

Patient and Public Involvement

Since the Bristol Enquiry (2001) and the Wanless Report (2002), patient and public involvement (PPI) has been seen as crucial for a patient-centred NHS. However, there are challenges to making it a reality, particularly in for patients who suffer health inequalities. In its first two years, Health link has worked on some of these challenges:

1. PPI in national policy implementation: recruiting a 39 member Choose and Book Patient Reference Group from Health Link's PPI Network, to advise on Choose and Book implementation in London, the design of the Choose and Book website and the national patient information leaflets, and national strategic issues such as free choice.

2. PPI to influence strategic decision-making: setting up the NW London Patients' Parliament, with funding from the NW London Strategic Health Authority (STHA) made up of members from 8 boroughs. We have designed governance materials including a Code of Conduct, and provided accredited training, chaired the Parliament's in its first year, building its capacity to contribute to strategic decisions. Parliament outputs include *Primary Care for Patients: Standards*, setting out what patients would expect from GPs.

3. PPI to help shape choice policy around health inequalities: outreach consultation for the London Patients Choice project, on a socially inclusive information and support specification for choice of provider, involving 14 groups at risk of exclusion from choice:

- Care home residents,
- Carers of those with dementia,
- Disabled people
- Faith groups
- Older people
- Young people
- Homeless people,
- Mental health service users
- People living in poverty
- People with a learning disability
- People with Basic Skills needs
- People with no IT skills
- Speakers of a non-English first language
- Parents of sick/disabled children

The resulting *Taking Soundings* report recommended steps to avoid Choice inequalities.

4. PPI to help commission materials to support patients in Choice: working in partnership with four of London's five STHAs, the Department of Health (DH) and NHS Connecting for Health, to develop a Patients' Information Tool, to enable patients to compare hospitals on what they told us mattered to them, in *Taking Soundings*. This comprised:

- Scoping national datasets for available data and surveying Trusts for remainder
- Working with the DH on a database comparing every NHS site on specified indicators
- Producing a lay description of the 150-plus Tool topics, tested with our Network
- Obtaining approval from NHS Estates, NICE, the Healthcare Commission, the Health Protection Agency, the Health and Safety Executive, and the Chief Nursing Officer, to the data descriptions in the Tool relating to their work.
- Developing an Accessibility specification (including Race and Disability Equality)
- Obtaining Ethical Approval to test the Tool with patients as they choose their hospital.

5. PPI to help the NHS design services around health inequalities: supporting the Whittington and Homerton Patients Forums to work in partnership with homeless volunteers, in monitoring and improving A & E services from the homeless perspective. This Project was independently evaluated and funded by the Kings Fund.

6. PPI in the determinants of health: working with the London Health Commission to develop networks and resources to help grass roots community groups to engage with pan-London bodies on the determinants of health and health inequalities. Funded by the Commission and supported by the Mayor.

7. PPI in specialised services: supporting and co-chairing a Patient Reference Group for the London Specialised Commissioning Group, testing a new approach to PPI recruitment through open advert, seeking specific skills from patient representatives (in finance and strategy for example), to match the complex subject matter.

8. PPI in cross-sector working on health: partnership working with Islington Social Services, St. Mungo's, Whittington A & E, Whittington Patients' Forum and Groundswell (the homelessness charity) to develop referral and signposting pathways for rough sleepers or homeless people attending A & E, so staff can help them access homelessness support.

9. PPI in cross-government working: establishing Partnership for Patients involving the NE London STHA, the Museums, Libraries and Archives Council, the London Libraries Development Agency and London Health Libraries. The Partnership is taking forward a Health Link feasibility study funded by the Department of Health, on the role of libraries in supporting patients' choice. NE London STHA is supporting the project through a secondment to Health Link.

10. Using PPI to connect Patients' Forums to their communities: conducting a 'Community Connections' project for Kensington and Chelsea PCT, and Chelsea and Westminster Patients' Forums, enabling dialogue between the Forums and local community groups, so they can draw the views of people suffering 16 types of disadvantage their future work.

11. Pan-London PPI: advising the GLA on PPI and NHS issues in London, acting as a special advisor on the London Assembly scrutiny on Primary Care. Establishing a PPI network of 125 patient representatives across 30 London boroughs, with funding from the GLA. Health Link has recruited from this Network to its Reference Groups, so that experienced patient representatives have supported those newly involved. Network members have attended one-off consultation events for example on Choosing Health (funded by the London Regional Public Health Group).

12. Training in PPI and outreach PPI: delivering the Learning and Skills accredited Certificate of Community Volunteering (CCV) with the Health Link module on patient representation. The Department of Health funded the development of this training and its independent evaluation by Aston Business School. In all, 74 patient representatives have either completed the training or in the process of doing so. We are developing this training further to skill up patient representatives in outreach work, enabling them to draw the views of 'marginalised' groups who may find traditional PPI structures excluding, into monitoring services and influencing commissioning in the NHS.