NAHR Working Group Meeting Minutes

Date of meeting : Thursday 3rd October 2013

Venue : ICC Birmingham BOA conference

Present: Marcus Bankes
John Timperley
Tim Board
Tony Andrade
Damian Griffin
Matt Wilson
Max Fehily (by telephone)

Apologies: To be advised by MB

1. Membership of Working Group
    a. It was agreed that Matt Wilson (PEOC, Exeter) would join the group. MW has been involved since the inception of the NAHR and is a keen supporter. It was also recognised that having a regional coordinator in the South-West would be useful

2. NAHR Submission forms
    a. New format
        i. MB showed the group the new format of the NAHR dataset form. This includes 6 pages (1-2 being consent, 3-4 being scores, and 5-6 being the dataset).
        ii. There was agreement that the new form was a significant improvement and the similarity with the NJR would be useful to admin staff and surgeons.
    b. Mandatory dataset
        i. This should occupy page 5
        ii. There was discussion about how minimal this should be balancing surgeon 'buy-in' with useful data.
        iii. It was agreed by the group that CAM, PINCER and MIXED would be combined as FAI in the diagnosis
        iv. DG suggested that recording the details of the operation was open to so much interpretation as not to be useful and for the mandatory dataset diagnosis and demographics would be sufficient at least initially. There was some disagreement about this with concerns that some record of the type of operation performed should be recorded. It was agreed that this could be reviewed.
        v. At the end of page 5 – a comment in bold would be entered to state something like 'You have now completed the minimum

dataset for NICE compliance – You may choose to turn to page 6 to complete the Advanced dataset'

c. Advanced Dataset
    i. This contains the remaining metrics in the original form that we would hope and encourage all young adult hip surgeons to complete.

ACTION POINT – MB will speak to Bluespier about changing form.

3. Follow-up
    a. Bluespier have the facility to follow-up patient by sending them a link to the NAHR allowing them to log on and complete scores. The escalating costs of this in future and non-compliance were discussed
    b. The timings for follow-up was discussed
        i. Too infrequent or too often and patients may disengage
        ii. DG suggested emails at 6 weeks, 6 months to remind people of the NAHR and to keep them engaged with scores at 12 and 24 months suggested in the first instance.
        iii. MW suggested that earlier scores at 6 months would allow earlier feedback reports to surgeons and may help engagement. There was general agreement.
    c. The escalating costs of follow-up in the future may require external funding including, possibly, public money
    d. Sending surgeons outcome reports would help engage surgeons with regular reports detailing 3 and 12 month outcome scores for their patients. Bluespier could do this.

ACTION POINT – MB will discuss with Bluespier to understand the process for patient follow-up and chasing of non-responders.

4. Data entry
    a. It was agreed that patients not having surgery could be entered onto the database and allowed to follow their own hip scores through rehabilitation as with MyClinicalOutcomes.

5. Data entry and Protection
    a. The aim was for surgeons to complete the new forms and pass into the current administrative process for processing NJR forms.
    b. Regional coordinators could assist surgeons with arguments to ensure their trusts remaining compliant with the guidance to submit data.
    c. A major concern of surgeons is that data may be used inappropriately in future.
    d. AJT reassured the group that the data was owned by the BHS with no public money and therefore no FOI requests could be made
    e. There was agreement among the group that it was not possible to categorically say that the registry would never require public money and therefore may come into the public domain. Indeed doing so may loose trust amongst surgeons.

f. The group agreed that it was vital to ensure that data collected was useful and not kept in a way that could be used against surgeons entering data.

6. Launch
    a. It was agreed that as soon as the new form was available it could be downloaded and used by surgeons.
    b. A formal relaunch of the new system was felt to be useful - perhaps at the BHS meeting in February in Exeter.

Date of next meeting – At ISHA meeting in Munich – time and date to be advised.