Meeting of the *London Cancer* Gynaecological Pathway Board

Held on Thursday 4th October 2018, 16:00 – 18:00 in meeting room 3, Wing A, 2nd Floor Maple House, 149 Tottenham Court Road, London W1T 7BN

Chair: **Alex Lawrence**

1. Welcome and apologies

- Introductions were made and apologies heard.
- AL welcomed Millie Light and Rowan Miller to the Board.

2. Minutes from last meeting and matters arising

- The minutes of the last meeting were agreed as an accurate record.
- Matters arising
    - Lymphoedema leaflet – PL will chase Kay Eaton for an update on the progress of the leaflet.
    - Open MRIs – at the last Pathway Board meeting it was agreed that for endometrial cancer, claustrophobic patients or those with a BMI which was too high did not need to have an MRI before referral to the specialist centre and an ultrasound could be performed centrally if clinically indicated. A letter confirming this has been sent to Gynaecology service leads. JB reported that RFH has a new magnet with a larger bore and claustrophobic patients are now finding MRIs easier.
    - SOP for cervical smears following a cancer diagnosis – the amendments proposed by the Board have been accepted by Tanya Allan and will be incorporated. NM reported that the gynaecology pathologist at UCLH has said cervical cancer stage 1A1s do not need to be reviewed by UCLH, but should be reviewed by local pathologists. All agreed that this was a standard of care and that pathology of cervical cancers should be reviewed centrally. PL queried how the results of the smear review are communicated to the patient and AL confirmed that the suggested amendment to the SOP had been to state the treating clinician should be informed of the result.
    - Education event – the education event scheduled to take place on 4th October has been postponed due to clashes with conferences and the availability of speakers. It will now be held on 21st January 2019 with the same planned programme. The Board agreed that it was good to have the event on the same day as the Board meeting. AL queried whether the Board was happy for education events to be sponsored by pharmaceutical/biotech companies. Tesaro has offered some sponsorship for this

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Naser Turabi – Programme Director

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event. It was agreed that it was appropriate for pharma companies to sponsor events and this will be confirmed with Tesaro.

ACTIONS:

- PL to follow-up on progress of the lymphedema leaflet with Kay Eaton.
- CC to confirm sponsorship for education event with Charlotte Simpson at Tesaro.

3. Update on transformation funding

- Helen Saunders presented an update on transformation funding.
- Each year there is a bidding process for the funding and this process is likely to take place again soon. It is not known what the value of the bid for 2019/20 funding will be, but for 2018/19 the bid value was £10m. The proportion of funding received depends on NCEL performance against the 62 day standard.
- Living With and Beyond Cancer (LWBC) funding is allocated for the whole of London and is separate to the Earlier Diagnosis funding.
- HS suggested that the Pathway Board could have input to the bid if there are transformation projects which they have identified. Input should be given via AL.
- HS stated that gynaecology performance is high on the commissioners' performance agenda.
- The slides presented by HS will be circulated to the Board.
- It was discussed that there tend to be more breaches on shared pathways. Discussions have been taking place on how to improve this and the key themes emerging are lack of radiology capacity and shortages of staff.
- HS clarified that transformation funding is allocated annually and so is not used for supporting short term staffing and this is also not a transformation project.
- NM queried whether additional clinics, which require more equipment, would be considered transformational, for example, the ultrasound clinic which is helping to meet the two week wait target.
- PJ asked whether the proposed NEL Diagnostic Hub at Mile End hospital will affect gynaecology. It was clarified that the Hub will perform straightforward scans and therefore free up capacity in the hospitals, but probably will not support gynaecology scans. Predefined groups have already been identified for surveillance.
- AL queried whether this would create a disparity with NCL, however, NM confirmed that UCLH performs specialist ultrasounds and hysteroscopy, so it is better to keep these 'in-house'.
- GG pointed out that PAH is in a different STP to the other Trusts, but approximately 95% of gynae patients are referred to UCLH. He was unclear about how this affected funding and was keen to be involved with the work of the Collaborative. It will be clarified whether decisions made by the Board regarding training or services need to go through the Herts and West Essex STP.

- GG also noted that there are issues with the pathway between PAH and UCLH. GG will work with NM to smooth the SMDT transfer.
- It was queried how patients are prioritised at the specialist centres if they have already breached the pathway. At both Barts and UCLH clinical priority is first, followed by the 62 day standard priority. UCLH tries to get patients through quickly if they have breached. It was pointed out that these are usually complex patients.

ACTIONS:

- The Board to identify potential transformation projects for next year's bid.
- CC to circulate HS presentation to the Board members.
- CC to ask HS to clarify commissioning arrangements with Herts and West Essex STP.
- NM/GG to work on smoothing the ITT pathway between PAH and UCLH.

4. Patient information leaflet on 2 week wait pathway

- BD presented the up-to-date version of the leaflet. This has had input from NM, patients and other clinicians, but requires further work.
- The purpose of the leaflet is for patients on the two week wait pathway to know what to expect and understand why it is important to attend appointments. It is hoped this will decrease anxiety, improve compliance and reduce DNAs.
- The leaflet is based on one created for the prostate pathway. At the last Pathway Board, it was agreed that one overarching leaflet would be developed for gynaecology, not one for each cancer.
- Gynae CNSs had provided feedback on 4th October and PL had agreed to put BD in touch with a gynae patient support group.
- There was a discussion about the leaflet and the following comments were made:
    - NM felt that it could not be pared down any further.
    - When is the best time to give the leaflet to the patient? It was suggested that the GPs should give this when referring patients on the 2 week pathway and CCGs should monitor that this is being done (via a tick box on the referral form) as it is important to make sure patients attend the 2 week clinics.
    - GPs should tell the patients they are being referred for possible cancer.
    - The first two paragraphs should be rewritten to mention the possibility of cancer in the first paragraph.
    - The glossary should be moved to the back page and 'what you need to do' should be moved forward.
    - Including the pathway helped patients to engage on the prostate pathway.
    - CT, CT PET and MRI should be removed from the 'first appointment'.

- BD will make the changes and send the draft back to AL. It was agreed that GPs should be engaged now to increase the probability of them giving the leaflet to patients. Afsana Bhuiya will be asked to review the draft.
- NP felt the leaflet may be frightening for patients and relatives, but SB disagreed. PJ said that some patients want and information and some do not.
- BD will discuss the draft with the patient group. It was also agreed to ask patients in clinic or on the pathway to review it as well as those not on the pathway to see if they felt it would be helpful.
- It was also agreed to pilot the leaflet.

ACTIONS:

- BD to make agreed changes to the leaflet.
- BD to engage with gyane patient support group.
- Afsana Bhuiya to be asked to review the updated draft.

5. Feedback from IOTA simple rules training

- AL gave a background to IOTA rules training. It has been used in RCTs and has been shown to increase the confidence of level two ultrasonographers in diagnosing ovarian cancers and recognising benign lesions.
- A training session was held at Barts on 6th September and feedback was good with most sonographers reporting that the training had increased their confidence and would change their practice.
- The next step is to roll the training out to BHRUT and hospitals in NCL. BCF, NMUH, RFH and Whittington Health were identified as hospitals for which training should be provided. UCLH does not need to be included as scans are performed by experienced doctors and they do not use IOTA rules.
- NP felt that the rules should apply to all, but it was agreed that was not necessary as Davor Jurkovic was very experienced in cancer diagnostics.
- At RFH ovarian cancer scans are performed by In Health. IOTA rules training would not be provided for private providers.
- The project will be evaluated by comparing the quality of scan reporting in a baseline audit with reporting following training.
- It was agreed to hold two training events in NCL, one near UCLH and one near Barnet Hospital.

ACTIONS:

- IOTA rules training events to be organised at BHRUT and near Barnet Hospital and UCLH.

6. Feasibility of HIPEC

- AL gave a presentation about HIPEC. It has been shown to increase survival in patients with ovarian cancer
- AL queried whether the Board supported a feasibility study in NCEL.

- There was a discussion about HIPEC.
- This is given in theatre after debulking and patients need to stay in theatre for 90 minutes. This will impact on theatre schedules.
- HIPEC is standard of care in Basingstoke for pseudomyxoma.
- It was agreed to undertake a feasibility study in ovarian cancer across both centres to ensure that a sufficient number of patients can be recruited, but that it would need to be clear what the objectives are and that robust data will be generated.
- NP asked why the prognosis for ovarian cancer in the UK is worse than other countries. A number of factors were suggested – surgical input, access to clinical trials, routine scanning and earlier treatments post- surgery.

7. HPV self-testing project

- There is £500k available for this project to increase uptake of cervical smears where this is low. It will be offered to 4 CCGs (2 in each STP) where uptake can be increased.
- AL outlined the project. It will be aimed at women who may be too embarrassed to attend for a smear test or those who have DNA'd or declined testing. Some self-testing packs will be sent out and some will be offered opportunistically in GP surgeries. PHE and the Screening Committee are engaged in the project.
- Those who test positive or who are high risk for HPV will be offered a colposcopy or smear test.
- Three groups been identified for self-testing:
    - Women who have not had a smear for 14 months;
    - Women who have asked to be removed from the cervical smear list;
    - Opportunistic testing after 6 months.
- Approximately, 15-20% positive take up is expected.
- NP said that in Australia this is already part of screening and it is also undertaken by private clinics.
- The swab to be used hasn't yet been decided. NP suggested Quintip as this seems to be easy to use and has increased uptake in his private practice.
- It is probable that some people will still not want to have a smear test, even following a positive HPV test.
- Barts is already running a feasibility trial of HPV self-testing and some of the Barts team have been involved with this project.

8. Industry sponsorship of education event

- This was discussed under matters arising.

9. Any other business

- PL noted that in January there had been a presentation to the Board about health promotion in some NCEL boroughs. She queried whether there were any health promotion projects for women with post-menopausal bleeds, for example. There is evidence that afro-Caribbean women in particular present late with post-menopausal bleeding.

- NM suggested that a sub-group should meet to discuss ideas for transformation projects. This was agreed and volunteers were requested.

ACTION:

- CC to email Pathway Board to request expressions of interest for participation in the sub-group.

10. Date of next meeting

- Monday 21st January 2019, 16:00 – 18:00

ACTION LOG

Action reference	Action	Owner	Date Due	Status
July-01	BD to speak to a group of women by next pathway board meeting and develop patient information leaflet	BD	04/10/18	Complete
July-02	LR to help get BD on the agenda for CNS forum in October	LR	04/10/18	Complete – meeting held on 4.10.18
July-03	AL to feedback to Tanya Allan that in point 8.1.22, it needs to state that the results will be communicated with the clinician that is treating the patient. Also to feedback to add that the patient can contact their CNS to discuss their results	AL	01/08/18	Complete – accepted by TA
July-04	BO'D to send out data slides to the Board	BO'D	01/08/18	
July-05	FE to check if there is a venue at NMUH we could use for the October Education event	FE	01/08/18	Complete – no longer needed
July-06	HS to attend October pathway board meeting and talk about transformation funding	HS	04/10/18	Complete
July-07	BO'D to send HS's slides to the Board	BO'D	01/08/18	
Sept-01	PL to follow-up on progress of the lymphedema leaflet with Kay Eaton.	PL	31/10/18	
Sept-02	CC to confirm sponsorship for education event with Charlotte Simpson at Tesaro.	CC	19/10/18	Complete
Sept-03	CC to circulate HS presentation to the Board members.	CC	5/10/18	Complete
Sept-04	CC to ask HS to clarify commissioning arrangements with Herts and West Essex STP.	CC	19/10/18	
Sept-05	NM/GG to work on smoothing the ITT pathway between PAH and UCLH.	NM/GG	Ongoing	
Sept-06	BD to make agreed changes to the patient	BD		

	leaflet.			
Sept-07	BD to engage with gyane patient support group	BD		
Sept-08	Afsana Bhuiya to be asked to review the updated draft.			
Sept-09	IOTA rules training events to be organised at BHRUT and near Barnet Hospital and UCLH.	AL/CC		
Sept-10	CC to email Pathway Board to request expressions of interest for participation in the sub-group.	CC	5/10/18	

Attendees

Name	Initials	Trust/Organisation
Alex Lawrence	AL	*London Cancer*/Barts Health
Nicola MacDonald	NM	UCLH
Heather Evans	HE	RFH
Philippa Lloyd	PL	Barts Health
Susan Boyde	SB	Patient Representative
Patricia Jupp	PJ	Patient Representative
Millie Light	ML	BHRUT
Rowan Miller	RM	UCLH/Barts
Jeremy Berger	JB	RFH
Ghazi Ghazi	GG	PAH
Narendra Pisal	NP	Whittington Health
Helen Saunders	HS	*London Cancer*
Caroline Cook	CC	*London Cancer*

In attendance

Name	Initials	Trust/Organisation
Becky Driscoll	BD	UCLH Cancer Collaborative
Katie Rosenthal	KR	UCLH Cancer Collaborative

Apologies

Name	Initials	Trust/Organisation
Karen Summerville	KS	UCLH
Lisa Reid	LS	PAH
Sharon Cavanagh	SC	UCLH Cancer Collaborative
Naveena Singh	NS	Barts
Sandra Watson	SW	HUH
Caroline Stirling	CS	UCLH

Name	Initials	Trust/Organisation
Sue Gessler	SG	UCLH
Rekha Wuntakal	RW	BRHUT
Rebecca Kristeleit	RK	UCLH
Jonathan Ledermann	JL	UCLH
Frances Evans	FE	NMUH