

BSUH NHS Trust Patient / Service User Disability Group Meeting

**Wednesday 15 January 2020, 2pm – 4pm, Possability Place, 14
Windlesham Avenue, Brighton, BN1 3AH.**

Meeting Minutes

Present

Hannah Pacifico (HP)	Patient Experience Manager, Brighton and Sussex University Hospitals NHS Trust
Julie Hartley (JH)	Get Involved Group (GIG) at Possability People
Madeline Peasgood (MP)	Epilepsy Action Volunteer
Darren Jensen (DJ)	SURDI
Nat/Katherine	Interpreters
Ricky Perrin (RP)	GIG member and volunteer
Iris Kepler (IK)	ESAID Viable
Alan Boyd (AB)	Project Coordinator, Healthwatch Brighton and Hove
Debbie Ludlam (DL)	Equalities and Engagement Manager, NHS Brighton and Hove CCG
James Hatch (JAH)	Public Involvement Officer, NHS Brighton & Hove CCG
Sophie Reilly (SR)	Healthwatch and Possability People Trustee
Sabrina Bentick (SB)	GIG member
Gwyn Chanlewis (GC)	Link Back at Possability People

1. Welcome & introduction from JH.

JH welcomed everyone to the group.

2. Review of items and actions from previous minutes in relation to the following items:

a) Managing medicines in hospital

It was decided to update on this when the appropriate team are available to come in.

Action: HP to contact the teams for future involvement.

b) Communications & Patients Portal

Patient Knows Best (PPK)

Patient Knows Best (PPK) is the new online portal which will be launching at the Trust in late February/early March. The portal allows patients to log in, track and manage their documents. Resources attached to patient pathways will also be stored here. Initially it will be used to store Outpatients appointments and documentation, and once the portal is up and running, patients will be invited to join the service when they receive their Outpatients appointments. Several members of the group had attended a meeting in December organised by the Trust to demonstrate how the portal worked, and it seems it has the potential to make an enormous impact on how patients can manage their hospital appointments.

SR: What is the accessibility for visually impaired users?

HP: The designers are aware of accessibility issues, and a large print version is available.

IK: Her screen reader cannot always access PDFs, this is a common problem.

HP assured IK that she has used the accessible version on PDF and it appears to be working well.

SB had received a text about an online GP service called LIVI and wondered if this was part of the same service as PPK. (LIVI is a company providing an app that lets patients see a GP by video on their mobile or tablet. The service is available for free through the NHS for patients of LIVI's partner GP practices).

HP: Patient Knows Best is not linked to any GP services. It is purely for patient management of their hospital documentation and records online, although there is potential for GP involvement later down the line. There is no video consultation aspect to Patient Knows Best.

IK: Is the data secure on all these services?

DL: If provided by the CCG like PPK, yes.

SignLive

HP: SignLive is an online interpreting service which the Trust hope to launch in A & E, no time frame as yet. This won't replace existing services for D/deaf patients but will provide a back-up. Interpreters will always be the first port of call.

DL: SignLive can also be used on laptops.

DJ: Are the staff in A&E aware of the system and will they be trained in how to use it?

HP: Staff will be trained, and I can pass on more information about SignLive from Barbara Harris (BH) Head of Equality, Diversity and Inclusion at the Trust, as she is handling this.

SR: It should be advertised to service users.

HP: We'll make sure that reception know about the service and can make service users aware, and we'll advertise it in reception.

DJ: I'd like to observe the training.

HP: I'll ask BH.

IK: Is it sign language?

DJ: Yes.

IK: Can it be typed out as well?

DJ: It can be typed out. This morning, I was with a client with sight impairment issues, and the hospital had booked a typist. You need to book the service in advance.

SR: It's good.

HP: We aim to access the service from ipads and laptops on the wards, although in an ideal world, we would always get an interpreter.

IK: The WIFI needs to be better.

HP: I'm on the wards a lot, and it is much better now.

IK: Sometimes the WIFI isn't switched on.

HP: The whole Trust works on electronics, so the WIFI is always on.

SR: You need to communicate to patients what you're doing – people need to be aware of these services in order to use them.

Action: HP to ask BH about DJ observing SignLive staff training.

c) Redevelopment of the Hospital site (3T's)

HP: There will be a delay to the delivery of Phase 1 of the development. The Trust is currently negotiating with the contractor, and no updated time schedule has been

confirmed as yet. The delay has had a knock-on effect on Phase 2, and also on the staff, particularly those working in the older parts of the building where work was due to take place soon. Due to the delay, next year's capital may be invested in the Barry Building in the interim.

Action: HP to feedback on delay of Phase 1.

HP: On a positive front, all of the glass fronting has gone in and the building is now watertight, which means that work can start on fitting the interior, which is great news. But there is concern that feedback on wayfinding hasn't been heard as clearly as it could have been by the designers. Style seems to have taken precedence over practical concerns in some cases. Clarification about what patients and users have said about wayfinding will be passed on to make sure feedback is heard.

Action: HP to update on wayfinding.

HP: BH has been in to look at issues like lift sizes, door frames and contrasting colours to check for accessibility.

IK: What are the colours?

HP: Grey and white, and the colours have been checked with the Eye Hospital to ensure that there would be no issues for users with sensitivity to colour/shades. The use of contrasting colours to aid accessibility was originally brought up by a dementia nurse, as people with dementia can be affected by certain colours and colour combinations. The Trust decided to adopt contrasting colours to improve accessibility for all users.

SR: This is really good, particularly as white bars on white walls are very common in hospitals, which is terrible for people with visual impairments.

JH: Are there any updates on the issue of toilet cords, which has come up before in our meetings, particularly with reference to the Barry Building?

HP: Cords in all the toilets are now anti-ligative, and this will carry through to the 3T's.

DL: Are there gender neutral toilets in the new build?

HP: As far as I know, this hasn't been decided.

Action: HP to feedback about gender neutral toilets in 3T's.

IK expressed concern about the placement of furniture, for example small tables in waiting rooms, which could be a problem for visually impairment users. HP explained that a virtual reality spec of 3Ts is used to look at placement issues like this.

d) Cancer Patient Survey

HP: This isn't available still. As discussed at the previous meeting, cancer care waiting times nationally have been poor, and cancer care performance varies massively between services - the shortage of radiographers at BSUH impacted figures downwards, for example. There is a recovery plan in place, and there will be a new standard for cancer care from April 2020.

Action: HP to present findings of the cancer patient survey when available.

AB explained that Macmillan Cancer Support and Switchboard have carried out two surveys in 2019 to get a better understanding of the needs and experiences of LGBTQ people living with cancer in Sussex and East Surrey. To find out more, please email Jessica.sandelson@switchboard.org.uk

AB told us about Healthwatch's current work looking at end of life patient care, and what a sensitive area it was for patients and their families and carers to talk about and share experiences.

GC said she's aware this is a tricky area through her work at Possability People's Link Back service. Link Back works at The Royal Sussex County Hospital with older patients who are well enough to leave hospital but need extra support to get on with their lives, so very involved with the discharge process. The service can support patients up to four months after discharge.

AB: Issues around discharge and ongoing support have been mentioned in our research.

HB: The Trust is still waiting for the new discharge leaflets.

Action: HB to update on the discharge leaflets.

GC explained more about Link Back, including the Early Response Service. This enables people to have a more timely discharge from hospital by getting home adaptations and equipment through the Disabled Facilities Grant (DFG). This ensures people remain safe and well at home at a vulnerable time recovering from a hospital stay.

MP: Could you refer to Link Back before you go into hospital?

GC: That's a good question, there is a gap in provision.

Due to the high level of interest in Link Back, it was decided to circulate further information about the service with the minutes.

Action: JH to circulate Link Back information with the minutes.

e) Patient Transport Service (PTS) and Travel Costs Criteria

(i) PTS (provided by the Trust)

Patient transport is for only available for non-emergency patients who are unable (for medical reasons) to use private or public transport services for their journey to and/or from hospital. A qualified health care professional must assess a patient's medical need for transport before it is booked for each journey – this can be a doctor, nurse, midwife or senior therapist working in the NHS. All PTS bookings will then be screened by the Transport Bureau for eligibility before the booking is accepted. Patients need to book it themselves. For patient transport queries please contact South Central Ambulance Service on [0300 123 9841](tel:03001239841)

SR: You can wait a long time for transport.

GC: Link Back are very aware of this. You have to book a 2 hour slot, and you have to be ready to go at any point during the slot. You don't know when the transport will come. It can be very difficult for patients.

(ii) Community Transport Sussex

Community Transport Sussex provides transport if you have restricted mobility through their volunteer car scheme. If you need to visit either the Princess Royal Hospital or Royal Sussex County Hospital sites, please call 01444 471919 (Mon-Fri from 9.30-11.30am). Please contact the team as soon as you have your appointment letter. For more information email enquiry@ctsussex.org.uk

Travel Costs

HP: The criteria to be eligible for travel costs are very complicated, and it's understandable that patients can be confused. If you are on a low income or benefits you may be entitled to reclaim your travel costs, to and from hospital. There are very specific financial criteria and eligibility requirements.

JH: Eligibility for travel costs is really confusing and definitely not one size fits all. The remit of the group can't cover the complexities of the criteria, so the best way to find out information for your individual situation is to visit <https://www.bsuh.nhs.uk/your-visit/help-and-support/patient-transport-and-travel-costs/>

HP: The cashiers departments at the hospitals will definitely be able to help.

- Cashiers Dept, Royal Sussex County Hospital, Ground Floor Barry Building: 09.00 – 17.00 Monday to Friday, Tel: 01273 696955 Ext 4301/7630.
- Cashiers Dept, Princess Royal Hospital, 1st Floor Main Building: 0900 – 17.00 Monday to Friday, Tel: 01444 441881 Ext 8103.

If you need to go outside the region, The South East Coast Ambulance Service NHS Foundation Trust (SECAMB) is the NHS Ambulance Services Trust for south-eastern England, covering Kent, Surrey, West Sussex and East Sussex. It also covers a part of north-eastern Hampshire.

HP: SECAMB could be an option but getting help with travel expenses would probably use up a lot of any allowances you may be entitled to in one go.

SR: So you could spend everything on one trip, that's no help.

f) Follow-up on LF's in-patient experience at the Royal Sussex

As LF was not in attendance, it was decided to follow-up at the next meeting.

Action: JH to put on agenda for next meeting.

g) Volunteering at BHUS

Volunteers can take on a variety of different roles at BSUH. To find out more, visit <https://www.bsuh.nhs.uk/work-and-learn/other-ways-to-join-our-team/volunteering/> or phone Royal Sussex County Hospital on [01273 664533](tel:01273664533) or Princess Royal Hospital on [01444 441881](tel:01444441881) extn. 8501/8525.

Friends of Brighton & Hove Hospitals also have opportunities for volunteers in the Royal Sussex through Small Acts of Friendship, in their charity shop, café and tea bar. To find out more, visit <https://www.brightonhospitalfriends.org.uk/support-us/join-us/volunteer-with-us/> or phone 01273 66 4936.

3. Guest Speaker - Alan Boyd from Healthwatch Brighton and Hove

We were delighted to welcome Alan Boyd, the Project Coordinator of Healthwatch Brighton and Hove. Healthwatch Brighton and Hove aims to make health and social care services work more effectively for the people who use them, with a focus on listening to and understanding the needs, experiences and concerns of people of all ages who use services, and to speak out on their behalf. It is part of a national network, with a local Healthwatch in every local authority area in England.

AB: Healthwatch Brighton and Hove is an independent organisation that exists purely for patients to ensure their voices aren't lost. We provide feedback and promote information, and we can have quite an impact, as the Trust and the CCG are aware.

HP: We think of you as a critical friend – you help us make improvements.

SR: We look at all NHS services.

AB: We're also approached by other organisations to speak on their behalf.

MP: What is your relationship with PALS? (The Patient Advice and Liaison Service)

AB: One of the things we've done with PALS is look at their letters of complaint. Healthwatch England actually has resources available to help with making a complaint, and we have information about making a complaint about local treatment or services. This is a free service.

(You can find out more by visiting <https://www.healthwatchbrightonandhove.co.uk/find-services/making-a-complaint/>)

AB: We don't provide advocacy services. A range of advocacy services for local people are provided by POhWER as part of the Sussex Advocacy Partnership.

(POhWER is a charity and membership organisation, providing information, advice, support and advocacy to people who experience disability, vulnerability, distress and social exclusion).

SR: There is a Healthwatch in different areas across the UK, and they are all linked together. This means we're aware of national Healthwatch issues.

Patient-Led Assessments of the Care Environment (PLACE)

PLACE is the system for assessing the quality of the patient environment. The assessments primarily apply to hospitals and hospices providing NHS-funded care in both the NHS and private/independent sectors. The assessments involve local people (known as Patient Assessors) going into hospitals as part of teams to assess such things as privacy and dignity, food, cleanliness and general building maintenance and, more recently, the extent to which the environment is able to support the care of those with dementia. The assessment focuses exclusively on the environment in which care is delivered and does not cover clinical care provision or how well staff are doing their job.

The assessments take place every year, and results are published to help drive improvements in the care environment. The results show how hospitals are performing both nationally and in relation to other hospitals providing similar services.

AB told us about Healthwatch participation in PLACE assessments at the Trust.

AB: We break the assessment into one visit per month. We choose the ward. Sometimes the choice is random, sometimes we choose a ward linked to a project we're doing. We spend 2/3 hours with a member of staff, and together we carry out the assessment. We look at the environment and food, not the clinical care or staff performance. Our findings are fed back to the Trust, staff and the patients experience group. We're getting into a cycle now where we can go back and review assessments made a few years ago to see if

recommendations have been followed and improvements made. The Trust react really well to our feedback.

IK: The food does need looking at, it's awful.

AB: We taste the food as part of the assessment, and what I've had has been very good, and the choice is much better. It's also very interesting to see and taste what can be done with modified food.

AB: I have to say, Healthwatch is all about you, and your views. You tell us what to look at. Healthwatch publishes an annual report, and themes regularly occur.

SR: Everything we decide to focus on is based on what you tell us.

AB: Getting information out about what we do is very important.

GC: We may be able to help. We could carry leaflets.

AB: Thanks, that would be great, we want to reach as many people as possible.

Action: AB to contact re GC re leaflets.

DJ: What is the make-up of your group? Because that can affect the assessments. Your service is not very accessible for the deaf community. If you're willing to help with that, that would be great.

AB: We could be more diverse, and we want to be.

JH: Maybe we could help you with that. GIG members have expressed an interest in doing access reviews at the Royal Sussex, so perhaps there's an opportunity for us to join you on the PLACE assessments? Several of our members and volunteers have training from Possability People in carrying out access reviews.

AB: We're very keen to have more people, and to have a perspective on accessibility for disabled people. Anyone joining us would have to go through our own Induction programme.

Action: JH to investigate this further.

JH thanked AB for speaking to us. To find out more about Healthwatch Brighton and Hove, please visit <https://www.healthwatchbrightonandhove.co.uk>

4. Open Space Topic - Hospital Passports

The Trust uses a 'hospital passport' to help people with learning difficulties or their carers tell staff important information about themselves and their needs.

Our group has discussed before how this could be adapted for people with disabilities or long-term health conditions, and it was decided that it was time to revisit this. A copy of the current passport was circulated with the last minutes, and JH circulated copies at the meeting.

MP: Where can you get this?

HP: You can download it from our website, you can pick it up at the hospital in A&E and outpatients. You fill it in and keep it up to date and keep it on you. It's for you to tell us what would help you, particularly in an emergency situation. What information would you like staff to know? For example, if certain situations can make you agitated or scared, write it down so that staff know and can help you with that. It can also help if you're unable to speak.

DJ: It would help a deaf person.

HP: Sticking to this format when thinking about any changes would mean it was recognisable across the Trust. We also want to look at promoting it.

SR: This is what I need.

HP: It's there to make the experience easier for you and for staff.

JH: Many of our members have said how distressing and exhausting it is to be constantly repeating information to different members of staff, particularly when you're in an emergency situation and you're in pain and vulnerable. If you're on your own, it's even harder. So a passport would help with that.

SB: Would paramedics use it?

HP: Yes, they would, any staff in an emergency situation would use it.

IK: This could work with Patient Knows Best.

HP: Further down the line we could look at uploading it to the portal, but we're not at that stage yet.

DJ: ReSPECT is coming in soon, that could be added.

(The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) is a process that allows people to record their wishes about how they would like to be treated in a medical emergency when they may not be able to communicate).

SR: Your care plan could say you had a passport.

DJ: A passport would really help when working with a service user with complex needs.

HP: BSUH want to go forward with Treat Me Well (Mencap's campaign to transform the way people with a learning disability are treated in hospital), so we're looking at the passport with them too. We need to get the message out that the passport exists.

IK: It needs to be better publicised.

HP: I'm sure we will go down the route of having it on on-line.

IK: Each hospital has to have it.

AB: One thing looking at it is the use of pronouns. The passport could ask which pronouns people would like to be addressed by.

DL: This is something we want to address generally.

JH: From the comments, it feels like there are lots of positives about having a passport. As we haven't focussed in too much on how it could be adapted today, I'm sure this is something we'll come back to. This always happens!

HP: Bear in mind that sticking to this template and making changes within it is the best way for consistency and recognition across the Trust.

Action: HP to update on further developments. You can download the passport at <https://www.bsuh.nhs.uk/your-visit/help-and-support/learning-disabilities/>

5. Any Other Business

JH: We were contacted by a service user to say that Changing Places toilets at the major hospital sites would make an enormous difference to the process of attending the hospitals for many disabled people. What is the situation with Changing Places toilets across the Trust?

(Standard accessible toilets do not meet the needs of all people with a disability. People with profound and multiple learning disabilities, as well people with other physical disabilities such as spinal injuries, muscular dystrophy and multiple sclerosis often need extra equipment and space to allow them to use the toilets safely and comfortably. These needs are met by Changing Places toilets).

HP: There are Changing Places toilets available across the Trust.

Action: JH get more info from Hannah.

SR: I had an emergency situation at the Royal Sussex, and I'm very disappointed that despite all the work we've been doing here, I had difficulties both communicating with hospital staff and with having my PA with me at night. Having to cope with issues like this makes everything worse. Staff would communicate with my PA even though I was right there, and my PA would say: "Ask Sophie". Staff should be trained to communicate better. My PA can't stay with me overnight in hospital. I need PA assistance overnight when I'm at home, so why should it be any different when I'm in hospital? This overnight policy needs looking at.

HP: Thank you for that. Staff should know how to communicate better, and we are looking at the overnight policy for carers and families.

Action: HP will follow up and report back.

JH thanked SR for sharing her feedback and thanked the group for attending and their contributions.

Next Meetings (more dates TBC)

All meetings will be at Possability Place, 14 Windlesham Avenue, Brighton, BN1 3AH unless stated otherwise.

- Wednesday 8 April 2020, 10am - 12pm (Please note change of time)
- Wednesday 3 June 2020, 2pm - 4pm

Contact Details

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PALS Services

Every hospital has a PALS service, below are the PALS details of the 4 NHS Trusts in Sussex and which hospitals and areas they cover. PALS will be able to deal with most hospital services and signpost for other health issues. Please note, however, that PALS services are not medically trained.

- **Royal Sussex County Hospital, Princess Royal Hospital**

Haywards Heath: 01444 441881 extn 68678

Brighton: 01273 696955 extn 64511 or 64973

bsuh.pals@nhs.net

<https://www.bsuh.nhs.uk/your-visit/help-and-support/patient-advice-and-liaison-service-pals/>

- **Community services in Sussex:**

<https://www.sussexcommunity.nhs.uk/contact-us/comments.htm>

- **St Richards, Worthing and Southlands**

<https://www.westernsussexhospitals.nhs.uk/services/patient-advice-and-liaison-service-pals-complaints>