

### TRANSFORMING LONDON'S HEALTH AND CARE TOGETHER NHS ENGLAND (LONDON) ANNUAL PARTICIPATION AND ENGAGEMENT REVIEW 2017/18

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# Welcome



Oliver Shanley, Regional Chief Nurse, NHS England (London)

#### In the year that we celebrate the 70th anniversary of the NHS, it is fitting that we pay particular attention to the experience of those who use our services.

At some time or other we have all been patients, as have our parents, our siblings, friends and colleagues. This makes the care the NHS provides important to all of us. And it's why it is so vital that you and your loved ones have an opportunity to share your experiences, and to shape how care is planned, organised and delivered.

This 2017-18 Annual Participation and Engagement Review from NHS England (London) shows how we are working with you and London's communities to make the NHS better for patients and the public. It demonstrates good practice, and identifies challenges and how we are working to improve.

Patients are at the heart of everything that we do, which is why we are committed to continuing to engage communities and patients in decisions about the future of health and care services. I hope that this review demonstrates our commitment, and shows the positive impact this year's work has been able to achieve.

I would like to pay special thanks to all the Londoners who worked with us this year; your ideas and support are very valued. I would also like to thank all the patient and public representatives who have worked with us in 2017-18.

Thank you, Oliver



Leadership

**NHS**70

### **Reflections of London's Health**

London is a diverse, vibrant and a relatively healthy place, but as the NHS celebrates its 70th birthday this year, we face some challenges. A growing and aging population mean that pressures on healthcare services are greater than they have ever been. Children and young people in London suffer from poorer health outcomes than elsewhere in the country and the rising numbers of older people in the capital are the biggest users of healthcare services.

#### **Health inequalities**

All Londoners deserve a fair opportunity to live a long healthy life but the reality is that London also has the widest health inequalities in England.

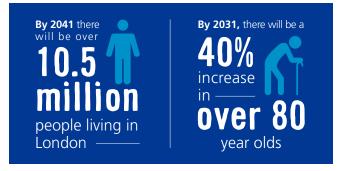
- London boroughs with high smoking prevalence are also some of the most deprived, and differences in tobacco use account for around 50% of the health inequalities found between social groups in London<sup>1</sup>
- Hospital admission rates for alcohol related conditions in Islington is double that in Kingston Upon Thames<sup>1</sup>
- Women in Tower Hamlets, can expect to spend 37 per cent of their lives in poor health – that's equivalent to 30 years<sup>2</sup>
- Babies born in Kensington and Chelsea are half as likely to have a low birth weight as those born in Redbridge.<sup>3</sup>



#### The Health Challenges

#### Adults

- London has the highest demand for **mental health** services of the whole country and a million Londoners will experience mental ill health this year. Mental illness remains underdiagnosed and undertreated, with a quarter of people with mental illness receiving treatment compared to 92% of people with conditions such as diabetes and heart disease (75%)<sup>4</sup>
- Each year more than 30,000 Londoners will receive a cancer diagnosis and the number of people living with and beyond cancer is expected to double by 2030<sup>5</sup>
- Over the course of a year some 8,000 people sleep rough in the capital. **Homelessness** may be a consequence of health problems, and often a cause of worsening health. Homeless people are more likely to die young, with an average age of death of 47 for men and even lower for homeless women at 43<sup>6</sup>
- There are still 1.2 million smokers in London with 8,400 deaths and 51,000 hospital admissions a year attributable to smoking.<sup>7</sup>



#### Young people and children

- London has a major childhood **obesity** problem. The proportion of 10 to 11 year-olds who are an unhealthy weight in London (38.5%) is higher than the proportion in England (34.2%). (7 source; Childhood obesity: a plan for action, 20 January 2017 update, department of health and social care)
- Nearly 10% of children and young people living in the capital aged between 5 and 16 experience some form of **mental ill health**<sup>1</sup>
- Poor air quality in London is more concentrated around schools. Asthma is the most common longterm medical condition affecting children and young people and 1 in 10 are affected by the condition.<sup>8</sup>

Sources: 1. Better Health For All Londoners CONSULTATION ON THE LONDON HEALTH INEQUALITIES STRATEGY August 2017 2. Public Health England, Public Health Outcomes Framework, Life Expectancy at birth indicator 0.1ii and Healthy Life Expectancy at birth indicator 0.1ii, 2013-15 3. Public Health England, Public Health Profiles – Fingertips online data tool, fingertips.phe.org.uk 4. Heathy London Partnerships - Annual report, Transforming Mental Health in London 2017/18 5. NHSE Five year Cancer commissioning Strategy for London April 2014 6. www.healthylondon.org/our-work/homeless-health 7. www.healthylondon.org/our-work/prevention 8. www.healthylondon.org/our-work/children-young-people/asthma

Leadership



### What we do

We lead the National Health Service (NHS) in England and our aim is to improve health and ensure high quality healthcare for all, now and for future generations. We want everyone to have greater control of their health and wellbeing, and to be supported to live longer, healthier lives by care services that are compassionate, inclusive and constantly learning and improving.

#### The NHS Five Year Forward View (2014)

The **NHS Five Year Forward View (2014)** and Next steps on the **NHS Five year Forward View (2017)** set out how we will achieve this and review progress made to deliver a more joined-up and responsive NHS.



#### Our main functions:

**Commissioning:** this is the process of planning, purchasing 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 the commissioning system: assuring and supporting local commissioners to deliver improved health outcomes and that they uphold constitutional commitments.

**National policy and strategy:** ensuring the NHS is sustainable and identifying priorities for change and improvement. Public engagement for national policy is done nationally.

**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.

#### NHS England (London)

Distribute more than **£18 billion on health and care services** including over **140 specialised services.** We work together with the following organisations:



In 2018/19, NHS England will be working 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 has commenced soon to align our leadership and collective resources around a shared set of priorities that will add the most value to the NHS.

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# Placing patients at the heart of what we do

The NHS Five Year Forward View (2014) and Next steps on the NHS Five year Forward View (2017) describes a new relationship between the NHS, patients and the public, including a commitment to engage communities and citizens in decisions about the future of health.

In addition, under section 13Q of the National Health Service Act 2006 (as amended in 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.

NHS England (London) has produced an annual participation and engagement review for the past

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I've found the London engagement network a great forum for learning, sharing and networking. It's been useful to hear from other areas through case studies.

The network offers valuable time with professionals, who offer inspiration and support. As a newcomer, I've felt welcomed and supported by the NHS England London team, and the network members

**Pam Froggatt - Greenwich CCG** Communications engagement Lead four years. This year's review highlights how we have involved patients and the public in our work in 2017-18. As in previous years, we commissioned an independent body (Insight to Impact Consulting Ltd) to recruit and train a group of Londoners to scrutinise our public involvement 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. London Patient Voice found areas of progress and a strengthening of engagement across the region. Their **report** included a number of recommendations on how we can strengthen and support engagement which we are working to implement.





#### In 2017/18 our regional work focussed on:

- Working with our national and regional colleagues to introduce a new participation indicator for CCGs in the Improvement and Assessment Framework
- Strengthening processes to ensure that NHS England (London) can evidence compliance with our legal engagement duties
- Expanding participation training for both NHS England and CCGs staff and for Patient Public Voice partners to help improve the quality and extent of engagement
- Developing the London Engagement Leads network to offer improvement, collective learning and peer support for engagement professionals in London
- Developing a Voluntary Sector Carers Grants Scheme, awarding funding for projects across London to support health and wellbeing of unpaid carers. In line with the Next Steps on the NHS Five Year Forward View, this scheme aimed to empower carers to make healthy choices, improve quality of life and reduce health inequalities.



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The London Engagement Leads network provides an invaluable forum for sharing learning and good practice around engagement. It is also provides a useful forum for presentations and discussions with others - and the IAF Patient and Community Engagement Indicator discussions over the last year have been particularly useful. The network is well led and supported by the Patient and Public Experience and Participation team whose members are very responsive

**Rosemary Watts – Southwark CCG** Head of Membership, Engagement and Equalities and London Engagement Network member

In 2018/19 we will continue to work with London's CCGs to improve further their ratings in the new participation indicator. We will continue to enhance regional engagement skills through staff development, including by introducing training sessions led by PPV partners. We also look forward to contributing to national Advisory Groups overseeing development of NHS Citizen, assurance of NHS England's duties under s13Q of the Health and Social Care Act, and assurance of CCGs' duties under s14Z of the Act.

Leadership

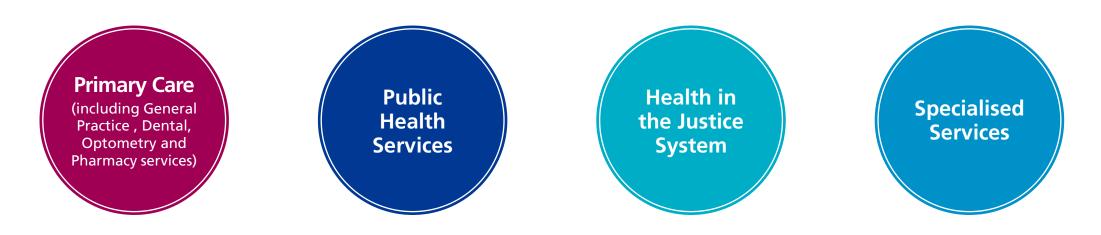
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# **Involving patients: Commissioning**

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

In practice, it involves a range of activities, including the health needs assessment of a population, the clinicallybased design of patient pathways, service specifications, contract negotiation and procurement, and continuous quality assessment. NHS England directly commissions a range of services. We work collaboratively with local commissioners to design these services so that they meet the needs of communities, improve health outcomes and meet our NHS Constitution commitments.

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.



Leadershi

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# How patients and the public contribute to primary care

#### What we do

Primary care includes the care provided by GPs, community pharmacies, optometrists, dental practices, and community and specialist dental services. In London, NHS England has now delegated commissioning responsibilities to all 32 CCGs, although for much of 2017/18 only 30 had the full responsibilities. This gives CCG's greater responsibility for deciding and managing local GP services, although NHS England still holds the contracts.

#### How do we involve patients and the public?

For **GP services** in CCGs where we had not yet delegated responsibilities, we engaged with patients, local groups and other stakeholders about the options on how services will be delivered in the future - for example, when a GP contract comes to an end. This can include letters to all registered patients, public meetings, drop-in sessions and online surveys. We also engage with patients on the specifications for new practices. We continue to involve patients who have been trained in bid assessment skills to contribute to the procurement of services. Key performance indicators for GPs have been set against areas that patients have told us are important to them. For GP services in CCGs with delegated responsibilities further work in 18/19 is taking place nationally through an Internal Audit Framework for delegated CCGs.

#### For Dental, Optometry and Pharmacy services

**(DOPs)** patient engagement is undertaken through the Patient Leadership Board. The Board was originally known as the Patient Advisory Board, however with its expansion, it was renamed in March 2017. It is cochaired by two Public Health England consultants and membership of the Board consists of appointed lay members alongside staff and other co-opted members. We encourage participation from board members in a variety of ways including correspondence, small group meetings, working groups, surveys and personal attendance at board meetings.

#### Looking back at 17/18 commitments

From 17/18 we commenced the procurement for London Region provision of orthodontics, restorative treatment (endodontics), new dental practices and sedation. These are all in progress and have dedicated Patient Leadership Board (PLB) members who represent the patient voice.

We include Board members as representatives on commissioning panels from the onset. Several members attended engagement events where they had the opportunity to meet stakeholders. They raised key questions following presentations by the commissioning team and others such as dental advisors, public health and procurement colleagues. Our Board members are now being supported through the invitation to tender (ITT) stage whereby bids are being scored and evaluated and bidders are making their presentations.

As part of our ongoing commitment to involve patient representatives in procurement, in April and May 2018 we held dental communications events across three separate evenings in London venues for contractors and their staff. We had PLB members present at each event. This provided the opportunity to acknowledge and share information about the important work that had been undertaken.

We have a large programme of delivery for orthodontics and have a dedicated patient representative on the Communications and Procurement work streams. Both members have been actively involved and have been sharing the progress of this work with fellow Board members this year.

The procurement of Intermediate Minor Oral Surgery (IMOS) across London meant a decommissioning of sites and longstanding providers who had been delivering the service for many years. These services were commissioned Primary Care Trusts (pre-2013) and subject to varying degrees of arrangements and bespoke agreements. In 2013 when NHS England was established, a new process was introduced to standardise provision, accessibility and monitoring. IMOS procurement saw active involvement of PLB members in Board briefings, developing questionnaires and updates. The new provision went live on 1 July 2018.



#### **Procurement of orthodontic services**

Primary care orthodontics is by far the largest procurement that the Commissioning team is undertaking and has required a high quality delivery programme with all stakeholders, from patients and their carers to hospital consultants.

To maximise patient engagement across all levels, a PLB member was engaged in the survey setting and advertisements for questionnaires that went to service users and clinical leads. As the procurement process has been so vital, we have engaged a further PLB member in meetings, on-going correspondence and the forthcoming Invitation To Tender stage which will include evaluation and scoring as well as attendance at presentations.

#### **Dentistry sedation**

The London Region is committed to reviewing its provision of sedation. The review has started with a patient safety audit to identify any concerns or issues. The audit might give rise to a procurement and or change of service and we have submitted a public involvement assessment form (S13Q duty) in anticipation of the need for engagement to inform decisions. We have engaged a PLB member who has a learning disability and we are supporting his engagement by meeting with him in person, supplying easy-read documents and briefing him ahead. The natural pace of this review happens to match the capacity of the PLB member and we will be putting in place mechanisms to enable that engagement. The PLB member also represents one of the core groups of patients who would access sedation.





#### Looking forward – 2018/19

- Restorative dentistry procurement is underway and we have offered training and support to the PLB member in readiness for scoring and evaluation of bids.
- We will strengthen the existing Patient Leadership Board and plan recruitment of new members
- We will hold Patient Leadership Board & contractor meetings
- We will strengthen Dentistry, Optometry and Pharmacy patient involvement at STP and CCG levels
- We have started to put in place the recommendations on the areas for development identified in the London Patient Voice's scrutiny report. This includes different ways of enabling PLB engagement. Specifically we are focusing on the following recommendations:
  - » consider ways of reducing the burden on PPV partners, including the use of sub-groups for the three areas under its remit. We have reduced the physical board meetings from six annual meetings to four quarterly meetings
  - » consider ways in which PPV partners can be engaged more fully throughout commissioning cycle. We presently have 3 procurements in progress all of which have involved PPV partners from the outset

- » consider supporting one of the Patient Leadership Group to sit on the senior board, to address lack of strategic connection
- » provide clear feedback with specific examples to PPV partners to assure them of how their input has made a difference in the commissioning of DOP services. We have a working document which catalogues PPV partner involvement as DOP board members and the impact. We aim to improve this.

#### $\overline{\langle}$ Team contact details

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Supporting Commissioners

Leadership

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Public health is about keeping people healthy and protecting them from threats to their health. The Public Health team at NHS England (London) works 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, antenatal and newborn screening, and health in the justice system. We also run the London Armed Forces Network to offer a space for ex-forces staff and their families to meet, support each other's health, and help shape healthcare services.

#### Early years and immunisation

#### 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 in immunisation?

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 their input to make improvements to the experiences of vaccinations.

We also 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, vaccine hesitancy and on how to improve uptake.

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

We also 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 where improvements can be made. Examples from 2017-18 include surveys for the Newborn Hearing Screening service at St George's Hospital, and the new Neonatal BCG service at Epsom & St Helier Hospitals.

#### Looking back in 2017/18

- We continue to review the role of patient and public representatives on the Immunisation Board, to make the best use of their involvement
- We used findings from an online survey to improve the uptake at community pharmacies of the seasonal influenza vaccine for at risk groups
- We completed research in the service barriers for uptake of Human papillomavirus (HPV) and meningococcal bacteria that cause meningitis and blood poisoning (septicaemia): A, C, W and Y (Men ACWY) vaccines which we are feeding into our commissioning of services.





#### Improving the eRedbook for parents

The 'red book' is the 'Personal Child Health Record', a book given to parents shortly before or after the birth of their child to which both health professionals and parents contribute information on the development of and care given to the child. NHS England sponsored a digital version, the eRedbook, and London was an early adaptor, with work to grow its use in 2017-18.

#### The eRedbook provides:

- a copy of a child's clinical health records
- reminders for screening, health reviews and immunisations
- space for parents to enter notes and photos
- tailored information based on the due date and child's age.

Mothers can use the eRedbook as a personal record of their pregnancy and their child's development, and to access their child's clinical health records.

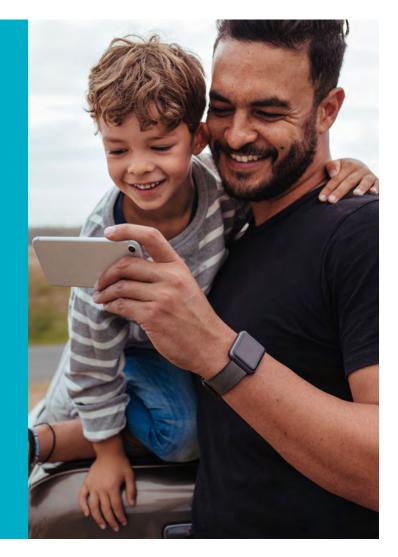
We commissioned feedback from parents, midwives and health visitors on how the eRedbook could be improved to increase uptake in London. This identified that that eRedbook needed to be



more useful and attractive to expectant parents, for example by providing information from NHS Choices about pregnancy. Feedback also suggested improvements to the design so it was more appealing to use. Following feedback

the interface was redesigned and more information was aimed at parents.

The eRedbook provider will be conducting regular focus groups with mothers to identify any issues which can then be rectified. There will also be regular focus groups and forums with health professionals to address any concerns they have so they can fully support the roll out of the eRedbook.





#### Down Syndrome Antenatal Screening test



We are conducting ongoing engagement with parents of Down Syndrome children on how to support informed consent for antenatal test and after the decision has been made. The aim is to understand how the test process and its implications can best be explained to parents, and what support and information is needed when the test results are received. In June 2018 Lewisham and Greenwich NHS Trust ran a 'Whose Shoes' Maternity Experience workshop with parents and staff. It identified improvements to maternity services support for parents having decided to progress with a pregnancy with Downs Syndrome. These included the quality of information and availability of positive support resources. See here for more information on the workshop **youtu.be/JJ7jU9z2k-o** 







#### Looking forward 2018/19

We will continue to engage patients and the public in their own healthcare needs, service design and delivery (e.g. self-administration). This includes:

- Use findings from our research into the service barriers for uptake of vaccines for human papilloma virus (HPV) and meningitis (MenACWY) to inform the commissioning of services
- Research the service barriers to Shingles vaccine uptake in GP practices
- Create the parent role of London Immunisation Champions to promote uptake among underserved communities.





Team contact details

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## Screening

#### What we do

#### The Screening commissioning team offers:

- Antenatal and newborn (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
- We aim to ensure each programme meets the needs of those who require it. Engaging patients and their representatives in commissioning these services is essential to achieving this aim.

#### How do we involve patients and the public?

We have patient representatives on the commissioning and programme boards that oversee our work. They work with us to review coverage of screening across London, identify ways to improve uptake, and develop new service models.

Patient representatives also work with us to review procurements, where they worked with us to develop questions for the bidders and evaluate bids. A major piece of work was the re-procurement of the AAA screening programmes where we have strengthened how patients and the public are involved.

#### Looking back in 2017/18

- We engaged patients in the procurement of Primary HPV testing as part of the cervical screening programme
- We have continued the recruitment of patient representatives to cervical screening and diabetic eye screening boards
- We have improved access to cancer screening for people with a mental health diagnosis, including those in secure forensic units. We have also improve access to diabetic eye screening, abdominal aortic aneurysm screening and bowel cancer screening for people in prisons
- We developed a report template to ensure consistent reporting of patient feedback for all cancer screening programmes
- We developed a patient engagement strategy to support the commissioning of high quality, adult screening programmes in London.

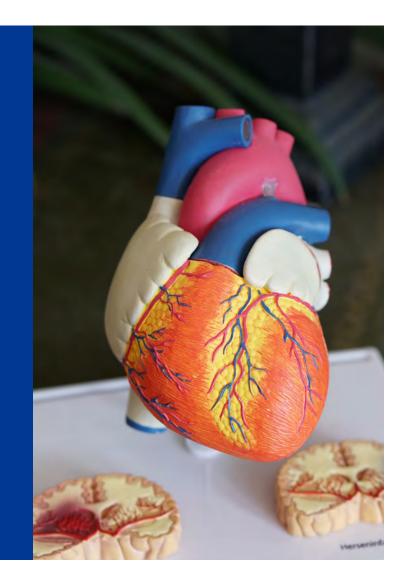




#### London Abdominal Aortic Aneurysm Screening Programme (AAASP)

- We recruited six patient representatives from the London AAA Screening Programmes to attend the steering group. They worked with us to develop the proposed London AAASP service model. As active members of the Steering Group the patient representatives were supported where necessary to review relevant documents, to attend meetings and give their views. Three representatives took part in the evaluation, moderation and scoring of tender bids
- To understand the impact of service model changes and identify areas for improvement, we conducted a patient survey of men who had been screened. The report from this survey has now been shared with all current London AAASPs and all potential providers tendering for the new service are required to reflect the findings in their service plans
- We have also included patient experience as an additional reporting requirement for potential new AAASP providers. This means that:

- Each provider must develop an AAA patient experience plan demonstrating how the service will implement measures to improve the quality of patient experience for people who use the service
- » Service user feedback will be measured on a par with all other quality standards and providers will need to evidence patient involvement in the development of service improvement plans
- » Workforce training and assessment must reflect the patient experience quality themes and providers' plans must demonstrate how feedback from staff is incorporated in to service improvement plans
- » Commissioners are working providers to develop and implement the Making Every Contact Counts approach. New providers will be expected to support patients access self-referral pathways to healthier lifestyle providers in order to support risk reduction of AAA.





#### Looking forward – 2018/19

- We will continue to Involve patients in the next round of AAA procurement in South London
- Develop/implement a strategy for supporting people with protected characteristics to attend screening
- Review patient involvement in ANNB programme boards as they move to STP level.





Leadership

# Health in the justice system

#### What we do

#### We commission healthcare in London's justice system, including:

- prison and youth offender institutions
- immigration and removal centres and initial accommodation for homeless asylum seekers
- mental health liaison and diversion services, and
- sexual assault referral centres.

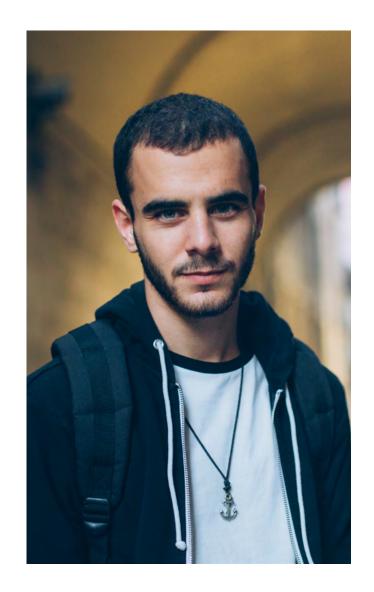
We aim to improve access to health support for those affected by crime. We also aim to improve access for those in contact with the justice system and to help reduce re-offending and promote recovery by positively engaging them in health.

#### How do we involve patients and the public?

We continue to work with Inspirit Training and Development Consultancy. Inspirit supports people with experience of the criminal justice system to work alongside us when we commission and assure services. This is through a Participation sub-group of service users, and through 'Commissioning Technicians' who have been fully trained in involvement, commissioning processes, consensus decision-making and assurance work.

#### Looking back in 2017/18

- Participation sub-group training in group facilitation to support members to deliver patient forums within institutions
- We included the views of service users in the transition of London prisons to smoke-free
- We used service users to help re-model the SARC (Sexual Assault Referral Centres) provision in London
- Commissioning of Child House services for children and young people who have experienced child sexual abuse.







#### **Procurement of the Child House pilot**

In the procurement of a pilot Child House in North Central London we worked closely with survivors and their carers to design and commission the new service.

We worked with survivors of childhood sexual assault to inform our service specification with support from Inspirit. Survivors were able to feed into the development of the service specification and ITT evaluation process. A panel of young people were also convened to help design the interview stage of the evaluation process through developing case scenarios, questions for bidders in response to these, and drawing up scoring criteria.

Subsequently, three adult survivors and carers of child survivors of childhood sexual abuse were involved in marking the substantive majority of the written tender submissions by bidders – including key sections on the service model. At interview stage providers were then interviewed by two panels. One consisted of commissioners, clinicians and the adult survivors or carers of child survivors; and the second consisted of a young persons' panel.

Following the tender the provider has continued to engage with local young people in the design of the service – including physical design of the facilities and formal name of the service. In the most recent exercise to choose the name of the service – The Lighthouse – over 300 young people were consulted in developing this name.





#### Looking forward 2018/19

- We have a strategic objective for 2018-19 to strengthen the voice and involvement of those with lived experience of the services we commission. This includes:
  - The Participation sub-group to support the procurement and on-going commissioning of services in London, including for Brixton and Wandsworth prisons
  - » Build a training model to ensure that children and young people can fully participate in the procurement and commissioning of services
  - » Work 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.



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Leadership

### **Specialised services**

#### What we do

Specialised services are those provided in relatively few hospitals and are located in trusts where there is appropriate expertise to look after patients with complex or rare health conditions. NHS England (London) commissions these for eligible patients, including London residents and patients referred from across the country to London trusts.

#### How do we involve patients and the public?

Our national Specialised Commissioning team is responsible for strategies for patient and public participation, leading on behalf of England's four regions and undertaking the recruitment of patient and public representatives. However some local and smaller scale initiatives are carried out regionally.

In London we use a range of methods to engage patients and the public, including one-to-one meetings, focus groups and wider public consultations. A patient representative sits on a monthly quality review meeting between ourselves and St Bartholomew's Hospital, which provides mainly specialised services. In our engagement initiatives, we work in partnership with a number of organisations such as Clinical Commissioning Groups, Public Health England, local Healthwatch and Strategic Transformation partnerships (STPs). We also ensure that providers' contracts and some of the national service specifications include requirements to engage with patients and the public. Their compliance and progress against this standard is monitored in contract and quality meetings with providers.

#### Looking back in 2017/18

We continue to ensure participation and engagement is embedded in our work but recognise it needs to be developed further.

Our work on service transformation in the different parts of London is progressing, building on the work reported last year on the South London Renal and Cardiac services and with the London Neonatal Operational Network. The South London Programme has strong patient and public representation and participation; there is evidence that this works well and the representatives have made valuable contributions. We ran Renal and Cardiac patient workshops which helped to shape the programme's key priorities.

We commissioned Young Minds for input into our new service design for additional Children and Adolescent Mental Health (CAMHS) beds. Case and Treatment Reviews (CTRs) now include a panel made up by an NHS England representative, a clinical expert/provider (independent of NHS England) and an "expert by experience" - a lay person – whose input helps to shape the care provided. Our five HIV networks covering the London STP footprints all now have local patient representatives. The London HIV Forum meets quarterly and includes five patient representatives, Local Authority representation and Patient Advocate Groups working together with clinical leads, pharmacists and commissioners. Joint collaborative work includes the Anti Retroviral (ARV) prescribing toolkit and the development of patient information leaflets.

Each of the Haemoglobinopathies Networks has local patient representatives. The London Haemoglobinopathies Forum has three patients representatives including two from the Sickle Cell Society and one from the UK Thalassemia society.

In March 2018 we reinvigorated the Regional Specialised Bleeding Disorders Forum for which patient representation is provided by the Haemophilia Society.



#### **Child and Adolescent Mental Health Services** (CAMHS):

The number and locations of specialised beds (Tier 4) in London was recognised as being inadequate, for example, there are no Learning Disability CAMHS beds and insufficient Adolescent beds in London to meet demands. NHSE (London) commissioned Young Minds to carry out engagement with young people and their parents/ carers for input into new service design. The recommendations from the report have been used to inform staff training for new service providers. All CAMHS units will now have a Service Users Forum.

We also undertook a procurement of Forensic CAMHS services, and a service user was on the panel to help contribute to the decision making process around procurement. The service user played a key role in this initiative, working in partnership with NHS staff.







#### Looking forward

- We will work closely with our key providers when they undertake changes to services to ensure there is effective patient public participation
- Our South London Programme will work with the Operational Delivery Networks (ODNs) to strengthen their patient involvement
- As part of our ongoing commissioning of CAMH's beds, we will ensure patients/public voice is heard and acted on as appropriate
- The HIV Newfill service review will be informed by patient representatives, with recommendations expected in the autumn
- The Effective Use of Immunoglobulins project has a patient representative who is presenting at a conference and supporting the development of patient leaflets
- A new clinical strategy will be launched for HIV and Hepatitis C strategies and we aim 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 will work in partnership with the Mayor's Office, NHS Blood and Transfusion service and the Anthony Nolan charity through large engagement events. These will also focus on

reducing the inequality for Black and Asian Minority Ethnic patients with limited or no matched donors

- We will be standardising the Patient Reported Experience Measure across London for patients with Sickle Cell, to support service improvement and pathway changes
- We will be working with the Thalassemia UK and clinical leads to design and pilot a standardised Patient Reported Experience Measure for this group of patients
- As part of the Bone Marrow Transplant National role, we will be supporting the piloting of new bone marrow transplant patient experience indicators across several London centres.

#### $\triangleleft$ Team contact details

vinicethomas@nhs.net Vinice Thomas, Director of Nursing and Quality Specialised Commissioning.







#### 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 in London.

The team has a leading role in assessing the quality of the services commissioned by NHS England and Clinical Commissioning Groups. 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

- **Safeguarding:** making sure children and adults at risk 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: enabling more people to live in the community with the right support, close to home
- Continuing Healthcare (CHC): ensuring commissioners in London have effective processes in place to assess eligibility for CHC and to commission good quality care packages; and managing independent reviews

- 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 public are able to participate in decisions about healthcare in London.

The Patient and Public Voice team within the Nursing directorate leads on strategy and governance for participation in NHS England (London). The team supports commissioners to involve patients, their carers and the public in regional and national programmes and in the governance of our work. We provide leadership and support to colleagues within the regional team and across all 32 London CCGs. We do this through the London Engagement Leads Network (for NHS England and CCG colleagues) and the Patient and Public Voice Accountability Group (NHS England only).



#### How do we involve patients and the public?

- The Patient and Public Voice Team produces this annual review and commissions London Patient Voice, an independent panel of Londoners, to scrutinise the quality of engagement work being done by NHS England in London. The team commissions and supports training for staff and members of the public involved in engagement activities. We have for several years run a regional assurance process reviewing all 32 CCGs' delivery of their engagement duties, and in 2017/18 were closely involved in developing and delivering the first national assurance process. The team also co-ordinates the oversight of NHS England's duty to involve the public in our directly commissioned services
- The London Transforming Care Board includes an individual with a learning disability to provide feedback to the board on progress and plans for Transforming Care both across London and individual Transforming Care Partnerships. This individual is the chair for the London Regional Forum for People with Learning Disabilities
- The Learning Disability Mortality Review (LeDeR) Programme team is responsible for ensuring that all deaths of patients with Learning Disabilities are reviewed and that health and social care services implement service improvements in response to the learning from completed reviews. Each review

involves engaging with the family of the person that has died, to gather their perspective on the care and treatment that their family member received. The pan London LeDeR steering group includes an individual with a Learning Disability and the LeDeR programme team consults regularly with self-advocates with Learning Disabilities from across London, to ensure that the voice of people with Learning Disabilities remains central to the work

- Care and Treatment Reviews (CTRs) are held for all patients who meet the criteria for Transforming Care. 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. In addition at least one expert by experience also attends to provide a non-clinical view. The London team recruit and co-ordinate a pool of experts by experience to support commissioners at each review
- We recruit lay chairs to manage Continuing Healthcare Independent Reviews. We consider challenges from families to decisions made by CCG's 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 five lay chairs. Patients, families and representatives are supported to be involved. An

online survey tool developed to help assess whether CHC services in CCGs provide a good experience continues to be available

- The Independent Investigation Review Group, which makes decisions about commissioning investigations following mental health homicides, has a member representing victims' families
- The Safeguarding team has involved patients and public in a number of projects in the last year, around female genital mutilation (FGM), Child Houses, complaints and PREVENT, set out in more detail below. NHS England is also a member of the Honour Based Abuse (HBA) Group led by the Metropolitan Police. This group includes members from community and support groups representing the public. The group enables sharing of ideas and planning to work collaboratively to tackle HBA.



#### Looking back in 2017/18

- The Patient and Public Voice team has worked in 17/18 to enhance regional patient and public engagement in five main areas:
  - » We have worked with our NHSE commissioners to continue to evidence compliance with statutory duties in relation to participation and engagement of the public (Statutory Duty S13Q), leading on quarterly reporting to national oversight groups for Primary Care, Public Health and Health in Justice
  - We have developed partnership working across London inside and outside of the emerging STPs. For example we were closely involved in the planning and delivery of a national event for CCG Lay Members and Trust Non-Executive Directors that focused on engagement in STPs, held at the Kia Oval in London in October 2017. We have participated in biweekly communications and engagement calls for the five STPs led by the Regional Director of Communications. We worked with Healthwatch England to encourage local Healthwatch to attend Quality Surveillance Groups
  - » London Patient Voice was reprocured in November 2017 to carry out an independent assessment of NHS England (London Region)'s public and patient engagement in 2016/17 and 2017/18. Its **report for 2016/17** was published in July 2018 and the recommendations have helped to shape this review



- » We have developed and delivered training for PPV partners and staff
- » We ran a regional Voluntary Sector Carers Grants Scheme, awarding funding for projects in six boroughs - Brent, Croydon, Barnet, Enfield, Westminster (Central London CCG) and Wandsworth. The scheme aimed to support health and wellbeing of carers, empower carers to make healthy choices, and reduce health inequalities. An example is set out below
- During 2017/18 the Female Genital Mutilation (FGM) programme involved the public in developing commissioning guidance for services aimed at women and girls who have been abused through FGM. This worked through the engagement

of service users and communities at an event in April 2017. The national programme has also hosted formal patient group meetings

• This year we have continued to support the development of the Child Sexual Abuse Hubs and Child House in London. The multi-agency project has gained feedback from young people using the services and their families. The involvement of children and young people in informing the development of the Child House and Child Sexual Abuse Hubs has been a core part of the project, led by the providers of the services and the steering groups in the five STPs. A significant result of this has been to highlight the need for sustained emotional support for the young people.



### Developing and strengthen regional engagement and participation capabilities through training and development

Building on the successful regional programme developed and delivered in 2016/17, in which 240 PPV partners were trained face to face and further 70 online, we worked with the national Participation team to deliver 6 one day sessions of the '10 steps to even better public engagement' course aimed at commissioners and commissioning support staff across London, and to deliver a two-day training event for PPV partners in March 2018.

The '10 Steps' training was attended by 48 people and covered: core principles and benefits of engagement; legal obligations and duties; good practice and practical tips. Participants worked in small groups to apply the training to a real project. 95% of attendees said they acquired new knowledge or skills and the programme consistently received positive comments.

The PPV partners training in March was delivered by Just Ideas and WSA Community Consultants. It attracted 21 participants, 95% of whom said that they would be more effective in their PPV role as a result of the training. One participant reported:

I found the training useful and learnt a lot about the role of patient and public voice members. It showed how we can influence future planning of NHS through various bodies we belong. I liked the role play which I found is a good way to find my strengths and weaknesses.

The London event was the first of a number to be run across the country and we have been working with a group of partners to review feedback from the course and adapt it for future participants.







#### **Participants said:**

I've been doing PPV and stakeholder engagement over the years but never had any training on it so it was really helpful to have the 10 Steps and all the guidance available, helpline and support that can be available from NHS England PPV teams

The examples of different methods of engagement was great and group project was very useful

Very informative course, knowledgeable and incredibly helpful facilitators. Relaxed nature of the course was really beneficial. Thank you!



#### PREVENT

#### The PREVENT agenda is a key priority for NHSE in relation to its safeguarding responsibilities.

The team work with CCGs and providers to ensure staff are trained to recognise risks of radicalisation and to respond appropriately to safeguard the public. This can sometimes seem somewhat different to the mainstream safeguarding work and can also be viewed as something that is difficult for health professionals to see as part of their caring roles.

The NHSE team work with partners to improve the understanding. This was strongly illustrated when the mother of a man who was radicalised spoke at a safeguarding conference. She told health professionals about her son's journey to radicalisation and how he joined a terrorist group but was later killed whilst fighting for them.

This mother described how there can be little support for families when their loved ones are involved in terrorism. She aims to speak to more front line professionals about how important it is to refer and seek support when it comes to radicalisation. The team have used this story to show the importance of real life case studies and credible speakers cannot be underestimated in reinforcing the message that PREVENT is about safeguarding and early intervention. It also demonstrates that there are people in the community who understand the pain and the trauma of extremism and can support others who may be suffering similar experiences.







#### **Voluntary Sector Grants Scheme for unpaid Carers**

Funding via the national team was made available by the London regional PPV team to fund small grants scheme some of which was used in Enfield to the develop the Dual Diagnosis (Psychosis & Drug/Alcohol Abuse) training programme for carers of people living with dual diagnosis issues including mental health. The work was commissioned from the Association of Psychological Therapies, and jointly funded with the Carers Centre.

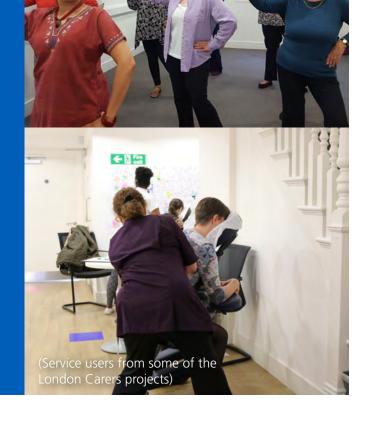
#### The impact has included:

- Ten carers completed the training as at June 2018
- Development of a comprehensive Carers Handbook
- Work being done with local mental health teams for similar courses to take place, and the development of an online course and resource.

#### **One participant reported;**

So many things have been useful – we learnt how to motivate our loved ones to make a life change so they live a life they wish to have. We learnt not to make the drug or alcohol use the problem but how to help them have a life with the drug or alcohol intake – as many people in society do

(Mrs S)





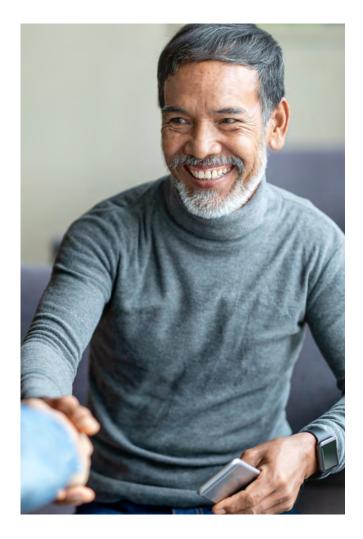
#### Looking forward 2018/19

- We are running further 10 steps training and PPV partner training in autumn 2018. Some of the staff training will be led by PPV partners and we are also developing sessions aimed at specific teams, including Specialised Commissioning. We will also develop with the national training lead a series of webinars for staff including how to support PPV partners
- We look forward to contributing to national Advisory Groups overseeing the further development of NHS Citizen, assurance of NHS England's duties under s13Q of the Health and Social Care Act and assurance of CCGs duties under s14Z of the Act
- We will lead improvements in public and patient engagement prompted by the London Patient Voice report and national assurance of CCGs, including through existing mechanisms such as the PPV Accountability Group and London Engagement Leads Network
- We will support the development and sustainability of safeguarding leadership across the five London STPs. This will include working with the Designated Professional Networks to ensure that the voice of children and families are included in the planning of services across STPs

- We will ensure that the NHS in London is able to implement the safeguarding children reforms in conjunction with the Metropolitan Police and the 32 London Councils. We will monitor the level of engagement of the public in the development of the safeguarding partnerships through the CCGs
- We will engage with the London Mental Capacity Act (MCA) Network to disseminate information and prepare to respond to the reforms to Deprivation of Liberty (DoLs) safeguards – the Liberty Protection Safeguards (LPS). We will ask the MCA Network to involve feedback from families when planning the implementation of the reforms
- There will be work with the Mayor's Office for Policing and Crime (MOPAC) to develop and implement a strategy to reduce the impact of gang violence and knife crime amongst children and young people. This will involve hearing from survivors and families of those who have died to shape plans for addressing knife crime.



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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.

All of our work is carried out in partnership with our Patient and Public Voice (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 quarterly 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.

#### Topics in 2017/18 included:

- Enhancing health in care homes leading a whole system approach
- Accessing specialist advice in a transforming NHS key features of an effective person-centred pathway
- Next steps for general practice in London scale, integration and incentives

### How patients and the public contribute to the Clinical Senate

New PPV members were recruited in the autumn of 2017 and we now have thirteen members. Following the recruitment of members, a learning and development programme was initiated for the group, to provide new members with the knowledge required for their role and to help refresh this for existing long standing members. The group have received training sessions around equality and diversity and NHS finance among other topics. They were also invited to take part in mental health first aid training.

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.

The Senate submitted responses to both the Mayor's draft health inequalities strategy and Health Education England's draft health and care workforce strategy during the year. The PPV group had the opportunity to discuss both documents during their meetings and were able to make significant contributions to the responses submitted by the Senate.

Additionally, the PPV group have made an essential contribution to Forum events held three times during the year. Members have made suggestions to the Council in terms of topics that they would like these events to cover and there has been a PPV representative on the planning group for each event to feed in the thoughts of the group. Members have given presentations as well as partaking in panel discussions.



#### Looking back in 2017/18

We recruited 5 new members in autumn 2017. The recruitment process was led by the PPV Chair and Vice-Chair and the new members have integrated well into the group. Unfortunately, due to members stepping-down during the course of the year, there are currently thirteen members, two short of the fifteen we originally had aimed for.

Forum meetings were held in May 2017, October 2017 and January 2018. For the October and January events, two PPV members were on each planning group enabling them to share their ideas to the wider group. We are working to improve how PPV members can be involved in the planning meeting. For example, many of the planning meetings take place via teleconference and some members have found it difficult to take part in these meetings due to the short notice of some of these. As part of planning for future Forum events, we aim to hold at least the first planning meeting face-to-face and provide appropriate advance notice for meetings.

The PPV group discussed the area of work that they would like to lead on and will focus their efforts on creating a checklist for 'gold-standard' patient and public involvement in Integrated Care Systems (ICS). Some of this work as begun with research around the progress of ICSs across London although we acknowledge further support for the group is required to enable them to advance this work.





### Reviewing and advising on proposals for mental health services

Islington CCG and Camden CCG requested advice on proposals for improving mental health services across the two boroughs. We established a review team co-chaired by a Senate Council member and a subject matter expert.

Membership of the panel included one 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.

Members then considered all of the information from the written submissions and discussions and agreed the advice that would be provided. The concluding task for the team was to review and sign-off the final report which was provided to the CCGs. The experiences and perspective that the PPV member brought to the review was essential and ensured that patients remained at the centre of discussions. The PPV member was an expert by experience and contributed significantly to the reviewing of all the submitted documents as well as the guestioning of clinicians and patients on the review day.









#### **Participants said:**

The review coordination was excellent, using the London Clinical Senate's methods which are established, tried and tested ... [The review day] explored themes on site with senior management and also service users, and with local authority leaders to discuss concerns emerging from the team of reviewers.

In my view the chairing and programme coordination was excellent, and I particularly appreciated that my participation was recognised as an equal, especially as I was given several opportunities to lead discussions of specific concerns on several themes.

The draft review report was a model of clarity and precision and reflected the detailed concerns with helpful advice to address them. I appreciated the additional opportunity to provide further comment. The final report was a work product in which I can take pride. I felt that my contributions were valued and have been fairly reflected.

I am convinced that the report will help to ensure that the ambitions of the scheme are successful.

(PPV Group Member)



### Traumatic injuries to brain across London (TrIBAL)

We commissioned a prospective audit of traumatic brain injuries across London that was conducted through the London Major Trauma System.

The final report from this was written in November 2017 and a round-table event was held with stakeholders across the system to discuss the findings and recommendations. One of our PPV members was involved in reviewing the report and attended the round-table event to contribute to the discussions and help form recommendations. The PPV member was an expert by experience and brought valuable insight and was able to relate the recommendations to patients.

Aside from our involvement in the PPV Group at a general advisory level, individual members participate in relevant projects by bringing insights arising from their own backgrounds and experience. Having lived experience of traumatic brain injury after a road traffic accident and the consequent long-term rehabilitation, I found that my contributions to the TrIBAL project were both valued in themselves, and considered as important inputs to what became a collaborative process.

(PPV Group Member)





#### In 2018/19 the Clinical Senate will:

- Recruit additional PPV members to increase current membership capacity to at least fifteen members in 2018/19. The process will again be led by the PPV Chair and Vice-Chair
- Improve the involvement of PPV members in the planning groups for Forum events, ensuring that adequate time is allowed for the group discussions and subsequent feedback to the planning group from representatives
- Continue to develop the learning and development programme for the PPV group, ensuring new members are adequately trained and supported and existing members receive training updates on topics that they feel are relevant and beneficial for their role.



### **Team contact details**

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**Clinical Networks** 

#### What we do

Clinical networks work across the boundaries of commissioner, provider, and voluntary organisations as a vehicle for improvement of care services. In this way we reduce variation in services, provide clinical expertise and leadership to inform decisions and strategic planning, and encourage innovation in how services are provided now and in the future.

Networks are focussed on mental health, dementia, maternity, diabetes, cardiac, stroke and end of life care.

#### How do we involve patients and the public?

We are invested in the value provided by strong patient and public involvement. We include patients and the public as members within the London clinical leadership groups, chairing specific working groups, and helping review literature and information.

Because of their active participation, our work is enriched through understanding what patients want, and means our work is directly shaped by their views.

#### Looking back in 2017/18

The London Clinical Networks found variation in the way patients and the public are in involved in the work undertaken by the networks. Whilst this flexible approach was previously deemed beneficial, it was agreed that greater consistency would be vital. As a result, a working group was formed with representation from each of the clinical network areas.

This group created user engagement guidance for all clinical networks project managers, which provides information on recruiting and managing people with lived experience within network projects. The guidance also contains a checklist of issues to consider and templates to use, thus reducing the time spent planning, searching and developing these, whilst ensuring the network achieves a consistent quality in both recruitment and management.





## Co-producing our work programme

People with dementia are the experts on what it is like to live with dementia.

The Dementia Clinical Network obtained expert insight from people living with dementia and carers by working with three service review panels from the Alzheimer's Society to gain their views into the network's delivery plan.

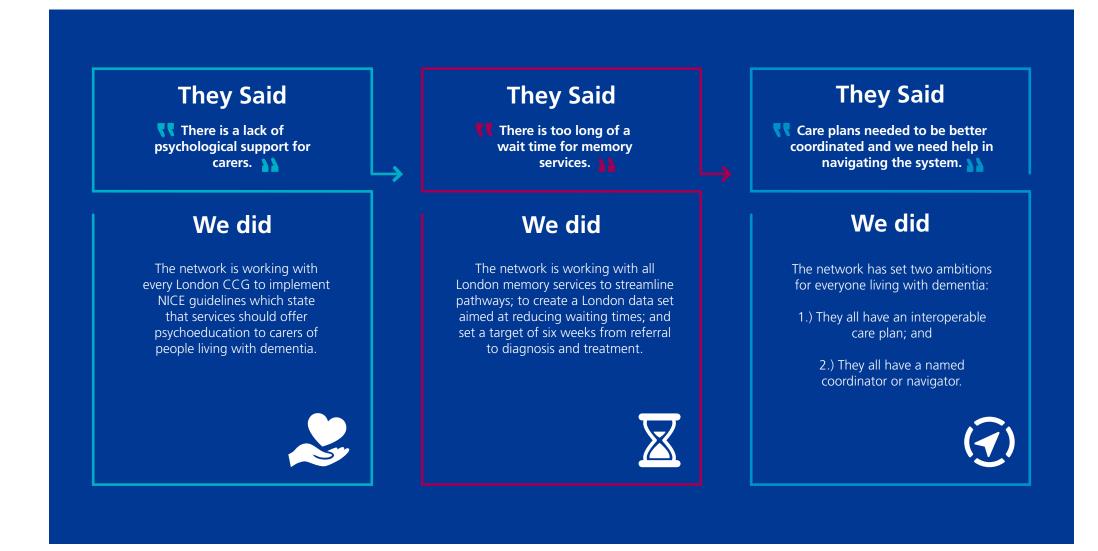
#### The groups were asked three questions:

- What areas of dementia care need improving in London?
- What do you think of the projects we are planning?
- What other projects would you like us to do?

Their feedback resulted in five key themes – which have formed the network's 2018/19 work programme.









# Ensuring involvement in mental health

All work programmes within the London Mental Health Clinical Network, as part of the London Mental Health Transformation Programme, contain patient and public involvement in various forms. These include, for example:

- Service user participation in clinical reference group meetings and related agenda items (such as in Early Intervention in Psychosis Clinical reference Group)
- Representation on a lived experience working group and commissioned service user input for specific work streams activities (such as Perinatal Mental Health)
- Reviewing and providing feedback on draft products (such as Stolen Years on-line resource)

- Using service user case studies to inform the development of our improvement support offer for improving access to Improving Access to Psychological Therapies (IAPT) services
- Presentation by a carer to the London Mental Health Transformation Board on user involvement in the development of primary care mental health services resources.

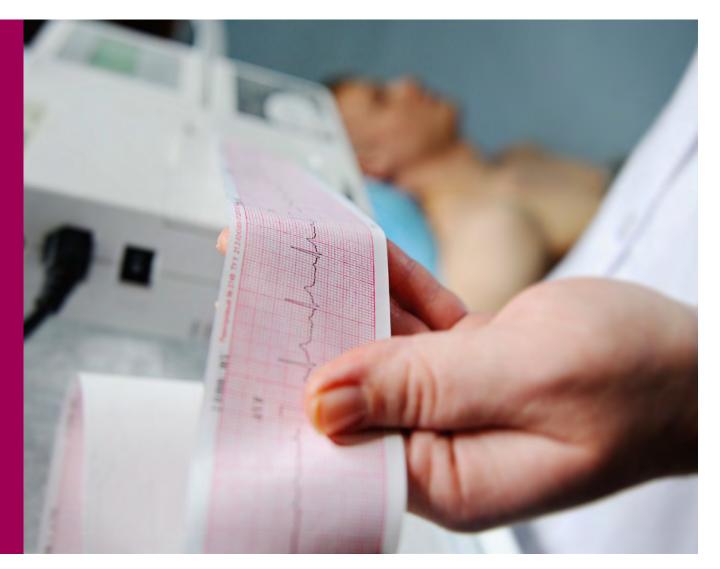




# Leveraging the third sector

The London Cardiac and Stroke Clinical Networks achieve a broad representation of patient and public voice through close relationships across the third sector, including organisations such as the Stroke Association, the British Heart Foundation, and the Atrial Fibrillation Association.

As an example, the networks, in conjunction with the three London academic health science networks (AHSNs), developed the **Atrial fibrillation (AF) toolkit**, a practical resource for London commissioners and providers. The three domains – Detect, Protect, and Perfect – provide the framework for focussed improvement efforts. Resources within the Perfect module provide educational materials on anticoagulation self monitoring for patients. These were developed by patients through working with third sector organisations.





#### In 2018/19 the Clinical Senate will:

- A workshop will be held in 2018/19 with patient and public representatives from across the London Clinical Networks and Clinical Senate to gain input in areas such as recruitment, education and demonstrating value. This insight will help form an action plan on how patient and public involvement can be further developed across the London Clinical Networks
- We will continue to ensure service users help us to design and improve mental health services and plan to commission a provider to recruit, train and support service users to input into all of our planned Mental Health Transformation Programme activities for 2018/19.





# Using women's voices to transform maternity care

#### Better Births set out a vision to transform NHS maternity services to make them safer and more personalised.

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 providers (midwives and doctors) working together to review and contribute to the development of local maternity care.

The London Maternity Clinical Network and the regional midwifery team have worked together to structure the maternity transformation programme to ensure that the voices of women are heard through a variety of routes.

Building on existing service user groups, we brought together a multidisciplinary working party to support the development of MVPs across London. This team coproduced and co-led a development day for Maternity Voice Partnerships in September, designed to provide the information, tools and best practice on:

- How to achieve co-production;
- How to collect feedback and reach diverse groups;
- How to build relationships at local level; and
- Creating a solid foundation for funding and how to develop a local business case.

Over 120 delegates benefitted from the day and we have seen establishment and strengthening of London MVPs since this time. We subsequently established the London MVP strategic group, 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 acting chair of National Maternity Voices, the national group of MVPs in England.

# The objectives of the London MVP Strategic Group are:

- Ensure that all MVPs across London are equally valued and adequately funded in accordance with the Better Births resource pack
- 2. Ensure that the service user Chairs across London are well networked, providing peer to peer support, mentoring and training where necessary e.g. via social media and quarterly meetings of London-based MVP Chairs
- **3.** Spread the message of co-production so that MVPs in London are involved in the outset in co-designing services, not just consulted as an afterthought

**4.** Ensure 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 capture the voice of and involve seldom heard groups.

Florence and Laura sit on the London Maternity Clinical Network Clinical Leadership Group and the London Maternity Transformation Board, ensuring that service user and MVP voices are heard at each of these strategic committees. They use a variety of communication channels including, social media, to connect with women and Maternity Voice Partnerships. They also liaise closely with National Maternity Voices as well as MVP representatives from other regions in England.

The group has begun its work by developing a baseline of MVPs across London, which has been presented to the Maternity Transformation Board to encourage appropriate and effective establishment.





#### Plans for 2018 include:

- Developing a resource for commissioners to provide practice support to establishing MVPs
- Developing and implementing a clear communications, plan including social media and vlogs (video blogs)
- Co-producing a further development day based on feedback from MVPs, addressing areas that they would value support, and
- Developing a resource to help identify service user experts and use their experiences in maternity transformation work.



# Team contact details

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Florence Wilcock Twitter: **@FWmaternity** Laura James Twitter: **@Jameslaja1** 



# **Healthy London Partnership**

#### What we do

Healthy London Partnership brings together health and care in London, as well as the Mayor of London, Greater London Authority, Public Health England and London Councils, to transform health and care for all Londoners.

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 1000s of different 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** and the national **Five Year Forward View.** 

#### 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 in 2017/18

#### Thrive LDN

Thrive LDN's 2017 *Are we OK London?* campaign started an open conversation with Londoners about mental health and wellbeing. As a result, it generated over 420,000 interactions and was the driving force behind greater partnership working on several citywide and local projects across London.

On the back of the campaign, Thrive LDN also held community workshops, in partnership with the Mental Health Foundation, in 16 of the 32 London boroughs to start conversations on a community level. *Thrive LDN: towards happier, healthier lives* publication is a summary of this work to identify what would make a difference to Londoners' mental health and wellbeing. Thrive LDN is supported by the Mayor, Sadiq Khan, and led by the London Health Board, in partnership with the Greater London Authority, Healthy London Partnership, NHS England (London Region), Public Health England (London Region) and London Councils.

Visit www.thriveldn.co.uk to find out more.

# "

One of the ways {institutions can help} could be to highlight some symptoms of mental health and explain them in more detail.

- How do you know you are ill?
- What does depression feel like?
- How is it different to just "not being bothered today?
- We all talk to ourselves when is the voice in your mind a mental health issue?

Knowing some of these things for people who have never experienced mental health issues - might allow people to seek help quicker.

(Croydon, 38)





#### **NHS Go app**

NHS Go is a health app created by young people for young people. 26 children and young people were interviewed or took part in focus groups and 104 surveyed to evaluate the app.

# "

I'd use the app as the first port of call for any problem. I'd go straight to the app first to try and figure out a solution on my own and if it's not then obvious I'd go a bit further, like to 111...

(Female, 17)

#### The evaluation showed:

- NHSGo is seen as a credible and trustworthy source of information. This is important, as trust is found to predict intention to enact positive health behaviours
- Those evaluated say they would 'definitely' use NHSGO again for a range of health reasons
- NHSGo is easy to use, well-structured and easy to navigate. People think it is inclusive and topical.

A set of recommendations to improve the app further are being taken forward in 2018/19.

In March 2017 NHS Go was announced a winner in the Patient Experience Network Awards for the category of Championing the Public and were given an opportunity to present their project at the conference. We also had a great presence on social media getting 400,000 impressions for tweets in relation to NHSGo.

Find out more at www.nhsgo.uk

#### London's Health Inequalities Strategy

The draft 'Health Inequalities – Better health for Londoners' strategy consultation closed on 30 November 2017. Almost 2,000 Londoners took time to share their views in the survey on Talk London, and helped shape the future strategy. There were also a range of discussions about what mattered to their health and what would improve their health. People also emailed and tweeted to make sure we heard from Londoners across the city.

The feedback highlighted a number of key issues such as public transport, a rise in crime and the impact on mental health.

You can read some of the pledges here: www.healthylondon.org/better-health-forlondoners/londons-health-inequalities

# Health based places of safety – mental health crisis care

Since the very beginning of this work the views of service users, experts by experience, groups that represent service users and the professionals who work with them, have been central to developing the minimum standards of care.

Over 400 Londoners have been involved, the majority of whom have lived experience of mental health crisis as a service user or carer. This has included people with specific experience of the section 136 pathway, and those with experience of wider crisis care in London. Representatives were sought from all areas of London as well as people from harder to reach communities, black and ethnic minority communities and children and young people. Where demographic information was provided, the proportion of white (65%) and BME (35%) represented in the service user engagement, reflects the proportion of these groups who are detained under section 136 in London.

The full summary document can be found here: www.healthylondon.org/crisis-care-local



### Breaking down barriers for young carers in London

Carers are vital 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.

Although young carers are integral to our society, they remain largely hidden. The impact that being a young carer can have has been well documented.

It's known that they're more likely to develop physical and mental illness, and will have less success in education than their peers. Despite this, there are few initiatives specifically targeting young carers within healthcare settings.

In London, we are challenging this by piloting identification cards for young carers. We aim to address some of the barriers faced by young carers when it comes to accessing healthcare in London. We started with a series of interviews with young carers and also healthcare professionals in paediatric and adult care. We explored their perceptions of young carers' rights and the support they need. We also involved young carers in a workshop focused on their rights within the NHS. Six major themes emerged, with identification being the biggest obstacle for young carers trying to access appropriate support. The idea of identification cards grew from there.

We used follow-up workshops and further consultation to create a design brief that young carers and healthcare professionals agreed would help overcome the identification barrier. The cards can equip young carers with the knowledge and confidence they need to encourage and empower them to assert their rights.

For more **www.healthylondon.org/breaking-downbarriers-for-young-carers-in-london** 





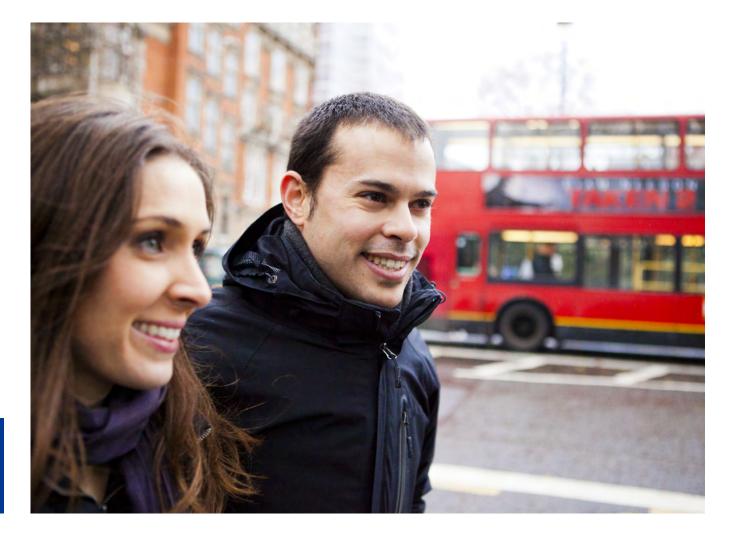
#### In 2018/19 Healthy London Partnership will:

- Increase Thrive LDN engagement across the city
- Continue with wider stakeholder engagement to secure support for Fast Track cities
- Engage Londoners on the priorities and ambitions of the Strategic Partnership Board and London Health Board, for example on the Health Inequalities Strategy, childhood obesity and the vision for making London the healthiest global city.



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Leadership

# Conclusion

We hope that this review has demonstrated the broad range of ways that NHS England in London involves patients, carers, families and other Londoners. From directly commissioning services, to ensuring that local health and care plans are designed to meet the needs of local communities, we continue to work with patients and the public in carrying out our responsibilities.

This report highlights real examples of how the quality of services have been improved by engaging patients and the public, by not just listening to their views but by actively working with them to ensure services are shaped around their needs. As London's health services continue to change to meet new challenges, the importance of working with individuals and different communities in London will remain paramount.

We recognise how people have different experiences of care which is why it is important that we continue to work together to plan, organise and deliver health services. We are fortunate that people share our ambition to improve services into the future, as seen in the energy and commitment of our Patient and Public Voice partners when working with us.

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 partners who have worked with us in 2017/18.

Finally, we know that we can still do more to involve patients and the public. As with previous years, we have commissioned London Patient Voice to conduct an independent scrutiny of our engagement work. This will help us identify what we can do more of and where we need to strengthen the role of patients and the public.







Leadership



# **Get Involved**

We hope this review has outlined the range of participation and involvement activity that is 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.** It supports patients, carers, staff and the public who want to find out more about participation across NHS England. It is a source of information and resources which will help people to develop their knowledge, skills and confidence to get involved in the design and delivery of health services.

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





england.LDNqualityhub.nhs.net





www.england.nhs.uk/london