

Appendix 1

**The Voice of Patients, Carers and Service Users in the
Wandsworth Clinical Commissioning Group**

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1. Foreword and Introduction

In 2010 major changes were proposed by the government which will have far-reaching implications for the NHS and the patients it serves¹. GPs and other clinicians have been given the responsibility to commission services for their local population.

As GP commissioners, we will work with local people, communities and our partners to transform the health of people living and working in Wandsworth. We will ensure delivery of high quality, patient-centred services. We want our local communities to be ambitious about their own health and to challenge us to deliver the best possible services within our resources.

For this to happen, the people and communities we serve should have a voice in *what* is provided and *how* it is provided. They need to understand who we are, what we do and how it is done, what services are available and how to use services effectively.

Wandsworth Clinical Commissioning Group (CCG) wants to develop a partnership with the people of Wandsworth which will be built on honesty, integrity and open communication. This relationship will enable patient views to inform the commissioning process and ensure we create pathways of care and services that fulfil our patients' needs.

Throughout this document, you will see comments from patients that we have recorded from different events held over the last few months and I hope that our planned approach reflects the ideas in these comments. I hope we create the right opportunities for people and communities to be involved and that people take these opportunities to help us make the right decisions.

To enable this to happen, patients and local communities² are being asked:

- How can we achieve this vision together?
- How do people want to be involved?
- What support is needed to make this happen?

"Patients must be heard and involved."

The voice of the Patient in the CCG will signal a significant cultural shift for both staff, patients, carers and service users in how commissioning decisions are made. The co-creation of such a strategy, between the CCG and patients, carers and service users, is the first stage in achieving our shared goals for Wandsworth

Nicola Jones

Clinical Lead and Chair for the Wandsworth Clinical Commissioning Group

¹ The White Paper on health Equity and Excellence – Liberating the NHS.

² Communities across Wandsworth have an opportunity to be heard including those whose voice is traditionally seldom heard (see appendix 3).

2. What will good commissioning look like?

Patients, carers and service users and the public currently involved in the NHS bring many skills and interests to the table and have very clear ideas on what commissioning should look like and how it should be developed. Some of these ideas were shared at the May 2011 workshop and are summarised in the following points.

"Could patients be represented in commissioning decisions at all levels, including the Board within the new organisation?"

Good Commissioning – Involvement:

- Needs to involve patients in an open honest and transparent way
- Recognises the diverse needs of the communities.
- Good two way communication with patients and communities
- Need to incorporate working with partners e.g. voluntary and community organisations, schools etc
- Decisions (including difficult ones) and the way they are made should be communicated to patients and the public

Good Commissioning – Knowledge:

- Is based on good local knowledge about the population and what the health needs are.
- Is based on good knowledge of all providers
- Is informed, needs led, not finance led taking into account quality as well as price
- Need evidence based approach and be holistic
- Takes into account individual patient needs
- Develop and identify GP champions in specific health issues

Good Commissioning – Competence:

- Needs to be carried out with good governance and proper accountability
- Needs to be delivered by highly skilled and well trained staff
- Needs quality monitoring and feedback systems
- Sticks to budgets
- Promotes efficiency

3. Drivers for Change

3.1. National drivers

The main driver for change to how services are commissioned is the Government's White Paper on Health³: Equity and Excellence – Liberating the NHS from July 2010. Other drivers include:

- The Equality Act 2010
- Duty to consult Overview and Scrutiny Committees (Local Government Act 2000)
- Care Quality Commission standards
- Local Involvement Networks (LINKs) and developing Healthwatch
- Quality, Innovation, Productivity and Prevention (QIPP) programme

³ The white paper, is not yet on the statute book and is currently still going through Parliament, however it is widely anticipated that it will become law and we do not expect at this stage any significant further material changes

- NHS Constitution
- The development of a national communications and engagement resource⁴

3.2. Local drivers

"We are indeed entering exciting times, personally I can't wait to see how it works in practice."

The Wandsworth CCG has been developed and given Pathfinder⁵ status. In addition the PPI work within Wandsworth has also been awarded Pathfinder status. Other local drivers include:

- Feedback from patients, carers and service users and communities at a variety of events including the recent PPI in Locality Commissioning workshop has indicated the need to build on and improve patient involvement in local health decisions.
- The Health and Well-being Partnership Board⁶ is being developed to bring together further involvement in both health and social care across Wandsworth.
- Wandsworth LINK has also received Pathfinder status to develop into the Wandsworth HealthWatch⁷.

4. A health needs snapshot of Wandsworth

As the largest Inner London borough, Wandsworth has some significant characteristics⁸ that are very different to not only the rest of London but to the national picture. With a population of approximately 290,000⁹, the age structure of residents is uniquely skewed towards the young - the 20-39 year old age group represents 48% of the population compared to 27% nationally and 36% in Greater London. This is further exemplified by the fact that one person households account for 38% of all households in Wandsworth. It is also a borough which experiences high levels of population turnover year on year, and the movement of young adults into the borough is expected to continue.

Wandsworth is home to a diverse range of communities and 20% of the borough's population is non-white, compared with 31% in Greater London and 12% nationally.

There are around 19,000 carers in Wandsworth; as such they make a significant contribution to the support that people receive through health and social care services. We will ensure that the needs and views of carers are taken into account as our action plans are developed.

⁴ On the national level, it is worth noting that during the transition to clinical commissioning, support for engagement work will be provided by a national 'communications and engagement resource'. The implications for this locally are still unclear.

⁵ Pathfinder organisations in health are agreed lead groups that can help share information and learning

⁶ The Wandsworth Health and Wellbeing Partnership brings together the Council, PCT, the GP consortium and other agencies to promote the health and well-being of the Wandsworth population and to develop a shared vision of and ambition for health improvement and health and social care services

⁷ HealthWatch is an initiative to tackle the inequalities within the NHS and to provide patients and public with a voice to air their views, suggestions and concerns to governing and commissioning bodies.

⁸ Wandsworth joint Strategic Needs Assessment 2010

⁹ In addition to this population the GP registered is in the region of 369000. On top of that there is an invisible additional population of around 100 comprising of statutory homeless people, asylum seekers etc.

Overall Wandsworth has a young, mobile and prosperous community. However, there are particular communities and geographies for which good health and health outcomes contrast badly with the majority of the population.

The residential wards of Latchmere, Roehampton, Queenstown and Tooting all exhibit significant disadvantage across most dimensions of deprivation. These communities display higher prevalence of diseases than the average for Wandsworth. Across Wandsworth there are around 11,000 registered patients with Diabetes and around 26000 living with Hypertension to name but two diseases. Early deaths¹⁰ from heart disease, stroke and cancer in Wandsworth are significantly higher than the norm, and early deaths from cancer are on the increase.

Statistically Wandsworth residents have a shorter life expectancy than their counterparts elsewhere in London. Males are expected to live 76 years and females 81 years, whereas male Londoners as a whole can expect to live 77 years and females 82 years.

Combined with high numbers of children living in poverty, teenage pregnancy and the homeless the population and health needs mix is both complicated and unique. This presents significant challenges in the context of a diverse multi cultural multi ethnic society

5. Current arrangements for PPI

What are the opportunities for the general public to get involved?

Patient and public involvement has been an important function in NHS Wandsworth since the PCT's inception in 2002. The role of the patient has developed over the years from a passive participant in health, to having a more influential role in the decisions that surround them. Much of the work in Wandsworth has been about strengthening this role and the channels that support this work.

6. Our Partners

In broad terms, as commissioners we relate to patients, carers, service users, other commissioners and external stakeholders. There are also outside influencers on each of these groups including national organisations or associations, the media, professional associations, local and national government and religious and community organisations, just as examples. We cannot work with every organisation but we should look to understand these outside influences on our patients and external stakeholders opinions and decisions. LINK – soon to become HealthWatch, has a statutory remit to ensure that patients and the public are involved in health and care developments. LINK has therefore been a key partner and will continue to work with us on the development and implementation of the patient voice in the CRG

7. Our Vision, Goals and Principles

7.1. The overall vision for the Wandsworth CCG was the subject of a recent workshop of GPs, staff and patients and carer representatives, however a working vision used over the last year (2011/12) is as follows:

¹⁰ Health profile 2010 – Wandsworth
Appendix 2

“Deliver health and wellbeing improvements for the population of Wandsworth and to transform the health of people living and working in Wandsworth”

This brings new opportunities for Wandsworth to:

- Deliver better outcomes for patients;
- Engage clinicians across service settings in commissioning;
- Put patients, carers and service users at the heart of decision making and improve the patient experience;
- Strengthen collaboration between Health, Social Care and other services that contribute to the health of the population;

“PPI guidelines are needed, as many do not get it right”

7.2. Goals

To deliver health commissioning in Wandsworth, patients, carers, service users and the public have told us what they want to see a meaningful and effective involvement and engagement system where:

- Responsibility for patient and public involvement is shared by patients, carers, service users and the CCG;
- Partnership working is the norm;
- The patient voice is heard throughout the process of commissioning within the consortium;
- All parts of the community are included in the partnership dialogue including those communities whose voices are seldom heard.
- The impact of patient involvement on commissioning is fed back to our communities;
- Decisions made by the consortium are fed back to patients and public;
- A clear structure to deliver PPI within the consortium is developed.

“I want to help patients get the care and treatment options that they want - maintaining a wide area of choice.”

7.3. Principles

In order to deliver these goals, patients, carers and service users have told us that they want to see the CCG adopt the following principles:

Inclusion and accessibility

- Involvement starts at the beginning with the individual consultation (between healthcare professional and patient) and should be based on a good rapport between clinician, patient and carer.
- Community representation should be actively encouraged within the structure and within patient groups
- Patient and public involvement activities should ensure representation from as wide a range as possible across Wandsworth and will be open to all patients including all those involved in their support, including carers.

- At each step along the Patient pathway it must be recognised that the patient can contribute to managing their care.

Information and Communication

- Patients should have a clear understanding of what their role is and when and how they can contribute.
- The flow of information to patients and how messages are communicated must be clear and meaningful, at an appropriate level, with sufficient detail and with plenty of time for people to consume the information.
- Use of jargon or acronyms should be avoided at all times.
- Consultation should be genuine if effective engagement is to take place.
- Patients have a right to information on the outcomes of consultation and information regarding decisions and to be told when their feedback has been rejected and the reasons for this.
- A diverse range of information (including community information) should be available in a variety of formats and languages including traditional and modern communication methods, to enable all parts of the community to participate.
- Communication and the relevant tools (e.g. websites) must be kept up to date and accurate

Locally driven involvement: demographics

- Practices have an important role in engaging patients and should have effective systems in place so to do. Practices should strive to have a Practice Patient Group.
- The process of involvement in commissioning should, where possible, start with the patient (bottom up). We must ensure that there are systems in place so that patient views can be assimilated
- At practice level, patient involvement and engagement activity should be reflective of the patient population.
- Borough wide networks, where possible should be developed to encourage involvement
- Patients can input through PALS (Patient Advice and Liaison Service), Practice Patient Groups, Patient Pathway Groups and Demographic groups. They can also feedback through LINK and Wandsworth Voluntary Sector organisations.

8. How we will involve patients? Key actions for involvement

"How will there be proactive work by the new consortium to engage with the local population?"

A broad programme of patient and public involvement and engagement has taken place across Wandsworth for many years and has been built up to involve many patients, carers, service users and members of the public in the work of the PCT. The purpose of our approach is three fold:

- to build on this work and develop an approach that evolves and remains relevant to the people of Wandsworth and fulfils the requirements of the commissioners.

- To reflect the uniqueness of Wandsworth as a borough with complicated health needs in diverse communities and to develop appropriate involvement and engagement processes to capture the voices from different communities including those that are disadvantaged or seldom heard¹¹
- To ensure that the commissioning processes within the CCG and the commissioning cycle are transparent and complete and that there is engagement and involvement at all levels

To achieve these goals and principles, a clear process for involvement and engagement at all levels will be developed and implemented. A detailed action plan will be developed, but the specific actions highlighted below have been agreed by the CCG and represent work in progress started as part of the development monies provided by the Department of Health.

THE KEY ACTIONS ARE:

8.1 Patient and Public Involvement Clinical Reference Group (CRG)

- ACTION: Development of the PPI Clinical Reference Group with a clear remit

The GP Pathfinder group delegated a PPI steering group to undertake the Patient and Public Involvement development work and report back to the Clinical Commissioning Group. This was convened in February 2011 comprising two GP leads, Dr Sian Job and Dr Peter Ilves, the NHS lead for PPI, a local authority representative, Sandra Storey, A representative from Wandsworth LINK and other representatives from NHS Wandsworth. The Chair of Wandsworth LINK, Jenny Weinstein, was invited to chair the group on behalf of patients and the public. This group has met on a regular basis to further the work programme agreed.

In line with the CCG, a Patient and Public Involvement CRG will be developed to take over the role of the PPI Steering Group and report to the CCG taking an overview of PPI operational activities within the Commissioning agenda. A key element of this CRG will be to develop an Action plan that meets the aspiration of both patients, carers and staff including developing more formal arrangements between commissioners, patients and their representatives.

The Clinical Commissioning Group should direct appropriate agenda items to the PPI CRG on an agreed basis and the CRG will feedback regularly to the Clinical Commissioning Group on these issues through PALS reports, PPI evidence logs and specific project reports. A number of workstreams are already in existence to support the development of patient and Public Involvement and these are outlined below.

8.1.1 Locality PPI Forums

- ACTION: The three locality PPI forums will bring together patients from each of the practices to work jointly alongside commissioners and clinicians on the Locality Commissioning Groups (LCG);

These forums will then evolve with the LCGs over the coming months. The forums' role would include considering issues brought forward from practice patient groups as well as working

¹¹ See Appendix 3 – A report on activities funded in the Voluntary Sector

closely with the LCG and CCG about commissioning issues. LCGs may expand the opportunities they have for PPI to suit their local arrangements.

The PPI CRG will consider and recommend (as part of the developing Action plan), how locality forums will operate.

8.1.2 Borough-wide biannual PPI health forum

- ACTION: To consider the establishment of a borough-wide biannual PPI health forum for GP commissioners and patients and the public, one of which could be organised around the CCG's AGM event;

Following on from the two successful patient events organised last year to establish principles, The PPI CRG as part of its remit will consider the development of a borough wide biannual PPI health forum. This would be a key opportunity for commissioners to come together in partnership with patients, carers and service users and discuss key issues and projects.

These meetings could be an additional resource for commissioners to engage with patients on their priorities and hear the issues coming up from patients, carers and service users and would be in addition to discussions at locality level, at the Clinical Commissioning Group and for specific projects and consultations.

8.1.3 Communications channels and PPI Resource Centre

- ACTION: Develop further the communications channels and PPI resource centre;

We will ensure that communication and relationship building are key activities to ensure we reach the widest group of people possible. Wandsworth is a diverse population comprising of a multitude of communities and a myriad of languages spoken. Developing appropriate communication techniques to facilitate high quality and creative involvement and engagement will be core to successful commissioning.

This will be facilitated by:

- A customer relationship management (CRM) system that has been developed for NHS Wandsworth to facilitate better communications with patients and the public and this system can be used to target communities through a variety of channels and enhance the involvement techniques from the PPI toolkit.
- a PPI resource centre and toolkit that has been developed to support commissioners when carrying out PPI activity. It provides a series of techniques that can be used with a variety of audiences and topics to enable commissioners to improve the quality of involvement activities.

9. Our Aspirations: What will good PPI look like?

- Good feedback system between commissioners and patients, carers and service users
- Properly resourced patient and public involvement programme

- Effective involvement processes in place and where appropriate patient groups in GP practices
- Engagement with a wide range of people and community organisations
- Patient information on involvement in healthcare at every practice
- Timely information reported to commissioners from patients for them to action and use to develop their commission plans
- Timely responses from commissioners on actions and decisions taken
- Patients, carers and service users participating in difficult decision making scenarios
- The exploration of co-production initiatives to utilise patient/community resources

10. Resources

To deliver PPI in the CCG, resources will be required.

Current NHS Wandsworth funding of £334,000 covers PPI staffing¹² including PALS, the Expert Patients Programme, Wandsworth Youth Health Jury, a small PPI budget, You're Welcome¹³ and the PPI Pathfinder budget allocated to Wandsworth.

To deliver PPI within the new Clinical Commissioning Group a similar level of funding will be required. Consideration of funding of PPI is key. This could be a mix of recurrent funding or one-off funding for specific projects. The exact budget needs to be discussed and agreed by the CCG. The list below indicates the level of resources required.

Staffing PPI Clinical lead PPI – Manager PPI – LCG Co-ordinator PALS/Complaints Coordinator Co-ordinator for EPP/YHJ Admin support
Training budget
Budget to support EPP
Development budget to support Patient Pathway work
Development work to support groups at Practice level
Development work to support outreach with Community Organisations
Small grants scheme to continue to support work with seldom heard groups
Organisational budget to deliver consultations, use of new media techniques, meetings, workshops
Advertising /publicity budget

¹² Not including clinical lead

¹³DH funding finishes for this project March 2012