

Joint Meeting of Disabled Patient and Carers Forums
Minutes of meeting of June 29th 10am – 12pm
Forest Lodge, Large Room Heatherwood Hospital

NB: Those present at this meeting should be aware that their names will be listed in the notes of the meeting which may be released to members of the public on request.

Trust Staff		
Najeeb Rehman	Equality and Diversity Manager	Present
Katie Jo - Tripp	Patient Access Matron	Present
James McErlean	Clerical Officer	Present
Christine Whelan	Head of Health & Safety	Present
Helen Oakes	Matron – Care of the Elderly	Present
Kevin Queenan	Chief Pharmacy Technician	Present
Lilly Aliyas	Safeguarding Nurse	Present
Liza Aljentera	Clinical Nurse Specialist for Dementia	Present
Caroline Reynolds	Deputy Occupational Therapy Service Manager	Present
Michelle Youens	Head of Nursing Medicine	Apologies
Helen Oakes	Matron – Care of the Elderly	Apologies
Alex Lukjaniec	Clinical Nurse Specialist for Dementia	Apologies
Patient Reps/Carers/Guest Speakers		
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Present
[REDACTED]	[REDACTED]	Apologies

Minutes taken by Najeeb Rehman, Group Chair

1.	Apologies	As above
2.	MacMillan and engaging with people with disabilities NN introduced the work of MacMillan and explained the Information Centre: <ul style="list-style-type: none"> Was set up 7 years ago Is based at Wexham Park and Frimley Park Provides information to meet different sensory needs of patients Liaises with Cancer Nurses and Clinical Nurse Specialists Provides a drop in service, for example around emotional support and information and advice on benefits Sign posts to complimentary therapy options, buddying for patients undergoing cancer treatment and other MacMillan teams 	

	<p>The footfall through the centre tends to be 50% patient and 50% families. Challenges to overcome for the Centre are raising awareness amongst Trust staff of what the Centre does, meeting diverse language needs of patients and meeting needs of the Lesbian, Gay, Bi –sexual and Trans communities.</p> <p>The Centre can provide British Sign Language interpreters and also information in Braille, easy read and large print. There is a Hearing Loop in place and also a text service which enables people who are Deaf to contact the Centre.</p> <p>The written information provided by the Centre covers what is cancer, screening, treatment and end of life care. Only adults are seen by the Centre, however information to support children is available. There is also information available on Motor Neurone Disease and Alzheimers, with information in the pipeline around Dementia, Autism and Mental Illness.</p> <p>NN also links in with services located in West Berkshire.</p> <p>■ asked about why there was a lack of awareness amongst staff. ■ mentioned that as an ex cancer patient her experience was poor and yet no member of staff told her about how MacMillan could have helped her. An idea which could help raise awareness is handing out simple leaflets for example when first meeting the Consultant.</p> <p>■ replied that MacMillan carry out Ward visits at Wexham and speaks to newly qualified Nurses and also visits Doctors events. MacMillan Nurse make contact with and work alongside Specialist Nurses, GPs and Multi Disciplinary Teams and support District Nurses and Community Teams.</p> <p>■ added that parking costs incurred by patients are covered by transport costs.</p>	<p>NN to work with the Group on producing a leaflet</p>
3.	<p>Autism Strategy Update</p> <p>■ explained that the Autism Act 2010 was the first disability specific act and coming out of this was a duty upon local authorities to produce a Local Autism Strategy (covering adults only).</p> <p>Slough Borough Council published their Autism Strategy 2013 – 2017. At the moment this Strategy is being refreshed.</p> <p>There is an Autism Board in place comprising of families, carers, health staff and different professionals. The Board plays a key role in reviewing how actions and outcomes have been met.</p> <p>The proposal for Slough is to split the single board in Adults and Children. If this goes ahead then this would happen over the next 2 months.</p> <p>Some of the issues people with Autism face when they come into hospital include:</p>	

	<ul style="list-style-type: none"> • Not understanding a hospital environment • Waiting times i.e. how long will they need to wait to be seen • Co – morbidities of patients with Autism <p>■ mentioned initiatives undertaken by A&E such as providing patients with pagers. LA confirmed that pagers are in place and in use at Wexham.</p> <p>KQ confirmed that pharmacy at Frimley Park provide pagers for patients with Autism.</p> <p>Other ideas which could help patients with Autism include:</p> <ul style="list-style-type: none"> • Providing a map of the hospital in photos • Coming into the hospital before their appointment so that the patient and parents/carers can familiarise themselves with the surroundings <p>Relating to website information Hampshire has some good examples and further information can be found via the Autism Action Team.</p> <p>■ mentioned what information available is important and where it is available. Hospitals know they must make reasonable adjustments e.g. developing an app.</p> <p>■ felt a quick win for the Trust could be to employ an Autism Liaison Nurse.</p> <p>■ asked about how important the use of passports was for people with Autism and discussion concluded that patients should be referred to the Learning Disability team.</p> <p>■ added that one of the outcomes of the Strategy was to have a GP register in place. IP agreed as this was in a MENCAP report which suggested that patients sign up to a GP register which would link to the primary care record.</p>	<p>NR to contact Nick Birtley at West Hampshire CCG about audit of pagers</p> <p>NR to provide GS with data on numbers of patients with Autism attending A&E</p>
4.	<p>Healthwatch Surrey Update</p> <ul style="list-style-type: none"> • Discharge of patient's survey • Survey of Deaf patients accessing Hampshire Hospitals <p>Healthwatch produced information for patients on being Discharged from hospital. A series of recommendations were made in the report titled "Difficult to know what to Ask"</p> <p>In June 2017 CQC carried out a survey of inpatients across the NHS and findings were as follows:</p> <p>Confidence in hospital</p> <ul style="list-style-type: none"> • Patients aged 16 – 35, Dementia patients and Mental Health had less confidence in the care they received <p>Discharge</p>	<p>IP to send report to NR</p>

	<ul style="list-style-type: none"> • Around 2/3rds of patients left with no information • 43% of patients receiving medication were not told about side effects • 40% of patients not involved in discharge • 40% of patients experienced a delay in discharge and waited longer than 4 hours <p>Emotional Support</p> <ul style="list-style-type: none"> • 25% of patients had no emotional support (notable issues around mental health) <p>■ mentioned that Healthwatch Hampshire are carrying out a project looking into discharge across different hospitals.</p> <p>There was discussion on pressure sores and grading assessments carried out including skin checks and how the policy is followed to ensure the patient is fit for discharge. ■ replied that the MDT Team for Discharge takes the lead on this.</p> <p>Survey of Deaf Patients using Hampshire Hospitals</p> <p>■ explained that Healthwatch Surrey have been doing some work into the experiences of Deaf patients using hospital services. A video of patients sharing their experiences has been produced.</p> <p>The survey findings included: Issues around bookings</p> <ul style="list-style-type: none"> • Only 51% of Deaf patients knew about the complaints process • 62% of deaf patients did not know PALs existed • 24% of Deaf patients felt their communication needs had been met • 42% of patients experienced a cancellation or changing of their appointment • 48% of Deaf patients had to use a friend/family member to sign for them as a BSL interpreter had not been booked • 82% of Deaf patients did not know the Gender of the BSL interpreter which is particularly important for issues of confidentiality • Only 8% of patients were offered information in accessible formats • 60% of Deaf patients felt the hospital/GP did not offer enough support • Only 11% of Deaf patients had been told a BSL Interpreter had been booked for them • Only 20% of interpreters given information about the booking • Patients with Learning Disabilities and Autism not getting information which is accessible and meets their needs • Hospitals need to review their policies to ensure processes meet the communication needs of patients <p>■ asked if GP referral flagged Interpreter needs. ■ replied that they were told an Interpreter had been booked but then on the day the Interpreter did not turn up.</p>	<p>CR to share with NR/KJP meeting dates for the Safer Discharge Group</p> <p>NR to circulate link to the video</p>
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	<p>■■ also mentioned that GP and hospital appointments had been cancelled but only 31% of patients had received a letter and only 15% of interpreters get told that the appointment has been cancelled.</p> <p>■■ summarised the key findings as being:</p> <ul style="list-style-type: none"> • Conflict of interest between patient and interpreter • Patient wishing to have an interpreter of the same Gender at the appointment • Interpreters not being given enough information about the appointment • Interpreter terms and conditions not being met <p>■■ mentioned that the survey results had been sent to Hampshire Hospitals.</p>	■■ to circulate the report
5.	<p>Group Workplan Progress</p> <p>NR went through the workplan and progress was summarised as follows:</p> <ul style="list-style-type: none"> • To date, 68% of staff are up to date with their Equality and Diversity training. Basic Deaf awareness is covered in the training. • Heatherwood redevelopment review meeting is being held at the end of July and NR will circulate an invite • The Chapel at Wexham now has automatic doors. • An accessible toilet is being planned for Physio department at Wexham • A permanent ramp has been installed to connect the Wexham Restaurant with the outdoor seating area • As part of Learning Disability week, the Team at Frimley Park had an information stall in the hospital's main reception to raise awareness of Learning Disabilities • At Frimley Park Learning Disability Folders are on all Wards • At Wexham Learning Disability Awareness training is being delivered for staff • Findings from a Healthwatch Surrey into the experiences of Deaf patients and interpreters using Hampshire hospitals services will be embedded into Accessible Information Workplan • Attending an afternoon tea event with the Deaf patients and carers at Woking 	
6.	<p>Any Other Business</p> <p>LAj informed the Group that there is one Dementia activity Nurse at Wexham Park and one at Frimley Park.</p> <p>KQ informed the Group that large print labels can be provided for patients and Pharmacy uses pager devices to alert patients.</p>	
7.	<p>Dates of next meetings:</p> <p>Sept 4th 10.00am – 11.30am Post Graduate Education Centre Seminar Room 1, Frimley Park Hospital</p>	

	Sept 11 th 10.00am – 11.30am, School of Nursing, Room 6, Wexham Park Hospital	
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