The title is misleading: an opinion paper is not a consensus paper

Sir,

The article ‘Consensus on current management of endometriosis’ by Johnson and Hummelshoj (2013) for the World Endometriosis Society (WES) Montpellier Consortium leaves an uneasy feeling of bias. The conclusions might be partly true considering the highly respected and knowledgeable participants. The article gives the impression that it is based on scientific arguments, but methodologically it is an opinion paper voted by those present. The conclusions therefore only have the value of an educated opinion of the participants, and do not reflect the opinions of those not participating. The conclusions do not represent a consensus on endometriosis and the title therefore is misleading. Indeed, a large number of surgeons involved in treating patients with severe endometriosis were absent since they were attending a deep endometriosis surgery meeting at the same moment.

It is beyond the scope of this letter to question or discuss any specific opinion on which the WES Montpellier Consortium agreed. To highlight some of the underlying biases, however, might be illustrative. ‘Women with endometriosis require individualized care over a long-term period . . . (conclusion 4)’ reflects the view that endometriosis is a recurrent disease. This concept is challenged by the low recurrence rates following adequate surgery of cystic ovarian and deep endometriosis. ‘A multidisciplinary network (conclusion 5)’ is a statement that is poorly defined while no evidence of superiority in endometriosis care has ever been provided. ‘The blind leading the blind’ should be avoided: it is unclear whether it is more beneficial for patients undergoing surgery for endometriosis to be operated on by a pelvic surgeon familiar with the disease and skilled in ureter and bowel surgery or by a gynecologist calling upon the urologist or bowel surgeon when needed. Conclusion 10 surprisingly suggests that severe endometriosis in adolescents should be treated differently. Conclusion 23, that ‘The best surgical approach to deep endometriosis is unclear’, is at least superficial since no distinction is made between a low rectum resection and a sigmoid resection considering the severe long-term side effects of the former.

The absence of some conclusions equally suggests bias. In the absence of data, we cannot exclude that medical treatment of severe endometriosis for many years without surgery makes the disease worse and later surgery more difficult. With the knowledge that in 8% of bowel resections the margins are not free, without documented increased recurrence, a strong argument can be made against the ultra-radicality of bowel resections. Finally, it is surprising that the efficacy of medical treatment is not discussed knowing that there is no medical therapy (except painkillers) with proven pain relief of endometriosis that does not affect menstruation or the menstrual cycle. This indeed makes blinding impossible, which induces bias and questions the results of the many randomized control trials.

In conclusion, the paper by Johnson and Hummelshoj is not a consensus paper but an opinion paper by those participating in the discussion. The conclusions and references are thus at risk of being incomplete with bias, and different from a consensus by a club of deep endometriosis surgeons.

Reference


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 post-meeting 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 long-term 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 emerging medical treatments for women with symptomatic 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 long-term 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 elusive.

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.

References


Neil P. Johnson1,2,3,* and Lone Hummelshøj1

1World Endometriosis Society, 89 Southgate Road, London NW3 3JS, UK

2Repromed Auckland, Auckland, New Zealand

3University of Auckland, Auckland, New Zealand

*Correspondence address. Tel: +44-0-77-1006 5164. Email: wes@endometriosis.ca

doi:10.1093/humrep/det282

Advanced Access publication on July 12, 2013

Consensus on current management of endometriosis

Sir,

We welcome the recent consensus statement from the World Endometriosis Society (WES) on the current management of endometriosis.