

OUR CITY, OUR HEALTH

**NHS ENGLAND (LONDON) ANNUAL
PARTICIPATION AND ENGAGEMENT
REVIEW 2018/19**





Contents

	Welcome	3
	Introduction - Our City our Health	4
	Involving Patients: Commissioning	10
	- Primary Care	11
	- Public Health Services	15
	- Screening	19
	- Health in the Justice System	23
	- Specialised Services	25
	Involving Patients: Supporting Commissioners	27
	- The Nursing Directorate	27
	Involving Patients: Leadership	36
	- The Clinical Senate	36
	- London Clinical Networks	40
	- Maternity	45
	- Healthy London Partnership	49
	Conclusion - Final thoughts	52
	Get Involved	53





Welcome



*Martin Machray – Acting Joint Regional
Chief Nurse and Clinical Quality Director NHS
England (London)*

2018 saw the NHS celebrate its 70th Anniversary which gave us the opportunity to celebrate all its achievements. In January 2019 the NHS Long Term Plan was published which looks to the future. So, this report covers a year where we both looked to our history and planned for the future.

The Long-Term Plan is an ambitious document which introduces new ways of working across primary care and with local authorities, Community and Voluntary Sector partners, patients and the public. The Plan has three central aims, making sure everyone gets the best start in life, delivering world class care for major health problems and supporting people to age well.

Underpinning this is a real commitment to support all our communities by:

- Joining up services between social care, health and the community and voluntary sector to provide fully integrated care with patients at the heart;
- Preventing illness and tackling health inequalities;
- Focusing on keeping people well and supporting people with health problems to help themselves to stay as well as possible;
- Engaging with local communities to ensure health and care services are developed locally, giving people more control over their own health.

This Annual Participation and Engagement Review from NHS England (London) shows how we have been working with Londoners to make sure the NHS works for them and their communities. The review also highlights how we have worked with Community and Voluntary Sector partners to hear the

voices of our more vulnerable residents and communities experiencing health inequalities.

Patients are at the heart of everything that the NHS does, and we are committed to co-designing our services with patients and the public. We know this is the only way we can be sure services deliver the right care in the right way. We will continue engaging communities and patients in decisions about the future of health and care. I hope that this review demonstrates this commitment and exemplifies the impact this year's work has had in creating positive change.

Finally, and most importantly, I would like to say a huge thank you to all the Londoners who took the time to work with us throughout this year. The energy, commitment and ideas they so generously contributed have made a real difference to the lives of their neighbours, their communities and to everyone who lives and works in the capital. We very much look forward to continuing to work with you during the coming year. We want to make London the healthiest global city and the best global city in which to receive healthcare. We can only achieve this together.





Our city, our health

London is one of the world's most exciting places to live, with its iconic landmarks, lively, vibrant districts and breath-taking scenery.

We are very proud that people from all over the world choose to make London their home and we warmly welcome the diversity and energy they bring which makes London such a special place to live. We have an abundance of assets such as energetic and enterprising people, globally successful businesses, world-leading academic institutions and some of the greatest healthcare innovations in the world.

Like other global cities, London also has some major challenges. Health inequalities prevent many Londoners from reaching their full potential and remains a significant contributor to ill health and early death. Too many Londoners suffer ill health due to social deprivation and economic exclusion.

Health inequalities across London present a stark picture. A boy born today in one part of London could die up to six years earlier than a boy born elsewhere in the city, whilst girls born in some boroughs could be expected to live up to a third of their life in poor health⁽¹⁾.

The Facts:

More than **8.8 million**
people live in London

This is projected to rise to **10 million**
by 2030

London has a **much higher** proportion of people aged **25-44 and under 5's** compared to the rest of England

By 2031, there will be a **40% increase** in people **aged 80 or over**

London has a **BME population of 41%** compared to **10%** for the rest of England

37% of children and **19% of pensioners** in London live in poverty



Sources: 1. fingertips.phe.org.uk/profile/public-health-outcomes-framework





Our city, our health (continued)



London's health challenges:

- **Cardiovascular disease, cancers and respiratory diseases** are London's leading causes of death.
- Patients with **Long term conditions** account for more than 50% of GP appointments and 75% of health and social care spend⁽²⁾.
- **Suicide** is the cause of death for 12 Londoners every week. Three quarters of people who commit suicide in London are male and suicide remains the biggest killer of working-age men⁽³⁾.
- There are 1.2 million **smokers in London** and smoking rates in adults in manual roles are double those of adults in managerial roles with 8,400 deaths and 51,000 hospital admissions a year attributable to smoking⁽⁴⁾.
- London is the '**childhood obesity capital of Europe**' and the proportion of London's 10 to 11-year-olds who are an unhealthy weight is higher than the England average⁽⁵⁾.
- **Children and young people** in London suffer from poorer health outcomes than elsewhere in the country.
- **Asthma** is the most common long-term medical condition affecting children and young people in London. **Poor air quality** in London is concentrated around schools⁽⁶⁾.
- London has the **highest demand for mental health** services in the country. 1 in 4 Londoners will experience poor mental health and nearly 10% of children age 5-16 have some form of mental illness⁽⁷⁾.

Our new vision for London's health and care:



To be the healthiest global city now, for all and for future generations



To be the best global city in which to receive healthcare

Sources: 2. www.rcgp.org.uk/about-us/news/2019/may/15-minute-minimum-consultations-continuity-of-care.aspx 3. Suicide in the United Kingdom 4. www.healthylondon.org/our-work/prevention 5. Childhood obesity: a plan for action, 25 June 2018, Department of Health and Social care 6. www.healthylondon.org/our-work/children-young-people/asthma 7. Better Health for All Londoners CONSULTATION ON THE LONDON HEALTH INEQUALITIES STRATEGY August 2017





What we do

Our mission is to improve health and secure high-quality healthcare for the people of England, now and for future generations.

Priorities and improvements for the decade

ahead - The NHS Long Term Plan

We believe everyone should have greater control of their health and wellbeing, and be supported to live longer, healthier lives with high quality health and care services that are compassionate, inclusive and constantly improving.

As society develops, health needs change. Technical and medical advancements also bring change to the way healthcare is delivered. The NHS must continually move forward so that in 10 years time we have a service fit for the future. **The NHS Long Term Plan** will do just that. It was drawn up by frontline staff, patient groups, members of the public and national experts. The plan is ambitious but realistic. It sets out how the NHS will give everyone the best start in life; deliver world-class care for major health problems, such as cancer and heart disease, and help people age well.

The Implementation Framework (2019) sets out further details on how the commitments in the Long-Term Plan will be delivered.



The NHS Long Term Plan



The NHS Long Term Plan - Video



The Implementation Framework

Our four main functions at NHS England (London)

Commissioning: this is the process of planning, buying and monitoring healthcare services.

We commission:

- primary care and specialised health services
- public health services, including healthcare for those in the criminal justice system
- screening and immunisation services, and
- armed forces healthcare.

Assessment and improvement of London commissioning services: We provide assurance that NHS organisations in London are commissioning effectively to meet their populations health needs and ensure best value for money. We support local commissioners in London to deliver improved health outcomes for the populations they serve and ensure that they uphold commitments made under the NHS constitution.

National policy and strategy: Our role is to ensure that the NHS is sustainable and identify priorities for change and improvement. Public engagement for national policy is undertaken at a national level.

Leadership: Working with national and local partners, we provide leadership to the commissioning system and help shape the future direction and transformation of the NHS.





What we do (continued)

The NHS in London

NHS England (London) - distribute more than £18 billion on health and care services through over 140 specialised services. To do this effectively we work together with the following organisations:

32

Clinical
Commissioning
Groups (CCGs)

5

Sustainability and
Transformation
Partnerships (STPs)

36

Hospital
Trusts

32

Local
Authorities

1

Ambulance
Service

Primary care (GPs, Dental Surgeries, Optometry
Practices and Pharmacy services)

The Community and Voluntary Sector

This year NHS England has worked in partnership with NHS Improvement to help transform the way we work together to provide single system leadership to the NHS. An ambitious programme of work commenced to align our leadership and collective resources around a shared set of priorities. In April 2019 the two organisations came together to better support the NHS and improve care for patients.

North West London

- Approximately 2.1 million residents
- Eight CCGs
- Eight local authorities

North Central London

- Approximately 1.5 million residents
- Five CCGs
- Five local authorities

North East London

- Approximately 2 million residents
- Seven CCGs
- Eight local authorities

South West London

- Approximately 1.5 million residents
- Six CCGs
- Six local authorities

South East London

- Approximately 1.8 million residents
- Six CCGs
- Six local authorities





Patients at the heart of what we do

The NHS Long Term Plan and the Implementation Framework describes a new relationship between the NHS, patients and the public, including a continued commitment to engage communities and citizens in decisions about the future of healthcare.

Under section 13Q of **the National Health Service Act 2006** (as amended by **The Health and Social Care Act 2012**) NHS England has a legal duty to involve patients and the public in our commissioning processes and decisions.

This participation and engagement review highlights the work that NHS England (London) has done to involve patients and the public between 1 April 2018 and 31 March 2019 and describes our ambitions for the future.

As with previous years, we commissioned an independent body (Insight to Impact Consulting Ltd) to recruit and train a group of Londoners to scrutinise our public engagement activity. This group, London Patient Voice, undertook an independent review of how we are meeting our legal duties to involve patients and the public in our work.

The review was undertaken against a background of three significant developments:

- The on-going integration of NHS England and NHS Improvement regional teams.
- Planning activity to meet the challenges that EU Exit will pose.
- The publication of the national Long Term Plan.

London Patient Voice found areas of progress and a strengthening of engagement across the region. Their **report** included several recommendations on how we can further support engagement. We have developed actions based on those recommendations which we are working to implement.



We found that the process of embedding Patient and Public Voice (PPV) and the understanding of the benefits continued to improve throughout NHSE (London) as a whole. The PPV representatives, NHS commissioners and clinicians we spoke to understand the unique contribution that PPV can make to improving access to services, design and delivery of new services and the improvement of existing ones. ”

David Winskill

Chair, London: Patient Voice





Patients at the heart of what we do (continued)

In 2018/19 our regional work focused on:

- Working with our national and regional colleagues to further develop and implement the participation indicator for London CCGs as part of the Improvement and Assessment Framework.
- Continuing to work with London CCGs to improve engagement practices.
- Strengthening processes to ensure that NHS England (London) can evidence compliance with our legal duties to engage with patients and the public.
- Expanding participation training for both NHS England and CCG staff and for Patient Public Voice (PPV) partners to help improve the quality and depth of our engagement.
- Developing the London Engagement Leads network to offer improvement, collective learning and peer support for engagement professionals across London.
- Delivering the Voluntary Sector Carers Grants Scheme. The scheme awards funding for projects across London to support health and wellbeing of unpaid carers. In line with the NHS Long Term Plan, this scheme aims to empower carers to make healthy choices, improve quality of life and reduce health inequalities.
- Leading improvements in public and patient engagement driven by the recommendations within the London Patient Voice report.
- Contributing to national Advisory Groups overseeing the development of NHS Citizen.

Project aim is:



I find the London Engagement Network extremely useful for various reasons. Firstly, we learn from each other and share similar issues and best practice. Secondly, we network and meet other people in a similar field and thirdly we all feel we are working towards similar goals and priorities. ”

Nadine Wyatt

Patient and Public Engagement Manager Sutton CCG



I thought the session was really informative and engaging, a great mix of group work and presentations. The pace, pitch and tone were just right. Thank you, it has been really helpful and useful, informative and thought provoking. ”

Participant from Ten steps to better participation and engagement training – Feb 2019





Involving patients: Commissioning

Health service commissioning is the process of planning, agreeing, paying for and monitoring services.

This involves a range of activities, including health-needs assessment of a population, the clinically based design of patient pathways, developing service specifications, contract negotiation, procurement and continuous quality monitoring.

NHS England directly commissions a range of services and works collaboratively with local commissioners to design these services so that they meet the needs of communities, improve health outcomes and meet the commitments outlined in the NHS Constitution.

If you're viewing this online, click on the buttons below to find out how we commission these services and how patients and the public have been involved.



Primary Care

(including General Practice, Dental, Optometry and Pharmacy services)



Public Health Services



Health in the Justice System



Specialised Services





How patients and the public contribute to primary care

What we do

Primary care includes the care provided by GPs, Community Pharmacists, Optometrists, Dental Practices, and Community-Based Health Services, including District Nursing services. In London NHS England has delegated commissioning responsibilities for these services to all 32 CCGs. This gives CCGs greater responsibility for deciding and managing local GP services, although NHS England still hold the contracts.



An official practice opening event 29th May 2019 - John McDonnell (MP for Hayes & Harlington) Sara Hurley (Chief Dental Officer – England) Simon Arnold (Councillor for Yiewsley) Tony Aslam (Patient Leadership Board) Dr Amit Rai (West Drayton & Yiewsley Dental Practice)

How do we involve patients and the public?

For GP services in CCGs we engage with patients, the public, local patient groups and stakeholders about options on how services will be delivered in the future, for example when a GP contract comes to an end. This can include sending letters to all registered patients, hosting public meetings, drop-in sessions based at the Practice and online surveys. We also work with interested patients on the specifications for new practices.

Service specifications are very important as they set out the service standards that the contract holders must meet when delivering the service. Key Performance Indicators (KPIs) are part of a service specification and are a way in which performance is measured. We work with patient groups to develop KPIs against areas that patients have told us are important to them. Additionally, we involve patients who have been trained in bid assessment skills to be part of the evaluation panel which scores all bids and decides which provider will be awarded the contract. For example, a restorative dentistry procurement was planned and we gave training and support to our Patient Leadership Board member in readiness for scoring and evaluation of bids.

For Dental, Optometry and Pharmacy services patient engagement is undertaken through the Patient Leadership Board (PLB). The PLB is co-chaired by two Public Health England consultants and membership of the Board consists of appointed Lay members alongside staff and other co-opted members. We work with and support Board members in a variety of ways including pre-meetings, training in specific areas, Board sub-groups and task and finish working groups.





How patients and the public contribute to primary care (continued)

Looking back 2018-19

This year we have responded to recommendations from the London Patient Voice report, Scrutinising NHS England's (London) Public and Patient Engagement. The report made several recommendations about the engagement of patients and the public in primary care services, as good primary care services which are accessible is really important to local communities.

The recommendations encouraged us to work more intensely with our PPV partners and our PLB members to provide targeted training and support for dedicated work areas, including primary care. Two PLB members also received procurement panel training and took part in a procurement for a new Dental practice.

Together with our existing PLB members, we continued to explore additional and alternative methods and strategies to increase patient and public engagement in line with the NHS England's commitment to PPV partners.

This year we strengthened the existing PLB and planned the recruitment of new members. We have explored innovative ways of recruiting people from diverse communities and population groups, for example, recruiting younger PPV members by working with colleges and universities.

Where possible, PLB members have had the opportunity to be involved in contractor meetings and have also taken opportunities to be involved in Practice visits. PLB members also meet with contractors and providers at engagement events and conferences.

We have focused on meeting the following recommendations:

- Easing the burden on PPV partners, by reducing the number of board meetings from six meetings per year to four and including the use of sub-groups for the three areas under its remit.
- Supporting one of the Patient Leadership Group to sit on the senior board, to address a lack of strategic connection.
- Providing clear feedback with specific examples to PPV partners to assure them of how their input has made a difference in the commissioning of Dental, Optometry and Pharmacy services.





In focus

A London Community Pharmacy Strategy

The London region are working with Local Pharmaceutical Committees (LPC) on the development of a London Community Pharmacy Strategy. PPV partners are an integral part of this process.

The purpose of the strategy is to:

- Define the community pharmacy offer to the wider health economy across London
- Provide an opportunity for the London Community Pharmacy network to respond to the ambitions laid out in the NHS Long-Term Plan
- Facilitate community pharmacy involvement and integration in STPs and Primary Care Networks (PCNs)

A Task and Finish group was established to develop, implement and monitor the progress of a project plan to develop the strategy. This document will be owned by pharmacists and is scheduled for LPC endorsement by 30th September 2019.

In focus

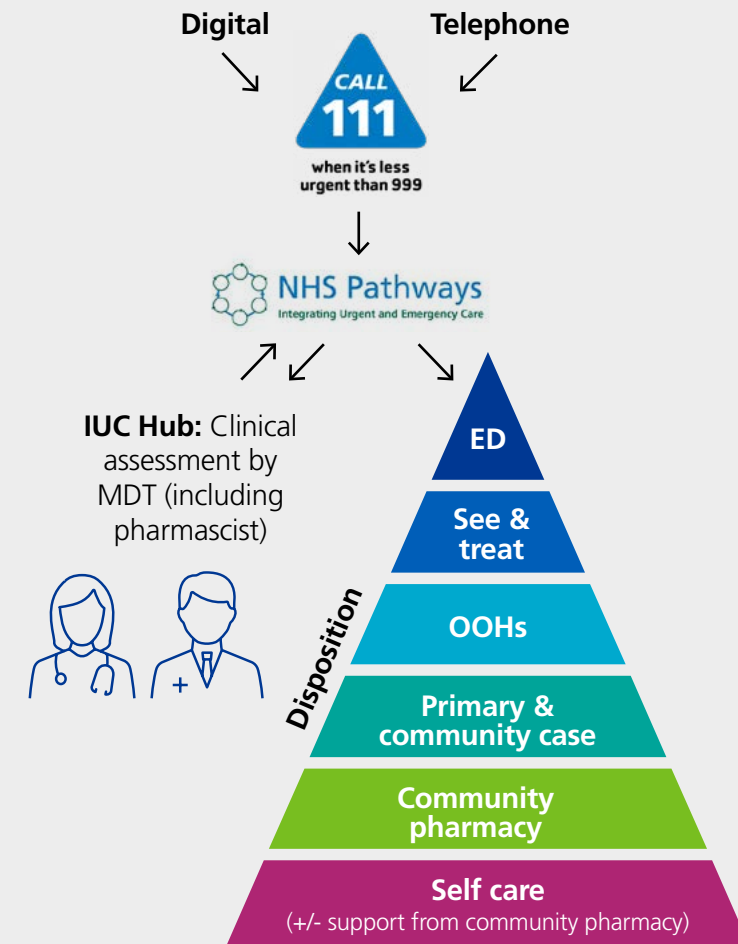
Digital Minor Illness Referral (SerwDMIRS)

In August 2018 NHS England (London) region announced a new pilot scheme called the Digital Minor Illness Referral Service (DMIRS) which seeks to refer patients who call NHS 111 with a minor illness directly to community pharmacies.

A series of launch events took place for community pharmacists across London to help raise awareness of the service including patient pathways, demonstration of the IT platform and how to register.

The DMIRS pilot will continue until September 2019. PLB members have been involved in the engagement events and on-line patient surveys. Members also met with contractors and stakeholders for the DMIRS to learn more about service provision.

NHS 111 Patient Journey





Looking forward

Over the coming year we will work with PPV partners to:

- Complete the procurement of the orthodontic service
- Finalise the new Community Pharmacy Strategy which will help define the community pharmacy offer to the wider health economy across London
- Include PLB members in sedation audit visits
- Fully involve PLB members in the Endodontic (restorative) procurement process for Ealing, Hounslow and Bromley
- Develop further training for PLB members as requested



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South East London





Public Health Services

Public health is about keeping people healthy and protecting them from threats to their health, such as preventable diseases. The Public Health team at NHS England (London) work closely with Public Health England and together we help improve the health of London's population. At NHS England (London) we commission immunisation services, adult and cancer screening services, antenatal and new-born screening and health services in the justice system.

What we do

The Early Years and Immunisation team commissions services to provide vaccinations against diseases, focusing on very young children, the elderly and adults with long-term conditions. The London Immunisation Board oversees our work.

We aim to:

- Achieve the World Health Organisation's goal to improve immunisation uptake and wipe out vaccine preventable diseases.
- Reduce differences in outcomes between the most deprived and least deprived boroughs in London.
- Promote the roll-out of new programmes and initiatives and test which of these improve access.
- Influence and engage with all stakeholders, including the national NHS England and Public Health England teams, the London Clinical Senate, London Immunisation Network, Practitioners and Londoners.

How do we involve patients and the public?

We use a variety of ways to involve patients and the public. For child vaccination programmes, we work with GP practices to capture patients' and parents' feedback and use that intelligence to make service improvements.

We review patient feedback from maternity providers at Programme Boards. Feedback is used to prompt discussions on how providers can improve patient experience and it informs our commissioning. By regularly considering patient feedback we require providers to demonstrate how they are improving patient experience and identify where improvements can be made.

We work with Public Health England and academic partners on how we can effectively capture patient experiences and public perspectives on vaccinations. By working with the public we can understand how to improve acceptability, understand the drivers for vaccine hesitancy and how to improve uptake.

Examples of our engagement work this year include:

- Gathering feedback from people over the age of 70 years on shingles vaccination delivery.
- Ensuring there were robust communication plans for parents and young people in preparation of implementing the HPV vaccination for 13-year-old boys.
- Undertaking insight work with university students on the provision of pop up clinics for Meningitis ACWY vaccinations.

We work with communications teams in Public Health England and NHS England (London) on how best to utilise social media to engage our public and regularly review the impact of social media on our campaigns and use findings to inform future campaigns.





Public Health Services (continued)

Looking back 2018-19

Our research into the barriers for uptake of vaccines for human papilloma virus (HPV) and meningitis (MenACWY) continues and findings from the research has informed service delivery. We have learned that young people are more likely to take up the vaccinations if they are well informed with appropriate materials. A survey of 144 university students at UCH identified that young people from more disadvantaged backgrounds were less likely to be vaccinated. Good awareness, knowledge of symptoms and their severity increased the likelihood of students opting to be vaccinated. Recommendations from the survey are that awareness campaigns should extend beyond freshers' week.

A pilot programme is being funded with a GP Confederation to run a central service open from 9am to 5pm, Monday to Friday. This will be supported by vaccine ambassadors (a service run by the British Immunological Society). The ambassadors are a team of volunteers who engage with new and expectant parents on vaccines and immunity and are particularly skilled at communicating with vaccine hesitant individuals, explaining the evidence base and importance of immunisation. This is an essential element of the service, providing time for parents and carers to speak to experts about their concerns and ask any questions they may have. Vaccine ambassadors also attend local nurseries, community groups, antenatal and postnatal classes to help raise awareness about vaccines.

In focus

School age vaccination service user experience feedback

A survey was undertaken in February 2019. A total of 316 secondary school pupils completed the survey from different boroughs across London including Barking and Dagenham, Hackney, Haringey, Islington, Newham, Redbridge, Tower Hamlets and Waltham Forest.

The findings show:

- The need to do more health promotion work targeted at pupils so that they understand what vaccines they are going to receive, as there are fairly high levels of concern pre-vaccination and many do not understand exactly what vaccination they are having 53% of the children had feelings of apprehension before receiving injections and this is also something that could be addressed through health promotion directed at pupils.
- Pupils reported that they were generally happy with the support received from the team and found them to be helpful, kind, caring and friendly.
- The nurses do an excellent job of explaining the vaccines pupils are going to be receiving.

A considerable number of children fail to have vaccinations because a signed consent form has not been returned to the school. One of the initiatives to address this, if parents can't be reached by a telephone call on the day, is to offer the teenage children the opportunity to self-consent using **Gillick competency**. Pupils who consent using Gillick competency generally reported positive experiences.

The findings and recommendations have been presented to the Immunisation Board and we are now encouraging providers to make more effective use of self-consent.





In focus

Digital Redbooks in London

London was an early adaptor of the digital version of the Personal Child Health Record (the red book) a book given to parents before or after the birth of their child. This enables both health professionals and parents to record information the development of their child and the care they receive.



A video on eRedbook is available [here](#).

We have supported NHS organisations who have chosen to introduce eRedbook and this has been received well by parents. So far 87% of parents surveyed online said they liked or loved eRedbook.

“

It's easy to use and with it being digital, I am definitely more inclined to use it than the paper version ”

“

It's easy to access, can't be lost or left at home like the old red book, and it reduces physical waste. It just needs to be more common across the UK now! ”





In focus

Shingles Vaccination Programme

To improve the uptake of the Shingles vaccination for people aged 70 or over, we are working with practices and patient groups to proactively identify eligible patients. A toolkit is now being written to help practices identify and invite eligible people for their vaccination supported by a campaign to help raise awareness.



Looking forward

- Vaccine providers continue to embed user feedback into their services, and present it to the Immunisation Boards to help inform commissioning intentions.
- Providers will survey students and parents around the implementation of HPV vaccine for boys in 2019 to provide greater public and patient insight to help support future campaigns.
- We will hold a seminar at Great Ormond Street Hospital in June 2019, so students can help us to develop a campaign to promote the uptake of Meningitis ACWY vaccine amongst young people.
- We will work to develop a robust engagement strategy to capture patient views on GP practice vaccine service delivery.
- We will evaluate the impact and effectiveness of the Vaccine Ambassadors.



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Screening

What we do

The screening commissioning team aim to ensure every programme meets the needs of those who require it. Engaging PPV partners in commissioning these services is essential to achieving this aim.

Screening offers include:

- Antenatal and new-born (ANNB) screening: such as genetic tests, infectious disease tests, foetal anomaly testing.
- Screening for adults and young people, including diabetic eye screening and abdominal aortic aneurysm (AAA) screening.
- Cancer screening: breast, cervical and bowel.

The Performance and Quality ANNB Boards have a standing item looking at service user feedback from services across London. The Board also requests that service providers demonstrate where changes have been implemented in response to the feedback.

The Screening service also receive feedback from Parent Advisory Groups through Local Maternity Systems to inform the commissioning of screening pathways.

How do we involve patients and the public?

We have PPV partners on the commissioning and programme boards who oversee our work. They work with us to review coverage of screening across London, identify ways to improve uptake, and develop new service models. PPV partners also work with us on procurements, including developing questions for the bidders and evaluating bids.

Looking back 2018-19

This year we have focused on developing a strategy for supporting people with protected characteristics to attend screenings.

The London Performance & Quality ANNB Screening Board has PPV partners who sit alongside representatives from a Sickle Cell charity, a young Stroke Survivors Group and the Sycamore Trust.

The Sycamore Trust supports parents, carers and individuals affected by Autistic Spectrum disorders and/or Learning Difficulties. They currently deliver service across the boroughs of Barking and Dagenham, Havering and Redbridge.





In focus

Service user experience of the Sickle Cell and Thalassaemia (SCT) screening

We commissioned the UK Thalassaemia Society (UKTS) and Sickle Cell Society (SCS) to carry out face to face interviews with women and couples who had recent experience of accessing the SCT programme. Women had been pregnant within the last 5 years were invited to participate. UKTS also invited people who knew that both parents carried a gene for sickle cell or thalassaemia and had accepted or declined Pre Natal-Diagnosis (PND). The interview findings include discussions from couples who said it was important for healthcare professionals to have knowledge of the conditions, genetic inheritance and the screening and diagnostic pathway, be aware that timing of PND is crucial to informed choice and provide direct access to counselling.

Commissioners have now shared the following recommendations with all screening providers:

- To provide direct access to maternity services to arrange a screening appointment.
- To take the screening sample at first appointment.
- To provide direct access to specialist counselling services to known at risk couples.
- Include positive outcomes for children affected by sickle cell and thalassaemia who live in England when counselling (outcomes may be very different in the country of origin).
- To provide a secure online web portal for self-referral and GP referral.
- To provide information on pre-implantation genetic diagnosis.
- Not hold any preconceptions about the choices a couple will make.
- To keep up to date by attending [external courses](#) completing [e-learning module](#).



In focus

Small change to improve early access to sickle cell and thalassaemia screening

Princess Royal University Hospital has made a very simple change that is having a big impact on improving early access to sickle cell and thalassaemia screening. In May 2018, the question 'Do you know if you are a sickle cell or thalassaemia carrier?' was added to the trust's online self-referral form and it has led to early access to counselling in pregnancy.

To date, 18 of the 26 women who have screened positive for sickle cell and thalassaemia have been identified from this referral form. This has enabled the screening team to offer the same test to the baby's father and complete counselling even before the woman has been booked for pregnancy care.

This means that women and couples have time to consider their options, including whether to accept PND. If their baby is found to be affected, they can then find out about caring for a baby with sickle cell disease or thalassaemia.

“

Language matters, especially if you're a health professional talking to parents-to-be ”

A poster was designed from learning taken from some mums who talked about the importance of language that health professionals use when talking to parents and parents-to-be about conditions like Down's syndrome, Edwards' syndrome and Patau's syndrome.

The poster, which can be found [here](#) aim to help promote language awareness among medical professionals.

Talking About Down's Syndrome?



Imagine Sophie, who has Down's Syndrome, is in the room with you, what would you say?

No thank you

risk
abnormality/disease/
problem/disorder
good/bad
difficult news
normal
suffer
a Down's
a Down's baby
mental handicap
retarded
severely affected

Yes please

chance/probability
difference/variation/
condition
expected/unexpected
or different news
typical/typically
developing
have
a baby with
Down's Syndrome
with a learning
disability
more complex

REMEMBER

Use high/low chance for **screening** results e.g. NIPT/combined test
Use positive or negative for **diagnostic** results e.g. Amnio/CVS





Looking forward

Over the coming year the Screening team will focus on ensuring boards and local trust screening groups provide structured opportunities for:

- User feedback surveys and recommendations to be regularly reviewed.
- Learning from other areas to be disseminated as a standing item on agendas.
- Monitoring implementation of recommendations for antenatal new-born screening at programme boards. This includes the evaluation of action plans.
- The continuation of supporting ongoing patient and public representation on our key decision-making boards.
- Further developing strategies for supporting people with protected characteristics to take up screening opportunities.



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Health in the justice system

What we do

The London Health & Justice Team is responsible for commissioning health care services in Her Majesty Young Offenders Institution Feltham and Liaison & Diversion services across London.

Liaison & Diversion (L&D) services aim to provide early intervention for vulnerable people as they come to the attention of the justice system. L&D services provide a prompt response to concerns raised by the police, probation service, youth offending teams and court staff. They then provide critical information to decision-makers in the justice system, in real time, when it comes to charging and sentencing these vulnerable people.

Additionally, L&D services act as a point of referral and are assertive with follow-ups for these service users to ensure they can access, and are supported, to attend treatment and rehabilitation appointments.

L&D service providers deliver an all age service across all sites available, to all points of intervention in the youth and criminal justice pathways. This enables providers to address a wide range of health issues and vulnerabilities, relevant to those with protected characteristics, as set out in the Equality Act 2010.

The L&D service must be accessible at the earliest stage once an individual is suspected of having committed a criminal offence. It must also be available at the point of need and at all relevant points of the youth and criminal justice system.

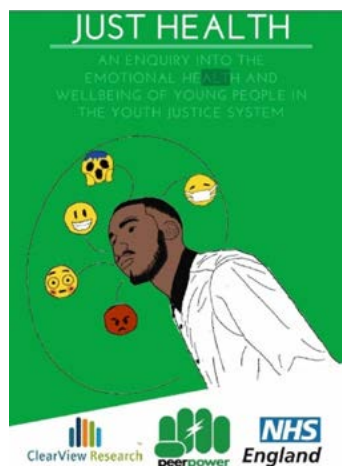
How do we involve patients and the public?

We commission Inspirit to ensure that the user voice is central to what we do. As part of this contract Inspirit run a commissioning technicians programme which trains and supports young people to become engaged with service providers to help shape services.

Commissioning technicians are people who have been in custody and so have experiences and insights that can help to improve health services.

The team also have an on-going contract with **Peer Power**. Peer Power is a social justice charity whose work supports the most vulnerable children and young people in society. During the previous year NHS England (London) commissioned Peer Power to facilitate a

consultation with children and young people, who had been in contact with the youth justice system, to ensure that the experiences and voices of young people inform the future design and delivery of health and wellbeing in commissioned services.



Looking back 2018-19

This year we have focused on:

- Working with the commissioning technicians to support the procurement and on-going commissioning of services in London, including services at Brixton and Wandsworth prisons.
- Developing a training model to ensure that children and young people can fully participate in the procurement and commissioning of services.
- Working with the established patient and public participation groups to ensure patients and public can be involved in decisions affecting the strategic direction of the team.



We feel that there is a systematic approach to gaining the views of those in Prison, and this is being extended to those in police custody. This engagement, focusing on service users, seems to involve PPE in commissioning level decisions.

London: Patient Voice Scrutinising NHS England (London) Public and Patient Engagement 2017 - 18





In focus

This year service users participated in the commissioning of new services for two London prisons. The Inspirit Public and Patient Engagement group helped to develop the questions which formed part of the tender document.

To ensure the voices of the more vulnerable are heard, we also support Learning Disability nurses who champion the needs of service users with learning disabilities or mental health challenges.

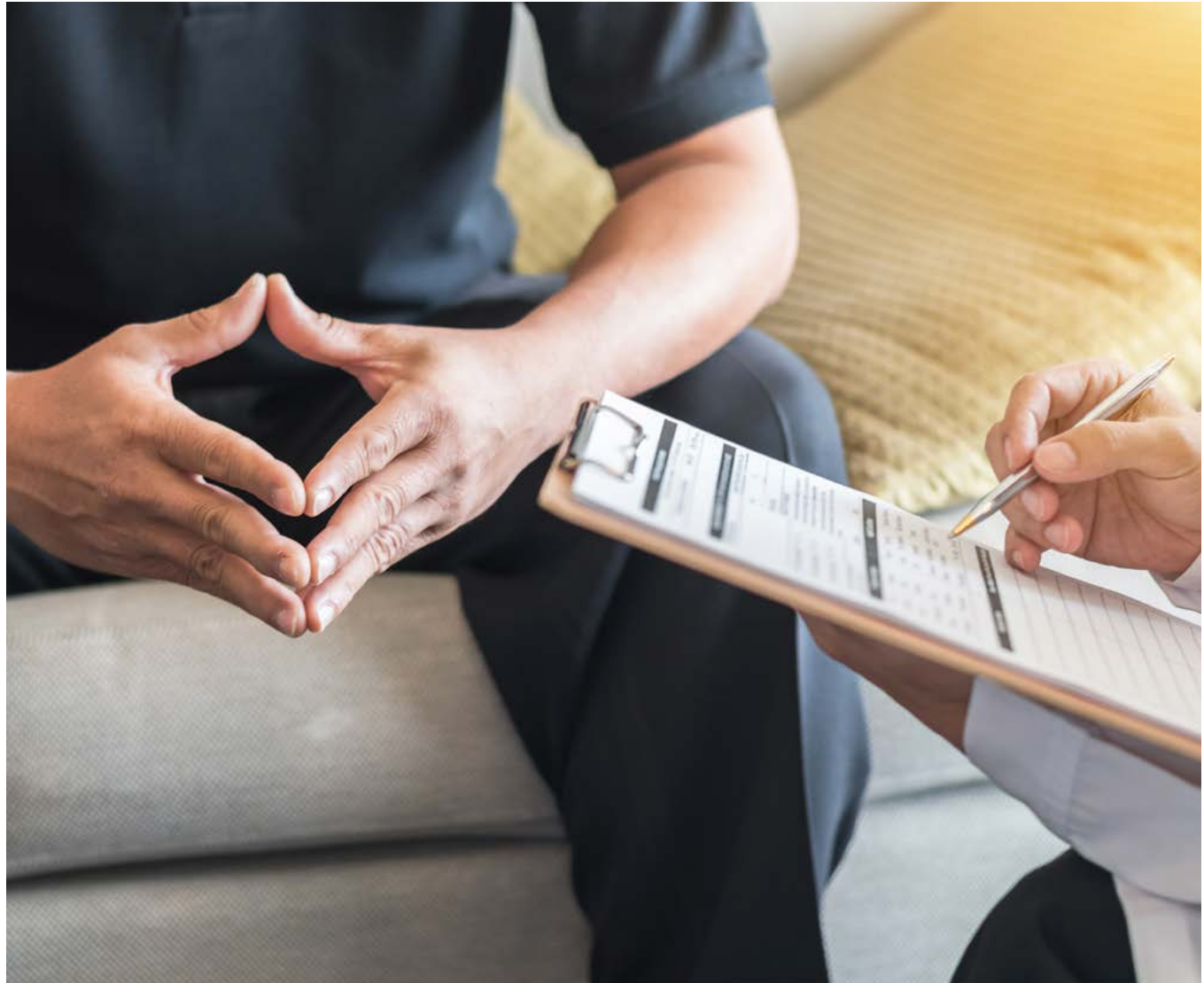
Looking forward

In 2019-20 we will concentrate on going further to ensure that the voices of those detained in police centres are heard to help drive forward service improvements.



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Specialised services

What we do

Specialised services provide care to patients with a range of rare and complex conditions, often at times when they are in greatest need. They can involve treatments provided to patients with rare cancers, genetic disorders or complex medical or surgical conditions. Specialised services are not available in every local hospital because they must be delivered by specialist teams of doctors, nurses and other health professionals who have the necessary skills and experience. NHS England (London) commissions these for eligible patients, including London residents and patients referred from across the country.

Examples of highly specialist services include neonatal critical care and kidney dialysis and very complex procedures only carried out in small numbers, such as using an artificial cornea to restore vision to blind patients.

How do we involve patients and the public?

In London we use a range of methods to engage patients and the public, including one-to-one meetings, focus groups and wider public engagements or consultations.

We continue to use different forums to encourage patient and public participation across the different elements of specialised commissioning. For example, the renal programme includes PPV partners on the south London Renal Operational Delivery Network.

The new north London Renal Clinical Advisory Group has a patient representative, with two PPV partners on the Kidney and Consortia, known as Transplant London PLC. There is also a strong public and patient representation in the cardiac programme.

Looking back 2018-19

There remains strong and active public and patient engagement on the different service review Boards hosted by Specialised Commissioning for the London region. As part of the process of developing service specifications for specialised services we now have PPV partners on each of the working groups. This role is pivotal to the development of services.

With the evolving Operational Delivery Networks (ODNs) for both the south London and north London Programmes, there has been an emphasis on strengthening engagement and providing a voice to patients and the public. In addition, following feedback from London Patient Voice, we are designing peer support groups to be launched for the different Operational Delivery Networks.

A new clinical strategy has also been launched for HIV and Hepatitis C with a commitment to include patients at a regional level to inform local implementation. To support the Department of Health strategy for increasing the numbers of blood and tissue donors by 2020, we are working in partnership with the Mayor's Office, NHS Blood and Transfusion service and the Anthony Nolan charity to deliver engagement events. The engagement will have a focus on increasing the number of Black and Asian Minority Ethnic donors to reduce the inequality experienced by patients from these ethnicities who have more limited or no matched donors.



**In focus**

Pan London Neonatal Operational Delivery Networks (ODN)

As part of the pan London neonatal ODN, parents, carers and representatives of patient groups have been included in a recent peer review of all neonatal units across London and England. Patient Public Voice is now embedded within the governance structure of the ODN, enabling the service to be further developed by using feedback from parents and carers to drive improvements. This helps to ensure sharing of good practice and driving equity in service delivery of this high intensity service.

Feedback around peer support for this ODN has highlighted the importance of PPV members and the role they can play within the networks.

**Looking forward****In 2019-20 we will:**

- Continue engagement with the PPV team to establish representation for all specialised services.
- Establish a process to gain feedback from PPV partners about specialised services for London.
- Develop a portfolio of good practice from the patient and public representatives.
- Showcase more case studies of patient and public engagement to demonstrate its impact and how it is making a difference.



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Vinice Thomas, Director of Nursing and Quality
Specialised Commissioning





The Nursing Directorate

What we do

The Nursing Directorate is responsible for developing a strategic approach to ensuring people have a positive experience of healthcare and that people are cared for in a safe environment. We also provide professional leadership to nurses and midwives across London. The team has a leading role in assessing the quality of the services commissioned by NHS England and CCGs.

This quality role includes:

- **Patient safety** - enabling and assuring robust processes for building a safety culture, learning and sharing safety lessons and implementing solutions to prevent harm to patients.
- **Safeguarding** - making sure at-risk children and adults are safeguarded from abuse and neglect, ensuring that the learning from serious case reviews and safeguarding adult reviews is shared across the London health system; advising on core policy changes and ensuring the implementation of any changes have a positive impact on the safeguarding of the population.
- **Transforming Care programme in London** – the Transforming Care programme will mean that fewer people will need to go into hospital for their care, enabling more people to live in the community with the right support, closer to home. For people who do need to go into hospital we want to make sure that they are as close to where they live as possible. To do this we are making sure that services in the community provide excellent quality of care so that they can support people.

- **Continuing Healthcare (CHC)** – ensuring commissioners in London have effective processes in place to assess eligibility for CHC and to commission good quality care packages. Managing independent reviews and leading regional work as part of the national strategic improvement programme for CHC.
- **Learning Disability Mortality Review (LeDeR) Programme** – driving improvements in health and social care and reducing health inequalities through learning from the deaths of patients with Learning Disabilities.
- **Participation** – ensuring patients have good experiences of care and that patients and the public can participate in decisions about healthcare in London.

The Patient and Public Voice (PPV) team in the Nursing directorate leads on supporting improvement, developing strategy and ensuring patient and public voice is represented in governance structures in NHS England (London). The PPV team support our specialist commissioners to involve patients, their carers and the public in regional and national commissioning programmes and governance.

The team also co-ordinates the oversight of NHS England's duty to involve the public (Section 13Q of the Health and Social Care Act 2012) in our directly commissioned services.





The Nursing Directorate (continued)

How do we involve patients and the public?

- The PPV team produce this annual review and commission London Patient Voice to scrutinise the quality of engagement work being undertaken by NHS England in London. They provide leadership and support to patient experience and engagement colleagues within the regional team and across all London CCGs. This is primarily achieved through the London Engagement Leads Network (for NHS England and CCG colleagues) and the Patient and Public Voice Accountability Group (NHS England only) which are our key mechanisms for providing support and assurance across London.
- The team commission and support training for staff and members of the public involved in all NHSE engagement activities and run a regional assurance process reviewing CCGs' delivery of their engagement work under the Duty to Involve statutory responsibilities (section 14Z2 of the Health and Social Care Act 2012).
- The Learning Disability Mortality Review (LeDeR) Programme team is responsible for reviewing the deaths of all patients with Learning Disabilities and that health and social care services implement service improvements in response to the learning from completed reviews. Every review involves engaging with the family of the person that has died. The LeDeR programme team consults regularly with advocates with Learning Disabilities from across London, to

ensure that the voice of people with Learning Disabilities are central within the programme.

- All patients who meet the criteria for inclusion in the Transforming Care programme are able to benefit from a Care and Treatment Review (CTRs). As part of the review the patient, advocate and family are invited to discuss the best care and treatment options available so that their views are fully understood and can be factored into care planning. A minimum of one expert by experience attends to provide a non-clinical perspective. The London Patient and Public Voice team recruits and co-ordinates a pool of experts by experience to support the CTRs.
- We recruit lay chairs to manage Continuing Healthcare Independent Reviews. Patients, families and representatives are supported to be involved and an online survey tool helps to assess whether CHC services provide good service user experience.
- The Safeguarding team has involved patients and public in key work streams including the Female Genital Mutilation (FGM) prevention and protection work, Mental Capacity Act (MCA) and Prevent.





The Nursing Directorate (continued)



Looking back 2018-19

Throughout 2018/19 the Patient and Public Voice team in London has supported regional and national NHS England and NHS Improvement staff, Specialised Commissioners, Patient and Public Voice partners and CCG Engagement leads in a number of areas to enhance their work and ensure that patient and public views shape health and care services across London.

- We have developed partnership working across London CCGs and STPs as they move towards becoming more integrated. We have supported local Healthwatches to become more engaged with system wide working and they are now embedded in our regional Quality Surveillance Groups as key partners and contributors.

- As local systems transform the way they work through the development of Primary Care Networks and Integrated Care Systems, we have worked with CCG colleagues through the London Engagement Leads Network to explore opportunities around changing engagement structures.
- This year as part of the national assurance process for the CCG participation indicator in the Improvement Assessment Framework (IAF), each CCG undertook a self- assessment against the indicator standards. This produced an overall RAG rating for each CCG. The team were closely involved in this assurance process and have been working with our CCGs to support development of local improvement plans as well

as sharing and supporting positive practice across London to help drive improvement at a regional level.

- Now in its second year, the London Voluntary Sector Carers Grant Scheme awarded funding for projects across London including Islington and Camden, Bromley, Hounslow and City and Hackney. The aim of the scheme is to support the health and wellbeing of carers to empower carers to make healthy choices and reduce health inequalities. This years projects included; The Young Carer Identification Card Scheme, The Bromley Well Carers' Support Service, Elder Carer wellbeing Support Network and the Integrated Neurological Carers Project.





In focus

Let's talk about Health Inequalities

In March 2019 the Patient and Public Voices team held a workshop with CCG Engagement leads to focus on local health inequalities. The aim of the workshop was to bring people together from across London CCGs to engage in a discussion about health inequalities in the context of the Long term plan. Participants were asked to consider the landscape for change in health and care in the future and the implications for patients and the public across London.

We collectively explored how we could continuously improve and further develop proposals to reduce health inequalities. This work helped to drive some key pieces of work across London.



I have really appreciated the range of topics and examples of good practice that have been shared through the Network. The NHS Right Care team were invited to offer engagement leads the opportunity to be pilots for their health inequality packs at the workshop. The Bromley pack identified which communities had higher hospital attendances due to respiratory conditions. This information was used to target those communities with flu information, keeping well and additional clinical training was put in place to help patients manage their asthma. This work contributed to Bromley having one of the best rates of flu uptake in London. ”

Kelly Scanlon

Head of Communications and Engagement,
Bromley CCG)



(Let's talk about Health Inequalities workshop)





Looking forward

The coming year will bring further transformation across the NHS with much closer integrated working between different healthcare organisations. There will be a focus on keeping London healthier, supporting people to managing long-term health conditions more effectively and making real the Long Term Plans focus on tackling health inequalities.

2019/20 will bring new opportunities and challenges:

- Supporting London CCGs to prepare for mergers within STP areas from Spring 2020
- Helping Commissioners and Primary Care teams to develop effective engagement mechanisms to support emerging Primary Care Networks across London
- The continuing integration programme of NHS England and NHS Improvement regional teams.
- The team will focus on rolling out our train the trainer package based on the 10 Steps to Even Better Public Engagement course. This will support health and care staff to ensure engagement with patients and the public is everybody's business and firmly embedded in emerging systems.
- We will develop our on-going support to our PPV partners who represent patients and the public at meetings of their Public and Patient Groups, Clinical Commissioning Groups, London Clinical Senate, London Clinical Networks, Healthy London

Partnership, NHSE (London region) commissioning boards and many other Boards and working groups.

- The transformation of STPs into Integrated Care Systems (ICS) within London will speed up as we head towards 2021. The PPV team will work closely with the London Engagement Leads Network as we move towards new ways of working to ensure that all commissioning decisions across London are driven by the experiences of the people who use health and care services. To help us do this we will work with the Network to explore the alignment of engagement structures, plot potential opportunities and mitigate challenges for patient and public engagement across the new system.



I really think that it is very important to keep the Network live and active, as it is a great source of resources and for us, PPE Leads, it is very important to be informed and updated about current trends and requirements.

Boba Rangelov

Patient, Public Engagement and Equalities Manager Ealing CCG)



London Engagement Leads Network

Continuing Healthcare

Looking back 2018-19

During 2018-19 the Continuing Healthcare team continued with their on-going recruitment of Lay people to chair Continuing Healthcare Independent Reviews. The reviews consider challenges from families to decisions made by CCGs about whether a patient is eligible to receive packages of care. The Chairs are independent and not employed by health or social care organisations. NHS England (London) currently has seven Lay Chairs. The Continuing Healthcare team also support patients, families and their representatives to be involved in the reviews.



In focus

PPV Regional Continuing Healthcare Delivery Board membership

During 2018-19 we recruited a PPV partner for Continuing Healthcare. The PPV Partner, who came into the role in January 2019, sits on the Regional Continuing Healthcare Delivery Board, which oversees the work of the regional team and its assurance of delivery across London, and ensures that it is aligned with other work programmes.

Recruiting a PPV Partner to the Regional Continuing Healthcare Delivery Board has benefited the decision making of the Board in various ways. The PPV Partner has taken an interest in the application of Personal Health Budgets (PHBs) helping to ensure that the Board focuses attention on the quality of care obtained through PHBs in addition to increasing the number of patients who have a PHB. The partner has also been involved in recruitment of the Independent Chairs of the Independent Review Panels, bringing a patient perspective to the interview panels.

Looking forward

Over the coming year we aim to develop additional training and support for our PPV Partners as we recognise the huge contribution they make in supporting other patients, families and carers during the Continuing Healthcare review process.

The Continuing Healthcare team also aim to encourage PPV Partners to take an active role in our regional work as part of the national strategic improvement programme for Continuing Healthcare.



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Patient safety

Looking back 2018-19

Over the past year the Patient Safety team have recruited and supported a PPV partner as a member of the bi-monthly Independent Investigation Review Group (IIRG). The IIRG aims to provide learning and sharing of best practice, as well as regional leadership, assurance, support and advice in the delivery of the Serious Incident Framework 2015 and the Department of Health guidance in relation to Article 2 of the European Convention on Human Rights and the investigation of serious incidents in mental health services.

The patient safety team has also involved patients and the public as part of their mental health work in the following ways:

- Public with lived experience are supported to present their stories at London mental health patient safety conferences to help improve patient experience and quality for other mental health service users.
- Families affected by mental health homicide contribute to improvement projects across London such as co-designing support materials following a mental health homicide to help other people in similar situations.

In focus

The PPV partner is an advocate from an organisation called Advocacy After Fatal Domestic Abuse (AAFDA). AAFDA specialise in guiding families through inquiries including Domestic Homicide Reviews and Mental Health Reviews, and they assist with and represent on Inquests, Independent Office of Police Conduct (IOPC) inquiries and other reviews.

The benefits of having a PPV partner from AAFDA is that they do not come from a Health and Social Care background. AAFDA members are people that have been personally affected by homicide and want to support those that are also affected. The PPV partner has made a valuable contribution to the Independent Investigation Review Group by providing challenge when needed and supporting the regional processes to ensure that families voices are at the heart of what we do.

Earlier this year we launched a suite of **materials** to support families and staff following a mental health-related homicide. This includes booklets and podcasts. A number of families affected by mental health-related homicide contributed greatly to the development of these resources – which have been widely circulated to mental health service providers.

Looking forward

Over the coming year the patient safety team will:

- Support our PPV partners as members on the Independent Investigation Review Group.
- Support families affected following a mental health homicide to contribute to improvement projects across London.



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Safeguarding

Looking back 2018-19

We have been working with providers and the Designated Professional Network to review how the Mental Capacity Act (MCA) is being implemented. We have found that some staff in organisations are not confident in assessing the capacity of patients to make their own decisions.

Significant work has been undertaken to contribute to the development of the reforms. One of the team is working with the NHS England and NHS Improvement national team and partners to develop the guidance to underpin the legislation. The team lead has worked with PPV groups to disseminate information and gain views from the public on this guidance.

This work has also led to the London Safeguarding Children Board in setting up an Adolescent Safeguarding Task and Finish Group to ensure that exploitation of older children is included as a safeguarding priority for London.

As part of our core work we continue to undertake monitoring of the CCGs and have challenged when we have not been able to see the engagement clearly. The plans for these are due in June 2019 and we will be reviewing these and will continue to monitor the level of engagement.

In focus

Children, young people & the Mental Capacity Act

With the support of the Children & Young People Participation Group an interactive exercise involving parent and carers was held to scope what resources would be of value to promote and support understanding, and thus application of the MCA. This was followed up with a presentation at the Learning Disabilities Mortality Review and MCA workshops in October 2018 regarding the MCA training pilot that utilises professional actors to portray service users.

This training provides practitioners with a safe space to hone their capacity assessment skills and plans to further develop this into a sustainable model are in train. This has underpinned further workshops and work with parent-carers, culminating in the co-production of a leaflet to support families when their loved one goes into an acute hospital.

Prevent

The NHS England (London) Prevent Conference was held on 8th November 2018 and attended by over 120 delegates including representatives from Adults and Children Safeguarding, Acute, Mental Health Trust and Primary Care with additional representation from the Home Office and Department of Health & Social Care.

The event focused on the current risk and threat posed by terrorism and what this means for health professionals in terms of safeguarding. The event ended with a moving account from Sally Evans who featured in the BAFTA award winning documentary 'My Son the Jihadi' about one of her sons who died fighting for the Al Shabbab terrorist organisation in Kenya. She described the effect that extremist narratives and grooming had on her vulnerable son, and the devastating consequences for the wider family in the aftermath of his radicalisation.

The telling of such a personal account has made a huge impact on the professionals who attended the event as it puts the risks into perspective for an area of safeguarding that can be difficult for professionals to always see as their responsibility.





Looking forward

There are significant reforms being implemented for children's safeguarding. These require CCGs to lead, with Local Authorities, on the development of a revised system to review child deaths. We are reviewing the arrangements to ensure that London CCGs are establishing quality bereavement services and on-going support for families.

During this year the Safeguarding team have identified safeguarding issues which require the child voice to be heard more effectively and have hosted workshops to inform guidance for practitioners to put the child first.

Over the coming year the NHS England and NHS Improvement safeguarding team will work to:

- Coordinate the implementation of the Mental Capacity Act amendments and Liberty Protection Safeguards to ensure that this provides improved outcomes for patients.
- Monitor progress of the child death review arrangements in terms of the level of family support provided.
- Review the response of the health system in ensuring that the adult at risk is consulted throughout the safeguarding process (Making Safeguarding Personal).



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The Clinical Senate

What we do

We are a multi-professional advisory body which brings together a broad range of health and care professionals with patients, carers and the public to consider issues which are important to the development of London's health services. We are one of twelve Clinical Senates in England. We support healthcare commissioners, providers and other bodies to improve health outcomes for their local communities by providing independent and impartial strategic advice and leadership.



How do we involve patients and the public?

All our work is carried out in partnership with our PPV Group. Its members have strong links with their local communities, including Healthwatch, and draw on these wider views to inform the Senate's work. The PPV Chair and Vice-Chair, appointed by the members, sit on the Senate Council, which provides overall leadership and oversight. PPV members form part of the Senate Forum which meets three times per year to debate significant strategic issues for London, share views and good practice. Bringing Londoners' views and experiences directly into the Senate debates has enhanced the discussion and influenced the advice provided.

The members of the PPV group meet monthly to discuss their work and contributions to the Senate's work programme. At many of these monthly meetings the group hear from speakers as part of their learning and development programme.

The Chair and Vice-Chair of the PPV group continue to represent the wider group on the Senate Council, ensuring that the views of patients and the public are considered in all Council discussions. In the last year we have recruited additional members to the Senate Council and the PPV group helped with the recruitment, with one PPV member sitting on the interview panel.

The PPV group have also made an essential contribution to Forum events held three times during the year. Members have made suggestions to the Council about

topics that they would like these events to cover and there has been a PPV partner on the planning group for each event to feed in the thoughts of the group. Members have given presentations at the events as well as taking part in panel discussions.

Looking back 2018-19

We improved the engagement of the PPV group in the planning of Forum events in the last year. For each Forum event we had two PPV members on the planning group. As requested by the PPV group, we ensured that the first meeting of the planning group was a face-to-face meeting to allow the PPV members to meet the rest of the planning group. We ensured that there was time dedicated on the monthly PPV meeting agendas for the whole group to discuss their thoughts for the next Forum event so that the partners could feed these views into the planning group.

We have asked the PPV group what topics they would like to receive training on as part of their learning and development programme and then found speakers to deliver a session on these topics. In the last year speakers have covered topics including, improvement science, pharmacy, allied health professions and primary care networks. The learning and development programme are continuing into 2019-2020.





In focus

Contributing to proposals for the relocation of Moorfields Eye Hospital

Islington CCG requested advice on proposals for relocating Moorfields Eye Hospital from its current City Road site to the site of the old St Pancras Hospital. We established a review team co-chaired by a Senate Council member and a subject matter expert. Membership of the panel included two of our PPV group members alongside clinical experts from London and further afield.

This was a substantial piece of work requiring a significant time commitment over a period of several weeks. Panel members initially reviewed extensive documentation relating to the proposals and later participated in a review day to discuss the proposals with a range of clinicians and patients who may be affected. This allowed the review team to explore the proposals and issues in more depth.

Panel members then considered the information from the written submissions and discussions and agreed the advice that would be provided. The concluding task for the team was the review and approval of the final report for the CCG.

The experiences and perspective that the PPV members brought to the review were essential and ensured that patients remained at the centre of discussions. The PPV members contributed significantly to reviewing of all the submitted documents as well as the questioning of clinicians and patients on the review day.

“

“The report they sent to us describing their plans to improve their current service by relocating was very comprehensive but didn’t have a lot of references to patient consultation. Therefore, my role together with another PPV member, was important in representing the users of their service as well as those delivering it.

The final report submitted to the CCG contained all suggestions agreed at the review from all panel members. I feel confident that the resulting re-location and service upgrade will be as welcome to Moorfields Eye Hospital’s patients as it will be to their staff and clinicians” ”

(Reflections from a PPV Group Member)





In focus

Influencing proposals for hospital services in South West London and Surrey Downs

We worked together with the South East Clinical Senate to provide joint advice to the three CCGs of Surrey Downs, Sutton and Merton on proposals underpinning their substantial change programme to provide sustainable hospital services in South West London and Surrey Downs. We established a joint review team with the South East Senate co-chaired by the Chairs of the London and South East Senate Councils.

Membership of the panel included a PPV group member from the London Clinical Senate and one from the South East Clinical Senate, alongside clinical experts from London and the South East.

This review was complex as the proposals looked at the reconfiguration of acute hospitals and encompassed all the services that they provide, compared to many of the reviews that we do that look at single services/specialties. Consequently, the panel included experts from all the specialities that would be affected.

Panel members reviewed extensive documentation relating to the proposals and contributed to discussion around the key lines of enquiry. The panel later participated in a review day discussing the proposals with a range of clinicians affected and with the panel deliberating on the information presented to reach their recommendations. The review panel then reviewed and signed-off the final report which was submitted to the CCGs.

The experiences and perspectives that the PPV members brought to the review were essential and helped form the recommendations provided to the CCGs. The PPV members ensured that the review panel did not lose sight of how the proposals would affect patients and influenced the final report produced.



“

This review was deep and thorough and the quantity of background reading supplied enabled both myself and my colleague representing PPV the South East Senate to understand the very many issues involved. I was given support with my queries on the more technical papers so when I arrived for the review, I was confident and able to participate as an equal throughout.

The review day was impressive, with tight chairing and a well-established process, which enabled the wide-ranging probing of the team giving evidence in the morning. This was followed by cogent and full deliberations in the afternoon, and throughout the day our patient voice was heard and valued. The draft report was very good, clear and easy to read, and reflected accurately the issues and priorities that we had agreed. I felt that our contribution was integral and ensured that the final report could be used by local organisations and people in the next stages of this important debate. ”

(Reflections from a PPV Group Member)





Looking forward

Throughout the coming year we will work to:

- Recruit additional PPV members to increase current membership capacity to at least fifteen members in 2019/20. The process will be led by the PPV Chair and Vice-Chair.
- Refresh the PPV members' guide as this has not been reviewed for a few years with the PPV group being involved in revising the guidance.



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London Clinical Networks

What we do

The London Clinical Networks bring together stakeholders including providers, commissioners and patients to align programmes of strategic transformational redesign. We provide the clinical expertise and leadership to drive commissioning decision making, reduce variation and direct service improvements.

Clinical Networks focus on areas such as mental health, dementia, maternity, diabetes, cardiac and end of life care.

The workstreams are varied in their scope and purpose, but all have an improvement and transformation focus. National guidance into a London vision by providing additional tools and support to Strategic Transformation Partnerships, commissioners and providers. Service users and carers work alongside programme leads and clinicians to shape London-wide improvement plans.

An example of one of our key workstreams is the Diabetes Clinical Network. Their role is to mobilise clinical leadership and subject matter expertise to improve health outcomes and reduce unwarranted variation in the experience of care for the type 1 and type 2 London diabetics.

How do we involve patients and the public?

The Perinatal, Early Intervention in Psychosis, Physical Health and Severe Mental Illness and Digital Increased Access to Psychological Therapies (IAPT) mental health workstreams all have service users and carers as active members of their clinical reference groups, and PPV partners also attend the Mental Health Transformation Board. There are a further 6 service users engaged with the Digital IAPT programme, both contributing to the steering group and testing and evaluating digital products and pathways to IAPT services. All workstreams link with acute trust engagement leads and related groups to maximise communication and feedback.

We have formal patient representation at our Diabetes Clinical Leadership Group, Type 1 Network and Foot Care Network. We have hosted a series of workshops with both the type 1 and type 2 diabetes populations to understand the outcomes that matter to people with lived experience of diabetes. We also have active representation, participation and engagement of Diabetes UK, Juvenile Diabetes Research Foundation Ltd (JDRF) and several other charities on many collaborative projects.

The cardiac clinical network has PPV partners in their Clinical Leadership group, Cardiac Rehabilitation, Familial Hypercholesterolaemia and Heart Failure working groups as well as some of the sub groups. We aim to have PPV partners on all our working groups by the end of the 2020. They bring a wealth of expertise and experience to the groups and can challenge the clinicians in a constructive way.





London Clinical Networks (continued)

Looking back 2018-19

In August 2018 the Clinical Networks and Healthy London Partnership commissioned the Advocacy Project to recruit, train and link people in London with lived experience of mental health issues (as carers or individuals) to the Adult Mental Health Transformation programmes workstreams. The workstreams include: IAPT, digital IAPT, early intervention in psychosis, Mental Health in Integrated Care Systems, Physical Health and Severe Mental Illness, perinatal mental health, and the London Mental Health Transformation Board.

This year the Mental Health Transformation team has helped the advocacy project create influential links with key partners engaged with all the workstreams.

We have developed an eighteen-month pilot project to increase Patient and Public Voices across our programmes and have recently commissioned a provider to help us deliver the pilot. We are working with the provider to ensure that service users and carers actively influence all our improvement and transformation programmes. So far sixty-three members of the public have expressed an interest in supporting our work, twenty-eight people have applied to join as PPV partners and twenty people have been trained as PPV partners and are linked into our workstreams.

We have a PPV partner on our clinical leadership group which meet quarterly. The PPV partner has worked with the End of Life Care clinical network to devise a leaflet for people who have been bereaved. This leaflet has been distributed to all registrars in London and to all Trusts and Hospices as a resource and has been well received.

Throughout the year we have had PPV representation at our London Clinical Leadership Group. Two PPV partners are members of the group and actively participate in discussions with clinicians and other health care professionals. Throughout the year this group has helped to shape the One London Diabetes Demonstrator Project, Diabetes and Oral Health project, FreeStyle Libre and the continuation of the Transformation Funding Treatment and Care Programmes.

This year we held an event to look at optimising digital opportunities in cardiac rehabilitation. Our PPV partner was part of a panel who agreed which innovators would present their technology at the event. He spoke at the event of over 100 delegates about his experience of cardiac rehabilitation around how technology and innovation can be used as an adjunct to rehabilitation.





In focus

Diabetes: What outcomes matter

The Diabetes Network teamed up with Oxford Centre for Triple Value Healthcare and Diabetes UK and held workshops in December for people living with diabetes in London. With separate sessions for people with type 1 and type 2 diabetes, the workshops aimed to create a better understanding of what outcomes matter to patients and the public. It is intended that the outcomes captured will form part of a London-wide service specification and quality standards for use in local commissioning plans and service contracts.

The objectives of the day were:

- To discuss what we mean by value in healthcare and the different forms value can take.
- To improve understanding of outcomes and how they relate to value.
- Develop a shared understanding of what outcomes matter to people with type 1 and type 2 diabetes.
- To agree how we use this understanding to:
 - » Influence local priorities for improvement in diabetes care.
 - » Work with local partners to develop commissioning, such as service specifications and contracts, for both type 1 and type 2 diabetes populations

Some key outputs from the workshops were:

- A number of citizens expressed an interest in opportunities to support the work of the London Diabetes Clinical Network.
- A group of volunteers were identified who are interested in supporting local diabetes improvement work within individual boroughs.



**In focus**

Co-designing a digital assessment tool for IAPT

Currently IAPT services ask a lot of repetitive questions to determine whether someone is suitable for IAPT and identify the best treatment option or onward referral option. We are co-producing an online tool with questions for service users to complete to simplify the assessment process.

In March service users and carers, East London Foundation Trust and the Mental Health & Integrated Care Systems workstream co-produced a DIALOG service user event attended by thirty service users and twenty-seven healthcare professionals from 8 Trusts. DIALOG+ is an app-based therapeutic intervention. DIALOG+ improves the communication between a health professional and a patient and, through that, outcomes of mental health care. It combines assessment, planning, intervention and evaluation in one procedure.

Co –designing how DIALOG can be used as a patient rated outcome measure is a critical part of ensuring all service users have a meaningful outcome measure supporting their recovery.

This project will:

- Reduce the amount of time clinicians spend on assessments so they have more time to provide face to face treatments.

- Improve the experience for service users by reducing time spent on the phone being asked lots of questions and focus more on having a conversation about what they are wanting help with, goal-setting and treatment planning.
- Quickly identify anyone who is at risk, particularly risk of suicide or self-harm, and immediately signpost them to urgent and emergency services.

The aim of the London DIALOG service user event was to understand:

- How DIALOG can be used as a patient rated outcome measure to support a person's recovery.
- Share ideas between service users and clinical staff.
- Collect feedback to understand how DIALOG implementation can be supported locally.
- Work together to understand how DIALOG can be owned and led by service users.





Looking forward

Mental Health

- There will be further recruitment and training of PPV partners.
- We will be widening the scope of DIALOG event by linking with trust engagement leads to co-create a service user led network for change.
- We will undertake further testing of Digital products (both Apps and Treatments) and further aspects of pathway for IAPT with patients and the public.
- Ensure the sustainability of the perinatal experts by experience group by formalising arrangements with trust engagement leads to embed experts with teams, with training continuing to be available via the workstream.

Diabetes

We will hold follow up workshops for the outcomes that matter to patients, providing an update on how work has progressed and continue to discuss working together to reduce unwarranted variation in outcomes and experiences. The intention is that this work will help shape the development of London Diabetes Standards to support future commissioning to be orientated around meeting the needs and other aspects of care that patients living with diabetes value.



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Transforming maternity care

What we do

We believe that fundamental to improving maternity services in London is listening to – and acting on – the voices of women and their families who use those services. A key way to achieve this is through Maternity Voice Partnerships (MVP), which are teams of women and their families, commissioners and clinicians (midwives and doctors) working together to review and contribute to the development of local maternity care.

The London MVP strategic group is a multidisciplinary group co-chaired by Florence Wilcock, an obstetrician with Kingston Hospital NHS Foundation Trust and the co-founder of the #MatExp social media grassroots movement, and Laura James, a service user advocate, former chair of Bromley MVP and founding member and former acting chair of National Maternity Voices, the national group of MVPs in England. It brings together MVP partners from across all of London, with representation from each Local Maternity System (LMS) or STP area.

The working group of the London Maternity Clinical Network is the PPV reference group to the Maternity Transformation Board. The PPV partners are members of both meetings, ensuring that there is an effective two-way flow of communication at each of these key meetings.

The London MVP Strategic Group works collaboratively with the London Maternity Clinical Network and London Maternity Transformation to ensure that there is PPV partner engagement across all key projects.

The objectives are to ensure:

- That all MVPs across London are equally valued and adequately funded in accordance with the Better Births resource pack.
- That the PPV partner Chairs across London are well networked, providing peer to peer support, mentoring and training where necessary, for example via social media and quarterly meetings of London-based MVP Chairs.
- That every woman in London knows about MVPs and how to feedback her experience or be involved in improving maternity care in her local area.

We especially want to increase the diversity of those involved with and feeding back to MVPs. They use a variety of communication channels, including social media, to connect with women and MVPs. They also liaise closely with National Maternity Voices as well as MVP partners from other regions in England.

How do we involve patients and the public?

The MVP strategic group is committed to helping establish a full quota of MVPs for each trust site in London. Since the strategic group was set up in 2018 the number of MVPs in London has risen from twelve to twenty-one, with three more about to be launched. There are now active MVPs available for each of the London trusts.

The strategic group has input into the My Health London maternity website and helped devise a [map](#) so that all women and families in London can find and contact their local MVP. Women can also use the map to discover maternity services across all of London. The website is accessed by approximately one-third of women giving birth in London.

LMSs are also the maternity component to each STP. The MVP strategic group has worked effectively with them by:

- Ensuring PPV partners from each LMS sits on the strategic group to ensure effective links to each area.
- Running a development day and providing dedicated workshop time to support and strengthen MVPs in each LMS.
- Providing bespoke support and input to local MVPs to provide expertise including, support with the recruitment of Chairs during the establishment of local MVP, support for the running of local MVPs and ongoing support for all PPV partner Chairs for local MVPs.





Transforming maternity care (continued)



Looking back 2018-19

This year we developed a resource for commissioners providing practical support to establishing MVPs called Effective Co-production through local MVPs. This was published in June 2018 and is available [here](#).

The MVP Strategic Working Group are also developing and co-producing a robust communication plan inclusive of external and internal stakeholders whom women want to distribute information to and to share best practice examples of effective co-production.

The second annual development day for London MVPs was held in October 2018. There were over 100 delegates with approximately fifty percent of PPV partners present. It included best practice examples from MVPs across London, updates on using the 15

Steps for Maternity toolkit, a series of interactive seminars on issues including presenting feedback effectively, promoting and publicising an MVP and increasing diversity in an MVP. There was also time for conversations in delegates own LMS.

A summary of the day can be found [here](#). A third development day is planned for October 2019.

Involving Experts by Experience in Maternity Improvement Projects is a [resource](#) that was co-produced to provide guidance and information on the best way of approaching co-production. The resource is for PPV partners and professionals to refer to and use when setting up or reviewing local MVPs or involving women and their families in maternity projects.



**In focus**

Co-producing information about bringing children into sonography appointments at Kingston

Sonographers were concerned about the presence of children in scan rooms as it can be distracting and disruptive. The MVP got feedback from PPV partners and there was a multidisciplinary discussion held at the MVP meeting to elicit all views.

After the meeting a small subset of the MVP members worked together including sonographers, midwives, women and obstetricians to develop a poster which outlines the reasons why bringing children to scans may not always be helpful. Some of the PPV partners who have had problems in pregnancy were very supportive about not bringing children in case the scan is bad news.

Information on Caesarean birth written by service users

There was a lack of detailed information about caesarean birth, both for planned and unplanned caesareans. The Whittington MVP wanted service users to be clear about their birthing options, to know that they can ask questions, to be informed that a caesarean, particularly a planned one, can be personalised and mother-and-baby centred.

They held an initial workshop with obstetricians, midwives, doulas, antenatal educators and users who had experienced a caesarean. It was agreed that a leaflet, written for users, by users, would be useful. Midwives could refer women and their families to the information at antenatal appointments.

Following the initial meeting a group of interested people gathered to meet at a series of workshops to create the leaflets. They were edited by users at every point. Quotes from parents who had experienced caesareans, including a father, were included. The MVP ensured that all medical information was accurate through liaising with midwives. The final version of the leaflet can be found [here](#).





Looking forward

- We will co-produce a development day, with a focus on continuity of care and addressing health inequalities, ensuring alignment to Better Births and the Long-Term Plan.
- We plan to publish guidance for MVPs on how to engage and reach diverse and minority groups.
- We will publish a case study on how to set up and sustain a community bank account for MVPs.
- We will develop a funding map of MVPs across London, to present to the London Maternity Transformation Board to highlight funding issues and encourage appropriate action.



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Healthy London Partnership

Healthy London Partnership



What we do

Healthy London Partnership brings together health and care in London. Our partners include the NHS in London, the Greater London Authority, the Mayor of London, Public Health England, and London Councils. We aim to tackle London-wide challenges to health and care by working together.

We know that to make London a healthier and happier city we need to work with people who live and work in London and with charities, businesses, social enterprises, schools and colleges.

Last year we worked with 1,000s of Londoners and 100s of organisations in all shapes and sizes. We believe that collectively we can make London the healthiest global city in the world by uniting all of London to deliver the ambitions set out in [Better Health for London: Next Steps](#), the national [Five Year Forward View](#) and the [NHS Long Term Plan](#).

How do we involve patients and the public?

Our approach to patient and public engagement aims to complement and support the work that NHS England, CCGs and London's STPs already undertake and builds upon the London Health Commission's engagement achievements and recommendations. This means engaging Londoners through a wide variety of activities including events, surveys, interviews, focus groups and roadshows - taking into consideration the diversity of London's population.

Looking back 2018-19

Through the [London Fast-Track City initiative \(FTCI\)](#), London was the first global city to exceed UNAID [95-95-95](#) ambitions for 2030: The UNAID ambition is that 95% of people living with HIV knowing their HIV status, 95% of those people on treatment; and 95% of those on treatment with suppressed viral loads. London has now

been picked to host the [first international Fast-Track Cities HIV conference](#) in 2019, which gives us the opportunity to showcase all the great work of the HIV community over the past 30 years.

A renewed London vision for health and care began in 2018/19. The process is being co-ordinated by Healthy London Partnership and sponsored by a group of senior health and care leaders. The vision will help us reframe and refocus the priority areas for London. The refreshed vision has seen further engagement with the health and care workforce, Londoners and other agencies and this work will continue into the autumn of 2019.





Healthy London Partnership (continued)

In focus

Thrive LDN's 2018 Are we OK London? campaign engaged with a more diverse audience, grew Thrive LDN's followers and subscribers and increased discussion and action around how inequality and discrimination can affect Londoners' mental health and wellbeing, with a potential reach of over 23 million people. The campaign culminated with a festival of cultural activity organised by young Londoners.

Over 100 Youth Mental Health First Aid (MHFA) England instructors have now been trained as part of the first stage of the **Thrive LDN Youth** MHFA in London Schools programme, in partnership with MHFA England. This has more than doubled the number of Youth MHFA instructors in London. Launched in August 2018, the ground-breaking programme is on course to ensure every state-funded primary, secondary school and further education college in London has access to Youth Mental Health First Aid by 2021.

Supporting Young Carers

Carers are vital to the health of the person they care for and indispensable to the NHS. Every year they save the NHS around £132 billion. An estimated 1 in 12 secondary school pupils are young carers – that means, under 18 and assisting in the care of a relative or friend who is ill, disabled or misuses drugs or alcohol. They care out of love, duty and a necessity borne out of gaps in care services.

In 2018/19 Healthy London Partnership organised engagement activities and workshops with young carers in Islington and Camden to learn more about the biggest challenges they face in a healthcare setting. The clear message from young carers was that they found it difficult to be identified. This meant they were unable to get the care and the support they needed.

Following this, we piloted Young Carer Identification Cards. The cards have helped to remove barriers young carers face. The cards can equip young carers with the knowledge and confidence they need to encourage and empower them to assert their rights.

The pilot scheme was made possible thanks to support from young carers from Family Action's Islington and Camden Young Carers Service and Whittington Hospital staff. The young carers we worked with have bold ambitions for this project for the future.





Looking forward

We will:

- Continue to further engage with Londoners on the priorities and ambitions of the Strategic Partnership Board and London Health Board, for example on the Health Inequalities Strategy, and the vision for making London the healthiest global city.
- Increase Thrive LDN engagement across the city.
- Encourage all children, young people and their families and carers to ask for advice to help them manage their asthma effectively.



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Final thoughts



NHS England (London) is tasked with several different roles from directly commissioning services to ensuring that local health and care plans are designed to meet the need of local communities. We hope that this review has provided a range of examples and a flavour of how we have worked with service users, carers, families and others in carrying out our responsibilities.

We have all been patients at some point in our lives and have different experiences of the care we or our loved ones have received. It is therefore important that together we can shape how that care is planned, organised and delivered.

We know that people share our ambition to continue to improve services in the future. Although we have seen significant changes in the NHS across the capital

this past year, this review demonstrates clearly the continued commitment, energy and enthusiasm of staff and patient and public partners in improving the way we involve Londoners to shape better healthcare. We are firmly committed to continuing to work together with Londoners, across all health settings, to improve services and to demonstrate the difference we can really make together.

The review highlights real examples of how the quality of services and the priorities we set are not just influenced by people but truly shaped by what they want. As the needs of the population change, we will continue to work with communities, groups and individuals to establish how best to meet all new challenges.

Next year's review will focus on further improvements in how we engage and act on what patients and the public are telling us, including work to engage Londoners in the next phase of STPs and Integrated Care Systems (ICSs). We also look forward to working in partnership with NHS Improvement to help transform the NHS in London to ensure Londoners get the high-quality care they deserve, with the overarching goal of making our capital the world's healthiest global city.

We are grateful for all those who have given their time and expertise to help shape our goals and would like to thank all our PPV partners who have worked with us in 2018/19.





Get Involved

For NHS England working in partnership with patients, carers, service users and the public is central to the way that we work.

We hope this review has outlined the range of participation and engagement activity taking place in NHS England (London) and how important it is to everyone who lives or works in our city.

There are always opportunities arising for interested individuals to become more involved and you can find out more at the [Involvement Hub](#). Involvement Hub which helps patients, staff and the public to find out more about participation across NHS England.

You can also find out more about how you can participate by contacting the team directly.



Get in touch

england.LDNqualityhub.nhs.net





NHS England and NHS Improvement

