Joint Clinical Research Board

Monday 17th June 2019
Room 1.32, Garrod Building, Whitechapel

Members present:

Coleen Colechin (CC)
Sandra Eldridge (SE)
Deanna Gibbs (DG)
Hemant Kocher (HK) – by telephone
Gerry Leonard (GL)
Jo Martin (JM)
Rupert Pearse (RP), Chair
Anju Sahdev (AS) – by telephone
Steffen Petersen (SP) – by telephone
Tim Warner (TW)
David Wheeler (DW)

In attendance:

Sven Bunn (SB)
Nick Good (NG)
Mays Jawad (MJ)
Jo Morgan (JMO)
Neeta Patel (NP)
Amy Schou (AS)

Apologies:

Mark Caulfield
Alistair Chesser
Jack Cuzick
Sharon Ellis
Margaret Johnson
Nick Lemoine
Stephen Kelly
Kieran McCafferty

Agenda Item	Action
1. Minutes and Actions from the last meeting RP opened the meeting and welcomed David Wheeler, now Joint Clinical Director of CRN: North Thames. The minute of the last meeting in December was agreed – June's meeting was cancelled due to a major diary-clash. Actions from that meeting: (i) Key Metrics to return as a substantive item for discussion at the next JCRB with a JRMO paper proposing metrics it can maintain and deliver. NG said that a set of Key Metrics are on the JRMO website and that he will be keeping that up-to-date with revisions every 6 months or so. RP welcomed this news. (ii) FS to send a list of Life Science Board members to NG, for onward circulation to JCRB members, as soon as it is available. FS having left it was agreed that SB would provide this info to NG for circulation. **ACTION**: NG to ask SB for a list of Life Science Board members. (iii) GL to contact BB to request further finance working group meetings take place and to include a review of the use of PAs. GL reported that meetings of this group are ongoing and related output is coming through. (iv) Any updates on implementation of Excess Treatment costs and related concerns to be sent to SE for onward communication to Senior Investigator meetings. GL reported that this issue has not come up since the last meeting and a new system for processing these, imposed by DOH/ NIHR is now in force. He said that it will	**NG/SB**

undoubtedly return in some form as an active issue. (v) NG to cover the appointment of joint clinical directors in the next Research News Bulletin. NG confirmed that this was included in the February 2019 Research News Bulletin. (vi) JM to pass this invitation to the new Network CDs and NG to extend an invitation to these meetings so that one of them can attend in the future. Duly passed on. DW attended this meeting and Margaret Johnson had sent her apologies. DW said that one of them will endeavour to attend these meetings in the future.	
1. Life Sciences SB had circulated a set of update slides. He confirmed that the LS strategy had now been approved and the Whitechapel site has been specifically mentioned in the Government's industrial strategy. The relocation of treatment centres to an integrated primary care service is a priority and this presents an opportunity to bring together research pharmacy and imaging. The aim is to grow commercial research in new spaces on site. There are a further 2-3 years of planning to go, being together various bits of land and optimising funding streams. The delivery structure covers 5 themes: (i) Research & innovation – work is ongoing as to how this brings in a full range of expertise and disciplines. Specific focus has not been agreed, eg, what does digital mean in this context and how we might make the best use of data sets. (ii) Education & training – this includes vocational training (iii) Digital infrastructure & data – this is the most advanced stream, involving SMD, Barts Health and bids to the Charity (iv) Business development – partnership work is underway (v) Infrastructure – this brings together the other 4 and assesses their requirements for space. RP welcomed this update and asked for any questions. SE asked how this work links with any existing work in relevant areas and how do we best avoid duplication or promote joined-up thinking. SB said that there is a lot of work going on to ensure we build on what already exists. This is a challenge for the Research & Innovation theme in particular. Developing specific aims and themes will help and ongoing dialogue and communication will ensure we capture existing relevant activity within new thinking. JM asked if only having the one NHS contract for commercialisation might slow things down. SB suggested that the single contract might be a positive; the real challenges were probably around the use of data for legitimate purposes, technical standards and governance. **ACTION**: JM to send SB information about the single NHS contract for commercialisation she had received. RP asked if our preferred option is a cost-based use of safe havens for data. SB confirmed that it was.	**JM**

TW asked how the financial model for this works. SB said that the basis is Trust and QM funding, with bids going to the Charity. This will increase with commercial income plus there will be rental income from facilities. RP thanked SB for coming and said he was very welcome to return to future meetings with further updates.	
2. Direct Care Teams MJ presented a paper that is going to the Trust Information Governance Committee in July. She reported that this 'task and finish' group had been set up to prepare guidance about direct care teams. It will then be up to the Tryst to make decisions in this area. There is a direct impact of this work on research nurses and others who will need access to patient data for research purposes. The proposal has been circulated widely and the feedback so far very useful. It appears that 80% of research teams are already following the proposed best practice, but the 20% who are not, include Tissue Bank staff. The proposed onus for implementing the policy sits with research teams (and NB it is not a JRMO policy but a Trust policy!). RP thanks MJ and for this presentation and Kieran McCafferty (not present) for his work on this. He stressed that this is not R&D-led, but is about the Trust's Caldicott Guardian's interpretation of the legal position. He stressed that research teams remain responsible for the data they access and working within relevant guidelines, including this. RP confirmed that once the IG Committee has approved this guidance he will take it to the SMD Executive and explain necessary next steps. There is no desire to shut down research activity, but it must take place within relevant guidelines. MJ commented that it remains essential that research information is presented to patients in a clear way. SE suggested that this not being JRMO-led could be made very clear for SMD. RP agreed this must be the case. There was discussion around the need for competencies to be stated in JDs and CVs on file. Also around the status of Trust managers and that this should explicitly include people on Honorary Trust Contracts. RP stressed that decisions around this need to be pragmatic and proportionate.	
3. Blood sample taking from Healthy Volunteers AS presented a paper of conclusion on this that had emerged from her research audit work. This reported that a situation has arisen, in relation to taking blood samples from colleagues and family for research purposes, that can impact negatively in research quality over time. There have also been allegations of coercion and potential malpractice in this area. AS said that there were 3 solutions to this over-reliance on 'friends and family' blood, these were: (i) Using NHS and Transplant Service blood – totally avoids possible coercion but can be expensive. (ii) Create a volunteer list – often used in commercial labs, but the downside is that	

someone needs to maintain and administer a central list of staff. (iii) Inter-departmental collaboration – in effect, 'friends and family' shared across a department or institute. This requires some organisation but not as much as option (ii). AS said that option (ii) is probably the best fit for QM-BH. RP thanked AS and said that this had come about in response to concerns raised. TW thought that a single cross SMD-Trust system would be useful as would some guidance on basic ethics in this area. There was discussion around possible implicit coercion and use of small, recurring pools giving potentially false pictures. It was agreed that there was no desire for a labour-intensive system but taking blood must follow an agreed process and be ethical. JM commented that labs bleed each other re diagnostic tests (usually figure punctures). GL thought that establishing a list would not be difficult but CC thought there could be costs of that, particularly ongoing maintenance. RP thought that this needed discussion within SMD; the solution must be straightforward and ethical. **ACTION**: AS and MJ will revise the paper on Blood Taking from Healthy Volunteers in the light of this discussion. **ACTION**: RP will take that revised paper on Blood Taking to SMD Executive for further discussion. **ACTION**: MJ will speak to QM Ethics to clarify any concerns around blood-taking from healthy volunteers.	**AS & MJ** **RP** **MJ**
4. Patients in research activity NP circulated a copy of a copy of the summary results of the recent Patients Research Experience Survey (PRES). This annual project had been led by NIHR and core questions are used across the UK with possible local customisation. Data was collected from September to December 2018 and our Network published its report in April 2019 with a national report following in May. The survey sample this year was 8.5k, double that of the 2017 survey. NP said that she has been working with teams to clarify what this data means to them and to work towards this year's targets. An achievable target for this year could be to get 10% of Q1 recruitment enrolled in the survey. She asked that all research leads in SMD and Trust help disseminate this year's PRES and encourage staff to take part and encourage patients to fill in forms. DW said that he was delighted by the local enthusiasm around this survey. RP thanked NP for bringing this along and said that the report needs to go to the Barts Health Research Board (BHRB) in August as Trust buy-in is going to be crucial. He also suggested that the paper to BHRB should focus on the clinical areas in which we do most research. **ACTION**: NG to confirm to NP the date and time of BHRB. **ACTION**: NP to produce a paper on the PRES and present it to BHRB.	**NG** **NP**

5. Data Sharing Policy GL reported that the working group on this had met several times and the draft policy that had been circulated was the outcome. It had become clear during discussions that this was essentially a Trust policy and so it would be drafted accordingly. SMD and other parts of Queen Mary might need something similar but the focus of this is on patient data and, as the University does not have patients, defining methods around this kind of data was specific to the NHS. He reported that there was an additional paragraph being added to cover non-exclusivity, plus other comments that had recently been received. CC said that Queen Mary Business Development needs to know about this. GL said that the initial thinking had been to have a joint policy but the University and Trust have distinct requirements in this area. The Trust focus is on the rules around sharing patient data, whilst the University, of course, has no patients. RP suggested that there be an introduction to the policy setting out why data sharing/ open data is a 'good thing'. That would set the contact and avoid some obvious concerns. GL agreed and said that moving towards a more open post-LSI world the policy may need to be revised further but the important thing is to establish a starting point. AS observed that Appendix 1 (examples of where research data is being shared) is missing. **ACTION:** GL to take the Data Sharing Policy forward to the Trust Policy Group and report back in due course.	**GL**
6. Review of JCRB TORs NG had circulated a draft of the Board's Terms of Reference with some proposed updating. This included some changes in terminology and a revised list of members. He thanked those who had made suggestions and, following a short discussion, this was agreed. **ACTION:** NG to revise the JCRB's TORs in accordance with this discussion and re-publish them on the JRMO website, flagging this up in the next R&D News Bulletin.	**NG**
7. Matters arising from Information Papers AS asked about performance to possible targets. GL said that some of these are being firmed up into formal targets for clinical areas. MJ said that performance is generally improving so this should not be a major problem with continuing focus. GL said there are a number of issues around whether the Network or local areas or the JRMO undertake peer review. RP agreed but said it is wider than that are there are various definitions or understandings of what 'peer review' is: It covers departmental capacity review, scientific review, and institutional review for, eg, sponsorship; all for different ends. He said that clinical boards need to know precisely what they are being asked to do so that the processes can be streamlined and communicated. MJ said that most of the review system is covered by SOPS but some clinical areas, such as	

Medicines, are more problematic through structural complexity, than others.	
8. AOB GL raised some good news of additional funding available from the Research Network, targeted on health needs in key areas. A copy of the information had been circulated and he urged Clinical Directors to get those working in key areas to review whether assistance from this fund might be relevant. The deadline for applications is tight: 27th June.	
9. Next meeting 16th September, BCI Boardroom, Charterhouse Square.	
10. Summary of forward Actions	
(i) NG to ask SB for a list of Life Science Board members.	**NG/SB**
(ii) JM to send SB information about the single NHS contract for commercialisation she had received.	**JM**
(iii) AS and MJ will revise the paper on Blood Taking from Healthy Volunteers in the light of this discussion.	**AS/MJ**
(iv) RP will take that revised paper on Blood Taking to SMD Executive for further discussion.	**RP**
(v) MJ will speak to QM Ethics to clarify any concerns around blood-taking from healthy volunteers.	**MJ**
(vi) NG to confirm to NP the date and time of BHRB.	**NG**
(vii) NP to produce a paper on the PRES and present it to BHRB.	**NP**
(viii) GL to take the Data Sharing Policy forward to the Trust Policy Group and report back in due course.	**GL**
(ix) NG to revise the JCRB's TORs in accordance with this discussion and re-publish them on the JRMO website, flagging this up in the next R&D News Bulletin.	**NG**

NG
25th June 2019