

## BSUH NHP Trust Patient / Service User Disability Group Meeting

Wednesday 4 September 2019, 2pm – 4pm, Possability Place, 14 Windlesham Avenue, Brighton, BN1 3AH.

### Meeting Minutes

#### Present

Debbie Wickens (DW)	GIG Project Assistant
Ricky Perrin (RP)	Sussex Bears Basketball / GIG member & volunteer
Madeline Peasgood	Epilepsy Action Volunteer
Sabrina Bentick	GIG Member / Epilepsy Action Member
Angelica Wydra	Healthwatch – Volunteer / Placement Student
Darren Jensen (DJ)	Surdi
Vicks/Catherine	Interpreters

**Apologies:** Hannah Pacifico (Patient Experience Manager, Brighton and Sussex University Hospitals Trust), Emily Barnard (Quality & Improvement Team), Matt Hutchinson (Head Nurse for Quality & Improvement), Samantha Lippet (Assistant Director of Pharmacy), Julie Hartley (GIG), Iris Kepler.

#### 1. Welcome & introduction from DW.

Unfortunately Hannah had taken unwell in the morning, and was not able to attend. The Quality & Improvement Team were also unable to attend.

Therefore we used this meeting space to talk through some of the topics and also to review how well we think these meetings are going and how we can make them more effective.

I will send these minutes to Hannah to give her an opportunity to feed back on the areas she had outstanding actions on

#### 2. Open Space Discussion on 4 September

##### i. Carer and Patient Information Group Update

Darren Jensen reported back that he had attended the CPIG (Carer and Patient Information Group) meeting on 25/06/2019. He has forwarded a copy of the minutes to DW.

No BSL interpreters were available on the day, so DJ found it quite difficult to follow and contribute, but HP did take notes throughout the meeting to assist DJ, which DJ has forwarded to DW.

MP commented that when people first go on anti-epileptic medication they find their brain works slower.

**Action:** DW to remind BSUH attendees that Hannah is looking for volunteers to review written communications via email.

**DW** initially I made an error and sent an email asking if anyone would like to attend the next CPIG meeting, which has been corrected. Email re-sent requesting volunteers for 'user-testing/review' of written comms by email.

## ii. Cancellations

SB twice turned up to an appointment, only to find it had been cancelled (Outpatients, Neurological, Hastings 2018).

Also the cancellation letters only have 1 standard phone number on them, it's hard to get through and this is no good for D/deaf people, they have to ask someone else to rebook for them.

**Action:** HP to pass this information back and request email and text alternatives for rebooking cancelled appointments.

## iii. Healthwatch Update from Angelica

The annual PLACE review is taking place between 15 – 25 October, involving a group of volunteers, across hospital sites.

## iv. MSK Service at RSCH

MP had an appointment, and said it was a brilliant service. However she was surprised that there were not more people attending, and only 1 other physio on the unit.

**Action:** Question from MP to HP, are we short of Physiotherapists?

## v. Accessible Information Standard (AIS)

Members shared information about the AIS - the Accessible Information Standard is a law which aims to make sure people with a disability or sensory loss are given information they can understand, and the communication support they need. DJ recommended contacting reception at your GP surgery to get registered on the scheme.

[Link to more information](#)

### What does the Standard tell organisations to do?

As part of the Accessible Information Standard, organisations that provide NHS care or adult social care must do five things. They must:

1. Ask people if they have any information or communication needs, and find out how to meet their needs.
2. Record those needs clearly and in a set way.
3. Highlight or flag the person's file or notes so it is clear that they have information or communication needs and how to meet those needs.
4. Share information about people's information and communication needs with other providers of NHS and adult social care, when they have consent or permission to do so.
5. Take steps to ensure that people receive information which they can access and understand, and receive communication support if they need it.

### **What does the Standard include?**

The Standard says that patients, service users, carers and parents with a disability, impairment or sensory loss should:

- Be able to contact, and be contacted by, services in accessible ways, for example via email or text message.
- Receive information and correspondence in formats they can read and understand, for example in audio, braille, easy read or large print.
- Be supported by a communication professional at appointments if this is needed to support conversation, for example a British Sign Language interpreter.
- Get support from health and care staff and organisations to communicate, for example to lip-read or use a hearing aid.

#### **vi. Possible Future Topics BSUH members are interested in**

- Discharge Booklets
- Hospital Passports (we have discussed this previously)
- Changing attitudes in hospital, raising awareness, pan-impairment

#### **vii. What do members want to get out of the meetings?**

- Get information, hear what's going on & learn about the new hospital building
- Hear others' perspectives and challenges
- Feed into and work together on improvements
- Represent their community, e.g. D/deaf community who are reluctant to engage themselves sometimes.
- They would like to see a willingness to change and to listen (from the BSUH)

#### **viii. What impact do we think we can have?**

- Raising awareness
- Share our lived experience to improve things
- Improve accessibility

# Historical Topics and Actions Outstanding

## 3. Managing medicines on admission, during stay & on discharge.

HP said she really wants to dispel “pyjama paralysis” ie not allowing patients to care for themselves when they can. It’s well known that BSUH hospital rounds aren’t as good as they could be, and they’re working on it. The in-patient survey will be published soon.

**Action:** HP to feedback on in-patient survey.

### i. What can patients do to help staff?

The BSUH Nursing Director has Top Tips for what patients can do to help staff.

**Action:** HP to share Top Tips.

### ii. Green Bag Scheme

HP is currently trying to tie together how people use the green/red bag scheme at BSUH. Green bags are used by people who live in their own home, red bags are used by people who are in residential/nursing homes.

TTH (To Take Home) – new electronic prescribing scheme.

**Action:** HP to feedback on the green /red bag scheme.

### iii. Transport issues

**Action:** DW transport issues will be kept on the agenda.

### iv. Communication on Discharge

There are 2 meetings a day monitoring discharges throughout the hospital.

We are aware that there is work going on to improve communication on discharge – a booklet is being reviewed ‘Let’s Get You Home’ I think it’s called, I believe there has been a focus group which the Link Back team attended (may have been the Patient Expert Panel). I think ‘Planning Your Discharge’ booklet also being reviewed.

**Action:** HP to find out more about monitoring discharges and provide information about the project that is working on the comms at discharge and the booklet.

**Action:** Can HP also provide the date of the next Patient Expert Panel.

**Action:** DW to keep medicines in hospital on the agenda.

---

## 4. Review of items and actions from previous minutes

### i. Redevelopment (3Ts) everything on schedule.

- **Stage 1:** current build ends 2020 is on schedule to open spring 2021
- **Stage 2:** starts spring 2021, completing 2023
- **Stage 3:** starts 2023, completing 2025

## **Development Focus Groups**

No more focus groups at the moment. There is a quarterly hospital liaison group meeting, the next one is on April 20, people living in a quarter mile radius of the hospital or those with a vested interest are able to attend. Contact Hannah if you are interested.

3Ts: this is a copy of the link for the virtual hospital tour:

<https://www.youtube.com/watch?v=058IXCEts3g>

## **Which services are moving into 3Ts?**

**Action:** Ongoing. HP to feedback when more is known.

## **ii. Access Reviews**

Healthwatch carries out monthly, unscheduled access reviews of RSCH. HP wants to work with Healthwatch to do accessibility reviews, and see if it works for us, also known as, Patient Led Assessments of the Care Environment (**PLACE**).

**Action:** DW to liaise with Healthwatch – ongoing. DW is now in touch with Alan Boyd from Healthwatch.

**Action:** HP will continue to ask about the more specific signage.

**Action:** HP & RP to find out more from (RP with Albion in the Community).

## **iii. Signage at RSCH**

If anyone sees bad signage, take a picture and email it with details to the Patient Advice and Liaison Service (PALS) at [bsuh.pals@nhs.net](mailto:bsuh.pals@nhs.net)

## **iv. Communications and Text Service**

The Trust is looking at a new patient portal service. This includes a text service that patients can use to text in. Unknown what the provision is for D/deaf people and interpreters. It was agreed this should be part of the tender.

**Action:** HP will check, and if possible, get a copy of the tender for Darren.

## **v. Bins and Emergency Chords**

There is a meeting in May to discuss this.

**Action:** HP to feedback.

## **vi. NHS Walk-In Centre in Brighton**

The NHS Walk-In Centre has had its contract extended until September 2019.

**Action:** DW to confirm.

## **vii. Outpatients & cancer care targets**

Ongoing.

**Action:** HP to feedback.

## 5. Open Space Discussion (from meeting in June)

### i. Electronic Signage

**Action:** HP to check what's in the pipeline for 3Ts, and what other new build hospitals have in terms of electronic signage.

### ii. Fire Alarms

In the US, fire alarms have flashing lights to alert D/deaf people.

**Action:** HP to check if 3Ts will have these, and to check the flash rate for the safety of people with epilepsy.

### iii. Patient Profiles

It was suggested that the Trust use 5 or 6 specific patient profiles rather than 100s for research purposes.

## 6. AOB

### Disability Staff Network

A Disability Staff Network is being set up across the Trust.

**Action:** HP to keep us updated.

### Bus Travel between Brighton & Haywards Heath hospitals

Free travel is provided to hospital patients plus a companion in possession of an in-date hospital letter, email or text message. The date of the appointment must be the same as the date the person is travelling.

They are valid for boarding and alighting at all stops in the following sections of route:

- Route **270, 271, 272** between Brighton and Perrymount Road (Haywards Heath)

These are not valid for travel on Saturdays.

### Feeder Routes

Brighton & Hove buses are sorry to advise that feeder routes don't accept hospital letters, emails or text messages.

---

## PALS Services

Every hospital has a PALS service, I have included the PALS details of the 4 NHS Trusts in Sussex and which hospitals, 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/>

- **Conquest Hospital, Eastbourne District General Hospital, Bexhill Hospital, Rye, Winchelsea and District Memorial Hospital**

<https://www.esht.nhs.uk/departments/patient-advice-and-liaison-service/>

- **Mental Health Services in Sussex**

<https://www.sussexpartnership.nhs.uk/patient-advice-and-liason-service-pals>

---

## Next Meeting

WHEN: Wednesday 6 November 2019, 2pm – 4pm

WHERE: Possability Place, 14 Windlesham Avenue, Brighton, BN1 3AH

## Following Meetings

- Wednesday 15 January 2020

---

## Contact Details

### Hannah Pacifico

Patient Experience Manager, Brighton and Sussex University Hospitals Trust

[Hannah.Pacifico@nhs.net](mailto:Hannah.Pacifico@nhs.net) / 01273 696955 Extension 64509

### Debbie Wickens

Get Involved Group (GIG) Project Assistant, Possability People

[debbie@possabilitypeople.org.uk](mailto:debbie@possabilitypeople.org.uk) / 01273 208 934