PPG Network Meeting Notes
Date: 21 March 2018
6pm – 8pm
336 Brixton Road, SW9 7AA

Present:
PPG representatives from Brixton Hill, Clapham Park, Corner Surgery, Dr Masterton & Partners, The Exchange Surgery, Herne Hill Group, Herne Hill Road, Hurley Clinic, Knights Hill, Minet Green, Paxton Green, Riverside, Springfield, Stockwell, Streatham Common, Streatham Hill, Streatham Place & Vassall

Guests:
Odette Battarel & Hassan, South East London Vision (SELVis) and Roger Lewis, Clapham Deaf Club

Apologies:
Received from individuals from Clapham Park, Corner Surgery, The Exchange, Hetherington, Riverside, Valley Road & Vassall

Meeting commenced at 6.05pm, opened by Wai Ha Lam

1.	**Welcome** Wai Ha welcomed attendees and outlined the focus for the meeting – Communication. How PPGs & practices communicate and the accessibility of information for all patients. She introduced Odette Battarel and Hassan from South East London Vision, and Roger Lewis from Clapham Deaf Club, who were there to share the experiences and barriers people with sight loss or who are profoundly deaf face in accessing health information. **<u>Presentation from Odette and Hassan</u>** Attendees were shown various images showing the degrees of sight loss (i.e. tunnel vision, macular degeneration, corneal dystrophy). The message from Odette and Hassan was one size does not fit all. People with sight loss should be asked in what format do they want to receive information; what works best for them? The sender should not assume that large print or Braille is sufficient. **Barriers to communication:** • The booking in touch screen within practices does not always work for people with sight loss, especially if there is no speech or audio provision within it. • Just finding the entrance to a practice can be challenging. Signage outside is unhelpful. • Being unable to see the information in practices as the font sizes are too small • Only sending correspondence by letter or in pdf format – which cannot be "read" by the receiver's software. • Because of the lack of accessible communication there are concerns about what key health information is being missed, i.e. stop smoking services,

diabetes support clinics, etc.

- Do not assume that everyone with sight loss uses Braille.
- Medication boxes only show the name of the medicine in Braille, there is no information about the possible side effects, how much of the medicine the recipient should take and how often – which can have serious consequences.
- Hassan did not know anything about the out of hours or 111 services –so has never used them.

Possible solutions

- Being able to use headphones (like in some banks) which can be put into the automated signing in facility that gives audio instructions to the user.
- Having footpath adaptations outside the surgery (raised paving), so individuals know when they are at the practice entrance.
- The council provides a service via their sensory/rehab team. A person can accompany someone with sight loss to navigate getting to the practice. They will walk the route to the surgery with you until you are familiar – pointing out the obstacles, landmarks, the practice entrance and the internal layout of the building.
- Sending communication in different formats, i.e. text message, larger font size, by email. People with sight loss who have PCs and smart phones are equipped with speech/audio software. Individuals should be asked what format they wish to receive information in, so that it works for them.
- Provide a list of available services, in appropriate formats for the individuals so they know what is in their local area.
- Practice answer phone could indicate how people can access the out of hours and 111 services. Don't assume everyone knows what to do and what these services offer.

Presentation from Roger

Roger talked about the barriers experienced by people who are profoundly deaf and those who use sign language to communicate.

Roger explained that written English is not a language for the profoundly deaf. British Sign Language (BSL) is a totally different language from English. Statistically literacy levels in the profoundly deaf are low due to English not being their first language. There is also a greater incidence of people who do not use BSL suffering from conditions such as diabetes and mental health issues which is largely due to not having accessible information, which results in associated costs.

There are accessible information standards and it is the practices responsibility to ensure that an individual's impairment is clearly evident on their records.

There is a lack of interpreters and there are lots of examples of people using their children to translate for them. With complex medical discussions there is already a language barrier, which can result in inaccurate translation which may have serious consequences.

People feel they have a lack of control over their own health, which stops them having a say.

What can help?

- Having a BSL interpreter available. This can be expensive but the profoundly deaf need this level of services to meet their needs.
- *Sign Health* offers a BSL interpreter service (Interpreter Now) which can be accessed via a webcam. There are costs involved but much less than having someone attend the practice. *Sign Health* is a specialist site which provides health information links.
- Text message reminders are useful
- Practice text touch screen – have it available with a language interface
- Within the practice staff should have a basic understanding of sign language, i.e. to be able to say good morning, mu name is… This goes a long way to beginning the dialogue with deaf people
- BSL chart is downloadable and could be kept in the reception area, so staff can make an effort to communicate in a simply way.

Questions and Answer

Q: Most practices have a TV screen in the waiting area. We are keen to have films uploaded and played on a loop with subtitles and also with the volume on.
A: This is good, but there is still a barrier for those who are hearing impaired. Maybe having a headphone slot so people can listen to the messages being played.

Comment: Every practice has to carry out a risk assessment. Maybe this can be widened out to hospitals too so that when they organise events, etc they are considering everyone's needs.
A: SELVis offers visual awareness training which highlights the things people need to consider and think about like colour contract, available software, posters, font size, having audio/visual aids and being aware of people's specific needs. Information needs to be accessible, so what is key?

Comment: An important thing when talking to deaf people is making eye contact

Q: How many people are there within a practice with hearing or visual needs? Should there be central provision for people with hearing or visual impairments?
A: Most people wouldn't want central provision as it may be too far from their own homes, they won't necessarily know how to get there and services within practices should be provided for the whole patient population.

Q: Is there any merit if staff understanding the BSL alphabet?
A: BSL is a fluid language so knowing the alphabet would not work.

Q: How is the speaking text available on practices computers?
A: Individuals use software on their devices, like Browse Aloud, Supernova, Jaws, and Apple has a voice over facility. Website design is important. There needs to be clearly labelled links.

Q: Why does the NHS not have standard commissioned videos, which all play audio at the same level? It seems that most NHS videos and information has different volumes and resolutions. There needs to be a standard level on all produced audio/visual materials which are commissioned by the NHS and played

	at one level. **A:** There should be targeted accessible information for the whole patient population PPGs were asked consider about how they communicate with their patients.
	Refreshment break
2.	**Network Update** Cheryl Alfred (CA) delivered an update to attendees: • Network board met in February and officers elected. A list outlining who's who on the board was available along with contact information. • Patricia Ross was informally introduced to the meeting, as the soon to be co-opted treasurer onto the board. • The Network was in conversation with Lambeth CCG regarding next year's contract and funding. CA mentioned that the Network reported to the CCG every quarter against agreed outcomes and targets. • Future network meeting dates were published on tonight's agenda for information • Network working with Lambeth CCGs information governance team to put on Data Protection training for PPGs. Training likely to happen at the end of April, in the evening. Contact Cheryl to express an interest in attending. • A recent training session with national charity Compassion in Dying was well received by the eight or so PPGs who were represented. A further session will be planned for later in the year which will be open to a wider PPG member audience.
3.	**Communication Tips** Sharon Hudswell led the wider discussion on communication starting with a presentation (click here). Questions asked included what is good communication? How do health care professionals communicate with patients and how do patients communicate with their health care professionals? How does the PPG communicate with the practice and the wider patient population? Key comments: • Non verbal communication is just as important as verbal communication • Do not make assumptions • A given message may not be received or understood in the way it was presented • Demystify the language • Use of email and text sometimes lead to an interpretation of the tone being used. • How do we as PPGs communicate with patients? Is it effective? How do we gather their views and engage with them? How do we know what we're doing is effective and representing their needs? **Open discussion** • Patients can ask for a double appointment to be able to discuss your needs in detail

- Will Lambeth adopt the approach – one appointment, one problem only?
- Sometimes there are many interconnecting problems, so a single appointment is not sufficient. This isn't in-keeping with providing holistic or patient-centred care
- I've been asked by my GP "What do you want to do about the situation"? Why should I have to find a solution to the problem?

Thinking about PPG Awareness Week

Attendees were asked to think about a focus for the week, with communication as a theme.

- Appointments are still a concern for many patients. Having to wait a long time to get a follow up appointment, after an initial consultation. We need to work with the practice to overcome this
- There are huge differences in how practices manage their appointments. Members shared their examples:
  - Grantham Practice – have not needed to use the Access Hubs. They are able to accommodate all their appointment requests in practice.
  - Paxton Green – have a "Walk and Wait" service between 8am & 10am each morning, where you will be seen by a GP, there is no time limit to the length of the consultation. There are also same day afternoon appointments available, although you may have to wait a little longer. The triage system means you are dealt with too. The practice does not use the Access Hubs and what is in place seems to work well for patients.
  - Clapham Park – Have a similar system to Paxton Green. There is a telephone triage system, where patients are called back by a health care provider.
  - Herne Hill Road – you are able to be an appointment fairly quickly, along with appointments further in advance

  It was suggested to share the good practice at a Practice Managers Forum meeting.

PPG Visibility

During PPG Awareness week it is important to publicise the PPG and its work/impact.

Question: Is there a protocol for patient communication and for PPGs to be able to communicate directly with patients?

Answer: The Network does not have a protocol. There are multiple channels to communication – in the waiting area, via the practice website, at PPG sessions and workshops.

Comment: Some practices are resistant. PPGs have a page on the website but are unable to update it autonomously; even being able to text and email patients is closely guarded by the practice (data protection).

Question: There is no effective monitoring of practices in terms of having an effective PPG. Having one is not a priority as there is no money attached to having one and there is no penalty for not having one. How can PPGs be taken seriously and be effective if practices are not monitored?

Response: It is about developing a relationship with the practice, sharing information

	within practices and to the wider network helps show the benefit and impact PPGs can have. **Comment:** PPG are run on the goodwill of volunteers and this is not always recognised. **Comment:** PPG members are encouraged to attend the Lambeth CCG public meetings held every other month. It is an opportunity to raise questions, challenge the decision makers and show that there is PPG solidarity and that PPGs should be taken seriously. **Comment:** Maybe practices should evaluate their PPGs - do they find them useful or not? **Comment:** There is no uniformity in the approach to PPGs from practice to practice. There is no protocol in place for the structure of PPGs. Whilst the Gold Standard has been developed, it is not working. Sharon asked for a show of hands from PPG members who would be interested in completing a Network questionnaire or survey in the near future on a range of topics including communication.

Meeting closed at 8.05pm