Report from London Patient Voice

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

June 2015

Chair's foreword

I am delighted to be the first Chair of London Patient Voice (LPV), working with a committed team of members, scrutinising NHS England London Region's (NHSELR) implementation of their obligation to involve patients and the public in their service commissioning decisions.

This report covers the work of NHSELR during the year 2013/14, the first year of operation since the implementation of the Heath & Social Care Act 2012. This obligates public and patient involvement in the provision of NHS services. Since 2012 there has been considerable and ongoing reorganisation within the NHS, and this was a challenging backdrop against which to conduct our investigation, as many staff - including the author of the NHSELR report into patient engagement - no longer held the posts that they had occupied during the period we were concerned with. It was also a challenge to identify who we should be speaking to in each commissioning area. It was not until March 2015 that the panel had the contact details they needed to begin their investigations.

As part of our investigations, we met a number of senior staff who exhibited a passionate commitment to public and patient involvement, often above and beyond that which was mandated in their job descriptions.

I am pleased that LPV has been able to find evidence of good patient engagement, and this is outlined within this report. This was the first year of operation, and much progress has already been made in the intervening period. We hope both that this progress will continue, and that the recommendations contained herein will be implemented as part of that development.

I want to thank all of the NHSELR staff and the public and patient representatives that took the time to meet with LPV members and give us the information needed to complete our work. I would also like to thank the Centre for Public Scrutiny for its support in making London Patient Voice a real 'critical friend'. And finally, a big thank you to all the members of the London Patient Voice panel for their hard work, support and commitment.

Sandy Marks

Sandy Marks – Chair London Patient Voice
June 2015

Contents

Executive Summary

London Patient Voice (LPV) is an independent citizen scrutiny group, which has the role of reporting on how NHS England London Region (NHSELR) implements its statutory participation duties, and involves patients in commissioning decisions. LPV has been tasked with making an independent evaluation of the NHSELR's account of how they met the duties, and producing an independent report on its findings.

Overall, we are pleased to see that many of the areas we looked at had started to set up systems, and in some cases were able to demonstrate a good start.

In March we met with the Director of Patients and Information, and Head of Patient Experience and Quality, we were pleased to see that many of the areas we would be looking at had started to set up systems to improve public and patient involvement, and that there was determination to ensure that the patient and public voice was heard.

Our research has found areas of good practice and a strong commitment from staff, and we highlight this throughout the report; however some examples include:

- Good chairing – by knowledgeable committed people with an inclusive style.
- The proactive and innovative use of social media to listen to the voices of patients in real time.
- Parity of esteem of patient 'lay' members within some of the areas reviewed by LPV.

But inevitably, given that this was the first year of NHSELR, there are areas for further development, and better ways of sharing and communicating the good practice that could be developed.

Members of LPV were assigned areas of research, and interviewed many people including commissioning leads, chairs of commissioning groups and patient / public lay members. Whilst the retrospective nature of this review presented challenges, LPV members discussed current activity as part of their investigations. This evidence does not feature within this report but the key messages below summarised from the 2013/14 review of activity are pertinent to current activity by NHSELR.

<u>Consistency of patient involvement practice</u> - during the course of our work, LPV searched for a link to clear, written policy document on the NHSELR's webpage

stating how the voice of the patient was listened to when commissioning decisions are being made. We were unable to find one.

Giving parity of importance - LPV feels that to be successful in helping to deliver better outcomes and improving services, patient voice must achieve parity of importance alongside Clinical Safety, Quality Assurance and Best Value.

Valuing lay members and equipping them with the training that they need to play a full role in influencing commissioning decisions will improve the impact of such engagement.

More than involvement – Feedback is vitally important to show lay members that they are contributing and evidencing impact.

Recruitment of lay members - *Londoners should be confident that lay members are representing and reflecting their views. While continuing to value the skill, knowledge and experience of current lay members NHSELR should also ensure that recruitment of new members better reflects the demographics of London's population*.

Conclusion

LPV concludes that against a background of challenging demands and circumstances, NHS England London Region 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. It is clear from our investigations that some areas have been able to achieve more than others in their patient engagement work; however LPV is satisfied that progress is being made and looks forward to supporting this journey in our participation report in 2015.

LPV would be keen to continue its work independently reviewing the way that NHSELR involves patients and the impact this engagement has. In particular it would like to focus on:

- Whether recruitment has become more transparent and inclusive.
- The consistency of training across commissioning streams.
- The transmission of best practice between lay members in different commissioning streams.
- Evidence of corporate hard wiring of the need and benefits of listening to the patient voice.

Recommendations

Our research, investigations and group discussions have led us to make the following recommendations to NHS England London Regional Team to improve their approach and practice in ensuring real participation and impact from their patient engagement. LPV recommends that:

1. To embed patient voice in commissioning, consideration should be given to producing a clear, concise statement of NHS England London Region's understanding of the practice and benefits of patient participation and engagement, support for lay members and how they will be recruited.
2. A Patient and Public Lay Member Recruitment Policy is developed. The policy should:
    a. Ensure that there are clear and transparent systems for appointing patient and public representatives to groups and committees.
    b. Provide for consistency across all commissioning areas.
    c. Address questions of equality, diversity, and access.
    d. Include a set of principles that can be followed to ensure the above is adhered to by all commissioning areas.
3. A corporate induction process is developed for appointed lay members. The induction should include:
    a. An overview of NHS England – its role and duties.
    b. An overview of NHS England London Region – its role and duties.
    c. Specific commissioning strand training to provide more information of the field that they lay members will be working within.
    d. Developing 'softer skills' of lay members - e.g. speaking up in meetings, influencing skills – to ensure that they are able to play a full and active role.
4. A review of Good Practice in patient involvement is conducted. This should include:
    a. Mapping out the different ways that the public and patients are involved.
    b. Appraising the different methods of engagement and understanding which approach works for which situations e.g. social media Vs focus groups.
    c. Highlighting areas of good practice.
    d. The development of a central good practice resource to avoid re-inventing the wheel when seeking to engagement with patients.
5. Commitment to listening to the voice of the patient is embedded within NHS London by making a named Director responsible for leading on Patient and Public Participation. Further, a senior member of staff for each commissioning strand should assume the lead responsibility for public and patient engagement

within that strand – this should be within their job description and sufficient time and resources identified and allowed for the role. They should be encouraged to seek out and, where appropriate, implement best practice from other organisations.

6. The Director identified in recommendation 5 should be charged with producing an annual report on Patient and Public Participation which is posted on the NHS England website. This should include an executive summary that is emailed to all NHS England London Region staff.
7. The identified senior members of staff to meet at least twice a year to provide a whole organisation view of patient participation and provide for further development.
8. Funding is made available to meet any identified training needs, including appropriate training for Chairs to support them to ensure that the views of lay members are represented in meetings.
9. There should be a named officer who will be the liaison point for future London Patient Voice investigations. This should be the director referred to in recommendation 5.
10. That NHS England London Region take account of and respond to the recommendations made by LPV within this report, and feedback to LPV on where recommendations have been implemented, modified, or rejected.
11. That NHS England London Region continues to support the independent scrutiny of its statutory duties via London Patient Voice supported by the Centre for Public Scrutiny.

In addition to these recommendations, LPV makes a number LPV of service specific suggestions throughout this report.

Context

The Health and Social Care Act 2012 imposed new duties on NHS England as commissioners of health services. These participations duties are:

Health and Social Care Act 2012 Participation Duties

Individual Participation

NHS Commissioners must promote the involvement of patients and carers in decisions which relate to their care or treatment, including diagnosis, care planning, treatment and care management. This duty requires Clinical Commissioning Groups and commissioners to ensure that the services commissioned promote involvement of patients in their own care including: personalised care planning, shared decision making, self-care and self-management support information with targeted support.

Collective Participation

NHS commissioners to ensure public involvement and consultation in commissioning processes and decisions which includes involvement of the public, patients and carers in: commissioning activities, planning of proposed changes to services monitoring, insight and evaluation.

NHS England London Region (NHSELR) is responsible for commissioning a range of health services across London and, as a Commissioner, must provide opportunities for Londoners to participate in the commissioning of services.

NHSELR has acted to give patients the opportunity to contribute to the commissioning process and is now keen to review how effective and inclusive its established framework was during its first year of operation (April 2013 – 2014). It therefore sought to establish an independent scrutiny body to carry out an independent review – this body was London Patient Voice.

About London Patient Voice

London Patient Voice (LPV) was established as the independent body to hold the NHSELR to account for how it is meeting the above statutory participation duties and how it ensures there is patient and public participation across the range of its commissioning activities.

The concept of LPV was developed by patients alongside public and voluntary sector participants at a NHSELR Co-design Event in December 2013.

The Centre for Public Scrutiny (CfPS) successfully tendered and was commissioned to enable the creation, development and support to LPV during its research. The CfPS recruited a total of 8 members of London Patient Voice through an open public process in the second half of 2014 (this later reduced to 7 members). The CfPS was seeking people with a strong commitment to maintaining a patient focus in the commissioning of health services for London, as well as a good understanding of the legal framework and relevant guidance relating to patient and public involvement in health.

The members of LPV are Londoners from a diverse range of backgrounds. All are service users with no conflicting interests.

LPV aims to fulfill the role of critical friend, to provide fair and objective comments and make constructive and realistic recommendations.

LPV Members

Sandy Marks – Chair
David Winskill – Member
Janice Tausig – Member
Juliet Campbell – Member
Nermine Taylor – Member
Two Young People from Mentor UK

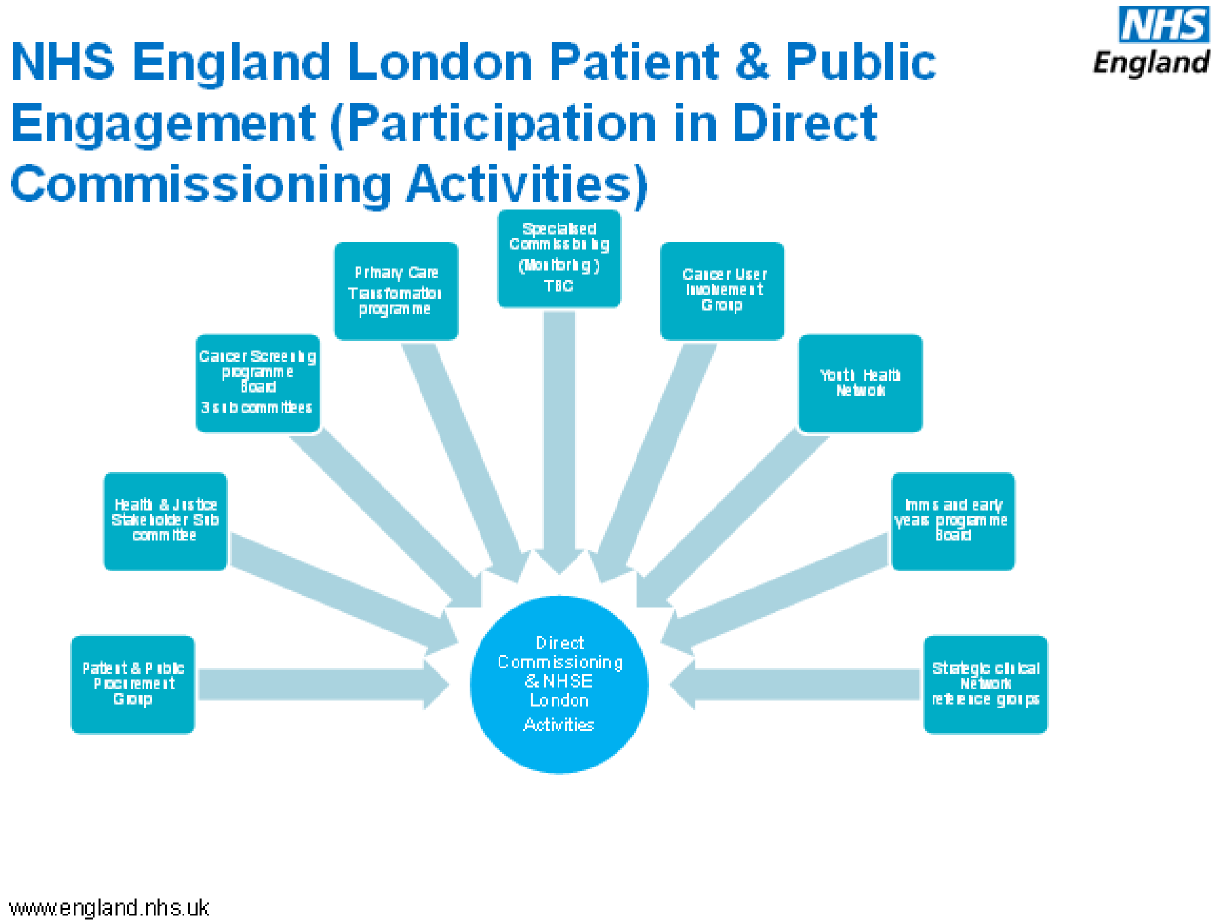
Methodology

LPV have met collectively over a number of occasions and also met with NHSELR commissioners and lay members. The following table details more fully their timetable for this project.

Sept 2014	LPV members appointed.
October - November2014	LPV member development sessions.
December 2014	Report delivered by NHSELR.
January 2015	LPV meeting to plan work programme and areas of responsibilities.
January / February	LPV began to research contacts and the commissioning work

2015	of NHSELR.
March 2015	LPV meeting with Lead Managers to gain a broad overview and map out remaining work required. Following the staff re-organisation, LPV received an updated contact list of people responsible for Patient and Public Involvement in the region.
April/May 2015	Meetings and interviews with Commissioners, Chairs of boards, and some lay members.
May 2015	LPV meeting to share preliminary research.
June 2015	LPV meeting to share conclusions and agree recommendations.
End of June	Final report delivered to NHSELR

The diagram below was used within the NHSELR's statutory obligations report, presented to LPV in December 2014. It portrays the many ways that patients and the public are involved in influencing commissioning decisions.



NHS England London Patient & Public Engagement (Participation in Direct Commissioning Activities)

www.england.nhs.uk

However for the purposes of this report, LPV has researched the following service areas and taken an approach as to whether NHSELR has met its collective and individual participation duties:

LPV has undertaken a review of the following areas:

- Primary Care Transformation
- Primary Care including:
    - General Practice commissioning
    - Dentistry
- Health in the Justice System
- Public Health including:
    - Screening
    - Early Years and Immunisations
- Cancer including
    - London Cancer Programme Board
    - London Cancer Use Partnership
- Patient and Public Procurement Group
- Strategic Clinical Networks
- Patient Voice Reading Group

The LPV report below describes the investigations, observations, comments and also highlights good practice that should be shared more widely. The report lists the individuals interviewed (by title) during this scrutiny in the evidence table at Appendix 1.

Primary Care Transformation

NHSE London Participation and Engagement Report 2013/14 said……
Extract from report

Supporting commissioning activities:
Engagement in primary care transformation - The Primary Care work stream has set up a range of user and public activities. This includes the formation of:

- A Primary Care Transformation Patient Board, Primary Care Transformation Clinical Board and the Primary Care Transformation Delivery Group.
- A range of patient focus groups.
- Identifying patients to join the GP standards Expert Panels.

Impact of involvement - The Patient Board has been reviewing many of the key documents produced by the programme and this will be fed into the Primary Care Transformation Board.

NHS England London Region's (NHSELR) Primary Care Transformation programme was part of the Transformation Directorate. The programme's role was to:

- Carry out a diagnostic of the state of London's primary care.
- Consider if it was fit for the delivery of services to meet the changing needs of the population.
- Establish a case for change.
- Detail a specification for London in the future.

The programme started in November 2013 when NHSELR published *Transforming Primary Care in London: General Practice a Call to Action* which examined the challenges facing general practice in London. This showed that London contains some examples of excellent general practice but that urgent action was needed to tackle significant variations in quality. The challenges identified included an increasing workload, an expanding population, and people living longer - with increased care needs.

The Primary Care Transformation Team brought together clinicians, patients and commissioners from across the capital to form three 'Expert Panels' between November 2013 and March 2014. They developed a strategy for service improvement and a case for change in three key areas:

- Proactive Care.
- Accessible Care.
- Coordinated Care.

The draft 'standards' (now known as 'specifications') were finalised in March 2014 by the Expert Panels and published in draft as *Transforming Primary Care in London: A Strategic Commissioning Framework*, which was then subject to 'road testing' during the following year (outside of the remit of this LPV review).

Evidence of engagement identified by LPV

- LPV found that Expert Panels had been created for each of the three key areas (bulleted above).
- Patients / lay members were involved in each of the Expert Panels. However these were people who were already involved with the NHS. Because of this – no formal training was offered or undertaken – other than clear and concise aims and objectives being given to the group at its meetings.
- The Chairs of each of the panels were effective in involving patients in the meetings, by ensuring that patients had an opportunity to have their say and ensuring that Doctors listened to patients and understood the difficulties that they were facing.
- The work that the Expert Panels were involved in was time limited, specific and focused. Patients made a difference because the Chair set out to involve them in devising the suite of 'specifications'; patients drew conclusions and made recommendations.
- Notes of every meeting were taken and circulated – some of which were seen by LPV.

Highlighted Good Practice - Accessible Care Expert Panel

From the evidence gathered, the Chair was very experienced and had a very clear idea of his role and knew how to work with patient 'lay' members to encourage and support them to participate and contribute. The Chair explained the aims and objectives of the panel to all members so that they were clear and workable. He would ensure that all those around the table including patient 'lay' members contributed in the meeting. LPV was able to test this out in an interview with a patient 'lay' member. 'Everyone felt that they were able to say what they wanted and felt that their time was well spent'.

LPV findings / observations

Whilst LPV was unable to see these Expert Panels 'in action', LPV has found evidence of effective patient 'lay' member involvement, and has outlined its reasons in the text above, however it would make the following suggestions to NHSELR:

- Feedback is vitally important to ensure that patients can see the impact of their contributions. Whilst good record keeping was kept of meetings and notes circulated; what was missing was the circulation of a final draft of the 'specifications' that each of the groups had created.

- Sharing work across the key areas – the patient that LPV interviewed felt that they had created a set of usable specifications – but would have liked to have known more about the other two Expert Panels – therefore LPV suggests that NHSELR create a briefing that shares patient engagement across the whole organisation and also with those lay members.

Primary Care

NHSE London Participation and engagement 2013/14 report said…..
Extract from report

Collective duty

Evidence of commissioning to support patient & Public engagement at GP practice level - GPs across London participate in a Patient Participation Group (PPG) Directed Enhanced Services (DES) which we as commissioners monitor and pay for if the requirements are met.

Impact of commissioning- Practices sign up to the PPG DES which requires that they constitute a patient participation group which reflects the demography of their practice population. It also required practices to establish and support patient participation groups which would have mandated input to the running and planning of services.

Individual duty

Evidence of commissioning to support patients in control- Practices are signed up to the Proactive Case Management DES.

Impact of commissioning- This DES pays practices to work with patients with long term conditions to agree care plans that support them staying healthy and out of hospital.

Evidence of commissioning to support patients in control - The creation of a Pan-London APMS service specification placed a requirement (rather than a choice) upon GP contractors to promote expert patient schemes and involve patients in decisions about their own care, including the method of consultation. Key Performance Indicators were included in the contract, including patient satisfaction measures.

Impact of commissioning - 5 APMS contracts were re-procured using the new specification, affecting more than 25,000 patients.

From April 2013 NHS England London Region (NHSELR) , as others, took on the role of commissioning primary care health services, as well as some nationally-based functions that were undertaken previously by the Department of Health.

Primary Care in London had been split in to three areas: *North West; North East and Central; and South*. In 2014, this was changed to five areas that enabled a more integrated way of working and they are now able to cover the whole of London as a team which has improved communication.

Within this section of London Patient Voice's review of patient participation in 2013/14 the focus has been on the commissioning of:

- General Practice
- Dentistry

General Practice

During 2013/14, NHS England London took over responsibility for commissioning and contract managing General Practice.

LPV was able to interview some of the Heads of Primary Care to form a partial view of patient engagement for the period in question.

Evidence of engagement identified by LPV

- Since 2013 NHS London Primary Care Commissioners continue to review contracts basing them around, access to good quality care, monitoring General Practice with an emphasis on supporting GPs in coordinated patient care and encouraging patients to be proactive in looking after themselves. They appear to be more hands on and pro-active.
- All new GP contracts are Alternative Provider of Medical Services (APMS) contracts, which are more heavily weighted towards performance against key performance indicators. This means that if a GP is not meeting targets, NHSE is able to monitor shortfalls more easily and may refuse to renew a contract. As APMS contracts are time limited, when a GP contract is due for renewal, the tender process is designed with patient / public engagement embedded within the selection criteria. Patients are asked to comment via surveys, via Patient Participation Panels, via focus groups or by directly talking with commissioners who take these views into account. For example when negotiating new or renewed GP contracts.
- LPV was told that the design of the tender process involves the Procurement Manager to ensure that it meets legal requirements as well as patient engagement objectives.
- LPV was told of a 4 stage process to the procurement / re-procurement process of General Practice: Stage 1 takes account of patient's needs and viability; Stage 2 face to face engagement with patients; Stage 3 a survey; Stage 4 procurement.
- During 2013/14, much of the preparatory work was undertaken for a toolkit for patient engagement in Primary Care. The toolkit was launched in 2014 ensuring consistency across a restructured service.

- General Practices are now legally required to have Patient Participation Groups to ensure the effective and responsive running and planning of their services encouraging proactive care.

From 2014, Clinical Commissioning Groups (CCGs) took on an increased role in the commissioning of Primary Care services, by becoming Co-commissioners with NHS England. The intention was to empower and enable CCGs to improve primary care services locally for the benefit of patients and local communities.

LPV findings / observations

LPV has found some evidence of effective patient 'lay' member involvement however it would make the following suggestions to NHSELR:

- General Practice commissioning has changed and as commissioners of new practices; there has been some evidence that NHSELR involve patients in assessing the effectiveness of services and whether to re-procure services or disperse patients; however LPV found instances when this did not happen. LPV suggests that commissioners review how patients are involved in General Practice Commissioning to ensure consistency. LPV is keen to follow this through in more detail in a future review.
- The change in contracting to the Alternative Provider of Medical services allows for greater control over services. NHSELR is better able to require and reward those General Practices that involve patients in the running and planning of services. LPV did not see first-hand evidence of this type of monitoring, and therefore it will be a focus of LPVs future work.
- There was little evidence that in 13/14 'training' was offered to patients when general practice in their area was changing. Training would have given a wider selection of patients the confidence to express their views in a manner that would have encouraged successful engagement. LPV suggests that training for patients be explored further.

Dentistry

This team is responsible for commissioning all dental and primary care optometry services within London. It sits within the wider directorate of Primary Care Commissioning.

This review focused on Dentistry – Optometry will be covered in a future review by LPV.

Evidence of engagement identified by LPV

- The NHS re-organisation in April 2013, allowed for commissioning and contract management of these services to be brought together under the management of a single team in one location in London. This was the first time that this had happened and therefore the focus in 2013/14 was to establish a clear baseline for the services, stabilise service provision where required, and develop single and consistent operating procedures.
- Consequently LPV found that there was very little patient engagement during 2013/14. LPV was told that this was intentional; that before they engaged with patients, they wanted time for the changes to bed in, challenges to be responded to and for staff to be fully aware of the new service and their roles and responsibilities.

LPV findings / observations

NHS England has a collective and individual duty to ensure that the public and patients are involved in their commissioning activities. Whilst LPV has some sympathy with the Dental and Optometry Service and their reasons for delaying patient engagement – it does not detract from the fact this it was a duty.

However LPV can see that the 'development' time in 2013/14 was put to good use, the commissioning lead:

- Familiarised herself with work such as that of Frances Newell.
- Developed a thorough recruitment process for 2014/15.
- Was clear about her role, and being led by the needs as outlined by experts and of the patients that use the service.

There was also recognition of the importance of engaging people in different ways e.g. teenagers are more likely to attend short focus groups; others will respond to social media and how Healthwatch can play a more important role.

Health in Justice Stakeholder Sub-committee

NHSE London Participation and engagement 2013/14
Extract from report

Collective duty

Evidence of involvement in the commissioning - Patients, carers and advocates have been involved in developing the Patient and Public Voice Framework and commissioning strategy for Health in the Justice System in London. This included co-designing our 5 year plan and recruitment of the Patient & Public Voice sub-group.
Impact of involvement - Patients and the Public have actively advised on changes to service models and specifications that were used in procurement processes. Based on their feedback, we developed our priorities for commissioning in 2013-4 including their active engagement in market development events.

Individual duty

Evidence of commissioning to support patients in control - Health in the Justice System Team included individual participation and Patient and Public Engagement in its procurement of healthcare in 3 London prisons. Individual patients and carers were asked to advise on the service planning and specification for healthcare.
Impact of commissioning - This led to service models based on self- care, self-management and patient peer mentors being awarded. There are good models of peer advocates supporting improved healthcare in London prisons including HMP Pentonville where its Prison Council is cited by User Voice, the national service user agency for people in prison custody, as one of 7 national examples of best practice.

The Health in Justice Commissioning covers specific areas of healthcare in the NHSELR, these include:

- Prison healthcare (including youth offender institutions)
- Immigration Removal Centres (IRCs)
- Children and Young People's secure settings
- Liaison and Diversion
- Police custody healthcare across England (from April 2016)
- Sexual Assault Referral Centres (SARCs) across England
- Health and Justice Clinical Reference Group (CRG)

LPV undertook interviews with 4 people: a lead Commissioner, Chair, lay member and an external organisation involved in the recruitment.

Evidence of engagement identified by LPV

- LPV was advised that there was very little done at an operational level to set up 'The Health in Justice Scrutiny Panel' between April 2013 and April 2014 – however its creation was very much on 'everyone's mind'.
- In September 2013 an event was held with patients and the voluntary sector to help Health in Justice to develop its five year plan and to gauge the direction of travel: This was the first time this was done and it informed some of the decisions made.
- In December 2013 a stakeholder event was held. The purpose of the event was to help the commissioners to embed patients and the public voice at the heart of the commissioning. Attendees were a mix of patients and professionals who drove the commissioning decision.
- Their contributions were used to create a document - The Patient Public Voice Framework, which is currently used as a guide.
- The Chair of the panel wasn't recruited until August 2014 – outside the remit of this report and scrutiny.

LPV Findings / Observations

- LPV felt that there was a visible commitment to setting up patient and public involvement to add value to the commissioning of services, however for the most part this work did not did not take place between April 2013 and April 2014.
- The stakeholder event produced a useful document the Patient Public Voice Framework; however this could have been more robust in its purpose. For example: the framework is currently being used as a 'guide' for commissioners – but that it is not binding. LPV suggests that it would have been better used as a tool where Health in Justice were specific about their commissioning intentions with regards to patient and public voice in the design and delivery of services. By using the document in a more robust way could have given Health in Justice a real opportunity to evidence how they have met their commissioning commitment.

Public Health

NHSE London Participation and Engagement 2013/14 said……

There was no reference to patient involvement or the impact of this involvement within the 2013/14 report.

Within this section of London Patient Voice's review of patient participation in 2013/14 the focus has been on the commissioning of:

- Screening.
- Early Years and Immunisations.

Screening

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.

Screening offers three groups of services:

- Ante-natal and new-born: (genetic tests, infectious disease tests for 30 conditions).
- Adults and Young people (non-cancer disease areas: diabetic eye screening, abdominal aortic cardiovascular screening, etc.).
- Cancer: breast, cervical and bowel.

All of these are overseen by commissioning boards (meeting 3 – 4 times a year) in addition to which there is the London Screening Programmes Committee (meeting twice per year). This oversees programme take up and looks at ways of improving coverage and uptake.

Evidence of engagement identified by LPV

- New governance arrangements had to be written and put into place whilst service continuity was maintained.
- Recognising the duties to involve patients in the commissioning process, LPV was told that lay members were recruited for the Adults and Cancer Boards

from patients and lay people that had been involved on other panels and boards. I.e. no expertise in subject matter, although they may have picked up a fair bit about how to put forward views and behave appropriately to ensure their views were heard.

- Representatives from the third and voluntary sectors were recruited including:
  - Age Concern
  - Diabetes UK
  - Jo's Cervical Cancer Trust
  - ARC
- Recruiting from these sectors had the advantage that individuals would bring a great deal of knowledge about specific disease areas and the demographic groups that Screening sets out to serve.
- LPV were told that lay members make significant contribution to the work of the boards. They are able to criticise and identify problems where programmes are not working properly. 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 and may become follow-up actions.

LPV findings / observations

LPV is of the view that the Screening Service clearly recognised both the duty and the desirability to involve patients in commissioning and took appropriate steps, both internally in the business unit, as well as working with experts to recruit experienced lay members to serve on appropriate committees. However LPV makes the following suggestions:

- The Lay members recruited did not reflect the demographics of London; whilst this seems to have been rectified in 2014/15 – LPV suggests that recruitment of lay members be improve. See main recommendations.
- Training of lay members is essential to effective involvement. There was little training offered in 2013/14 although most of the representatives, many originally referred by treating clinicians, were able to bring knowledge of their disease area, were articulate and also had knowledge of the wider issues in the NHS and determinants of health.

- On a broader point, because so many Public Health (PH) duties are now with London's Borough Councils, it has been difficult to liaise with so many Directors of PH, Health and Wellbeing Boards (HWWB) and Health Overview and Scrutiny Committees (HOSCs). This is a resource that could be tapped into to articulate the voice of patients if appropriate and efficient channels are identified and developed.
- LPV did not see evidence of patient involvement within Ante-natal and new-born screening, this will therefore be a focus for LPV in its next report.

Early Years and Immunisation

The Public Health roles and responsibilities assumed by NHS England London Region (NHSELR) London in April 2013 had previously been shared by a number of organisations – the NHS, NHS London and the London Primary Care Trusts. At the point of reorganisation these were distributed to a number of new and existing organisations and bodies including:

- Clinical Commissioning Groups (CCGs).
- Local Authorities.
- Commissioning Support Units.
- NHS England.
- A number of other pan NHS groupings.

Evidence of engagement identified by LPV

- LPV was told that in view of all the re-organisation, it was decided to postpone the recruitment of lay members to commissioning boards in 2013/14 – instead focusing on the preparation for recruitment in 2014/15.
- However, mindful of the duty to consult, the Early Years and Immunisations Service decided to look to existing channels and use social media to listen to the voices of patient and service users.
- LPV were told that staff ensured that the Early Years and Immunisations Service was kept informed of what the following organisations and sources were saying:
  - HWBB and HOSCs
  - Joint Strategic Needs Assessments on Borough websites
  - Family Nurse Partnership Boards
  - PLD Parliaments
  - SANE, MENCAP, Mind, Mental Health Avengers, Mumsnet

- Several blogs and twitter streams were established (#LondonParents #eChildRecords #LondonImms #StopMenigitis #HPV4Men and various other # topics).
- LPV was told that all feedback was captured, sometimes from up to 25 tweets per day and themes were identified and collated. All this was fed back to the appropriate teams for discussion and became part of the process for identifying and choosing commissioning solutions.
- Three examples of how this had worked were shared during the interview:
  - There had been an online 'Mumsnet' campaign for the digitisation of the Red Book. This is given in hard copy to new mums: 135 000 babies a year are born in London and, as a result of the online campaign and tweets, a digital version is now available to all mothers .
  - They have increased access in 1307 pharmacies for flu and pneumococcal vaccines
  - And (off subject) they recruited HRH Harry to support Armed Forces veterans and families!

LPV findings / observations:

It is clear that the Early Years and Immunisation Service recognised the importance of and duty to consult the patient. However, due to the substantial constraints outlined above, a conventional programme of recruitment, training and assignment of lay people to Boards was felt to be beyond the resources of his business unit in 13/14.

LPV makes the following suggestions:

- The use of social media and activities using other channels became the way that the service listened to the voices of patients and service users.
- This approach had allowed the voice of people actually using or about to use services to have their voice heard in an immediate and dynamic way. They might well be people remote from committees and panels and this approach was open and inclusive – NHSELR should model this practice and use it in other services.
- Public Health staff used existing channels to "broadcast" the voice of the patient and ensure that these messages were taken into account in the commissioning process. LPV was also told that they tried to ensure that information is shared in both directions and that users know what, if any changes, their comments and ideas have made.

Highlighted Good Practice – innovative engagement

LPV feel that the innovative use of social media demonstrates that there are other ways of listening to the voices of patients and carers other than through the traditional appointment of representatives to committees.

Cancer

NHSE London Participation and Engagement 2013/14 said……

There was no reference to patient involvement or the impact of this involvement within the 2013/14 report.

London has poorer outcomes over the range of cancers than most European capitals and, unusually, performs worse in some cancer outcomes than other British cities. This is all the more surprising because of the concentration of clinical resources in London.

Within this section of London Patient Voice's review of patient participation in 2013/14 the focus has been on the commissioning of:

- The Pan London Cancer User Partnership (PLCUP)
- The London Cancer Programme Board (LCPB)

The Pan London Cancer User Partnership

The Pan London Cancer User Partnership (PLCUP) is a standalone organisation that has been set up to inform and advise on cancer services in London. It reviews, influences and advises commissioners on the provision, quality and organisation of services but has no role in any clinical aspect of service provision.

Members of the partnership sit on strategic bodies that include the NHSE London Cancer Programme Board (LCPB) to influence commissioning.

Evidence of engagement identified by LPV

- Lay members of the partnership were recruited in 2013/14 via a job description that was widely circulated to the members and stakeholders of a range of cancer related organisations – charities, support groups, Cancer Network User Partnership, Cancer Voices etc. Recipients were invited to apply.
- Commissioners tell us that the forms were assessed and scored against predetermined criteria and 10 cancer patients/carers were appointed; this number rose to 14.
- In appointing members, commissioners tell us that efforts were made to reflect the demographics of London but, as applications effectively came from a self-selecting group, it was very hard to adequately reflect the gender, age,

ethnic and social make up of London. Most of the members are women and the cohort is under representative of young (up to 30 years of age) people.

- Members sit on four PLCUP panels, which meet about four times a year.
  - Early Detection Advisory Group.
  - Patient Experience.
  - Living With and Beyond Cancer.
  - Clinical Cancer Leadership Advisory Board.
- These panels feed in to the LCPB via two nominees from the Partnership. These are the two Co-Chairs of the Partnership; one is one of the regional clinical directors of NHS London and the other is a lay member.
- An induction Training Day was held in 2013/14 and information updates were forwarded regularly. Commissioners tell us that there was a standing offer to lay members to attend outside conferences and training events: attendees were expected to report back to their panels to update colleagues on what they had learned.
- Agendas and papers for meetings were sent well in advance and there was the opportunity to request more information and clarification before the actual meetings by emailing the appropriate Chair.
- Commissioners told us that early on a culture of members communicating and talking outside the environment of a formal meeting had started to develop and has now established a firm hold on the communications culture.

LPV findings / observations

- The PLCUP seems a well organised and mature network that articulates the voice of patients, individuals in recovery and carers at the LCPB.
- LPV spoke to a lay member and it was clear that commissioners had fostered an atmosphere of mutual support and information sharing that engendered well-presented and appropriate views being articulated at the Board.
- There could have been more training but this seems to have been compensated by the excellent intra-membership communications network.
- It was the Commissioner's view that the two members delegated to the LCPB enjoy parity of esteem with clinical and professional members and are listened to.

Highlighted Good Practice – parity of esteem

The Pan London Cancer User Partnership is a standalone organisation that has been set up to inform and advise on cancer services in London. Two of its members sit on strategic bodies that include the NHSE London Cancer Commissioning Board. These nominees are the two joint chairs of the Partnership; a regional clinical director of NHS London and a lay member. This is an excellent example of parity of esteem between lay and professional members and helps demonstrate that it has been embedded into the work of the Partnership

The London Cancer Programme Board

As described above two lay members from the PLCUP sit on the London Cancer Programme Board – a strategic level body that commissions cancer services for London.

LPV were interested to test if the parity of esteem described above happened in reality.

Evidence of engagement identified by LPV

- Members of the PLCUP have been involved in London's Cancer Networks for a number of years.
- There was little training for existing PLCUP members as it has been considered unnecessary but as the partnership is refreshed – training will be offered to equip lay people with knowledge of the cancer commissioning landscape.
- LPV was told by the lay member interviewed that she would describe herself as a "fully contributing member."
- She continued that she prefers not to use the expression *parity of esteem*: "They know me. They don't see me as an equal but understand and respect the views of a carer who has had experience of cancer services. They listen to my point of view".
- Communications was felt to be excellent and they regularly and frequently meet as well as exchange correspondence.

LPV Findings / observations

- LPV concurs with NHSELR's view that lay members on the PLCUP are respected and listened to within the commissioning process.
- However it is important that membership of the group is regularly refreshed and that adequate and appropriate training is designed and delivered to new recruits.
- LPV commends having a lay person as co-chair. This is an innovative step that recognises the valuable contribution that patients and carers can make in shaping services.
- This model of delivering patient voice is very specific to cancer and LPV is unsure if this could be replicated to its full extent in other areas such as immunisation or, screening. However LPV suggests that NHSELR could replicate some of the processes outlined above and tap into a well organised, well informed and articulate cohorts of carers and patients.

Patient & Public Procurement Group

NHSE London Participation and Engagement report 2013/14 said……

Evidence of involvement in procuring services across the region*- To ensure the public had an opportunity to be involved in the procuring of directly commissioned services, a pool of citizens were recruited to be part of a procurement project team, they were trained and there are now 25 people who take part in the full range of procurement activities for each new procurement taken within the region.*

Impact of involvement *– There is citizen representation on the regions procurement project teams, citizens have the opportunity to score prospective contractors on the patient specific items within the contract, and be part of the selection process.*

LPV gathered information from telephone calls with the Head of Procurement.

Evidence of engagement identified by LPV

- In 2013, NHS England London Region (NHSELR) Procurement Department set out to recruit a panel of patients to form a pool of lay members that could be called up on to be involved in procurement activities.
- LPV was told that the procurement team went out to all Healthwatch groups in London to ask for volunteer patients to be part of the Procurement Project Group. Recruited as Patient Evaluators, they were asked to commit to:
  - Attending project meetings, on average once a month.
  - Being involved in scheduled key project milestones.
  - Assist the group in understanding the perspectives of patients, carers and the public in relation to the procurement.
  - Preparing for meetings by reading meetings papers, raising any issues prior to the meeting and becoming familiar with relevant terms.
  - Acquiring knowledge and understanding of the service user perspective.
  - Working effectively and constructively in a team.
  - Declaring any interest that they may have in relation to any of the projects.
- Patient evaluators are able to claim for travel and are required to keep any information confidential.
- Prospective Patient Evaluators are required to:
  - Attend an initial session that explains their responsibilities as evaluators in the procurement process.
  - if selected, attend training on the evaluation system called AWARD; and

  - Sign a disclosure of interest form.
- The Patient Evaluators that are selected are asked to provide feedback on the process at the end of the evaluation. Their feedback is then reviewed and necessary adjustments made (if warranted).
- Initial training for interested patients to become evaluators was held on the 25th March 2014; of the 16 people registered to attend 14 attended. With a further two more joining at a later date.
- Their involvement in procurement exercises was outside the scope of this review as it took place from May 2014 onwards.
- Speaking about the impact of Patient Evaluators, LPV wase told by the person interviewed that patients bring an invaluable contribution to any procurement process. They are able to evaluate and question bids from a patient perspective that commissioners sometimes miss. However again this was outside the scope of this particular investigation.

LPV findings / observations

It was clear to LPV that the intention was to recruit, train, develop and support a pool of patient evaluators to play a full role in procurement activities. However it was not up and running within the first year of NHSELR and therefore NHSELR did not meet their statutory duty to involve patients within commissioning arrangements.

- However much work to recruit patient evaluators had taken place during 2013/14, which has since led to the group taking part in many procurement exercises.
- LPV will return to this when scrutinising the next participation report.

Strategic Clinical Network reference groups

NHSE London Participation and Engagement report 2013/14 said……
Extract from report

Engagement & Co-production - A co-production event exploring the psychological support for people with diabetes in London. The event invited people with lived experience of diabetes and health care professionals to discuss together the following three questions: What has been good about services you have experienced? What is missing that could make a difference?, what are the essential components needed for an excellent service?
The mental health strategic clinical network in London works closely with three voluntary sector providers, MIND, Rethink, and NSUN.

Impact of involvement - The analysis of the discussions from the co-production event provided a wealth of information that informed the recommendations for our recently published guide: Commissioning recommendations for psychological support – focussing on London's diabetes care pathway.

The London Strategic Clinical Networks (SCN) brings providers, commissioners and patients together - to create alignment around programmes of transformational work that will improve care.

They focus clinical advice and leadership on specific conditions and patient groups. The networks play a key role in the new commissioning system by providing clinical advice and leadership to support local decision making. They work across the boundaries of commissioning and provision.

Established in 2013, the networks serve key areas of major healthcare challenge where a whole system, integrated approach is required:

- Cardiovascular (including cardiac, stroke, renal and diabetes).
- Maternity and Children's Services.
- Mental Health.
- Dementia and Neuroscience.

Evidence of engagement identified by LPV

- More than half of the SCNs had patients and/or carers as members of their clinical leadership groups.

- Renal SCN identified patient experience as one of their three work streams.
- A Patient and Public Involvement (PPI) SCN team was created consisting of a strategic lead and three PPI managers drawn from across the different networks. Part of the early priorities identified was a need to inform SCN teams about PPI working and engagement models and methods.
- A report on patient engagement within the Cardiovascular (Stroke) SCN was published in July 2013.
- SCN conducted a review of its own PPI during the period LPV are scrutinising, which was published in January 2015.
- A seminar was held in June 2013 to train SCN teams in the principles of patient engagement.
- A follow-up seminar was held in March 2014 to train SCN teams in the tools and techniques of patient engagement.
- PPI is explicitly mentioned within the job descriptions of the core team.
- Some representation was provided through not-for-profit sector organisations, as in the case of Mental Health, where clinicians were said to be reluctant to have individual service users on the panel.

LPV findings / observations

LPV found the PPI work of the Strategic Clinical Networks to be in many ways exemplary, and we would encourage other NHSELR commissioning areas to emulate their approach. However it would make the following suggestions:

- Caution should be exercised when seeking representation through not-for-profit sector organisations. This should not be seen as a substitute for direct public and patient involvement.

The Patient Voice Reading Group

NHSE London Participation and Engagement report 2013/14 said……
Extract from report

Evidence of involvement in reviewing the Regional Teams public facing publications *- To support the organisation to have public facing documents that are fit for purpose, a virtual reading group was recruited to which provides the regional team with a public review of documents before they are published.*

Impact of involvement *- The public reading review group have reviewed a wide variety of documents and made recommendations for changes, all recommendations have been accepted by the authors and the documents have then been published. All author requests and reviewer comments are captured on specifically designed templates.*

LPV interviewed the Patients and Information Support Manager.

Evidence of engagement identified by LPV

- NHS England London Region (NHSELR) began recruiting to the group towards the end of 2013, by writing to the groups below and also via London Regional Opportunities bulletin:
  - All London Healthwatch.
  - People who had worked with NHSE in the past.
  - London Voluntary Service Council.
- From this in January 2014, 15 members were recruited to the group, together with a group supported by Merton Healthwatch.
- The Patients and information Support Manager acted as the central point of contact and conduit for sending out publications to be reviewed and for forwarding comments back to the original author. It is the author's decision as to whether any changes are made to the documents and the person interviewed was unaware if any amendments had been made.
- Between Jan & March 2014 – 4 documents were reviewed:
  - One for Sense (multiple documents).
  - Paediatric oncology leaflet.
  - Leaflet on 'Care.data'.
  - Transforming Primary Care: Changes to GP standards.

LPV findings / observations

The Patient Voice Reading Group has the potential to significantly improve access to health care and improve outcomes by making it easier for patients and carers to better understand the literature that is made available about their disease area and the specifics of their treatment. LPV makes the following suggestions:

- That the organisation and co-ordination of this group is urgently reviewed to ensure that the benefits of this resource are maximised.
- That a quality monitoring framework be adopted to provide evidence of the impact of the Reading Group.
- That feedback is given to members of the group as to whether their recommendations have been implemented – this needs to be included within a monitoring framework above.
- Published copies of literature with Reading Group input should be distributed to members of the group.
- Training should be offered to members – LPV considers that this would enhance the service provided by the Reading Group.

Areas unable to be reviewed by LPV

The following areas were not included within this review. LPV will be reviewing these and the impact of involvement on commissioning decisions in its next review.

Collective duty

Direct commissioning

- Specialised commissioning **

Supporting direct commissioning activities

- Nursing Team
- Patient Safety Team
- Participation & Opportunities bulletin
- Intelligence team

Individual duty

Direct Commissioning

- Specialised commissioning **

Supporting direct commissioning activities

- Nursing

Supporting Commissioning Activities - not part of direct commissioning

- NHS111
- Specialised commissioning
- Nursing
- Patient safety

** Whilst some investigations took place, this was not sufficient for LPV to form a view of engagement within this commissioning area. This will be a focus for the year ahead.

Appendix 1 - Interviews and evidence list

Below is a list of people interviewed by members of LPV during its investigations.

File reference	People interviewed	LPV Member
LPV 13/14 - 1	Strategic Clinical Network Lead	Sandy Marks
LPV 13/14 - 2	Patients and information Support Manager	Sandy Marks
LPV 13/14 - 3	Head of Procurement	Sandy Marks
LPV 13/14 - 4	Head of Primary Care Commissioning – Strategic Lead for Commissioning Intentions	Janice Tausig
LPV 13/14 - 5	Head of and Co-Commissioner for Primary Care NW London	Janice Tausig
LPV 13/14 - 6	Lay Member – Access Expert Panel	Janice Tausig
LPV 13/14 - 7	Chair of National Association of Primary Care	Janice Tausig
LPV 13/14 – 8	Primary Care Transformation Team Manager	Janice Tausig
LPV 13/14 – 9	Director of Nursing South London	Janice Tausig
LPV 13/14 - 10	Chair - Access Expert Panel	Janice Tausig
LPV 13/14 - 11	Head of Primary Care and Co-Commissioner for SE and SW London	Janice Tausig
LPV 13/14 - 12	Regional Lead for Dental and Optometry Commissioning	Janice Tausig
LPV 13/14 - 13	Chair – Health in Justice	Juliet Campbell
LPV 13/14 - 14	Director of Training and Development - Inspirit	Juliet Campbell
LPV 13/14 – 15	Lay member – Commissioning Technician	Juliet Campbell
LPV 13/14 – 16	Head of Health in Justice Commissioning	Juliet Campbell
LPV 13/14 – 17	Lay Member – Adult Screening Services Board	David Winskill
LPV 13/14 – 18	Head of Screening	David Winskill
LPV 13/14 - 19	User and Patient Experience Facilitator – Pan London Cancer Use Partnership	David Winskill
LPV 13/14 - 20	Head of Early Years and Immunisation	David Winskill
LPV 13/14 - 21	Lay Co-Chair – Pan London Cancer User Partnership and London Cancer Programme Board	David Winskill
LPV 13/14 - 22	Senior Manager	Nermine Taylor
LPV 13/14 - 23	Chair of the National Specialised Commissioning Patient Voice Group	Nermine Taylor
LPV 13/14 - 24	Head of Patient Voice – presentation and context setting for NHSELR and wider NHS	All LPV
LPV 13/14 - 25	Director of Patients and Information & Head of Patient Experience and Quality	Sandy Marks David Winskill Janice Tausig

Due to timings two LPV members were unable to take part in the interviews / research.