

FW: Confidential enquiry proposed topic

Moore Ruth (UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST)

Sent: 02 May 2014 11:02
To: Carnwell Sarah (UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST); Moore, Alison [Alison.Moore@sath.nhs.uk]
Attachments: image001.png (6 KB)

Hi Sarah
Please put this on the QIPP group agenda - see email below
Many thanks
Ruth

Ruth Moore
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From: Jenny Kurinczuk [jenny.kurinczuk@npeu.ox.ac.uk]
Sent: 30 April 2014 15:02
To: Sanjeev.deshpande@sath.nhs.uk; Moore Ruth (UNIVERSITY HOSPITAL OF NORTH STAFFORDSHIRE NHS TRUST)
Subject: Re: Confidential enquiry proposed topic

Dear Sanjeev and Ruth

Re: Topic proposals for the MBRRACE-UK perinatal confidential enquiry programme:
1. Neonatal Necrotising Enterocolitis (NEC)
2. Kernicterus (bilirubin encephalopathy)
3. Mortality from early-onset Neonatal Infection - Opportunities for improvement

I hope this email finds you both well.

Thank you very much for your interest in the work of MBRRACE-UK and for proposing three topics for the perinatal confidential enquiry which will start in 2015. Your proposals were considered alongside the other 12 proposals (15 in total) which had been submitted, following the three stage process which has been developed by HQIP.

The three topics fared differently along the process and so I will have to describe this in detail for each.

1. Neonatal Necrotising Enterocolitis (NEC)
This topic was only considered during the first stage. This was because of the difficulties which were envisaged in conducting a confidential enquiry for this topic. Some of the issues included the proposal to only consider those babies who received surgery given the variation in practice between centres and indeed surgeons regarding when decisions are made to operate (case definition issues); it was not clear how even using the Badger system we could reliably identify

cases for inclusion (even if we solved the problem of case definition); the evidence base for care is sparse and so we envisaged difficulties in assessing care against standards which are lacking; and finally we are aware of a number of trials and studies which are underway which will inform care but won't report for some time. As a consequence of all of these anticipated difficulties, although obviously this is important topic, we did not think that we would at this stage be able to usefully operationalise a confidential enquiry.

2. Kernicterus (bilirubin encephalopathy)

This topic progressed from the first stage of consideration to the second stage which is the stage at which we discuss in detail the proposed topics with the members of the Independent Advisory Group (IAG) appointed by HQIP and then scoring takes place from which four are considered in the final, third, stage. Although considered an important topic (clearly a devastating and potentially preventable condition in some cases) the issues which were discussed (prior to individual scoring by members of the IAG and the MBRRACE-UK collaboration) were: the likely very small number of cases (based on the incidence estimate you provided this would be about 8 per year); it was not clear to us how we would identify the cases and that a BPSU study conducted over several years seemed the only likely route to case identification.

Given that the scoring is an matter for individuals it is not clear from this stage what factors individuals took into account as they scored, however, once the scores had been accrued this topic was second last. I suspect the small number of cases had some effect on this.

3. Mortality from early-onset Neonatal Infection - Opportunities for improvement

The process of scoring in the second stage leads to the top four topics being selected for the final stage of topic selection where we (the MBRRACE-UK team) consider the four topics in detail and give a presentation to the IAG members as to how a confidential enquiry for each of the four topics might run. This includes the likely burden of disease, the consequences, available standards and so on.

We give a neutral presentation for each of the four topics outlining the relevant issues and the IAG make the decision. The MBRRACE-UK team are not involved in the decision making at this stage (we are not even present in the room) so I am not able to reflect anything of the discussion that the IAG had concerning this topic.

However, what I can tell you is that your topic was not one of the two final topics chosen by the IAG.

Information about the topics which have been selected will be available in the next week on the MBRRACE-UK website (<https://www.npeu.ox.ac.uk/mbrrace-uk/topic-proposals>).

The opportunity to propose further topics will come round again in September when we will again be seeking topic proposals via the MBRRACE-UK website.

Sorry to have to send this disappointing news but I would be only too happy to have a chat about this if you wanted any further information about the process and/or outcome. I hope the information I have provided is helpful as I know that last year's feedback was very limited and this was probably a source of frustration. I hope you find this more detailed feedback more satisfactory.

With best wishes and thanks again for your interest and for taking the time to submit three topics.

Jenny

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