BRITISH SOCIETY for GYNAECOLOGICAL ENDOSCOPY

December 2013

Dear Endocentre Lead

I am writing with an update of developments in the Endocentre project and to request feedback about planned future developments. Specifically, I write about the following:

- Endocentre meetings in 2013
- End of year Surgery Audit
- Initial data review
- Evolution of the database
- Specialised Commissioning

Endocentre meetings in 2013
We had a very constructive Endocentre leads breakout meeting at the recent ESGE conference in Berlin and there were some very good suggestions made about future developments.

They were so few people able to make the Endocentre meetings planned at the RCOG that it did not justify the room hire costs, so these did not proceed. I will give more advance notice for meetings next year, so hopefully more can attend. There will be a breakout session at the Annual Scientific Meeting in Norwich, so keep this in your diary.

End of year Surgery Audit
Just a gentle reminder that all 2013 data will be audited at the end of December, so please ensure all your cases of surgery for rectovaginal endometriosis that include dissection of the pararectal space have been entered by then. The audit will be completed and published in mid January. Those provisional centres who have reached the criteria (minimum of 12 cases in 2013) will become accredited centres for 2014. Similarly accredited centres who have maintained their numbers will retain their accreditation. If the criteria have not been met the accredited centres will become provisional for one year, whereas a provisional centre would be removed from the list. So please take some time to get your surgery data complete, it won't be counted if added after 31st December 2013.

Initial data review
The initial review of data from 2009 - 2012 has been undertaken and it has given useful information about the quality and completeness of data entry. The data show approximately 400 cases of severe rectovaginal endometriosis being added to the database annually from the current 18 Accredited Endocentres and 22 Provisional Endocentres. This is considerably more than in the early years of the project when there were 131 named Endocentres and only about a 100 cases annually. The higher number of cases has been achieved by a smaller cohort of centres entering more data, which I think represents the evolution of the project and is a great achievement; well done to all.

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We now have reached a stage where many external bodies are interested in the Endocentre project and the data it can yield. It is timely to start analysing the data and producing some output. As you know the standard operating procedures for the Scientific Advisory Group have been established and the centres which entered the most complete data have been invited to nominate a member for the Scientific Advisory Group (SAG). These are (in alphabetical Order):

Chelsea and Westminster Endometriosis Centre
Cornwall Endometriosis Centre
Maidstone and Tunbridge Wells Endometriosis Centre
Queen Alexandra Hospital Endometriosis Centre
The Edward VIIth Endometriosis Centre
UCLH Endometriosis Centre

It is hoped that the first meeting of the SAG will be in early 2014 and this will guide the use of the data and planned publications and audit.

Evolution of the database
The meeting In Berlin and various feedback received over the years have highlighted areas for development. So I would be grateful if you would feedback any views you have on the proposals that are being considered.

To make data entry simpler there is preference to limit the database to cases of severe disease only, and not enable its use for lesser disease. This would include the following groups:

- Rectovaginal endometriosis where the pararectal space is dissected
- Endometriosis that requires opening the bladder
- Endometriosis that obstructs, distorts or invades the ureter(s)

A future upgrade of the database might start by asking which type of case is being entered from the above list and only then would it direct you to the data collection.

The initial data review has shown that not all data fields are completed and therefore fields need to become mandatory entry to stop this happening. Greater use of drop down menus and easier data entry will be used to make data entry as easy as possible.

Long term (12 and 24 month) follow up is hard for centres to consistently achieve and this may reflect difficulty with following patients up in the modern NHS, plus practical difficulties with travel/geography etc. A future database development could use web based data entry that he patient can enter themselves from a PC or a smart phone. There is a project being developed on this at present.

The questionnaire for Quality of Life currently uses a visual analogue score and EQ5D questions. Whilst the VAS should remain it has been suggested that there are better validated questionnaires to use and that we should consider using EHP-30 which is dedicated for endometriosis and widely accepted by the pharmaceutical industry. I would be grateful if you would take some time to have a look at EHP-30 (just Google it) and feedback comments.

Finally, there is the issue of common staging of disease so we can be confident every surgeon is describing the same thing. Suggestions include using a modern scoring system such as the Enzian system. Again, grateful for your views.

Specialised Commissioning

As you are aware surgery for severe endometriosis in England now falls under the remit of specialised commissioning, not local commissioning consortia. This will have an impact and you can expect change as the new systems of NHS England become active. Currently the commissioners have accepted the BSGE model and if you are an accredited centre you will be eligible to provide these services. We need to work with commissioners to ensure that the most appropriate tariff is used for this work as the coding and HRG allocation is not sufficiently sophisticated at present. Further developments in HRG's will feed in better tariffs, so the situation should improve. There are details on tariffs on the BSGE website in the Endometriosis Centres section.

I hope this update is useful. Please send any feedback to the BSGE secretariat where is will be collated for review.

Regards

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Chairman Endocentre Portfolio.