



The Voice of Seldom Heard Groups



Patient and Public Involvement

A new structure for delivering health services is being pioneered in Wandsworth in anticipation of the Health and Social Care Bill becoming Law in the spring or summer of 2012. The borough Health and Well Being Board and Wandsworth Clinical Commissioning Group have become pathfinder bodies charged with finding ways of involving patients and the public in all aspects of health care. As part of these developments LINK will develop into a new health watch dog known as Wandsworth Healthwatch, probably in October 2012. There will also be a national body called HealthWatch England.

Wandsworth LINK has been working with the new Clinical Commissioning Group (CCG) to develop a strategy for involving the whole community in the future commissioning and development of health services. This strategy stems from the commitment of the GP leads on the Commissioning Group to develop systems that involve patients and the public, including people whose voices are not always heard, at all levels in the process of planning and delivering services. It is a work in progress.

The Seldom Heard Project

The CCG were given Department of Health funding to pilot patient and public involvement (PPI) and £20,000 was earmarked to engage seldom heard groups. As part of our contribution to this PPI initiative LINK sent out an invitation to apply for funding to local community organisations and groups of people with disabilities or sensory impairments. The groups were asked to seek out the views of their members on health needs and to find out how they would like to be involved in future consultations on health. There was also a requirement to attend a PPI conference in November 2011 to discuss the CCG engagement strategy.

Nine community organisations applied for, and received grants of £2,000 each to help the engagement process and several others have since been consulted to get their views on what they would like to see happen. This is what they had to say about their experience of health services.

The Experience of Funded Groups:

1. Generate Opportunities

The charity supports people - adults and children - with learning disabilities. Here in Wandsworth they run 4 youth clubs and 3 social clubs for adults in the borough, plus several one-to-one friendship groups. Also they have a work experience project (The Bridge) in Balham and support a number of people in work situations across London.

Generate have devised an 'Easy Health' website to assist communication between patients with learning disabilities and health professionals. The website (www.easyhealth.org.uk) was developed in response to a consultation with people with learning disabilities about difficulties they had with information they received at GP surgeries.

Activities: Generate has over two years worked to deliver training to doctors and staff at GP Surgeries. This training is co-delivered by a person with a learning disability. 12 one or

two hour sessions were held in 2011 and next year they plan to extend this to at least 6 dental surgeries in the borough.

They held one consultation event in Balham in September and plan to hold another in January in Earlsfield. These events were advertised through 'easy read' illustrated leaflets. Generate believe events like this are useful, not only for the information they convey, but because they also help to build links between clients, their families and the project.

Health Issues & Recommendations: One of the issues that emerged from the consultation exercise was a specific concern over waiting. For example, some people with autism were not bothered by long waits to get an appointment but became very distressed if the appointment did not take place at the advertised time. The group suggest GPs could mark this problem on patients file, so that 'queue-jumping' can take place to avoid their stress. Hospital food menu cards were also highlighted. Many of their clients can't read and so fail to make choices and end up with sandwiches or going hungry.

Technical and medical terms are a further problem, and patients usually need someone with them to remember what the doctor said to them. Another suggestion is that people with learning disabilities be allocated double length appointments to allow time for the communication process, and that GPs have the Easy Health guide available on their computer screens.

2. New Testament Assembly Church Tooting

NTA Tooting is a well-established church with often more than 600 at Sunday services and a membership of more than 350 people - predominantly of African Caribbean and African backgrounds. Whilst attending to the spiritual needs of its members it is also actively involved in improving the health and social needs of the community it serves.

Activities: In recent years NTA has engaged with statutory bodies about developing and providing services that are more appropriate and culturally sensitive to the Afro-Caribbean and African community's needs. For example they carried out consultations for NHS Wandsworth on polyclinics and on improving mental health and well-being. The church also provides a site for delivering mental health services to the community under the Improving Access to Psychological Therapies programme.

Health Issues & Recommendations: Despite this history of involvement, leading members of the NTA spoke to LINK of a continued lack of trust of the NHS among the Afro-Caribbean and African community. They reported a lack of understanding and courtesy from gatekeepers like receptionists, which puts people off using services. Also they outlined the difficulty of engaging the community through impersonal communication like questionnaires. Face-to-face meetings and telephone conversations are seen to be more effective. So New Testament did not use its grant to conduct any further surveys of attitudes to health concerns. They said they have already conducted surveys of mental health issues and other concerns like diabetes and strokes.

They say there is a wealth of health experience and skills in the community which could be tapped if approached in right way. It needs to be an interactive process, and to work requires an investment in capacity building to develop health champions based on existing community groups.

After meeting with LINK, the New Testament Assembly members agreed to look at ways to develop an expert patient group in within the black and ethnic minority (BME) community by using the existing grant to skill up people. The aim would be give them confidence to transmit the experience of the BME community to GP patient groups and to be able to offer awareness training to GP practices. In addition they could become a reference group for the BME community on health issues and break down some of existing barriers. In the long term this could help improve health outcomes for the community. They also agreed to see if they could get a group of people interested in being involved in this, with a view to meeting GP commissioners.

3. Putney Vale Residents Association

The Putney Vale Estate was council built in the 1950s and was recognised nationally as isolated and neglected by a department of health funded project in 2010. This highlighted areas of major concern to residents and Putney Vale Residents Association has been addressing these problems by working to improve the quality of life on the estate.

Activities: One recent example has been the successful campaign to get the council to repair and reopen the residents' hall. The residents are a mixture of council tenants, leaseholders and some freeholders, and they represent a wide diversity of backgrounds and ethnic groups which include amongst others Polish, Somali and Asian communities.

PVRA held two successful consultation events in July and September to ask residents about their health concerns. The July event brought together elderly people from lunch clubs, combining questionnaires with musical entertainment and an excellent lunch. The September consultation was part of a Family Fun Day attended by over 200 local residents, who completed their health questionnaires before making for the buffet lunch and magic show. The association also used part of their grant to produce a newsletter to publicise and report on the events.

Health Issues & Recommendations: The health concerns revealed by the surveys focussed on the need for a more flexible and accessible appointment system, for regular clinics on the estate, and the difficulty of access by public transport to health services. But addressing some of these concerns may call for a joined-up response.

The association's Shirley Price was encouraged to learn that the Commissioning Group is going to make reducing Wandsworth's high level of falls a priority. But she told LINK that they have been trying for months without success to get the highways department to repair the large number of cracked and uneven pavements on the estate which have led to a number of falls among elderly residents. She says, "I feel that the current challenge is how to get this 'working together' to make an impact on the local council and whether we will see any changes as a result at grass roots level."

4. Roehampton Trust

Roehampton Trust was set up in 2010 with the aim of generating a community hub on the Roehampton estate, a deprived locality with a variety of needs. Trust member Pam Harris describes it as an area with a missing middle - having a high proportion of elderly residents and young mothers, with not a lot in between.

Activities: The trust has used the PPI grant to establish a newsletter - Roehampton Voice - to get themselves known and to organise a number of consultations on health concerns. The bi-monthly newsletter is now into its 3rd edition and is helping to provide a focus for the community and inform local people about the NHS changes. It is also a way of building up the organisation. Some students from Roehampton University are helping them with the production and journalism of the publication.

Several consultation events have been organised on the estate, including a meeting addressed by local GP Peter Ilves, a health and wellbeing survey of elderly residents, a survey of mothers at the Roehampton Festival and a joint venture with Putney Vale Residents Association. The small core of volunteers that make up the trust have also got another initiative off the ground - a cafe for the over 60s. Established in a local church, it provides a weekly opportunity to bring older members of the community together. They aim to extend this by running recreation classes in the church hall with the aim of laying the foundations for a future community centre, a long term project that could help provide a focus for the social regeneration of the area.

Health Issues & Recommendations: The main health issues that emerged from the consultation events were the familiar problems of access and communication. Just getting to hospital from the estate can involve a couple of bus changes.

5. Somali Community Advancement Organisation

The Somali Community Advancement Organisation was established in 2006 to provide support to the Somali community in Wandsworth. Many are refugees from the civil war and experience a variety of problems associated with the experience of trauma and poor nourishment. SCAO says more than 80% of local Somalis are unemployed. It describes its mission as follows: 'to help elders, women and children from the Somali community integrate better into current society by identifying their needs and providing appropriate solutions.'

Activities: After receiving funding, SCAO held two consultation meetings, in September and October, on the health concerns of the community. 85 people attended the consultations and out of those events SCAO produced a report on local concerns about health care and the delivery of that service.

Health Issues & Recommendations: The main issue arising from the report is the language barrier. 60% of patients said they were dissatisfied with the service they received from their GPs, and when asked why, their response focussed on the difficulty of communication. It says any possibility of involving Somalis in the PPI programme will depend on how the communication problem is addressed. Using children and other family

members for interpreting doesn't really work as the children cannot communicate accurately back to their parents.

The report recommends the formation of a group of Somali patients who can act as the voice of the community in the local health service. It says this Somali Group will not only help patients but also add value to the consultation process. But it recognises there are many challenges to be overcome if PPI is to be achieved ' GPs may feel they do not have enough time, information and support to engage patients to the desired level...The implicit power dimension within the consultation may also make it difficult for some patients to become engaged...Some feel unable to express themselves fully as long as the GP is the 'expert' in the situation.'

The SCAO report recommends the following steps to improve effective participation in the commissioning process:

- Create a body of Somali patients' advocates to facilitate interaction between GPs and patients
- Ensure easy access to information in the appropriate format
- Recognition and respect for each other's skills and experience

6. Thomas Pocklington Trust

The Thomas Pocklington Trust offers people with sight loss the help, support and care they require to lead an independent life, based on their individual requirements. There are 1400 registered blind people in the borough, but this is almost certainly an underestimate as many visually impaired members of ethnic minorities are looked after by their families and not registered. The trust provides a housing and resource centre based in Wandsworth, which provides information to people in preferred formats, including a talking news service and a comprehensive website. They also run a volunteer befriending scheme which aims to include the views of people who can be hard to reach and vulnerable.

Activities: They held a series of consultations in small groups and on an individual basis in August and September, and invited contributions via the talking news service. In January the trust is planning an event for blind deaf people to discuss how communication can be improved for this very isolated group.

Health Issues & Recommendations: Communication is the overriding concern. Appointment letters are inaccessible to many visually impaired people, so patients need to be consulted over their preferred method of communication. Some visually impaired people have been left in unfamiliar waiting areas without being given an orientation or informed where facilities are, or reassured that their guide dogs will be looked after during a consultation.

Odette Battarel of the trust says many people with visual impairment lack the confidence to complain about their treatment. Even the preliminary steps of finding the right number to call to make a complaint or filling in a form are all difficult. She reports that having to explain their condition time and time again to receptionists and other frontline health

staff is a wearing and discouraging process. They want this information to be upfront on their patient notes, and for staff to receive awareness training to make the delivery of health care a more welcoming process. Thomas Pocklington intend to use some of the PPI grant to train up patients to do this training, and to involve Wandsworth in the national Vision Strategy.

7. Wandsworth Carers Centre

Wandsworth Carers Centre provides information and support to carers in the borough. That includes emotional support to individuals and to groups, to make it easier to cope and alleviate isolation and stress. It also aims to provide a voice for carers in community consultations.

Activities: The Carers Centre held a consultation event in October addressed by Dr Nicola Jones of the CCG, and attended by 50 carers. Like other groups WCC members complained of ‘consultation fatigue’, and saw little evidence of improvements following previous consultation exercises.

Health Issues & Recommendations: The needs of carers were often overlooked in consultations, eg. when a serious condition is diagnosed GPs need to be aware of younger family members who may be called on to perform caring roles - particularly in marginalised social groups. Doctors need to address causes of depression and stress among carers as well as treating symptoms.

There is a need for better transition between child and adult services for people with disabilities. There is a need for a GP Carers’ lead. Use LINK and Carers Centre to feed issues into Health and Wellbeing Board. Use email and virtual network to communicate to carers.

GP practices need to:

- register all carers & provide rooms for carers’ support and expert patient groups
- provide posters, leaflets and suggestion box for carers’ services
- have carers’ representatives on patient groups
- offer awareness training to staff by carers
- refer carers to Carers Centre

8. Wandsworth Independent Living Forum

Wandsworth Independent Living Forum (WILF) is a recently established umbrella organisation of charities representing disabled people. It seeks to be the voice of disabled people in Wandsworth, promoting awareness, advocacy, and mutual support - all by, and for disabled people. It aims to facilitate access to personal budgets, be a signposting and referral service, and provide peer advice, empowerment and training.

Activities: WILF has met regularly and its members echo many of the issues recorded by individual organisations elsewhere in this report. WILF had not received its PPI grant by the end of 2011, but intends to use it in the New Year towards the setting up of a website and publication of regular newsletters for those who are not internet users. The website/newsletter will include health advice and information from a disability related perspective

Health Issues and Recommendations:

- Avoid cancelling appointments wherever possible. A lot of disabled people have to make special arrangements to visit a clinic or surgery involving transport, and being accompanied by a helper - even for a simple procedure. Cancellation means starting from scratch.
- Installation of hoists so that wheelchair users can be adequately examined, and/or can access scanning equipment. Physical access to surgeries - doorways, lifts, height of desks, loop system, good signage. Disabled people should be involved with the design of physical environment.
- Visually impaired people are still complaining the correspondence addressed to them is not in large print. Easy Read is helpful for many groups - not just those with learning disabilities.
- Installation of Sign Translate at all surgeries and clinics.
- Some GPs unwilling to make house calls to a patient whose disability prevents them from coming to surgery. Prescribing over the phone is not acceptable.
- Communication skills - addressing people face to face (not talking to the person with them, unless there is a strong reason to do so).
- Getting people into specialised care early enough - some with long term conditions felt there were delays which impaired their chances of progress, or things were left too late.

9. Wandsworth Neurological Conditions Group

The Neurological Conditions Group (NGA) is a joint project supported by the NHS and Wandsworth's Adult Social Services department. It represents patients and carers with experience of long term neurological conditions, like MS, ME, Acquired Brain Injury, Parkinsons, or MND. The group aims to improve both social care and health services for those with long term neurological conditions, and to directly involve people with these conditions in the process.

Activities: The group has produced 2 DVDs of interviews with patients who explain about what it is like to live with neurological conditions so that GPs, clinicians, nurses, social workers, care workers and others can have a better understanding. The latest DVD was

produced with the PPI grant and features interviews with 10 people with conditions such as ME, MS and acquired brain injury. They are also using the PPI grant to develop a neurological conditions website and a neuro alliance to ensure the voice of people with these conditions will be heard in the NHS and the wider community.

Health Concerns & Recommendations: The NGA believe that there is no shortage of information or policy recommendations about what the NHS needs to do to improve its treatment of neurological conditions. The problem, it says, is the lack of coherent implementation of these policies. It quotes a number of studies that have been undertaken in other parts of the country, and says that the 2010 West Berkshire report offers a model that could be followed in Wandsworth. It recommends that:

- the CCG map current provision of services against the West Berkshire model
- a neuro forum involving expert patients should be involved in this research and planning, and be available as a resource for GPs and commissioners
- the provision of specialist nursing should be examined
- there should be a GP champion for neuro conditions
- adult social services be included in consultations so that patients' personal budgets are part of an integrated approach

Non-Funded Groups Consulted:

In addition to the 9 groups funded by the PPI grant LINK consulted other community organisations and organisations of people with disabilities to hear their health concerns and their ideas for future involvement in the commissioning of health services.

Asian Community Centre

The Asian Community Centre provides support for elderly or disabled people mostly from the Indian sub-continent. It has around 60 regular clients, usually referred by social services, who attend the centre in Trinity road for meals and activities. The centre has been providing these services for many years, but is concerned about its future when its clients transfer to personalised budgets. The organisation's founder Dr Islam said that the majority of their clients had no complaints about the service they received from the NHS.

Connect (Wandsworth Aphasia Hub)

Connect is a national charity representing people with aphasia. Aphasia is a communication disability caused by damage to the language centres of the brain which can occur after a stroke, brain tumour or head injury. Many people with aphasia lose the ability to speak, read or write. The main focus of Connect in SW London is to provide signposting and support for people with aphasia and to look at how their interests can be incorporated in the commissioning of health services.

Activities: The group organises conversation groups and home and hospital befriending schemes, and runs a Conversation Partner programme.

Health Issues & Recommendations: Communication is the overriding concern, and health service providers need to be aware of the difficulties people with the condition experience. Through contact and training provided by expert patients they need to provide aphasia-friendly systems of communications.

Deaf Access Group

The group represent the interests of the deaf community in Wandsworth and works closely with the Neurological Conditions Group.

Health Issues & Recommendations: Without proper means of communication deaf people cannot access health services, and at present there are several incompatible and outdated systems of communication in use. There is also a shortage of interpreters and signers available in the emergency services. So the group recommend the establishing of a common policy of communication arrangements, for example using loops and online interpreting. The NHS and local authority need to co-ordinate services and pool information on their websites. There is also a need for awareness training for health staff - to be delivered by and with deaf people. There should also be an online forum for services for the deaf community.

Health Team for Homeless People, Refugees and Asylum Seekers

The Wandsworth NHS team for Homeless People, Refugees and Asylum seekers delivers health care to some of the most marginalised and hard to reach sections of the local community. Set up in 1995 it offers advice, support and care to Somalis, Tamils, Iranians and others fleeing persecution. Most are referred to the team by the Home Office and are often hard to contact and suspicious of authority. The team visit them in their hostels and temporary accommodation, and provide health-related support in accessible community venues. Many suffer the effects of trauma - physical injuries, and mental health issues. To circumvent the cultural stigmas attached to mental illness, the team have become skilled in asking relevant questions to get the right medical support. Many of the people they support are not registered with GPs as patients, and would otherwise slip through the net of provision. Marginalised children are a priority for the team, and safeguarding issues are paramount in determining how the team work. Wandsworth is one of the few boroughs in the country offering a service like this.

Sound Minds

Founded in 1994, Sound Minds is a user-led charity and social enterprise using music and arts activities to transform the lives of people experiencing mental ill health. Mental health service users, many of them from the Afro-Caribbean and African community, are actively involved in running the organisation. Many of its staff, and the majority of its directors and volunteers originally came to receive the service they now help to provide. Its rules require that service users are in a majority on the Management board.

Activities: through its allied organisation Canerows and Plaits, the charity trains former mental hospital patients to become ward visitors, and to follow this up with home visits

and a befriending programme. It recently carried out a survey of mental health services in the Springfield and Queen Marys hospitals. Service users were critical of a lack of privacy, inadequate information and wanted more one to one communication and contact with staff.

Health Issues and Recommendations: Sound Minds is concerned that GPs don't see mental health as a priority, and although they are committed to purpose of the PPI initiative, remain to be convinced that real changes will follow. All their referrals are from PCT Mental Health teams - will GPs refer patients to Sound Minds? They want to see a mapping of MH needs in the borough, and recognition of the role of racial discrimination and deprivation as major factors in causing mental illness.

Wandsworth Community Empowerment Network

WCEN is a collaboration of local community groups that seeks to facilitate dialogue and collaboration between the providers of public services and service users.

Activities: It has built up strong relations with black and ethnic minority organisations in SW London and has hosted several meetings on the new NHS commissioning process between them and health service providers.

Health Issues & Recommendations: WCEN contends that statutory bodies need to move away from top-down forms of communication and consultation, and instead get involved in various forms of co-production and partnership with community and faith organisations if effective services are to be delivered.

Wandsworth Lesbian, Gay and Bisexual Forum

The group provides a focus for a section of the lesbian, gay and bisexual (LGB) community in the borough. Members of the LGB community have complex health needs, and issues of confidentiality play a big role in their relationship with health service providers.

Health Issues & Recommendations: Information about HIV/AIDS continues to be an issue with younger gay men among whom it is often seen as an 'old mans disease.' Some members of the LGB community are uncertain about disclosing their sexuality to health care staff, and there are still problems over access in terminal care to those who are not 'next of kin'. GP surgeries and clinics need to make publicity material welcoming to LGB people and to train staff and carers to be aware of the needs of this group of service users. There is also a need for a new AIDS awareness campaign targeted at young people. This is a community that could respond well to electronic consultations via an online forum.

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Key Themes

Particular responses from funded and other groups have been provided in this report, highlighting the distinct experiences of these sections of the community. However key linked themes emerge from most of the groups:

- **Access and communication** difficulties are key problems for marginalised groups, which is one reason why their health outcomes are poorer.
- The role of **expert patients** in strategic decision-making and in improving health outcomes must be recognised and incorporated into the commissioning process
- Commissioners must expect providers to have **inclusive, welcoming, sensitive and accommodating attitudes** to all service users.

Policy Recommendations

To address these issues a number of common suggestions emerged about involving people:

- Health service providers should conduct an **audit of their systems of access and communications with service users**
- Ensure **diverse representation on consultative groups** (in a way that does not necessarily require attendance at meetings)
- Ensure that representatives of diverse groups **advise on tender specifications** - especially on issues of access
- Use representatives of diverse groups to **train and advise commissioners and service providers to raise awareness and change attitudes**
- Use community leaders and voluntary organisations to **consult people in community resources** where they feel comfortable
- Set up **online health groups** and forums

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David Peers

December 2011