human reproduction

LETTER TO THE EDITOR

## Reply: When is a consensus not a consensus?

Sir.

We are grateful for the interest of Professor Koninckx et al. in our paper and we wholeheartedly welcome debate with such respected colleagues over what we consider to be a key document for women with endometriosis.

It seems to be the opinion of Koninckx et al. that our paper entitled 'Consensus on the current management of endometriosis' (Johnson et al., 2013) is an opinion paper and not a consensus paper. It must be stated at the outset that there is no consensus in the literature as to what constitutes a 'consensus paper'. That our colleagues do not agree with some of the statements does not make this any less of a consensus from the 56 participants of the World Endometriosis Society (WES) Montpellier Consortium, whose affiliations and potential conflicts of interest are fully disclosed in the publication of a process that carried an explicit and rigorous methodology.

The WES Montpellier Consortium represented 34 national and international, medical and non-medical, organizations (from 51 invited organizations—all of those accepting the invitation then nominating their representatives from within their organization to the consortium) from a range of disciplines. We acknowledged that 'a different group of international experts from those participating in this process would likely have yielded subtly different consensus statements'. There was a rigorous and systematic pre-meeting process designed to make the areas covered as comprehensive as possible, a 1-day consensus meeting and a postmeeting process (which included an online survey of consortium participants to refine the level of the consensus over our statements) that is clearly described in the methods section and the supplementary data link of the paper. We adopted a priori the GRADE system (Guyatt et al., 2008) to appraise evidence and the ACCEPT Group consensus grading system to ascribe the degree of consensus around each statement (Kroon et al., 2011). The different disciplines represented spanned five continents and included medical societies, fertility societies, endometriosis organizations representing women who suffer from endometriosis, as well as surgical societies (including the International Society for Gynaecologic Endoscopy, the American Association of Gynecologic Laparoscopists, the European Society for Gynaecological Endoscopy and the Australasian Gynaecological Endoscopy and Surgical Society). We consider that our methodology led to as robust and comprehensive a consensus process as possible and that our methodology sought to minimize bias (that can never be completely eliminated in any process); we leave this to the reader to judge.

It is healthy to debate the merits or otherwise of our more controversial statements and Koninckx et al. have mooted excellent opinions to challenge some of our statements. However, much evidence does

point to endometriosis as being a disease with a high recurrence rate after surgical removal (10-55% at 12 months following surgery, with an additional 10% per year after that) (Vercellini et al., 2009; Guo 2009), although there will inevitably be differences in outcomes based on the expertise of surgeons undertaking laparoscopic removal of the disease, one of the recurrent themes in our paper. We have already highlighted that 'not all women with endometriosis require a large number of experts and some women are treated effectively for the rest of their lives by a single surgical procedure'. We agree that we cannot exclude the possibility that medical treatment for many years without surgery may make the disease worse and later surgery more difficult (although there are fewer published data to support this concept than the concept that disease progression is halted or slowed by longterm medical treatment that might make later surgery less difficult). The poor correlation between the completeness of excision of bowel endometriosis and future persistent or recurrent symptoms might tend to deter surgeons from 'ultra-radicality' in surgery, but, along with a growing literature in relation to deep endometriosis, it supports our statement that 'the best surgical approach to endometriosis is unclear'. We have dedicated three sections of our paper to the efficacy of medical treatments of symptomatic endometriosis; statements 15 and 16 relating to empirical medical treatments, 25-28 to medical treatments and 29-37 to emerging medical treatments for women with symptomatic endometriosis. Koninckx et al. surely cannot be suggesting that randomized control trial (RCT) results should be generally disregarded owing to the difficulty of participant blinding in trials of hormonal treatments. We agree that such blinding is important when subjective outcomes such as pain and quality of life are assessed, but blinding is only one of the many quality features that serve to make the results of RCTs the least biased evidence when assessing the effectiveness of interventions. Without evidence from RCTs, we will struggle to even start to assess the merits of the multiplicity of studies of heterogeneous quality, we are prone to many more biases than are RCTs, and any form of consensus will prove yet more

In highlighting the controversy that remains regarding management of adolescents with endometriosis, management of women with deep endometriosis and the roles of networks of expertise (sometimes referred to as 'centres of excellence'), Koninckx et al. have pinpointed the very areas where we feel that we need to 'drill down' in relation both to improving our evidence base through clinical research as well as debate of such evidence as exists to reach consensus in these areas of clinical care to optimize outcomes for all women with endometriosis. Particularly in relation to deep endometriosis, we welcome collaboration with a group who modestly describe themselves as a 'club of deep endometriosis surgeons', but who represent a strong opinion from the surgical perspective in our field.

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## References

- Guo SW. Recurrence of endometriosis and its control. *Hum Reprod Update* 2009; **15**:441–461.
- Guyatt GH, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P, Schünemann HJ, GRADE Working Group. GRADE: an emerging consensus on rating quality of evidence and strength of recommendations. *BMJ* 2008;**336**:924–926.
- Johnson NP, Hummelshoj L, for the World Endometriosis Society Montpellier Consortium. Consensus on current management of endometriosis. Hum Reprod 2013;28:1552–1568.
- Kroon B, Johnson N, Chapman M, Yazdani A, Hart R, Australasian CREI Consensus Expert Panel on Trial evidence (ACCEPT) Group. Fibroids in infertility—consensus statement from ACCEPT (Australasian CREI Consensus Expert Panel on Trial evidence). Aust N Z J Obstet Gynaecol 2011;**51**:289–295.

Vercellini P, Somigliana E, Viganò P, De Matteis S, Barbara G, Fedele L. The effect of second-line surgery on reproductive performance of women with recurrent endometriosis: a systematic review. *Acta Obstet Gynecol Scand* 2009;**88**:1074–1082.

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