Peninsula Cancer Alliance

Joint Meeting of the Peninsula Cancer Alliance (PCA) Breast Care Nurses and

Familial Breast Cancer Site Specific Groups (SSGs)

13th September 2017: 11:30-13:30

Lifton Farm Shop (Strawberry Fields Conference Room), Lifton, PL16 0DE

FREEDOM OF INFORMATION

This group will observe the requirements of the Freedom of Information Act (2000) which allows a general right of access to recorded information including minutes of meetings, subject to specific exemptions. No one present today had any objections to their names being distributed in the minutes.

Draft Meeting Notes

Chair: Dr Carole Brewer

Reference

1.0 Welcome and introductions.

Please refer to separate attendance list available here.

2.0 The minutes of the previous meeting were considered and accepted as accurate.

3.0 **Matters Arising**

Group members were offered the opportunity to provide updates from their respective Trusts:

3.1 **Plymouth Hospitals NHS Trust (PHT)**

PHT has been unable to provide a designated family genetics clinic; this issue has been raised previously. However, the nursing team at PHT are now nearly fully established and therefore there may be scope to provide such service in the future.

3.2 An Enhanced Breast Surveillance patient information leaflet has been drafted, the purpose of which is to assist with obtaining consent to surveillance.

3.3 **Royal Cornwall Hospitals NHS Trust**

Discussion arose around access to prophylactic surgery for patients with a moderate family history, in the absence of BRCA gene mutation, and on what basis they are being offered treatment across the Peninsula.

3.4 It was suggested that prophylactic surgery makes no difference to the outcome of primary disease, and in order to ensure parity of access to treatment for patients across the Peninsula, the group may need to work towards a consensus statement on how moderate/high risk patients are managed.

3.5 It was agreed that this matter would be raised at the proceeding Breast SSG meeting this afternoon, in order to obtain perspectives from surgical colleagues.

3.6 **Action**

Nina Kamalarajan (NK) to contact the breast surgeons across the Peninsula to establish current practice. Once collated, the information will be shared with the relevant SSG members across the PCA to facilitate further discussion.

3.7 **Torbay and South Devon Healthcare NHS Foundation Trust (TSD)**

Family genetic clinics for high risk and new patients have been reduced to one per week. It was noted that some high risk patients are not attending clinic; this may be due to a lack of risk perception/awareness.

3.8 The Clinical Genetics Team at Guys and St Thomas NHS Foundation Trust have developed a new app, using personal, family and medical history to assess a person's risk of inherited cancer. Further information on this app is available via this link.

3.9 Guys and St Thomas' Hospitals have also developed a flow chart to assist risk assessing patients for breast and ovarian cancer.

3.10 **Action**

NK to share circulate the risk assessment flow chart via email distribution to the group.

3.11 **North Devon Healthcare NHS Trust (NDDH)**

NDDH share breast screening services with Exeter, and also provide a "virtual clinic"

3.12 **Royal Devon and Exeter NHS Foundation Trust (RDE)**

Family history clinics have moved to the Heavitree site; Exeter will continue to liaise with NDDH to ensure that there is consistency of service provision across the Trusts.

3.13 **Royal Cornwall Hospitals NHS Trust (RCH)**

RCH are currently providing services to the best of their ability in view of staffing challenges.

3.14 **Breast Care Nurses**

Historically the Breast Care Nurses group have met before the Familial Breast Cancer Group; consensus needs to be reached as to whether the nurses would like to continue to meet separately or jointly with the Familial Breast Cancer Group.

3.15 **Action**: NK to set up a poll for the Breast Care Nurses to ascertain how the group would like to hold their meetings going forward.

3.16 Josephine Brand-JB- (current Breast Care Nurses Group Chair) announced that she is to step down as chair and that nominations for a new chair will need to be raised prior to the next meeting.

3.17 **Action**: NK to contact all breast care nurse group members via email; All nominees need to have their nomination supported by at least one existing group member.

3.18 JB announced that there will be a breast care nurses' study day on 2nd October 2017 at Darts Farm, Topsham. CPD points are available to attendees and the meeting invitation is also extended to colleagues from other related disciplines.

3.19 It was noted that TSD have a dedicated metastatic breast cancer nurse. It was discussed that NDDH and the RDE would benefit from the support of an appropriately trained nurse to support their metastatic breast cancer patients.

3.20 **Action**: NK to liaise with breast cancer CNSs/service managers at TSD and RDE to look at national guidelines and service recommendations for metastatic breast cancer nurses.

4.0 **BRCA Testing-Rapid BRCA Testing to Inform Management**

Advances in technology have changed; BRCA testing now takes about 4 weeks from receipt of sample to result.

4.1 The outcome of BRCA testing affects the subsequent management of patients and therefore, the group discussed the need to ensure that the urgency of referrals is clarified at the outset in order to assist triage.

4.2 The Peninsula Cancer Genetics Service has piloted an email referral system and this has been well received.

4.3 The group discussed genetic testing and surgical decision making and the complexities associated with this. It was suggested that there are a sub-group of patients who may benefit from the additional information that genetic screening can provide.

4.4 The e-referral system at Exeter was explained: the referral e-mail box is checked twice daily. The referral system is consultant led and ALL referrals are reviewed by a Consultant Geneticist. The longest referral wait should be no longer than 3 days.

4.5 The group discussed whether or not the e-referral system should be used for all patients or just urgent referrals.

4.6 It was agreed that women whose treatment depends on the results, or whom have a terminally ill relative + any other referrals deemed urgent would be accepted.

4.7 The group discussed a need to define what criteria would meet an "urgent referral".

4.8 **Action**:

NK to contact Dr Brewer and Dr Castle in order to ascertain a statement on the criteria for an urgent referral.

Referral Proforma to be distributed to the group.

5.0 **Triple Negative Breast Cancers and BRCA Testing-New NICE Guidelines**

It was previously recommended that BRCA testing is offered to patients under the age of 40, and patients under the age of 50 with family history.

5.1 As of March 2017, the NICE guidelines [CG80] now recommend testing for all triple negative patients under the age of 50.

5.2 The NICE CG80 March 2017 update is available here.

5.3 It was suggested that if in doubt, the Genetic Consultants would be happy for clinicians to send an email enquiry asking for advice and guidance as to what can be done from a genetic perspective.

It was clarified that referrals in the following situations should be considered:

(i) Very young patients (30 and under).
(ii) Patients at risk of Li-Fraumeni Syndrome.

6.0 **Patient Pathway-Clinical Genetics Input into Breast MDT (for women seeking risk reducing surgery)**

6.1 It was agreed that MDTs are the right forum for discussion to take place and that there needs to be input into Breast MDTs by Clinical Geneticists.

6.2 Genetic testing will increasingly inform patient management and such MDT processes should be supported at each individual centre.

6.3 An example was provided as to how such patients are managed at RCT; the MDT (which includes geneticists, psychologists and surgeons) decides which patients are offered surgery; the formal outcome is then recorded following discussion.

6.4 It was noted that the pathway for these patients is relatively straight forward, however, there are patients for whom such a decision is not so clear cut and that having a clear structure of patient population is helpful.

6.5 The group acknowledged that it would be helpful to come up with a reporting process, and identify where in the patient pathway MDT discussion with genetic input should occur.

6.6 It was agreed that it would be helpful to identify what current practice is in place, what the pathway for this group of patients currently looks like and what information would be required for MDTs to incorporate genetic input into their meetings.

6.7 **Action**:

NK to liaise with RCHT to establish how they facilitate genetic input at their MDT. This information will then be shared with the MDT leads to inform discussion as to whether it would be beneficial to replicate across the Peninsula.

7.0 **NICE Breast Screening-Current Practice**

The group discussed current variation in practice across the country for the over 50 population and how risks are assessed.

7.1 It was agreed that any change in current practice would need to be applied consistently across the Peninsula and that we would need the support of a centrally made decision.

7.2 It was noted that many of the London Centres follow the Royal Marsden Guidelines instead of NICE.

7.3 Concern was raised that there are people in the Peninsula with BRCA gene mutation over the age of 70 who are not being screened and that there is supporting evidence (published by the Royal Marsden) that this cohort of patients should be screened up until the age of 80.

8.0 **AOB**

None.

9.0 **Date of Next Meeting**

TBC

Summary of Actions

Reference	Subject Matter	Summary	Action
3.6	Service Provision	Prophylactic surgery for patients with moderate family history in the absence of BRCA gene.	NK to obtain baseline of current practice across the Peninsula.
3.10	Sharing Practice	Breast and Ovarian Cancer risk Assessment.	NK to circulate information.
3.15	SSG Issues	Joint meeting with Familial Breast Cancer Group.	NK to poll the Breast Care Nurses to establish how the group would like to hold their meetings going forward.
3.17	SSG Issues	New chairperson required for the Breast care nurses group.	NK to email all breast care nurses re nominations.
3.20	Equity of Service Provision	Metastatic Breast Cancer Nurse Specialists	NK to discuss further with breast cancer nurses and service managers at TSD and RDE.
4.8	Genetic Services	Clarify "Urgent Referral" criteria.	NK to contact Dr Brewer and Dr Castle to obtain consensus statement. Referral preform also to be circulated to the group.
6.7	Sharing Practice	Genetic input at MDT meetings	NK to obtain information from RCH to share.