

BSUH NHP Trust Patient / Service User Disability Group Meeting

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

Meeting Minutes

Present

Hannah Pacifico	Patient Experience Manager, Brighton and Sussex University Hospitals Trust
Madeline Peasgood (MP)	Epilepsy Action / GIG member & volunteer
Iris Keppler (IK)	ESAB Viable / GIG member & volunteer
Julie Hartley (JH)	GIG member & volunteer
Debbie Wickens (DW)	GIG Project Assistant
Ricky Perrin (RP)	Sussex Bears Basketball / GIG member & volunteer
Richard Barraball (RB)	GIG member
Darren Jensen (DJ)	Surdi
Natalie/Michelle	Interpreters
Janet Jones (JJ)	GIG member

Apologies: Lilly Kennard (GIG)

1. Welcome & introduction from DW.

2. Managing medicines on admission, during stay & on discharge.

- a. **How best to maintain your medicine routine while staying in hospital, e.g. with diabetes, parkinson's, heart conditions, epilepsy**

Extended visiting hours

HP advised visiting hours of 10am – 10pm are being trialled in certain wards.

With longer visiting hours, it was hoped that staff would have more time to make medicine delivery more specific to the patient. Visitors often helped with their relative's care such as feeding and relaying requests, and it was hoped that this would free up staff time.

There was some fear that relatives would be expected to help with patient care. HP assured the group that families were not expected to assist, but they do tend to help if they're there.

Opening up visiting hours is to enable people to come in at times that suit them. If they have more access to patients and staff, they will feel more informed about and involved in the patient's care.

There were concerns that discussing care in front of relatives could be problematic for patients. Staff are trained to recognise this, and patients can always ask for confidential access to nursing/medical staff. It was noted that this depends on how well the patient could articulate their concerns. It also was noted that carers usually want to be kept in the picture, so extending visiting hours should help families who do want to be involved.

Certain wards are not appropriate for longer visiting hours - for instance neurological wards where extensive rehab takes place. MP explained her recent experiences of medicine failing to be delivered on time on a ward, and expressed her concern.

Action: MP to give HP info and HP to follow up.

More examples were given of in-patients not getting their medication when they asked for it.

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. Their in-patient survey will be published soon.

Action: HP to feedback on in-patient survey.

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.

Green Bag Scheme

The 'green bag' scheme makes it easier for patients to bring their own medication with them in to hospital if required, keeping everything safe and secure and together in one place. They can be used when patients are admitted to a ward and taken home again when they are discharged from hospital. Using a green bag benefits patients and NHS staff as it helps the right medicines to be given without delay, with relevant drugs all in the same place including up to date information about what the patient should take and when. For patients with long-term health conditions, this can be vitally important.

HP is currently trying to tie together how people use the green bag scheme at BSUH.

Action: HP to feedback on the green bag scheme.

b. Delays at discharge waiting for medicines to be dispensed

Prompt delivery of medicines

Prompt delivery of medicine is essential for speedy discharge. A new electronic prescribing procedure, To Take Home (TTH), is being looked at by BSUH. This should take out the need for staff to visit the pharmacist, speed dispensing and reduce delay on discharge.

Instructions for medication

Instructions for taking medicines need to be clear on discharge notices, particularly for patients with chronic diseases who need to keep to a strict routine, and when new medicines are introduced. Waiting a long time for meds to be delivered or having to leave before meds arrive could also have serious consequences for patients. BSUH are working on putting more information on the discharge notices, and using clear, concise language to make it easier to understand.

Interpreters

No interpreters at discharge causes delays. Interpreters, Braille and so on should be easier to book now as there is a new patient admin system, Medway, which has been in place since October 2018. All patient information across the Trust has been entered in, and the system should flag up if a patient needs an interpreter. Wards are also much more aware of how to use interpreters. An example was given of a D/deaf couple where the husband was going in for an operation and there was no BSL interpreter.

Action: Darren to give HP details, HP will get in touch with the couple to look into it.

Transport issues

Delayed discharge means disruption of travel plans if ambulances or taxis are booked and ready, and for relatives collecting their family member. If ambulances are not available, this also delays discharge. Patients feel they should manage their own transport instead of relying on an ambulance. BSUH don't manage transport. But you can claim expenses back if you need to take a taxi – this is dependent on your benefit status.

For more information about travel costs when visiting the hospital:

<https://www.nhs.uk/using-the-nhs/help-with-health-costs/healthcare-travel-costs-scheme-hctcs/>

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

Lack of Communication

Concern around this, especially at discharge. Lack of communication is the biggest complaint BSUH get. BSUH implements the Patient First Improvement System (PFIS). This training equips teams with skills and tools to eliminate those issues that come up time and again, such as lack of communication and delayed discharge. HP is heading up a project about communication for 2020. This will look at improving the beginning and end of patient stay in hospital. Communication is vitally important, and staff should always make time to speak to patients.

Monitoring Discharges

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

Action: HP to find out more about monitoring discharges.

The group were pleased that the issue of delayed discharge was being taken so seriously, although aware that it will be bubbling for a while.

c. Prescriptions which can only be dispensed from certain hospital pharmacies

Hospital prescriptions are not the same as pharmacy prescriptions and can only be dispensed by the hospital pharmacy. Patients must ensure they give themselves time to visit the hospital pharmacy during opening hours if they are collecting prescriptions themselves.

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

16.04.2019 Additional information re medicine in hospital

Provided by **Samantha Lippett** BPharm (Hons), PGDip, MSc, DIC, MRPharmS, IPresc.

Samantha is **Assistant Director of Pharmacy**, Medicines Governance, Information, Education & Research & Medication Safety Officer. **Samantha will be a guest speaker at the next BSUH meeting.**

a. Delivery of medicines in hospital

“We are piloting a self-administration scheme for insulin. This will help inform a wider self-administration policy which is in development. We aim to have a pharmacist review of all medication within 24 hours of admission. They ensure all medicines are prescribed correctly and at the right time. We would encourage you to speak with the ward pharmacist or technician if you have concerns about medications for your chronic conditions. The hospital also has a critical medicines list which includes Parkinson’s medicines and insulin; all staff are trained to make every effort to ensure these medicines are given on time.”

b. Meds – delay on discharge.

“Pharmacy aim to process all discharge prescriptions within two hours of receipt. In some circumstances it may take a little longer, for example if a patient is prescribed a complex regime or requires a blister pack. Please be assured that our primary aim is to ensure that any medicines prescribed are safe and appropriate for you and sometimes this takes more time. Medical teams are encouraged to prescribe discharge medicines ahead of your anticipated discharge date/time so that you have no unnecessary delay.”

c. Meds – reports that prescriptions that can only be dispensed from a specific hospital pharmacy.

“Legally only the hospital pharmacies can dispense medicines prescribed on our BSUH prescriptions. When appropriate we ask GPs to prescribe non-urgent medications for certain conditions but often due to the specialist nature of medicines prescribed in hospital it is not appropriate to ask the GPs to do this, at least not initially. Many community pharmacies may not keep these specialist medicines and in hospital your prescription will be reviewed by a specialist pharmacist who is skilled in managing these complex conditions.”

3. 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: HP to get us on Healthwatch's May review.

Lifts

There are 3 sets of double lifts in Stage 1. There will be clear signage on the lifts and the walls near the lifts.

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

Edges of Stairs

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

iii. Signage at RSCH

Simon is all over this, and Possability People are ready to help. In the redevelopment, signage is on cards so it can be moved and clarified easily. It is compliant with visually impaired needs, but will improve when the new development is complete. Meanwhile, 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

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. Urology

Whilst nothing has yet been formally decided about relocation of Urology once the redevelopment is complete, there are ongoing discussions around the location of a surgical robot as part of 3Ts which could potentially mean Urology may come back to RSCH in some

capacity. This is still in the planning phase and is not planned for stage 1. It is likely that patients who are being seen for urologic cancers will be seen at the RSCH for phase 1, where the cancer services will be based.

vii. Drones

The Trust has a drone policy, and there are lots of contingencies in place. The helideck and Air Ambulance have policies. These policies will be in place in the new build.

viii. NHS Walk-In Centre in Brighton

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

Action: DW to confirm.

ix. Outpatients & cancer care targets

Ongoing.

Action: HP to feedback.

4. Open Space Discussion

Electronic Signage

A & E now has electronic updates of the wait time to be seen by a clinician. There will be more electronics in the new development. HP expressed the wish not to rely on electronics, but to enable communication from staff. It was noted that D/deaf people are still often called to appointments, and visual displays with the patient's name are needed instead.

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

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.

Patient Profiles

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

5. AOB

Disability Staff Network

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

Action: HP to keep us updated.

Carer and Patient Information Group (CPIG)

The CPIG team at BSUH review patient information leaflets, discharge notices and patient letters for readability and clarity, making sure there is no jargon and the information is logically ordered, structured and easy to understand. Writing for patients is a challenge for

many staff in the Trust, so CPIG also includes patients to review leaflets online and to attend meetings. The aim is to write best practice templates.

Action: Anyone wishing to get involved with CPIG to contact DW, who will pass their details to HP. Plan is to have pan-impairment volunteers.

BSUH Patient Information Leaflets on www.bsuh.nhs.uk

There are now patient information leaflets covering all eventualities on the front screen of the BSUH website. Ask if you need a different format.

Update 09/04/2019: One of our GIG volunteers has successfully tested a selection of the online Patient Leaflet PDFs with the NVDA screen reader.

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.

Endometriosis

The Trust does have an endometriosis specialist, Ms Rebecca Malick, Consultant, whose outpatient clinics are based out of PRH. There is a voluntary support group based in Brighton.

Voluntary support group: A support group for sufferers of endometriosis is run at the Royal Sussex County Hospital by volunteers Hilary Denyer and Carol Pearson from Endometriosis UK. Meetings take place at Sussex House, 1 Abbey Road in Brighton.

If you are interested in receiving further details about the meetings, please contact Hilary and Carol on sussexcoastendo@gmail.com or by text on 07972 126134.

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: Tuesday 4 June from 2pm – 4pm

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

Following Meetings

- Wednesday 4 September 2019
- Wednesday 6 November 2019
- Wednesday 15 January 2020

Contact Details

Hannah Pacifico

Patient Experience Manager, Brighton and Sussex University Hospitals Trust

Hannah.Pacifico@bsuh.nhs.uk / 01273 696955 Extension 64509

Debbie Wickens

Get Involved Group (GIG) Project Assistant, Possability People

debbie@possabilitypeople.org.uk / 01273 208 934
