



Report from London: Patient Voice

Scrutinising NHS England (London)'s Public and Patient Engagement 2017 - 18

March 2019

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Chair's foreword and introduction

I am delighted to be writing the introduction to the fourth review undertaken by the members of London Patient Voice (L:PV) into how NHS England (London) (NHSE (L)) discharges its duty to involve patients and public when it commissions services.

London continues to be the only NHS England region to commission these reviews and this reflects the commitment of the organisation to Public and Patient Voice (PPV) and to improve how it listens to and supports PPV.

This year, we also looked at the practice of PPV in the London Clinical Senate, London Clinical Networks and Healthy London Partnership. We feel the review has benefitted from this as it has given us a wider perspective on governance and practice of PPV in London. Further, it offers insight into other organisations that NHSE (L) takes account of when making commissioning decisions.

Our review was undertaken against the background of three significant developments:

- The continuing integration programme of NHS England and NHS Improvement regional teams.
- Planning activity to meet the challenges that Brexit will pose.
- The publication of the national Long Term Plan (LTP).

Taken together, they involve very significant amounts of management time and resources. At the time of the review, there was uncertainty about the structures, responsibilities and roles of the new organisation but there was also the opportunity to reboot certain aspects of NHSE (L)'s PPV practice.

We were disappointed that we were unable to scrutinise some areas (notably GP commissioning) but we have continued to receive enthusiastic and open handed support from officers, clinicians and PPV representatives.

In short, we found that the process of embedding PPV and the understanding of the benefits continued to improve throughout NHSE (L) as a whole.

The PPV representatives, NHS commissioners and clinicians we spoke to understand the unique contribution that PPV can make to improving access to services, design and delivery of new services and the improvement of existing ones.

However, we feel that with the emerging changes, that there is an opportunity for the new organisation to recognise and further establish PPV at its heart, as being an essential asset for

service development and improvement and ensure full parity with NHS commissioners and clinicians.

In this review we were able to talk to a lot of PPV representatives and found their commitment to the importance of what they are doing to be stronger than it was four years ago.

Every day there are many hundreds of people who travel to meetings of their Public and Patient Groups, Clinical Commissioning Groups, London Clinical Senate, London Clinical Networks, Healthy London Partnership, NHSE (L) commissioning boards or one of many other patient groups or reconfiguration working panels to sit as the PPV representative and give voice from the patient point of view.

They will have consulted with peers, read the papers for the meeting and, in many cases will have read further and researched on the web. Many will have submitted questions and requested more information and some will have developed suggestions to bring to their meetings. They will bring a wide range of work, community and lived experience and, working alongside NHS professionals and clinical colleagues, offer ideas, comments and challenge.

We did notice though, that the many of the previously identified general issues and challenges to the effectiveness and parity of what they are doing and how it is organised continued to recur in our conversations.

- There was still variability in the recruitment of PPV, despite guidance and policies. It is seen to be unstructured and opaque with little clarity on whose responsibilities lie where.
- There have been improvements in training opportunities for PPV representatives to engage in but quality and range of training remain inconsistent across the organisation. It is not uncommon to find PPV representatives who have had no training at all: opportunities for training seem to be a function of the enthusiasm (or not) of individual officers.
- Co-training with PPV representatives and training for NHS staff and clinicians on getting the best from and working with PPV is rare.
- Financial support to attend 3rd party training, conferences and exhibitions is almost non-existent: we heard of no examples of project managers flagging these opportunities and recommending attendance.
- Support (timeliness of papers, advice and help) can be exemplary or poor.
- Some PPV representatives have reflected on the value of going to meetings where decisions have already been taken up-stream. More encouragingly, other representatives report full involvement in the co-design of service specs as the norm.
- Some PPV representatives have commented on the lack of clarity about responsibilities/accountabilities, which makes it difficult to see how decisions can be influence.

- Whilst the Annual Engagement Review highlights areas of achievement, there seems to be little feedback on what PPV activity has achieved and its impact on commissioning decisions from an individual PPV perspective. This can make the role of PPV representative frustrating and often seem pointless (which it is if the PPV is not being listened to).
- The availability and awareness of PPV reimbursement policy are patchy and poorly understood.
- Many PPV representatives spoke of isolation in their role and of being unaware of the experience, knowledge and experience of other PPV representatives working in different clinical and geographical areas.
- PPV representatives told us of differences in practice across the various groups they were members of and how opportunities to improve practice are being missed.
- Unlike their professional colleagues, PPV representatives feel that they have no where to go to with complaints or grievances or for advice and guidance.

In writing this report and our recommendations, we have been mindful of emerging issues:

- Under LTP there will be much more focus on integrated care, creating new joint ventures and improving the patient experience.
- There will be opportunities to improve planning to get existing and new structures in London to deliver better and faster for Londoners.
- The role of STPs/integrated care systems within London is expected to intensify, and so their future role in NHSE commissioning decisions needs to embed PPV

We also acknowledge that as NHSE (L) is reorganised and people move on and new teams and structures appear, L:PV reports will have a crucial role in providing corporate memory of what currently works well and recommendations on how the full potential of PPV in improving London's health services can be achieved. As the reorganisation settles there will be an opportunity to re-engage with L:PV to take stock of what the new organisation has achieved, and how it is meeting its statutory engagement duties.

Whilst our review was specifically looking at London and how it engages PPV, our learning, findings and recommendations will resonate with colleagues in other regions and nationally.

In our report there are recommendations for improvements at the programme board level but we felt it appropriate to make overarching recommendations about PPV that, if adopted, we believe will better equip NHSE (L) to improve health services and reduce inequalities for all Londoners.

Our recommendations are designed to be workable and to form the basis of a transition programme that will allow the new NHS organisation to better hear the voices of users and carers in transforming and improving the vital health services that Londoners depend on.

These high-level recommendations are presented in the next section.

Thanks are due to all the officers and PPV representatives we met during the past few months. They were enthusiastic about sharing experiences and ideas and keen to see PPV progressing as an integral part of improving care for Londoners.

I am also grateful to my fellow L:PV members for all their hard work, questions, challenges, suggestions and, especially their good humour.

Finally, a thank you to Su Turner of Insight to Impact Consulting for her organisation, patience and words of wisdom.

David Winskill

Chair, London: Patient Voice

Governance and Recommendations

In our meeting with the officers responsible for PPV in NHSE (L) it was clear that there was some progress in implementing previous recommendations, and that they represent an organisation that is anxious that PPV achieves the status of commissioners and clinicians in the commissioning process.

Taken collectively, we believe that these recommendations will contribute to the unleashing of the full potential that PPV has in improving services, access and outcomes for Londoners.

We recommended that:

- The new organisation demonstrates commitment to PPV, by ensuring that responsibility for PPV continues to be held at a Director level. This should be reflected in a job title that reflects the post holder's commitment to adequately support and champion PPV.
- Appropriate and adequate resources should be given to a team responsible for PPV to ensure that appropriate HR support functions for PPV representatives are embedded. Such support would include the recruitment and induction process, training, general enquiries, co-ordinate support for PPV representatives, process expenses claims and allowances and offer advice on disputes, inter-personal issues and other matters.
- The NHSE (L) PPV or other appropriate section of NHSE (L) should, as a matter of urgency research and produce a continuously updated register of PPV representatives. Having no definitive list of the individuals who, taken together, represent such an important organisational asset will hamper any initiatives to improve recruitment, training and support and best use of PPV. Such a register will allow NHSE (L) to understand its cohort of PPV representatives reflect the demographic profile of London and, where necessary, target seldom heard groups.
- Consideration be given to strengthening the voice of PPV at a corporate level. This should include the addition of PPV representatives on the Accountability Group. Brief would be to feedback and advise the PPV Directorate on all aspects of PPV experience and practice and develop recommendations for improvement and change.
- To inform the activities and recommendations of the above group, the national PPV survey should contain a tailored section that specifically seeks out the London experience. This will help the group to understand whether PPV in London feel valued and listened to,, and how they are supported and contribute.
- Through the PPV Directorate, the new organisation should take the lead in promoting and assuring PPV across London (commissioners and providers). It should be aware of practice in other NHS regions and establish minimum standards as well as promoting

best practice. Consideration should be given to how to make the new organisation responsible for quality assurance of practice.

General

- Recruitment: use existing national guidance to strengthen communication on how PPV vacancies are identified, whose responsibility it is to initiate recruitment, how a role description is written and agreed, channels used to recruit and how selection is undertaken.
- It became clear that, in some commissioning strands (especially screening (see later), neo-natal and one or two others), excellent work was being done in collecting service user feedback and using the information to make improvements to existing service provision. However, this is no substitute for involving PPV at the commissioning level. L:PV hopes that efforts will be made to recruit PPV in these areas as part of a wider determination to make the overall pool of PPV available to NHSE (L) to better reflect London's demographics.
- Training: access to online resources (wherever possible) should be password free and open to all. The range of resources should be reviewed and redeveloped to reflect the specific challenges and inequalities and to equip PPV representatives with appropriate skills. To break down silos and foster common purpose, shared training involving NHS staff, commissioners and PPV representatives should be promoted. Specific attention should be paid to training for chairs.
- Mentoring and networking: to tackle the isolation of PPV representatives, arrangements should be made to encourage the sharing of skills, information and experience. This could be supported by a PPV dedicated website and a programme of conferences and seminars.
- L:PV, recognising the challenges and valid differences of opinion and approaches to the commissioning process, recommends that PPV representatives should be involved at the earliest possible stage and, wherever possible, co-production should become the norm. This is to offer PPV representatives greater ownership of the commissioning cycle.

Aims and Methodology

Following a London-wide recruitment process in 2017/18, new members were recruited to London: Patient Voice (L:PV), to work alongside the existing Chair. They attended training sessions, read previous L:PV reports and started work scoping out and planning their first review.

Members were divided into work strands, in line with NHSE (L)'s commissioning responsibilities, with an overarching theme of Corporate leadership and governance:

- Primary Care
- Public Health (Screening and Immunisation)
- Health in the Justice System and Armed Forces Health
- Specialised Commissioning
- In addition, this year, the group looked at the London Clinical Senate, London Clinical Networks and the Healthy London Partnership.

Each of the strands:

- Scrutinised NHSE (L)'s own self-assessment (Participation and Engagement Report) published in December 2018;
- Developed key lines of enquiry, and identified those people that they wanted to interview;
- Interviewed key NHS England staff and where possible Patient and Public Voice (PPV) Partners.

This report focuses on these areas and gives a commentary on what L:PV has observed.

Timetable of review

Aug / Sept 2018	Research and meeting preparation
October - February 2019	Interviews across the four strands - with staff and some Patient and Public Voice Partners.
8th February 2019	Review and recommend L:PV team session.
March 2019	Final report with recommendations (this report) submitted to NHS England
30th April 2019	L:PV Chair and Insight to Impact Consulting Ltd attend PPV Accountability Group to report on this report

Primary Care - GP Commissioning

L:PV members: Jane Allberry and Brigitte Shallow

NHSE (L) is responsible for ensuring that there is appropriate PPV engagement in GP commissioning. This is difficult, given that they have mostly delegated responsibilities to CCGs. In our last report, we said how difficult it was to find out about how effectively NHSE (L) meets its statutory responsibilities in this area. Our specific recommendations were:

- Patients and the public in London should be provided with a clear statement of opportunities to engage in the commissioning of GP services, and advice about how to get involved, and what they are able to influence.
- NHSE (L) should in future report on how they have fulfilled their statutory duties for engaging with patients and the public in commissioning services, setting out clearly how they have done this for all GP services (not just re-procurement of services under the APMS contract), what evidence they have that patients and the public have been engaged effectively, and some examples of what difference the engagement has made.
- While it is good news that going forward NHS England is assessing CCGs in terms of how far they have engaged with patients and the public, we want to see evidence that CCGs are being assessed specifically on their engagement on the commissioning of GP services - because this is an area of such great importance to local populations and an area where NHSE (L) has delegated its responsibilities and so must assure itself that CCGs are meeting the requirements on their behalf.

We also said that, for our 2017/18 report, we intended to research how far NHSE (L) was meeting its PPV responsibilities for GP commissioning; and, by talking to representatives of CCGs, Healthwatch and local GP Patient and Participation Groups, how this might be improved.

We were unable to return to this area satisfactorily, as we were told that NHSE (L) were in the process of developing the necessary assurance system to provide this oversight and scrutiny. Given the importance of PPV engagement in the commissioning of GP services, we were concerned that we could not investigate this area further.

Service Specific Recommendation

- *We recommend that NHSE (L) urgently creates a system to assure itself of effective PPV involvement in CCGs' commissioning of GP services.*

Last year, L:PV reviewed Dental, Optometry and Pharmacy services, and were pleased with the involvement of and support to PPV. We have therefore not reviewed this again in this report.

Public Health

L:PV Members: Nkechi Nwazota and David Winskill

Public health is about keeping people healthy and protecting them from threats to their health.

The Public Health team at NHSE (L), working closely with Public Health England, commissions a wide range of services. Public Health services include:

- Cancer Screening services for breast, bowel and cervix
- Non cancer screening, AAA (abdominal aortic aneurysm) and diabetic eye screening
- Antenatal and newborn screening
- Immunisations
- Child Health Information Services

In October, L:PV met with Public Health colleagues to take a holistic view of Public Health commissioned services. We met with the Director of Public Health Commissioning, Health in the Justice and Military Health, the Head of Screening and with colleagues named below.

Screening

Breast Screening

L:PV spoke to the Breast Screening Commissioner, and heard that there is a Pan London PPV Breast Screening group that meet quarterly to contribute to the discussions on how to improve the breast screening programme.

We heard that there are six services, each having different ways of engaging with PPV - either via surveys and questionnaires to canvas feedback, complaints and compliments. The insights revealed are co-ordinated and reported to the quarterly meetings, with reports on how issues have been resolved. L:PV heard that there is a high-level programme board which is involved in procurement, however, this does not have PPV on it.

PPV are recruited to the Pan London PPV Breast Screening group through service providers, and different approaches are used to gaining feedback such as texting, working with Clinical Commissioning Groups and Local Authorities and talking to GPs. They use the group to pick up on London-wide issues. We heard that a major challenge to representative engagement is the transience of London's population. We also heard that women from seldom heard groups were presenting late, and that there was a goal to reach out to these communities.

Current PPV representatives are long standing, and were a part of the PPV programme. Most were recruited 4-5 years ago so have had the PPV training.

Whilst there is clearly a corporate commitment to engaging with service users, the emphasis is on establishing feedback on users' experiences of using the service, rather than having a strategic voice in the commissioning services.

See collective recommendations at the end of the screening section.

Adult Screening

L:PV spoke to the Adult Screening Commissioner to find out more about this area of work. Whilst there are many services, in the time that L:PV had with the Adult Services Commissioner, we focused on the AAA programme (Abdominal Aortic Aneurysm).

L:PV heard that work was underway to recruit representatives to two new programmes for North and South London, using the model that had been successfully used for the AAA programme - Surveillance Men. Surveillance men are those already in the system and who have experience of adult screening services. All feedback is fed into how the service is procured and refined. They are involved in service design and NHSE use paper surveys to gather views (preferred method for the group).

L:PV also heard there was extensive patient involvement at all levels during the recent London AAA Screening Programme Procurement. This included patient involvement in the options appraisal and the London AAA service redesign; membership of the procurement Steering Group and participation in the Evaluation and Moderation of the AAA London Tender bids, by 6 AAA Service Users.

The AAA Surveillance Patient Survey was conducted prior to the procurement and distributed to over 1036 existing service users. 52% of these responded, reflecting a high level of engagement and provided insight and areas for service improvement for providers and commissioners. As a result of the positive response to the AAA Surveillance Patient Survey, a London AAA Patient Forum is planned during 2019-20 to maintain and develop patient involvement.

L:PV commends the commitment to getting the views of service users to try and improve services and take-up, the introduction of the AAA Patient Forum is positive, and would be an opportunity to consistently use PPV in commissioning decisions.

Bowel Screening

L:PV spoke with the Bowel Screening Commissioner, to explore this strand and heard that there are two screening programmes (one for those aged 60 to 74 and another for those aged 55 years old).

One PPV representative sits on the London wide FIT (screening) implementation group thus providing direct patient voice input into assurance, implementation and scrutiny of commissioning decisions about FIT for Bowel Cancer Screening Programmes. This group also responds to national consultations, feeding in to the National FIT procurement exercise. Meetings of the London-wide board are quarterly, and surveys are undertaken at an early and later stage, which

ask specific questions about their experience. L:PV heard that there is a response rate of around 50-60%.

L:PV learned that there is a National Specification, however the ambition is to tailor it for Londoners. There are Incentives via CQIN (Commissioning for Quality and Innovation) - which set take-up targets. All feedback from surveys is presented to the board meetings, which is fed into commissioning and contract monitoring discussions.

In particular L:PV heard of an example that collected qualitative and quantitative feedback from Bowel Scope (those aged 55yrs) in the North East London screening site; which was outside the Bowel Scope national specification. Bowel scope feedback with five star rating by patients at Barking Havering and Redbridge screening site was mentioned as an example of innovative practice.

As with other services within the remit of Public Health there is commitment to localising national service specifications. L:PV welcomes the commitment to gaining user feedback, and that there is PPV presence on the London programme board.

Cervical Screening

L:PV spoke with the Cervical Screening Commissioner to find out more about this area of responsibility.

Cervical Screening Board used to have PPV representatives on its membership, recruited through HealthWatch and external adverts. However, they do not currently have PPV representatives, and feedback from PPV previously involved was that they did not feel that they were involved in the right place.

We heard that there has been a decline in the uptake of cervical cancer screening, and therefore new methods are being trialed to improve. The Board and the team are also currently looking at how PPV can be included more meaningfully, and are considering establishing a focus group.

The Transforming Cancer Services Team are also trying to get people interested in a focus group, and they are looking at working with PPGs in GP practices.

As with other service streams, there is an acknowledgment that PPV is important in service delivery but there is uncertainty how best to feed PPV into strategic commissioning decisions.

See collective recommendation at the end of the screening section.

Service Specific recommendations

As previous points have highlighted that there is no consensus about the involvement of PPV at strategic commissioning conversations and decisions. The team need to share their views and

look at how the voice of PPV can add value and not just be service feedback driven. We recommend:

- *Consider establishing a directorate-wide objective for PPV to as a means of strengthening the internal framework to share PPV learning and expertise across the public health team.*
- *Ensuring that there is PPV at High Level Programme Boards - to influence decisions upstream.*

Antenatal, child health and child immunisations

L:PV met with the Head of Antenatal Newborn , Immunisation Programmes and Child Health Information Services to find out more about this area of work.

We heard that shortly before or after a baby is born, the parents / carer is given a personal child health record (PCHR) - otherwise known as the "red book". This red book is used to record key information about the baby's growth and other important information.

Following the involvement of PPV, L:PV heard that the book is becoming totally electronic and babies born now will be the first generation to go paperless! NHS Digital was used to gather the information, however this was done by one to one surveys and questionnaires, as opposed to a focus group.

There is an Advisory Board that meets to discuss the Redbook, however there are no PPV on the board. When asked whether this would be possible, we were told that there is no reason why PPV cannot be on the board. There are 5 Antenatal and newborn boards - one for each of London's STPs, however none have PPV voices.

There is however, a Pan London Board which has a PPV representative on it, and whilst they do not have the direct commissioning input, they can feedback and influence providers. There are links to the Maternity Networks on STPs. "Our job is not to set up lots of groups but to ensure that the groups in the system have a voice and the information is pulled together".

The Immunisation Board is looking at how they engage PPV and how to refresh it to ensure that they meet objectives and make it meaningful. They will be having conversations with local Healthwatch, to understand the barriers in local areas.

As with other Public Health strands, there is a National Specification, for which the challenge is to understand and overcome local barriers. Therefore strong partnerships with GPs, Local Authorities and Clinical Commissioning Groups need to be utilised, and improve the use the role of Immunisations Champions to promote.

Service Specific Recommendations

L:PV supports the action by the Immunisation Board to review its engagement with PPV, and L:PV recommends that the board learns from the good practice that we have identified within this and previous reports.

Health in the Justice System

L:PV met with the Head of the Health in the Justice system to explore this area of work.

L:PV learned that there is quite a structured approach to hearing the voices of the detained population. Inspirit (an engagement organisation) were commissioned to ensure that the user voice was at the centre of what they did. Inspirit train and support 'Commissioning Technicians' who are paid via Inspirit for their contributions. These technicians have been in custody, and so have experiences and insights that can be used to improve health services.

An example cited was the commissioning of new services for two London prisons, the Inspirit Public and Patient Engagement group is helping to form the questions and tender process. For Young People, there is a Project called Peer Power, which is similar to Inspirit but for Young People. Both organisations are helping to establish the understanding that detainees and prisoners need to have their voice heard and ensure that services are right. To ensure the voices of the more vulnerable are heard, there are Learning disability Nurses who champion the needs of those with learning disabilities or mental health challenges.

Inspirit is contract managed, and there are quarterly reports from Inspirit for performance management.

Engagement services, currently provided by Inspirit and Peer Power, are up for re-tender and the National Team will be providing support in re-tendering the main contract. Questions are wide ranging but would include information on equity

L:PV learned that moving forward, more work will be done to get the voice of those detained in police centres.

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

Recommendations

L:PV supports the desire to capture the voice of those detained in police centres, and recommends that staff learn from the good practice that we have identified within this and previous reports, and from their colleagues across NHSE (L).

Services for Veterans and Members of the Armed Forces Community

L:PV explored support for veterans and the armed forces with the Director of Public Health.

Since April 2013, NHS England has had the responsibility to commission services or facilities for members of the Armed Forces or their families. These services must be in line with the NHS Mandate and also in line with the commitments made by the Government under the Armed Forces Covenant.

NHS England commissions:

- all secondary and community health services for members of the Armed Forces, mobilised Reservists and their families if registered with DMS Medical Centres in England;
- specialised services, including specialist limb prosthesis and rehabilitation services for veterans.

NHS England has a dedicated team of Armed Forces healthcare commissioners who commission the majority of services required by the Armed Forces community (including mobilised reservists and some families) This duty 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). NHS England has been working with other partners including a full range of services supporting charities, the Department of Health and Local Government Association to improve the services available to veterans and raising awareness of veterans' health and mental health issues within ex-service communities. This is all part of helping to connect other parts of the health system for this population, notably with Clinical Commissioning Groups (CCG's), local authorities, providers and health and wellbeing boards.

As part of the research for this review, L:PV had visited a meeting of the Armed Forces Network, and were impressed by the engagement and format. L:PV understands that the purpose of the network is for it to be a facilitative process to get the views of veterans and the services supporting them. L:PV learned that its value is that it isn't part of 'the system'. It is made up of a mix of individuals (veterans) who are passionate to bring improvements and keep organisations grounded; and representatives of veteran organisations.

CCG's are responsible for the health needs of people in their patch, however issues that are raised at the network are also fed back through appropriate service channels for example the CCG or local authority. Notes of any actions to take forward are shared and updates given at future meetings.

Armed Forces Public Patient Partnership Involvement Group

L:PV spoke to the Chair of the Armed Forces Public Patient Partnership Involvement Group (3PIG).

3PIG is a national group, supported by NHSE London (with London members) that brings together patients, families, carers and the charity sector, alongside commissioners academics and professionals: they all represent or support the armed forces community to have a voice in the national commissioning of armed forces' and veterans' health services.

They feed into the Armed Forces Oversight Group, which Nicky Morgan has a seat at. They comment on all commissioning policies covering services. These include:

- Complex trauma
- Combat stress
- Prosthetics
- Mental health

There are two main components of 3PIG

- The core group of approx 16 people, who comment, inform and influence commissioning proposals and policies;
- A much larger Lived Experience Group; this is formed of veterans, carers, partners, spouses, children: it includes those with experience of serious injury, bilateral/unilateral amputation, PTSD, blindness etc.

We heard that the Lived Experience Group draws on and articulates the experience of its members who are prepared to share their stories "... with anyone who might want to hear them." This includes informing the core group's input into commissioning activities.

Planning is currently taking place on producing a work plan for 3PIG; strengthening ties with national armed forces and veterans bodies and refreshing the membership of both the core group and Lived Experience Group Priorities include:

- Revision of the Group Terms of Reference
- Revised Format for 3PIG meetings
- Tracking common themes and issues

- Acting as a conduit for information passage to the Armed Forces Community with regard to NHS initiatives such as the GP Friendly Practices and the Veteran Aware Hospitals direct to patient communities
- Creation of an Expert Patient Database to provide effective and appropriate “lived experience” patients, families and carers
- Production of Case Studies to support the requirement for patient and family engagement
- Production of a work plan for the next 12 months that can respond to the emerging long term plan for the NHS
- Inclusion of liaison with NHS in the other home nations to ensure the Armed Forces Community in those areas have the opportunity to be heard

NHS has a legal requirement to consult and to support this has a central engagement budget that includes an Armed Forces component. Expenses for 3PIG are being paid and there are continuing discussions about paying an allowance to the Chair, who feels well supported by NHS officers.

Overall, it was felt that there is a lack of relevant training available to members but that there are online training opportunities. To compensate for this, we heard about the development of an induction pack specifically for 3PIG representatives.

On the effectiveness of the group, overall, it was felt that voices are listened to and that NHS bodies feedback initiatives that are happening as a result of 3PIG input.

Conclusion

Like so many voluntary groups that L:PV has spoken to, 3PIG is an enthusiastic, well informed and committed group whose effectiveness and ability to contribute to commissioning pivots on the activities of one person. The chair is dedicated to improving Armed Forces and Veteran's health care and sees reduction in health inequalities as one of the main objectives for the group.

All of the NHS officers we spoke to when researching this report were fully aware of the centrality and importance of listening to PPV and the benefits to improving services.

However, L:PV feels that progress is not as fast or as smooth as it could be as there is ambiguity about whose responsibility it is to support organisations like 3PIG and what resources are and should be available.

Recommendation

Groups such as 3PIG (like many other individuals and PPV groups) will carry on making a crucial contribution to commissioning, however they do this with very limited resources and support. L:PV recommends that support for 3PIG is reviewed.

Specialised Commissioning

L:PV Members: Yemi Fagun and Deborah Frimpong

Specialised Commissioning refers to the procurement of services that are provided for rare and/or complex conditions for which patient numbers are small or where the cost of such services will significantly impact on local Clinical Commissioning Groups. The commissioning of these services is therefore done at a national level. Not surprisingly, these services will not be provided at every location.

This presents on the one hand certain opportunities for patients (for example, to be treated where there is proper expertise) and on the other hand, challenges first from a patient voice perspective (e.g. how regional input is made into what are essentially national services) but also from reduced availability of services locally.

Specialised Commissioning covers six broad areas, called National Programmes of Care (NPoC). L:PV understands that the structure and membership of NPoCs and the Clinical Reference Groups (CRGs) that provide clinical advice to the NPoCs, are coordinated at a national level with the responsibility lying with the NHSE national team. Regional NHSE teams, like NHSE London, are responsible for monitoring the Providers of those services. Each regional team also acts as lead commissioner for specific conditions. For example, NHSEL is responsible for the Paediatric Intensive Care CRG.

The National Programmes of Care are:

- Internal medicine - digestion, renal, hepatobiliary and circulatory system
- Cancer
- Mental health
- Trauma - traumatic injury, orthopaedics, head and neck and rehabilitation
- Women and children - women and children, congenital and inherited diseases
- Blood and infection - infection, immunity and haematology

This year L:PV was able to gain some insight into a small part of Specialised Commissioning, and in particular how the voice of patients and carers are heard in the following areas:

- Women and children, including Neonatal services
- Adult Mental Health (High Secure Units)

We also focused on how lay representation was assured at the “infrastructure” level, specifically CRGs, since they (CRGs) played such an important role in the commissioning of specialised services.

Specialised Commissioning and PPV

In January 2017, NHSE published its Framework for Patient and Public Participation in Specialised Commissioning. One of the aims of the document is to strengthen and further embed patient participation in commissioning, and it advocates that this should begin at an early stage of the cycle e.g. planning. It also details the number of PPVs that ought to be on each level of governance, for example on the Specialised Commissioning Oversight Group, the NPoC Boards, the Rare Disease Advisory Group, CRGs, the Quality Assurance Implementation Programme Board etc. This is a welcome publication, more so that it makes very clear what the roles of the PPVs should be.

Recommendation

NHSEL should ensure that all commissioning staff and clinical committee members referred to in the framework are not only aware of the publication, but that its contents are reflected in practice across the organisation and its advisory bodies.

Each CRG has three slots for patient representatives. Previously, L:PV learnt that this was usually one from a relevant charity and two carers/service users. In talking to NHSE London and going through membership of the CRGs, L:PV discovered that these slots were not always filled.

Furthermore, in one recent recruitment exercise, L:PV learnt that only one application was received. We also learnt that due to the nature of different medical conditions, some CRGs found it more challenging to recruit PPVs. When vacancies are not filled following advertising, we understand that the vacancy is left on the CRG page, but no further adverts are placed. Therefore, it is clear that the "Patient Voice" is not always present in every situation.

In response to our enquiries, L:PV learnt that PPV vacancies are advertised via the following forums:

- NHS England website, in the Involvement Hub
- NHS England In Touch bulletin
- NHS England Specialised Commissioning bulletin

It is not clear how high public interaction is with these publications/webpage and given that these forums are not always successful in attracting responses. L:PV is aware that in some instances, local networks are also used to recruit patient representatives, but this does not appear to be the case always and seems to depend on which team is recruiting.

Another way patients or the public can get involved with the work of a CRG is by registering as an interested stakeholder. In our last report we committed to find out more about how this seemingly invaluable way of getting views from a wider range of people, worked in practice.

This invitation is given via the NHSE website. Once someone registers their interest, their details are logged in a national database and any relevant information is emailed to them as it becomes available. This database is updated monthly. This is commendable.

However, it is not clear to L:PV whether this opportunity to engage is publicised in any other forum. Furthermore, NHSEL were unable to say how successful the call for this type of involvement had been. This is something worth considering, even if at a national level.

Recommendations:

- *That NHSEL may wish to explore other ways of actively publicising vacancies, especially where it has been difficult to recruit representatives (on CRGs or groups they have responsibility for).*
- *Consideration should be given to exploring expansion of the 'interested stakeholder' mechanism as a means of capturing the totality of PPV across London.*

Mental Health Services (High Secure)

LPV spoke to the Senior Mental Health Lead, to find out more about how PPV is embedded.

Psychiatric units vary depending on the level of risk to patients themselves and/or others. Secure psychiatric hospitals manage and care for those patients who present a risk to others. NHSE commissions all secure psychiatric hospitals. The level of security varies depending on the level of risk: there are low, medium or high security hospitals. The higher the risk, the more the physical, procedural and relational security measures that will be put in place within the unit. High Secure Units are for those who present a 'grave and immediate' risk of harm to the general public and have additional, mandatory security directions which are set by the Secretary of State.

Typically patients will have complex mental health issues, sometimes together with substance abuse problems. Most will have been involved with the Criminal Justice System and many are transferred from prison, either under a hospital order (as an alternative to a custodial sentence) or on a Ministry of Justice transfer direction for treatment in hospital. The Mental Act 1983 cannot be used to treat people in prison so if prisoners require treatment (and do not consent), they may require transfer to a secure hospital, depending on their risks to other people and the risk to their own health. All the patients in High Security are detained under the Mental Health Act.

There are 3 high secure hospitals in England and Wales. The NHS England London hub is responsible commissioning services and ensuring quality at Broadmoor Hospital, in Berkshire, which is provided by West London NHS Trust. Broadmoor Hospital admits male patients from across the South of England, including London. National High Secure Services for women and for male patients who are deaf who have learning disability or autism are provided at Rampton Hospital, which is in Nottinghamshire.

L:PV members were told that there are a number of ways in which the patient and public voice is heard in what is a complex environment. These include:

- Carers groups - each hospital has a Carers Group through which input from those close to patients is obtained
- Ward meetings and Hospital Patient Forum. Typically each ward will choose a patient to represent the interests of the patient group at the hospital wide patient forum.
 - At Broadmoor The Patient Forum is held every month and attended by ward representatives from all area. Patients co-chair the meeting and products from the meeting are typically co-produced. NHSE commissioners and case managers attend the meeting on a regular basis.
 - Broadmoor often involves patients in ad hoc decision making for example suggesting names for the wards at the new hospital (patients chose the names of London Tube Station for their wards).
- Adult Secure Services CRG members' attendance at Service User Forum meetings at the hospital.
- The patient forum can be used to consult with patients as a group. For example the Department of Health team recently attended to discuss proposed revised security directions for the high secure hospitals.

The L:PV team also learnt that there is an expectation that consultation with the Service/Patient User Forum will take place on every ward and that this maximises input from patients or those close to them.

Recommendation

It is recommended that NHSEL continue to attend relevant forums, and assure themselves that the Service Users Forums are being consulted on every ward and that services are adapted as a result of these consultations.

Neo-Natal

L:PV met with the Paediatric Intensive Care Lead and the Network Director from UCL Partners to better understand patient involvement within Neo-Natal commissioning.

The London Neonatal Operational Delivery Network (ODN) is supported by NHSEL and hosted by UCL Partners. Its purpose is to see improvements within the neonatal babies in London through the use of expert clinicians and patient experiences.

L:PV learned, from desktop research, that more than 95,000 babies are born premature or sick each year (BLISS Report) and one in 10 babies need specialised care after birth which could cover three levels of neonatal care; special care, high dependency care and intensive care, which may involve transferring the babies to different hospitals for specialist care.

There are 26 neonatal units across 19 trusts that provide neonatal care in London. The parents become the main carer and often, at times have to learn new skills to help possible lifetime illnesses.

The report stated that it was much easier to recruit parents to the Parent Advisory Group (PAG) because of their day-to-day contact with staff within the hospital, whilst recruiting to CRGs was more difficult, possibly due to parents not wanting to take time away from their children. It also said that recruitment was predominantly white middle class women within the group, which included eight members. There were also difficulties due to the fact that once infants were discharged those parents would not necessarily feel the need to stay involved with the neonatal network.

Sadly, we were not again able to speak PPV representatives during this review, or to the chair of the PAG, but we were given an overwhelming report of the Chair's strong commitment to the organisation. The PAG meets quarterly and they produce a lively, colourful, inviting and informative newsletter, which includes a lists of networks and links.

Recommendations:

- *More thought should be given to how to strengthen the voice of PPV on the CRGs, so that voice and experience is not lost when people leave the system; including with different cultural groups.*
- *The London Neonatal Operational Delivery Network " Case for Change - March 2017 document be more widely distributed as it is a useful and informative document with sound recommendations.*

London Clinical Senate and Networks

L:PV members: Jane Allberry and Brigitte Shallow

London: Patient Voice (LP:V) was asked to review the London Clinical Senate (LCS), London Clinical Networks (LCN) and Healthy London Partnership (HLP) Public and Patient (PPV) involvement as part of our work programme for this year.

London Clinical Senate

The London Clinical Senate is an independent body that provides strategic advice and leadership to support commissioners to arrive at the best healthcare decisions for their populations. The Council has 24 members who are senior clinicians, and the PPV group has 14 members. The chair and vice chair of the PPV group attend the Council meetings and there are monthly meetings of the PPV group - and views from those meetings are taken to the Council meetings.

In addition, there is a third Senate group, the Forum, which is a broad and diverse multi-professional group of senior health professionals and includes patients, public health, social care and professional bodies. Individuals contribute to the advice on reconfigurations when requested and the group as a whole meets three times a year to discuss issues of relevance to the NHS, e.g. workforce. When the Council has a request for advice, there is a review panel set up, and at least two of the PPV representatives will sit on that panel along with relevant clinicians.

We met members of the PPV group and subsequently sought views from them on a range of issues in writing (see summary of responses attached at Annex A). We also separately met the support team for the London Clinical Senate.

Generally, we came away with a positive view about the Senate's PPV engagement:

- The London Clinical Senate Council greatly valued the input from the PPV group - their views were valued and listened to;
- There had been a thorough and effective system for recruitment and induction of PPV representatives, and on the whole they felt well supported;
- The PPV group members were confident, well-informed and committed;
- The Council also took views from other PPV representatives when carrying out reviews, which was appropriate and effective.

However:

- There were some concerns expressed that issues the PPV representatives wanted to address were not always a priority for the Senate, e.g. looking at the impact of proposed reconfigurations on all equality groups;

- There could be some improvements in the support provided, e.g. access to the meeting buildings a little earlier as people with certain access needs found the last minute arrangements difficult;
- There were concerns among the PPV group members with how far the Senate was of value, given that there seemed to be little scope to take actions following the discussions;
- There were three reviews in the past year which all involved PPV input on the panels, although panel members were not always clear of the impact of their input.

We were conscious that most organisations involved in planning reconfigurations would ensure that they sought patient and public views, but our view was that what was crucial about having the PPV representatives on the Senate was that it made sure that those views were given sufficient weight; and there was openness and transparency about those views. We were also aware that the team supporting the London Clinical Senate was working with others in NHSE (L) to improve the system for PPV engagement, e.g. the recruitment and induction processes, and so they seemed to be on the case in terms of making necessary improvements.

Recommendation

Whilst there is some very positive work, we recommend that the LCS should systematically review the concerns raised by PPV representatives and monitor and address issues where possible.

London Clinical Networks

London Clinical Networks (LCN) were established in 2013. They provide expert clinical advice and leadership to inform the planning and delivery of care for local populations.

There are 9 networks: Cardiac, Stroke, Dementia, Maternity, Diabetes, Respiratory, Frailty, Mental Health and End of Life Care.

The governance structure is similar to the Clinical Senate, with a Clinical Director in place backed by a Clinical Leadership Group. They hold regular events, which bring together a range of stakeholders, including Health and Social Care providers, commissioners and patients around programmes of strategic transformational redesign to improve quality and outcomes. They provide the clinical expertise and leadership to

- Improve quality outcomes
- Advance the delivery of services
- Reduce unacceptable variations of care

The LCNs are hosted within the medical directorate of NHS England (London region). They are non-statutory bodies with no legal duty to commission health services but, as an expert advisory body whose advice is evidence based, they have a significant influence on London wide commissioning decisions.

Unfortunately during this review, we were not able to speak to any representatives directly involved in the LCN activities. We were therefore only able to undertake a 'desktop' review of the work of the LCN via the website and annual report.

We found that PPV was fully embedded as a key stakeholder in all the Network events. Although referenced in the annual report, particularly in relation to diabetes and Maternity, it was our view that the key role of patient and public voice and its contribution to their work could be more explicitly referenced. PPV representatives in other areas have previously indicated that they are not always clear about how their contributions have directly influenced commissioning. This seems a missed opportunity to highlight this area of the work of the LCN.

Recommendations

As mentioned above, the team supporting the LCS and LCN PPV representatives are working to improve the recruitment and management of PPV representatives and have produced a draft document "Patient and Public Involvement in Clinical Networks and Senate ". Their work on this is impressive and we would recommend that NHSEL:

- *Should develop this policy as something that could be used by all managers working with PPV representatives.*
- *Ensure PPV contribution and influence are more explicitly referenced in the LCN annual report.*

Healthy London Partnership (HLP)

LPV met with the Senior Communications Manager at Healthy London Partnership (HLP) who gave an overview of HLP. HLP operates with about 140 staff embedded in different programmes, and links up statutory and voluntary sector partners to take a pan London approach to delivering on the NHS improvement programmes.

It has no statutory responsibilities, but does have buy-in from all the agencies that make up the constituent parts, although that does not necessarily mean that agreed policies get implemented.

In many ways although HLP provides an added layer of complexity in the London governance/ decision-making processes, we heard that real benefits have been achieved on some of the smaller projects and some really helpful work has been undertaken on promoting collaboration and communication. The growth of STPs meant that some issues had reverted to being more sub-regional than London wide but that had not proved to be an issue.

We heard that the different parts of the HLP were expected to follow the NHSE guidance on engaging PPV representatives. Each programme determines how patients are involved in their workstreams. We were told that chairs of groups were appropriately briefed about how to support and respect the representatives. We asked if he had ever had negative feedback, e.g. PPV

representatives saying their views were not sufficiently considered, but we were told not. We also asked about specific examples of where PPV input had made a difference, and we were told of the following examples:

- 'Homeless health', which is co-chaired by someone with lived experience, which saw the development of a form for the handover of patients who present voluntarily in A&E with a mental health crisis in partnership with service users with lived experience. The form led to an 82% reduction in patients getting lost in the system.
- The 'Choosing Wisely' programme, which has 2 PPV representatives on the Board. The Board led on the review of 8 treatments via 6 task and finish groups. PPV representatives were recruited via open invitation through the other partner agencies, which ensured they had some different representation from the members on the program boards. The task and finish groups were not quorate without PPV representation.
- 'Thrive London' was presented as another example of good practice particularly with hard to reach groups.

It is difficult for L:PV to draw too many conclusions about HLP's approach to patient involvement in terms of NHSE (L) meeting its statutory responsibilities to engage with patients and the public when commissioning, as HLP is not a commissioning body.

The HLP did seem to offer some variety in their engagement activities particularly with hard to reach groups, that others could learn from. In terms of good practice they seem to have a good approach generally, e.g. they have representatives on their programmes, consult more widely such as with London Choosing Wisely, but as we were unable to speak to PPV representatives, we cannot corroborate this.

In relation to PPV, all these groups seem to be clear about their duty to involve patients and the public, how they do so as we already know is variable according to the PPV representatives and officers involved.

However, we did wonder given the number of different advisory groups that exist, who has oversight and responsibility for ensuring that they do not overlap and duplicate their efforts.

Recommendations

That the HLP have clear oversight of the contribution of the different advisory groups to minimise overlap and duplication.

Summary and next steps

This is the fourth review by London: Patient Voice, and one that comes at another time of change for NHS England.

As mentioned in the foreword, L:PV has used the opportunity of its work and this report to play a crucial role in providing corporate memory of what currently works well and recommendations on how the full potential of PPV in improving London's health services can be achieved.

We recommend that as the restructure continues, and the new organisation emerges, that the substance of this report and its recommendations are heeded, and used to create an approach to PPV that is truly strategic, co-ordinated and impactful.

Following receipt of this report, NHS England London will review and respond to L:PV with details of how it will implement the recommendations.

Interviews and evidence list

Below is a list of people interviewed by members of London Patient Voice during its investigations, and referenced notes of meetings that were used to aid the development of this report.

L:PV File ref	People interviewed	L:PV members involved
L:PV 2019 / 1	James Ludley, Senior Communications Manager at Healthy London Partnership (HLP)	Jane Allberry and Brigitte Shallow
L:PV 2019 / 2	Deborah Bull -Senior Mental Health Lead	Yemi Fagun and Deborah Frimpong
L:PV 2019 / 3	<ul style="list-style-type: none"> • Kathy Brennan, Paediatric Intensive Care Lead and Suzanne Sweeney - Network Director from UCL Partners 	Yemi Fagun and Deborah Frimpong
L:PV 2019 / 4	<ul style="list-style-type: none"> • Matthew Bazeley, Director of Public Health Commissioning, H in J and Military Health • Christa Caton, Breast Screening Commissioner, • Stella Ward, Adult Screening Commissioner • Ade Michael, Bowel Screening Commissioner • Tony Wright, Cervical Screening Commissioner • Deborah Green ,Head of Antenatal Newborn , Immunisation Programmes and Child Health Information Services • Sinead Dervin, Head of the Health in the Justice system 	David Winskill and Nkechi Nwazota
L:PV 2019 / 5	Nicky Murdoch, chair of the Armed Forces Public Patient Partnership	David Winskill
L:PV 2019 / 6	Helen Keynes - NWL Head of Quality/Regional Lead for Patient Experience and Patient Public Voice Martin Machray - Director of Nursing	David Winskill
L:PV 2019 / 7	Sally Kirkpatrick Chair: London Clinical Senate's PPV Group	David Winskill
L:PV 2019 / 8	London Clinical Senate PPV members	Jane Allberry Brigitte Shallow David Winskill
L:PV 2019 / 9	<ul style="list-style-type: none"> • Selina Robinson (Senior Project Manager London End of Life Care Network) • Katie Humphreys (Clinical Senate Senior Project Manager). 	Jane Allberry Brigitte Shallow David Winskill

Appendix A

A survey of PPV representatives on London Clinical Senate took place and a brief analysis of their responses is set out below:

RECRUITMENT - how open and transparent are recruitment channels; how did you find out about the LCS PPV Rep vacancies; were you invited/recommended to join?

The recruitment process was generally seen as robust and transparent: "I was recruited using a detailed objective process, consisting of written application, interview and live event involving discussion with clinicians about current matters. The role was explained in detail." There had been advertising through various channels as well as spreading the word through interested parties: "PPV places are advertised as widely as possible - through the NHS patient contacts, through Healthwatch, using VCS contacts and their newsletters, and asking comms leads in CCGs and Trusts to spread the advert, as well as on the LCS's own website. Finally word of mouth from existing representatives and council and forum members is put to use." They tried to get a fair representation across London.

TRAINING - were you offered an induction or other training: how was it delivered -online/face to face; how well did it prepare you for your LSC role? Do you receive on-going training or attend conferences. Would LCS pay for you to attend non-NHS events?

Mixed responses, and arrangements quite informal (particularly induction), but generally the PPV representatives felt that training had been provided and that individual requests were supported. "After successful interview there was an induction over the telephone that explained the work of the senate and how it operated. We have been on several training courses including a 3-day face-to-face patient leadership training at the London Academy and most recently 2-day face-to-face mental health first aid training course." "You learn on your feet and by having an experienced person with you at your first clinical review and so on. Everyone recruited needs a basic knowledge of the NHS and probably has a specific interest in one aspect of it ..."

SUPPORT - are agenda and papers for meetings delivered in a timely way; do you have access to advice and support to allow you to understand complex issues? Is the remuneration/expenses policy clear, transparent and fair?

Very positive views about quality of papers and getting them in advance and about advice and support: "The LCS programme manager and lead draw up the agenda and papers before being sent to the chair of the group for approval and so on. They are circulated a week in advance of the meeting. If there is a complex topic to discuss a clinical expert will always be brought in to talk to the group during a regular meeting." "The agenda and papers are of uniform high quality, clearly presented in a timely manner. I have received excellent support from the clinical and programme lead and their staff." Remuneration/expenses policy clear but some concerns about fairness: The remuneration policy is clear. However, I do not feel it is fair as I believe the PPV Group members should receive Level 4 payments given the expert advice they provide. I believe that this can also be demoralising and should be reviewed. There are £5 per meeting costs refunds available but I have not applied for these as I imagine the administrative costs to the NHS would be far greater than the sums I would receive." Some concerns about access to and suitability of buildings/rooms: "One recurring problem is access through access controlled doors to actually attend meetings." "Some of our activities take place in venues which are not very suitable to hear active discussion. Changes in venue at short notice can be disruptive to attendance. The Skipton House venue is less accessible than the prior arrangement where we were trusted with access cards. This is not a trivial point as we travel from various localities and when we arrive we may require to attend to various needs. Pressure within the system often means that we have to wait until the start time of our meetings before we can be seating in the meeting room..." DN - there is a much longer quote but this is quite personal and so I am not sure a good idea to include all of it?

PARITY OF ESTEEM/OWNERSHIP - do you feel that the same weight is given to your input/comments, as it is when clinical colleagues speak at meetings? Do you feel that you are an integral part of LCS? Do you feel comfortable about challenging clinical or other colleagues? Are your questions and requests for more information responded to? Do you feel what you say is reflected in final recommendations? Do you feel that you are being kept in the loop on other LCS matters or perhaps get information second hand?

Generally very positive response: "I do feel that the LCS offers equal opportunities to all its members and that I am very much an integral part of the LCS. I have always had my questions or requests for information responded to. I think the Chair has a wonderful way of being able to allow members to challenge anyone in the LCS with utmost diplomacy and flair." "I have always felt parity." Some scope for improvement however: "I believe that the issue of parity of esteem would be partly addressed by implementing INVOLVE guidelines. If PPV Group members are not considered expert members, how can they really have a basis for parity of esteem with senior clinicians?" Some feeling that PPV representatives sometimes brought in rather late in the process, and also a frustrated wish to link more with other PPV groups in the NHS in London: "Occasionally, I feel that pan London developments not reach us at an early enough stage for us to provide meaningful input, even though we have a representative on one of the key HLP boards. I feel that there is sometimes a disconnection between boards and agencies, or between different levels of service such as the pursuit of pan London policies by the Mayor's office and the developments by STP and CCG levels. Another issue I would like to raise is the lack of contact we have with other patient and public groups ..."

CO-PRODUCTION - do you think that recommendations and decisions are made elsewhere and you are being invited to "take the rough edges off"? How could the process be improved?

Quite mixed responses, eg some views that co-production not really what could be expected, and reasonable involvement was effective: "As a strategic group, the London Clinical Senate's main activities are to provide objective leadership and communications to promote transformations consistent with 5YFV. In this it has set a good example by ensuring that its PPV is vigorous and engaged. We have occasionally been involved in co-production ... however, at our level we would not usually expect to co-produce clinical developments at operational level ..." Others felt decisions were taken elsewhere but the PPV recommendations taken into account: "One honestly believes that, although decisions are made elsewhere, one's recommendations are taken into account. However, it would be helpful if the agreed final document is circulated to members so that they could feel their points of view/recommendations have been adopted!"

FEEDBACK - how do you know that your views have been listened to? Short examples or citations of LCS PPV input into documents/reviews would be welcome.

Again quite mixed views, but generally very positive. Some said no proof - "I'm not sure that other than people appearing to listen in meetings that I have any proof ..." but others said it was clear in the reports and minutes of the meetings: "I do know that my view has been listened to when it appears in the minutes of meetings." "In the reviews in which I have participated, actions have emerged that reflected exactly the points I have raised ... We have urged that the Senate forum be conducted in ways more amenable to recording and feedback from live discussions of current topics, and as a result the agenda for forums are now published ahead and are less susceptible to sudden changes so that we can prepare considered comments."

WHAT ELSE?

Miscellaneous comments eg the Clinical Senate should look more thoroughly at the impact of reconfigurations on particular equality groups, staff generally need to be better trained on patient/public engagement.