

LISTENING TO OUR PATIENTS AND PUBLIC

NHS England (London) participation
and engagement report 2014/15

NHS
England



Welcome

Health is personal.

We have all been patients at some point in our lives, as have those we love: our parents, our siblings, our children, our wider family and our friends. And each of us will be patients again.

During those times when either us or our loved ones have needed care, we have been able to very clearly judge how that care has been delivered – or how it should have been delivered. Was it compassionate? Were all our needs met? Did we feel that we were listened to? Was the process we had to go through to be cared for easy?

That's why it's so vitally important that you – and your loved ones – have a chance to share your experiences about the care you receive and how you would want to receive care. It's important too that you have every opportunity to shape how that care is planned, organised and delivered.

It's our ambition at NHS England that this becomes a reality – that patients are at the heart of everything we do. The NHS *Five Year Forward View* (2014) which sets out the future of our NHS includes a clear vision for a new

relationship between the NHS and patients and communities with a commitment to engage communities and citizens in decisions about the future of health and care services.

This report explains how we are working hard to make this happen by promoting participation and engagement with patients, carers and the public in the London region. It highlights examples of good practice and identifies weaknesses and how we propose to improve.

We know we have a way to go and with your help, we will achieve it. Because it's personal.

I'd value your views on our work so far in London as outlined in this report and any ideas you have about how we can improve or how you'd like to participate.

Finally, thanks to all the patient and public representatives who have worked with us in 2014/15. Thanks too to staff and the reading group who have contributed to the information in this report.

Thank you
Caroline



Caroline Alexander
Chief Nurse
NHS England (London)

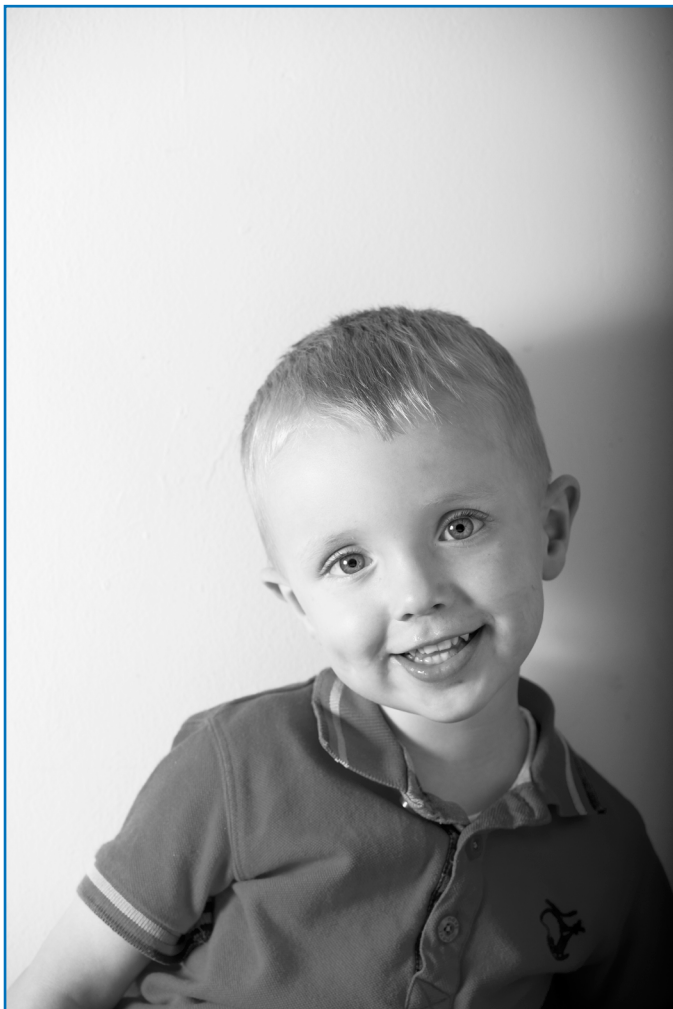


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London's health: an overview

8.7 million
people living in London



Londoners are younger than the national average with

nearly 25% of Londoners under the age of 25

Rising to
10 million
by 2039



Life expectancy

differs significantly across London.

A **female** baby born today can expect to live 86.2 years in Kensington & Chelsea and 82.4 years in Barking & Dagenham. A **male** child can expect to live 82.6 years in Kensington & Chelsea and 77.5 years in Tower Hamlets.



Health challenges facing Londoners

Children

1 in 4 children live in poverty

1 out of 5 children aged 4-5 in London are overweight or obese

2 out of 5 children in London are an unhealthy weight when they start secondary school

More than **100,000** children will experience mental health issues this year

Adults

57% of adult Londoners are overweight or clinically obese

Over **1 million** Londoners suffer from disorders like anxiety and depression

Tobacco kills **8,500** Londoners a year

Over **100,000** Londoners are diagnosed with a sexually transmitted infection each year

London accounts for **2 in 5** cases of TB in England

What we do

NHS England leads the National Health Service (NHS) in England. Our mission is to improve health and secure high quality healthcare for the people of England, now and for future generations.

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

The NHS *Five Year Forward View* (2014) sets out how we will achieve this.

NHS England (London) leads the NHS in London. We have four main functions:

Commissioning: agreeing the appropriate primary care services, as well as specialised health services, such as mental health, HIV treatment, ex-forces healthcare and healthcare for those in the criminal justice system.

Assurance and support 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)

Spends more than

£18billion



on health and care services, including over

140

specialised services



We work together with the following organisations to provide world class services for present and future generations.

32
CCGs

35
hospital
trusts

19
Strategic
Resilience
Groups

33
local
authorities

1
ambulance
service

Together, we ensure that the money we spend on running the NHS and transforming services is spent effectively for patients and efficiently for the taxpayer.

Placing patients at the heart of all we do

Our ambition is to place patients and the public at the heart of everything we do. To achieve this, genuine patient and public participation is essential. The [Five Year Forward View](#) (2014) 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 by the Health and Social Care Act 2012) NHS England has a legal duty to properly involve patients and the public in our commissioning process and decisions.

This summary highlights the work that NHS England (London) has done to involve patients and the public between 1 April 2014 and 31 March 2015 and its plans for the future.

Our first Annual Participation and Engagement Report detailed our activities in 2013/14. The regional executive team commissioned the [Centre for Public Scrutiny](#) to create, recruit and train a group of Londoners to scrutinise our public involvement activity. This group, [London Patient Voice](#), undertook an independent review of the extent to which we succeeded in involving and engaging patients and the public in our work.

Their report acknowledged that there was a greater focus on building foundations, preparing and setting up processes to engage our patients and the public and less evidence in this first year to show how patients and the public had been able to influence our work. Our regional executive team have agreed with their recommendations and they will be taken forward this year to improve our practice.

**Click
here**

to find out more
about the Health
and Social Care Act



Health and Social
Care Act 2012

“NHS England (London) has enthusiastically accepted the responsibility to listen to the voice of the patient and has made satisfactory progress overall in meeting its collective and individual participation duties.”

**London patient
voice**

Scrutinising NHS England (London)'s Participation and Engagement report 2013-14

Involving patients: commissioning

Commissioning can be defined, in simple terms, as the process of planning, agreeing, paying for and monitoring services.

In practice, it's a complex process, consisting of many actions ranging from the health-needs assessment for a population, through the clinically-based design of patient pathways, to service specification and contract negotiation or procurement, with 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.

Primary care

including general practice (GPs), dentistry, optometry and pharmacy

Armed forces healthcare

Health in the justice system

Specialised services

including cancer, orthopaedics, mental health

How patients and the public contribute to **primary care**

What do we do?

Primary care relates to the care provided by GPs, community pharmacies, optometrists, dental surgeries and community hearing care providers. NHS England (London) commissions many of the primary care services in London previously commissioned by Primary Care Trusts (PCTs) and has a duty to commission services that improve quality, reduce inequalities, promote patient involvement and promote more integrated care.

Clinical Commissioning Groups (CCGs) have a huge part to play in driving up the quality of primary care but we have responsibility for performance managing primary care contracts.

Contact the team



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How do we involve patients and the public?

For GP contracts, this involves engagement with patients, local groups and stakeholders about the options on how these services will be delivered in future, for example, when a GP contract comes to an end. Engagement methods include letters to all registered patients, public meetings, drop in sessions and online surveys.

Primary care procurement has included engagement with patients on the specifications for new practices. Patients have been trained in bid assessment skills to take part in the associated oversight processes.

Key performance indicators for GPs have been set against areas of priority in the service that patients have told us are important to them.

Each London Borough should have a Pharmaceutical Needs Assessment (PNA) report. Since 1 April 2014, this report is the responsibility of each borough's Health and Wellbeing Board and assesses the need for community pharmacy provision and services. The PNA takes in the views of stakeholders such as patients, clinical commissioning groups, local authorities, GPs and community pharmacies.

In focus

In focus

Patient and public voice within community pharmacy



There are several examples of where patient representation plays a role in how NHS England (London) commissions community pharmacy. These include:

- The **Pharmaceutical Services Regulation Committee** reviews and makes decisions on new and existing community pharmacy applications across London. A lay member is part of the committee and decision making. Through this, decisions about whether to open, close, change the hours or level of community pharmacy service provision in any area of London are made with the public's input.
- The **Dental, Optometry and Community Pharmacy Patient Advisory Board** for NHS England (London) has a patient representative who provides feedback on patient experiences of services for these professional groups.
- The **Pharmacy Local Professional Network** is a steering group which brings together all parts of pharmacy services (e.g. community, hospital, CCG and education) to provide professional advice to NHS England. This group will be inviting lay members to participate fully in their activities.

Shaping a proposed new eye strategy for London



Attendance at an event in February 2015 included individual patient representatives with an interest in improving eye health in London as well as those affiliated to voluntary sector providers and charities (e.g. RNIB, Guide Dogs).

Patient and public representatives participated in small group discussions about proposed work streams and helped to prioritise key work areas including low vision services and access to sight tests.

Wider eye health network meetings have been convened by London's Eye Health Local Professional Network Chair. Key work streams have been identified for a variety of commissioners (NHS England, Clinical Commissioning Groups, local authorities) at which patient and public involvement will be required.

Attendees indicated areas of work that they are interested in getting involved in, in order to develop the strategy for London.

In focus

Public and patient voices at the centre of shaping dental services across London



Dental commissioners in London, under the guidance of patient and public voice leads, recruited 17 representatives in October 2014 to contribute to a patient board on an emerging dental commissioning programme.

Each representative nominated themselves for a role on the London Dental Patient Board and the group is made up of seven males and 10 females, all over the age of 18 and drawn from across London. Care was taken to ensure that membership was inclusive and reflects a broad section of society. The group is chaired by a Consultant in Dental Public Health.

Monthly meetings were arranged initially over a six months period from November 2014, when the first meeting was held, to enable the group to form and receive presentations and briefings to develop their understanding of commissioning and provider arrangements. This served as a robust induction and enabled the group to meet dental providers and commissioners from across the wider network.

Almost one year on, members are gaining in knowledge and are confidently contributing to key service change and discussions. Meetings now take place every two months and include slots updating, informing and seeking the viewpoint of the members on the commissioning activity that is being planned and executed. Topics include out of hours and urgent dental care, community dental services, oral surgery provision and commissioning new dental practices. Commissioners present their plans and seek the comments of the group as well as asking for volunteers to work more closely with them on project specifics.

The scope of the Board is expanding to include projects related to optometry and community pharmacy. Whilst there was an intention to move to a lay Chair, the group has indicated its preference to continue with a clinical Chair.

In focus

Redesigning out of hours urgent dental care with patients and the public



NHS England has been working on plans to ensure Londoners with urgent dental care needs can access the services they require whenever they need it, even out of normal working hours, by enhancing the NHS 111 service.

London Dental Patient Board members contributed detailed input to the project following presentations from dental commissioners and the NHS 111 team. They shared their experiences of using the current services, were provided with details of the commissioning activity, took part in the steps to re-commission the service and attended a market stimulation event where changes to the service specification were discussed with potential and current service providers. They also contributed to small group discussions which included details of how responsive the service would need to be, exclusions from the service, different ways to configure provider models and key aspects of accessibility. Some helped in the development of questions to be included in the pre-qualifying and invitation to tender sections of the procurement process.

Further to their contribution, they were also asked to participate in focus groups led by Newcastle University Research Team about the wider use and experience of using NHS 111. The outcomes of this work included:

- the value of enabling patients to discuss urgent dental needs with a dental professional as part of their assessment rather than a call handler was considered important and reassuring for patients.
- the role that the dental nurse triage service has in helping patients to navigate access to dentistry and provide access to pain relief advice overnight was also valued highly by the patient representatives and underpinned the ongoing model of commissioning for London. This coupled with the patient experience information from the service providers strongly steered the decision to continue and strengthen provision in this way.

Looking forward: primary care

During 2015/16, the team will:

- ▶ include patient and public engagement and involvement training in the performance and development reviews for staff of Band 7 level and above.
- ▶ ensure the Head of Primary Care is a patient and public voice champion.
- ▶ use co-commissioning initiatives to engage with clinical commissioning groups and local authorities to engage with public and patients using their existing local networks.
- ▶ develop a communication strategy to inform every GP's Patient Participation Group of emerging strategies and impact locally.
- ▶ engage with the Healthy London Partnership using their panel of patients to discuss development and re-provision of services.



How patients and the public contribute to **armed forces healthcare**

What do we do?

NHS England has a dedicated team of Armed Forces healthcare commissioners, who look after commissioning the majority of services required by the Armed Forces community, which includes mobilised reservists and some families. This is carried out by NHS England's National Support Centre and its three lead area teams: North Yorkshire and Humber (North); Derbyshire and Nottinghamshire (Midlands and the East); and Bath, Gloucestershire, Swindon and Wiltshire (South, including London).

Our team at NHS England (London) serve this community through commissioning cervical screening for London armed forces garrisons as well as facilitating the London Armed Forces Network.

Contact the team



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How do we involve patients and the public?

NHS England (London) facilitates the London Armed Forces Network, which was established in April 2013 to offer ex-forces staff, reservists and their families a space to network, find solutions to challenges and profile the range of services created to deliver the Armed Forces Community Covenant. We actively engage the full range of agencies and charities that support the armed forces, as well as welcome individuals to attend and contribute their voice.

Examples of how the London Armed Forces Network has helped include:

- 'T' joined the forces when he was 16 and left 12 years ago. He didn't cope well with civilian life and became an alcoholic with depressive tendencies. He attended several network meetings and was really enthusiastic about gardening and potato growing. He has since been supported by two charities to go on a gardening course run by [Thrive](#), a charity that uses gardening to bring about positive changes in the lives of people living with disabilities or ill health, or who are isolated, disadvantaged or vulnerable. Thrive has since joined our network.
- 'P' was a widow of an airman and found herself alone after her husband died. She couldn't find any group in London to support her or understand her issues. She set up a widow's association and she came to our network to present what they do. Her story was so profound that many other ex-forces charities are now referring widows and widowers to the group. 'P' raised the issue of end-of-life care for ex-forces staff and the network escalated this immediately to the Ministry of Defence.

How patients and the public contribute to **public health services**

What do we do?

Our NHS England (London) public health services teams work closely with [Public Health England](#) and strive to protect and improve Londoners' health and wellbeing, and reduce health inequalities, through:

Early years and immunisation

The Early Years and Immunisation team is responsible for ensuring services are commissioned to provide vaccinations against diseases, focusing on very young children, the elderly and adults with chronic conditions. The London Immunisation Board oversees this work, which aims to:

- achieve the WHO goal to improve immunisation uptake and eradicate vaccine preventable diseases
- reduce disparities in outcomes between the most deprived and least deprived boroughs in London
- promote the roll out of new programmes and initiatives and field-test which of these improve access and complement the national regimes indicated by the Joint Committee on Vaccination and Immunisations (JCVI)
- Influence and engage with all stakeholders, including the national NHS England and Public Health England team, the Clinical Senate, London Immunisation Network, practitioners and Londoners.

Screening

Our screening team offers three groups of services:

- antenatal and newborn: genetic tests, infectious disease tests, foetal anomaly etc.
- adults and young people (excluding cancer): diabetic eye screening, abdominal aortic cardiovascular screening
- cancer: breast, cervical and bowel.

These are overseen by screening commissioning boards, meeting three to four times a year, and the pan-London Screening Programme Board (meeting twice per year). These are responsible for take up across London and identifying ways to improve coverage and uptake.

The major task for the Screening Service in 2013/14 was to build a completely new business unit to take up assorted roles and responsibilities for a range of organisations that had been disbanded as well as sharing some responsibilities with other new ones. This has been achieved.

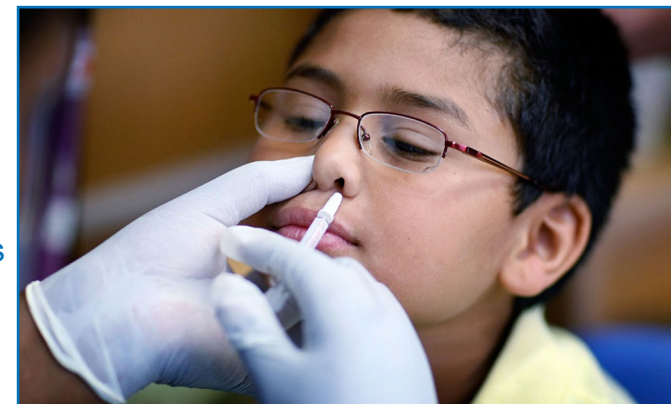
How do we involve patients and the public in immunisation?

The immunisation team is committed to ensuring the patient voice is at the heart of all we do. There are patient representatives on the London Immunisation Board to support decision making and strategy development on improving uptake of routine immunisations for all ages.

Three representatives from diverse backgrounds were recruited via an application process managed by the Patient and Public Voice team. The successful applicants received a corporate induction and we allocated a mentor and link-commissioner to support them. The representatives have added considerable value to processes and decision making. They have reviewed their induction, which has resulted in an improved process and checklist for the next cohort, and the drafting of Immunisation Q&A and glossary of terms. As a result of their feedback we have reformatted our presentation and reports to be easier to read and understand. They have also attended one of our team development events and our flu evaluation events, both of which also used social media to collect feedback.

To ensure the youth voice was heard, a young person was specifically chosen as a representative, and they have provided useful feedback about vaccines for teenagers. We have since also had two college student work experience placements, who have both drafted project reports about how to improve engagement with teenagers and young adults and one of our student placements is now working part-time in a London borough's public health team.

Our social media campaigns during our team development and flu evaluation events gave us over 100 useful comments from Londoners which we have built into our evaluations. We are keen to engage as many Londoners as possible in our work and have been working closely with the communications teams from NHS England and Public Health England to harness the reach of social media to support this. This has been a success, with regular #imms dialogues on Twitter taking place between NHS commissioners and a wide variety of individuals and groups.



A young Londoner being protected against the flu

Contact the team



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How do we involve patients and the public in screening?

Screening is an important way for individuals to assess their health and NHS England (London) strives to ensure each programme meets the needs of those who require it. The only way to do this is to engage patients and their representatives in their commissioning.

The governance of the screening programmes is overseen by multidisciplinary boards. There is an overarching board for all programmes and also one each for antenatal, adult (non-cancer) and cancer programmes. These include external partners, such as Public Health England and local authorities, as well as patients, carers and the community and voluntary sector. Each has an active role in inputting and challenging the work of the screening team.

Patient and public members are recruited for the adult and cancer boards from other panels and boards. Representatives from the community and voluntary sectors were recruited through Age Concern, Diabetes UK and Jo's Cervical Cancer Trust. Lay members made a significant contribution to the work of the boards. They have been instrumental in helping to shape new programmes by informing boards of patient experiences and helping to frame service specifications as well as being involved in procurement activities. These contributions are recorded in minutes of meetings and may become follow-up actions. Lay members for the [Diabetic Eye Screening Programme \(DESP\)](#) were very involved in the procurement of the new services by sitting on the steering group, reviewing and commenting on documents, scoring and moderating panels.

The governance for re-procurement of screening programmes across London includes patients and their representatives. This includes the membership of the steering groups and subgroups. Patients are also included in the panels scoring and evaluating tenders. Specific exercises to identify patient preferences in the provision of services are included within procurement methodology.

Contact the team



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In focus

In focus

Working with patients and Londoners to improve cancer services in the capital



Breast screening reconfiguration

A group of women from across London were recruited to review the proposed breast screening reconfiguration plans and advise on patient matters. They attended a focus group and their comments and suggestions were fed back to the breast reconfiguration steering group. The group have had a progress report on the work in this area.

NHS England (London) is transforming cancer services across the capital with the help of partners, patients and the public.

Find out more in the leadership section

Engaging patients in commissioning new diabetic eye screening providers



During the recent re-procurement of diabetic eye screening services across the capital, the team encouraged active patient and public involvement about what is important to Londoners in terms of how they access and use the services.

Londoners living with diabetes were asked to complete an online survey, developed with input from the London Diabetes Strategic Clinical Network. This was distributed to multiple forums, including Twitter, Facebook and via email. Where online routes would limit responses, paper copies were sent to dedicated diabetes groups or hospital screening clinics.

A report was produced summarising the responses of 221 Londoners to the survey.

This report was made available to scorers of the new London diabetic eye screening provider tender, to provide insight into the views of a small sample of service users and help inform the decision making process for individual scoring of each tender.

Looking forward

During 2015/16, the immunisation team will:

- ▶ continue to engage lay representatives in our commissioning at all our Immunisation Boards.
- ▶ be interviewing parent-group about vaccination uptake and their concerns and we will be discussing the recommendations at the Immunisation Board.

During 2015/16, the screening team will:

- ▶ recruit user representatives for participation on the programme boards, with an aim to have representation on 16 Programme Boards by January 2016.
- ▶ review user involvement on the Cancer Screening Programmes within NHS England (London).
- ▶ continue to work with third sector groups across several London Boroughs where uptake to breast screening programmes is poor.

How patients and the public contribute to **health in the justice system**

What do we do?

The NHS England (London) Health in the Justice System team commissions healthcare in a variety of settings across London: prison and youth offender institutions; immigration and removal centres; initial accommodation for homeless asylum seekers; police custody suites; mental health liaison and diversion services; and sexual assault referral centres.

We aim to prevent crime and anti-social behaviour and reduce risk (to individuals and communities) by improving access to health support for those affected by crime. We also aim to improve access and positive engagement with those in contact with the justice system to help reduce re-offending and promote recovery.

Contact the team



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How do we involve patients and the public?

Our Health in the Justice System team actively engages patients and the public in the commissioning process of our services.

We worked with two service user-led organisations - Inspirit Training and KELP Participate - to help us build an authentic patient and public participation infrastructure.

These organisations were tasked with developing a group of people who have either experienced healthcare in the justice system themselves or, who have closely supported someone who has, to work as “commissioning technicians”. The organisations support the group to be a critical friend and scrutinise our work to improve the patient voice in our commissioned services.

Since working with them, we have secured a group of seven trained and supervised commissioning technicians who form a core patient group. The group is facilitated by a dedicated chair who is a member of a London Healthwatch with experience in health and service user-led structures.

In focus

In focus

Listening and engaging with our patients in the justice system

During 2014/15, Inspirit undertook an assessment of the provider agencies with the intention of developing baseline standards for improvements. This report is about to go to the patient and public participation group and the Health in the Justice System Quality Forum for sign off. Inspirit will now work with the commissioning technicians to ensure the providers build appropriate standards to ensure meaningful and authentic participation. The commissioning technicians are very excited about this project as they feel it allows them to directly contribute to shape change in the patient experience.

Since this work was completed the providers have undertaken some immediate improvements to promote engagement. We believe this is a direct result of the assessment itself and the conversations with Inspirit and patients. The model of assessment used determines the level at which activities were taking place and how those activities are being managed, providing ideas on making short, medium and long term improvements.

The patient and public participation group members have been helping to structure some patient groups in our secure settings to use feedback and consultation as a process for understanding the current experience and how improvements might be made.

During the re-procurement of the three Greenwich prisons throughout 2014/15, we worked with the commissioning technicians to help shape some of the questions used in our procurement documents. The commissioning technicians, still new to this work, enjoyed the project and were very enthusiastic about ongoing projects. Through 2015/16, the commissioning technicians will work, with Inspirit's ongoing training and supervision, to manage the improvement plans for each of the secure settings and will explore how patient and public participation can be further developed in our other services.

Looking forward: health in the justice system

During 2015/16, the team will:

- ▶ Work with the commissioning technicians to increase recruitment and to accredit their training formally as a National Vocational Qualification.
- ▶ Empower the commissioning technicians to form part of a quality assessment team to inspect our commissioned services against a self-assessment demonstrating quality in the services delivered.
- ▶ Pilot a patient and public participation-led Overview and Scrutiny framework in a local borough to improve the impact of our commissioning.
- ▶ Work with commissioners on the re-procurement of three prison services and identify what role patient and public involvement can play in this. Liaison and Diversion services identify mental health issues and vulnerabilities that offenders may have so that they can either be supported through the criminal system pathway or diverted into a treatment, social care service or other relevant intervention or support service.
- ▶ Ensure patients can actively contribute to the governance structures supporting the transfer of healthcare from police custody.
- ▶ Work with providers of Liaison and Diversion services to consider how to introduce meaningful patient and public participation into this service model.
- ▶ Enable patient and public participation core group members to play an active role in the Health in the Justice System team's meeting structure.
- ▶ Work with providers in the immigration removal centres on capturing patient experience and improving involvement.
- ▶ Explore the opportunities to engage with the Havens, the three sexual assault referral centres in London, to assess their models for participation. This will be co-designed with The Survivors Trust, a network of people surviving sexual and domestic violence. There will be a Service users' dialogue conference in November 2015 with a wide range of stakeholders including Rape Crisis Centres and the Voluntary, Community and Social Enterprises, commissioners, Mayor's Office for Policing and Crime, Metropolitan Police Service, NHS and local authority colleagues.
- ▶ Explore opportunities for greater public engagement.

How patients and the public contribute to specialised services

What do we do?

Specialised services are those provided in relatively few hospitals, usually with catchment populations of more than one million but accessed by comparatively small numbers of patients. Trusts that offer these services can recruit staff with the appropriate expertise and enable them to develop their skills.

Specialised services account for approximately 14% of the total NHS budget, spending circa £13.8 billion per annum. The commissioning of specialised services is a responsibility of NHS England.

They are commissioned for any eligible patient, including London residents as well as patients referred regionally and nationally.

Contact the team



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How do we involve patients and the public?

NHS England's national Specialised Commissioning team is responsible for the national Public Patient Initiative Strategy, leading on behalf of England's four regions, and undertaking the recruitment of patient and public representatives.

Although the national team have the structure and resources allocated for engagement and participation, some local and smaller scale initiatives are carried out regionally. The channels we engage patients and the public through are typically 1:1 meetings, focus groups and wider public consultations.

Throughout 2014/15 we have undertaken a wide range of patient and public involvement initiatives through our networks, peer reviews, guidelines/pathway development, commissioning and procurement processes. In our engagement initiatives, we work in partnership with a number of organisations

such as Clinical Commissioning Groups, Public Health England and Healthwatch.

In addition, embedded within the contracts and some of the national service specifications is the need for providers to ensure patient and public engagement. We regularly monitor compliance and progress against this standard in our regular contract and quality meetings with our providers.

During 2014/15, there have been a number of key outcomes and benefits to patients, service users and the public, ranging from better patient experience, positive feedback, a more co-ordinated and seamless clinical pathway, the patient voice being heard in our service development and commissioning activities.

Find out how we engage Londoners in specialised commissioning

Clinical Reference Groups

Specialised services Clinical Reference Groups (CRGs) bring clinicians, commissioners, public health experts together with the patients and carers who use the relevant services. The CRGs are clustered around the six national Programmes of Care (PoC): internal medicine (digestion, renal, hepatobiliary and circulatory system), cancer, mental health, trauma (traumatic injury, orthopaedics, head and neck and rehabilitation, women and children (including congenital and inherited diseases) and blood and infection.

Members are volunteers who have a particular interest, knowledge or experience of a specific area of specialised healthcare and wish to contribute to its development.

The groups are the main source of clinical advice on the development and assurance of specialised services contracts.



Networks

Most specialised commissioning services are underpinned by service specifications which were designed and developed by local CRGs. These groups have public and patient representatives who have contributed to the service specifications' development.

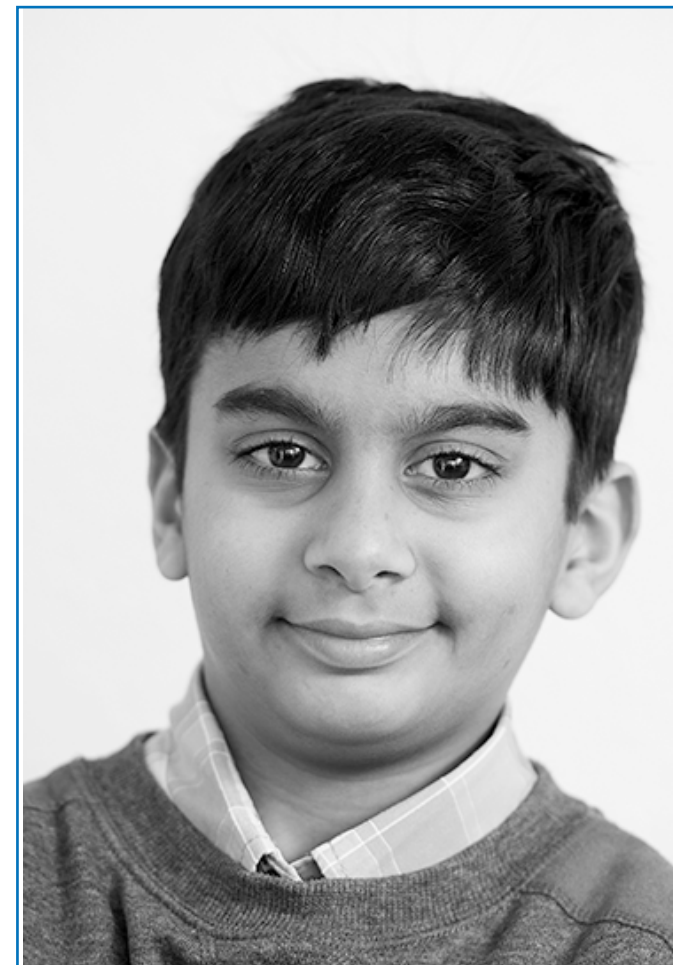


Peer review assessments

Peer review assessments are undertaken on our behalf by the Quality Surveillance Team, part of the National Specialised Commissioning team. The user representatives on the review panels contribute to the development of the services.



Consultations, forums, focus groups and more



In focus

Involving patients in Clinical Reference Group guidance development

The national Bariatric guidelines were developed by CRG with user involvement.

The work has led to pathway changes, with the impact that only eligible patients are accepted.

Further work will be undertaken with primary care and service audits of the work.

Our clinical networks rely on involvement by patients and the public to help steer their direction

Cardiology

Cardiology network meetings are attended by British Heart Foundation groups who represent patients and service users. Through this group patient representation has led to involvement in the development of clinical pathways. A great example of this was the 'door to balloon time' which was a key patient safety indicator for improving clinical outcomes.

HIV

The HIV service specification requires providers to engage with those who use their service and to maximise opportunities for their participation in any service developments. During 2014/15, service users supported the commissioning and development of HIV services and the delivery of the London workplan. Through the network, we ensured that the patients' voice

was a key part of commissioning with regards to the HIV audit and drugs related issues.

Patient and public engagement has been through attendance at bi-annual and bi-monthly London meetings. As a result, there has been a revision to the governance of the Clinical Advisory Group in 2014/15 with a review of the Terms of References, stakeholder job roles (including Public Patient Engagement) and a recruitment plan to increase service user representative numbers from four to eight.

In several London HIV services, patient representatives are employed as part of the Multi-Disciplinary Team, for instance, in Central North West London, Chelsea and Westminster and King's. These key roles and the wider patient networks can often offer support advice and advocacy. The

In focus

Involving patients in our networks

Bloomsbury patient network is one of the best examples in North East London.

The Homerton has a specific focus on services for black African women who are a key target group affected by HIV in the area. The service has established a research network to address health inequalities and access. Other examples of networks are:

- HIV clinical advisory groups
- Combined HIV Audit and Drugs groups
- HIV New starters audit sub-group (short life task group)
- Service User Review Group

Through these groups there are opportunities for patient and public representatives to participate in supporting time-limited groups and ensuring service user voice are represented. This will be monitored further in 2015/16.

Neonatal services

Carers and third sector representatives are full members of the London Neonatal ODN board working with the specialised commissioners, CRG representatives and network clinical leads, to scrutinise the development, monitoring and planning of neonatal services in London. They provide a valuable patient voice and feed back to regional commissioners and CRG members.

In 2014/15 a system was developed for carers to start working with a range of ODN stakeholders via the carers' ODN working group. The impact has been that carer representation is now fully embedded in the management of governance, risk and network development and planning. The carers group now have a system for working with the ODN stakeholders to improve services at local and regional level. As an example, the style and

content of the network website was reviewed and their feedback will now be used to update and improve the information available online.

Hepatitis C

In 2014/15, there was user representation on the London Area Team Regional panel for the assessment of providers expressing an interest in becoming lead provider centres for Hepatitis C networks. The networks are now being implemented and will enable improved access to patients for assessment and treatment with the new Hepatitis C drugs. Going forward, the networks will have a key role in working with Hepatitis C user groups and this will involve improving access to treatment for hard to reach patients accessing drug and alcohol treatment programs both in the community and in the prisons.

In focus

Patients are a critical component of our review panels

Here are some examples of how patients play a key role in peer review assessments.

Urology

The review identified problems for patients working office hours accessing the assessment service, leading to late diagnosis. As a result, the commissioner and provider are developing an action plan for 2015/16 to address issues raised in the review. Clinicians are proposing to open evening clinics to improve access for patients who are unable to attend clinics held during office hours

Testicular cancer

The review identified delays in transferring test samples between sites to the assessment centre.

As a result the Trust is proposing to improve arrangements for transport of samples between sites. For 2015/16 the commissioner and provider are developing an action plan for 2015/16 to reduce avoidable delays between assessment and treatment.



Our Chief Nurse, Caroline Alexander, meeting a valued member of one of our patient groups at an event in March 2015

In focus

Active patient involvement across specialised service development

Cancer and cardiac services

A case for change *Improving specialist cancer and cardiovascular services in north and east London and west Essex* (October 2013) described how some specialist treatments for five types of cancer and heart disease needed to be provided in fewer hospitals. We worked with University College London (UCL) Partners to determine the best positioning of these services. A 38-day engagement exercise was undertaken to inform the development of commissioners' recommendations. In 2014/15 the programme undertook a second phase of engagement and further scrutiny to enable local people to offer feedback on commissioners' preferred options and input into planning the implementation work. For instance, as travel and access has been raised consistently during the first engagement phase, an advisory workshop on this issue (and others

including pathway integration and managing impacts on other services) was held.

The programme is engaged with all interested and affected patients and community groups in the area, and the team liaised with local branches of Healthwatch to receive their feedback and ensure that all affected groups were included. We are awaiting the final outcome of this and its impact on the services.

Gender surgery

London and South regional commissioners have worked with contracted male to female surgery providers to produce a national capacity plan that will deliver access to gender surgery within 18 weeks during 2017/18. The draft service specification and commissioning policy for gender identity services were subject to public consultation in March 2015. The final specification and

commissioning policy will be subject to national prioritisation during 2015/16. We will feed back on the outcome and how this has been taken forward in our next annual report.

Hepatitis C: Sofosbuvir early access scheme

Two user representatives were on the NHS England (London) evaluation panel for the tendering for recognised lead centres that would provide high cost drugs to treat and cure Hepatitis C. Six London centres were nominated under the Early Access scheme.

It paved the way for the introduction of the second tranche of new Hepatitis C drugs and the development of the Hepatitis C operational delivery networks.

In focus

How involving patients in specialised mental health services has transformed care across the capital

Individual patient participation is integral to the care provided within specialised services in particular mental health services. Some of the key areas where patient and user involvement has had positive effects on care and service provision on a more personal level are shown below.

Transforming care: care and treatment reviews

Care and Treatment Reviews were undertaken during 2014/15 with adults, young people and children with learning disability and/or autism who were being cared for by specialised mental health services. Through these meetings with the service user and the service user's Multi-Disciplinary Team, we were able to work with service users to review their care, treatment and pathway options. This resulted in a proactive process of discharging 16 service users into community

settings and transferring a further 10 patients into a more suitable hospital setting during 2014/15. Our forward plans for next year are to continue to identify placements in the community, and packages of care to support service users with required treatment and service needs. We will also take part in discussions across London on market development along with CCGs.

Secure mental health services: service user/professional forum

As part of the National Outcome Recovery Group, the service user/professional forum provided an opportunity for us to work with clients to develop care pathways and improve user involvement. The impact has been seen in good participation from service users and we are delighted that the forum was very well presented and organised by an ex-service user. For 2015/16, we will focus on patients

taking the lead on chairing their formal care planning review meetings and continuing to engage with personalised care planning.

Service users and professionals presentation

An Assertive Treatment of Recovery Resistant Patients with Severe Anorexia Nervosa Conference was held and there were presentations by service users and professionals. This provided an opportunity to review procedures for interventions and management of Nasogastric/Percutaneous Endoscopic Gastrostomy (PEG) feeding. As a result, the issues of consent for voluntary patients and those detained under the Mental Health Act were highlighted. To build on this for the next year we aim to continue the Multi-Disciplinary Team review with patient and carers and, using a collaborative approach,

In focus

analyse all possible courses of action considering benefits and consequences.

Child & Adolescent Mental Health Services (CAMHS) patient treatment plans

We supported the redesign of services and the treatment plan for a young person with complex needs to improve their inpatient care experience and promote their discharge to an appropriate residential setting. Through the Care Programme Approach, Mental Health Act Tribunal meetings, parental involvement and an advocacy group (the Challenging Behaviour Foundation), more lateral thinking on treating challenging behaviour and modifying staff intervention led to an improvement in the young person's presentation and consequently, discharge to a suitable community placement was supported. The impact has been positive progress towards joint agency working with local CAMHS and using person centred planners to inform professionals involved to keep young

people within the community. In 2015/16, we will continue to explore commissioning of complex packages of care and expertise to enable care in the community, moving away from inpatient treatment.

Environment development

Through patient user groups we gained feedback from patients on the neuro-rehabilitation environment at St Marys at Roehampton. The outcome was a better environment and patient experience. The impact was streamlined targeted services for rehab patients which we hope to build on in 2015/16 through implementing new services.

Public consultation on changes to specialised mental health services in South West London

In partnership with CCGs in South West London, NHS England (London) ran a public consultation and a series of engagement events between 29 September and 21 December 2014 on proposals for the

reconfiguration of mental health inpatient services in South West London.

Many people who access the specialised mental health services in South West London live outside London. In order to ensure as many people as possible were able to participate in the consultation, our Specialised Commissioning team held a dedicated consultation event about the proposed changes that was streamed live over the internet and remained available for people to view until the end of the consultation period.

Based on the consultation responses, NHS England (London) approved the preferred option to site specialised mental health services in two new centres of excellence in March 2015. The new buildings will be built by 2021 and will give people the best chance to recover in the best environment, significantly improve estates, support staff to deliver high quality care and ensure that services are sustainable in the long term.

Looking forward: specialised services

During 2015/16, the team will:

- ▶ Showcase how patients' comments have directly influenced the design of services and the impact they have had.
- ▶ Identify opportunities to build on our achievements. One example is with the HIV patient representatives/service users as stakeholders within the London Clinical Advisory Groups. There will be further work to align service specific strategies with the NHS England-wide strategy to ensure there is parity in access for users in expenses, training and support.
- ▶ Continue to work with Operational Delivery Networks across London to develop the governance structures, board and steering group processes from the London Neonatal work and to replicate this work elsewhere in the networks.
- ▶ Undertake further work to align service-specific strategy with NHS England-wide strategy to ensure there is parity in access for users in expenses, training and support.
- ▶ Monitor and build on the work undertaken by the peer review assessments, for example the development and monitoring of an action plan arising from the Urology and testicular cancer peer reviews.
- ▶ Continue work around *Improving specialist cancer and cardiovascular services in North and East London and West Essex* (October 2013) and the outcome of the public consultation as well as the plans to improve the access to gender surgery and the response to the public consultation.
- ▶ Work more closely with our national colleagues to share the lessons learnt from patient and public engagement and participation initiatives, recognising this is currently an area for further development and presents good opportunities to further improve our engagement within London.

Involving patients: supporting commissioners

NHS England (London) is responsible for supporting and ensuring local commissioners deliver improved health outcomes and uphold constitutional commitments.

Since April 2013, NHS England (London) has hosted and facilitated a bi-monthly CCG Engagement Leads meeting as a forum for communication, support and sharing best practice. It is also an opportunity for the London CCG and CSUs to come together to help influence and shape the development and improvement of health services.

This group co-produced a template for the 2013/14 CCG annual reports, which were required to be submitted to CCG governing bodies by the end of September 2014. These reports were reviewed by our team and feedback meetings arranged with each CCG. In Spring 2015, *Statutory Participation Duty – London CCG Summary and Case Studies 2014* was shared with CCGs.

During 2014/15, formal assurance meetings were held quarterly with all London CCGs.

A “deep dive” with each CCG was also conducted to understand whether patients and the public were actively engaged and involved. Key lines of enquiry (KLOEs) were developed based on the national assurance framework requirements (see box) and on the co-produced annual reporting template. Evidence on how each CCG complied with their statutory duties in relation to patient and public participation was requested.

Once reviewed the evidence was discussed in detail during the assurance meetings. All CCGs in North West London and South London were assessed as *Assured*, together with ten in North Central and East London. Two further ones were *Assured with Support*; subsequent support meetings have been held with them.

A report summarising good practice across London outlined in the 2014/15 assurance deep dive is being developed and will be shared with CCGs and their London direct commissioning leads to help further improve the quality of participation and engagement activity.

The **national assurance framework** requires that each CCG will:

- know their community and understand their needs
- co-develop a Joint Strategic Needs Assessment and Joint Health and Wellbeing Strategy, and participate in their ongoing refresh, ensuring alignment with the CCG’s integrated plan and commissioning intentions
- have transparent arrangements in place to feed patient and public insights into CCG decision making, including evidence from local Healthwatch, patient feedback, complaints and concerns
- commission person-centred care which promotes support for self-management, shared decision making and personalised care planning, including offering personal health budgets to all patients who may benefit
- use information technology as an enabler to delivering patient and public engagement activity.

Supporting London commissioners to engage and involve patients and the public

NHS England (London) has several directorates, including the clinical, medical and nursing directorates, which provide professional advice and support to our direct commissioners and in some cases to CCGs. During 2014/15, our team have supported commissioners by:

The Patient and Public Voice team

The Patient and Public Voice team, in the Patients and Information Directorate, hosts and facilitates the CCG Engagement Leads Group. In addition to co-production activities around CCG assurance and annual reporting, the secured and facilitated the development of a London Region CCG Insight Dashboard through the NHS Quality Observatory during 2014/15

The team also produced three editions of the Participation Opportunities Bulletin, advertising opportunities to be involved in the commissioning activities of the London regional team.

The team promoted the regional Fieldforce training offer available through the South London CSU to help build staff capacity for patient and public voice within NHS England (London). This offer was also publicised through the London CCG Engagement Leads Group.

They recruited patients and public representatives to 20 GP Access Standards focus groups. Part of the engagement process for the standards was to run a series of focus groups with key patient groups, including children and young people, learning disabilities, homeless, LGBT, over 65s etc. The focus groups enabled the perspectives of various patients to be obtained and to further develop the standards before their planned publication in November 2014.

Patient and Public Voice Statutory Obligations Steering Group

This group, facilitated by the Patient and Public Voice team, raises awareness across all

directorates of NHS England's responsibilities and co-ordinated activity around the collection of evidence for the annual statutory report. Group members act as engagement champions within their directorate.

The Patient Safety Team

This team, within the Chief Nurse directorate, provides advice to both NHS England (London) direct commissioners and CCGs on the statutory duty of candour and being open, ensuring that where there has been an incident the patient and/or family and carers have a full explanation and apology, where justified, and that support is provided where appropriate. The team also has a role in assurance of CCGs' delivery of this duty.

Safeguarding Leads

The Safeguarding Leads in the Chief Nurse Directorate talk with patients and carers when undertaking quality assurance visits to commissioned services in order to help assess the quality of provision. They also

commissioned four workshops for family carers supporting people with dementia and learning disabilities, which according to feedback has raised awareness of the Mental Capacity Act; and awarded funding to Safeguarding Adult Boards and CCGs for awareness-raising projects on the Mental Capacity Act.

Regional Infection Control Lead

The Regional Infection Control Lead supports patient-centred care in a number of ways, for example, all patients identified with a MRSA bacteraemia have to have a Post Infection Review (PIR) undertaken by their care provider. As part of this we are reviewing individual patient case reviews, which ask if patients and carers have been involved in the process, and provide a view and feedback regarding learning on individual patient care with thematic lessons. Feedback is provided at provider, CCG, regional and national level. An example of thematic response is on the implications of urinary catheters which is being addressed as part of the national HCAI strategy.

Care and Treatment Reviews (CTRs)

A Care and Treatment Review (CTR) is held for all Learning Disability patients in an assessment bed who do not have a discharge date, or where additional support is required to ensure their discharge date and plan are realistic. This is led by the Commissioning Operations and Chief Nurse Directorates.

Each CTR takes a full day, with the CCG, provider multi-disciplinary team, patient, advocate and family invited to discuss the best care and treatment options available for the patient, including whether this care can be delivered in the community. The patient, their family and/or advocate are invited to each CTR, to ensure that the patient's views are understood and factored into planning.

Two independent reviewers attend each CTR, to ensure an independent view is provided. This includes an Expert by Experience, who provides a non-clinical perspective rooted in experience of Learning Disability services. The reviewers' input is incorporated into the outcome report and independent reviewers are asked to complete a survey for each review they attend. This work ensures patients



are at the heart of decision making regarding the next steps in their care. The professionals involved in this process ensure that the best options are offered to the patient and thus they receive the best, most appropriate levels of care.

Continuing Health Care (CHC) Lead

The Continuing Health Care (CHC) Lead has worked with a national stakeholder group to develop a Single Operating Model and Assurance Framework for CHC, setting out

Introduction

Commissioning

priorities. This will determine the Key Lines of Enquiry for assurance of CCGs in 2015/16. In addition London, Midlands and East regions have worked collaboratively to develop an online Self Assessment tool for CCGs based on the priorities, known as CHAT, which five London CCGs are piloting.

A patient survey has been designed and will be built into the online tool. The tool will help NHS England identify struggling CCGs or specific areas which need improvement and can generate action plans to be monitored through the CCG assurance meetings. Survey data will give us a better understanding of whether the CHC service in CCGs provides a good patient experience, and identify areas for improvement.

Following anecdotal feedback from individuals and their representatives who have attended Independent Review Panels (IRPs) for CHC funding we understand that participation can be a daunting prospect. Individuals and/or their families are an integral part of the process, but are sometimes reluctant to attend an IRP in person. In response NHS England (London) has produced a film to provide

Supporting commissioners

information to individuals requesting a review of a CCG's decision about eligibility for CHC about what to expect when they attend.

The film includes interviews with the CHC team; panel members and family members who have attended a panel to talk about their experience.

We hope by showing what to expect at a panel, and hearing from individuals who have been through the process, we will put people at ease, illustrating that whilst still slightly formal, the panel is not like a court or tribunal hearing; panel members are friendly, will listen to individuals and make a fair decision. We hope that all individuals and their representatives will want to attend the panel, or will have the confidence to ask for advice if they need it.

Commissioning cancer services

Several advisory groups with patient input support the commissioning of cancer services across London: Cancer Commissioning Liaison Advisory Group (CCLAG), Cancer Commissioning Board, & Pan-London Cancer User Partnership Group.

Leadership

Conclusion

This work is also supported by the Transforming Cancer Services Programme.

For example the Strategic Clinical Network facilitated a meeting with children, young people and families affected by cancer to seek their opinions on oncology services - the key themes from the discussions were that better communication and information was needed, along with high quality, consistent care close to home.

Find out how we are transforming cancer services across the capital with partners, patients and the public.

Involving patients: leadership

NHS England provides leadership to the commissioning system working with national and local partners. Working with others, we intend to shape the future direction and transformation of the NHS.

London's medical directorate provides professional advice and support through their various commissioning responsibilities and programmes of work including work by the London Clinical Senate and the Strategic Clinical Networks (SCNs).

London Clinical Senate

The London Clinical Senate is a multi-professional advisory body which brings together a broad range of health and social care professionals with patients and carers to consider issues that are key to the development of London's health services.

It has an important role to play in supporting transformation of health and health care in London.

The London Clinical Senate supports commissioners, providers and other bodies to improve outcomes and make the best decisions about health care for their local communities by providing independent and impartial strategic advice and leadership.

The London Clinical Senate is one of twelve Clinical Senates in England.

Strategic Clinical Networks (SCNs)

Strategic Clinical Networks bring together those who use, provide and commission services to improve quality and equity of care and outcomes using an integrated, whole system approach.

Hosted by NHS England, SCNs work across the boundaries of commissioner, provider and voluntary organisations as a vehicle for improvement for patients, carers and the public. In this way, SCNs will reduce variation in services, provide clinical advice and leadership to inform decisions and strategic planning, and encourage innovation in how services are provided now and in the future.

London SCNs are focused on cardiovascular (including cardiac and vascular, stroke, renal and diabetes), mental health, dementia, neuroscience, children and young people and maternity. Additional clinical networks are established in: end of life care, respiratory and tuberculosis.



How patients and the public contribute to the London Clinical Senate

All of the clinical senate's work is carried out in partnership with our Patient and Public Voice Group (PPV). We believe the advice which the senate provides is stronger and has greater impact if patients and the public are involved in developing it and support its adoption.

PPV members have strong links with their local communities, including through 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 for the senate and oversees its work.

All PPV members are part of the Senate Forum which meets quarterly to debate significant strategic issues. Topics in 2014/15 included: supporting Londoners to self-care (this meeting was co-chaired by a PPV member); responding to the London Health Commission recommendations; and transforming the healthcare workforce.

Ensuring Londoners' views and experiences are brought directly into the senate debates has enhanced the discussion and influenced advice provided.

The Senate Council set up two programmes to take forward areas identified through Forum meetings as vital to improving health and contributing to the future sustainability of health services:

- Developing a framework for commissioners to support young adults with long term conditions to self-care. The Senate Forum identified this population as a gap and the programme scope was developed by the PPV. The programme board responsible for overseeing delivery is chaired jointly by a member of the PPV and a member of the Senate Council, with other PPV members involved. The approach includes several community engagement events with young adults so that final recommendations are truly co-produced and validated by those they are aiming to support.

- Using the unique opportunity of clinicians' interactions with patients to treat tobacco dependence, which is the greatest single cause of premature mortality and health inequalities. Two of our PPV members sit on the programme board and help to steer and promote the work.

During 2014/15 the Clinical Senate was also asked to provide advice on other strategic issues, including:

- The specification within a commissioning framework to support primary care transformation
- Proposals for improving inpatient mental health services in south west London

Contact the team



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How patients and the public contribute to **London Clinical Senate**

the quality and integration of care was drawn from the senate

- Plans to implement agreed changes to improve maternity, neonatal, gynaecology and paediatric services in North West London.

Every review team includes PPV members. They have a specific role in exploring how providers and commissioners of services being reviewed have engaged and responded to people affected by their proposals.

They ensure issues important to patients, carers and the public are considered and that the impact of the senate's advice on patients and carers is considered and reflected in review recommendations.

Patients, service users and carers involved in the proposals or plans being reviewed may also be interviewed by review teams to hear their views on specific issues.

Sometimes we draw in additional patient or service user views for example; the review team for mental health services included a senate PPV member with experience of mental health services and a member from Rethink.

Feedback on the value of the advice provided by the Senate has been positive. For example, the methodology used to develop the advice relating to primary care was felt to be very robust and led to changes which are reflected in the final specification.

PPV involvement has been an important factor in the strength of all the advice we provide.



How patients and the public contribute to Strategic Clinical Networks (SCNs)

Diabetes SCN

People with type 1 diabetes double their risk of developing an eating disorder such as anorexia or bulimia, and 40 per cent of 15 to 30 year old women with diabetes regularly omit insulin over concerns about eating and weight (“diabulimia”).

Recognising the importance of this issue, the SCNs for diabetes, mental health and children and young people held an engagement event for more than 100 people to raise awareness and understanding of the health challenges facing this group. Individuals were recruited through specific diabetes eating disorder charities, the SCN’s Twitter account and the voluntary sector to co-design the programme, which linked delegates from across commissioning, paediatric diabetes, adult diabetes, dietetics, psychological services, eating disorders teams and social care.

A series of multi-professional education days were commissioned and led by King’s College

London in response to delegate feedback to further this initiative and disseminate skills.

Children and Young Persons (CYP) SCN

An autumn 2014 engagement event by the CYP SCN, in conjunction with the Association of Young People’s Health (AYPH), was held to find out what young people think of health services. Participants were recruited through AYPH and via NHS England (London) and SCN social media channels.

The event provided a platform for young people to candidly share views and to consider the sort of services they would like to receive. Comments such as “help us understand where to go to get help - and please make it simple” suggest that young people find it confusing to navigate through a complex healthcare system. Further work will be undertaken to look at the specific healthcare needs of young people by the CYP Programme within the Healthy London Partnership.



How patients and the public contribute to Strategic Clinical Networks (SCNs)

The CYP SCN also facilitated a meeting with children and families affected by cancer to seek their opinions on oncology services.

Parents were asked for their views on which services should be co-located, the definition of shared care and ideal arrangements and the key issues surrounding transition to adult services.

The young people and family members were recruited using AYPH contacts and awareness was also raised via social media activities.

The key themes from the discussions uncovered the need for better communication and information, along with high quality consistent care close to home.

These views fed into the Paediatric Oncology Independent Review report, which has been finalised but not been released as yet.

Maternity SCN: 'Whose Shoes' Workshops

A 2013 Care Quality Commission (CQC) survey found that London was perceived to have the worst maternity care in England. In response, the Maternity Strategic Clinical Network piloted Whose shoes? user experience workshops across five London hospitals, providing participants the chance to explore a wide range of scenarios and topics in order to identify opportunities for change in maternity services.

Participants included maternity service users and other interested parties along with housekeepers, receptionists, anaesthetists, sonographers, ambulance staff, midwives, obstetricians, trainees, students, trust volunteers, user experience teams and commissioners.

Themes were captured by an artist on a pictorial wall, which then served as a basis for action plans that were co-designed between staff and service users, ensuring that people

Click on the picture above to view the user experience toolkit designed following the workshops

using maternity services are treated with dignity, compassion and respect at all times.

Examples of changes that have already been made to services range from the creation of new information promoting place of birth choices, to producing a film to aid smoking cessation in younger women and providing a service for women who have had a traumatic birth experience.

How patients and the public contribute to Strategic Clinical Networks (SCNs)

Mental Health SCN

People with long term conditions (such as diabetes) often have mental health issues such as anxiety and depression.

To explore the psychological needs and support required for people affected by diabetes and how organisations commissioning diabetes services can build stronger partnerships with mental health teams, the London Mental Health SCN held a co-production event for service users, commissioners, mental health and diabetes healthcare professionals and the voluntary sector through Diabetes UK.

This work was used as a basis for commissioning guidance which aims to bring body and mind back together through practical recommendations and examples of integrated models of care.

Service users were involved throughout the entire process, from the original engagement piece to informing the content of the co-

production event and the development of the guidance for commissioners and providers.

Following the development of standards for the London Mental Health Strategic Clinical Network's crisis commissioning guide, an engagement workshop was held to verify that the standards resonated with people with lived experience of mental illness.

Mind, the mental health charity, helped to recruit, facilitate and host the event. The information collated at the workshop helped to shape the commissioning standards and also build on the case studies for lived experience stories.

Key statements produced at the workshop formed the table discussions at the Crisis Care Concordat launch.

Click on the picture below to view the commissioning guidance developed with patients and Diabetes UK

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Other ways patients and the public contribute to **leadership**

Patients and information directorate

The patients and information directorate facilitated the NHS England (London) Engagement Steering Group, leading to the delivery of the patient and public engagement and participation approach for the region.

Through the Head of Patient and Public Voice, the directorate provided advice, guidance and best practice on involving patients and the public in the region's work and to meet statutory duties.

The directorate also hosted and facilitated London Healthwatch Engagement leads meetings throughout the year, bringing capacity to help the local Healthwatch branches to share information.

The directorate also developed the Transforming Participation Framework, through which the regional scrutiny framework has been implemented; developed the London Patients Voice (LPV) and submitted the 13/14 Regional Participation Duty Report.

The directorate was responsible for the effective procurement of the scrutiny provider, won by the Centre for Public Scrutiny, and for subsequent management of the contract, which continues for a second year.

A Reading Group continued to be supported to deliver a "critical friend" function in respect of providing constructive feedback on documents for publication in the public domain, and to contribute suggestions and comments for how the document might be improved for the public. Four reviews took place during the year.

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"The responses were really helpful. I collated the responses into a report which was presented at our project board meeting. As a result of the comments we are looking to combine some of the leaflets into one and also make it clearer who the audience of the leaflet is."

Author feedback

Following a patient's review of their NHS literature

Nursing directorate

Local Supervising Authority

The Local Supervising Authority (LSA) for Midwives includes lay auditors as part of the LSA Audit teams - they bring a fresh user perspective into the process and an ability to recognise how it feels to be a woman using a London maternity service. The involvement of lay auditors highlights the importance of women's views, and ensures that both Supervisor of Midwives (SoM) teams and the services they work for are regularly reminded that women's experience and views must be central to service provision and development.

London LSA currently has seven LSA lay auditors undertaking the role; this gives them the opportunity to undertake up to three LSA Audits each per year. The lay auditors have also been invited to attend Contact SoM meetings, speak at the annual LSA Conference and join the London Maternity Strategic Clinical Network and a number of other Maternity Forums.

Lay auditors attended all audits in 2014/15, and at most of these audits were able to speak to a group of recent users, either specifically invited for the audit, or meeting at a regular group at a Children's Centre, for example. Their views were supplemented where appropriate by brief interviews with women currently using the service, such as those in antenatal clinics, antenatal and postnatal wards.

Examples of where lay auditor comments or recommendations have been acted upon during the last year include:

- At St George's, the previous audit mentioned the birth centre rooms looking a little clinical, with the bed as the focus in the middle of the room and the resuscitaire visible. This year, the bed had been moved to the side of the room, and the resuscitaire moved outside.
- At Epsom & St Helier, the lay auditor recommended strengthening links with the MSLC. In 2014, a lay member of the Maternity Services Liaison Committee



Contact the team



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Nursing directorate

attended the audit, and there was evidence of SoMs working to recruit new members through direct contact with women, and via Children's Centres.

- At Homerton, the lay auditor recommended that the team promote and raise visibility within the hospital. In response the team produced a SoM bookmark with an overview of the role of Supervision and how to contact a SoM, which is included in the woman's notes at booking.

Lay auditors were originally recruited to the role in 2012 when they received two full days of training. They have received annual updates from the LSA since commencement of the role in 2012. This has included report writing, sharing good practice and raising the profile of the Service user's voice.

There has not been a need to recruit additional LSA lay auditors to the role in London during 2014/15.

Despite having spent three years working on LSA audits in London, and often having a number of years' involvement with local Maternity Service Liaison Committees, the lay auditors are still able to provide an outside perspective whilst developing a greater understanding of the technical language, and becoming more familiar with the maternity services in London.

Compassion in Practice

The Chief Nurse for London has also led on the implementation of Compassion in Practice in London.

During 2014/15, the team developed a compassion in the community film which aims to identify the culture, environment and conditions required for effective compassionate leadership to develop and flourish, and to showcase compassion in a non-acute hospital setting. Service users and clinical staff worked together to produce the script and service users appeared in the DVD. This was launched in February 2015.

Click on the picture above to view the short compassion in the community film on youtube

On 25 March 2015, the directorate hosted the Leadership, Culture and Compassion Conference. This included an expert in patient and public involvement chairing the My life, my journey: Patients in control workshop. Facilitators included the Patient in Control Lead and a patient leader, identified and recommended through discussion at the Conference Steering Group. The workshop was an opportunity to:

- Hear feedback from patients and carers about what helps them be in control
- Understand the carer's experience

Nursing directorate

- Listen to a patient's story of living with a long term condition and what's important to him to maintain his sense of self
- Consider how patients play a critical role in leading their own care.

Patient experience

Finally, the Chief Nurse has also led a programme of work around patient experience. A regional Patient Experience Summit was held in July 2014, with the aims of:

- bringing together senior leaders and stakeholders across the health economy to determine a programme of action that will make real improvements in patient experience in London.
- influencing and support providers, commissioners, the NHS Trust Development Authority and others to drive improvements in patient experience and provide assurance of quality.
- through consensus, enlisting support for priority actions in London.

The event established a range of actions under four key themes: Leadership, Accessibility, Patient Feedback and Staff Experience. A multi-stakeholder regional steering group, including London Region Healthwatch, has overseen this work.

One key action arising was an engagement event with system stakeholders including patients and public alongside providers and commissioners. A half day event was held on 20 March 2015, with 37 attendees, including patient and lay representatives from the Clinical Senate Patient and Public Voice Group, Strategic Clinical Networks, Healthwatch and CCGs.

The centre point of the event was a marketplace session in which all participants, divided into small groups, were able to see practical examples of themed interventions and then discuss how they may be applied locally to effect change.

In feedback four attributes of interventions stood out:

- Focusing on a simple message which builds human connections, for example developing 'my name is...' to 'my aim is...' as a pilot across London.
- The use of ready made toolkits, backed up by evidence and research, which can support local action.
- Patient leadership is crucial, with patient buy-in implicit in every action.
- The need to measure and address the whole patient experience, along pathways, sectors and settings, rather than focusing only on individual episodes of care.

Several other reported attributes focused on different aspects of 'staff support and learning'. This included 'compassion from the top': the critical need for senior leadership to hear first-hand from patients and staff. Implementation is being taken forward in 2015/16.

Primary care transformation

In March 2014, NHS England (London) released an engagement document entitled *The London GP Development Standards: A Framework for Service Improvement*. The document was developed by a clinical board and three expert panels working in partnership with CCG leads and patients.

London CCGs and NHS England (London) worked in partnership with others to ensure that the service changes proposed in the initial draft would meet the needs of Londoners, address current and future challenges and develop a strong mandate for the overall direction of general practice development across London.

In addition, there has been further development on answering 'how' this specification could be delivered. It is clear that changes are needed to support primary care in delivering a new vision.

Starting in April 2014, NHS England (London) led a comprehensive year-long engagement phase to road test the standards through

patient focus groups, charity groups and a challenge panel of multidisciplinary clinicians. The development of the specifications was also overseen by a Clinical Board, Patient Board and Transformation Board.

The patient focus groups consisted of 20 separate cohorts, representing different demographics – for example mothers with children, commuters, carers, gypsy travellers, homeless, those living with chronic diseases, teenagers, dementia sufferers etc. Each focus group discussed their particular needs in terms of accessible care, coordinated care and proactive care through structured and facilitated sessions lasting two hours.

Travel expenses were paid to enable and encourage people from all sectors of society to attend meetings as required. To further engage with people, the team went outside of London, including visiting travellers communities. A number of half day charity events were organised to gain their views on specific topics.

In addition, the Patient Board had 25 members and met every two months from June 2014 to review and input into the *Transforming Primary Care in London: A Strategic Commissioning Framework*, which they approved and was published in March 2015. The *Framework* aims to support primary care transformation across the capital.

This work is being taken forward by the Healthy London Partnership, which launched in March 2015.

Transforming community services in London

The TransformLDN initiative was established in July 2014 between the nursing and transformation teams, with the support of a network of leaders from health and social care from all 32 London boroughs. Its aim was to create a shared vision that binds all to a community-led revolution in health and social care in London.

What we did

A new vision for London's community services was co-created based on research, best practice and patient and staff feedback via National Voices. An early draft was shared through crowdsourcing, online workshops and a conference, the result of which was our Declaration. It contains four foundations for excellent community services:

- Get personal
- Focus on outcomes
- Make boundaries invisible
- Real leaders, happy workforce.

Over 1,000+ people from 150+ organisations got involved and shared their views contributed to the Declaration.

Service user feedback was used to test and refine the Declaration by

- Four face to face focus groups with people with long term conditions, older people, young mothers and young people
- Online workshop (crowdsourcing)
- Literature review of papers relating to patient centred care

The findings were tested back with the patients who took part in the crowdsourcing to ensure that they were reflective of their views. This created an updated Declaration based on the combined views of staff and service users.

This initiative is being taken forward through 2015/16.

Find out more



www.transformldn.org

OUR DECLARATION*

We declare that a community-led revolution in
HEALTH & SOCIAL CARE WILL TRANSFORM
 THE HEALTH AND WELLBEING OF
London

THE FOUNDATION OF OUR REVOLUTION HAS FOUR PARTS...

<p>CARE IS ABOUT ME</p>  <p>ME AND MY FELLOW LONDONERS ARE AT <i>the heart of care</i> EVERYTHING IS PLANNED & DELIVERED AROUND OUR NEEDS</p>	<p>MAKE LONDON <i>healthier & happier</i></p>  <p>LONDONERS LEAD HEALTHIER AND HAPPIER LIVES, WITH LESS TIME SPENT IN HOSPITALS</p>
<p>WORKING AS ONE TEAM</p>  <p>EVERYONE INVOLVED IN MY CARE, REGARDLESS OF WHICH ORGANISATION THEY ARE PART OF, WORKS AS ONE TEAM</p>	<p><i>Happy staff</i> WITH THE RIGHT SKILLS</p>  <p>THE PEOPLE WHO CARE FOR ME, AND THEIR LEADERS ARE INSPIRED, MOTIVATED AND SKILLED</p>

*1,000+ service users and health and care staff, from 150+ organisations, representing all 32 borough of London, have created this declaration together through a process of crowdsourcing. Find out how you can use it and how you can join our movement today at www.TransformLDN.org

Transforming cancer services

In April 2014, the Transforming Cancer Services team was established to provide pan-London leadership for cancer across the system and provide cancer commissioning support and expertise to 32 Clinical Commissioning Groups and NHS England (London). The team works in partnership with partners, patients and the public to deliver improvement.

Some examples of how they involved patients and the public are shown below:

Work on understanding cancer waiting time

Members of the Pan-London Cancer User Partnership (PLCUP) undertook an evaluation of patient choice issues as they relate to cancer waiting times breaches. This was fed back to the Transforming Cancer Services team (TCS) and informed work to improve on waiting times.

Remodelling of the National Cancer Patient Experience Survey

A group of patients and carers, along with health professionals and commissioners, advised on themes for the remodelling of the National Cancer Patient Experience Survey through a joint workshop with NHS England.

The group's input was presented to NHS England towards the development of the new survey.

National Cancer Patient Experience Survey results

The PLCUP reviewed and appraised the survey results. This led to identifying the Trusts in London that have improved their patient experience and recommending service improvement initiatives.

Get to Know Cancer initiative

The TCS team recruited and commissioned training for volunteers - cancer activists - to support the Get to Know Cancer campaign. The team ran three cancer pop-up shops and

coordinated the involvement of cancer activists and charity partners.

Throughout the 2014/2015 football season the Get to Know Cancer stall was present at Tottenham Hotspur each month. Cancer activists and charity partners attended to promote the Get to Know Cancer messages.

Prostate Cancer Project

The project, which began in 2012, aims to establish a prostate cancer follow up service in the community. In the previous two years focus groups were held with men with prostate cancer to establish what level of service would be acceptable.

In 2014/2015 surveys were produced for patients already receiving community follow



Transforming cancer services

up under the old system and those about to be discharged to the new follow up system. A follow up survey was also sent out after they had received their new appointment with the GP, a HNA form and prostate cancer information.

The project is due to report in December 2015.

Increasing user involvement across the TCS team

Patient representatives play an active role on the Living With and Beyond Cancer Long Term Conditions sub group and the Early Detection Advisory Group.

Patient/carer representatives continued to sit on the Cancer Commissioning Board, Cancer Programme Executive and the Cancer Clinical Leadership Advisory Group to inform design, delivery and commissioning.

All Londoners set to receive the best cancer care in the world

Healthy London Partnership is taking up the work of the Transforming Cancer Services team. It is delivering the *Five Year Cancer Commissioning Strategy* (April 2014) to ensure patients are diagnosed sooner and receive the same effective, high-quality care wherever they seek treatment in London. It focuses on five key areas:

- Improving early detection and awareness
- Developing centres of excellence and reducing variations in quality and experience
- Helping people living with and beyond cancer
- Supporting commissioning and contracting
- Improving patient experience.



Contact the team



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Conclusion

This annual report demonstrates the impressive enthusiasm and commitment of both lay members and staff to improve our effectiveness as an organisation by involving and engaging patients and the public in the most appropriate ways across a wide range of activities. It is clear that while there are pockets of excellence, variation remains in the scope, methods and outputs of patient participation across this organisation and an on-going need to understand the best ways to involve and engage in different circumstances and to improve sharing of best practice. It is our intention to continue to work to improve how we engage and involve Londoners to help us make decisions which improve services across all health settings and to get better at demonstrating the difference they are making.

The contract with London Patient Voice to provide independent scrutiny of our work has been extended for 2015/16 providing continuity and opportunities to build on and evidence recommendations. In addition, LPV's experience of the first year will allow them

to enhance and adapt their approach and to scrutinise new areas for which there was limited review in year one.

In March 2015 NHS England London took part in a national stocktake of participation and engagement activity, which highlighted the amount of patient and public related work underway in all areas of commissioning business and from departments whose contributions influence and enhance the quality of that commissioning.

This work will culminate in consultation on new guidance relating to arrangements for involving the public in commissioning processes, specifically in planning, reporting and governance structures. The new guidance will form the basis of training programmes for staff.



Get involved

NHS England considers working in partnership with patients, carers, service users and the public to be central to the way that we work. Hopefully this report will have 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 capital city.

We are committed to ensuring that public and patient voices are at the heart of shaping our healthcare services. There are always opportunities arising for interested individuals to become more involved.

We want to involve people from diverse backgrounds offering as wide a range of knowledge and experience as possible. Relevant training will be offered according to the needs of each situation and the level of commitment required will be set out clearly at the outset.

So, if you want to know more about how you can participate, please let us know.



Get in touch



england.qualityhub@nhs.net



[@nhsenglandLDN](https://twitter.com/nhsenglandLDN)