**Royal Marsden NHS Foundation Trust**

**Patient and Carer Advisory Group**

**Tuesday 8 June 2021, 1800-1900 (Part 1) and Thursday 10 June 2021, 1800-1900 (Part 2), online video meeting**

**Part 1**

**Present**:

**In attendance**: Sara Lister (SL; Head of Psychological Support, Pastoral Care and Patient Advice and Liaison Service (PALS)) and Craig Mortimer (CM; Quality Officer)

**Part 2**

**Present**:

**In attendance**: Dr Nicolò Matteo Luca Battisti (NMLB; Medical Oncologist) and Maureen McGinn (MMcG; Project Manager), Andy Dimech (AD; Acting Chief Nurse) and Craig Mortimer (CM; Quality Officer)

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| **Part 1** |  |  |
| **26/21** | Welcome, declarations of interest and ground rules for management of the online video meeting |  |
|  | XX welcomed members and staff to the meeting. There were no declarations of interest. |  |
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| **27/21** | **Notes of April 2021 meeting for agreement**The notes of the last meeting were agreed. |  |
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|  | **Matters arising** |  |
| **28/21** | *None* |  |
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| **29/21** | Mental health |  |
|  | Sara Lister, Head of Psychological Support, Pastoral Care and Patient Advice and Liaison Service (PALS), reported. The service was renamed *psychological support* from *psychological medicine* 10 years ago. The team includes psychotherapists and psychologists, both clinical and counselling. There are art therapists, a psychosexual therapist and a family therapist. A consultant psychiatrist attends for six sessions a week. Cancer treatment may exacerbate mental health issues, for example, chemotherapy can interfere with the functioning of mental health medicines. Some cancers affect mental health for example some types of pancreatic cancer which are linked with depression.Limited resources prevent the Trust offering support to carers in most cases. There is counselling for couples and family therapists.Six sessions are offered initially, then possibly six more depending on the clinical situation of the individual There has been an increase in complexity of mental health needs with the Covid-19 pandemic. Pre-existing support may have been interrupted. Patients have been more distressed. The pandemic has led to therapeutic sessions taking place over the telephone and as online video meetings. During the first wave of the pandemic some patients felt better with a different perspective. In the later waves some patients presented with more advanced cancer as they attended their GP and hospital later due to the pandemic. This had an impact on the individuals’ mental health. A befriending service offered by volunteers was set up to help isolated patients in the pandemic with a weekly telephone call. If members would like to join the befriending service as a volunteer, please contact Craig who will put the member in touch with the Head of Volunteering. The psychological support service has become more accessible with the adoption of remote sessions. There have been far fewer appointments where the patient did not attend. More deliberation is required by the staff member when the patient is taking part in a session while at home. Remote sessions are harder for the staff member; they have to listen even more carefully. Patients are more likely to open up when at home allowing deeper work to be carried out. Most referrals are from doctors and Clinical Nurse Specialists although patients under active treatment can also refer themselves. A triage system is in place for all referrals. Videos, posters and the Patient Advice and Liaison Service (PALS) promotes the service.It is the clinical team’s responsibility to support patients as they reach the end of their cancer treatment. The psychological support team receive more referrals for patients towards the end of treatment rather than during treatment. As treatment ends, emotions catch up with patients particularly for those who have experienced changes due to the disease and treatment. The psychological service will see patients up to 2 years after treatment finishes. Following discharge, the GP can refer the patient to the Improving Access to Psychological Therapies (IAPT) programme which supports long-term conditions. The Royal Marsden was one of the first Trusts to offer psychological support services for staff which it expanded during the pandemic. Five to 10 sessions are offered. Referrals have increased with a focus on anxiety. Staff receive one-to-one counselling and have been told it is ‘okay not to be okay’. Administrative staff were the second biggest group of staff, after clinicians, to seek psychological support. Careful use of language can help counter the stigma of mental health issues, for example suggesting that distress is to be expected. With staff it is much more acceptable. Therapists talk about loss and grief to help people to come to terms with bereavement.Sara invited members to describe their experiences. Members described their feelings about the stigma and how they thought it made them ‘weak’ and a ‘failure’. The support once given was very different to expectations. The work to remove the stigma needs to continue. Sara may ask volunteers to describe their experiences in a video after the idea is explored with colleagues. Patients need to be positive otherwise treatment will not work and the service needs to be demystified. Patients need to hear that it is alright to talk rather than thinking because they are looking after everyone else in their family that they are coping. | **All & CM** |
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| **30/21** | Member’s report – appointment e-mail reminders update |  |
|  | XX gave a progress update about discussions with staff about the unannounced introduction of e-mail reminders for appointments. At a meeting with staff XX and XX highlighted issues staff are not aware of. Text messages are now being sent out for certain clinics to make patients aware of the new e-mail appointment reminder. There are some complications with the system if the appointment is not associated with a clinic appointment. Leaflets are to be produced with a recommendation by XX and XX that they be circulated wider than the outpatient department. Rescheduling of appointments using digital means is being trialled by Private Care. The long-term aim is to move to e-mail reminders as there is a cost to use texts messages. The integrated patient portal will solve most of these issues. It is not possible to provide electronic reminders for all appointments for example for radiology due to differing IT systems. Patient representatives will be involved as the portal is developed. XX, in his role as a Governor, is a member of the Digital Health Record Board. There was discussion about the significance of the lack of universal electronic appointment reminders and whether it is better to stop the roll out. Consideration was given to whether patients would expect an e-mail/text reminder if they receive them for other appointments elsewhere in the Trust.  |  |
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| **31/21** | Relaunch of review of PALS and Viewpoint |  |
|  | *Deferred.* |  |
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| **Part 2** |  |  |
| **32/21** | Vaccination update and farewell |  |
|  | Andy Dimech, Acting Chief Nurse, summarised the latest news about the Covid-19 vaccination programme. The Trust started its vaccination programme in December 2020 in the second wave of the Covid-19 pandemic. The programme began with the Pfizer vaccine and then moved to the AstraZeneca version. The Royal Marsden is in the top five Trusts in London for the vaccination rate of its staff, with 87% vaccinated. There have been some challenges including a lower uptake of 81% of the vaccine among Black, Asian and Minority Ethnic (BAME) staff. Vaccinations were offered flexibly to staff with clinics held in the evenings and weekends. Conversations were had with individuals to reassure them. Some reluctant staff took a wait-and-see approach as the vaccination programme was rolled out. A personal approach was taken to persuade staff including asking staff to take the vaccination with someone present who they trusted. Reluctant staff were thanked when they took the vaccine. When one person in a community took the vaccine it encouraged others. Issues mentioned as a reason for reluctance included social media reports, community discussions and stories of infertility and tracking. A booster will be offered later in the year. Last year 85% of staff had the flu vaccination which was the highest rate ever. Storage and transport of the vaccines is now understood with the Pfizer vaccine able to be stored in the fridge for longer than initially recommended. Staff without easy access to a computer will be spoken to earlier in the process next time so they are made aware of the booster sooner. Patients are very keen to receive the vaccine which is given before treatment. Tests for clotting are offered to patients as clotting is a risk for cancer patients. The Trust was the first to set up a surgical Cancer Hub to support cancer surgery across the region. At one time there were seven different organisations’ surgical teams operating simultaneously. The initiative worked very well. There is consideration of making the vaccination compulsory for staff. The NHS has not yet mandated this, but the Trust will look at high-risk patient areas. Internal guidance may be developed to describe who can work in those areas.Andy described the Trust as a fantastic place to work and a centre of excellence as he prepares to leave to return home to Australia. Andy thanked PCAG for all the work the group has carried out over many years to make the Trust a better place for patients. Members bade Andy farewell and expressed their gratitude for his support during his time at the Trust. |  |
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| **33/21** | Developing a senior adult oncology programme at The Royal Marsden |  |
|  | Dr Nicolò Matteo Luca Battisti, Medical Oncologist and Maureen McGinn, Project Manager, reported. There are more than 4.1 million people aged over 65 with a cancer diagnosis. Older patients are diverse in their health needs. There is a higher burden of health needs caused by a decline in organ function with age, more side effects caused by cancer treatment, reduced social support and complications from medication interactions. A diagnostic and therapeutic approach applied in a holistic way has been learnt from geriatric medicine colleagues. This approach supports prediction of side effects, an estimate of prognosis and the early identification of issues. Side effects and unplanned admissions are reduced, and quality of life and communication are improved. A personalised approach is taken. Other needs are addressed under the care of a multi-disciplinary team for example: counselling about falls, balance and strength work, memory clinics, counselling, rationalisation of medicines and nutrition advice.NHS England is urging hospitals to improve assessment of frailty to help guide treatment. At Guy’s Hospital some clinics are led by geriatricians at the invitation of the oncologists. Access to a range of services including specialist nurses, therapists, pastoral care, allied health professionals, psychologists and social workers improves the care of older patients. A baseline of unplanned admissions has been identified for patients over the age of 70 which will be referenced as the programme is introduced. Patients will be screened to identify those who would benefit from a fuller assessment under the programme. The second aspect of the programme is to establish a multi-disciplinary team meeting to assess the complex needs of patients. This model of care has been followed for several years in the USA and Europe. Approval for the trial has been agreed with RM Partners. The year-long trial will run for people over 70 receiving systemic anti-cancer treatment in Sutton. It is expected that 10 new patients will be enrolled each month with the aim to expand, to include all relevant patients in the unit, one other unit and involve another organisation. The number of unplanned admissions and quality of life will be used to assess improvements in the care of the patient compared to current practice.Nicolo and Maureen invited questions. The programme will improve communication with patients in a systematic way. This model supports active engagement with patients and will help with decision making including stopping the patient being under-treated as well as over-treated. With the permission of the patient, the involvement of carers will be an asset in supporting the patient. For example, to remind patients to take tablets.A third of patients are psychologically distressed. The involvement of a psychologist will support the mental health of patients.There should not be a rationale to exclude patients from clinical trials based on age; the decision should be based on the individual not their age. This is a key challenge. Usually, older individuals are excluded from clinical trials because of strict criteria.Nicolo made clear that PCAG is very welcome to be involved as the programme is introduced at the Trust. Coordinate my Care metrics will be recorded and there is an expectation that there will be an increase in advanced directives due to improved completion of Coordinate my Care records. Coordinate my Care is an NHS service that records the individual’s wishes, and then shares them, electronically, with all the medical professionals who will be involved should the patient suffer a medical emergency.Good relations with the patient’s GP will be established for continuity of care. Whether the programme reduces the workload on GPs will also be investigated.The lack of access to a geriatrician at the Trust will be covered by drawing on the expertise of the broad multidisciplinary team.Members were asked to send further questions on to Nicolo and Maureen via Craig. | **All** |
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| **34/21** | Members’ reports – therapy services project |  |
|  | *Deferred.* |  |
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|  | **Any other business** |  |
| **35/21** | Cavendish Square private care facility |  |
|  | XX noted he had visited the new private care facility in Cavendish Square following the open invitation from Rachel Tustin, Director of Operations, at the April meeting. Tim was impressed with the facility. XX had telephoned beforehand to book his visit. |  |
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| **36/21** | **Date of next meeting** |  |
|  | * Part 1: Wednesday 25 August 2021, 1800-1900, online video meeting
* Part 2: Thursday 2 September 2021, 1800-1900, online video meeting
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