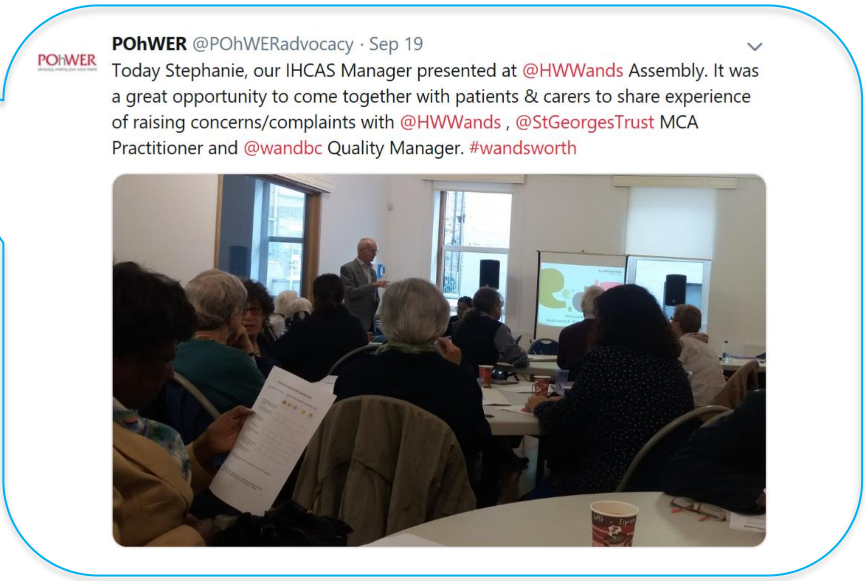
Healthwatch Assembly September 2018 – Communication and Feedback



POhWER @POhWERadvocacy · Sep 19

Today Stephanie, our IHCAS Manager presented at @HWWands Assembly. It was a great opportunity to come together with patients & carers to share experience of raising concerns/complaints with @HWWands , @StGeorgesTrust MCA Practitioner and @wandbc Quality Manager. #wandsworth

At our events we often hear that communication with healthcare professionals could be better, so at our Assembly in September 2018 we discussed with 34 local people how professionals could better hear what we need and involve us in decisions.

We wanted to hear if people felt that they could have their say by raising feedback, concerns and complaints if necessary, about health and care services. Good feedback can help to resolve problems and inform improvements, so we talked about this and recorded what people said. Many local organisations are looking at improving how they collect feedback, so we wanted to hear what people thought works well, and less well.

We also wanted to show people *how* to raise a concern and provide feedback to healthcare organisations, so we had a presentation from our Healthwatch Information and Signposting lead about where people can go to find the information they need.

We then had a presentation from the Independent Health Advocacy Service for NHS complaints, POhWER, which explained how people can get help from their advocates when they have a complaint about an NHS service, or from Voiceability if it is a social care service.

Finally, Wandsworth Council told us what happens when people raise concerns with the council and how they use the information from these concerns to investigate and improve council services, and how they have been changing the way that they work as a result. Copies of the presentations from the event can be found on our website.

Below we have summarised key themes from our discussion. More detailed notes from the discussions can be found in Appendix 1.

Communication and involvement in health and care and treatment decisions

This session was introduced by James Godber, Mental Capacity Act (MCA) Practitioner/Speech and Language Therapist, St George's Hospital. He spoke about the need for people to be involved in decisions about their care and wanted to hear peoples' experiences of communication in healthcare settings. Feedback could be included into future training, information and guidance for staff at St George's Hospital.

We asked participants two questions.

1. We asked them to give examples of a positive interaction with a healthcare professional and how this helped them.

2. We asked what advice would they give a health or social care professional about how best to communicate with them when it comes to making decisions?

We also left paper surveys with additional questions on the tables (see Appendices 2 and 3).

Comments we received about communicating with healthcare professionals and having a greater share in making decisions about our own health care are summarised below (read in full in Appendix 1).

People wanted to know:

- What will happen next in their 'pathway', including:
    - what to expect during a medical examination
    - how they might feel afterwards
    - any side effects, or expected side effects, of medication
    - more about their condition
    - what might happen, and what to do, if something goes wrong.
- When making decisions they want to know the benefits, risks and consequences, as well as different possible approaches and how much choice they have.
- That their information will be shared with relevant professionals across organisations.

The interaction should involve:

- Listening (mentioned by most participants) and specifically:
    - to understand the needs of the patient's broader needs (including emotional); actively listening to uncover underlying issues, such as social isolation.
- Understanding and empathy:
    - *"Good interaction is reading between the lines".*
    - Consideration of the impact on someone's life, wishes and beliefs.
    - Consideration of the impact on a person's carer.
    - Not making assumptions.
- Respect, including knowledge of the individual and their carer, and of their decisions about treatment or medication. Patients shouldn't be made to feel inferior.
    - *"a GP respected a patient's decision to not go into hospital. Patient had capacity, and was provided with the information, to make an informed decision".*
- Honesty and straightforward information.
- Working with other health and care professionals in the system and looking at other problems outside of their own area of expertise and considering the full 'care journey'.
- Continuity of contact (e.g. reviews of medication).
- Responsiveness and reliability.
- Some felt positive when the interaction was relaxed, warm and patient; and not making people feel like they were wasting time or rushed and stressful, which can be frustrating.
- They felt all of the above would increase the patient's confidence.
    - *"Being empowered, knowing that the doctor knows, understands, increases confidence."*
    - Positive experience shared: *"Dr gave information about condition and explained diagnosis and impact the medication would have."*

The format of the conversations should include:

- Time to describe the problem fully.
- Time to make decisions and revisit if necessary (such as information or a leaflet they can take and follow-up later).
- Having an alternative person to speak to if they aren't making progress with another professional; the Patient Advice and Liaison Service was mentioned as useful for this.
- Clear, accessible information in Plain English.
- Information in alternative languages, or an Interpreter.
- Evidence that the professional understands them/their condition and empowers them to make decisions and move on with treatment.
- Consideration of variability of mental capacity – perhaps a 'light touch' service to support them with additional needs such as managing finances.

We'd like to mention that there were also many positive comments about people's experience of communicating with healthcare professionals.

Feedback and raising concerns

We later we discussed people's experiences of making complaints or raising concerns and how complaints processes can be improved. We used complaints statements developed by Healthwatch England[1] and a complaints charter developed by the London Ambulance Service[2] to aid the discussion. Groups were asked to examine the topic at different stages of the process - either before, during, or at the end of the process of raising a concern.

We asked about the positive and negative experiences people had when raising concerns, and what might hold them back from saying something. The following themes came out of our discussions:

Not knowing how to raise a concern or complaint.

Not knowing the name of staff or who to speak to, or not having evidence to back up a concern or complaint.

Many felt that nothing would result from raising a complaint and that professionals give the impression they are not interested to hear what they have to say:

- Some people said they thought it wouldn't make any difference
- One respondent said that due to time pressures GPs/practice managers don't want to hear about additional problems
- *"Consultants/GPs may be time-consumed/not have enough time"*

Some comments suggested that people might feel put off because of their perceived position compared to the health care professional:

- Many mentioned feeling embarrassed, disempowered or fear; some specifically mentioned that they might face repercussions
- One person mentioned feeling that they are caught in the middle of issues between the different professionals involved
- *"Doctor or medical professional knows best"*
- Low expectations because it's a free service, but people might expect more if paid

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[1] https://www.healthwatch.co.uk/blog/2018-07-19/making-it-easier-share-your-feedback-—-new-single-complaints-statement-social-care

[2] https://www.patientsforumlas.net/uploads/6/6/0/6/6606397/london_ambulance_complaints_charter_nov17_v2[1].pdf

Certain groups may not complain or may find it difficult to complain, for example:

- People who are still receiving treatment or trying to sort out their affairs after a medical procedure
- Older people might not like to complain
- Parents with children
- People living in care settings
- People who are less assertive, or who find it difficult to communicate, might not be able to give their views
- People who speak English as a second language
- People who are ‘not online’.

The following might help people more successfully raise concerns or complaints

- Being able to share feedback without making a complaint or being able to de-escalate a complaint at any stage.
- It should be easy to navigate the procedures for feedback and should be made easier for individuals whose first language is not English.
- Health care professionals should be easily approachable. One person said it was difficult to access the Practice Manager and that when she did manage to arrange a meeting with her, she didn’t seem to be interested in her complaint. Whereas another individual said that when professionals were calm and welcoming people, this helped them be calm.
- Honesty from health professionals – including being clear on the difference between an apology and liability. And acknowledging the fact that people mainly want to see a commitment to improvement in the event of an unfavourable outcome.

  “Vulnerable people want Professionals to be honest when they have gone wrong. Confident that [a] mistake has happened.”
- People want reassurance that if something goes wrong it won’t happen again, and evidence of change – perhaps a “you said, we did” approach.
- People want reassurance their care will not be affected negatively.
- Giving feedback should be the joint responsibility of patients and health care professionals and people should feel that their feedback is useful. One person gave an example of when a service had found their feedback useful as they didn’t have evidence to make improvements without it. Others spoke about how they felt they might be perceived.
- Duty of Candour should be followed.
- Response times for complaints should be made clear.
- People should be helped to better understand the healthcare system.
- One respondent said that consultants and medical professionals should be given training on how to interact with people.
- One group felt that front line staff should be better supported by the whole organisation – with a focus on organisational learning.

Appendix 1. Notes from the sessions

Discussion 1: Do health and social care services know what you really think?

1. Can you give examples of a positive interaction with a healthcare professional and how this helped you?

- What was good or not good about communicating with them?
- Were your wishes and beliefs at the centre of the plan for care and treatment?
- Please note if mental capacity was an issue

Group 1:

- Saw GP. Had pain in the left foot. He had Diabetes appointment when happened to mention feet they sent me to X-ray Department and had broken foot. Good cross discipline thinking.
- Being responsive to the issue.
- Mum has dementia. A doctor listened beyond issues and identified complaint - Active listening to notice main issue - social prescribing was isolation and loneliness.
- Good interaction is reading between the lines.
- Emotional intelligence.

Group 2:

- Pals can be helpful when communication breaks down.
- (variability)Negates/not listening to baseline/ making assumptions.
- Being empowered/knowing that the doctor knows/understands increases confidence.
- Straight and honest/including who the decision maker is/ But delivery is key.
- Give time (time!).
- Empathy/sympathy important.
- Listen.

Group 3:

- I have to go to St. George’s for Dental care due to the medication I am on. But last time, to see a tooth out, they sent me to a dentist on Garratt lane. When I came out I was bleeding and my daughter had to take me back to St George’s.
- Because I am on Warfarin, I have to have dental treatment at St. George’s - but it’s a long wait.
- Epsom Hospital - Cancer service.

  (When I had first bout of cancer St George’s didn’t do anything below the torso, and so sent me to Epsom) I think St. George’s might do it now.
- Epsom explained to me that you can’t have radiotherapy, the second time you have cancer.
- St. George’s – Heart condition.
- The consultant said that they will look after me for about one year, but after that, I will have to be supported/referred to my GP (I’ll be 86 then). I was a bit shocked.
- I usually see the same person at St. George’s. I do think they should sometimes do a check as to whether you need to keep taking all the pills you have prescribed.
- I don’t think I need to take all the pills they give me.
- I feel like the pills give me more stress than the illness I have got. They change the manufacturer of the pills - the colour is different.

- I think St George's is marvellous at everything I don't know why people complain that they don't look after older people.
- Staff are clear when they speak to me (at St. George's).

Group 4

- A positive interaction whereby a GP respected a patient's decision to not go into hospital. Patient had capacity and was provided with the information to make an informed decision.
- A 'light touch' service for people with mental health problems – as deemed as having mental capacity clients do not manage finances well and will subsequently beg or there is antisocial behaviour. May not take meds as prescribed. Difficult situation due to the cross over between mental health and mental capacity – variable capacity.

Group 5:

- Dr in lung clinic @ St George's – lots of tests, given diagnosis and medication. Referred to lung physiotherapist. She listened and focused on the patient. Felt they were given time to describe problem fully. Dr gave information about condition and explained diagnosis and impact the medication would have.
- Wandsworth Neuro team (community) reception staff were excellent. Despite having a generic phone line/email (impersonal/hostile) but staff are responsive and reliant. Gave confidence.
- Colonoscopy Clinic at St George's – had driven self to treatment and so couldn't have medication during the procedure. Staff relaxed and straightforward in information/communication. Warm, approachable and were good about the fact that the patient didn't want medication.
- Audiology at St George's – saw for ear problems but diagnosis was around migraines. She dealt with one problem even though it wasn't her area.
- Staff reassuring and supportive in help making patients feel they are not wasting their time.
- Eyes – retinal issue. Consultant said there was nothing the NHS could do but you can be seen privately. Now policy has changed so you can get it on the NHS. But if not for her intervention they wouldn't be started on the treatment.

Group 6:
Positive:
Empathic, human relationship, same gender, patience, trust, felt listened to and understood
Negative:
Words used, not the same gender, rushed, stressful, frustration

- There seems to be a pressure to keep the conveyor belt moving
- Are wishes and beliefs considered
- Looking at the pros and cons – looking at different approaches
- Sharing the burden
- Having space
- Attitude – 'this hospital is at your disposal'
- Consider the care journey – including urgent treatment, A & E and the GP – and discharge
- Perception of who they believe
- Should feel supportive – not leaving feeling isolated
- Is there capacity?

2. What advice would you give a health or social care professional if they wanted to know how to best communicate with you when it comes to making decisions?

Group 1:
No response to this question

Group 2:

- Put yourself in my shoes

- Shared understanding – how much choice do I have?
- Consequences of a decision
- Plain English and accessible information (in preferred format)
- Evidence that they understand your condition
- Respect the patient and their knowledge – ask them and the carer
- Consider the impact on the person's life
- Is the carer coping?

Group 3:
No response to this question

Group 4:
- Simple language, jargon free
- Written material that is accessible to the patient, including different languages
- Interpreters
- Time to make a decision and revisit if necessary
- Power balance
- Time to ask questions

Group 5
No response to this question

Group 6:
No response to this question

Discussion 2: Feedback and raising concerns

Before raising concerns

1. Tell us about any positive or negative experiences you have had when deciding to raise concerns.
Did anything hold you back from saying something?

Group 1:
- No being clear how to complain
- Moved as opposed to making complaint about GP
- Positive response
- Need you said we did. Positive complaining so does not happen again
- Negative. Don't complain because don't think it will make any difference
- Old people in particular not wanting to make a fuss/or repercussions
  How many older people (75+) make complaints?

Group 2:
- Foot clinic SGH- imbalance of power, group MDT difficult to find out the name of the surgeon, podiatrist felt in difficult position and were embarrassed to be in the middle of it.
- To GP surgery-I demanded a face to face meeting with practice manager. She met with me although she did not appear interested in my feedback.
- I had to ask the receptionist for practice managers name and it was difficult to speak to her (later found out she only worked part time).
- The practice should have taken an interest in the performance of their systems.

2. Is there anything else that could happen in the early stages to help make raising a concern easier?
3. Are there any groups of people that might find it particularly difficult and what would their challenges be-how could this be improved?

Group 1:

- Financial readiness.
- Medical negligence - could not get medical negligence in writing so did not feel he had a case.
- No knowledge where to be to complain.

Group 2:

- It needs to be easier to share feedback without making any complaint.
- People who are less assertive or have difficulty communicating will be unlikely to complain or give feedback - English second language. People not on line. People who don't understand procedure.
- Consultants and medical professionals should receive training to deal with people.
- People who are incredibly busy - working people, with families etc are unlikely to complain.
- I recently had procedure cancelled but did not find out until I arrived. The receptionist was very helpful, told me where to go to reimburse my fares etc.

During the process of raising concerns

1. Tell us about any positive or negative experiences you have had of the process of raising concerns.

Group 3:

- They don't want problems.
- Consultants/ GPs may be time-consumed/ not have enough time.

In Wales, everything is calm and people are welcoming - they are calm, so it makes you calm.

Group 4:

- Writing to CEO gets a response.
- Can complaints be de-escalated to "concerns" i.e. PALS?
  -view not taken seriously by PALS-go to commissioners
- Difficult to know who to complain to.

2. Is there anything else that could have happened to have made it better?

3. Are there any groups of people that might find it particularly difficult and what would their challenges be-how could this be improved?

Group 3:
No response to this question

Group 4:

- People in care settings
- People do not know what they are entitled to in terms of response/ response time.
- Councillors expect a response in 2 weeks - encourage people to copy in a councillor in their enquiry.
- Service should be easy to navigate, and we should not need someone else to advocate for us.

At the end of the process

1. Tell us about any positive or negative experiences you have had at the end of the process of raising concerns.

Group 5:

- Resolution was equitable.
  - Wife was in care home - due hospital appointment
  - Ambulance did not come to pick up
    (Hospital did not know) - had been waiting 6-8 hours

- Driver said was not taking because didn't like attitude - including the care home staff
- Written complaint to PALS - pass to hospital transport manager
- Person no longer required because fired
- Service had not had evidence before although had had some complaints.

Group 6:

Positive:
Use of word 'Formal', Joint Responsibility, Honesty
Negative:
Discharge, complaint, planning, no change, dependency/disempowerment/frustration/fear, lack of home adaptations.

- Give feedback and provide evidence of change
- Integrated health and social care working – joined up working
- Commitment – apology vs liability

2. Is there anything else that could have happened to have made it better?
3. Are there any groups of people that might find it particularly difficult and what would their challenges be - how could this be improved?

Group 5:

- Should expect customer service standards - need to know what to expect so knowing should make complaint.
- Don't want to have felt have been receiving it all. Your care won't have been affected negatively.
- Need to collect evidence and note witnesses
- Want to know these will be improved it won't happen again. Confidence have been told the truth and honest about when things have gone wrong
- Frightened of going back
- To do it as soon as you can - nip in bud raise as soon as possible
- Vulnerable people Professionals to be honest when they have gone wrong-Confident that mistake has happened.
- People might find it difficult when they are still trying to sort life at after medical procedure.
- Older people won't complain because doctor or professionals knows best
- Brought up to expect.
- Because it's free there is nowhere else to go-if paid would have higher expectations.
- Sometimes the patient hasn't helped themselves – responsibility for their own health

Group 6:

- Local – best to feedback to staff services
- Then escalate
- Joint shared responsibility/Duty of candour – 10 day response
- The front line should be supported by the whole organisation – perhaps an organisational learning team
- What is the perception of complaints?

- Fear or feel free to speak out
- Complaints demographics: higher for 0-5 dropping people who are 20-40 and higher again for 65+

Appendix 1. Survey questions

Communicating with healthcare staff: Questionnaire

Please answer questions 1 to 3 by ticking a box	Not at all	Not very	Somewhat	Considerably	Very
	☹	🙁	🙂	☺	😀
Q1. Please think about a typical discussion with healthcare staff about what was happening with your healthcare. To what extent were they helpful in supporting you to make your own decisions about your care?					
Q2. Overall, how good do you feel the information you received was about the following:					
a. What the treatment would involve					
b. What the benefit and risks of the treatment would be for you					
Q3. To what extent did you feel your opinion and views were considered when a decision about healthcare treatment was being made? For example, did you feel able to ask questions and were you asked questions about your thoughts or opinions)					

Q4. In your own words, can you give an example of a positive interaction with a healthcare professional and how this helped you?

Q5. In your own words, what advice would you give a healthcare professional if they wanted to know how best to communicate with you when it comes to making decisions?

Appendix 3 - Survey results

	Response 1	Response 2	Response 3	Response 4	Response 4	Response 5	Response 6
1.Thinking of a typical discussion with healthcare staff - to what extent were they helpful in supporting decisions about your care?	Considerably	Somewhat	Considerably	Considerably	Not very	Considerably	Considerably
2a. How do you feel the information you received was about what treatment would involve?	Considerably	Somewhat	Considerably	very	Somewhat	Considerably	Considerably
2b. How do you feel the information you received was about the benefits and risks of treatment	Considerably	Somewhat	Considerably	Considerably	Not very	Somewhat	Considerably
Q3. To what extent did you feel your opinion and views were considered in decisions about treatment?	Very	Somewhat	Considerably	Not very (could ask questions but HP made decisions	Not at all/ Not very/Somewhat	Considerably	Considerably
Q4. An example of a positive interaction with a healthcare professional that helped you	Benefits and risks of HRT	What to do in crisis	Recent health check honest advice	Diagnosis of Bronchiectasis, as knew less about cough	Community team receptionist fab; as not in contact with doctors		Following a discussion with nurse, Ward doctor change attitude and improved treatment
Q5. Advice about how to communicate with you about making decisions	Understand why patient has visited	Simplify contact details	Be honest, Full disclosure	Listen to the patients, avoid medical decisions	Give time to make decision instead of there and then	Listening and information leaflet, Follow-up phone call	Listen and reply with plain language and no Jargon