**Royal Marsden NHS Foundation Trust**

**Patient and Carer Advisory Group**

**Thursday 11 February 2021, 1200-1300 (Part 1) and Wednesday 24 February 2021, 1200-1300 (Part 2), online video meeting**

**Part 1**

**Present**:

**In attendance**: Katharine Malhotra (KM; Lecturer Practitioner), Siobhan Cowan-Dickie (SCD; Clinical Specialist Physiotherapist, Living with and Beyond Cancer), Anna Collins (AC; Matron) and Craig Mortimer (CM; Quality Officer)

**Part 2**

**Present**:

**In attendance**: Nikki Snuggs (NS, Team Leader Breast Care, Clinical Nurse Specialist), Katy Hardy (KH, Clinical Nurse Specialist, Colorectal Team), Anna Collins (AC; Matron), Emma Blondrage (EB; Digital Services Training Manager) and Craig Mortimer (CM; Quality Officer)

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| **Part 1** |  |  |
| **1/21** | Welcome and ground rules for management of the Zoom meeting |  |
|  | XX welcomed members and staff to the meeting.  At Part 1 XX introduced XX to her first meeting as a Patient and Carer Advisory Group (PCAG) member.  At Part 2 Lila welcomed XX as an observer as Sloan considers joining the group. |  |
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| **2/21** | **Notes of December 2020 meeting for agreement**  The meeting agreed the notes of the last meeting. |  |
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|  | **Matters arising** |  |
| **3/21** | *None* |  |
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| **4/21** | Physical activity strategy |  |
|  | Katharine Malhotra, Lecturer Practitioner and Siobhan Cowan-Dickie, Clinical Specialist Physiotherapist, Living with and Beyond Cancer, reported. The Trust has developed a physical activity strategy to support people to be active. The project has been awarded money from the Trust’s Innovation Den to highlight opportunities to be more active in areas within hospital buildings and to develop walking routes off site. The project will be supported by Living Streets. Walks on site will have improved signage. For off-site walks there will be interactive maps. The description of each walk will say how long it is. The intention is for the walks to have places to sit and cafes along them to support a social interaction element. Volunteers may be used as guides for walks. Staff will also take patients on walks for therapy. Staff will also be encouraged to take the walks so they can champion them to patients. The project will involve inpatients as well as outpatients.  Instead of an app, QR codes will be used to exclude fewer people. The Maggie’s Centre will be approached to become involved. People not attending onsite at the hospital will be encouraged to join the 5K Your Way programme.  XX highlighted the PCAG projects looking at making roads safer to cross around the Royal Marsden hospital in Chelsea and suggested that the projects link up. XX also appealed for more members to join the safer roads projects.  Kath agreed to contact the outpatients team to see whether it is possible to contact patients on a walk via their mobile phone when they need to return for their appointment. This might help overcome the reluctance of patients to leave the hospital in case they miss their appointment.  XX offered to guide a walk around Chelsea for members of PCAG when it is possible to meet again.  XX thanked Kath and Siobhan and offered PCAG’s support as the programme develops. Members were invited to e-mail any further questions to herself, XX, XX or Craig Mortimer. | **DF & KM**  **All** |
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| **5/21** | Vaccination programme update |  |
|  | Anna Collins, Matron, briefed the meeting about the Trust’s vaccination programme. Seventy-two per cent of staff had received at least one dose of the vaccine by the first week of February. Patients on active treatment are now being vaccinated based on need. The young and fit or those patients on follow-up are not being offered the vaccination.  The Trust is taking part in a national research project investigating the antibody reaction of patients who have been vaccinated.  Wastage of vaccines is not an issue as the vaccine is only prepared when there are enough patients to receive it. There have been no issues with communication affecting the vaccination programme.  The vaccine has been offered to all staff. Some have felt unwell after receiving the vaccination. The majority have had an aching arm; some have had the shivers. Tests are carried out to check that the symptoms are not caused by Covid-19.  Anna will confirm that patients will receive the second jab at the Trust if they have received the first one there and how patients’ GPs will be informed.  Staff that are seconded to other trusts are volunteers. They are given a Covid-19 test on their return and like all other clinical staff are tested weekly. People will not be given a different vaccine as their second dose.  XX highlighted an e-mail phishing scam using the vaccine as the hook.  XX asked members to send any further questions via e-mail. | **AC**  **All** |
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| **6/21** | Members’ report: PCAG website pages project |  |
|  | XX reported. The sub-group working to develop PCAG’s website pages has come up with many ideas. The website pages will describe PCAG, its aim and achievements as well working as a recruitment tool.  XX described the website page of the Cancer Patient Partnership Group of Addenbrooke’s Hospital, Cambridge. The page explains what the group is and achievements with proof including a patient buddy system and moving from addressing outpatient letters to the patient not the GP. There is also a video. The Cambridge approach confirms what the PCAG sub-group is thinking as it develops PCAG’s website pages.  XX noted there may be a risk in putting too much material online. XX agreed, including wishing to avoid the posting PCAG meeting notes on the pages.  Diana is to speak with Derek Stewart, an external trainer who has supported PCAG over a number of years, about ideas for producing a video. Derek has useful experience and background as a drama teacher.  XX will have more to say about the *Listening Post* section of the website after meeting with Natalie Doyle, Nurse Director for Patient Experience. XX will explore with Natalie options to run a virtual *Listening Post* while Covid-19 restrictions remain. In usual times, *Listening Post,* a ‘stall’ hosted by members twice a month, once at each site, informally collects low-level comments, suggestions and feedback from patients and carers. It is held in public areas of the Trust including waiting rooms and the restaurant in Sutton. The comments are used by PCAG to identify trends affecting patient experience and new projects. The comments are also anonymously shared with the Trust.  XX is drafting the frequently asked questions (FAQs) section. It was agreed to include a description of the difference between PCAG and the Patient Advice and Liaison Service (PALS) in the FAQs.  Other organisations’ web pages, including internationally, have been checked with the intention to benchmark the sub-groups’ ideas. However, there were, except for the Addenbrooke’s group, no equivalents to PCAG found.  Members congratulated the sub-group on its work. | **FMcK** |
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| **7/21** | Clinical Audit Committee – prostate cancer |  |
|  | XX highlighted a survey of prostate cancer patients who have used an electronic portal for administration of appointments. Of those responding 95% were happy with the portal. The 5% who were unhappy was because they could not receive clinical advice through the portal. The results are encouraging. There followed discussion, including a suggestion to add a link to Macmillan information as an alternative to advice from the Trust. XX highlighted another digital project whereby pharmacy staff provide information for patients. |  |
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| **Part 2** |  |  |
| **8/21** | Open-access follow up |  |
|  | Katy Hardy, Clinical Nurse Specialist, Colorectal Team and Nikki Snuggs, Team Leader Breast Care, Clinical Nurse Specialist, reported.  Patients on an open-access follow-up programme, if they have symptoms, can contact their clinical unit to arrange to return to the hospital before their next appointment. For colorectal patients, the programme starts after treatment ends and will run for 5 years, or 7 years if the disease treated was metastatic. For patients with a genetic risk of disease the programme lasts longer. It is recognised that patients prefer to have consultations with staff who are familiar with their history. The colorectal programme operates on a one-to-one basis and takes the form of a telephone appointment. The breast cancer unit has many patients requiring a large team of nurses to manage the open-access programme; for colorectal patients there is one staff member only. Members suggested that breast cancer patients would have a better experience if there was a limit of only one or two staff that they talk to on the programme. Patients have a choice of whether they join the programme or not. Patients can continue having face-to-face appointments if they wish or where there may be an issue with English not being the first language.  Open access is being expanded, including to the prostate and thyroid units. Not all hospitals offer open-access follow up. The programme was originally set up to reduce the number of appointments patients had to attend and to improve patient experience. Clinic time is also saved. Open-access follow up should ideally be about patients moving on outside of hospital. The original West London Network project began in 2009/10 based on work carried out at Hillingdon Hospital. The approach is now being expanded nationally as stratified follow up/remote surveillance for breast patients.  There are six nurse practitioners that run the open-access programme for 3500-4000 breast cancer patients. The large number of patients makes it difficult to assign staff to individual patients. However, if a patient wishes to speak with an individual member of staff it is possible if the patient and staff member work together. Nikki will make the point to her colleagues that patients can ask for a particular staff member as their contact. Group sessions have been switched to one-to-one telephone calls during the Covid-19 pandemic with the desire to continue doing this after the pandemic. Individual members who had experience of open-access follow up supported this change as they had found the group session too generic. Group sessions will be reintroduced but will address different information needs than the previous version. Patients and the Maggie’s Centre will be involved in the redesign of the group sessions. There are challenges in individualising the content of group sessions, but more use of themes may be possible. Members highlighted that as well as the content timing is important. The earliest new group sessions will be ready is in a year. Limited resources prevent inclusion of carers in the programme. The Maggie’s Centre can support carers. Before the pandemic, the team also ran seminars four times a year for 50-80 people including carers.  XX directed any further questions to Craig. | **NS**  **NS**  **All** |
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| **9/21** | Integrated Governance and Risk Management Committee – invitation to PCAG |  |
|  | XX reported. The Integrated Governance and Risk Management Committee (IGRM), the Trust’s patient safety committee, has invited PCAG to highlight any issues with how patients are told what to expect as Covid-19 restrictions are applied and change.  As the vaccination programme proceeds, arrangements for patients will be expected to change. As this happens XX believes that there may be a need for more real-time management of the information given to patients. XX invited members to identify what they would wish to know as procedures change. Questions about the vaccine and return of visitors were highlighted.  Any further questions should be e-mailed to XX, XX, XX, XX or XX. | **All** |
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| **10/21** | Survey of patients about their experience of virtual appointments |  |
|  | XX asked the meeting whether PCAG should survey patients to understand their experience of virtual appointments. The survey results would be used to identify small changes to improve patient experience. To avoid biasing the results it is proposed the survey would take place by post with a paper questionnaire rather than online so that all people contacted have the same opportunity to take part and be heard. It might be more likely that patients comfortable with responding to an online survey may also prefer virtual appointments compared to those patients not so comfortable with completing an online survey.  Overlap with the Friends and Family Test was discussed. It was also noted that Addenbrooke’s Hospital has written a short reference note to support virtual consultations.  XX offered to liaise with the Clinical Audit Committee where the proposal for the survey and questionnaire would be scrutinised and agreed.  The meeting supported running the survey. | **FS** |
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| **11/21** | Next meeting highlights |  |
|  | XX highlighted that mental health will be an item at a meeting soon. The item will cover mental health issues for patients, carers and staff. Points may address timing, the provision for carers and families and are BAME people differentially affected. XX asked that members consider the topic and send through to herself or Craig any points that members would like covered at the meeting. | **All** |
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|  | **Any other business** |  |
| **12/21** | Trialling Microsoft Teams instead of Zoom |  |
|  | Emma Blondrage, Digital Services Training Manager, was introduced to the meeting. Emma will be guiding members in using Microsoft Teams for online video meetings as the group moves from Zoom. Following the feedback of members who had tried to follow the link sent a few days before, the short session after today’s meeting has been postponed.  Emma explained that Microsoft Teams can be downloaded for free with its meeting function working similarly to Zoom. Emma asked members to download Teams and experiment before feeding back to Craig. The issues will then be discussed at the rescheduled session. There then followed a discussion. Craig will let members know the date of the rescheduled session. | **All**  **CM** |
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| **13/21** | **Date of next meeting** |  |
|  | Part 1: Monday 12 April 2021, 1200-1300  Part 2: Friday 16 April 2021, 1200-1300 |  |