. In 2019/20, there were over 152,000 paediatric attendances at emergency departments in NCL, with a third of all attendances occurring at North Mid. These ED attendances resulted in over 27,000 non-elective admissions at NCL sites, of which over 16,000 (62%) were overnight admissions. North Mid and Barnet hospitals had the highest number of non-elective admissions, which corresponds with their greater number of ED attendances.

All providers in NCL offer planned paediatric inpatient care, although the scale of the offer varies markedly between different sites. In 2019/20, there were over 62,000 elective paediatric cases at NCL sites, of which over two thirds were carried out at the specialist sites/centres, GOSH, RNOH, Moorfields and UCLH. Of the non-specialist elective activity, over 85% was carried out as a day case.

Children and young people's services in NCL cover a very broad range of services, which have been outlined in Appendix J. It is impossible to reflect every single specialism in a document of this type, so we have therefore looked thematically at the types of care pathways and focused on examples of where the pathways are complex and there are opportunities for improvement. Opportunities explored in this chapter are therefore broader than the maternity and neonatal services section of this report.

There are ongoing areas of work that form some of the context of this review and we have touched on these in the narrative. Most significant is a regional improvement programme derived from the Long Term Plan, which is focused on priorities for children and young people; there are opportunities identified in this document which could enhance this ongoing programme of work. There are also significant interdependencies with the current reviews of mental health and community services which both cover children's services and children's cancer services, which are explored within this chapter.

Thematic areas reviewed in this chapter of the report are:

Emergency care in a hospital setting for children and young people – this is where a child or young person attends an emergency department for immediate care. This is one part of a much longer pathway of care involving both primary care and community services. This programme of work has not looked at the end-to-end care pathway and we therefore focus in this document on attendances at a hospital, their volume and acuity. We make links to other programmes of work where there may be opportunities to be explored to improve the care pathway.

Emergency surgical pathways for children and young people – this is where a child or young person needs an emergency operation or procedure, which could be as a result of an accident for a broken bone or serious cut that needs repairing, or for a medical condition such as appendicitis.

The GIRFT report highlights the current delivery models for low-complexity emergency surgery found across the country:

- **Non-specialist Trust:** emergency care for children with conditions such as testicular torsion or appendicitis is provided by local, non-specialist hospitals
- **Specialist Trust:** where the specialist hospital has an ED, emergency care is often centred within those specialist hospitals

There are a range of conditions that could be looked at and we cannot explore all of them in this document. We have chosen to focus on two conditions, appendicitis and testicular torsion, alongside the anaesthetic skills that are needed to support emergency surgery.

Care for children and young people with long-term conditions (LTCs) – there are a range of long-term conditions that affect children and young people. The most common of these is asthma, which affects more than one in 10 children, through to diabetes, epilepsy and red blood cell disorders. The management of all LTCs is crucial early in life to support better outcomes into adulthood. With the right support and advice, it should be possible to help children and young people and their families manage their long-term condition better on a day-to-day basis at home and reduce the requirement for hospital services, particularly as an emergency.

In this chapter we focus on emergency admissions for children with long-term conditions, which can be impacted by the quality and comprehensiveness of the care planning, and management.

There are links between the prevalence of long-term conditions and wider determinants of health, and there is a need to link from this programme into wider work around public health and prevention which is not explored within Start Well. Work is already ongoing in this area through public health and prevention, and the children and young people's regional improvement programme, and this review amplifies areas that may become a focus.

Planned (or elective) care for children and young people – this is planned care such as a review with a hospital consultant, or an operation that can be done on a planned basis, where the child or young person can wait before treatment.

Elective low-complexity surgery can be delivered in the following ways:

- **Centralised:** child and family travel to the specialist hospital for surgery
- **Hub and spoke (network):** specialist paediatric surgeon travels to a local hospital (spoke) to deliver elective surgical care. This model is often used when there is a challenge in recruiting a surgeon with the required expertise
- **Local care:** general surgeon with paediatric interest delivers surgery at the local hospital

Examples of planned care include an operation to take out a child's tonsils or a planned operation to correct a squint. These still need to be carried out in a timely way, but they are not urgent in the same way that an operation is needed for appendicitis.

National policy and guidance

A review into paediatric general surgery and urology, published in February 2021, by GIRFT aimed to identify variation in NHS care and then learn from it. The report outlined several challenges related to paediatric surgery, alongside a set of recommendations.

The report found a significant degree of variation in the delivery of paediatric general surgery and urology across England, suggesting there are several opportunities to improve care for children receiving this care.

Review of the existing models of care across England highlights that there is a trend for increasing volumes of low-complexity elective and emergency surgery being concentrated in specialist Trusts. Surgical care of babies and children with the rarest and most complex surgical conditions is being spread across specialist trusts, spreading expertise too thinly.

Ensuring that children’s voices are heard by hospitals is critical. On many occasions set out in the GIRFT report, clinicians had a clear understanding of where improvements to quality of care could be made, but communication links to management were lacking.

In non-specialist Trusts where communication between the ward and board was strong, leadership were able to recognise the need to treat children in a safe, child-friendly environment. However, it was noted that Trust leadership can often be under pressure and issues surrounding paediatric surgery are not always top priority. Developing stronger clinical leadership and having responsive relationships between management and clinicians is essential to improving the care children receive.

The GIRFT programme also highlights the need for a child-friendly environment of care, given its importance for the wellbeing of the child and their family at an already stressful time. The report highlighted that there was variation between sites across the country, with some trusts not having the environment that is optimal for a child’s experience. GIRFT suggests that mixed adult/child clinics, wards and theatres can have a negative impact on the child’s experience and raises possible safeguarding issues. This is important, as a negative healthcare experience can have long-lasting impacts on a child.

Local context

The Start Well programme is focused on general paediatric services and care provided in a hospital setting with the full scope of the review set out in Appendix A. There are other programmes of work and services focused on early intervention and prevention, community and mental health services and at the other end of the spectrum the most specialist services, such as cancer care, which are out of scope of this programme of work. This section references areas where there are significant interdependencies between services that are out of scope and initiatives within them that will impact on hospital-based care.

Children and Young People's Transformation Programme

The Children and Young People's Transformation Programme was established nationally to oversee the delivery of the children and young people's commitments in the Long Term Plan[60]. The programme's vision is that every child and young person in England will have equitable access to high-quality health and care services, which are tailored to their needs, and available when they require them. These services will be joined up across health and social care settings to ensure the best outcomes are achieved, enabling every child and young person to achieve their goals and life potential.

The Children and Young People's Transformation Programme has three key aims:

- **Integration:** developing new models of care and integrating services for children and young people, known as the triple integration: 1) primary and secondary care, 2) healthcare with social care and education, 3) physical and mental health. Proven models of care will be scaled up across the country
- **Improvement:** improving the quality of care for children and young people with long-term conditions like asthma, epilepsy, diabetes and obesity
- **Inclusion:** including children and young people in national policy and programme development to ensure that services are designed to meet their needs

In London, a regional improvement programme has been established within each ICS, to provide infrastructure to support the delivery of the national transformation programme. Each ICS in London has been asked to focus on the following areas:

- Emotional health and wellbeing, learning and special educational needs and disability
- Developing out of hospital care
- Improving the management of care for children with complexity and long-term conditions

Across London, delivery of the work programme is supported by the North and South Thames Paediatric Networks and through the children's and young people's infrastructures, which have been established at ICS level.

Good progress is being made in NCL towards delivering on these objectives; work is being led by a small team, including a senior clinical leader and programme director and is drawing in a wide range of colleagues across health, local authorities, and social care. Figure 52 summarises the key areas of focus in NCL.

[60] https://www.longtermplan.nhs.uk

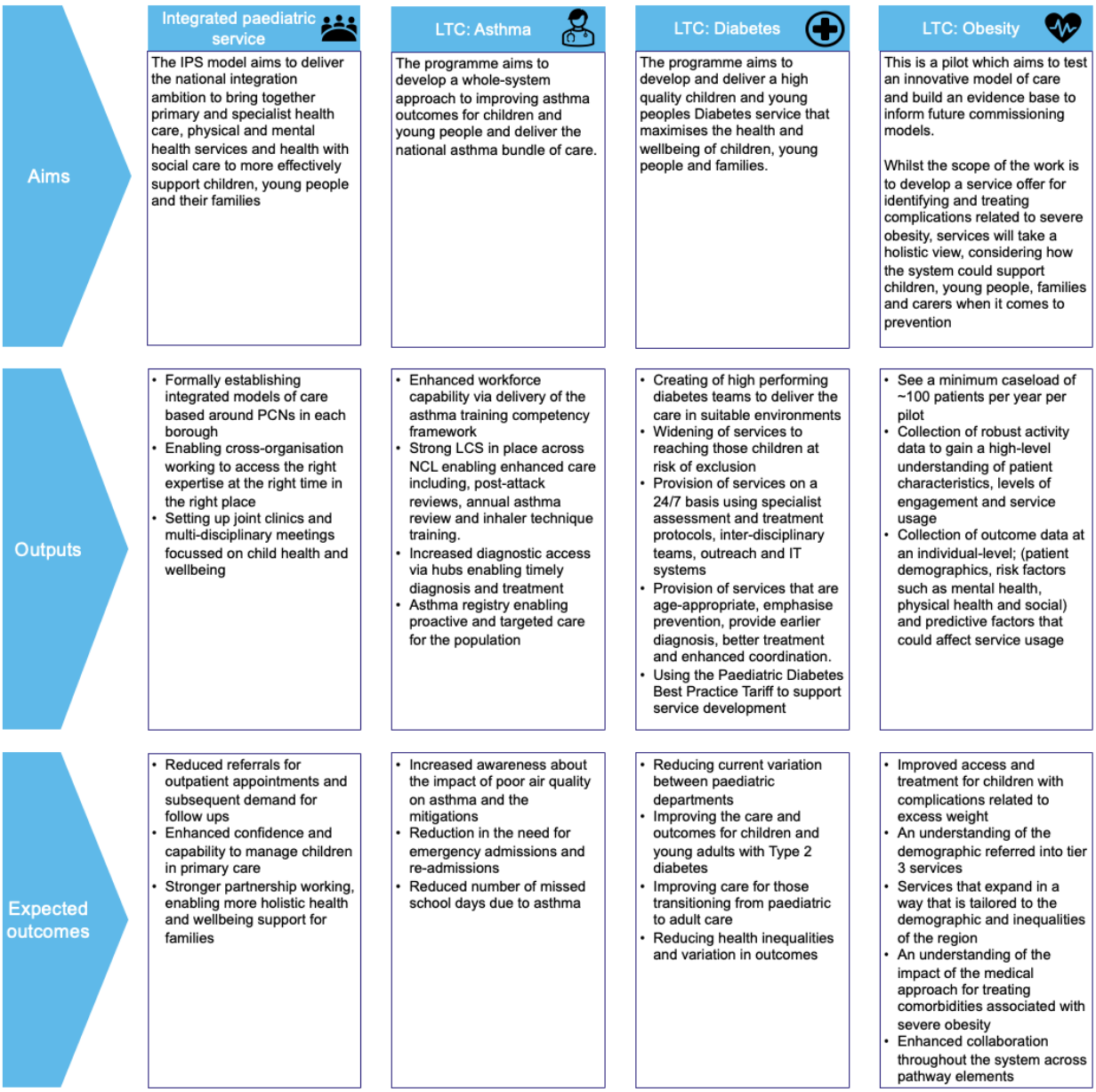


Figure 52: Children and young people transformation programme overview

Interdependencies

There are several local interdependencies that should be considered, including those between neonatal, maternity services, as well as the wider community and mental health services.

Cancer services for children and young people

A key interdependency for the Start Well programme is the management of cancer services, where there are overlaps with more general paediatric services in terms of both staff and infrastructure. Cancer services are commissioned via NHS specialist commissioning, and to reflect the requirements of the national service specifications published at the end of 2021, a children's cancer operational delivery network for North Thames has been established.

The purpose of the network is to make recommendations regarding service configuration that will enable equitable access to comprehensive and integrated care for all children.

Whilst cancer services are out of the direct scope of the Start Well programme, given that there are significant interdependencies at service and site levels, the recommendations made by the ODN will need to be considered in future service design.

Cancer services for children are led by principal treatment centres (PTCs), which are the main, largely tertiary services providing very high dose chemotherapy, stem cell transplants and surgery connected to cancer, for example tumour extraction and radiotherapy.

UCLH is the specialist centre in the North Thames region and beyond for paediatric radiotherapy, providing a full range of photon, proton beam, molecular radiotherapy and brachytherapy to patients. The proton beam centre at the new Grafton Way Building at UCLH is one of just two such centres in the country, the other being in Manchester, and now that it is up-and-running it will avoid many children with complex cancers, particularly brain tumours, needing to be treated abroad.

PTCs are supported in a hub and spoke arrangement by a network of paediatric oncology shared care units (POSCUs). These units provide care closer to home, including emergency access for patients should they have an infection after chemotherapy. Some, but not all, POSCUs are also able to deliver chemotherapy.

Many POSCUs are adjacent to, or within, general paediatric wards and there is of course, some overlap in staffing and facilities between the two, particularly in the management of acute complications of cancer and its treatment.

There is a requirement in the specialised commissioning service specification that POSCUs are co-located with a paediatric ED, as there needs to be 24-hour access to ensure safe patient management, for example as infections in immunocompromised children require immediate treatment[61]. POSCUs designated to deliver higher-risk interventions also need to be able to offer HDU support if a child deteriorates.

NCL cancer services

UCLH and GOSH have historically operated as a joint principal treatment centre for North Thames, with UCLH focusing on the teenage and young adult practice (13 years old and older), and GOSH on the younger children (under 13 years, although some risk stratified patient cohorts in this age group are also managed at UCLH).

Changes to the NHS England specialist commissioning specification for PTCs[62], published in November 2021, require PTCs to be co-located with a level 3 paediatric intensive care unit (PICU) in case a child deteriorates rapidly during treatment. This has required a review of the joint PTC arrangements and after careful consideration, UCLH and GOSH have put forward a proposal to NHSE as the commissioners of the service to make changes to the

[61] https://www.england.nhs.uk/wp-content/uploads/2021/11/1746-paediatric-oncology-shared-care-unit-service-specification-.pdf

[62] https://www.england.nhs.uk/publication/childrens-cancer-services-principal-treatment-centres-service-specification/

designation of the joint service in order to meet these enhanced requirements. An outcome on the proposal is expected over summer 2022.

Through its cancer centre GOSH, already meets the new service specification for the treatment of children under the age of 13, including an on-site level 3 PICU for all ages (0-16 years). It is therefore proposed by UCLH and GOSH that GOSH becomes a standalone PTC for the under-13 cohort, continuing to work in close partnership with the UCLH service, which will seek designation as an enhanced level B POSCU. This will allow UCLH to continue to deliver safe, high-quality care for younger patients (under 13) in the areas in which it specialises, as part of the current joint PTC arrangements, including inpatient admission for some radiotherapy patients and delivery of concurrent chemotherapy (inpatient and day case) for others. Enhancements are proposed to the existing UCLH HDU provision for this younger cohort, which are being evaluated in order to determine compliance with the new cancer specifications and with those for high dependency care. Discussions are ongoing between teams at GOSH and UCLH as to whether any further service changes will be required which would also need to be considered by the ODN and by commissioners.

No changes are proposed for patients aged 13 and above, although a new national specification for teenage and young adult services is anticipated. UCLH has a world-leading teenage and young adult service, which subject to any changes that arise in the national specification, would remain a PTC for patients 13 and over, working as part of a joint PTC for children and young people.

North Mid, Whittington Health and Barnet Hospital (part of Royal Free London) are currently all designated POSCUs. The Barnet POSCU serves a very wide population beyond NCL, including a large part of Hertfordshire. Whilst any changes to the current POSCU arrangements are out of scope of this review, alignment to other key interdependent services will need to be taken into account in any potential service design.

Whilst cancer services are out of the direct scope of the Start Well programme, given that there are significant interdependencies at service and site levels, agreed recommendations by the ODN will need to be taken into account in any future service design.

Community and Mental Health Services

In January 2021, NCL CCG, in collaboration with ICS system partners, started a strategic review of NHS-funded mental health services, and a separate review of community services, to address long-standing inconsistencies in service offer, access and outcomes for the NCL population.

Both reviews covered both children and young people's, and adult services, and these services are therefore out of scope for the Start Well programme. The outcomes of both strategic reviews are important interdependencies for the Start Well programme.

The priority areas identified in the reviews of mental health and community services will need to be taken into account

CYP mental health key priorities:

- Increase capacity to address waiting times for assessment and treatment across CAMHS

- Increase capacity to address eating disorder waits (bring in line with LTP) and roll out community disordered eating service
- Review Crisis Hubs and impact on wider system e.g., understanding the impact of closing crisis hubs

CYP community services key priorities:

- Improve equity in access to children's community nursing, including hospital at home, palliative care
- Address workforce issues within community paediatrics, including looked-after children's health services and review of models across NCL
- Develop medium-long-term plan relating to improved access to therapies (speech and language therapy, physiotherapy and occupational therapy)
- Improve pathways and access to Autism Spectrum Condition (ASC) /attention deficit hyperactivity disorder (ADHD) assessment, treatment, and pre/post diagnostic support

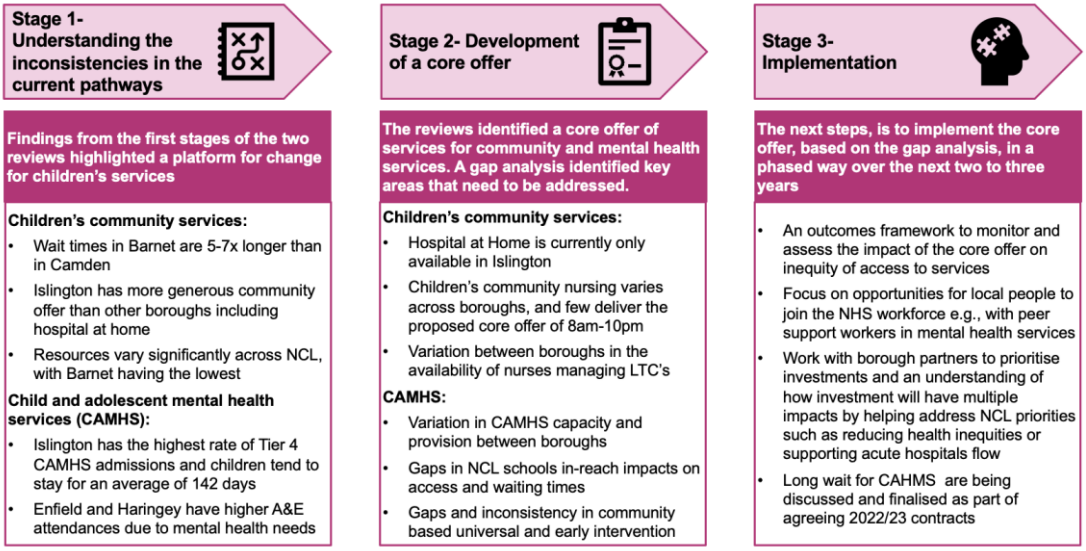


Figure 53: Community and mental health services review overview

Workforce

Paediatric services do not exist in isolation. There are important staffing interdependencies with other services and specialties that need to be recognised and which will be an important consideration in any planning for future services.

Paediatric and neonatal medical workforce

Across most neonatal units in NCL, middle grade paediatric trainees (ST3+) are an important part of the workforce delivering care. Middle grade paediatric trainees are placed on rotations as part of their core general paediatric and neonatal training.

At Royal Free Hospital there is a different medical staffing model supporting the special care unit. The unit is currently staffed by seven fixed-term consultant paediatricians with recent neonatal experience, who are supported by junior medical staff (ST1/ST2 or GP trainees). After hours, a general paediatric consultant and the junior medical staff are resident on site, covering both the paediatric ward as well as the special care unit. There is additional on call backup provided by non-resident fixed-term consultants with recent neonatal experience.

As described in section 5.5, this model is in place to ensure the safe running of the service through the addition of seven fixed-term consultant neonatal posts.

Paediatric surgery
At non-specialist organisations across NCL, emergency paediatric surgery is usually undertaken by adult surgeons, for example emergency care requiring treatment of fractures is usually undertaken by adult orthopaedic surgeons and emergency appendicectomies by adult general surgeons. For elective surgery, such as ENT, this is carried out by both adult surgeons with an interest in paediatrics, and those that are specialist paediatric surgeons. Some specialist elective paediatric surgery is carried out locally across NCL by paediatric surgeons from Great Ormond Street Hospital as outreach.

Paediatric anaesthetics
There is a staffing interdependency around anaesthetics, where many anaesthetists work across both adults and paediatrics patients. This is of such significance that it is covered in a separate section below.

6.3 Patient experience insights

Patient experience and insight into children and young people's services was gathered from primary and secondary sources and is summarised in Appendix F.

Young people and their parents and carers shared feedback under a number of key themes, offering examples of excellent practice, as well as areas for significant improvement. These included:

- Improving communication between Trusts and patients
- Improving one-to-one communication between individual staff members and individual patients, making communication clearer and more accessible
- The environments in which children and young people receive care
- Recognising the importance of the link between physical and mental health

The voices of children and young people, as patients, will remain central to the next stage of the programme, as there is a strong call for improved communication from services with people receiving their care.

"…they felt physical symptoms were 'taken more seriously' than other health problems such as mental health difficulties." - (Young Healthwatch Enfield, May 2019 - February 2020)

"Young people told us that the promotional materials that health and social care services currently provide are not necessarily adapted or appealing to a younger audience" - (Young Healthwatch Enfield, May 2019 - February 2020)

"I was given a console whilst staying at the Royal Free – this made me feel happier and cared for, I wasn't bored." - Young person at specialist insight group, May 2022.

6.4 Local successes

There are examples of successes in the care of children and young people in NCL. Our staff have reflected on some of these successes that have been set up in local communities to support parents in keeping their child healthy and keeping services as close to home as possible.

Below, we have outlined some of these successes in NCL.

Example 1: Hospital at Home, Whittington Health

Whittington Health has set up a hospital at home service for children and young people living in the borough of Islington. Specialist community children's nurses work in partnership with acute paediatricians at both Whittington Health and UCLH, to provide safe care at home for acutely unwell children and young people (0-18) enabling them to be discharged from hospital more quickly or preventing admission in the first place. Expansion of the hospital at home service across other NCL boroughs, is being considered as part of the community services review.

The nurse-led team conduct home visits and can administer IV antibiotics, monitor the trajectory of an acutely unwell child, and provide additional support to enable a carer to look after them within their home environment. The model has been recognised as a model of good practice, with the intention that it is replicated across NCL.

Example 2: ABC Parents, North Middlesex University Hospital

Having a child can be a challenging and anxious time for parents and carers. Parents arriving at ED with their children reflected on the scary experience and that they wish they knew what to do and when. In response to this feedback, North Mid set up ABC Parents to empower parents by sharing resources to keep children healthy and safe. The ground-breaking parent education programme offers free two-day, free of charge, courses to parents and carers in Enfield and Haringey. The aim of the programme is to empower parents and carers to keep children healthy and safe.

The courses provide:

- **Child health advice:** opportunity for parents and carers to gain knowledge and guidance related to health and wellbeing for parents and children
- **Opportunities to learn together:** working with local parents, free courses are provided on lifesaving, first aid and health
- **Community support:** opportunity to meet other parents and carers, build networks, share resources, and get support from Child Health Champions

The course has received positive feedback from parents and carers.

"I'd really recommend this to other local parents – brilliant leaders, invaluable skills taught! Thank you" – ABC course participant

Example 3: 'Super triage' and the 'power hour', UCLH

Work is underway in each NCL borough to develop and deliver integrated models of care through an integrated paediatric service (IPS). The UCLH children and young people's team has been working with GPs and commissioners from two primary care networks (PCNs) in Camden and Islington to improve integrated pathways between primary care and paediatric services. The model involves three core elements: access to advice and guidance to support general paediatric referrals, joint primary care clinics led by primary and secondary care clinicians, and multidisciplinary meetings to provide specialist advice, guidance, and learning. The model seeks to ensure patients receive the right care, in the right place, at the right time, and that this care is delivered through whole system partnerships, centred around whole families.

In the second half of 2021/22, GPs and paediatricians worked together to develop the IT, governance, operational and clinical infrastructure to jointly manage 0–18-year-olds who GPs were intending to refer to general paediatric care.

For the Kentish Town South PCN this involved a weekly four-hour joint clinical session named 'super triage', involving a consultant paediatrician and a GP trainee. The focus was on general paediatric problems, although a broad selection of problems were included for triage. The implementation of 'super triage' and 'power hour' has benefitted children and young people. Waits to be seen have been reduced by months and feedback has been overwhelmingly positive from patients, GPs and paediatricians. Paediatricians and GPs have enjoyed gaining insight into each other's services and the informal communication between clinics about patients and pathways has resulted in smooth operations.

UCLH, Whittington Health and Islington commissioners are now jointly looking at further rollout in Islington and are committed to ensuring that practical resources and evaluation tools are aligned.

Example 4: Supporting better outcomes for children with asthma

Through the paediatric asthma network a number of initiatives have been developed to support children and young people with asthma across NCL.

A paediatric asthma locally commissioned service (LCS) is under development to support primary care to identify, manage and treat children and young people with asthma in the community.

Across NCL clinical teams will use the national asthma training competencies framework, which is due imminently, to refine their knowledge and skills to the most appropriate level, to support children with asthma in a primary care setting.

Children and young people's hubs are being established across NCL to ensure that children and young people with asthma have access to appropriate diagnostic capabilities, to enable earlier diagnosis and proactive treatment and management.

Community-based initiatives have also been implemented to support better asthma outcomes, such as the Asthma Air Quality campaign, where communications materials have been developed to raise awareness about the risks associated with poor air quality for children with asthma**.** School-based programmes will build on excellent work in Islington on

‘Asthma Friendly schools’ to spread this model across the whole of NCL, working across health and education to ensure children with asthma are supported whilst they are at school.

The development and implementation of a paediatric asthma registry within our digital population health management platform will enable frontline health and care professionals to proactively identify gaps in children’s asthma care by using data from all NHS organisations, as well as using data driven insight to target at risk populations and identify variation.

6.5 Opportunities for improvement

Across NCL there are areas of outstanding care for our children and young people, however data analysis and engagement has highlighted that we can do more to better meet the needs of our local population.

There are a number of factors that need to be understood in terms of the analysis of children’s and young people’s services in NCL. First, the huge breadth of services within NCL, particularly given that Great Ormond Street Hospital and UCLH provide care for not just the local NCL population, but also nationally and internationally. Secondly, there is variation between hospitals regarding the upper age definition of a child or young person before they are classified as an adult. UCLH classes patients as paediatric up until their nineteenth birthday, Royal Free London and Whittington Health take the eighteenth birthday as a cut off and North Mid classifies a patient as an adult from their sixteenth birthday onwards. There are some pathways, such as diabetes and CAMHS, where the cut off may vary within hospitals.

For consistency of analysis, in this review we have used the NHS data dictionary definition, which classifies a child or young person up until their nineteenth birthday[63]. There is therefore a disconnect between the cut off for the analysis and some of the ways in which services operationally are managed. Where this is relevant to the analysis, it will be highlighted in the narrative. There is, however, a broader issue about the fact that there is no standard service definition within NCL, which impacts on the way in which children and young people transition into adult services. This is covered in more depth in the opportunities for improvement.

We have identified a number of opportunities to improve care so that all children and young people have access to the same services, no matter where they live, and that care follows a seamless pathway regardless of the age of the child. This chapter will explore those opportunities and outline the case for change for children and young people’s services.

[63] NHS Data Model and Dictionary. Available online: https://www.datadictionary.nhs.uk/nhs_business_definitions/child_or_young_person__community_services_.html

1. Increasing emergency demand and lack of capacity at EDs

Across NCL, the number of children and young people accessing emergency services is increasing. Between April and December 2021, NCL provided emergency care to an additional 73 children and young people a day, compared to the same period in 2016. Staff across NCL have reflected on the challenges in respect of increasing ED pressures and the impact this is having on both patient and staff experience.

This section will explore the impact of increasing emergency pressures and consider the opportunity to optimise admission and attendance avoidance models, both in the hospital and out of the hospital, to ensure that children and young people are being seen by the right people, at the right time and in the right setting.

Paediatric emergency activity

Across NCL, our sites deliver emergency care for 160,000 children and young people a year. Children and young people are more frequent users of ED than adults[64]. Across NCL, almost a quarter of all ED attendances are for children and young people, with the highest rate in those aged 0-4. Of those accessing our emergency services, 17 percent are registered with a GP outside NCL, with a flow into NCL from neighbouring areas such as Hertfordshire to the north, and Westminster and Harrow to the west.

The attendances at paediatric EDs in NCL varies, although this is broadly in line with the Trust catchment populations. The number of children and young people attending ED every month ranges from 4,100 at the North Mid to 1,800 at UCLH. The North Mid covers a large catchment area, serving the most deprived areas of northern Haringey and southern Enfield. The total number of CYP attending ED at North Mid is the highest in London and is greater than UCLH and Royal Free Hospital combined.

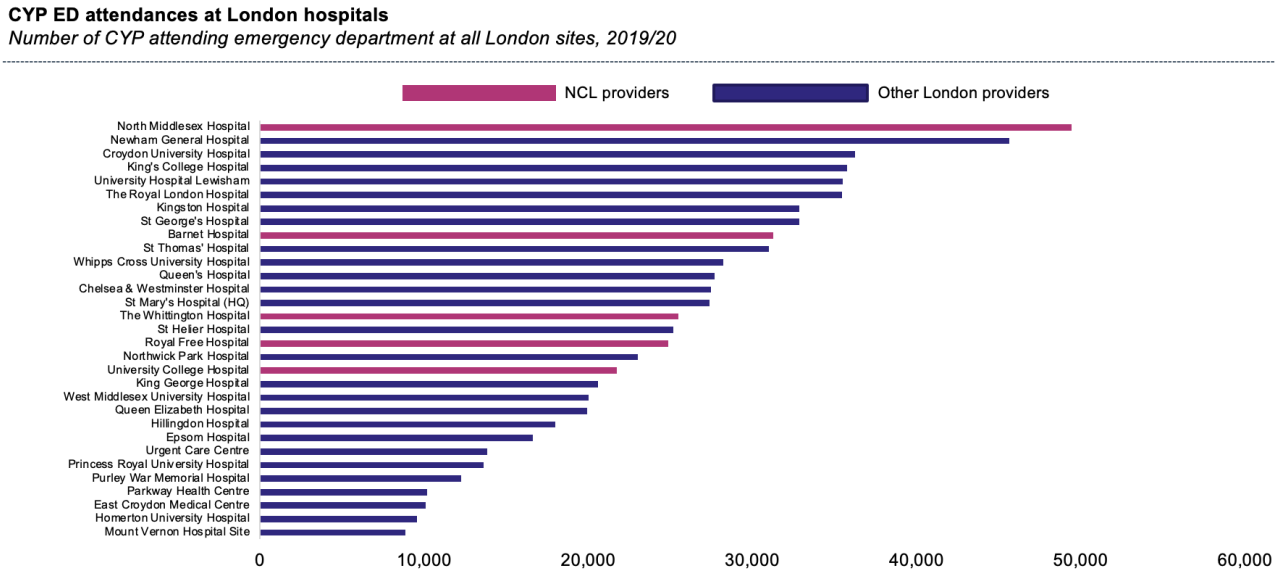


Figure 54: CYP ED attendances at London hospitals

[64] https://www.rcpch.ac.uk/sites/default/files/2018-06/FTFEC%20Digital%20updated%20final.pdf

Prior to the pandemic, the total number of children and young people accessing NCL ED services each year had increased slightly, with just under 4,000 more attendances (3 per cent) in 2019/20, compared to 2016/17. Between April and December 2021, there were over 136,000 ED attendances in NCL, compared to around 116,000 in the same period of 2016. This means that across NCL we are providing emergency care to an additional 73 children and young people a day, compared to 2016. Whilst demand for emergency services declined during the pandemic, attendances are now in line with pre-pandemic levels (Figure 55).

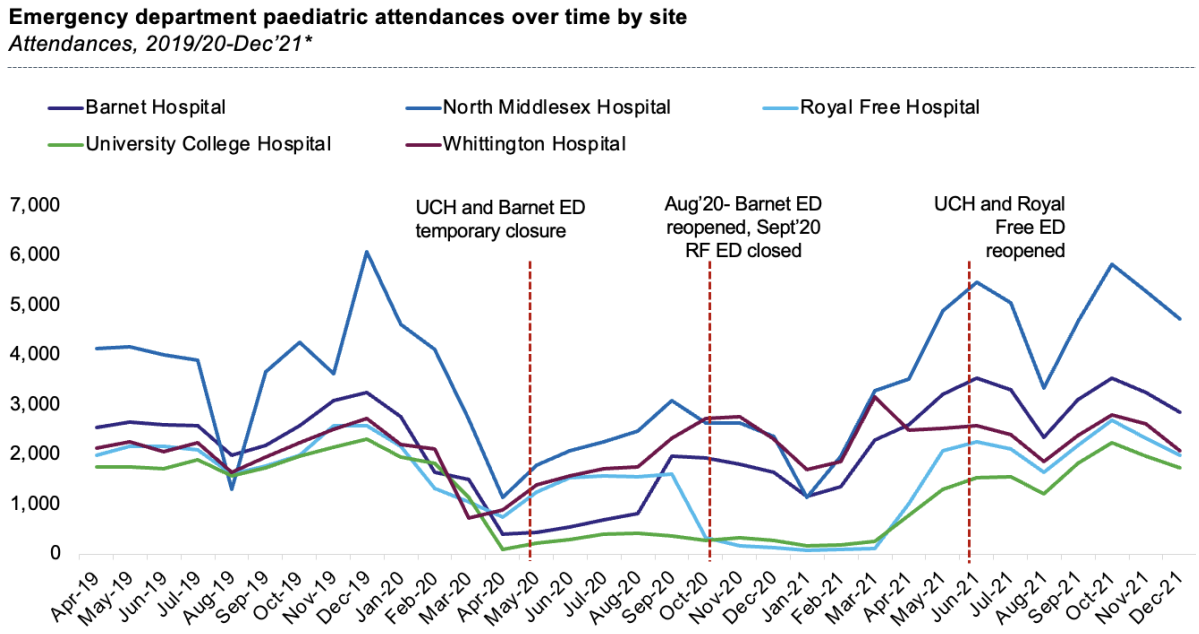


Figure 55: Number of paediatric emergency department attendances

Some population groups access our emergency services more than others. National data indicates a link between deprivation and access to emergency care; children and young people from the most deprived areas are 60-70 per cent more likely to attend ED than those from more affluent areas[65]. Within NCL, children and young people living in the most deprived areas were four times more likely to attend ED than those living in more affluent areas. Data in NCL also highlights that children and young people living in the most affluent areas of our system also had high rates of attendance as compared to the average. This highlights that there are other factors that drive higher attendance rates, beyond deprivation, that need further exploration in subsequent phases of the programme (Figure 56).

[65] Facing the Future: Standards for children in emergency care settings https://www.rcpch.ac.uk/sites/default/files/2018-06/FTFEC%20Digital%20updated%20final.pdf

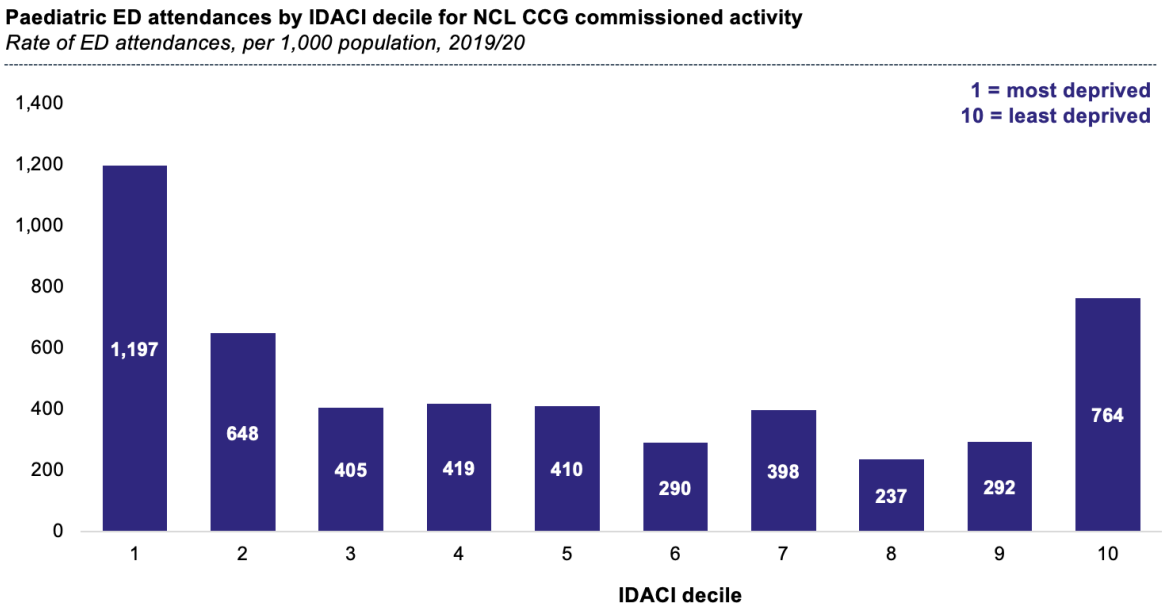


Figure 56: Rate of ED attendance by deprivation

NHS England's key commitment for emergency healthcare is to ensure attendances at EDs are seen, admitted or discharged within four hours. Rising pressures and reduced capacity to meet these demands means that we are not currently meeting this target. In 2019/20, over 15,500 children were waiting longer than four hours to be seen and just over 1,300 children had to wait longer than 10 hours. Being treated quickly in ED is important for both the experience and outcomes of children and young people. Having to wait 10 hours to be treated is not acceptable for our patients.

"There were long waiting times with uncomfortable chairs whilst waiting in waiting area and a mix up in communication. The appointment seemed rushed, and they didn't bother to X-ray me, despite being in pain. It was a really bad experience." - Young person in Haringey, Patient Focus Group, May 2022

Changing emergency complexity

Low acuity attendances

As well as the changes in demand, data analysis and feedback from clinicians indicates a change in the complexity of our patients. Children and young people accessing our emergency services will have different levels of severity of need (often referred to as acuity).

Across NCL, the number of low acuity attendances varies between Trusts, with North Mid and UCLH having the highest proportion of paediatric ED attendances with lower acuity cases.

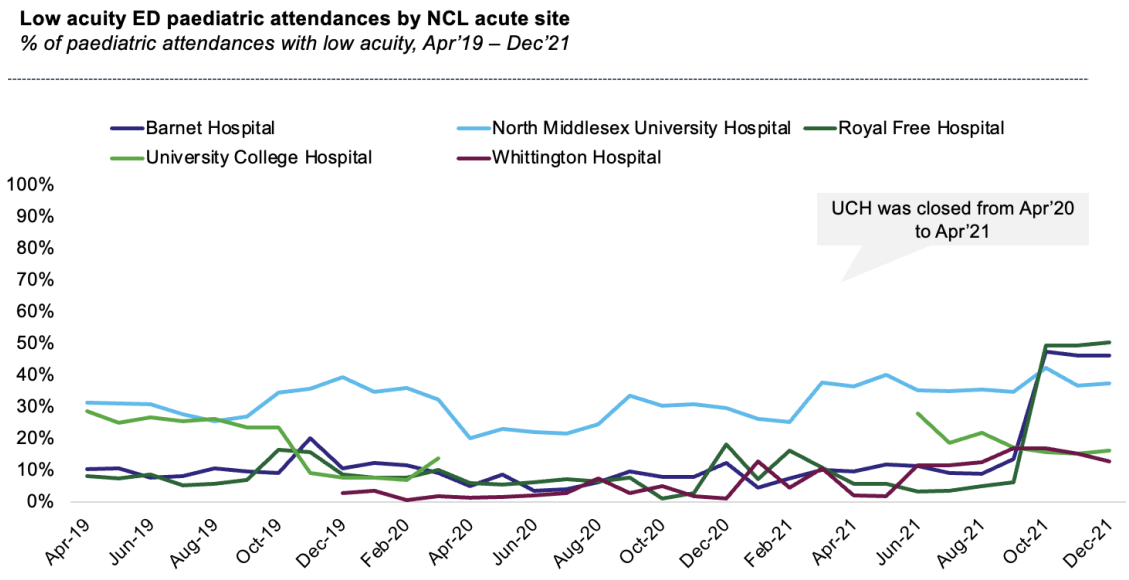


Figure 57: Proportion of ED paediatric attendances defined as low acuity

N.B Increase of low acuity attendances at Royal Free and Barnet Hospital is due to implementation of a new IT system

Whilst some low acuity attendances require acute emergency care, a large proportion of cases could have been treated in the community, or primary care. There are several factors that can contribute to the increasing low acuity attendances, including the access to primary care services, flows from the 111 service and population behaviours.

Admission avoidance pathways

To help manage patient flow, EDs have a number of different admission avoidance pathways in place. These pathways are designed to provide a better patient experience for those who require treatment but don't need to be admitted. Across NCL, there are varying models of both ED attendance and admission avoidance, which are outlined in Appendix I. A successful admission avoidance pathway will help avoid unnecessary admissions and successful ED avoidance pathways will prevent unnecessary ED attendances, by treating the patient in the community instead. Combining these models helps to reduce emergency pressures on the organisations.

In NCL, there is a varying conversion rate, particularly for admissions that last for less than a day. This suggests that there are varying levels of success with respect to admission avoidance models at the different sites.

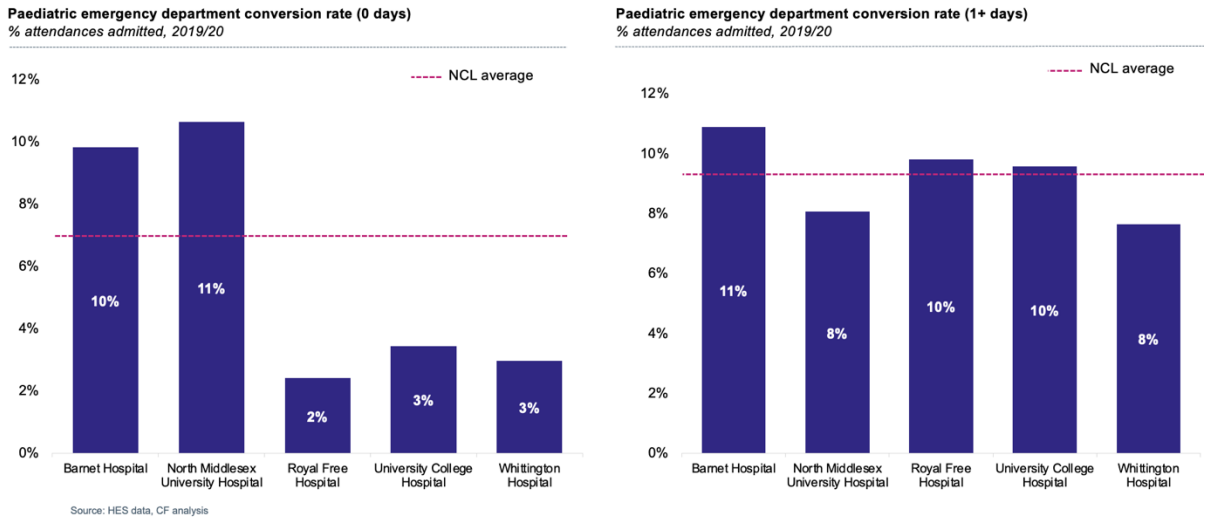


Figure 58: Conversion rate from ED attendance to non-elective admissions.

N.B does not include admissions to assessment units

We know that improving the efficiency of acute hospitals and helping sites to address the emergency demand cannot be undertaken in isolation. It requires a well-functioning and well-integrated system, with leadership that commits to, and prioritises integration. There is an opportunity for the ICS to look at successful integration models, both nationally and internationally, to help address the emergency demand and pressures.

Mental health attendances

Staff have reflected that there is a challenge in the number of children and young people accessing emergency care with mental health related conditions. For vulnerable young people in crisis, with no physical health needs, ED and paediatric wards are not the right environment to be seen in.

In line with NHS policy, NCL has a joint Children and Young People's Mental Health and Emotional Wellbeing Transformation Plan[66], which sets out the local strategy to improve access and interventions for children requiring mental health and wellbeing support. A core component of this is support for children and young people who require intensive and specialised intervention. A number of initiatives have been implemented to ensure this patient cohort can access the right help first time and reduce inappropriate ED attendance, including: a 24/7 crisis line, crisis hubs, Mental Health Practice Educators in acute paediatric settings, social care and CAMHS, home treatment teams and targeted support for children and young people with particular needs, such as disordered eating.

"They need to take into account a patient's mental health, not just the physical symptoms they are presenting themselves with." - Young person in Haringey, Patient Focus Group, May 2022

Working together as a provider collaborative, in NCL we have been working to implement initiatives to address mental health admissions and attendances. The work to date has resulted in the discharge of 70% of children and young people who attend ED home, reduced admissions by 34%, decreased length of stay by 43%, reduced admissions for young people

[66] https://northlondonpartners.org.uk/wp-content/uploads/2022/04/CYP-MH-Transformation-Plan-Final.pdf

with autistic spectrum disorder by 50% and decreased unnecessary tier four inpatient admissions.

Despite the good work already being undertaken, we know from data that vulnerable young people with learning difficulties, or complex mental health and social care, are accessing emergency care.

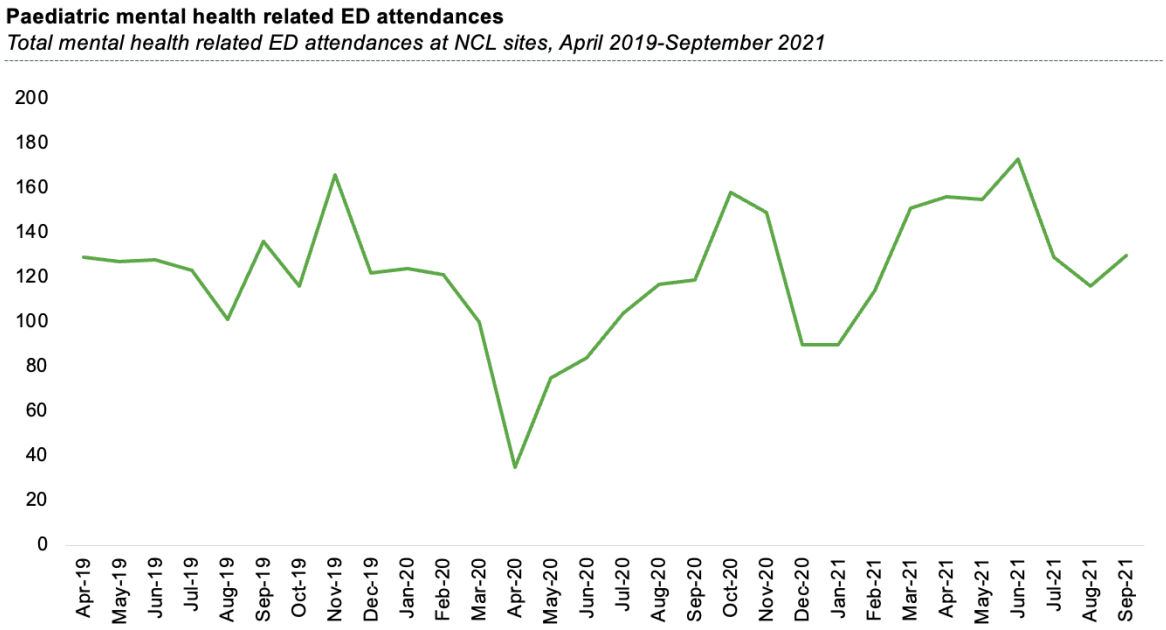


Figure 59: Number of mental health related paediatric ED attendances in NCL

This can be a difficult and challenging situation for all involved, particularly young people who struggle to receive the dedicated support they require at an already challenging time and in an environment not set up to meet their needs.

"…they felt physical symptoms were 'taken more seriously' than other health problems such as mental health difficulties." - Young Healthwatch, Enfield May 2019 - February 2020

It is important that NCL continues to build momentum behind the implementation of interventions to improve access to support outside the acute hospitals.

Addressing emergency department pressures

There are good examples to draw on when developing innovative ways to reduce pressure on paediatric emergency departments at different points in the care pathway.

Through the regional improvement programme, work is underway in each NCL borough to develop and deliver integrated models of care through an integrated paediatric service (IPS). This is an innovative way of achieving the triple integration of primary and specialist care, physical and mental health services, and health with social care at a local level. The super triage at UCLH outlined in section 6.4 is an example of the ICP in action in NCL.

The approach in NCL has drawn upon the established model in North West London, Connecting Care for Children (CC4C), where published data based on a combination of single practice and multi practice hubs, showed the success of the proposed model. In one

hub, 39% of new patient hospital appointments were avoided, with children supported via primary care more appropriately. There was also a 22% reduction in ED attendances and a 17% reduction in admissions. In addition to this, 88% of parents felt more comfortable about taking their child to see their GP in the future.

The NCL regional improvement programme has developed a strategic integration framework based on this work and will support boroughs in NCL to deliver an IPS pilot across the next 12-18 months. The pilots are a key delivery vehicle for integrated working and enable a 'network of care' approach for children, young people and their families. Following evaluation, they provide an opportunity to consider how this model of care can be delivered more holistically to deliver important system benefits.

Conclusion

Pressure on emergency departments is a national challenge and some sites in NCL are the busiest in London, with a very high number of children and young people accessing emergency care. The current organisation of emergency care means that in the north of the system, sites such as North Mid are providing emergency services for a large catchment population. In the south of the system, there are three sites providing emergency care within close proximity of each other, serving much smaller catchment areas. With the pressures on emergency care, there is an opportunity to consider how best to support sites to ensure there are sufficient resources to deal with the needs of the local population.

2. Long-term conditions management

Long-term conditions are complex and affect many children and young people across NCL. Effective management of these conditions is important in avoiding unnecessary hospital admissions. For children and young people with long-term conditions, hospital admission and care should be avoided when treating these conditions.

In NCL, the hospital admission rates for different long-term conditions vary and by different populations. For example, children and young people living in the most deprived areas are more likely to be admitted for asthma and diabetes than those in more affluent areas.

This variation in admissions highlights that there is more we can do to support our populations in managing these conditions. There also needs to be a significant focus as a system on prevention of these conditions, including a focus on the wider determinants of health. It is crucial that NCL continues to support community initiatives for long-term conditions, whilst also addressing the current inequities in access to support.

For children and young people with long-term conditions, care should, as much as possible, take place outside of a hospital setting. Despite total hospital admissions in England reducing for these long-term conditions since 2014/15, there is still a national focus to continue this reduction. The Long Term Plan sets out reforms to redesign community care around these long-term conditions, in order to improve care and reduce pressures on

emergency services. This section will explore long-term conditions in children and young people in NCL and what more we can do to improve outcomes.

Asthma

Asthma is the most common long-term condition in NCL, with over 380 emergency admissions per 100,000 children aged between 0 and 18 years old. There are differences in the rate of emergency admissions, with children living in the most deprived areas twice as likely to be admitted compared to those living in the least deprived. As such, it is crucial that we review and continue to implement, community and wider care to reduce these large numbers of emergency admissions.

NHS England has developed a summary of actions for health systems as a bundle of care for children and young people with asthma, based on the London asthma standards (Figure 60).

Component of Patient Pathway	System Action
Organisation of Care	Integrated Care Systems should have a named lead with asthma expertise who is responsible and accountable for the dissemination and implementation of asthma standards and good asthma practice
Environmental Impacts	All healthcare professionals working with CYP, with expected or diagnosed asthma, should understand the dangers of air pollution, indoor air quality and parental smoking and ensure they discuss these risks and potential mitigation strategies with them. Integrated care systems should ensure staff are equipped with the tools that will enable them to do this.
Early and Accurate Diagnosis	The diagnosis of asthma in CYP should be based on clinical features of a comprehensive history and when a diagnosis of asthma is made in CYP, this should be recorded in the notes and coded accordingly. Diagnostic hubs should be used to support diagnoses.
Effective Preventative Medicine	All CYP with asthma should have a Personalised Asthma Action Plan. Prescription of inhaler medication should include the appropriate device and education. Inhaler technique should be reviewed and graded, and regular asthma reviews should be conducted.
Managing Exacerbations	All providers of emergency and urgent care should adhere to minimum standards of assessment, treatment, referral, discharge planning and follow-up.
Severe Asthma	Each ICS should ensure that CYP with severe or difficult to treat asthma should have access to a severe or difficult to treat asthma service.
Data and Digital	ICS leads for CYP asthma should use the reports from the CYP Asthma dashboard to benchmark their services against national averages and use this information to make targeted improvements in asthma services.
Competencies, Training and Education Needs	All people involved in the management of CYP with asthma should be trained to the appropriate level depending on their role. Tier 2 training for example is currently supported by Health Education England through their e-learning for health platform. ICS' will be held to account to ensure their CYP asthma workforce have met the required levels of training.

Figure 60: National bundle of care summary for asthma in children and young people

The initiatives that are currently being rolled out in NCL have been put in place to help address the care bundle.

As described in section 6.4, there are several initiatives currently in place to better support outcomes for children and young people with asthma in NCL. These initiatives have had initial success but need to be continued and rolled out across the system.

Diabetes

Despite having a considerably lower rate of emergency admissions than asthma, there are differences in emergency admissions for children and young people with diabetes in NCL. The rate of emergency admissions varies by deprivation. The admissions rate for children in the most deprived decile is three times higher than the NCL average of 23 per 100,000.

There are also age differences across NCL, with young people aged 16-18 years old being significantly more likely to be admitted to hospital. The increased likelihood of admissions for those aged 16-18 years highlights the importance of a good transition to adult services.

UCLH has the highest rate of admission for NCL children and young people, with admission being more than twice as likely than at any other NCL provider. This increased admission can be partly explained by the fact that UCLH provides care for young people up to their 19th birthday and therefore admits a large proportion of children aged 15 and over, who are known to have a higher rate of admission than the NCL average. Furthermore, UCLH accepts any referrals from local providers for young people who struggle to manage their diabetes or who are extremely complex. These patients are admitted at UCLH rather than offering shared care, as the specialist adolescent service at the Trust allows expertise to be utilised from across the multidisciplinary team that is not available at other providers.

Nationally there have been variations in the access to pumps and continuous glucose monitoring (CGM), in part driven by historic differences in funding across the boroughs and CCGs. It is important that NCL considers holistically how to support children to manage their diabetes, with a focus on the populations that struggle the most with the demands of diabetes care on a day-to-day basis, as well as ensuring that all boroughs have access to the same technologies. If children or their carers are unable to control their condition, they will continue to be admitted to hospital, which we know is not the optimal care setting for children and young people with diabetes.

As part of the regional priority for children and young people's diabetes, there is an opportunity to identify best practice both nationally and internationally (for example models of care in Sweden and Netherlands) based principally on the integrated practice unit (IPU) concept. There are also opportunities to utilise a whole system approach to think about how best to deliver care across the diabetes pathway, both within an acute setting and in the community.

Sickle cell disease

Sickle cell disease refers to a group of diseases that are inherited and affect the red blood cells of a patient. We know that sickle cell disease is most common in children and young people from African and Caribbean backgrounds. This is reflected by the rate of sickle cell admission, with children and young people of Black ethnicity being significantly more likely to be admitted due to sickle cell disease than the NCL average. Given the demographic of the population around the North Mid there is a high rate of hospital admission for sickle cell disease, as well as a high rate at UCLH, which is a regional referral centre.

There is a specialist community sickle cell disease service covering Camden and Islington. The service supports children and young people from birth to adulthood and focuses care around the patient, using specialist support community health pathways. The service is dynamic, recognising and addressing the complex needs of these patients and their families. There is an opportunity for this community-based service to spread beyond Camden and Islington, and into the north of NCL to support those patients who may currently have no access. This is one of the areas of focus in the community services review.

3. Organisation of paediatric surgical care

The current organisation of paediatric surgery in NCL is not optimal to provide the best experience for children and young people.

Fragmented elective surgical pathways and increased volumes of elective care being delivered at specialist Trusts is resulting in low volumes of activity at local non-specialised sites. For our staff, this results in challenges in maintaining skills and competencies.

Variable emergency surgical pathways across NCL mean that some children and young people are being transferred for treatment who could have been treated at local hospitals. In NCL there are no consistent system-wide protocols on pathways of emergency care and the management of transfers, with decisions often being made on the basis of the skills and confidence of the team.

This sections explores the current challenges of both emergency and elective surgical care and outlines the opportunity to consider a networked approach to paediatric surgical care, to reduce transfers and ensure consistent pathways.

Infants, children and young people have different requirements in terms of surgical care. There are marked developmental changes within the paediatric age range; neonates, infants, and prepubertal children under the age of 8–12 years all have particular anatomical and physiological differences.

The GIRFT review into paediatric general surgery highlighted that the majority of emergency care is being delivered in non-specialist Trusts, whilst the majority of elective care is being delivered at specialist hospitals. Organisation of emergency and elective surgical care cannot be considered in isolation. There are key interdependencies between the two, particularly in respect of staff maintaining their skills and competencies. This section explores the opportunities for improvement in respect to both emergency and elective care.

Emergency paediatric surgery

Children and young people with complex medical conditions or those undergoing specialist procedures, such as cardiothoracic and neurosurgery, are usually treated at specialist children's units; in NCL this is predominantly at GOSH. For children aged under three years, the anatomical differences and challenges with intubation mean they would most likely need to be transferred to a specialist hospital for treatment; again, in NCL this would predominantly be GOSH. However, all local hospitals need to be able to resuscitate and stabilise children and infants of all ages prior to transfer to a specialist centre[67].

National guidance states that low-complexity emergency surgical activity for children aged three and older should be managed at a local Trust[68].

[67] https://rcoa.ac.uk/gpas/chapter-10
[68] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/PaediatricSurgeryReport-Sept21w.pdf

Clinicians have reflected on real challenges in the provision of emergency care, particularly in relation to treating children between the ages of three and five who require emergency surgery. Currently there is variation in whether a child is treated on site or transferred to a more specialist hospital.

In NCL there are no consistent system-wide protocols on pathways of emergency care or for the management of transfers, particularly for children aged 3-5 years. Treatment at local hospitals can be dependent on the confidence and skills of both the surgeons and anaesthetists covering the emergency rota to manage the care of children. Guidance states that all general anaesthetists are expected to be able to deliver care for children over three years old, however we know from speaking with our clinicians that this is not always the case.

Transferring children and young people may delay treatment. This can be stressful, for both the patient and their families and can also increase the risk of adverse outcomes[69]. Our staff have reflected that arranging a transfer can be stressful and time consuming for the team, who need to make sure the child or young person gets the treatment they need in a timely manner. It can often take multiple phone calls to secure a transfer which in some instances is to a unit outside NCL.

From April 2020 to March 2021, 144 children and young people were transferred from an NCL provider to other hospitals for an emergency surgical procedure; 18% of these transfers were to hospitals outside of NCL. In some instances, individuals were transferred up to three times before receiving emergency treatment. Whilst transfers may be necessary for complex cases, for example specialist plastic surgery, there are instances where treatment, particularly low-complexity surgery, could have been undertaken at the local non-specialist hospital.

Of those transferred for emergency treatment, almost 75% were transferred to GOSH (Figure 61). Its specialist nature means that GOSH does not have an emergency front door, neither an ED nor ambulatory care unit, so emergency transfers onto the ward need to be planned.

[69] Are we there yet? A review of organisational and clinical aspects of children's surgery. In: p 55, National Confidential Enquiry Into Perioperative Death, editor. London 2011 https://www.ncepod.org.uk/2011sic.html

GOSH provide excellent emergency care for children and young people requiring complex treatment and the pathway for this works well across NCL. However, staff feedback has highlighted that the role of GOSH within emergency care pathways is not fully defined or agreed across the system in respect to lower complexity cases. This ambiguity can be difficult to manage on a day-to-day basis and can result in inappropriate cases being transferred.

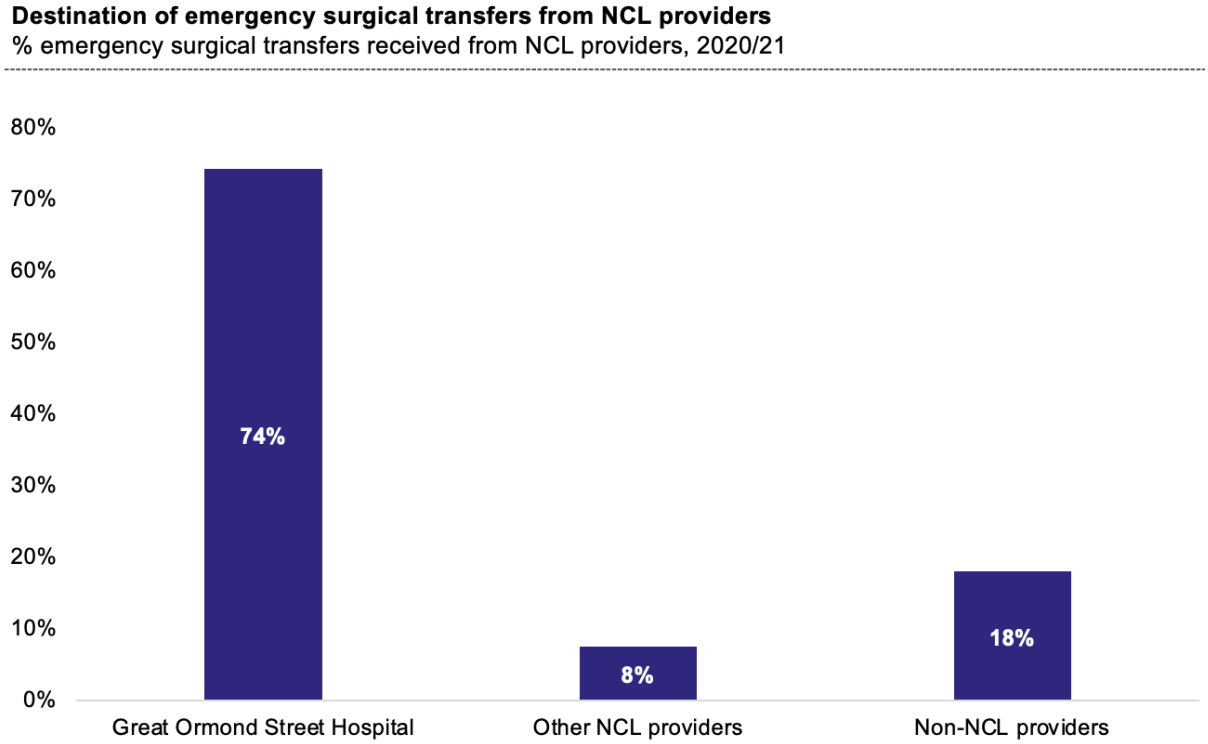


Figure 61: Emergency surgical transfers from NCL providers

As a specialist provider, GOSH has a role as a national and international centre and needs to accept referrals from a much wider geographical patch. Whilst some cases do require specialist care, we need to ensure that the role of GOSH is fully defined for our clinicians, ensuring we are utilising this scarce and specialist resource in the most effective way.

Example emergency surgical pathways

Whilst the transfer of patients can occur for a range of conditions, the management of acute appendicitis and testicular torsion have been cited as challenging low-complexity emergency surgical pathways[70], with unwarranted variation in the volume of activity delivered and some critical time delays in treatment. Below we explore the current management of these conditions in NCL and highlight where outcomes could be improved. We have also described the current pathways for emergency care for plastic surgery.

Testicular torsion

Testicular torsion is a time-critical surgical emergency. The transfer for surgery can lead to unacceptable delays and increases the risk of a young child losing their testicle. We know from speaking with clinicians and reviewing the data, that there are two different issues that need to be addressed within NCL: the outcomes for those children who are operated on at

[70] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/PaediatricSurgeryReport-Sept21w.pdf

local Trusts, and the lack of clarity about where to refer on for a more specialist opinion and/or surgery.

Measuring a functioning pathway can be difficult and nationally the number of orchidectomy, or testicle removal, procedures as percentage of all acute scrotal procedures is widely used as a measure of effectiveness. National estimates suggest a rate of 20% or lower for orchidectomy as a consequence of torsion is a well-functioning pathway.

Figure 62 outlines an outcome of an audit carried out by the North Thames Paediatric Network which shows that all organisations within NCL have a rate of 20% or above, potentially indicating that local pathways are not optimal. The actual numbers of procedures undertaken by each Trust also varies, with 50 or more undertaken at the Royal Free London (figures are for Barnet and Royal Free Hospitals combined), just under 30 at the Whittington and around 10 at both UCLH and Great Ormond Street. The audit undertaken highlights a potential relationship between low volumes and higher rate of orchidectomy variation in volumes. By way of a comparison, Chelsea and Westminster Hospital as the specialist surgical provider in West London, has an orchidectomy rate of 4%.

Orchidectomy procedures

% non-elective orchidectomy procedures of total acute scrotal procedures, 2017-20

Organisation	% orchidectomy procedures	England average orchidectomy rate
Great Ormond Street Hospital	**27%**	**20%**
North Middlesex Hospital	**20%**	
Royal Free London (Barnet and Royal Free Hospitals)	**27%**	
University College Hospital	**23%**	
Whittington Hospital	**28%**	

Source: North Thames Paediatric Network

Figure 62: Acute scrotal procedure activity in NCL

The GIRFT report states that non-specialist Trusts should be able to provide emergency care for testicular torsion in children aged three and over. However, within NCL there is variation and a lack of clarity regarding the management of some children over the age of three, particularly those between three and five years old. Clinicians recognise that managing children aged three and above is the standard to aim for, but highlighted that this can be challenging, with differences in local expertise and confidence. This variation means that some Trusts may need to transfer 3–5-year-olds to specialist hospitals but there are also examples of children over 10 being transferred with suspected torsion.

Figure 63 outlines the varying age cut offs that each site within NCL will provide emergency care to. This highlights the varying age limits between the different sites and further add to the pathway complexities.

Orchidectomy procedure age range
Age that a site will conduct an orchidectomy procedure

Provider	Age range for orchidectomy procedure
Great Ormond Street Hospital	**All ages**
North Middlesex University Hospital	**3+**
Royal Free Hospital	**5+**
University College London Hospital	**5+**
Whittington Hospital	**5+**

Figure 63: Emergency orchidectomy age cut-off. N.B Pre COVID-19 Barnet Hospital transferred patients to Royal Free Hospital and currently transfer to North Mid

These challenges highlight a need to change the way in which we deliver emergency care for children and young people with suspected testicular torsion. There is an opportunity for the NCL system to agree system-wide protocols, which include a principle of who should assess a patient and therefore decide if a transfer is required. There is also an opportunity for NCL to consider alternate long-term solution to paediatric anaesthetic resource, drawing on expertise across the system.

Appendicitis

The latest GIRFT review on paediatric surgery highlighted that there was room to improve the national standard of care for appendicitis. The review highlighted that nationally, 10% of children undergoing an appendicectomy were having a normal appendix removed. This compares unfavourably with the USA and other European countries, where the rate was 2.5% or lower.

In NCL, the percentage of children having a normal appendix removed is in line with the GIRFT report findings, ranging from 5.4-9.7%. Whilst no Trust was above the national average, the current rates indicate that there is still opportunity for improvement, to reduce variation between providers and reduce the rate to be in line with international standards[71].

[71] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/PaediatricSurgeryReport-Sept21w.pdf

Appendicectomy of normal appendix
% children undergoing appendicectomy having a normal appendix removed, 24 month up to Q2 2021/22

Trust	Percentage of children having a normal appendix removed	GIRFT national figure	London median
Great Ormond Street Hospital for Children NHS Trust		10%	6.2%
North Middlesex University Hospital NHS Trust	6.2%		
Royal Free London NHS Foundation Trust	5.4%		
University College London Hospitals NHS Foundation Trust	9.7%		
Whittington Health NHS Trust	6.1%		

Figure 64: Appendicectomy of normal appendix N.B GOSH data is not available

To support improved outcomes, the GIRFT report recommends:

- Strengthening the training of general surgeons in paediatric surgery to improve leadership
- Sharing the care of the child with a possible appendicitis between general surgeons and paediatricians in non-specialist Trusts

The review of appendicitis treatment by GIRFT also highlighted variation in the number of laparoscopic (minimal access) appendectomies. Advantages of removing the appendix via ‘keyhole’ surgery includes reducing pain and scarring following surgery. Overall, specialist Trusts perform a higher proportion of minimal access appendicectomy than non-specialist Trusts.

In NCL, there is variation in the percentage of admission for appendicectomy that are minimal access, varying from 43-80%. With the expectation of UCLH and GOSH, all Trusts within NCL are below both the national and London median for minimal access appendicectomy.

Appendicectomy rate that is minimal access
% appendicectomy admissions that are minimal access, 0–16-year-olds, 24 month up to Q3 2021/22

Trust	Percentage of admissions for appendicectomy that are minimal access	National median	London median
Great Ormond Street Hospital for Children NHS Trust	**92.9%**	**80.2%**	**80.3%**
North Middlesex University Hospital NHS Trust	**70.3%**		
Royal Free London NHS Foundation Trust	**65.6%**		
University College London Hospitals NHS Foundation Trust	**80.0%**		
Whittington Health NHS Trust	**43.4%**		

Figure 65: Appendicectomy rate that is minimal access by NCL Trust

There are many reasons for lower rates, but several reasons cited in the report include concerns about the suitability of equipment in place at Trusts for performing surgery safely in children and young people and lack of experience in paediatric laparoscopic appendicectomy.

Given that many non-specialist Trusts are able to perform this procedure effectively in adults, there is a need to address the challenges in paediatrics and reduce the variation within NCL.

Plastic surgery

Royal Free Hospital is the specialist centre for plastic surgery in NCL for both adults and children. The hospital is also a regional centre for paediatric plastic surgery and therefore also provides care for children and young people who live outside NCL. GOSH also runs a plastics service, however they only provide care for a small number of complex elective cases. Our staff have reflected that the paediatric plastic surgery provision generally works well in NCL, with the single centre in NCL giving the advantage of having all services and expertise concentrated in one place.

Although the service generally runs well, staff have identified a number of key challenges, namely in respect to children aged under three, and particularly those that are under 18 months. Staff have reflected that for these children, anaesthetic cover and capabilities are the main constraints, rather than surgical expertise. Most paediatric plastics care that is undertaken at Royal Free Hospital is emergency care, which means that a 24 hour, seven day a week service is required. However, only a small cohort of anaesthetists are confident to anaesthetise very small children, so out of hours cover becomes particularly difficult. If surgery can wait until the next morning, which most emergencies can, anaesthetic rotas can be changed to ensure that the correct cover is available to complete the procedure at the start of the next day's list. However, on occasions where the procedure is time critical and cannot wait until the morning, very young patients sometimes need to be referred to GOSH

or, very rarely, the Royal London. For patients, their family and our staff this can be extremely stressful.

Whilst there are many benefits to a single centre for care, ED clinicians from local hospitals reflected on challenges they sometimes face when trying to refer patients to the Royal Free Hospital. Capacity constraints at the Royal Free Hospital or the very young age of the child can result in situations where ED staff have to ring round other local hospitals to accept these children, leading to potentially long waits in ED. This can be exacerbated further as the role of GOSH in the emergency pathways is not clearly defined. There is an opportunity for the system to agree consistent NCL-wide protocols which include clarifying the age range (under three years old) and the role of GOSH in the emergency pathway.

Staff reflected that there is a potential opportunity in NCL to explore more shared learning for ED clinicians to reduce the pressure on the specialist plastics team at the Royal Free Hospital.

Elective paediatric surgery

Complex elective paediatric surgery is delivered by specialist paediatric surgeons at specialist Trusts; in NCL this is predominantly provided by GOSH, with some GOSH consultants also operating at UCLH. The GIRFT review states that most low-complex cases can be treated as day cases at non-specialist Trusts[72]. As with emergency surgical care, the majority of elective anaesthesia for children is delivered by general anaesthetists who will treat both adults and children.

Low elective surgical volumes

Nationally, increasing volumes of elective surgery are being undertaken at specialist Trusts and decreasing volumes being delivered at non-specialist Trusts. Specialist services that deliver excellent patient outcomes are built through high-volume delivery of care to patients within that specialism.

Whilst across NCL there is excellent elective care being delivered across specialisms, there are services which currently do not have a sustainable volume of cases in order for our staff to maintain skills and competencies. Below we explore one example.

Ophthalmology

GOSH, Moorfields Hospital, North Mid and the Royal Free Hospital all provide a specialist paediatric ophthalmology service, with Moorfields providing all its treatment on a day case basis. In 2019/20, NCL delivered 1,953 specialist elective ophthalmology spells between the four different providers. The volumes between the different providers varied significantly. Despite not being a specialist provider, North Mid has a paediatric ophthalmology service, however, the service provides fewer than two elective ophthalmology operations a week for children and young people, across a range of ages. These particularly low volumes could be challenging to ensure that clinicians are able to maintain their competencies in treating children.

[72] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/PaediatricSurgeryReport-Sept21w.pdf

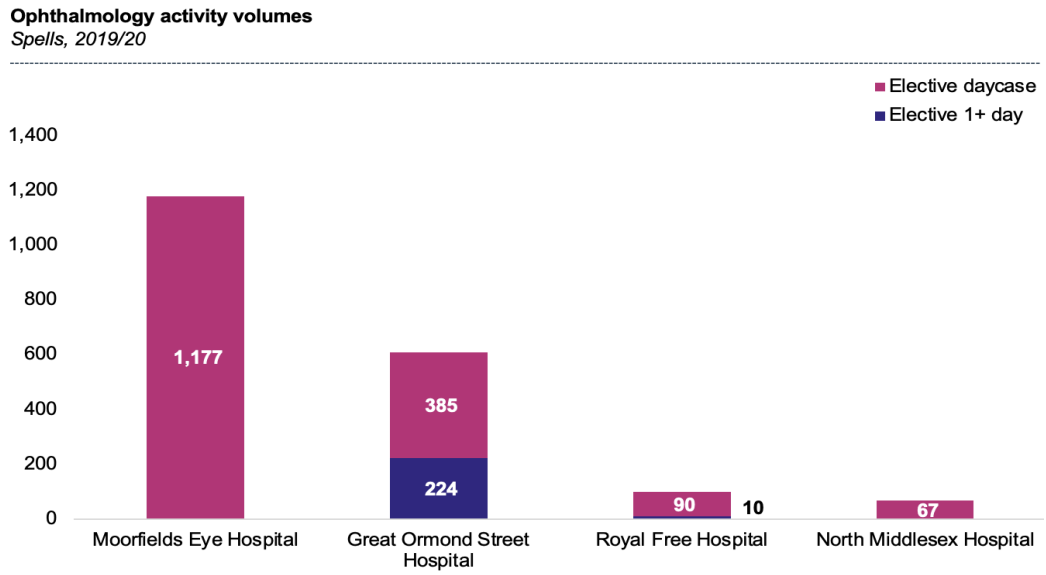


Figure 66: Volume of elective ophthalmology activity at NCL sites

Considering the low volume of cases delivered at the North Mid, there is an opportunity to consider how this pathway currently operates and whether there are opportunities to consolidate services and utilise this specialist resource differently.

At the other end of the spectrum in terms of high-volume provision, there are close working relationships between Moorfields and GOSH ophthalmology teams, with some shared or joint appointments between the two organisations for several ophthalmology pathways. Virtually all Moorfields' surgery takes place on a day case basis, meaning that the hospital has very few overnight beds and no beds for children and young people. Children requiring a planned overnight stay prior to surgery will normally be admitted overnight at GOSH and then transferred to have their surgery at Moorfields, although this pathway is rarely used.

Discussions have started between GOSH and Moorfields on how their relationship can be further strengthened for patient benefit, ensuring that we make the most of having two world-leading Trusts within our local system.

Maintaining staff skills and competencies

The low volume of elective surgery at non-specialist Trusts means there is reduced exposure to paediatric surgery and anaesthesia. This can make it challenging for staff to learn and practice the necessary skills and maintain their competencies. Across sites, anaesthetists, junior doctors, and consultants within paediatric services have all reflected on these challenges. This also has a subsequent impact on the ability of these Trusts to deal with emergency paediatric surgery, as there is a risk that staff may become deskilled if they are not seeing a sufficient volume of cases on an elective, or planned, basis.

Paediatric anaesthetic provision

Throughout engagement, the provision of paediatric anaesthetics has been noted as a significant barrier for surgical care, across multiple specialties. There is challenge in provision of anaesthetic cover across NCL, with only a small cohort of anaesthetists comfortable in providing services for very small children.

For general anaesthetists who cover general on call rotas, there are particular challenges to maintain their skills in managing children aged 18 months or under. In NCL, the elective surgery for this cohort of patients is predominately delivered by GOSH, although activity is also provided by UCLH and RNOH. As a result, the exposure of anaesthetists outside of GOSH, UCLH and RNOH to this cohort of patients is limited.

Currently there is variation in the number of paediatric-trained anaesthetists on each site. GOSH, UCLH, Barnet, Royal Free Hospital and Whittington Hospital have paediatric specialist anaesthetists, whilst the low volumes of paediatric elective surgery at North Mid means it has not been feasible to recruit to this role. This can have a subsequent impact on emergency care at what is a very busy emergency site, with some staff not comfortable in providing treatment.

There is an opportunity for NCL to think about how collaboration around anaesthetic provision could help anaesthetists to maintain their skills for younger patients. There may also be innovative ways in which the system can consider workforce solutions or further training opportunities.

Network opportunity

The GIRFT review into paediatric general surgery found that the most effective models of care involved formal and informal networks of care. This ensured effective lines of communication between Trusts, both specialist and non-specialist, to allow effective delivery of care in the right environment.

The LTP also sets out a vision for paediatric specialised and non-specialised surgical services to deliver care coordinated via a clinical network that will drive improvements in the quality, equity in access and outcomes[33]. Although NCL has several specialist networks that include paediatrics (ENT and ophthalmology) there is no overarching paediatric surgical network. Implementation of a network would provide the following opportunities and is a consideration that should be explored during the subsequent phases of the programme:

- Overarching governance, paediatric clinical oversight and leadership to align pathways, processes and policies
- Ability to design services that meet the needs of the local population and reduce unwarranted variation
- Ability to effectively manage patient flows and activity cross sector
- Training opportunities to increase competencies and confidence
- Innovative staffing models, such as exploring network arrangements, to address challenges in staffing sustainability
- Collaboration around paediatric anaesthetic provision in NCL
- Strengthening how clinical data is collected, shared and analysed

4. Long waits for elective care

Long waits for elective care is a national challenge that has only been made worse by the COVID-19 pandemic. At best, the waiting time for treatment for children, young people and their families is stressful and frustrating and at worst it can see children and young people's health and impact their wider lives.

In NCL, the waiting list has increased 8.5% since May 2021. For children and young people, long waits for treatment can also impact other aspects of their lives such as their development, ability to access education and lead active lives.

This section will explore the current waiting list and the opportunity to build on existing joint system working to reduce the waiting lists.

The last eighteen months have seen a growing challenge in delivering timely treatment for elective patients. As a result of the pandemic, non-urgent work was suspended nationally from April to July 2020. This was to ensure that there were sufficient beds and staff capacity to treat patients who became severely ill with COVID-19. Since then, elective work has restarted, however across NCL we have seen an increase in the waiting lists for both admitted and non-admitted care.

"Hospitals need to be more realistic and more honest about waiting times for care"- Young person in Haringey, Patient Focus Group, May 2022

Admitted waiting list

An admitted waiting list is defined as those waiting for surgical treatment. Admitted waiting lists across the country have been increasing and NCL is no exception. There are currently around 4,300 children and young people waiting for treatment in NCL. Of those waiting for care, over 330 have been waiting over a year and 1,600 over 18 weeks.

Whilst there has been progress in treating children and young people who have been waiting over 52 weeks, the number of individuals waiting between 18 and 51 weeks is still increasing (Figure 67). This suggests there is not enough capacity within the system to manage the current backlog. For children and young people, waits of this nature can have a significant impact, as many treatments are age or development stage critical[73].

[73] https://www.rcpch.ac.uk/news-events/news/paediatricians-respond-elective-care-backlog-report

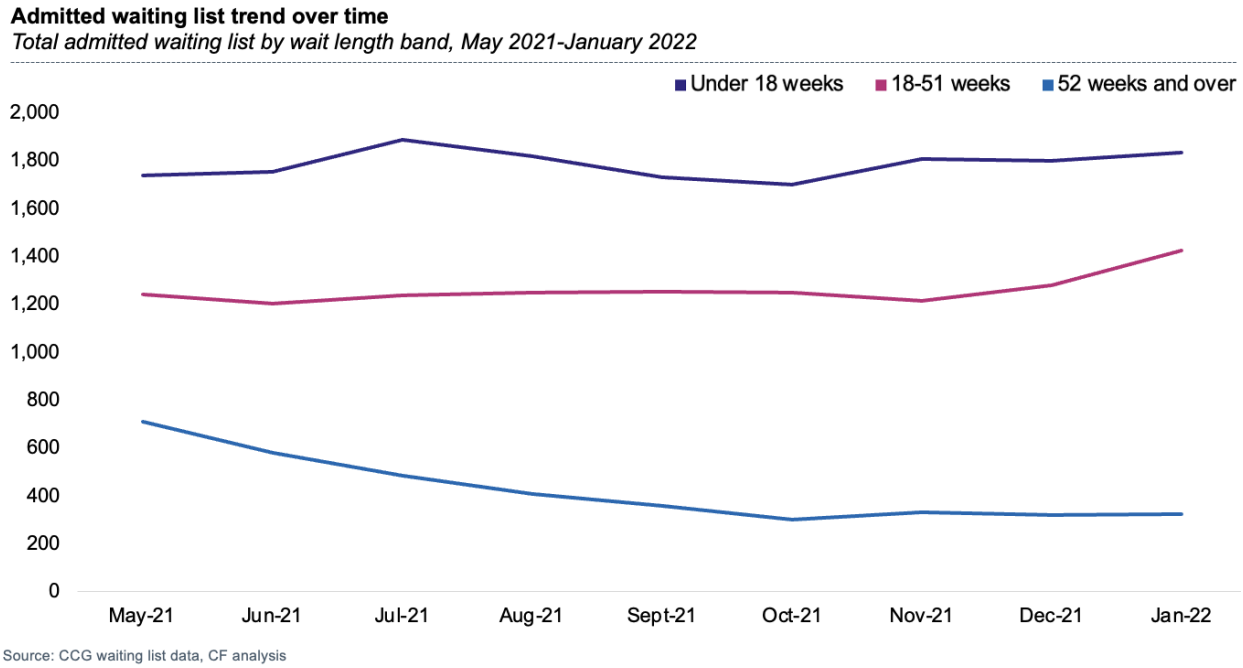


Figure 67: Number of paediatric patients on the admitted waiting list in NCL split by waiting length band

Specialties have experienced differential sizes of waiting list, meaning some children and young people are waiting longer for routine procedures than others. The most common specialty areas on the waiting list, as of February 2022, are ophthalmology, paediatric dentistry, ENT and orthopaedics (Figure 68).

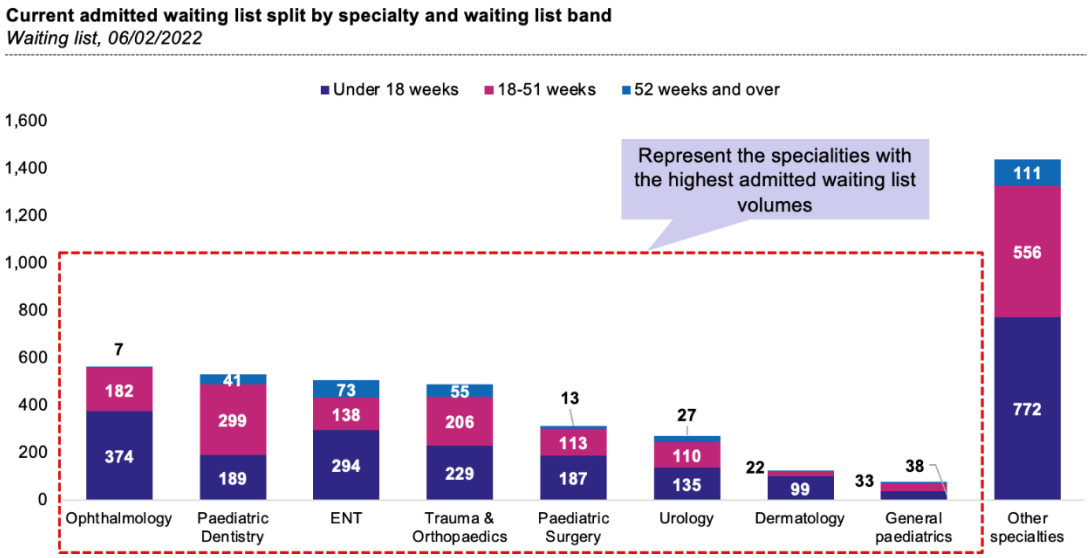


Figure 68: Number of patients waiting for treatment split by specialty

There are several factors that can contribute to growing waiting lists, including bed and staff capacity, theatre efficiencies and organisational productivity. Below we outline several specialties with high elective waiting lists across NCL, although the entirety of paediatric waiting lists are in scope of this case for change.

Paediatric dentistry

Poor oral health can affect the everyday lives of children and young people. The ability to speak, eat, sleep and play can all be impacted by oral issues.

NCL has a large community-based specialist dental service that is provided by Whittington Health. This service takes only paediatric referrals from primary care in NCL. It is currently delivered across 21 different sites across north London (not just NCL) and treats patients with conditions that cannot be treated in a general dental practice, such as for those with learning disabilities, complex medical conditions and for looked after children. The community service receives around 7,000 referrals from high street dentists each year, of which the vast majority can be seen with clinical appointments in a community setting close to home. Much of this demand is driven from high levels of untreated tooth decay that is referred in from primary care.

Children and young people in NCL who have complex dental needs are transferred to GOSH or UCLH who are able to perform high-complexity dental procedures under general anaesthetic. These pathways are well established, generally work very well and have strong working relationships between the different organisations. However, staff have reflected that there can be significant challenge in discharging patients from specialist providers into primary care, with clinicians mindful of putting pressure on community teams that are already stretched. Currently, low-complexity dental cases requiring general anaesthetic in a hospital setting are provided by Whittington Health

There are currently 529 children and young people waiting for a dental procedure in NCL. Of those waiting, 89 are under the age of five. Children who need teeth taking out are waiting upwards of a year for treatment, with some potentially requiring courses of antibiotics during this time to fight infections. Since April 2021, the total admitted waiting list has increased by over 30%, which is the equivalent to an extra 13 children and young people being added to the waiting list every month (Figure 69).

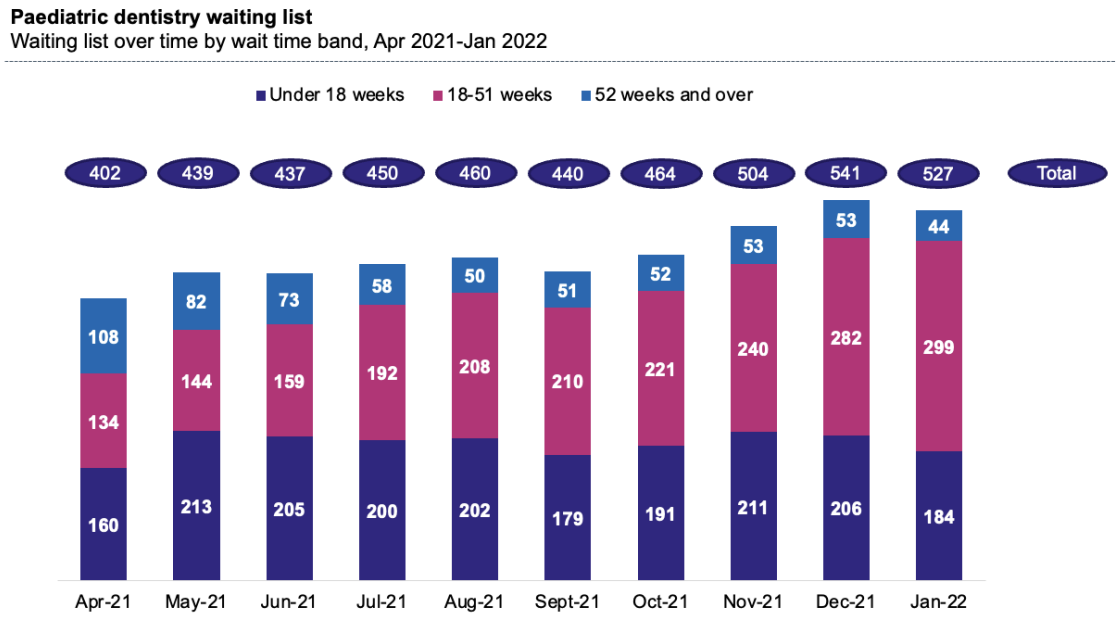


Figure 69: NCL paediatric dentistry waiting list over time

We know from speaking to our staff that there are challenges in ensuring children and young patients are treated close to home. The number of sites that have dedicated surgical lists in NCL is constrained and there is an urgent need to consider how to increase capacity across the system to tackle the growing waiting list and ensure that care is delivered as close to home as possible.

"I could not have asked for better care from the hospital staff. The only issue we had was establishing an appointment in the beginning after the referral from our dentist - this took a very long time but once in we received first class treatment and care." - UCLH National Patient Experience Survey 2020

To help tackle the waiting list, additional regional capacity has been created via the introduction of Project Tooth Fairy. This project has established a dedicated surgical centre, based at The Royal London Dental Hospital, which undertakes dental surgery for children across London. Whilst the additional capacity has been helpful to a small degree, the current arrangement does not completely meet the needs of NCL.

Equity of access within the current arrangements and the wider impact on health inequalities is important to consider. The current arrangement of Project Tooth Fairy to support patients from Enfield, Haringey and Barnet means that potentially those from the most deprived areas are having to travel even further for treatment in east London. Evidence shows that children in deprived communities have poorer oral health than those living in more affluent communities and delays in the treatment of oral conditions will further widen these health inequalities[74]. Preventive care plays a critical factor in reducing the risk of tooth decay in milk teeth.

Further issues have been highlighted which relate to the provision of dental care that is delivered under other clinical specialities. For example, some dental work is provided by the oral maxillofacial team at Barnet Hospital. These patients are not being referred into the established community pathway from primary care and this variation can impact on the triage of these patients, making it difficult for clinicians to fully understand the issues. There is an opportunity to understand which clinical conditions are being seen by oral maxillofacial teams and whether it is clinically appropriate, as well as why these patients are not being referred to the established community pathway.

Ear, nose and throat (ENT)

Elective paediatric ENT is only delivered at Barnet Hospital and UCLH. In February 2022, 505 children and young people in NCL were waiting for an ENT procedure, of which 73 had been waiting over a year. Despite the overall waiting list not changing, the number of children waiting for between 0 and 18 weeks almost doubled between April 2021 and January 2022, suggesting an extra 16 children are added to the waiting list each month over this period (Figure 70).

[74] https://www.local.gov.uk/sites/default/files/documents/tackling-poor-oral-health-d84.pdf

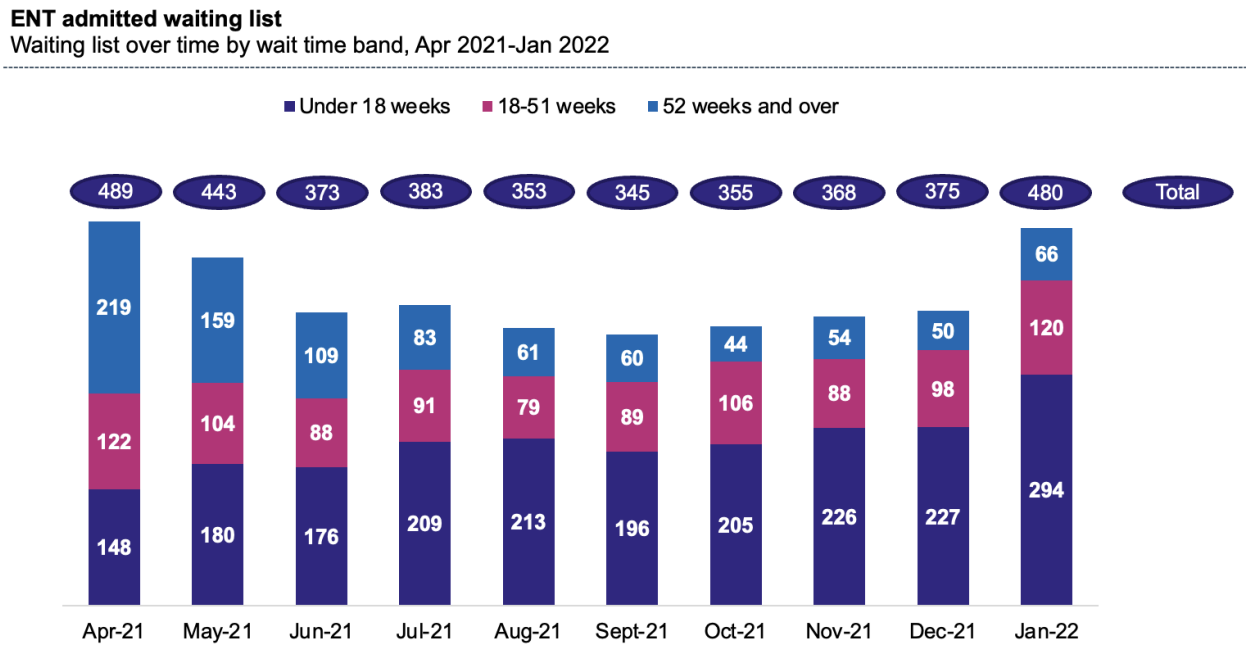


Figure 70: NCL paediatric admitted ENT waiting list over time

Clinicians have reflected on capacity constraints at Barnet Hospital. Whilst there is a desire to allocate more paediatric theatre lists, there is a lack of capacity to do this at a predominantly emergency site, alongside conflicting priorities including cancer and general surgery activity. This is equally a tension for paediatric maxillofacial surgery, for which Barnet is also one of the main elective centres in NCL.

Elective care collaboration in NCL

Within NCL there are existing areas of collaboration in terms of delivering elective surgical care, which has supported organisations in tackling the growing waiting list. Below, we explore two examples of collaborative working that provide opportunities to build upon.

Orthopaedics

In NCL, GOSH, the RNOH and the Royal Free Hospital have paediatric orthopaedic services. Given the specialist nature of GOSH and the RNOH, they have an existing clinical partnership in place around planned orthopaedic care. Many paediatric patients seen at GOSH requiring ongoing specialist support transition to adult services at the RNOH.

Currently the Royal Free Hospital has one part-time surgeon covering the elective paediatric orthopaedic practice. A long waiting list had started to build up prior to COVID-19 and this continued to grow significantly during the pandemic. The current volume of activity delivered by Royal Free Hospital is 318 elective spells per year, equating to six elective spells a week.

Building on the existing clinical partnership between the two organisations, over the last year there has been positive collaboration between the Royal Free Hospital and RNOH around planned orthopaedic care for children and young people. The Royal Free Hospital temporarily closed to new referrals in autumn 2021 and the RNOH provided support to clinically manage the just under 400 long waiting patients who had not been seen, offering both theatre and outpatient capacity. This joint working has had a positive impact on the wait

times at the Royal Free Hospital, with the waiting list significantly reduced and able to reopen to new referrals.

In the longer term there is a need to think about the sustainability of the small low-volume service at Royal Free Hospital. Clinicians need the support of working in a larger multidisciplinary team and very small services lack resilience in managing the waiting times for patients.

There is an opportunity to consider how to build on the excellent collaborative work between the RNOH and Royal Free Hospital to help manage the service in a much more integrated way to prevent waiting times building up again in the future.

Endoscopy

Endoscopy is a key diagnostic step in the gastroenterology pathway, and we know that it is one of the areas that has been significantly challenged through the pandemic, both for adults and children. Since the pandemic, the Royal Free Hospital has been unable to carry out paediatric endoscopy on site, in part due to inappropriate recovery space for children and young people, but also because of wider capacity constraints within theatres. GOSH is supporting the Royal Free Hospital by providing endoscopy capacity on their site for the Royal Free surgeons. However, the capacity GOSH is able to offer does not match the levels of referrals received by the Royal Free Hospital and consequently waits for less urgent care are beginning to build up.

There is an opportunity to review provision and to consider building on the existing close working relationships between the two specialist teams, GOSH and Royal Free Hospital, in conjunction with UCLH's teenage and young person specialist gastrointestinal (GI) service, to streamline the specialist paediatric gastroenterology pathway with NCL.

Non-admitted waiting list

As of February 2022, there were around 4,000 children and young people waiting for non-admitted care in NCL. Patients who are waiting for non-admitted care do not require hospital admission and are typically waiting to be seen in an outpatient clinic.

Of those waiting for care, around 1,000 have been waiting over a year and around 7,000 for over 18 weeks. As with the admitted waiting list, there has been progress in those waiting for over a year since May 2021, but the number of children waiting for over 18 weeks has increased by almost 40% (Figure 71).

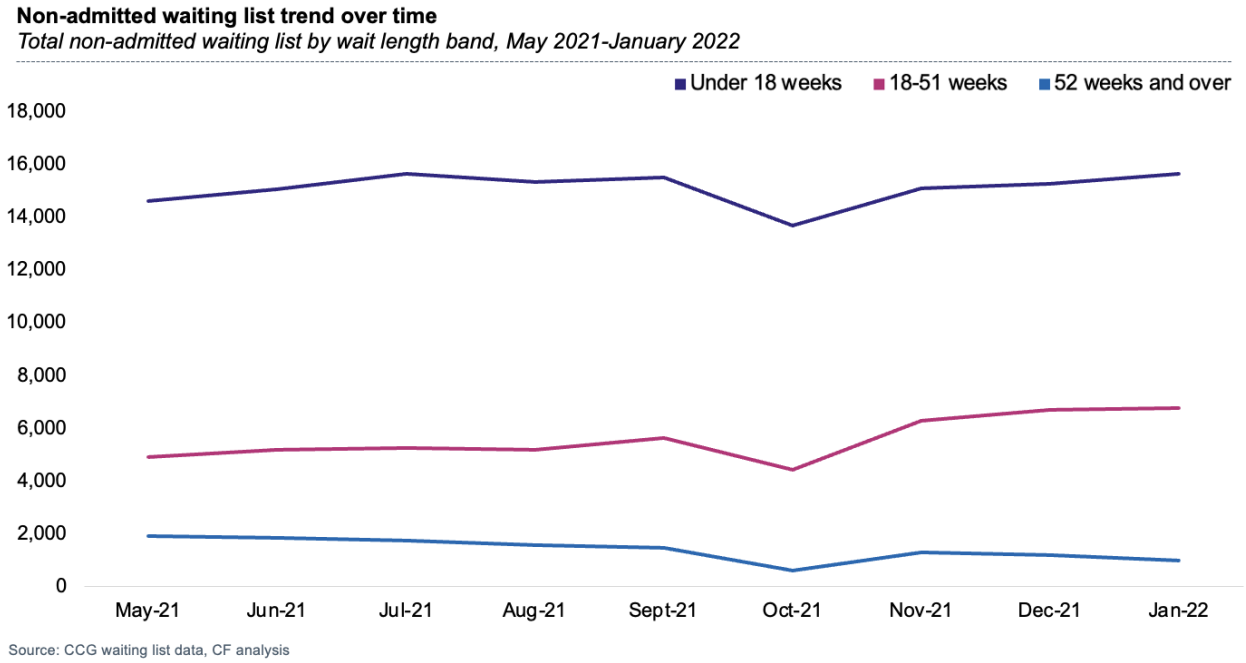


Figure 71: NCL non-admitted waiting list over time

As the overall waiting list for non-admitted care increases, staff have reflected on the number of duplicative referrals being received. Across a range of different specialties there are a number of children and young people with more than one GP referral to the same specialty. Across NCL in 2021/22, 1,500 children and young people had multiple GP referrals to the same outpatient specialty.

An example which was cited frequently during engagement with staff, was the challenge with regard to the paediatric allergy service. The paediatric allergy service in NCL is predominantly delivered by paediatricians with a special interest in allergy. It is an outpatient specialty and is currently delivered across all secondary care sites in NCL. The services at the sites vary in size, the number of referrals received and the workforce available to support them. Paediatric allergy services usually require the input of specialist nurses and dieticians, as well as doctors. During the COVID-19 pandemic, all the services built up a backlog, in part due to the need to deliver some key elements face-to-face (such as food challenges).

Staff also reflected on the impact of duplicative referrals. As outlined in Figure 72, one in 20 individuals referred to allergy services have more than one GP referral. This may be reflective of the long waits in this specialty, although it is a challenge to unpick from the general paediatric data as many sites do not code it as a separate specialty.

There may be opportunities for NCL hospitals to collaborate further around paediatric allergy, to ensure that resource and expertise is spread evenly across hospital sites.

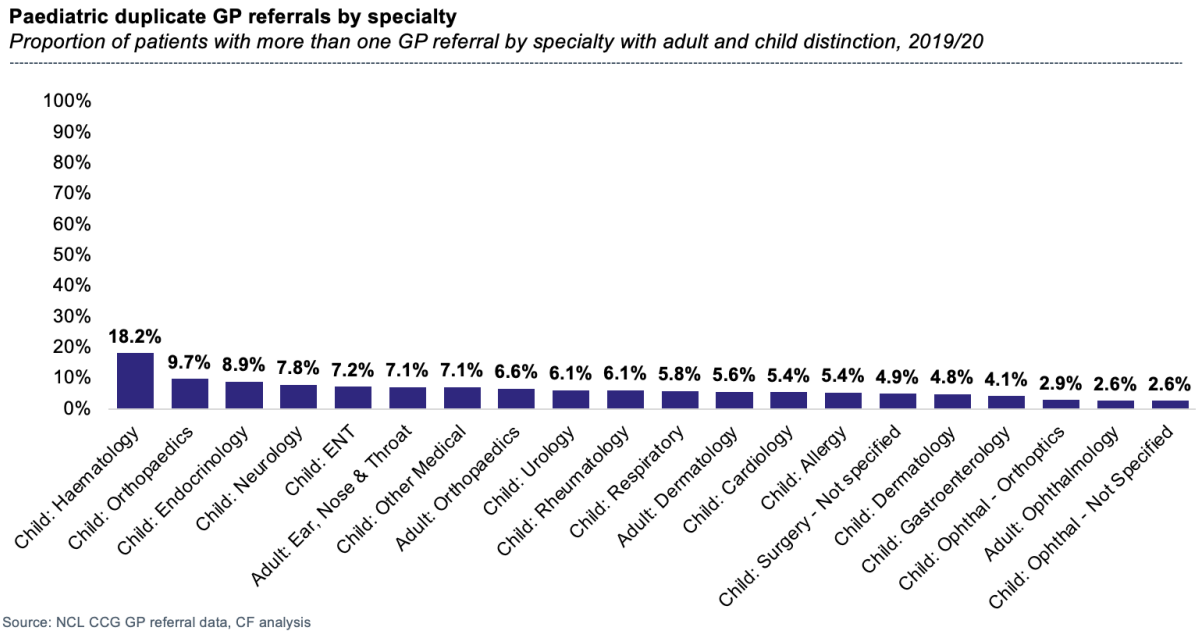


Figure 72: Duplicate GP referrals by specialty

Whilst feedback from this review highlighted paediatric allergy services as a key challenge, the data on duplicate referrals indicates challenges in other specialties. There may also be the opportunity to consider innovative ways of managing the outpatient waiting list, such as through more virtual appointments, joint working with primary and community care and the introduction of innovative models, such as patient-initiated follow-up.

5. Transition to adult services

The transition from adolescent to adult services is an important step and a poor experience can be associated with a deterioration in the health of these individuals.

The cut off age for paediatric services varies between the different sites in NCL which means that some young people move to adult services at 16, whilst others move at their 19th birthday.

This section explores the opportunity to improve the process for transition, ensuring that children and young people are engaged throughout the process.

Children and young people with any form of disability, chronic disease or significant mental health problem, can face significant challenges in transitioning from adolescence to adulthood. As young people move into adulthood, they must deal with changes in the care needed and the way in which is delivered, with an expectation of greater independence in the management of their care.

There is a body of evidence highlighting that for young people with chronic conditions, the process of transitioning from paediatric to adult services is associated with a deterioration in

their health[75,76]. It is therefore critical that health and care services are able to effectively support a smooth transition between services.

Transition is a continual process, from neonates to paediatric services, from paediatric services to teenagers and young adults (TYA) and from TYA to adult services. A smooth transition between these services and adult care is important. Work undertaken in 2016 by Leeds Teaching Hospital Trust found that effective delivery of a transition model of care requires leadership, a whole team approach and collaboration between different organisations[77]. The transition must ensure that the patient continues to receive the same standard and level of care they received previously, whilst being informed about any changes, in order to support them and their families through the transition.

Across NCL there is a challenge in providing consistent care across transition into adult services as described in section 6.4.

It should also be recognised that patients using acute services also use community and mental health services and the age cut offs and definitions may also vary across these services too.

There is an opportunity to consider the current processes and model of care, working with children and young people to refine and improve. This will include thinking about how our organisations can work collectively between children and adult services, as well working in partnership with families to support their child through the transition and manage expectations.

"Holistic care is needed to help patients navigate stages as they grow – independence, education, career paths and employment opportunities in conjunction with their illnesses. Patients want to develop the independence but still need to be signposted to where they can go to access support." - UCLH Paediatric and Adolescents Division Patient Feedback Event

6. Support the recruitment and retention of workforce

Workforce sustainability is a national challenge and NCL has challenges in the recruitment and retention of the paediatric workforce.

Vacancy rates for paediatric nurses vary between the sites, from 13-36%. This section will explore the paediatric workforce challenge in NCL and the impact that these shortages have on our staff and their experience.

Our staff deliver excellent care across our paediatric services, however over the last two years, the ongoing high numbers of patients with COVID-19, winter pressures and increasing demand has meant that the emotional resilience of our staff continues to be tested. During clinical engagement, challenges around rotas were highlighted, particularly

[75] Lotstein DS, Seid M, Klingensmith G, Case D, Lawrence JM, Pihoker C, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. Pediatrics 2013;131(4):e1062-70.
[76] McDonagh JE, Viner RM. Lost in transition? Between paediatric and adult services. BMJ 2006;332(7539):435-6.
[77] https://www.hct.nhs.uk/media/4084/brochure-the-burdett-national-transition-nursing-network-final-july-2020.pdf

for nursing and junior doctors. Staff also emphasised significant pressures on paediatric ED staffing, including consultants and nurses.

There have been significant recruitment efforts to help reduce the vacancy rates of paediatric staff, however there are still gaps to fills. Vacancy rates are particularly high in paediatric nursing, with rates ranging from 13% - 36% across the NCL sites. Currently, 81 posts are unfilled and a further 45 are filled by either bank or agency staff.

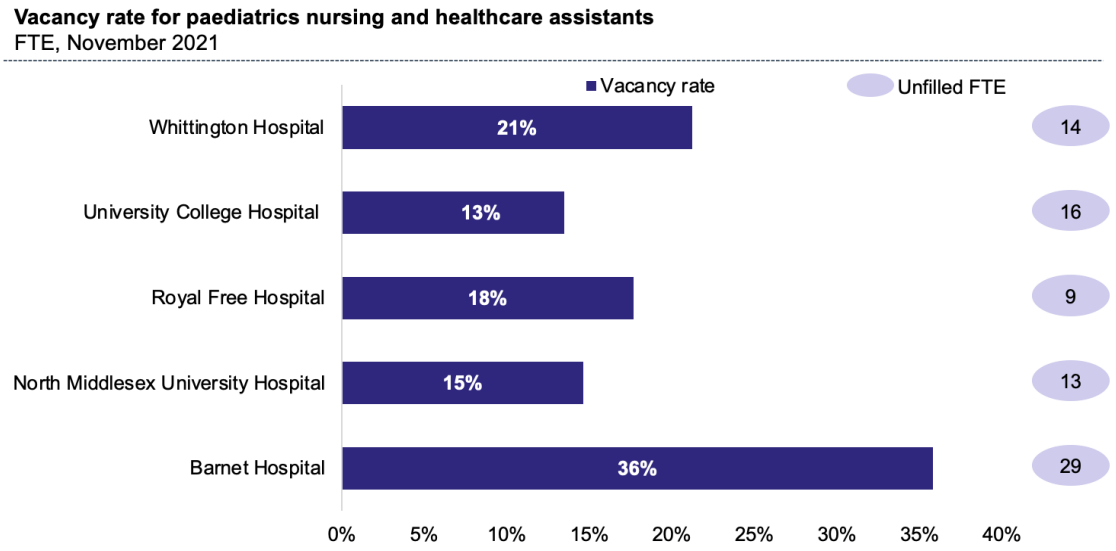


Figure 73: Vacancy rate for paediatric nursing and healthcare assistants

Often our own staff are having to cover the shifts, which increases the pressure on them and impacts their resilience. This can contribute to staff burnout, which in turn may further worsen the workforce challenge. Taken together, the vacancy rate, high spend on temporary staff and poor staff experience highlight challenges to workforce sustainability.

Considering the paediatric nursing workforce challenges faced by all Trusts in NCL, there is an opportunity to consider how working collaboratively as an ICS can help to develop innovative workforce solutions in NCL.

7. Improve the environment and infrastructure for paediatric surgical care

Facilities and environment for paediatric surgery are crucial in ensuring that children and young people have the most positive healthcare experience possible. The GIRFT review of paediatric general surgery and urology highlighted that variation in volumes of paediatric surgery has resulted in a lack of infrastructure.

National guidelines have been created to ensure that the environment is of a certain standard, but some NCL sites do not meet these recommendations. This section will explore how missing these recommendations can impact on patients.

A positive and safe experience of healthcare can have a long-term impact on children and young people. The environment in which care is delivered is critical and recognised in

national guidance. The Royal College of Surgeons standards[78] for paediatric surgery outlines that the environment in which children and young people are treated in should be:

- safe
- suitably staffed and equipped
- child and family friendly

The environment and infrastructure can have an impact on both the care delivered, but also the experience of children, young people, their families, and carers.

Child-friendly environment

When it comes to delivering paediatric surgery, we know that the environment of some sites is not proving the best experience for children and young people. National guidance recommends that children should be separated and not managed directly alongside adults[79]. Children, where possible, should also be operated on in child-friendly theatres, have separate recovery rooms and should be on a dedicated children's list if possible[80]. All theatre staff should also have child-specific training to ensuring the best possible experience for children and young people is provided.

However, within NCL not all sites are able to meet the recommendations. Currently not all our sites are able to provide dedicated paediatric theatres or child-friendly environments. This is in part driven by the low volumes of elective activity and pressures of managing both adult surgery and the recovery from COVID-19.

The impact of the current estate and organisation means that some sites are struggling to manage their activity or are having to manage activity in a way that does not meet best practice guidance. There are also productivity implications for Trusts; dedicated paediatric lists provide opportunities to improve efficiencies of elective surgery.

Organisation	Elective surgical operating hours per month	Dedicated paediatric lists	Dedicated paediatric theatres
North Middlesex University Hospital	40	✓	✗
Royal Free London (Barnet and Royal Free Hospitals)	72	✓	✗
University College Hospital	288	✓	✓
Whittington Hospital	80	✓	✗

Figure 74: Organisation of surgical services at NCL Trusts

Improving and optimising the current facilities is important in ensuring a positive experience, as patients' families have reflected to us the importance of facilities and their environment on how they experience care. The parent of one child reflected that *"If the hospital stay is for more than one day, it deserves a private room or shared room with separate bathroom". – Patient feedback, UCLH, 2021*

[78] Royal College of Surgeons: Standards for Children's surgery, 2013
[79] https://www.gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/PaediatricSurgeryReport-Sept21w.pdf
[80] Royal College of Surgeons: Standards for Children's surgery, 2013

HDU bed capacity

There is a need to support the management of children and young people along the critical care pathway in a setting which is appropriate to their care needs, and which maximises capacity for level 3 paediatric intensive care capacity for those who need it the most.

Figure 75 sets out the levels of care on the critical care pathway and the requirements to meet them[81].

Type of critical care unit	Explanation
Paediatric critical care (PCCU)	A discrete area within a ward or hospital where paediatric critical care is delivered.
Level 1 (PCCU)	A discrete area where Level 1 paediatric critical care is delivered. With Paediatric Critical Care Network agreement, CPAP for bronchiolitis may be initiated or continued in a number of Level 1 Paediatric Critical Care Units.
Level 2 (PCCU)	A discrete area where Level 1 and Level 2 paediatric critical care are delivered. Other than in specialist children's hospitals, Level 2 Units should be able to provide, as a minimum, acute (and chronic) non-invasive ventilation and care for children with tracheostomies and children on long-term ventilation but should not be expected to deliver specialist Level 2 interventions such as acute renal replacement therapy. Within specialist children's hospitals, Level 2 Units may provide some or all of these additional specialist interventions. This unit may also be called a Paediatric High Dependency Unit (PHDU).
Level 3 (PCCU)	A unit delivering Level 2 and Level 3 paediatric critical care (and Level 1 if required). This unit may also be called a Paediatric Intensive Care Unit (PICU).

Figure 75: Level of care on paediatric critical care pathway

All hospitals should be able to undertake basic critical care.

Only GOSH and RNOH have designated capacity for immediate critical care for children and young people under 13 years of age; however, all sites are able to offer flexible support on a pop-up basis, meeting the level 1 and when required level 2 criteria. UCLH also has established HDU capacity for over 13s to support its specialist adolescent practice, which meets the level 2 criteria.

Whilst this flexible utilisation of capacity works well for some defined medical conditions, such as respiratory infections or diabetic ketoacidosis, it can be much more challenging in supporting potential surgical complications.

As referenced in this chapter, there is an interdependency around paediatric critical care capacity with the changes to the specification for children's cancer.

[81] Paediatric Critical Care Society. 2021. Quality Standards for the Care of Critically Ill or Injured Children. Available online: https://pccsociety.uk/wp-content/uploads/2021/10/PCCS-Standards-2021.pdf [Accessed June 2022]

6.6 Summary of findings

This section has highlighted areas of challenge and outlined opportunities for improvement for children and young people's services in NCL. The number of children and young people accessing emergency care is increasing across NCL, placing pressures on our units and our staff. The organisation and location of ED in NCL means that some sites are dealing with larger catchment areas and face greater demand pressures. North Mid has the busiest ED in London and serves some of the most deprived areas. It is important that the resources and models of care are in the right places in NCL to support the local population needs.

The increasing number of lower acuity attendances means it is important that NCL continues to prioritise the implementation of the integrated paediatric service model. This is an opportunity to help manage the increasing emergency demand and ensure that children and young people are accessing care in the right setting, with the right people and at the right time.

The management of LTCs is critical to help avoid admissions into the acute hospital setting. Children and young people from more deprived areas are more likely to be admitted. Work is already underway in NCL through the regional improvement programme, and it is important that this is accelerated across NCL to prevent avoidable admissions and level up care to reduce the current variance in services.

There are opportunities for improvement in paediatric elective and emergency surgical pathways in NCL. Currently surgical pathways are fragmented and unclear for our staff. For emergency care, lack of clarity and protocols on the transfer of children and young people means too often children and young people are being transferred, often to specialised hospitals, for treatment that could be undertaken at local hospitals.

The organisation of elective paediatric surgery in NCL means pathways are fragmented. The shift towards more elective surgery taking place at specialist sites means that many sites deliver low volumes of elective surgical activities. Our staff face challenges in maintaining skills and competencies, which also has a knock-on impact on the emergency care, with staff lacking the confidence to provide the treatment required.

There is an opportunity across NCL to rationalise emergency and elective surgical care pathways. In line with guidance, there is an opportunity to consider a networked approach. The network could be leveraged to help maintain skills and competencies across the board.

The growing paediatric waiting list in NCL highlights the need to think differently about how elective care is delivered. Joint working between local and specialist hospitals has supported a reduction in the waiting list for specialities such as orthopaedics and there is an opportunity to build on these successes elsewhere to help tackle the growing backlog.

The review has highlighted high vacancy rates for the paediatric workforce. Challenges in recruitment and retention are a system-wide challenge and there is an opportunity to think about how to work as a system to address these gaps. Filling these with bank and agency staff is not sustainable and does not provide the best quality of care for the population.

Section seven: Financial context

Financial sustainability is a national challenge. Paediatric and maternity services account for 15% of spend of the acute (non-specialist) Trusts in NCL.

This section will outline the financial challenges in NCL and illustrate the variability of costs for different providers.

7.1 Financial sustainability

Financial sustainability is essential to enabling the NHS to continue to deliver high quality care now and in the future. The NHS Long Term Plan in 2019 set out a path to put the NHS back into financial sustainability after years of deficits. This involves returning to financial balance, achieving greater productivity, reducing the need for care through better integration and prevention, improving providers' financial and operational performance, and making better use of capital investment. The aim is to ensure that public money is used to maximum benefit.

In the context of world-wide and national cost of living increases and two years of emergency increases in public spending due to the COVID-19 pandemic, financial sustainability has taken on renewed importance.

Paediatric, maternity, and neonatal services are an important area of clinical spend for hospitals in NCL. In the financial year 2019/20, Trusts in NCL (excluding the specialist trusts) collectively spent over £80m on paediatric services and over £154m on maternity services.

This equates to 5% of their total clinical expenditure on paediatrics and 10% on maternity. The proportion of total spend on paediatrics and obstetrics for NCL Trusts is in line with the London median spend of 6% and 11% respectively. It is worth noting that NCL is a net importer of activity, with Trusts treating more patients from outside NCL than the number of NCL patients going elsewhere for treatment.

As part of its overall responsibility to ensure financial sustainability alongside high quality services, NCL ICS will need to identify opportunities to deliver better quality care in paediatric, maternity and neonatal services at similar or the same costs to the population they serve.

7.2 Variability of costs across NCL

The preceding chapters of this case for change demonstrate variations in service provision across NCL, whether in workforce models, pathway management, or the physical estate and its usage this means there is a variability in costs across providers.

If organisations can standardise practice to combine good quality service through sharing best practice there is opportunity to improve quality and efficiency across NCL and therefore make better use of financial resources.

Workforce is the largest area of spend for our services. Workforce challenges such as high vacancy rates lead to reliance on expensive bank and agency staffing, particularly for

nursing, in order to have sufficient staff to deliver safe care. Having services staffed by permanent staff can help to deliver high quality and more consistent care.

7.3 Capital and investment in estates

The focus of the case for change is on the clinical considerations around care, including how the estate impacts on clinical care to ensure that it does not detract from care and meets best practice standards.

Estates are funded through capital investment, which comes with associated costs. As part of this, it will be important to understand the age and safety of all units and replacement timelines for large pieces of equipment, in order to develop plans which accurately reflect the opportunity to proactively develop the system estate as part of the next phase of this work.

In subsequent phases of the Start Well programme we will need to consider the capital implications of delivery of best practice models of care and incorporate this into ICS prioritisation process for allocating capital funding.

There is an ongoing process within the ICS to make best use of capital funding over the next few years and a collaborative process for prioritising the capital available against clinical priorities.

7.4 Summary and next steps

In reviewing future models of care there is the potential to not only address population need and provide more consistent and higher quality services for maternity, neonatal children and young people's pathways, and also to do this in a sustainable way.

After the decision point in the autumn 2022, and as aspects of the case for change potentially develop into an options appraisal process, the level of financial modelling and scrutiny will be vitally important to ensure the appropriate value for money assessment is considered.

Section eight: Equalities

8.1 Overview

The aim of this chapter is to pull together the data from across the case for change and the wider literature to describe service provision and outcomes for children and young people's (aged 0-18 years) planned and emergency services, and maternity and neonatal services across NCL by different equalities dimensions. In line with our statutory duty under the Equality Act 2010, there is a specific focus on the health needs of those with protected characteristics. Furthermore, we have included inclusion health groups, who are a priority focus in the Core20PLUS5 approach to reducing health inequalities[82].

Reducing health inequalities and ensuring equity in NHS service provision and experience are key drivers of this piece of work, and the health system in NCL is committed to tackling these differences. Where available, local NHS and other data has been used to inform this narrative. Where local data is not available, we have considered a non-systematic review of nationally available data and scientific literature undertaken by public health professionals working within NCL. A summary of potential inequalities in service access and outcomes for protected characteristics and inclusion health groups is provided, with a focus on the intersectionality between ethnicity and deprivation.

Where data has been referenced from elsewhere in the document, it has been acknowledged.

8.2 Protected characteristics

Ethnicity

Children and young people's use of planned and emergency services

As highlighted in the earlier population health chapter, NCL has a diverse population of children and young people.

The prevalence of several long-term conditions in children and young people in NCL varies by ethnicity, but those from Bangladeshi and some Mixed and Black communities are disproportionately impacted, highlighting more opportunities for prevention and early intervention, and greater need for NHS services. Asthma prevalence is highest among Bangladeshi and Mixed White and Black Caribbean children and young people (Figure 25); epilepsy prevalence is highest among Mixed White and Black Caribbean, Bangladeshi, and those from any Black background; and learning disabilities are more prevalent among Bangladeshi children and young people (Figure 26). Black children and young people have high admission rates to hospital for sickle cell anaemia, as this is a condition which predominantly affects these communities. The variation of mental health conditions by ethnicity is more complex (Figure 76).

[82] NHS. Core20PLUS5- an approach to reducing health inequalities. Available online: https://www.england.nhs.uk/about/equality/equality-hub/core20plus5/ [Accessed May 2022]

Mental health hospital admissions by ethnicity
Mental health admission rate by ethnicity, 2020/21

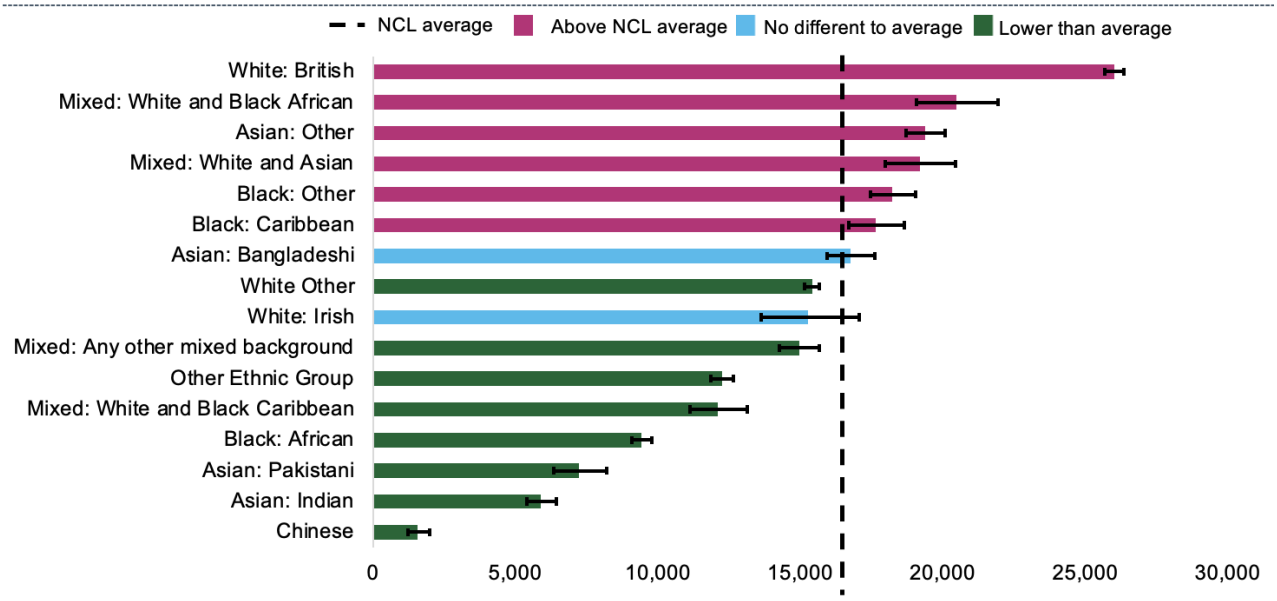


Figure 76: Mental health admissions by ethnicity

In NCL, where recorded, children and young people of Black British or Black Other ethnicities are almost 50% more likely to attend the ED compared to White British children and young people (Figure 77). There is ongoing work to better understand the drivers of ED utilisation by different communities in NCL. However, higher ED attendances for children and young people from ethnic minority groups can indicate poorer access to preventative and early intervention services and poorer management of their long-term conditions in primary care. These data should also be interpreted in the context of the broader and growing evidence base[83], which demonstrates generally poorer health in ethnic minorities.

[83] Kings Fund. 2021. The health of people from ethnic minority groups in England. Available online: https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england [Accessed May 2022]

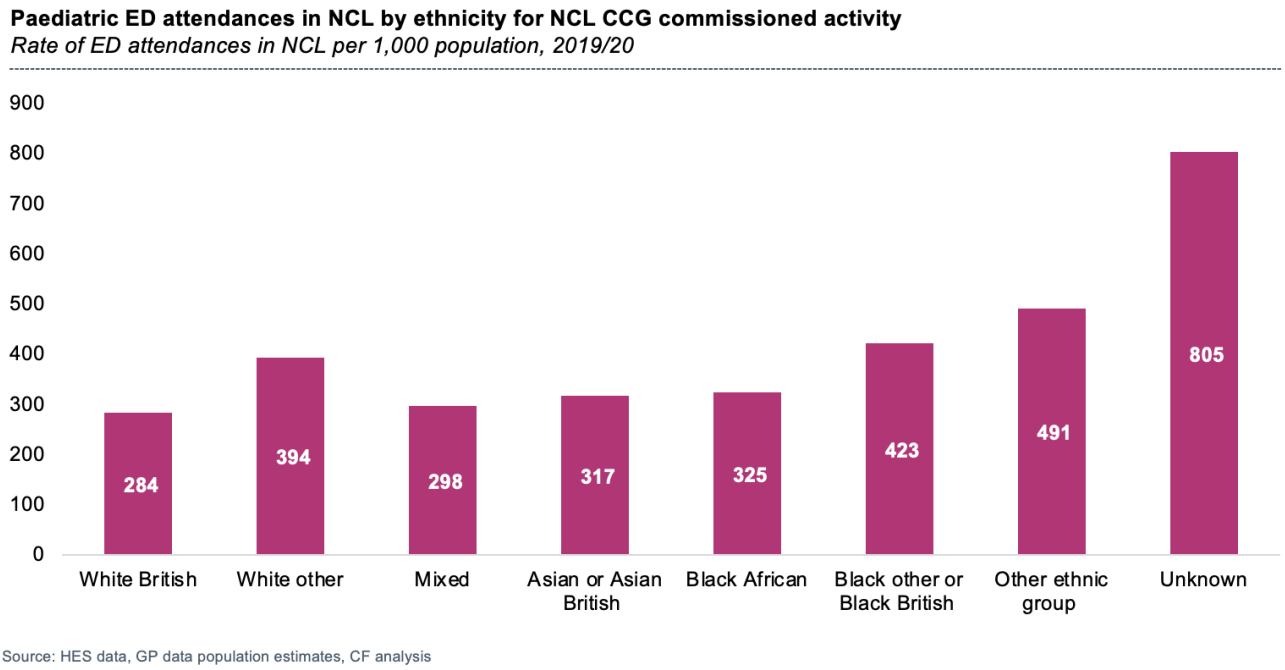


Figure 77: Paediatric ED attendances by ethnicity

Median days on elective care waiting lists, however, are similar for all ethnicities. While it is positive that waits appear to be similar once on lists, there needs to be ongoing consideration of whether there is equity in access to planned care in the first place.

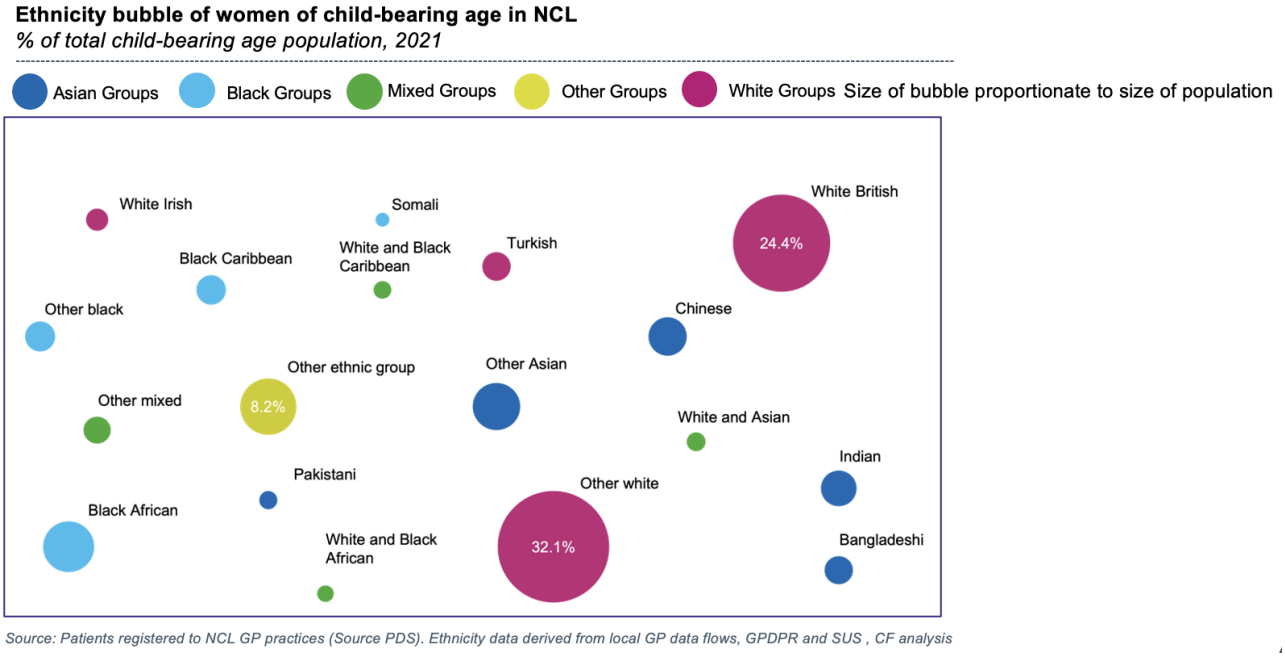
Some cultural practices can predispose children and young people to a higher risk of long-term ill health. Consanguinity is associated with a higher prevalence of congenital conditions and developmental delay among children, especially when close relatives marry over multiple generations[84]. Female genital mutilation (FGM) can result in bleeding, infection, urinary difficulties and higher risk of complications in childbirth including the death of the new born[85]. Data on consanguineous relationships are limited, but it is generally more prevalent in Muslim communities with South Asian, Middle Eastern and sub-Saharan African ancestry[86 87]. While not advocated in any mainstream religious community, FGM is practiced as part of minority Muslim, Christian, Jewish and African religious groups[88]. The estimated prevalence of FGM is lowest in Barnet (1.6%) and highest in Haringey and Islington (2.7%), with a London average of 2.1%[89]. Where services are providing care for communities that

[84] Ajaz M, Ali N, Randhawa G. UK Pakistani views on the adverse health risks associated with consanguineous marriages. Journal of community genetics. 2015 Oct;6(4):331-42.
[85] World Health Organisation. Femal Genital Mutilation. 2022. Available at: https://www.who.int/news-room/fact-sheets/detail/female-genital-mutilation
[86] London Borough of Tower Hamlets. Consanguinity ad Child Health: JSNA Factsheet. Available online: https://www.towerhamlets.gov.uk/Documents/Borough_statistics/JSNA/Consanguinity-JSNA-Fact-Sheet.pdf
[87] Saggar AK, Bittles AH. Consanguinity and child health. Paediatrics and Child Health. 2008 May 1;18(5):244-9
[88] United Nations Population Fund. Female Genital Mutilation (FGM) frequently asked questions. 2022. Available at: https://www.unfpa.org/resources/female-genital-mutilation-fgm-frequently-asked-questions#religions
[89] City University London. Prevalence of Female Genital Mutilation in England and Wales: National and local estimates. Available online: https://www.trustforlondon.org.uk/publications/prevalence-female-genital-mutilation-england-and-wales-national-and-local-estimates/

may have consanguineous relationships or practice FGM, there should be specific and sensitive consideration of these needs[90].

Maternity and neonatal services

Sixty percent of women of child-bearing age identify as White British and Other White, while approximately 16% identify as Asian and 12% as Black (Figure 78). Across England and Wales in 2020, 59% of live births were White British, 12% were White Other; 12% were of any Asian ethnicity, 4.8% were of any Black ethnicity; and 6.7% had mixed ethnicity[91]. Local information is not available on the ethnicity of births as ethnic group is not collection at birth registration. Understanding ethnic inequalities in the health of pregnant women and people is important as they can have a negative impact on health outcomes for them during maternity, and for their babies.



Source: Patients registered to NCL GP practices (Source PDS). Ethnicity data derived from local GP data flows, GPDPR and SUS , CF analysis

Figure 78: Ethnicity of women of childbearing age in NCL

The prevalence of long-term conditions in pregnant women and people also varies by ethnicity, which increases the complexity of pregnancy and delivery. Black women giving birth in NCL have a significantly higher prevalence of obesity and Asian women have a higher prevalence of diabetes (Figure 17). Analysis shows that babies born to mothers or people of Black and Asian ethnicities in NCL have a higher rate of admission to neonatal units than babies born to White women or people (Figure 32).

[90] City University London. Prevalence of Female Genital Mutilation in England and Wales: National and local estimates. Available online: https://www.trustforlondon.org.uk/publications/prevalence-female-genital-mutilation-england-and-wales-national-and-local-estimates/

[91] Office For National Statistics. 2022. Figures on births by gestation, ethnicity, index of multiple deprivation and area of usual residence, 2020. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/adhocs/14212figuresonbirthsbygestationethnicgroupindexofmultipledeprivationimdandareaofusualresidence2020 [Accessed May 2022]

While it is not always possible to look at all outcomes by ethnicity because of a lack of ethnic group recording (births and deaths), combined with *statistically* small numbers at a local level, these findings in NCL are consistent with the broader evidence base. This demonstrates persistent and stark differences in maternal outcomes for people of ethnic minority groups[92]. These are highlighted in the 2021 MBBRACE-UK report, which shows that in the UK and Ireland maternal mortality is more than four times higher for Black women and people, two times higher for mixed ethnicity women and people, and almost twice as high for Asian women and people compared to White women[93].

Continuity of carer and the relationship between caregiver and receiver has been proven to lead to better outcomes and safety for mother and baby. Therefore, improving continuity of carer for people from Black and other minority ethnic groups throughout pregnancy may contribute to improved maternal outcomes and reduced ethnic inequalities in health. Section 5.5 explores midwifery continuity of carer and the extent to which this has been implemented in NCL.

Deprivation, including geography

For children and young people, deprivation is a measured on a small area basis based on income through the Income Deprivation Affecting Children Index (IDACI). For women and people giving birth, the indices look at multiple aspects of deprivation including housing, education, income, health, environment as measured through the Index of Multiple Deprivation (IMD)[94]*.*

Children and young people's use of planned and emergency services

Within NCL there is considerable variation in the level of deprivation and therefore the potential impacts that this may have on the health of children and young people. Across NCL, 23% of children and young people live in the 20% most deprived areas in the country, with a further 30% living in the 21-40% most deprived areas. See section 4.2 for further details.

Children and young people living in the 20% most deprived areas of NCL are significantly more likely to have diabetes than the NCL average (Figure 24) and those in the 40% most deprived areas being significantly more likely to have asthma (Figure 23).

Children and young people from the most deprived areas of NCL are up to four times more likely to attend ED than those living in some of the more affluent areas, but those in the 10%

[92] Public Health England. 2020. Maternity high impact area: reducing the inequality of outcomes for women from Black, Asian and Minority Ethnic communities and their babies. Available online: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/942480/Maternity_high_impact_area_6_Reducing_the_inequality_of_outcomes_for_women_from_Black__Asian_and_Minority_Ethnic__BAME__communities_and_their_babies.pdf [Accessed May 2022]

[93] MBRRACE-UK. 2021. Saving Lives, Improving Mothers Care. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf [Accessed May 2022]

[94] For children and young people, deprivation is a measured on a small area basis based on income through the Income Deprivation Affecting Children Index (IDACI). For women and people giving birth, the indices look at multiple aspects of deprivation including housing, education, income, health, environment as measured through the Index of Multiple Deprivation (IMD). English indices of deprivation - GOV.UK (www.gov.uk)

least deprived areas also have high rates of ED attendances. Children and young people living in the 40% least deprived areas are more likely to be admitted for mental health conditions. Admission rates for sickle cell anaemia are higher among children and young people living in more deprived areas. Median days on elective care waiting lists are similar across different areas of deprivation, but again, further work is needed to understand if children and young people from different areas get equitable access to elective care in the first place given their differential health needs.

These findings are consistent with the broader evidence base, which consistently shows worse health and development outcomes among the most deprived children and young people [95] [96] [97].

Maternity and neonatal services

Women and people giving birth living in communities with different levels of deprivation experience different health outcomes.

The 40% most deprived areas in NCL have the greatest number of births, but generally have lower fertility rates. Geographically, the highest delivery rates in NCL are in pockets across the area (Figure 14). Maternity admissions in NCL by level of deprivation shows that almost half of all maternity admissions in NCL are in the most deprived 40% of the population.

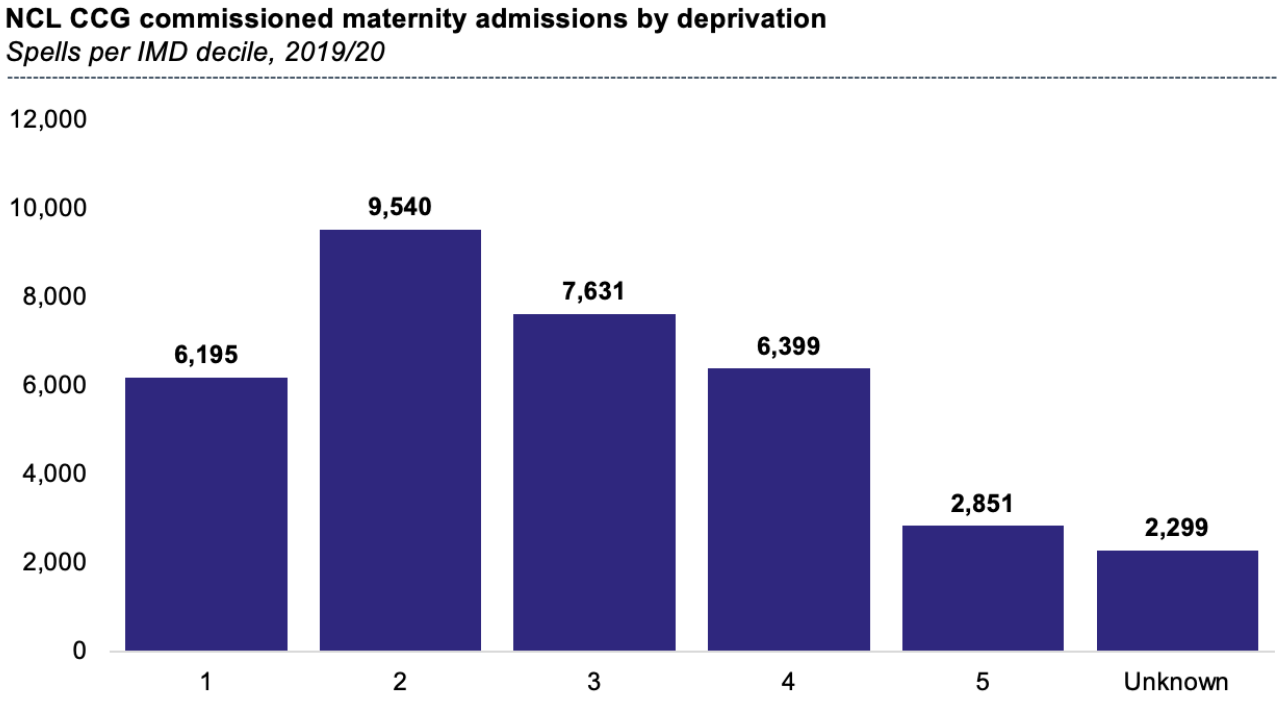


Figure 79: Maternity admissions by deprivation in NCL

Nearly two-thirds of maternity admissions at the North Mid hospital are from women and people living in the 30% most deprived areas. All NCL boroughs have lower proportions of

[95] D Pillas et al. 2014. Social Inequalities in early childhood health and development: a European-wide systematic review. Available online: https://pubmed.ncbi.nlm.nih.gov/25122581/ [Accessed May 2022]
[96] C Coughlan et al. 2022. Social and ethnic differences in healthcare use by children aged 0-14 years: a population-based cohort study in England from 2007 to 2017. Available online: https://pubmed.ncbi.nlm.nih.gov/34244166/ [Accessed May 2022]
[97] National Child Mortality Database. 2021. Child Mortality and Social Deprivation. Available online: https://www.ncmd.info/publications/child-mortality-social-deprivation/ [Accessed May 2022]

women accessing early maternity care compared to the English average, with Barnet having the lowest.

There are also variances in the rate of still births. Stillbirth rates in the 20% most deprived areas are 55% higher than the 20% least deprived areas. While local data shows a more recent reduction, geographically, between 2018 and 2020, Haringey had the highest stillbirth rate in England and is a borough with areas of high deprivation. During this period, a woman living in Haringey was almost twice as likely to have a stillbirth compared to a woman living in Camden (see section 5.5).

There is less variance in infant deaths across NCL. However, while the infant death rate in the most deprived areas is statistically similar to the NCL average, the largest numbers of infant deaths are in the most deprived areas because of the larger numbers of births.

There are further differences in the health behaviours among pregnant women and people living in the most deprived areas of NCL, which will negatively impact on health outcomes. With a prevalence of 18%, pregnant women and people from the 20% most deprived areas are significantly more likely to be obese (Figure 18), while 7.8% of mothers in the 40% most deprived areas are smokers at the time of delivery compared to 3% of mothers who live in the 40% least deprived areas (Figure 16).

These findings from NCL are consistent with the broader evidence base. The available evidence highlights stark differences in experiences, utilisation, and outcomes in maternal care for women experiencing deprivation[98].

Intersectionality between ethnicity and deprivation

Intersectionality refers to the overlapping and interconnected nature of population characteristics, which often combine to exacerbate health and social inequalities. The available data[99] demonstrate clear intersectionality between ethnicity and deprivation, with some ethnic groups more likely to be living in the most deprived areas of NCL. Throughout this analysis there are multiple examples of poorer outcomes and higher healthcare utilisation being associated with both deprivation and ethnicity. While higher levels of deprivation may explain some of the poorer health outcomes experienced by certain ethnic groups, the Marmot review suggests that racial discrimination may also play a role[100].

Although the main cause of deprivation across London is access to high-quality housing[101] there are differences in the causes across boroughs, and there are variations within communities. Low household income is a key driver of deprivation among children and young people, with poverty clustering in some communities, and often in small areas[102].

[98] A Lindquist. 2015. Experience, utilisation and outcomes of maternity care in England among women from difference socio-economic groups: Findings from 2010 National Survey. Available online: https://pubmed.ncbi.nlm.nih.gov/25227878/ [Accessed May 2022]
[99] North London Partners in Health and Care. 2021. Local communities in North London: patterns in age, deprivation and ethnicity
[100] Marmot. 2020. Health Equity in England: The Marmot Review 10 years on. Available online: https://www.health.org.uk/publications/reports/the-marmot-review-10-years-on [Accessed May 2022]
[101] Local Communities in North London: patterns in age, deprivation and ethnicity
[102] English indices of deprivation - GOV.UK (www.gov.uk)

Other protected characteristics

The following section overviews service provision and outcomes for the remaining protected characteristics for which there was either inadequate data available for a robust analysis or the data demonstrated relatively lower relevance to the outcomes of interest to the services within the scope of the Start Well programme. Pregnancy and maternity have been excluded as they are a major focus of the case for change.

Age

For all trusts in NCL, ED attendances are highest among children and young people aged 0-4 years, who are twice as likely to attend ED compared to other age bands. In contrast, those aged 11-18 years are more likely to be admitted for mental health conditions. Median days on elective care waiting lists are similar across age bands.

National evidence shows that pregnancy among adolescents has been associated with adverse maternal outcomes[103], and the number of teenage suicide deaths over the first year after pregnancy has increased: 11 per 100,000 teenagers giving birth, up from 2.5 in 2014-2016[104]. A higher proportion of women aged under 20 years in NCL have a Caesarean section.

A report into maternal deaths and morbidity between 2017 and 2019 across the UK found that the national maternal mortality rate was almost four-fold higher for women aged 40 years or over, compared with women aged 20-24 years[105]. It also found that less than a third of mothers who gave birth over the age of 45 nationally received the recommended care for older mothers. In NCL, 7% of all mothers giving birth are aged 40 and above.

Sex

There are differences in the prevalence of long-term conditions among children and young people by sex, with boys having a higher prevalence compared to girls (see section 4.2). However, more young women are admitted to hospital for mental health conditions, specifically eating disorders. Median days on elective waiting lists are similar for boys and girls.

Disability

In the UK, 9% of children and young people are disabled, and people with disabilities and learning disabilities, have a higher prevalence of long-term conditions and a lower life

[103] T Ganchimeg et al. 2014. Pregnancy and childbirth outcomes among adolescent mothers: a World Health Organization multicountry study**.** Available online**:** https://pubmed.ncbi.nlm.nih.gov/24641534/ [Accessed May 2022]
[104] MBRRACE-UK. 2021. Saving Lives, Improving Mothers Care. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf [Accessed May 2022]
[105] MBRRACE-UK. 2021. Saving Lives, Improving Mothers Care. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf [Accessed May 2022]

expectancy than the general population[106] [107] [108]. Multiple barriers exist to accessing healthcare for people with disabilities, including problems with communication and care provision, inadequate facilities, and physical barriers to accessing services.

Women with disabilities account for approximately 6% of the population of women giving birth in the UK and are at higher risk of maternal mortality and all severe maternal morbidities, compared to women without disabilities. There is some evidence that women with disabilities experience inequitable access to care, particularly around communication, postnatal care, and infant feeding[109].

Gender reassignment

No data exists nationally or locally on the trans and gender-diverse population, including on the proportion of pregnant women or people who are trans or gender-diverse.

Trans and gender-diverse people face significant discrimination and stigma that act as barriers to accessing healthcare and increase the risk of mental ill health[110]. Available evidence has highlighted negative experiences that impact on accessing healthcare, demonstrating the importance of using gender-inclusive language to help reduce discrimination and stigma.

Marriage and civil partnership

There is no local or national data on the marriage and civil partnership of pregnant women or people using NHS services because it is not routinely collected.

Half of live births in England and Wales occurred outside of marriage or civil partnerships in 2020 and this proportion is increasing; however, this statistic reflects not only single mothers, but a substantial and growing subset of couples who are cohabiting and/or in a relationship without being married.

In 2021, 17% of families in London were single-parent households[111]. There is a substantial body of evidence suggesting that children and young people growing up in single-parent

[106] Family Resources Survey financial year 2020-21. Available online: https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2020-to-2021 [Accessed May 2022]
[107] S Cooper et al. 2018. Management and prevalence of long-term conditions in primary health care for adults with intellectual disabilities compared to the general population: a population-based cohort study. Available online: https://pubmed.ncbi.nlm.nih.gov/28730746/ [Accessed May 2022]
[108] NHS Digital. 2020. Health and care of people with Learning Disabilities. Available online: https://digital.nhs.uk/data-and-information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2018-to-2019/condition-prevalence [Accessed May 2022]
[109] R Malouf. 2017. Access and quality of maternity care for disabled women during pregnancy, birth and the postnatal period in England: data from a national survey. Available online: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5642776/ [Accessed May 2022]
[110] London Assembly Health Committee. 2022. Trans health matters: improving access to healthcare for trans and gender-diverse Londoners. Available online: https://www.london.gov.uk/sites/default/files/health_committee_-_report_-_trans_health_matters.pdf [Accessed May 2022]
[111] Office For National Statistics. 2022. Figures on births by gestation, ethnicity, index of multiple deprivation and area of usual residence, 2020. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/adhocs/14212fi

households are more likely to have worse outcomes across a whole range of indicators, including physical health, psychological wellbeing, and educational attainment[112].

Systematic reviews have demonstrated that single women access maternity services later, are less likely to have complete antenatal and postnatal care and are less likely to breastfeed than married women or women with a partner[113].

Religion

There is no local or national data on the religion of children and young people or pregnant women or people using NHS services because it is not routinely collected.

Data from the Annual Population Survey show that in 2018, an estimated 43% of the population in NCL were Christian, 13% were Muslim, 6% were Jewish, 7% were any other religion, and 31% had no religion. Barnet had the largest Jewish population and Enfield had the largest Muslim population[114].

A national analysis found that a lower proportion of people who had no religion were estimated to be satisfied with their health compared to people from specific religious groups[115]. A recent review of Muslim women's experiences of maternity services in the UK highlighted that healthcare professionals appeared insensitive to Muslim women's needs due to a lack of understanding of the religious values and practices, which impacted Muslim women's confidence in discussing their specific needs [116].

NCL has a relatively large Jewish population with 6% of people identifying as Jewish. Across London, Jewish women are more likely to delay booking of antenatal appointments resulting in missed opportunities for early health promotion and screening[117]. In Hackney, Orthodox Jewish mothers have reflected that health visitors may lack the cultural competence to most effectively support members of their community through pregnancy while health visitors may also believe that their services are needed less frequently in such communities with strong social support networks[118]. Inequalities in child health outcomes have also been noted

---

guresonbirthsbygestationethnicgroupindexofmultipledeprivationimdandareaofusualresidence2020 [Accessed May 2022]

[112] I Lut et al. 2021. Health outcomes, healthcare use and development in children born into or growing up in single parent households: a systematic review study protocol. Available online: https://pubmed.ncbi.nlm.nih.gov/33574152/ [Accessed May 2022]

[113] V Raleigh et al. 2010. Ethnic and social inequalities in women's experience of maternity care in England: results of a national survey. Available online: https://pubmed.ncbi.nlm.nih.gov/20436027/ [Accessed May 2022]

[114] Office for National Statistics. 2019. Population by religion, borough. Available online: https://data.london.gov.uk/dataset/percentage-population-religion-borough [Accessed May 2022]

[115] Office for National Statistics. 2020. Religion and health in England and Wales: February 2020. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/religion/articles/religionandhealthinenglandandwales/february2020#main-points [Accessed May 2022]

[116] T Firdous et al. 2020. Muslim women's experiences of maternity services in the UK: qualitative systematic review and thematic synthesis. Available online: https://pubmed.ncbi.nlm.nih.gov/32070299/ [Accessed May 2022]

[117] McDonald H, Moren C, Scarlett J. Health inequalities in timely antenatal care: audit of pre-and post-referral delays in antenatal bookings in London 2015–16. Journal of Public Health. 2020 Dec;42(4):801-15.

[118] London Borough of Hackney. Health Needs Assessments: Orthodox Jewish community in Stanford Hill, north Hackney. 2018. Available at: https://hackneyjsna.org.uk/wp-content/uploads/2019/08/Orthodox-Jewish-Health-Needs-Assessment-2018.pdf

among the Charedi Jewish community. For example, children are more likely to miss out on vaccinations leading to greater risks of infectious disease outbreaks among these communities and infants from North London's Orthodox Jewish communities also have poorer oral health outcomes, with higher rates of dental cavities and less frequent tooth-brushing[119].

Sexual orientation

There is no local or national data on the sexual orientation of children and young people or pregnant women or people using NHS services because this data is not routinely collected.

National survey data shows that overall, the proportion of people who reported identifying as Lesbian, Gay, or Bisexual (LGB) was higher in London (3.8%) compared to England and Wales as a whole (2.7%) in 2019 and was highest among young people aged 16-24 years (6.6% in England and Wales) [120].

8.3 Inclusion health groups

Inclusion health includes any population group that is socially excluded.

Homeless people

Children experiencing homelessness are more likely to present and be admitted with minor illnesses at paediatric emergency departments but tend to have a lower rate of hospital admissions overall. On average, they have shorter hospital stays, but are more likely to re-attend emergency departments following discharge[121] [122].

Pregnant women and people who are homeless experience poorer maternity outcomes, including lower birth weight and developmental delays relative to non-homeless women and people[123] [124] [125]. This can be partially explained by nutritional deficiencies and stresses resulting from homelessness, but pregnant homeless women and people are also less likely to access antenatal and postnatal care due to barriers such as stigma, affordability of transport, long travel distances and unsuitable times of appointments.

---

[119] [119] Klass C, Mondkar A, Wright D. Oral health and oral health behaviours of five-year-old children in the Charedi Orthodox Jewish Community in North London, UK. Community dental health. 2017 Mar;34(1):60-4.
[120] Office For National Statistics. 2021. Sexual orientation UK, 2019. Available online: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2019 [Accessed May 2022]
[121] T Lissauer et al. 1993. Influence of homelessness on acute admissions to hospital. Available online: https://adc.bmj.com/content/69/4/423.short [Accessed May 2022]
[122] N O'Brien et al. 2022. Emergency department utilisation by homeless people in Dublin, Ireland: a retrospective review. Available online: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8928284/ [Accessed May 2022]
[123] S Reynolds. 2021. The complex issues of the perinatal woman experiencing homelessness. Available online: https://link.springer.com/chapter/10.1007/978-3-030-58085-8_6. [Accessed May 2022]
[124] Yamamoto et al, 2015. Comparison of childbirth delivery outcomes and costs of care between women experiencing vs not experiencing homelessness. Available online: v [Accessed May 2022]
[125] R Richards et al. 2011. Health behaviours and infant health outcomes in homeless pregnant women in the United States. Available online: https://www.publications.aap.org/pediatrics/article-abstract/128/3/438/30705/Health-Behaviors-and-Infant-Health-Outcomes-in?redirectedFrom=fulltext [Accessed May 2022]

Prevalence of households owed a duty under the Homelessness Prevention Act ranges from 9.6% - 22.0% across the NCL boroughs. Camden has the lowest prevalence whilst Haringey has the highest. Specifically, among households with dependent children, prevalence ranges from 11.1% - 18.1%. Camden is again the borough with the lowest proportion, while Islington and Haringey have the joint highest[126].

People with drug / alcohol dependence

There is limited evidence on the healthcare outcomes for children who misuse substances or who have a family member who misuse substances. One study found that children who live with a family member with alcohol dependency are more likely to be admitted to paediatric emergency departments with injuries as a result of victimisation relative to other children, but there was no difference in overall admissions[127].

NCL has a significantly lower rate of both alcohol-related admissions among under 18s and admissions due to substance misuse among 15–24-year-olds, compared to the England average[128] [129]. The proportion of 15-year-olds who have used drugs (excluding cannabis) in the past month ranges from between 0.7% - 2.4% across NCL boroughs. Enfield has the lowest prevalence, whilst Haringey has the highest[130].

Pregnant women and people who misuse substances are at greater risk of poor maternal health outcomes, obstetric complications and are overrepresented in maternal mortality statistics[131]. Attendance at antenatal care tends to be lower, with those women and people who do book appointments tending to do so later and skip their appointments which may be due, in part, to guilt and fear of stigma[132].

According to population estimates, prevalence of alcohol dependence across NCL boroughs ranges from 1.03% - 1.79%, with Barnet representing the lowest proportion and Islington the highest[133]. Meanwhile, adult prevalence of opiate and/or crack cocaine use is estimated

[126] OHID. Public Health profiles. Available online: https://fingertips.phe.org.uk/search/homeless#page/1/gid/1/ati/402/iid/11501/age/-1/sex/-1/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1 [Accessed May 2022]

[127] S Paranjothy et al. 2018. Risk of emergency hospital admission in children associated with mental disorders and alcohol misuse in the household: an electronic birth cohort study. Available online: https://www.thelancet.com/pdfs/journals/lanpub/PIIS2468-2667(18)30069-0.pdf [Accessed May 2022]

[128] OHID. Public Health profiles. Available online: https://fingertips.phe.org.uk/search/alcohol%20admissions#page/4/gid/1/pat/15/ati/167/are/E38000240/iid/93492/age/173/sex/4/cat/-1/ctp/-1/yrr/3/cid/4/tbm/1 [Accessed May 2022]

[129] OHID. Public Health profiles. Available online: https://fingertips.phe.org.uk/search/substance#page/4/gid/1/pat/15/ati/167/are/E38000240/iid/92755/age/156/sex/4/cat/-1/ctp/-1/yrr/3/cid/4/tbm/1 [Accessed May 2022]

[130] OHID. Public Health profiles. Available online: https://fingertips.phe.org.uk/search/drug#page/4/gid/1/pat/6/ati/402/are/E09000007/iid/91810/age/44/sex/4/cat/-1/ctp/-1/yrr/1/cid/4/tbm/1 [Accessed May 2022]

[131] S Steele et al. 2020. Substance misuse in pregnancy. Available online: https://www.sciencedirect.com/science/article/abs/pii/S1751721420301615 [Accessed May 2022]

[132] MBRRACE-UK. 2021. Saving Lives, Improving Mothers Care. Available online: https://www.npeu.ox.ac.uk/assets/downloads/mbrrace-uk/reports/maternal-report-2021/MBRRACE-UK_Maternal_Report_2021_-_FINAL_-_WEB_VERSION.pdf [Accessed May 2022]

[133] Public Health England. 2021. Alcohol dependence prevalence in England. Available online: https://www.gov.uk/government/publications/alcohol-dependence-prevalence-in-england [Accessed May 2022]

to range between 0.63% - 1.31%. Barnet again has the lowest prevalence and Islington the highest[134].

Vulnerable migrants

Migrant children represent a diverse group, and their healthcare needs are likely to be equally varied. There is evidence that children who are European migrants are more likely to have poor oral health, more likely to be obese and at significantly higher risk of developing a mental health condition[135]. Vulnerable migrants, including both asylum seekers and undocumented migrants, are known to experience barriers to healthcare access, including fear of being charged for care or reported to immigration authorities, racial discrimination and language barriers[136].

Pregnant migrants to the UK, particularly asylum seekers, tend to book and access antenatal care later than recommended, often due to barriers including language proficiency, lack of awareness, lack of understanding of the purpose of antenatal appointments, fear over the involvement of immigration authorities and low income[137]. Migrant women have poorer maternal and birth outcomes, including higher rates of maternal mortality, obstetric complications, lower birth weight and preterm birth[138].

Gypsy, Roma, and Traveller communities

There is some evidence to suggest that children from Gypsy, Roma and Traveller communities may be more likely to attend at emergency departments for both injury and non-injury related presentations, with a particularly higher incidence of attendance with burns[139]. Meanwhile, childhood infection rates may also be elevated due to generally poorer sanitation and site conditions[140].

Pregnant women and people from Gypsy, Roma and Traveller communities are less likely to use antenatal and postnatal healthcare services. This could be a result of various barriers including high mobility, frequent threat of eviction and a cultural tendency to seek healthcare

---

[134] Public Health England. 2019. Opiate and crack cocaine use: prevalence estimates by local area. Available online: https://www.gov.uk/government/publications/opiate-and-crack-cocaine-use-prevalence-estimates-for-local-populations [Accessed May 2022]

[135] World Health Organisation. 2018. Health of refugee and migrant children. Available online: https://www.euro.who.int/__data/assets/pdf_file/0011/388361/tc-health-children-eng.pdf [Accessed May 2022]

[136] Wood and Devakumar. 2020. Healthcare access for migrant children in England during the covid-19 pandemic. Available online: https://bmjpaedsopen.bmj.com/content/4/1/e000705 [Accessed May 2022]

[137] G Higginbottom et al. 2019. Experience of and access to maternity care in the UK by immigrant women: a narrative synthesis systematic review. Available online: https://bmjopen.bmj.com/content/9/12/e029478.abstract [Accessed May 2022]

[138] [138] S Asif et al. 2015. The obstetric care of asylum seekers and refugee women in the UK. Available online: https://elearning.rcog.org.uk/sites/default/files/Principles%20of%20antenatal%20care/TOG_Asif_2015.pdfn [Accessed May 2022]

[139] H Beach. 2006. Comparing the use of accident and emergency departments by children from two local authority Gypsy sites with that of their neighbours. Available online: https://pubmed.ncbi.nlm.nih.gov/16887157/ [Accessed May 2022]

[140] P Aspinall et al. 2005. A review of the literature on the health beliefs, health status and use of services in the gypsy traveller population, and of appropriate health care interventions. Available online: https://kar.kent.ac.uk/9170/ [Accessed May 2022]

only for immediate concerns[141] [142]. Incidence of maternal and child mortality during pregnancy is higher for people from Gypsy, Roma and Traveller backgrounds and they are also more likely to experience poorer maternal outcomes including stillbirth, low birth weight and early childhood mortality[143] [144].

At the 2011 Census, the proportion of the NCL population identifying as White Gypsy or Irish Traveller ranged from 0.076% in Camden to 0.15% in Haringey[145].

Carers

Young carers may miss out on access to support for their own needs due to their caring responsibilities. In some cases, parents being cared for may be reluctant to disclose their situation to agencies that can support due to uncertainty over repercussions for their family. Young carers are also at an increased risk of developing emotional and mental health conditions, particularly if they care for a parent with a mental illness or who use substances[146].

There is little evidence on access to maternity care for those people who provide informal care. Informal carers, however, are known to face barriers when accessing support for their own healthcare needs. These include logistical challenges such as finding the time to attend appointments or having alternative care in place to be able to attend, system issues such as healthcare staff lacking recognition of the unique needs of informal caregivers and focusing instead on the health of the person cared-for, limited information and awareness of the provision available, and cultural or language barriers[147].

As of the 2011 Census, the proportion of the population who were carers in NCL boroughs ranged from 7.4% in Haringey to 9.1% in Barnet[148]. It is not possible to determine how many of these carers were young carers or were pregnant.

[141] L Siebelt et al. 2017. Use of UK health services by Gypsies, Roma and Travellers: triangulation of two mixed methods studies. Available online: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)33016-7/fulltext [Accessed May 2022]
[142] P Aspinall et al. 2005. A review of the literature on the health beliefs, health status and use of services in the gypsy traveller population, and of appropriate health care interventions. Available online: https://kar.kent.ac.uk/9170/ [Accessed May 2022]
[143] S Cemlyn et al. 2009. Inequalities experienced by Gypsy and Traveller communities: A review. Available online: https://www.equalitycumbria.org/sites/default/files/documents/awaz-cumbria/09_inequalities%20experienced%20by%20g%20t%20communities%20a%20review.2009.07.11.pdf [Accessed May 2022]
[144] Z Matthews. 2008. The health of Gypsies and Travellers in the UK. Available online: https://raceequalityfoundation.org.uk/health-care/the-health-of-gypsies-and-travellers-in-the-uk/ [Accessed May 2022]
[145] LG Inform. Available online: https://lginform.local.gov.uk/reports/lgastandard?mod-metric=1845&mod-area=E06000031&mod-group=AllSingleTierAndCountyLaInCountry_England&mod-type=namedComparisonGroup [Accessed May 2022]
[146] Dharampal and Ani. 2019. The emotional and mental health needs of young carers: what psychiatry can do. Available online: https://www.cambridge.org/core/journals/bjpsych-bulletin/article/emotional-and-mental-health-needs-of-young-carers-what-psychiatry-can-do/69A86D664B700FD8E478DB3298DE14B1 [Accessed May 2022]
[147] Arskey et al. 2003. Access to healthcare for carers: barriers and interventions. Available online: https://eprints.whiterose.ac.uk/73281/3/document.pdf [Accessed May 2022]
[148] Office for National Statistics. Provision of unpaid care. Available online: https://www.nomisweb.co.uk/census/2011/qs301ew [Accessed May 2022]

8.4 Recommendations

There have been some challenges in assessing information to fully understand the experience, access and outcomes for children, young people, pregnant women and people across NCL because of the breadth of this case for change and a lack of systematic data collection on all protected characteristics across NHS services and for inclusion health groups. There are, however, some clear areas for further action to inform work to reduce inequalities, improve outcomes, and make services more equitable.

- **Ongoing review.** The inequalities identified in this document should be (a) kept under review and updated before service proposals are finalised; and (b) borne in mind when developing proposals so that the CCG (and after 1 July 2022 ICB) can meet its legal duties under s149 of the Equality Act 2010 and in the NHS Act 2006 (s14T)

- **Clinical audit of stillbirths.** Stillbirth data show a high rate within Haringey, and across among the most deprived communities. To understand the core drivers of these poor outcomes a clinical audit of maternal service provision against NICE guidance is recommended. This should include a review of the stillbirth rate by a broader range of protected characteristics, and particularly ethnic group. The audit should be used to identify where existing services need to improve and any wider opportunities for prevention and earlier intervention in NCL.

- **Active engagement of women and people with key protected characteristics.** National evidence shows that older women, women with disabilities, and women that identify as lesbian or bisexual are at risk of poorer maternal outcomes and receive poorer quality care. However, no local data are available to assess maternity and neonatal service outcomes for women from these protected characteristics. It is recommended that such women with the above protected characteristics are actively engaged in order to support the co-design of more inclusive and responsive maternity and neonatal services.

  Local data does show that Black and Asian women and those in more deprived areas are more likely to have underlying health conditions that put them and their baby at greater risk, with higher rates of neonatal admissions. Future work, proactively involving these communities, needs to look at whether there are more opportunities for prevention and earlier intervention, whether services are culturally appropriate and accessible, and to determine key issues contributing to poorer outcomes.

- **Inclusion health needs assessment and service review.** An inclusion health needs assessment, using largely qualitative methods, is currently underway for NCL. National evidence indicates that inclusion health groups are at risk of poorer outcomes and experience lower quality care. It is not possible, however, to measure the outcomes for many inclusion health groups using routine NHS data. Given this, the scope of this needs assessment needs to be reviewed to ensure maternity, neonatal and children and young people's services are included to inform future work in the Start Well programme.

Section nine: Conclusion and next steps

There has been significant energy and collaboration across the system in the process of compiling this document. Stakeholders have been able to describe the opportunities for improvement across maternity, neonatal and children and young people services in NCL. The current challenges outlined, and the opportunities for improvement that have been identified, are extensive.

Deprivation, variation, and equality

This case for change has taken a population health approach and looked with an equalities lens at the need, use and outcomes for the population as a whole.

As set out in detail in the preceding chapter, in taking forward the Start Well programme there are a number of areas in relation to equalities which will need to be explored, including some for immediate action.

- Ongoing review of the equalities dimensions identified in this document before service proposals are finalised and borne in mind when developing proposals
- Clinical audit of stillbirths
- Active engagement of women and people with key protected characteristics
- Inclusion health needs assessment and service review

Maternity and neonatal services

Service users have reflected that they want their maternity care to be safe and personalised. They want options explained to them in a way they understand, and they want to feel involved in their choice of birth place. NCL services may need to go further to provide further support to pregnant women and people to make these choices in a way that helps them to feel informed and involved in their choice.

Given the diversity of those that use our services, NCL will need to consider carefully how the midwifery continuity of carer model can be further implemented to ensure we are providing the right support to those that will benefit from it most. It will need to do this in the context of ensuring implementation of the latest Ockenden recommendations around safe staffing of units.

In many areas, NCL maternity and neonatal services deliver high-quality care and outcomes for patients, with the outcomes for neonatal mortality for those admitted under 32 weeks being the lowest in the country in 2020[149]. To support the best patient experience and care, we must ensure that the type of capacity in NCL hospitals best meets the need of service users. Flows into the sector for the specialist services and

[149] https://www.rcpch.ac.uk/sites/default/files/2022-03/NNAP%20Annual%20Report%20on%202020%20data.pdf

the utilisation of the higher acuity capacity (level three neonatal care, and obstetric-led maternity care) points to a complex maternal and neonatal population that may increasingly need the support of this acuity of care. Contrastingly, the Royal Free Hospital SCU (level one) is unable to look after babies that need significant respiratory support, and staff are unable to maintain their neonatal competencies solely within the unit due to low numbers of admissions; this represents a challenge for a site with an obstetric-led unit looking after pregnant women and people who are deemed to be higher risk. Actions are in place that mitigate the clinical risk caused by low admissions, however the long-term risk remains as it will continue to be difficult to staff the unit in a sustainable way.

Further modelling of demand and capacity will be required to determine how capacity can be aligned to meet the needs of population and that the capacity that is available meets modern estate requirements. This will need to be done jointly across both maternity and neonatal services given the importance of the link between them for the safe care of pregnant women and people and their babies.

Children and young people

The current organisation of paediatric services in NCL means we are not always able to provide services that meet the needs of our local populations and deliver the best care and experience for children, young people and their families to which we aspire.

We know that the pressures on our emergency departments are increasing and that there is more we could do to help ensure that children and young people can access emergency care in the right places for their needs.

Staff have highlighted that surgical service pathways can be fragmented and unclear, with many children and young people unnecessarily transferred to other hospitals for emergency care that could have been delivered locally. The shift towards elective surgery being delivered by specialist hospitals means that some of our local sites are delivering lower volumes of care, which makes it difficult for our staff to maintain their skills and competencies. There is a real opportunity for NCL to think about how we organise surgical care and explore the benefits of a network approach. We know from elsewhere that a network approach can help to maintain skills and competencies.

We also know that children and young people are currently waiting too long for planned treatment. This can have a real impact on their development and lives. We need to consider how organisations across NCL can continue to work jointly to address the backlog.

Workforce

The maternity, neonatal and paediatric workforce in NCL is one of our most valuable assets. They deliver outstanding care and make the difference to thousands of patients' lives every day. However, we have found that there are significant challenges in recruiting, retaining, and maintaining the skills of our workforce. Particular challenges have been identified with nurses, midwifes and AHPs. In the medical

workforce, issues have been identified with maintaining skills and competencies in some services, which are managed by a very small number of clinicians.

We heard very clearly through engagement with clinical leaders about the significant pressure and burden this puts on staff already working in services. This is not a challenge unique to NCL; however, given the knowledge, skills and expertise in NCL we may be in a unique position to overcome some of these challenges through innovative, more joined-up ways of working, making NCL the best place to work.

Interdependencies

Services for maternity, neonatal and children and young people's care do not exist in isolation. There are important interdependencies that need to be recognised and which will need to be taken into account in taking forward the opportunities for change set out in this document:

- Workforce interdependencies, particularly between paediatrics and neonatal services and also between adult and children's services, particularly for anaesthetics, surgery and emergency care
- Paediatric cancer services, particularly the requirements of the service specifications both for primary treatment centres and paediatric oncology shared care units and the fixed location of radiotherapy/proton beam capacity
- Recommendations being rolled out from the NCL strategic reviews of mental health and community services
- Initiatives underway through the regional improvement programme for children and young people

Summary

We all want services that can meet our needs now and, in the future, and our case for change shows that there are strong drivers to think about how we update how our maternity, neonatal, children and young people services are delivered. Our current challenges explain why services cannot stay the way they are. The opportunities highlighted show where we can improve, to make tangible improvements for our local population and our staff.

Next steps and feedback on the case for change

We want to receive the views of as many patients, residents, staff and partners as possible to inform the next phase of Start Well. To do this, we are running a period of engagement activities between 4 July and 9 September 2022.

Taking into account what we hear, as well as other information gathered during this period, commissioners will decide on the next stages of the programme.

How you can feedback

There are several ways to join in the engagement and give us your views on the Case for Change which include completing the questionnaire, attending one of our meetings, drop-ins or engagement events or writing to us with your own feedback.

All feedback will be evaluated by Verve Communications, an independent company who have been engaged to receive and evaluate feedback regardless of how it is submitted.

From 4 July 2022, you can complete the consultation questions using our online survey at:

https://nclhealthandcare.org.uk/start-well/

The same questionnaire is available in hard copy and can be completed and returned in the post using the Freepost address provided.

If you attend any of the public meetings or drop-in events, your views will also be captured and fed into the evaluation.

Who we want to hear from

We want to hear from anyone with an interest in the services covered by Start Well, and are especially interested in hearing the views of:

- Anyone who is currently using the services or has had recent experience of them
- Anyone who might need these services in future
- Families and carers of people who use, have used, or might use these services
- Residents of Barnet, Camden, Enfield, Haringey, Islington and neighbouring areas who might use these services in North Central London
- Staff and professional representative bodies such as trade unions, Local Medical Committees and Royal Colleges
- Community representatives, including the voluntary sector
- Staff and partners in health and social care
- Relevant local authorities

By inviting people to take part in the engagement exercise, we want to understand whether:

- We have considered all of the relevant information in developing the draft case for change
- What is most important to people when planning services in the future

Glossary

A&E	Accident and emergency department (also ED emergency department).
AHPs	Allied Health Professionals including dietitians, physiotherapists, occupational therapists and speech and language Therapists.
Ambulatory care	Same day care where patients are assessed, diagnosed, treated and are able to go home the same day, without being admitted into hospital overnight.
Anaesthetist	The doctor responsible for giving an anaesthetic to the patient during a surgical operation.
ATAIN Programme	Avoiding Term Admissions into Neonatal units A national programme of work to reduce harm leading to avoidable admission to a neonatal unit.
BAPM	British Association of Perinatal Medicine
Baseline analysis	Investigation of the current situation
Better Births	Better Births sets out the national vision for the planning, design and safe delivery of maternity services.
Birth Rate Plus	Birth rate plus is a safe staffing toolkit
Borough (Integrated) Partnerships	Borough (Integrated) Partnerships will bring together a range of organisations, both commissioners and providers of health and social care to improve the health and wellbeing of the local

	population and reduce the health inequalities that exist within each NCL borough.
CAMHS	Child and Adolescent Mental Health Services
Cardiology	Diagnosis and treatment of disorders of the heart and the blood vessels.
CCG	Clinical Commissioning Group: Responsible for commissioning most of the hospital and community NHS services in the local area that will meet the needs of the local population (until 31 June 2022).
Census	The census is a survey that happens every 10 years and gives us a picture of all the people and households in England and Wales.
Core20Plus5	Core20Plus5 is a national NHS England and NHS Improvement approach to support the reduction of health inequalities at both national and system level.
CPG	Clinical Practice Group
CQC	Care Quality Commission The independent regulator of health and social care in England
CYPMN Board	Children young people, maternity and neonatal board which oversees all NCL quality improvement programmes related to children and young people's (physical and mental health), maternity and neonatal care.
Day case	Surgery which is performed on a same day basis.

Demographics	Statistical data relating to the population and particular groups within it.
Dentistry	Related to the diagnosis, prevention, and treatment of diseases, disorders, and conditions of the mouth.
ED	Emergency Department (also Accident and Emergency, A&E)
Elective	Planned care
Emergency surgery	Surgery that cannot be delayed, for which there is no alternative therapy or surgeon, and a delay could result in death or permanent impairment of health
Endocrinology	Medicine related to hormones
Endoscopy	A test to look inside the body with a tube with a small camera inside.
ENT	Medicine related to ear nose and throat conditions and procedures.
Fetal	Related to an unborn baby
Gastroenterology	Medicine that treats disorders of the oesophagus (gullet), stomach, small and large intestines (bowel), liver, gallbladder and pancreas.
GIRFT	Getting It Right First Time is a national programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change.

GMC	General Medical Council protects patients and improves medical education and practice across the UK.
GOSH	Great Ormond Street Hospital for Children NHS Foundation Trust
GP	General practitioner
Gynaecology	Area of medicine that involves the treatment of women's diseases, especially those of the reproductive organs.
HDU	High Dependency Unit
HEE	Health Education England
HES	Hospital Episode Statistics is a database containing details of all admissions to hospital, A&E attendances and outpatient appointments at NHS hospitals in England.
HIV	Human Immunodeficiency Virus
ICB	Integrated Care Board 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 in the ICS area. ICBs will replace CCGs from 1 July 2022.
ICS	Integrated Care System Integrated Care Systems (ICSs) are partnerships 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 their area.
ICU	Intensive care unit

Index multiple deprivation	Indices of multiple deprivation (IMD) are widely-used datasets within the UK to classify the relative deprivation (essentially a measure of poverty) of small areas. Multiple components of deprivation are weighted with different strengths and compiled into a single score of deprivation.
Intersectionality	Intersectionality refers to the overlapping and interconnected nature of population characteristics, which often combine to exacerbate health and social inequalities.
IPS	Integrated paediatric service, integration of primary and specialist care, physical and mental health services, and health with social care at a local level.
JHOSC	Joint health and overview scrutiny committee, with representatives from each of the borough health and overview scrutiny committees.
LD	Learning disability
LMNS	Local maternity and neonatal system local stakeholders working together to deliver the national maternity transformation plan.
LNU	Local Neonatal Unit
LOS	Length of stay. How long a patient is in hospital, and is calculated subtracting the day of admission from day of discharge.
LTP	Long Term Plan The national plan that ensures the NHS is fit for the future.

Maternal medicine	Provides outpatient and inpatient care for women affected with any medical disease in pregnancy.
Maxillofacial	Surgical specialty focusing on reconstructive surgery of the face, facial trauma surgery, the oral cavity, head and neck, mouth, and jaws.
MBBRACE	MBRRACE-UK: Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK
MDT	Multidisciplinary team
Median	Median is the middle number in a sorted list of numbers
Midwifery	Speciality caring for mothers and newborns during pregnancy and childbirth.
Moorfields	Moorfields Eye Hospital NHS Foundation Trust
M&M	Mortality and morbidity
MVPs	Maternity Voices Partnerships are NHS working groups made up of women and their families, midwives, doctors, health visitors and commissioners working together to review and contribute to the development of local maternity care.
National Maternity Transformation Programme	National Maternity Transformation Programme seeks to achieve the vision set out in Better Births by bringing together a wide range of organisations to lead and deliver across 10 work streams.
NCCR	Neonatal Critical Care Review is a report commissioned by NHS England setup in response to the Better Births report in 2016 which recommended a dedicated review of neonatal

	services. This report sets out the actions required by the local and regional NHS to improve the care of babies and enhance the experience of families.
NCL	North Central London
NCL CCG	North Central London Clinical Commissioning Group covering Barnet, Camden, Enfield, Haringey and Islington.
NCL CCG Governing Body	Oversees the work of North Central London Clinical Commissioning Group and ensures that decisions about changes to local health services are debated openly and fairly.
Neonatal	Related to care provided to babies born prematurely (before 37 weeks' gestation), babies that are born unwell or with additional needs.
Neurology	Medicine dealing the diagnosis and treatment of conditions and disease involving the central and peripheral nervous system.
NHS	National Health Service
NHSE/I	NHS England and NHS Improvement
NICU	Neonatal Intensive Care Unit
NICE	National Institute of Health and Care Excellence Evidence-based health and care recommendations developed by independent committees
NLP	North London Partners in Health and Care

NNU	Neonatal Unit
North Thames Paediatric Network	North Thames Paediatric Network brings together 25 provider hospitals in the North Thames region (19 District General Hospitals and six providers of specialist services).
North Mid	North Middlesex University Hospital NHS Trust
NTS	London Neonatal Transfer Service supports transfer of babies between neonatal units
Obstetric	Care related to pregnancy, childbirth and the postpartum period.
Ockenden	Okenden Report Findings, conclusions and essential actions from the independent review of maternity services at the Shrewsbury and Telford Hospital NHS Trust.
ODN	Operational Delivery Network
Oncology	Medicine related to the treatment and care of cancer.
ONS	Office for National Statistics
OPELMF	Operational Pressures Escalation Levels Maternity Framework NCL Framework for managing times of high demand.
Ophthalmology	Medicine related to the diagnosis and treatment of eye disorders.
Orthopaedics	Medicine related to bones and joints.

Paediatric	Hospital care for children and young people up to age 18.
Perinatal	The period of time spanning pregnancy and up to a year after giving birth.
PICU	Paediatric intensive care unit
POSCU	Children's Paediatric Oncology Shared Care Unit delivery of children's cancer services which operate as part of a Children's Cancer Network which is led by a Principal Treatment Centre.
Primary care	Primary care services provide the first point of contact in the healthcare system, acting as the 'front door' of the NHS. Primary care includes general practice, community pharmacy, dental, and optometry (eye health) services.
QIS	Qualified in Specialty, enhanced nursing training for neonatal nurses.
Quaternary care	Highly specialist and unusual care.
Radiology	The field of medicine that uses imaging techniques (such as X-rays) to diagnose and treat disease.
Rheumatology	Medicine that deals with conditions of the joints and other parts of the musculoskeletal system.
RNOH	Royal National Orthopaedic Hospital
Royal College Obstetrics and Gynaecology	The Royal College of Obstetricians and Gynaecologists (RCOG)

Royal Free London	Royal Free London NHS Foundation Trust (including Barnet Hospital, Chase Farm Hospital and Royal Free Hospital and maternity services at Edgware Community Hospital)
RTT	Referral to treatment
Safeguarding	Safeguarding (child protection). The process of protecting children from abuse or neglect, preventing impairment of their health and development, and ensuring they are growing up in circumstances consistent with the provision of safe and effective care that enables children to have optimum life chances and enter adulthood successfully.
SCU	Special Care Unit
SDEC	Same day emergency care
Secondary care	Includes hospital services, Child and Adolescent Mental Health Services (CAMHS) and child development centres.
SI	Serious Incident is an adverse events, where the consequences to patients, families and carers, staff or organisations are so significant or the potential for learning is great.
Specialist commissioning	NHSE specially commissioned services to support people with a range of rare and complex conditions.
Specialised Commissioning Regional Oversight Board	Oversees London transformation programmes for specially commissioned services.

SPMHS	Specialist Perinatal Mental Health Service, a service that serves the needs of pregnant and postnatal women with moderate to severe mental health needs who live within the five NCL boroughs.
SRO	Senior responsible officer
Stakeholder	Organisations or individuals with an interest or who could be impacted by the programme.
ST3	Trainee specialist who has passed postgraduate examination to enter higher training. In third postgraduate training year
STP	Sustainability Transformation Partnerships were introduced in 2016. They bring together local NHS organisations and local authorities to develop proposals to improve health and the quality of care to provide better services. They will be superseded by the ICB in July 2022.
Sub-specialty	Specialty children's surgery, (e.g., orthopaedics) to distinguish from general paediatric surgery
Tertiary Care	Specialist hospital care
UCLH	University College London Hospitals NHS Foundation Trust
Urology	Health care related to treatment of conditions of the male and female urinary tract and male reproductive organs.
Voluntary Sector	The voluntary sector (third sector, civil society or the not-for-profit sector) refers to organisations whose primary purpose is to create social impact rather than profit.

Whittington	Whittington Health NHS Trust
WTE	Whole time equivalent

Appendices

Appendix A: services in and out of scope

In Scope
All NHS funded children and young peoples elective (i.e. planned) care pathways (meaning elective services delivered within a hospital setting for children and young people aged 0-19 years)
All NHS funded emergency children and young people's care pathways (meaning emergency services delivered within a hospital setting and part of an acute stay or children and young people aged 0-19 years)
All NHS funded maternity and neonatal services delivered in both community and hospital settings

Out of Scope
Children and Young People's community services
Mental Health including CAMHS
Specialist provision: e.g. standalone eating disorder service at RFH and specialist inpatient and day-case provision at UCLH
Cancer haemato-oncology including and complex adolescents and POSCU location
Primary Care contracts
Local Authority Commissioned Services with the NHS
0-19 Services Delivered by Local Authorities

The interface between secondary and tertiary providers means that neonatal and some children and young people's services at specialist hospitals at GOSH, RNOH and Moorfields are in scope

Appendix B: CYPMN board membership

Full members of the Board are:

Position	Name
Chair: ICS Children, Young People and Maternity lead (Joint SRO)	Emma Whicher
CCG Executive Director of Strategic Commissioning (Joint SRO)	Sarah Mansuralli
Executive Director level lead UCLH	Tim Hodgson
Executive Director level lead Royal Free London	Mike Greenberg
Executive Director level lead Whittington Health	Michelle Johnson
Executive Director level lead North Mid,	Sarah Hayes
Executive Director level lead GOSH	Sanjiv Sharma
Executive Director level lead for child and adolescent Mental Health	Mehdi Veisi
Medical Director for NHS Commissioning in London, representing specialised commissioning as the commissioners for neonatal services	Simon Barton
CCG GP Governing Body member	Jo Sauvage
ICS lead Nurse – as quality lead for Ockenden response	Chris Caldwell
Local authority Chief Executive	Ian Davis
Specialist Networks (ODN and NTPN)	Grenville Fox Mamta Viadya
Local authority Director of Children's Services	Ann Graham

The standing attendees on invitation are:

Position	Name
Chairs of enabling workstreams – finance and analytics	Kevin Curnow – Finance lead (Chief Finance Officer, Whittington Health) Sarah Dougan – Analytics lead (Director of Population Health Intelligence, NCL ICS)
Clinical Director Children, Young People Regional Improvement Programme	Oliver Anglin
Clinical representative from the LMNS	Shereen Nimmo (LMNS, Co-Chair)
Programme Team	Anna Stewart, Rhona Hobday, Alice O'Brien, Kate Fruin
Programme Lead CYP Regional Improvement Programme	Sam Rostom
Specialised commissioning, children, young people, maternity and babies lead	Rachel Lundy/Sara Nelson (Job Share)
Programme SRO and Director LMNS	Rachel Lissauer and Angela Velinor
Director of Public Health	Kristen Watters
Interim Director of Aligned Commissioning	Daniel Morgan
Communications Lead	Chloe Morale Oyarce
Chief Executive, CF	Hannah Farrar

Appendix C: clinical leaders interviewed for the Start Well programme

Organisation	Total interviewed
Barnet Hospital	8
North Middlesex University Hospital	9
Royal Free Hospital	8
University College London Hospitals	10
Whittington Hospital	8
Great Ormond Street Hospital	3
Royal National Orthopaedic Hospital	1
NCL LMNS	5
London Neonatal ODN	4
NHS E/I	1
North Thames Paediatric Network	1
Total	**58**

Appendix D: themes from clinical Start Well clinical interviews

Paediatric services

High quality services, dedicated paediatric training and the commitment of the workforce were highlighted as strengths

High quality paediatric services	• Across ED, staff take pride in the work they deliver, providing quality emergency care for all individuals • NCL has exemplar paediatric services to be proud of. Oncology and complex needs at UCH, allergy and diabetes services at NMUH, acute paediatric service at WH, and cardiology and asthma at RFL were cited.
Resilience and commitment of the workforce	• The workforce across all Trusts have a patient focused approach and always try to do what is best for the patients • Despite the impact of the pandemic and temporary changes, the workforce across NCL has remained resilient, building back from the changes made during the pandemic
Dedicated paediatric training and additional support for ED staff	• A greater focus on children in ED is leading to improvements in care. For example, employing paediatric emergency medicine consultants at Barnet has provided better training and support for staff in ED. • Training of paediatric staff was acknowledged as important in delivering excellent outcomes, with significant effort being undertaken to deliver the required staff training
Appetite for collaboration and recognition of the opportunities it brings	• Improving outcomes, collaborating and sharing goals across the system were recognised as being important to success • In the past, partnership working was highlighted as key to previous successes across the system, and improving the outcomes and experiences of patients

Increasing emergency demand, gaps in service provision and recruitment of workforce were cited as challenges

Current paediatric capacity is not aligned to demand	• There is increasing demand of emergency services, with high volume low acuity patients accessing the service • Paediatric bed capacity at the North Middlesex University Hospital has been reduced, despite the increasing demand • There is a growing waiting list for children's surgical procedures which will further exacerbate capacity challenges
Models of care are not optimal for children, with gaps in service provisions	• Obtaining surgical input for children under 5 years old, and in particular under 3 years old, is challenging. Across the system, it is also difficult to obtain anaesthetics expertise in young children. • Often complex surgery is performed by adult surgeons which is not the optimal pathway for children. • Some care pathways, and the role of specialist providers within them, are not fully defined
Developing and maintaining skills is challenging where patient volumes are lower	• The current configuration of services results in many providers in a small area offering the same services • Low volumes of activity means that some Trusts struggle to deliver complex activity to support training and to maintain rotas • Duplication and fragmentation of services can make it difficult for families and children to navigate
Recruitment and retention of workforce is challenging across NCL	• Trusts are experiencing challenges in recruiting and retaining workforce, particularly paediatric nurses and AHP roles • Significant vacancies at junior doctor and SHO levels were also highlighted • Duplication of the local services also contributes to the difficulties in recruitment

Maternity and neonatal services

Delivery of good outcomes, patient experience and effective working relationships were cited as strengths for maternity and neonatal services

Neonatal services within NCL deliver good outcomes	• The neonatal network and neonatal services working together across NCL were recognised as providing excellent care, particularly for neuro developmental follow-up • Feedback from families is positive. The integrated family rooms at Barnet were cited as best practice and a setup to aspire to for the rest of the system.
Effective working relationships and a positive culture within the neonatal units	• Effective partnership working both within the units and between the neonatal services was highlighted • The culture of neonatal units across NCL were frequently described as non-hierarchical, promoting inclusive and supportive relationships across the network • Within the neonatal units, staff feel there is good integrated working and respect between all staff grades
Maternity network is effective and works well within NCL	• A long history of working together across NCL puts the system in a positive place for future collaboration • The maternity network is a well led network and is enabling the system to think about and develop their maternity workforce
Patients and their families experience good maternity care	• Patients within NCL are positive about the care and the experience of the service they receive • The community-based services provided by Whittington Health are highlighted as very strong and effective

Inequalities in maternity outcomes, gaps in perinatal mental health provision and workforce training were cited as challenges

Gaps in perinatal mental health service provision	• Maternity services are not currently aligned to the needs of the population and can result in inequity of service provision • Perinatal mental health needs are not fully met by the current service provision
Inequalities in maternity outcomes	• Existing inequalities in respect to maternal services need to be addressed • There are areas of inequity surrounding access to maternity services and service provision. Within NCL there is not a consistent offer of community maternity services.
Capacity and demand are not well aligned for neonatal services	• At the Royal Free, the level 1 neonatal unit is not aligned to provision of complex obstetric care. • A Level 1 unit was frequently cited as not sustainable for the system. The unit is under utilised and resource intensive to run. • Across NCL there are current capacity issues with cots. ITU and HDU cots are often over capacity. Difficulties in accessing repatriation and flows from boroughs outside NCL, such as Hertfordshire, also contribute to the cot capacity constraints.
Challenges with workforce recruitment, retention and training	• Low throughput of complex cases at some units makes maintaining practical skills hard for staff and does not support training opportunities • Across all grades, workforce recruitment and retention remains a challenge for maternity and neonatal services although this is worse in certain units • In particular, training and recruiting specialist nurses is difficult and there are often not enough midwives to support with training

Appendix E: staff survey outputs

A staff survey was circulated around the acute Trusts to understand their views on how the health system in NCL currently works and provide an opportunity for staff to convey their views of any challenges that the system faces. Eighty-seven staff from a range of professions submitted the survey, of which 94% were from UCLH, Barnet Hospital and Royal Free Hospital. The following themes were identified:

Challenges faced by the organisation

- Respondents reflected that staff shortages and losing experienced staff was a challenge for their organisation
- Respondents felt that staff were not always fully appreciated considering the workload that they undertake
- Staff reflected on the mismatch of care at Royal Free Hospital between the SCU (level 1) neonatal unit and the complexity of some of the maternal care delivered
- Staff identified long waiting lists as a challenge in their organisation

Addressing challenges faced by the organisation

- Staff highlighted the need to improve staff experience to address challenges faced in their organisation whilst improving diversity of the workforce, particularly leaders
- Respondents reflected that some challenges at their organisation could be addressed through improved system collaboration, including sharing IT systems, working at different hospitals and increased transparency between organisations

Challenges for the NCL system

- Respondents reflected that the variation of care across NCL was a challenge that needed to be addressed
- Staff further highlighted the SCU (level one) neonatal unit at Royal Free Hospital as a challenge for the system as a whole
- Staff highlighted the need to take a collaborative approach to working in NCL to centre care around the patient

Appendix F: capturing patient experience through a thematic review of existing data

A review of existing patient experience data at acute providers in North Central London was undertaken, to better understand the reported experiences of those using the services covered by the Start Well programme.

This review is not intended to be a comprehensive representation of the experiences of pregnant women and people, babies, children, young people and their families. It does, however, provide an early overview to contribute to the case for change.

Further insight will be gathered during engagement on the case for change, as described in section two.

The aim of the review of existing data was to understand:

- What are the current experiences of pregnant women and people, babies, children, young people and their families when using children and young people's services, maternity and neonatal services at hospitals in NCL?
- What are the expectations of those using the services?

Gathering data on patient insight and experience

For the purposes of this review, the term 'data' refers to information contained within secondary sources such as reports and studies. These sources could have been developed based on quantitative (surveys, questionnaires etc.) and qualitative (interviews, focus groups etc.) methods.

The sources of data for the review were gathered in several ways including:

- Requests to Trusts in NCL for pre-existing reports
- Requests to Healthwatch organisations for pre-existing reports
- Requests to community and voluntary sector organisations for pre-existing reports
- Internet research to source published reports
- Accessing data available via national bodies which included including the Care Quality Commission (CQC) and NHS Digital

Requests for data specified that we were most in interested children and young people's services, maternity and neonatal services at hospitals in NCL.

Limitations of the review

When reading the thematic analysis, it is important to acknowledge the limitations of this review.

- The data analysed was not originally gathered for the purposes of developing a case for change and, in some cases, was focused on achieving a particular

outcome. Consequently, the area of discussion within the document review may have been specifically focused on limited themes

- Data was gathered using mixed methodologies, which included discussion groups, focus groups, fieldwork and questionnaires or surveys
- The scope of services addressed in some reports may not exactly match the scope of services in the Start Well review. When the scope is wider than services covered by Start Well, where it is possible to isolate it, only data relating to pregnant women and people, babies, children, young people and their families when using children and young people's services, maternity and neonatal services at hospitals in NCL has been included
- Data was gathered over an extended period, and at times, in extraordinary circumstances – for example the COVID-19 pandemic. This may have had an impact on patient experience
- Many of the usual activities carried out by groups who frequently gather patient insight and experience data were curtailed by the COVID-19 pandemic
- Across the reports reviewed, data was gathered by professional researchers, patient experience professionals, volunteers (trained and untrained) and voluntary sector groups. This leads to variation in the depth and quality of data available
- More data was available for maternity services than for children and young people's services. This may be because of the increased emphasis on patient voice in these services over the past few years

Sources of data

Following a three-month period of information gathering the following sources were identified.

Report title and *source*	Date published (or period covered)	Overview of source	Indicative reach reported in the source
NHS Long Term Plan Report: Summary of findings from *Healthwatch Barnet, Camden, Enfield, Haringey and Islington*	April-May 2019	NCL Healthwatches asked local people for feedback on the NHS Long Term plan based on their experience of local services. *Whilst Start Well services are not specifically examined, some feedback references services in the scope of Start Well, and looks at general patient experience priorities*	1,000 responses
Young Healthwatch Report *Enfield Healthwatch*	December 2019 to February 2020	Healthwatch Enfield, working with a group of six volunteers aged 16-25, conducted a survey to explore the experiences of young people's use of health and social care services in Enfield and to understand where they think there is most need for improvements and information.	151 responses
Views from women and their families in North Central London A participatory action research project. *Better Births*	Summer 2018	To improve representation, a diverse group of 15 women who had recently used maternity services, were recruited as Patient and Public Voice Partners. The group were trained in participatory appraisal, and over a five-month period engaged with parents to gather their experiences of, and priorities in re-shaping, maternity services in NCL.	179 participants
NCL Equity and Equality Strategy: Summary of key themes from Lived Experience Team meeting	February 2022	Birth Companions convened a group of four women with lived experience of disadvantage and inequality during their maternity care to discuss the ways in which a focus on language and practical steps could help improve	Four women with lived experience of disadvantage and inequality

NCL Local Maternity and Neonatal System (LMNS) /Birth Companions		equity. This report provides a summary of those discussions.	
NMUH MVP annual report	May 2021	A Maternity Voices Partnership (MVP) is an NHS working group: of team of women and their families, commissioners and providers working together to review and contribute to the development of local maternity care. *The annual report summarises activities.*	N/A
Royal Free London - Maternity Voices Partnership Annual Report 2020	April 2020 – March 2021	As above	N/A
Evaluation of temporary changes to paediatric services winter 2020/21 Engagement Analysis report. UCL/RREAL	January – April 2021	Following the implementation of the temporary configuration of paediatric services in NCL during the COVID-19 pandemic, an engagement exercise was commissioned by system leaders, to understand the experiences of those impacted by the changes. Engagement activities were undertaken across local people and stakeholder groups, parents and young people who had used the services during the period of the temporary changes and staff working in the services affected. *Only the feedback from patients was analysed for this report.*	146 patient surveys. Five service user groups
NCL Fertility Policy Development: Engagement.	22 November 2021 and 13	Engagement on the draft Fertility Policy to seek views from patients, residents, clinicians, voluntary and community	439 responses

Feedback Report NCL CCG	February 2022	groups, fertility groups and other audiences. The report provides an in-depth analysis of the qualitative and quantitative insights captured during the engagement. *Only feedback from patients was analysed for this report.*	
UCLH Maternity Voices Partnership Annual Report 2019-20	2019-20	A Maternity Voices Partnership (MVP) is an NHS working group: of team of women and their families, commissioners and providers working together to review and contribute to the development of local maternity care. *The annual report summarises activities.*	N/A
Conversations with our local community about Whittington Health and their plans for the future. Healthwatch Islington	April 2019	Whittington Health asked Healthwatch Islington to support the development of its Estates and Clinical Strategies for the years ahead. The Trust was interested to learn about resident's experiences and thoughts in relation to the following areas: • Maternity and gynaecological services • Children and young people's services • Urgent and emergency care services • The use of digital technology in healthcare, and what affects people's attitudes to this • Whether people prefer services closer to home or closer to a hospital and what affects that choice	90 people
Whittington Health Maternity Voices Partnership Annual Report 2019-2020	December 2020	A Maternity Voices Partnership (MVP) is an NHS working group: of team of women and their families, commissioners and providers working together to review and contribute to the development of local maternity care.	N/A

		The annual report summarises activities.	

Analysis

Summary of themes arising from local reports and surveys

Analysis resulted in three main themes emerging that were common across the sources. These were:

- Communication
  - Communication between Trusts and groups of patients
  - Communication between individual staff members and individual patients

- Personalisation of care and continuity of care

- Equality and inclusion in relation to the experience of care

Across these themes, positive and negative experiences were reported and insight into patient expectations was captured. It should be noted that there is some crossover between the main themes that emerge, so insights and experience could have been reported under several headings in the following analysis.

Overview

Whilst it is inevitable that insight reports tend towards highlighting areas for improvement, it is important to note that across all sources there was wide support, thanks and praise for maternity, neonatal, children and young people's service in NCL. The Evaluation of Temporary Changes during the COVID-19 pandemic, carried out by UCL/RREAL notes that:

> "Participants described paediatric services before the changes in a favourable way (proximity of services, comprehensive service offer, and relationships between provider organisations)" (UCL/RREAL, January-April 2021)

The same report summarised feedback from 146 patient surveys and five service user groups who responded to the engagement exercise by saying:

> "Parents of service users were generally happy with the service they received before the temporary changes; they valued staff and their expertise, reporting a positive experience, and the accessibility of the services, in particular in case of emergency or long-term conditions." (UCL/RREAL, January-April 2021)

Other reports noted that some local people could see opportunities for improvement. In NCL's Healthwatch report on resident engagement on the long-term plan, 18% of participants said they would prioritise:

“Improved services for children and young people, to give them a strong start in life” (Healthwatch Barnet, Camden, Enfield, Haringey and Islington, April-May 2019)

Communication

Across all data sources, by far the most frequently occurring theme was communication. This theme recurred regardless of source and was deemed to have a significant impact of a patient’s experience of care in NCL hospitals.

Communication between Trusts and groups of patients

The communication between Trusts and groups of patients in both maternity and paediatric services was raised across several different reports, with participants highlighting both good practice and areas for improvement.

In maternity services, this was a particular concern, especially when it came to birth choices:

> “[there are] too many sources of information, and uncertainty about which sources to trust, a reliance on written rather than verbal communication and assumption that women have the information they need, or know where to look for advice” (Better Births, Summer 2018)

There was also a reported lack of clarity about who to contact in Trusts, when seeking support or information:

> “All the information that parents need is there but for some reason it’s not connected up ... which means you are stranded. Maybe you just need one key person ... it would definitely make it a lot easier for mums and dads.” (Better Births, Summer 2018)

There were also positive reports where Trusts had focused on good communication in care environments. In a report following a visit to UCLH, the Maternity Voices Partnership said:

> “We noted many positives during our visit: The Antenatal Clinic felt calm and welcoming, the staff are friendly, there is a visible midwifery presence, MCU [maternity care unit] layout encourages patient and staff engagement, 'Thank you' boards are uplifting.” (UCLH MVP)

Communication between individual staff members and individual patients

Communication between individual staff members and individual patients was another theme across several the reports reviewed. Feedback, analysis and comments could be grouped under several sub-themes:

- the consistency of communication
- the content or clarity of communication

- the tone of communication

In maternity services, pregnant women and people spoke of the importance of staff accessing a consistent record of information and having that information read every time. For one woman, this was particularly challenging, as it didn't take account of her changing needs in different appointments.

> "Some days I might be able to tell you, this is what I need, this is the care that I have in place, and on other days I might not feel well to explain, and then it becomes that I'm not cooperating, you get labelled again as difficult…" (Better Births, Summer 2018)

> "Communication was felt to be key. It is not only about the words that are used, but also the tone that is used, and the spaces provided for listening to women." (NCL LMNS/Birth Companions, February 2022)

Young people also reported a need for more age-appropriate communication, with the Young Healthwatch Enfield report stating:

> "Young people told us that the promotional materials that health and social care services currently provide are not necessarily adapted or appealing to a younger audience" (Enfield Healthwatch, May 2019 - February 2020)

The content and clarity of communication was raised in reports by both young people accessing NHS services and by those using maternity services.

Young Healthwatch Enfield trained six volunteers, aged 16-25, to carry out a survey exploring the experiences of young people's use of health and social care services in Enfield and to understand where they think there is most need for improvements. They found that more than two in every three young people (71%) said they understood the information given to them during appointments, but explained that they felt the language used within this information could be quite technical.

> "'I sometimes have had to ask what something means when they throw jargon at me." (Enfield Healthwatch, May 2019 - February 2020)

NCL's Healthwatch organisations summarised this feeling in their engagement report looking at the NHS Long Term plan reporting that 50% of individuals do not understand what the doctor or nurse is telling them. (Healthwatch Barnet, Camden, Enfield, Haringey and Islington, April-May 2019)

Those using maternity services reported feeling confused or overwhelmed at times, with one woman requesting: "clear verbal and written explanations of how things work at every step" (Better Births, Summer 2018)

The tone of communication came up in several reports in which the authors had specifically asked about experience of individual care. The 'Better Births' report, which looked at the experiences of 179 women over a five-month period in 2018, quotes people as referring to their experience of some staff having a "poor bedside manner"

and being “unprofessional, uncaring, unkind”. Another mentioned being “not believed or listened too regarding pain” (Better Births, Summer 2018)

At the ‘Lived Experience’ meeting in February 2022, convened by Birth Companions there was in-depth discussion around the language used by professionals about those using the maternity service:

Participants talked about terms (such as complex, vulnerable and complex) being vague and unclear. Needs or experiences that come under these definitions may not be made explicit to women, they may not be aware of why they are being classed in this way, or how it relates to their care. “If it’s complex, tell me why I’ve come to be complex”. Women felt much of this language doesn’t recognise women’s unique circumstances. (NCL LMNS/Birth Companions, February 2022)

There was also a great deal of praise and positive experience reported:

> “A woman who had a difficult birth wanted to say thank you - doctors, nurses, registrars, you don’t realise the impact you have had on my life ...”

And staff who were:

> “Attentive but respectful, giving space when needed and extra support when required” (Better Births, Summer 2018)

Young people highlighted inequity in the ways they experienced physical and mental health being recognised and treated by medical professionals. (It is unclear in the report whether this experience refers to primary or secondary care).

> “…they felt physical symptoms were 'taken more seriously' than other health problems such as mental health difficulties.” (Enfield Healthwatch, May 2019 - February 2020)

Healthwatch Islington’s report, “Conversations with our local community about Whittington Health and their plans for the future,” summarised the inconsistent experience of patients stating:

> “Participants reported a range of good and bad experiences, with some finding staff helpful and others finding staff rude.” (Islington Healthwatch, April 2019)

Personalisation of care and continuity of care

Themes of personalisation of care and continuity of care were strong across several sources.

For the personalisation of care, choice and agency in the care received was a strong theme in the reports reviewed.

> “‘Personalised care means that I am given all the different options, and that I can make my own informed decisions as to how, where and when I wish to give

> birth to my child. It means that those decisions are respected and supported" (Better Births, Summer 2018)

For those accessing maternity services, reports highlighted a feeling amongst some using the service that they lacked control of their own choice of care. The Better Births report quoted several participants feeling "pressure to have medical interventions" and equally "pressure to have no medical interventions" at hospitals in NCL. However, others reported feeling fully involved in decisions about their care stating:

> "I had an emergency c-section in my second pregnancy. The doctor was amazing and took the time to ask how they could make the experience more natural for me as this [was] not what I wanted." (Better Births, Summer 2018)

The same report also highlighted making partners feel more welcome:

> "If you had a nominated birth partner they could be supported. They could be the person that the hospital gives responsibility to - it would help them to be part of the process." (Better Births, Summer 2018)

Specific interventions mentioned in reports included "more scans during the pregnancy and longer stays after giving birth." (Islington Healthwatch, April 2019)

Related to the personalisation of care, the care environment was also mentioned as having a significant impact on how tailored care felt. "Poor internal comfort conditions including lighting and temperature", "lack of privacy on noisy wards" and "dirty or messy facilities" were all mentioned in the Better Births report. (Better Births, Summer 2018).

Similar comments recurred in the Healthwatch Islington report carried out on behalf of Whittington Health:

> "Some wanted more privacy and better facilities such as a café, and a bigger waiting area." (Islington Healthwatch, April 2019)

For young people, there was a clear split between those who felt they had some agency and the care they received and those who didn't:

> "Over half the young people we engaged with (56%) told us that they felt listened to by health and social care professionals." (Enfield Healthwatch, May 2019 - February 2020)

Continuity of care was mentioned in several sources when looking at maternity services. Women mention "not being able to get to know a midwife and build up a relationship" and "lack of access to the same midwife antenatally, in labour or postnatally" (Better Births, Summer 2018) as being a concern, as well as the reduction in the provision of care once they have given birth.

> "You get all this amazing attention through pregnancy that abruptly ends." (Better Births, Summer 2018)

Equality and inclusion in relation to the experience of care

The specific focus of several of the reports we reviewed was to ensure that the voices of those from ethnic minority backgrounds, those with disabilities and those with neuro-diversity were captured. Consequently, themes related to equality and inclusion were prevalent.

The theme of understanding the needs of different minority ethnic and cultural groups recurred across several reports, with access to interpreters, information in languages other than English and the need for other kinds of communication support being highlighted. One woman who shared her experiences in the Better Births report highlighted this, saying:

> "Lack of interpreters during labour, felt [me feeling] vulnerable, invisible and unable to communicate/complain" (Better Births, Summer 2018)

The desire for more "access to peer groups to offer support" was one suggestion made by a participant, as well as "access to FGM specialists" (Better Births, Summer 2018). The report highlighted a perceived need for greater staff support and training to understand the needs of diverse communities served.

Supporting mental health was a recurrent theme for those using maternity services and for young people accessing NHS services too. Women using maternity services spoke of the good support received in their experience of care and a desire for this to be available to all women:

> "Having a specialist team who knew how to deal with her mental health needs was really important. Once she got the help it was amazing, but she had to ask for it - it wasn't presented to her. There could be lots of other mums out there struggling, without getting the support they need." (Better Births, Summer 2018)

Young people participating in Enfield's Young Healthwatch engagement reported that almost three in every four young people felt mental health services were most in need of improvement (73%) and over two in every three young people want more information on mental health and wellbeing (67%). (Enfield Healthwatch, May 2019 - February 2020)

Another area highlighted was the needs of those with learning disabilities and autism. In their engagement report looking at the NHS Long Term plan, NCL's Healthwatches reported that 37% of parents and carers of people with learning disabilities, autism and other difficulties, reported that they felt their child/the person they care for experienced delays in receiving treatment due to having additional needs. The report also highlighted:

> "Analysis carried out suggest that people with Learning Disabilities, autism and other disabilities do not have access to universally-high-quality primary care services in the borough and that there are opportunities to improve all care services, particularly where access to services and awareness are concerned."

(Healthwatch Barnet, Camden, Enfield, Haringey and Islington, April-May 2019)

Appendix G: final Ockenden Report 15 Essential Actions

1. Workforce planning and sustainability	**Essential action – financing a safe maternity workforce** The recommendations from the Health and Social Care Committee Report: The safety of maternity services in England must be implemented
	Essential action – training We state that the Health and Social Care Select Committee view that a proportion of maternity budgets must be ring-fenced for training in every maternity unit should be implemented
2. Safe Staffing	**Essential action** All trusts must maintain a clear escalation and mitigation policy where maternity staffing falls below the minimum staffing levels for all health professionals.
3. Escalation and Accountability	**Essential action** Staff must be able to escalate concerns if necessary There must be clear processes for ensuring that obstetric units are staffed by appropriately trained staff at all times. If not resident there must be clear guidelines for when a consultant obstetrician should attend.
4. Clinical Governance-Leadership	**Essential action** Trust boards must have oversight of the quality and performance of their maternity services. In all maternity services the Director of Midwifery and Clinical Director for obstetrics must be jointly operationally responsible and accountable for the maternity governance systems
5. Clinical Governance - Incident Investigation and Complaints	**Essential action** Incident investigations must be meaningful for families and staff and lessons must be learned and implemented in practice in a timely manner
6. Learning from Maternal Deaths	**Essential action** Nationally all maternal post-mortem examinations must be conducted by a pathologist who is an expert in maternal physiology and pregnancy related pathologies. In the case of a maternal death a joint review panel/investigation of all services involved in the care must include representation from all applicable hospitals/clinical settings.
7. Multidisciplinary Training	**Essential action** Staff who work together must train together. Staff should attend regular mandatory training and rotas. Job planning needs to ensure all staff can attend. Clinicians must not work on labour ward without appropriate regular CTG training and emergency skills training
8. Complex Antenatal Care	**Essential action** Local Maternity Systems, Maternal Medicine Networks and trusts must ensure that women have access to pre-conception care.

	Trusts must provide services for women with multiple pregnancy in line with national guidance Trusts must follow national guidance for managing women with diabetes and hypertension in pregnancy
9. Preterm Birth	**Essential action** The LMNS, commissioners and trusts must work collaboratively to ensure systems are in place for the management of women at high risk of preterm birth. Trusts must implement NHS Saving Babies Lives Version 2 (2019)
10. Labour and Birth	**Essential action** Women who choose birth outside a hospital setting must receive accurate advice with regards to transfer times to an obstetric unit should this be necessary. Centralised CTG monitoring systems should be mandatory in obstetric units.
11. Obstetric Anaesthesia	**Essential action** In addition to routine inpatient obstetric anaesthesia follow-up, a pathway for outpatient postnatal anaesthetic follow-up must be available in every trust to address incidences of physical and psychological harm. Documentation of patient assessments and interactions by obstetric anaesthetists must improve. The determination of core datasets that must be recorded during every obstetric anaesthetic intervention would result in record-keeping that more accurately reflects events. Staffing shortages in obstetric anaesthesia must be highlighted and updated guidance for the planning and provision of safe obstetric anaesthesia services throughout England must be developed.
12. Postnatal Care	**Essential action** Trusts must ensure that women readmitted to a postnatal ward and all unwell postnatal women have timely consultant review. Postnatal wards must be adequately staffed at all times.
13. Bereavement Care	**Essential action** Trusts must ensure that women who have suffered pregnancy loss have appropriate bereavement care services.
14. Neonatal Care	**Essential action** There must be clear pathways of care for provision of neonatal care. This review endorses the recommendations from the Neonatal Critical Care Review (December 2019) to expand neonatal critical

	care, increase neonatal cot numbers, develop the workforce and enhance the experience of families. This work must now progress at pace.
15. Supporting Families	**Essential action** Care and consideration of the mental health and wellbeing of mothers, their partners and the family as a whole must be integral to all aspects of maternity service provision Maternity care providers must actively engage with the local community and those with lived experience, to deliver services that are informed by what women and their families say they need from their care.

Appendix H: AHP staffing recommendations

Dietetic Staffing on Neonatal Units - Recommendations

https://www.bda.uk.com/uploads/assets/ab614d3e-e095-4e4f-96ae1458204e8810/BDA-Formatted-Staffing-Recc.pdf

Occupational Therapy Staffing on Neonatal Units - Recommendations

https://www.rcot.co.uk/sites/default/files/Occupational%20therapy%20staffing%20on%20neonatal%20units%2022.08.pdf

Physiotherapy Staffing on Neonatal Units – Recommendations

https://apcp.csp.org.uk/content/neonatal-staffing-recommendations#:~:text=Physiotherapy%20Staffing%20Recommendations%20for%20Neonatal%20Units%20in%20England,by%20the%20NHS%20England%20Neonatal%20Peer%20Review%20process

Speech and Language Therapy Staffing on Neonatal Units - Recommendations

https://www.rcslt.org/-/media/Project/RCSLT/neonatal-speech-and-language-therapy-staffing-level-recommendations.pdf

Pharmacy Staffing on Neonatal Units - Recommendations

http://nppg.org.uk/wp-content/uploads/2018/10/NPPG-Neonatal-Pharmaciststaffing-recommendations-published-with-RPS-Oct-2018.pdf

Appendix I: front end attendance / admission avoidance in NCL hospitals

Advice and guidance

GPs email consultants for advice and consultant responds within 2 days.

Consultant connect / consultant phone

GPs call and speak directly to a consultant. The aim is to be able to discuss the child who is with the GP to give advice for treatment or agree that the child should be sent straight to ED as a paediatric expected patient.

Often GPs will call for advice on whether to refer a child to outpatients or not, or to chase up appointments for those on waiting lists, so not all calls are directly linked to emergency activity.

Rapid access clinics / rapid referral clinics / same week emergency clinics /

Clinic slots available at short notice, from same day to two week waits, via consultant triage following a call from a GP.

MSK rapid access clinics

Physiotherapy-led clinic slots available at short notice / GP direct access with short wait.

Ambulatory review clinic

Children and young people who need regular IV medication or review following either an ED attendance or an admission, but who do not need to be in an inpatient ward, can be seen in an ambulatory clinic each day for several days running.

Paediatric assessment unit (PAU)

PAUs are units where children and young people can be observed or receive treatment over a few hours, when they require more than an ED assessment but do not require a ward admission.

Community paediatric nurses / clinical nurse specialists

For children and young people with long-term conditions or needing complex care, parents are able to call on community paediatric nurses or clinical nurse specialists for advice before attending hospital. Often advice or a visit from the nurse will avoid the need to attend hospital or the child or young person may be admitted straight to a paediatric assessment unit or paediatric ward bypassing ED.

Neonatal blood test clinics

Nurse-led blood tests around detection of jaundice to reduce babies needing to attend ED

Hospital at home

Children with a range of conditions e.g., croup, asthma, jaundiced babies, IV antibiotics will be reviewed at home by a nurse after discharge from hospital.

Virtual Ward

There is still no definitive definition of a virtual ward. It is currently being considered as a way of treating children at home who would normally be in a hospital bed. An example is a child receiving ambulatory care at home from a community nurse and also receiving a daily phone call from a hospital doctor each day of their treatment. There is overlap with hospital at home.

ABC Parents / parent champions

Education and support to empower parents and carers to better manage their children's health, and to support other parents.

Admission avoidance method	Barnet Hospital	North Middlesex University Hospital	Royal Free Hospital	University College London Hospital	Whittington Hospital
A&G	Yes	Yes	Yes	Yes	Yes
CC/Phone	Yes	Yes	Yes	Yes	Yes
RAC / SWEC	Yes	Yes	Yes	Yes	Yes
MSK RAC			Yes		Yes
Ambulatory Clinics	Yes	Yes	Yes	Yes	Yes
PAU		Yes		Yes – but in CYP SDEC (same day emergency care)	
Community/ Specialist nurses	Yes	Yes	Yes	Yes	Yes
Neonatal Blood test clinic	Yes		Yes	Yes	Yes
Hospital At Home			Partial (some conditions)	Yes	Yes
Virtual Ward	Yes (phone)	Yes (pilot)	Yes (phone)		
ABC Parents / Parent Champions		Yes			Yes

In addition, UCLH have the following admission avoidance initiatives:

- RESPOND screening clinics for asylum seeking refugees – shown to reduce ED attendances
- ANNP neonatal clinics to avoid neonates attending ED
- Super triage and GP-based MDTs and clinics to reduce ED attendances – piloted in nine GP practices.
- Liaison with community health visitors
- Weekly multi-professional ED safeguarding meeting, which flags vulnerable families who may repeatedly attend ED, but can be redirected to clinic
- Senior decision makers in ED – avoid unnecessary admissions
- Clear discharging rights from ED - Robust safety netting and advice
- Admissions to day care directly for specialty patients e.g. GA MRI
- Asthma/wheeze management: review on ward by CNS teams, given care plans and advice
- Acute phone line access for Haemoglobinopathy patients

Appendix J: planned paediatric services included in the Start Well programme

Organisation	Elective Specialities (Medical)	Elective Specialities (Surgical)	Outpatients (Medical)	Outpatient (Surgical)
North Middlesex University Hospital NHS Trust	Allergy Asthma Audio vestibular Medicine Cardiology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases	Ophthalmology Orthopaedics General Paediatric Surgery Urology	Allergy Asthma Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Renal medicine Rheumatology	General Paediatric Surgery Gynaecology Ophthalmology Orthopaedics Urology
Royal Free London NHS Foundation Trust the Royal Free Hospital	Allergy Asthma Audio vestibular Medicine Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Neuro-disability Neurology Renal medicine Rheumatology	ENT Gynaecology HBP Oral and Max Fax Ophthalmology Orthopaedics General Paediatric Surgery Plastic Surgery	Allergy Asthma Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Neuro-disability Neurology Renal medicine Rheumatology	Dentistry ENT General Paediatric Surgery Gynaecology HBP Oral and Max Fax Ophthalmology Orthopaedics Plastic Surgery Urology
Royal Free London NHS Foundation Trust Barnet Hospital	Allergy Asthma Audio vestibular Medicine Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Neuro-disability Renal medicine Rheumatology	ENT Gynaecology Oral and Max Fax Orthopaedics General Paediatric Surgery Urology	Allergy Asthma Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Neuro-disability Neurology Renal medicine Rheumatology	Dentistry ENT General Paediatric Surgery Gynaecology Oral and Max Fax Ophthalmology Orthopaedics Plastic Surgery Urology

Royal Free London NHS Foundation Trust Chase Farm Hospital (out patients only)			Allergy Asthma Cardiology Dermatology Diabetes Endocrinology Gastroenterology General medical paediatric care Infectious Diseases Neurology Rheumatology	Dentistry ENT General Paediatric Surgery Gynaecology HBP Ophthalmology Oral and Max Fax Orthopaedics Plastic Surgery Urology
University College London Hospitals NHS Foundation Trust University College Hospital	Allergy Asthma Cardiology Dermatology Audio vestibular Medicine Adolescent Services Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Rheumatology	Dentistry ENT Gynaecology Head and Neck Orthopaedics General Paediatric Surgery Thoracic surgery Urology	Allergy Asthma Audio vestibular Medicine Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Infectious Diseases Neurology Renal medicine Rheumatology	General Paediatric Surgery Gynaecology Oral and Max Fax Orthopaedics Urology
Whittington Health NHS Trust The Whittington Hospital	Allergy Asthma Audio vestibular Medicine Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Rheumatology	Gynaecology Ophthalmology Orthopaedics General Paediatric Surgery Urology	Allergy Asthma Audio vestibular Medicine Cardiology Dermatology Diabetes Endocrinology Epilepsy service General medical paediatric care Gastroenterology Rheumatology Infectious Diseases Neurology Renal medicine	ENT Ophthalmology Orthopaedics Plastic Surgery Urology

Appendix K: paediatric care provision at NCL sites

Hospital	NMUH	Barnet	Royal Free	UCLH	Whittington	GOSH	Chase Farm	Moorfields	RNOH
Beds	16 + 9	20	20	31	23	423	0	12	32
Age range:	0 -16	0-17	0-17	0-18	0-17	0 - 18	0-17	0-16	?-19
Emergency Surgery	Yes	Yes	Yes	Yes	Yes	Yes	No	N/A	N/A
Day Surgery	Yes	Yes	Yes	Yes	Yes	Yes	16+ only	Specialist ophthalmology services only	Specialist orthopaedic services only
Out Patient Care	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Specialist ophthalmology services only	Specialist orthopaedic services only
Elective Inpatient Surgery	Yes	Yes	Yes	Yes	Yes	Yes	No	Specialist ophthalmology services only	Specialist orthopaedic services only
Elective Inpatient Medical Care	Yes	Yes	Yes	Yes	Yes	Yes	No	No	Specialist orthopaedic services only
Dedicated High Dependency Unit	Beds flex *	Beds flex *	Beds flex *	Beds flex *	Beds flex *	Yes	No	No	Yes**
Intensive Care:	No	No	No	No	No	Yes	No	No	No
Ambulatory Unit	Yes. 24/7 unit for <48 hour stay	Yes	Yes - planned care	Yes	Yes	No	No	No	No
Urgent Care	Yes	Yes	Yes	?	Yes	No	Yes	No	No
Emergency Department	Yes	Yes	Yes	Yes	Yes	No	No	Specialist ophthalmology services only	No

*There are no dedicated HDU units however paediatric ward provision can be flexed if required to provide high dependency care
** RNOH has four level two HDU beds on site