

Healthwatch Waltham Forest Annual Conference The Power of People

5th October 2016 Mallinson Suite, Waltham Forest College 707 Forest Rd, London, E17 4JB

Introduction

On the 5th of October 2016, Healthwatch Waltham Forest held its 3rd annual event, 'The Power of People' at the Waltham Forest College. The focus of this event was public involvement across all services in Waltham Forest. It was for professionals, voluntary sector and individuals who all work, volunteer or provide public involvement in the borough. We wanted to create an opportunity for people to share their successes and ideas to increase public involvement. We ran 6 workshops and by the end of the event we created a set of principles for good public involvement in Waltham Forest. The event was very well attended by over 90 local residents, voluntary and community organisations, service user representatives and health and social care professionals.

This report covers what speakers shared at the event, key learning from the group workshops and the principles for good public involvement which came out of the workshop groups. It also includes feedback from the event. The target audience is anyone in the borough involved in public involvement, whether it's the voluntary sector, health professionals, or local residents who are getting involved. The aim is to summarise learning from the event and provide practical principles that can be applied across groups and across different public and service user engagement activities.

To provide accessibility to the deaf and hard of hearing community, there was a speech-to-text report (STTR) writer available to annotate what was said onto a projector screen for the audience to read. We also organised BSL translators. Most of the notes below are taken from the transcript from the STTR writer, which we can make available on demand. Whilst they may not be accurate word-by-word, they will give you an insight into the discussions that took place.

Summary

There was input from people of all backgrounds and experiences. Still, many themes were common across the workshops, and some of the final principles were very similar. Bringing them together and summarising them, the key principles for good public engagement that came out of the workshops were:

- **Empowerment:** All engagement needs to include education and empowerment on the subject being consulted on. The stance should be that "all patients & carers are paying customers & need to feel confident to challenge establishments when they feel it appropriate".
- **Go to where people are:** To engage with a diverse population, it is important to go to groups, understand their needs, and meet accessibility and communication needs.
- Collaboration: To have a collaborative approach, ensuring patients, their friends and family are consulted, as well as frontline staff, in order to get a balanced view on the service and be as objective as possible.
- Clear and accessible information: To avoid people getting overwhelmed and discouraged, there need to be clear definitions, information on engagement opportunities, and material accessible to lay people.
- Two-way dialogue: There needs to be ongoing feedback and updates between service user representatives, the group they represent, and the service they are engaging with. Telling people how their input added value would encourage confidence and engagement in the system. Agreed timescales for ongoing feedback should be a part of the process.
- Ongoing support: Patient leadership involves engaging with all patients to develop and deliver an assertive, constructive voice. This involves availability of ongoing to support patient and service user representatives.
- Clear roles and work plans: Patients, service users and carers who contribute to a group need clear tasks and roles, so they can work constructively. Groups should have a clear work plan and aims, so that they are clear on what their role is and can work strategically achieve their goal.
- One size does not fit all: Need to consider different ways to engage different groups, such as using different routes of communication, different messages, and knowing which group is appropriate to approach for a specific topic. Also consider that not everyone wants to be involved, some people are not comfortable with sharing their views, and so sometimes you need to cherry pick people.

Keynote Speaker: Julie Bailey, founder of Cure the NHS

Julie spoke about her experience campaigning for a safer NHS. She described the harm that can happen when patient engagement is done incorrectly, and when patient groups silence and refuse to listen to individuals. Julie also spoke about success stories she has come across, such as innovative schemes which had been designed by viewing care from the patient's perspective, and by involving patients in design and implementation.

Julie's secrets to good patient participation are:

- Motivating people: by nurturing and encouraging them, drawing on their individual qualities, whilst also being supportive of people's vulnerabilities.
- Strength in numbers: Julie described how it can be very isolating and demotivating to speak alone. People need support and other's around in order to feel confident to speak up.
- Make engagement accessible and inclusive: by varying times of meetings, opening up meetings to public, providing board papers in advance and in easy text that people can understand.
- "Complaints are like gold dust": Julie suggested that patients can see things professionals can't see, and listening to their complaints the way they would be handled in John Lewis could save the NHS a fortune.
- Patients are a crucial resource: Julie emphasised that organisations need to use patient groups as a resource for meaningful feedback which can help make necessary changes. She underlined that their skills and involvement should be mobilised for benefit of NHS.
- Independent participation: Julie noted that patients should be involved as critical friend not cheerleaders. Regarding Healthwatch as a national organisation, Julie noted that they need to do more to be an independent resource that supports individuals and helps the NHS learn from the public's voice.

Speakers: Chloe Kastoryano, & Simran Chawla: Public Involvement Advisers, National Institute for Health and Care Excellence (NICE)

Chloe and Simran from NICE, a national organisation which works independently to produce national guidance on health and social care, spoke about how patient and carer involvement is part of everything they do. NICE's guidelines use best available evidence to help improve quality and promote effective use of resources, and lay members are involved in all stages of the work in order to ensure that the guidelines meet their needs.

Chloe explained how they always involve 4 key stakeholders:

- Lay members: there are always at least two on every committee.
- National charities who speak to patient on day-to-day basis
- Patient experts: individuals with the condition, who can speak about what it's like, how it affects their quality of life, what treatment is like, and how it compares to other options.
- The Public: anyone can comment on any work NICE produces. NICE Respond to every single comment they receive.

She emphasised that engagement is always an open and transparent process. Everything is publicly available on the website, and when guidelines go out in draft form to website, there are four weeks during which national charities and patient representative organisations can comment on these drafts. Every single comment receives feedback on how it did, or why it did not, influence the guideline.

Why do NICE involve patients

Chloe explained the benefits to involving patients: help identify new evidence, new information

Patient centred Outcomes: Patients can point out the outcomes that are important to them. Qualitative data on outcomes that matter to patients can help improve the work NICE produce.

"Lived experience is by far the most important thing when it comes to making decisions about how services should be designed, commissioned, delivered."

"Those of us with condition are the real experts on how it feels. Others, no matter how brilliant, cannot have that insight".

Empowerment: Involving patients also empowers individuals to be more involved in their own condition and understand their day-to-day outcomes.

"Being involved with NICE means I've kept my own skills up to date, such as my IT skills. It has boosted my confidence and self-esteem."

Simran spoke about how individuals and local organisations are crucial in making sure NICE guidelines get implemented. **Giving Healthwatch NICE teeth** provides good examples of where local Healthwatchs picked up the NICE guidelines and looked at how they are being implemented, and have gone to service providers when they weren't being implemented.

For individuals, NICE guidelines tell you what you need to know about a specific condition. The specific recommendations about how it should be treated, what you're entitled to ask for, what questions you should be asking, and its written friendly for patients and service users.

One person commented:

"The conversation is different when you have a conversation with the specialists, and you're asking about your condition, and you're loaded with all emotions and expectations and all this stuff is going on, and you're not really clear exactly what you want to say, but you ask something and they fob you off. If you read the NICE guidelines and take it along to your next consultation you have a different conversation. I have done it, and it is very effective."

Simran responded that this is hugely useful because it demonstrates the value of individuals, but also groups on the ground, that are actually turning what NICE are saying into reality, and it is great to hear that this is what the impact looks like. There is a link on NICE's website on what to do if NICE guidance isn't being followed.

Workshop 1: Having your say in primary care

This workshop was lead by Frances Hollwey from The Patients Association. Frances spoke about her experience working on a project which aimed to build capacity of local GP Surgeries' Patient Participation Groups.

Patient Participation Groups (PPG) are generally made up of volunteer patients who have the aim of making sure that their practice puts the patient, and improving their health, at the heart of everything it does. All GPs have to have a PPG, however Frances and her colleagues found that some GP surgeries in Waltham Forest had no PPG set up yet.

Frances outlined how the Patients Association and local residents worked together to help establish PPGs at all local GPs, and to strengthen the impact service users can have on their local surgery. They reached out to all 44 GP practices in Waltham Forest, encouraged participation of young people by working with Leyton Sixth Form College, and published a set of principles on how a good PPG should be run.

Frances discussed some barriers that were faced:

- Unresponsive surgeries: Some surgeries were unwilling to fully participate in the project, and it was not easy to build relationships with some practice managers.
- Patients' worries: Frances mentioned that some patients were found to be worried about speaking out when practice staff were involved in the meetings.
- Retention: There were problems with recruiting and retaining members.

Frances spoke about future directions for PPGs:

- One size does not fit all: Some PPGs may meet monthly, whilst others have a virtual community for those who cannot attend physical meetings, and others may have separate meetings about specific topics, attended by different groups of patients.
- Communication is key: it is important that information about the PPG is readily available to all patients, in the format of leaflets, posters, information on the website, social media.
- **Be creative:** PPGs need to be creative when thinking of engagement methods, and use streams of communication appropriate for different groups, including those hard to reach. For example with older people who cannot attend the meetings, there could be home visits or other methods of engaging to ensure that they are not excluded.
- **Retain patients**: efforts need to be made to keep patients interested. PPGs need to see the results of their work, and focus on a couple of key topics at a time, in order to avoid getting overwhelmed.

In the second session Frances was joined with Gen Ford, chair of Addison Road Medical Surgery's PPG and chair of Waltham Forest Patients' voice. Gen was involved in Frances' work to build capacity in PPG's locally, and following the project she is carrying on the work independently with Patients' Voice. The summary for this and the principles is included in the next section.

Two principles for good public engagement in PPGs were agreed on by the group:

- Principle 1: To have a clear work plan and aims, so that PPGs are clear on what their role is and can work strategically to improve their surgery.
- Principle 2: One size does not fit all. PPGs need to consider different ways to engage different groups, ensuring good communication through the use of social media, networking, and always consider the hard to reach people.

Workshop 2: Being a patient leader

This workshop was lead by Gen Ford, Patient Participation Group Chair for Addison Road Surgery and member of Waltham Forest patient's voice - an independent group of local PPG chairs. She spoke about how she has developed her local PPG and is now seeking to form a central forum for chairs of patient groups.

Gen explained how her PPG has managed to recruit people with a range of expertise ono the group, and to organise their own patient survey assessing the state of the service, with over 600 responses. Their practice began to see that they had something to offer, and worked together with the PPG on the top 3 priorities from the survey.

Gen said that Patients' Voice want:

- "A joined up, representative and independent PPG" who would act as a "critical friend".
- Patient's should be involved in the planning stage of services, instead of being a reactive group.

Based on her experience, Gen spoke about some keys to good practice for PPGs and patient leaders:

- Clear purpose: when starting a PPG it is important to decide what issues will be dealt with and how, and to set out objectives and a constitution in the first meeting.
- Patient ownership: the agenda should be set by patients, and patients (not practice manager) should be taking minutes, so that minutes fully represent what patients say.
- **Focus on improvement:** PPGs should not focus on personal complaints, but see the bigger picture and focus on ongoing improvement. PPGs should engage with their practice in a constructive manner, offering solutions and ideas.
- One step at a time: to avoid getting overwhelmed, PPGs should focus on 1 or 2 key points at a time, and then then move down the list.
- **"Bite sizes":** volunteering should be broken down into "bite sizes" for each person, so that each individual has a clear role without being overwhelmed, and can feel that their contributions are valued and important.
- Support: There needs to be a support structure and training available for all patient leaders.
- Inclusion: PPGs need to ensure that everyone is culturally and linguistically engaged, including people with accessibility needs, homeless people, and others who are hard to reach. Engagement should involve going out to reach those members, instead of waiting for them.

Gen asked the group what difficulties they have encountered when trying to be a patient leader.

- Difficulty joining: One person spoke about the difficulty trying to join their PPG. It took many attempts and much perseverance to get on the group, and this already puts up a barrier.
- Lack of information: Another commented that currently not many people know about PPGs. There is a need to advertise it better, to ensure all people know about the opportunity. Gen mentioned that she ran an open day at their practice, and that it was marketed it well. However, unfortunately not all PPGs do this at the moment.
- "Patient" label: One person mentioned that they are seen as patients and not "customers", and that NHS staff may not be seeing healthcare as a customer oriented service.

Patients commented that PPGs should be involved at the very beginning, when considering how services can keep people healthy rather than fixing them up. Engaging and educating patients can help promote self management, and prevent people running to their GP unnecessarily.

"There needs to be a change in culture by engaging and educating patients."

Two principles for being a good patient leader were agreed on by the group:

- Principle 1: Patient leadership involves engaging with all patients to develop and deliver an assertive, constructive voice addressing the big picture of improvement and change, while continuing to support patients on a day to day basis.
- Principle 2: Patients, service users and carers who contribute to a group need clear tasks and roles, so they can constructively achieve good for the group.

Workshop 3: How to engage the public in safeguarding?

This workshop was lead by Sue Toole, Chair of Healthwatch Waltham Forest Board, who explained that Healthwatch had been involved in helping the Safeguarding Boards to recruit lay people. Sue explained how lay people have been recruited recently and they will play a role on the Safeguarding Adults Board to represent a lay perspective. This led to a discussion around barriers, and how to overcome them and inspire communities to be engaged in raising safeguarding concerns:

Participants discussed barriers:

- Complex issues: Issues are often complex and the volume of work can be time consuming. Lay people may not have a full understanding of the system and become disillusioned with this process.
- Lack of feedback: Individuals and agencies said they had been very disappointed that, having made a referral, they had no feedback on how the issue was resolved and this led to a lack of confidence in the service. There is a need for feedback systems so that the voluntary sector and lay persons, including carers, get some feedback with what happened once issues are raised.
- Hostility: Several people had felt hostility when supporting people to make a referral.

To overcome these barriers and promote public engagement in safeguarding, people suggested:

- Public understanding about safeguarding: Participants said that in order to get the public to report issues, there needs to be a coherent understanding of what "safeguarding" is.
- Clear referral pathway: A clear signposting system and readily available information around warning signs and thresholds for the public are crucial. This should include information on when referrals should be made, and a visual pathway for referrals. This can also help avoid unnecessary referrals following awareness campaigns.
- Targeted communication: Given the lack of resources, safeguarding education should be aimed at targeted audiences, and produced in a format that is likely to be read and heard by the public. For example using visual content and making use of social media for younger audience. They could use example scenarios to raise public awareness, such as fictional versions of the biggest issues, and publicize these through local media.
- Strong links and feedback systems: Strong links between lay people, voluntary sector and advocacy services can ensure referrers get feedback and feel valued for their contribution. One way to achieve this is to hold more public meetings in order to report buck on public engagement in safeguarding issues.

Two principles for good public engagement in Safeguarding were agreed on by the group:

- Principle 1: to have a clear definition of safeguarding and visual pathway for referrals. A simple awareness raising poster for the public with key issues and a flowchart of the reporting process.
- Principle 2: There needs to be more effort in letting referrers know about outcomes, giving them feedback and updates on progress of their referrals. This would encourage confidence and engagement in the system.

Workshop 4: What is Enter & View?

This workshop was lead by Joyce Osei, Volunteer and Enter & View Project Coordinator at Healthwatch Waltham Forest (HWWF). Enter & View is a statutory power conferred upon Healthwatch by the Health and Social Care Act 2012, and it gives Authorised Representatives of HWWF the right to enter and observe publically funded health and social care services. Joyce spoke about how HWWF has used Enter and View and worked with the public to get a lay perspective on the service concerned and as an opportunity for service users to talk about their experiences with the service.

Benefits of Enter & View include:

- Patient insights: Enter & View allows us to get insights from patients which CCG cannot, and understand what people want. This gives both insight into negative aspects patients notice, and good practice which patients would like to see continued.
- Identify practical challenges: Recently HWWF assessed accessibility and inclusion at hospitals in collaboration with other Healthwatchs across North, Central & East London. This occurred just before the new Accessible Information Standard was implemented, and helped identify where work is needed and where good practice can be shared.
- Practical recommendations: Following the challenges identified by patients, representatives can come up with a set of ideas to improve services. For example, recommendations from a recent Enter & View visit into care homes were met by positive changes, such as introducing menus at meal times, involving service users in decision making, looking at complaints systems, and the introduction of herb gardens. HWWF has a system in place to follow-up whether recommendations have been implemented.
- Influence new service specifications: Findings are shared with services and the Care Quality Commission (CQC). Carl Edmonds spoke about how he worked with Healthwatch on the phlebotomy Enter & View project, and how the recommendations influenced the new specification for services.

During the discussion some people expressed areas in which they thought an Enter & View visit was necessary, such as Isolation rooms in Whipp's Cross and Urgent Mental Health referrals.

Two principles for good public engagement in HWWF's Enter & View projects were agreed on by the group:

- Principle 1: To have a collaborative approach, ensuring patients, their friends and family are consulted, as well as frontline staff, in order to get a balanced view on the service and be as objective as possible.
- Principle 2: When going into service for Enter & View, the stance should be that "all patients & carers are paying customers & need to feel confident to challenge establishments when they feel it appropriate".

Workshop 5: Representing a diverse population

This workshop was lead by Caroline Rouse, a board member of Healthwatch Waltham Forest. The discussion included how the Waltham Forest Clinical Commissioning Group's (CCG) Patient Reference Group are recruiting to their public forum to represent the local population, and how diversity is represented or not in other patient groups such as GPs PPGs.

Caroline and the group spoke about key points to ensure inclusion of all members of a diverse population:

- Work with existing community groups and networks: support them to build their own voice through capacity building, and maintain long term relationships.
- Remember that there is diversity within diversity: one person from a specific group does not represent the whole group.
- Transparent, two-way dialogue: It is Important to get feedback and have a two way dialogue. We need to make sure groups are not left feeling they have been "used" for consultation and then left again. Representatives are often constrained by time and can forget to feedback, so it is important to ensure that support is available. Establishing a feedback loop can ensure meaningful dialogue so that people know where their contribution has gone and the difference that it has made. The group agreed that there need to be transparent agreed timescales and feedback should be part of the process throughout.
- **Enough time and budget for engagement**: there needs to be enough time and a proper budget allocated to engagement activities and facilitation costs, in order to reach various parts of the community including those hard-to reach groups or those with communication needs. Information needs to be given with enough time for people to feed back.
- Targeted engagement activities: There need to be more small workshops giving specific groups a chance to have a say. Currently a lot of people from different communities and backgrounds are excluded.
- Accessible information: The CCG website is written in difficult academic language, which is not always accessible to lay people. There needs to be more readily available information faced towards people of all backgrounds.
- Safe space: There is the perception that lay members cannot challenge authorities and professionals, and a concern that they might be seen as trouble makers. A shift away from this perception is necessary when trying to encourage patients to speak up.
- **Patient education:** All engagement should include education of patient groups, not only when there are issues but long before they arise, so that patients can be involved at the very early stages of preventing issues.

- Clear information about involvement opportunities: long lists of local involvement opportunities can be bewildering. There needs to be better information on each group and their purpose so that individuals can decide where to get involved to best fit their aims.
- Clear complaints system: complaints can put a patient on their back foot. It is hard to know what happens after a complaint is made, unless the individual keeps on chasing it, which takes up a lot of energy and time. The system does not feel joined up and no one wants to take responsibility for a complaint. Clear information needs to be available on who is responsible,
- Terminology: Instead of calling something a complaint, it could be rephrased as an "issue", something that can result in mutual dialogue and have set timescales for feedback. Some people want a move from patients to consumers.

"calling us patients already puts up a barrier, as it indicates we are in a dependent relationship"

Two principles on representing a diverse population were agreed on by the group:

- Principle 1: All engagement needs to include education and empowerment on the subject being consulted on, with diversity being transparent at every level. Agreed timescales, ongoing feedback and a two-way dialogue should be a clear part of the entire process.
- Principle 2: To engage with a diverse population, it is important to go to groups, communicate to understand their needs, and ensure to meet any accessibility and communication needs. This has to be resourced properly.

Workshop 6: How communities can join forces with Healthwatch

This workshop was lead by Daniela Muenzel, Community Engagement, Outreach & Research Officer at Healthwatch Waltham Forest. Daniela spoke about how voluntary and community sector can work with Healthwatch to ensure they reach and engage as many local residents and patients as possible from all parts of the community. Two speakers joined the workshops to explain how their community has worked with Healthwatch; Kat Fisher from YMCA East London and Fran Reeves from Significant Seams.

They explained some of the benefits of Healthwatch working with community groups:

- Relationships: community groups already have a relationship with their group, so HWWF can use these networks to reach more people.
- Saves time: A lot of people already share their health & social care experience with local community groups working together can avoid repeating the same questions and stories.
- Learn more about your community: working with Healthwatch to ask people about their health & social care needs and experiences also helps local groups understand their community better, specifically what experiences they've had in health & social care. This can help develop further what support their community needs, and come up with new projects to support their community.
- New relationships: because HWWF works with various local voluntary organisations and are aware of new developments in health & social services, we can put groups in touch with relevant local consultations that providers and/or the council are carrying out, or with other local groups whom you could work with. For example Kat mentioned how YMCA East London was involved in the Health & Wellbeing Strategy consultation and co-hosted a focus group to ensure the views of young people.

Daniela spoke about how HWWF overcame some issues that faced when working with community groups:

- Do what you can: Groups are often already busy and do not want to take on the extra work, so we work together with them based on what they can do, whether its sharing one key issue in their community every month, 2 patient's stories every week, or simply telling their group about HWWF.
- Financial support: We have offered financial resources for groups to do targeted research projects on Health & social care issues in their community. Fran spoke about spoke about working with Healthwatch the Small Grants fund received from Healthwatch. Significant Seams ran five focus groups using this money, and the work helped their trustees think

- about involving the volunteers and considering their needs when setting the organisation's agenda.
- The value of working with Healthwatch: some groups do not see the value of working with Healthwatch, so we do our best to communicate how Healthwatch can help benefit their user group and use the information to make health & social care better for everyone in the borough.

Participants suggested how Healthwatch can engage better with local groups:

- Clear engagement material: HWWFs comment cards, could have more clear prompts such as a photo of Whipp's Cross. Photos can get people to understand what it is we want to hear from them, and help them relate back to an experience.
- Holistic approach: Because health is a holistic concept including social, job, family aspects, it is beneficial to work with groups who address all of these areas in the local community.
- Go to where people are: If we go directly to where people are and approach people in their own familiar environment, it is easy to talk to them.

"It's about engaging people in an environment they are comfortable in."

- Targeted advertising: different parts of the community can be best reached through different methods.
- Sensitivity: engagement should be sensitive to individuals' needs. We don't want to overwhelm people with large ideas, or approach them with topics that can be perceived as invasive or confusing. People can be vulnerable, and not everyone can engage easily and support is sometimes needed to help people engage and build trust.
- **Don't have expectations:** It is important to keep topics informal and approachable, and not always try to get the views that we want or that are expected, but to properly listen to people.
- Feeding back: It is important to value the community and feed back about their "added value". Engagement should not just be a listening session but an ongoing conversation where groups are told about the impact their views are having, and are allowed to contribute ongoing input.
- **Emphasise the benefit:** Healthwatch needs to keep emphasizing the added value they can bring to local community groups.

Two principles on how HWWF can work effectively with communities were agreed on by the group:

- Principle 1: Targeted advertising based on who you want to involve. Go to where the people are. Cherry pick people, not everyone wants to be involved, some people are not comfortable with sharing their views, and that's fine.
- Principle 2: Listen to people and give them more power. Some people are willing to share expansive advice, they should be consulted directly and receive feedback on how their views added value.

Attendants' feedback

The Event was generally well received. Participant feedback is as follows:



In addition, attendants commented what they **liked** about the event:

Some people enjoyed meeting and speaking to other people.

"Taking part in group sessions and learn other people. Also the issues raised in groups."

"Chance to meet others, share stories, ideas for practice"

"I thought it was a nice friendly atmosphere and an opportunity to meet both professionals and lay people easily."

Several people commented that they liked the speakers:

"I liked the keynote speaker"

"I liked the NICE presentation" "She was so clear about how we can participate with NICE!"

"Presentations were of a very high standard"

And many people commented that they liked the workshops:

"Liked the small group discussions"

"Workshops were useful as they were interactive and a better venue for comments"

"I liked the information sharing"

The efforts we made for accessibility needs:

"I quite liked that you made sure that the projector screens were available for everyone information there to be seen"

And general positive comments including:

"Lovely food"

"Well organised and well attended. Lovely discussions and interaction."

"Thank you very much for the work you are doing, it was very well organised."

"It was good to have smaller workshops, hope it all helped with what Healthwatch aims and objectives were met at this conference."

There were also some suggestions for future annual events:

"Video record the speakers and put these upon your website. Grow your list and others will get involved!"

Some feedback about what participants disliked included:

Issues around timing:

"Not enough time to engage in group sessions"

"The amount of tea breaks"

Sound:

"The sound acoustics made it difficult to hear"

"When the speakers were not loud enough"

"Difficulty hearing"

And visibility:

"The screens were not at a height to see except for the people sitting at the front."

"Workshops: small group could be labelled better."

The comments have been taken on board and will help improve next year's Annual Event.