The Royal Marsden NHS Foundation Trust
Patient and Carer Advisory Group

Monday 20 February 2017, 1200-1400, Board Room, Chelsea

Present:

In attendance: Sarah Rushbrooke (Deputy Chief Nurse), Dr Andrew McLeod (chairman of the Consent Steering Group), Marie Stacey (Chairman of the Friends, Chelsea) and Craig Mortimer (Quality Officer)

Action

1/17 Welcome from the Chairman
XX (Chairman) welcomed members wishing them a happy new year.

Members were reminded of the meeting ‘idea box’ into which members can anonymously ‘post’ suggestions for agenda items and feedback about meetings.

2/17 Notes of Thursday 01 December 2016 for agreement
The notes were agreed. Fiona reported a discussion with Sarah Rushbrooke, Deputy Chief Nurse, about identifying projects that PCAG members could get involved with. XX and XX are still gathering information before they launch the Wallace Wing environmental improvement project. The cost of producing short films for the website was confirmed.

Matters arising

3/17 None

Agenda items

4/17 Consent taking for treatment
Dr Andy McLeod, Joint Chairman of the Consent Steering Group, described how the Royal Marsden ensures that the consenting of patients for treatment is properly done. The Consent Steering Group helps teams to develop consent forms for treatment. Andy provides advice about the consent policy and trains doctors on consent taking. Recent changes to the law makes it clear that doctors should no longer be paternalistic about decision making, instead the process should be shared with the patient. Consent is a process. Patients are told about the treatment that can be offered and then given a consent form to consider. The Trust uses mainly customised consent forms that are specific for a particular procedure/treatment. A clinician able to perform the treatment/procedure or trained in taking consent for the treatment/procedure will complete the form with the patient. Information on the form and verbally given by the clinician will be supported by an information sheet.

Patients come from elsewhere for surgery including abroad. Advocates help with taking consent for Arabic patients. The Trust’s policy is to avoid using family members as interpreters.
The consent process is audited to check that it is being undertaken correctly.

Treatments are very complicated for example there are risks in undertaking further investigations. It is very difficult to convey complexity. Patients vary in the amount of information they want; some patients want a recommendation from the doctor and don’t wish to know anything further. Risks continue to be added to forms for example the risk to fertility. Communication of risk is being improved and personalized for example a 70 year old man with a certain level of fitness will be given a different level of risk to undergo a procedure compared to a younger fitter patient. Patients are being supported to become more autonomous. It is usually 1-2 weeks before surgery that consent is taken. If the patient is referred from another hospital then the consent taking may take place closer to the procedure. Usually, the closest to the procedure for taking consent is a week and the furthest away is 2 months although some forms are still signed on the day, but that is risky. A good quality discussion should be held in clinic. The consent form should not have too much weight attached to it; the clinical notes are very important in recording what the clinician has discussed with the patient regarding treatment options. Patients should be empowered to ask questions.

Two members of PCAG, XX and XX, are members of the Consent Steering Group; two more, XX and XX, are remote members who review draft consent forms by post and e-mail. Andy believes it is vital to have lay input on the terminology used in the forms.

Consent taking must be attempted in some form in emergencies, where urgent care is required and complications are arising. If the patient is unable to give consent then the decision can be made by the team with the defence of necessity or best interest. The safeguarding adults team support clinicians to make best interest decisions on behalf of patients who are unable to make decisions themselves.

XX noted that the consent forms have over time become clearer and more user friendly, but the consent process is dependent on the health professional to explain what is important to the individual. The consent form acts as an aide memoire to the clinician. Arabic advocates and an interpretation service are used when taking the consent of non-English speaking patients.

Supporters for patients are generally helpful. If someone is bringing undue influence then the clinician can ask to see the patient with an independent supporter.

If an additional procedure is foreseeable then the clinician will tell the patient that they may have to do an additional procedure once circumstances are clear after the operation has begun. Generally, don’t narrow further options by favouring the minor procedure option.
rather than the major option.

Andy concluded his item by thanking PCAG for contributing to the Consent Steering Group.

The Friends of the Royal Marsden
XX, Chairman of the Friends of the Royal Marsden, Chelsea and XX, Vice Chairman of the Friends of the Royal Marsden, reported. The Friends is an independent registered charity that started 82 years ago. The Friends of the Royal Marsden, Sutton, is a separate organisation. Members of PCAG were surprised to hear about the differences between the two sets of Friends.

The motto of the Friends in Chelsea is ‘Helping, Caring and Giving’. The Friends give money to provide equipment and amenities to enhance patient experience. The Friends have 230 volunteers who work 20000 hours annually. On average there are 25 volunteers in the hospital daily, Monday to Friday and a few in at the weekends.

Friends pay an annual subscription and must commit to 2 hours a week. New members undergo an induction and training about patient confidentiality. Those Friends that work in the snack bar undertake food hygiene training too. The Friends run the outpatients snack bar, a shop, of which 85% of customers are staff and a trolley shop. Fourteen Friends look after patients’ flowers and others help with meals on the palliative care ward. Thirty volunteers ‘meet and greet’ patients at the main and Dovehouse Street entrances. Other operations include the tea trolley in the medical day unit, helping staff with paperwork, provision of magazines, newspapers and second-hand books, and maintenance of the gardens. The Friends fund the Trust’s Arts Forum to enable it to improve the hospital environment for patients, visitors and staff.

All volunteers with direct patient contact are required to be checked by the Disclosure and Barring Service.

Sarah Rushbrooke, Deputy Chief Nurse, briefed the meeting about the Friends of the Royal Marsden, Sutton. The Friends in Sutton have 200 volunteers, run a snack bar and shop and visit wards. They do not ‘meet and greet’ patients. Sarah meets with both sets of Friends and is able to share learning between them. A new group, the Volunteer Management Group, has been set up to oversee volunteer matters including the formalisation of training and Disclosure and Barring Service screening as well as to share learning. Representatives of the Friends of the Royal Marsden, Radio Marsden and the Royal Marsden Charity attend the group as well as XX on behalf of PCAG.

The Friends will fund items that are not essential, but which make a big difference to patient experience for example 4000 blankets (£50000), cystoscopes (£44000) and wheelchairs (£12000). £1m has been given to the Trust over 5 years. The Friends receive money
through sales, donations, subscriptions, legacies and fund raising events. The Royal Marsden Charity and the Friends of the Royal Marsden fund different things. The Friends do not fund private care amenities or equipment.

Patients have to wait a minimum of 2 years after treatment before they can join the Friends.

6/17 Rushbrooke’s round up
Sarah reported. The Trust was inspected by the Care Quality Commission (CQC) in April 2016. The final version of the inspection report was received by the Trust on 13 January 2017. A number of factual inaccuracies in the first draft report were identified by the Trust when received in October 2016. Sarah considers the result fantastic with the Trust rated overall as ‘good’, but there was still some disappointment. Chelsea site was rated ‘outstanding’, Sutton ‘good’ and community services ‘requiring improvement’. The Trust was ‘outstanding’ for the caring category of the inspection across the whole organisation. In hindsight, the Trust should have asked the CQC to reschedule its inspection of community services as it was only 2 weeks earlier that Sutton Community Services disaggregated from Merton Community Services. The CQC has given the Trust six ‘must dos’.

For cancer services:
1. Implement and embed the World Health Organisation Safety Checklist in the outpatients department.

For community services:
2. When patients (aged 16 and over) are unable to give consent because they lack the capacity to do so, the Trust should ensure staff act in accordance with the Mental Capacity Act 2005.
3. Ensure that records contain accurate information in respect of each patient and include appropriate information in relation to the treatment and care provided, particularly with regard to risk assessments
4. The provider should take action to understand the shortfalls in recording of risk assessments and individualised care plans in the integrated community teams
5. Review the staff compliment for community adult services to ensure there are sufficient numbers of appropriately skilled staff to meet patient’s needs
6. The provider should strengthen the reporting on the assurance of effectiveness of governance arrangements to the trust board; this specifically relates to community services.

The last four items are recruitment related. There is huge pressure on community services staff due to the difficulty to fill vacancies. The Trust is prioritising what it has the capacity to do. An action plan is being developed which will cover more than just the six ‘must dos’.
CQC will arrange a ‘Quality Summit’ of stakeholders including commissioners and the Trust to review the action plan.

The inspection was arduous. The Trust had to supply a lot of information.

In response to a question Sarah stated the Trust does refer patients to palliative care on time, but wishes to do this even earlier as a gold standard. A set of triggers are being trialled for earlier referral of patients to palliative care services.

A huge amount of work has been undertaken between Community Services and Epsom and St Helier NHS Trust about discharge of patients home. Sarah paid tribute to the ‘amazing’ Community Services staff.

Sarah responded to a request from a PCAG member about a recent newspaper report ‘NHS in dash for cash’ which described a supposed move towards private care by the Royal Marsden. Sarah explained 45% of the Trust’s income comes from private care. The funds supplements NHS care and sustains the estate. The Trust is first and foremost an NHS hospital.

The new Chief Nurse, Eamonn Sullivan, started on 23 January. Eamonn had previously worked at University College London Hospital and at Guys and St Thomas’s with a background in the military and also community services. Eamonn is prioritising community nursing.

**Any other business**

*None*

8/17 Next meeting
Wednesday 12 April 2017, 1200-1400, Committee Room, Sutton