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Saunders, Douglas, Thorn, Petra, Savova, Vanya, Baor, Liora, Hershberger, Patricia, Laruelle, Chantalle, Fang, Ma, Maher, Bonnie, Benyamini, Yael, ter Haar, Lies, Indrielle, Tereza, Linkeviciute, Alma, Visser, Marja and Lui, Steve

Routine psychosocial care in infertility and medically assisted reproduction - a guide for fertility staff: External Review Report

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# European Society of Human Reproduction and Embryology

## External Review report



## GUIDELINE : “ROUTINE PSYCHOSOCIAL CARE IN INFERTILITY AND MEDICALLY ASSISTED REPRODUCTION – A GUIDE FOR FERTILITY STAFF”

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REVIEW PERIOD : 04/08/2014 – 30/09/2014

### INVITED REVIEWERS:

#### OPEN INVITATION

1. Slide on the ESHRE website
2. Mailing to members of the SIG Psychology and Counselling as their (primary or secondary interest)
3. Social media (LinkedIn, Twitter and Facebook)
4. ESHRE e-newsletter

#### INVITED REVIEWERS – PERSONAL INVITATION:

1. Coordinators and deputies of the ESHRE SIGs Psychology and counselling and Quality and Safety in ART.
2. Presidents of relevant International organizations
3. President of European and National societies on gynaecology, fertility, or counselling
4. European patient organizations through Fertility Europe

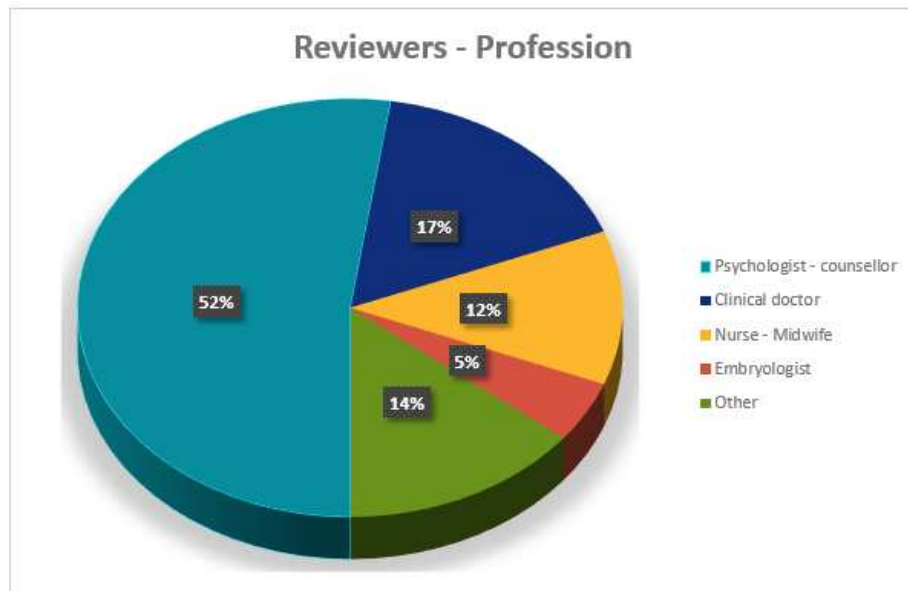
## REPORT ON THE RESPONSE FROM THE INVITED REVIEWERS

42 reviewers submitted comments

### NUMBER OF REVIEWERS PER COUNTRY:



### PROFESSION OF THE REVIEWERS



*Other* : Bioethicist (1) - social worker (1) - PhD researcher/candidate (2) –  
Management (1) – not specified (1)

## LIST OF EXTERNAL REVIEWERS

| Name                    | Country               | Organisation  | Expertise   | COI |
|-------------------------|-----------------------|---|---|-----|
| Douglas Saunders        | Australia             | University of Sydney  | Clinical doctor   | No  |
| Petra Thorn             | Germany               | Private Practice  | Psychologist - counsellor                               | No  |
| Vanya Savova            | Bulgaria              | Sofia University / Nadezhda Reproductive Medical Centre / Nadezhda Wo   | Psychologist - counsellor                               | No  |
| Liora Baor              | Israel                | The Infertility Counseling Group within Israel Fertility Association (IFA)  | clinical social-worker, psychotherapist and researcher  | No  |
| Patricia E. Hershberger | USA                   | University of Illinois at Chicago   | Nurse – Midwife   | Yes |
| Chantalle Laruelle      | Belgium               | erasme hospital, fertility clinic   | Psychologist – counsellor                               | No  |
| Ma Fang                 | China                 | Western China Medical Center, Sichuan University, P.R. China  | Clinical doctor, researcher and teacher                 | No  |
| Bonnie Maher            | Ireland               | Rotunda Hospital; HARI Unit   | Psychologist - counsellor                               | No  |
| Yael Benyamini          | Israel                | Tel Aviv University   | Psychologist - counsellor                               | No  |
| Lies ter Haar           | The Netherlands       | Medisch Centrum Kinderwens  | Embryologist  | No  |
| Tereza Indrielle        | UK                    | University Hospital Coventry and Warwickshire   | private counsellor and hospital O&G doctor              | No  |
| Alma Linkeviciute       | Italy                 | European Institute of Oncology (IEO) and University of Milan  | Bioethicist   | No  |
| Marja Visser            | The Netherlands       | Academic medical center / CVV   | Psychologist - counsellor                               | No  |
| Steve Lui               | UK                    | University of Huddersfield  | Senior Lecturer/ former Embryologist                    | No  |
| Daniela Leone           | Italy                 | University of Milan   | Psychologist - counsellor                               | Yes |
| Danièle Besse           | Switzerland           | Reproductive Medicine Unit (UMR) CHUV, Lausanne   | Psychologist - counsellor                               | No  |
| Lalatte Faustina        | Italy                 | Fondazione IRCCS Ospedale Maggiore Policlinico, Genetic Unit  | Clinical doctor   | No  |
| Adelheid Rigo           | Belgium               | HUB, Hogeschool Universiteit Brussel (Odisee); capus Gezinswetenschappen, Huart Hamoiriaan 136,1030 Brussel   | Psychologist - counsellor                               | No  |
| Hana Gilaie Guinor      | Israel                | Infertility Counseling Group within The Israeli Fertility Association (IFA)   | Psychologist - counsellor                               | No  |
| Marysa Emery            | Switzerland           | Centre de Procréation Médicalement Assistée   | Medical Doctor- psychosomatic and psychosocial medicine | Yes |
| Deborah Lancaster       | Wales, United Kingdom | University of South Wales   | Psychologist - counsellor                               | Yes |
| Nezihe Kizilkaya Beji   | Turkey                | Istanbul University Florence Nightingale Faculty of Nursing (Dean); Nursing Association of Reproductive Health and Infertility/Turkey (founding member) | Nurse - Midwife   | No  |
| Zaira Donarelli         | Italy                 | "ANDROS Day Surgery" Psychology Unit  | Psychologist - counsellor                               | No  |

|                     |           |   |  |     |
|---------------------|-----------|---|--|-----|
| Vera Higi           | Hungary   | Versys Clinics Human Reproduction Institute   | Psychologist - counsellor                  | No  |
| Diana Guerra Diaz   | Spain     | IVI, Barcelona  | Psychologist - counsellor                  | No  |
| Laura Salerno       | Italy     | ANDROS Day Surgery Clinic, Psychology Unit  | Psychologist - counsellor                  | No  |
| Claudia Melo        | Portugal  | Faculty of Psychology and Social Sciences, University of Coimbra                                      | Psychologist - counsellor                  | Yes |
| Stamatios Karavolos | UK        | Newcastle Fertility Centre/<br>Newcastle University   | Clinical doctor                            | No  |
| Laure Camborieux    | France    | /   | Psychologist - counsellor                  | No  |
| Tracey Chester      | England   | British Infertility Counselling Association   | Psychologist - counsellor                  | No  |
| Herborg Holter      | Sweden    | Reproductive medicine, Sahlgrenska University Hospital, Göteborg                                      | Nurse - Midwife                            | No  |
| Cailin Jordan       | Australia | Hollywood Fertility Centre, Perth   | Psychologist - counsellor                  | No  |
| Helena Volgsten     | Sweden    | Uppsala University  | PhD, researcher                            | No  |
| Akiko Mori          | Japan     | St.Luke's International University  | Nurse - Midwife                            | Yes |
| Carolyn Cesta       | Sweden    | Karolinska Institutet   | PhD Candidate in Reproductive Epidemiology | No  |
| Mariana Moura Ramos | Portugal  | University of Coimbra, Faculty of Psychology  | Psychologist - counsellor                  | Yes |
| Stina Järholm       | Sweden    | Department of Obstetrics and Gynaecology. SahlgSahlgrenska University Hospital, Reproductive Medicine | Psychologist - counsellor                  | No  |
| Nicky Hudson        | UK        | De Montfort University  | Other (not specified)                      | No  |
| Charmain Russell    | UK        | CARE Manchester   | Management but former nurse, counsellor    | No  |
| Tanja Tydén         | Sweden    | Uppsala University  | midwife and Professor at Uppsala Univ      | No  |
| Anne Meier-Credner  | Germany   | Spenderkinder, BKiD   | Psychologist - counsellor                  | No  |
| Heribert Kentenich  | Germany   | Deutsche Gesellschaft für Gynäkologie und Geburtshilfe (DGGG)   | Clinical Doctor                            | Yes |

*Other reviewers*

| <b>Name</b>                    | <b>Country</b>  | <b>Organisation</b>  | <b>Expertise</b> | <b>COI</b> |
|--------------------------------|-----------------|--|------------------|------------|
| Wendy Kramer                   | The Netherlands | www.donorsiblingregistry.com   | Unknown          |            |
| Maria Cristina Sousa Canavarro | Portugal        | Universidade de Coimbra, Faculdade de Psicologia e de Ciências da Educação | Unknown          |            |

## METHODOLOGY FOR PROCESSING THE REVIEWERS' COMMENTS

- a) All comments were collected in a single file.
- b) The chair of the guideline development group (Dr Sofia Gameiro) and the research specialist updated the guideline based on the comments and formulated a response to every comment. In case of difficult issues the guideline development group was consulted.

## REVIEWER COMMENTS REPORT

All comments of the reviewers are mentioned below with the response of the guideline development group. Although specifically mentioned in the invitation to the reviewers, a number of reviewers did not use the appropriate form to send in their comments and hence did not declare any potential conflicts of interest. However, the GDG feels that these too are valid comments that lead to improvement of the guideline. To distinguish them from the comments from reviewers that have correctly used the form and declared COI, these comments are summarized in a second table starting from page 57.

Comments are structured per reviewer and per chapter:

*Comments to - I : Introduction and scope of the guideline*

*Comments to - II : Summary*

*Comments to - 1 : Psychosocial care in fertility clinics: patient preferences and wellbeing*

*Comments to - 2 : Psychosocial care before treatment*

*Comments to - 3 : Psychosocial care during treatment*

*Comments to - 4 : Psychosocial care after treatment*

*Comments to - Appendices*

*General comments*

## COMMENTS (FORMALLY SUBMITTED PER PDF-FORM)

| Reviewer         | Chapter | Comments  | Reply   |
|------------------|---------|---|---|
| Douglas Saunders | 1       | Page 12,Line 5. Clinic characteristics: In some places, psychological counselling is mandatory and couples may see the counsellor as a "gatekeeper" or barrier leading to rejection if they are too frank- this needs addressing.<br>Concept of patient privacy needs reinforcing   | Thanks for your comments. The GDG is aware that there is high variability in the way clinics organize the provision of psychosocial support. However, it is impossible within the scope of the present guidelines to address all this variability or to assign or comment on the different responsibilities to different members of staff because these are also dependent on the cultural and legal country contexts. We tried to clarify this in the section Target users of the Guideline. |
|                  | 3       | Page 18, Line 27. Behavioral. Communication between Clinic and Patient , particularly by telephone must be organised so that it is at a private and mutually convenient time.<br>Emotional. Staff should be aware that men and women may react differently to repeated unsuccessful cycles.   | Thanks for your comments. We are unclear about what are you trying to address or which change or correction you are suggesting to be made. This section is purely descriptive; it describes patients' needs and does not present recommendations about how to address them.   |
|                  | General | This set of Guidelines obviously does not address another big psychosocial area - namely the use of donor oocytes,sperm, and embryos. Obviously for another time.   | Thank you, we will try to work on these issues in the future.   |
| Petra Thorn      | II      | page 18, line 28: line 15 from bottom: inverted commas are wrong<br>page 20, last box: bullet point in empty line should be deleted<br>page 22, middle: maybe language improvement: ... of the same age who never UNDERWENT fertility treatment. ....<br>page 23 ff: a formatting suggestion: the numbers 1 2 and 3 etc. in the yellow boxed may look better if the text below is indented. | Thanks for your comment.<br>We have corrected these issues  |
|                  | 1       | page 36, line 289: here for the first time, a word is underlined, should this be the case?<br>Maybe italics would be better to differentiate from a link in the text  | Thanks for your comment.<br>This was corrected  |
|                  | 2       | page 57, line 66: there is a new line here (A significant proportion...), but the line before consists of one sentence only - is the new line justified?<br>page 79. line 782 and 783: again two words are underlined, but they are not active links  | Thanks for your comment.<br>This was corrected  |
|                  | 3       | Page 91 lines 79ff: instead of circles as bullet points, here there are lines (before ,there were circles), dito lines 80 and 81 ff   | Thanks for your comment.<br>We have corrected the mentioned errors  |

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|---------------------|----------|---|---|
|                     |          | <p>page 112, lines 714 ff : here are the circles as bullet points</p> <p>page 118, in the box: both times, "program" has the US spelling, but the document uses UK spelling in counseLLing etc.</p>   |   |
|                     | 4        | <p>page 130, line 354: the term "multiple pregnancy" may be misleading, we are writing about pregnancies with multiples but not several (or multiple) pregnancies. This is similar on page 140, line 554 (in the box), I would recommend looking at how we used the word "multiple" in order to avoid using it in an ambiguous way - it is so closely associated with multiple pregnancies.</p>   | <p>Thank you for your comment. We acknowledge the problem with the term, but think it is clear from the context and could not be formulated in a better way.</p>  |
|                     | Appendix | <p>page 150 and 151: on 150, the active links to the tools are not underlined, on page 151 COMPI is underlines, on 152 they are not. I would suggest to underline all active links, but nothing else in the entire document.</p> <p>page 157: we don't have a professional association for Eline Dancet and Christos Venetis</p> <p>page 158: in the declaration of conflict, the German Society for Fertility CounseLLing should be spelled with LL in both mine and Tewes declaration. You can add in mine: Chair of the German Society for Fertility Counselling.</p>  | <p>Thanks for your comment. These errors were corrected</p>   |
| <b>Vanya Savova</b> | II       | <p>p. 22, line 41: women who experienced multiple failed ART cycles or high stress during treatment may be more likely to experience symptoms of anxiety during pregnancy.</p>  | <p>Thank you.</p>   |
|                     | 4        | <p>My only comment on the guideline topics concerns the issues on attachment during and post-IVF/ICSI pregnancies. The statement, in general, is that post-fertility treatment patients relate to the foetus normally, which is directly linked to the quality of their attachment (Bond and attachment are not one and the same but are related):</p> <p>p. 21, line   : 36 the way couples relate to their foetus is similar when the foetus is conceived with ART treatment or spontaneously.</p> <p>I think that the data on attachment is inconsistent:</p> <p>p. 129, lines: 208 – 217: Antenatal attachment to the foetus: The systematic review conducted by Hammarberg and colleagues included seven papers in which antenatal attachment to the foetus was assessed (Hammarberg, et al., 2008). Four studies found no differences in antenatal attachment to the foetus between women who conceived through ART and women who conceived naturally. In contrast, one study reported that women after ART formed a more intense protective attachment to the foetus during the pregnancy than women that conceived spontaneously, whereas the two remaining studies found that women pregnant after ART delayed preparation of a baby room and had 'fewer conversations' with the foetus. Finally, the review reported similar paternal-foetal attachments between fathers of ART and spontaneously conceived babies.</p> <p>May be we could relate the four studies, stating normal attachment, with the general ART population, having up to 3 cycles. The rest of the patients - with repeated failures (more than 5 cycles), such with multiple spontaneous losses/abortions and egg-</p> | <p>Thanks for your comment. The GDG review the evidence in question and is confident that there is no convincing evidence supporting the idea that people who do fertility treatment (irrespective of its specifics) are more likely to present attachment disorders. Experiencing increased anxiety or concerns is conceptually different from presenting an attachment disorder as defined in the DSM-5 (Reactive Attachment Disorder, only diagnosable in children).</p> |



recipients, pregnant after multiple unsuccessful cycles – clearly do have attachment disorders. It's one of the biggest challenges in the medical doctors' and my daily routine work. The three remaining studies in the paper of Hammarberg et al. (2008) give data about preoccupied and avoidant patterns, respectively.

It's theoretically justified to accept the concept about inconsistent data about attachment instead of normal, secure, etc. The Guideline presents huge data about high and increased anxiety during treatment and post-ART pregnancy. The longer the medical history, the higher the anxiety during pregnancy. We see that high specific infertility-related anxiety and secure attachment are mutually exclusive states. Bernstein and colleagues (2009) report: "The process of transition to parenthood appears to be different among previously infertile women and involves higher levels of anxiety, avoidance behavior, and lack of preparation for taking home a newborn." and daily practice gives evidence on avoidance. (Extreme examples of rejection (from clinical practice) are shock/denial due to positive pregnancy test and wanting to abort.) I don't know which style prevails in previously complicated and prolonged treatment pregnancies– avoidant or preoccupied because I'm researching on the problem, but I'm sure it's not secure.

p. 130, lines 227-230: (McMahon, et al., 2011). Women who had conceived through ART reported a more intense emotional attachment to their foetus than spontaneously conceiving women after controlling for demographic, psychosocial, and reproductive history variables.

Previously, in 1994 McMahon et al. (1997, Hum Rep) report "When IVF mothers were differentiated according to the number of treatment cycles, more differences in anxiety level were revealed, with most increases occurring in mothers who had experienced two or more treatment cycles.", even though the general conclusion is on absence of attachment differences between IVF patients and controls.

As we know from attachment representation studies (Fonagy & Steele & Steele, 1991) maternal representations of attachment during pregnancy predict the organization of infant-mother attachment. Attachment problem is crucial for infertility treatment because it has long lasting family consequences. That's why I propose to pay much more attention to the problem and to clarify the issue through a precise and detailed definition.

I enclose the citations from the Guideline, providing link between multiple failed treatment cycles, pregnancy anxiety and, I suppose, attachment disorders.

Thank you very much for your attention! If you have any interest on the issue of attachment and infertility treatment, I'll respond to any questions, remarks and proposals!

Thank you for inviting me for the review! I look forward to hearing from you! Best wishes!

Dr. Vanya Savova

|                                |   |  |  |
|--------------------------------|---|--|--|
|                                |   | <p>Psychosocial care after treatment:<br/> P.133, line: 340: Fertility staff should be aware that women who conceived with IVF/ICSI may experience more pregnancy specific anxiety than women who conceived spontaneously (Hammarberg, et al., 2008).<br/> P.140, line 550, 551, 552 However, there is some evidence suggesting that women who have experienced repeated treatment failure and high distress during fertility treatment might experience more anxiety during pregnancy.<br/> P. 140, line 554: Fertility staff should be aware that women who experienced multiple failed ART cycles or high stress during treatment may be more likely to experience symptoms of anxiety during pregnancy (Hammarberg, et al., 2008)<br/> P.130, lines: 226-240: more intense emotional attachment (McMahon, et al., 2011); higher attachment (Chen, et al., 2011).</p>   |  |
| <b>Liora Baor</b>              | 4 | <p>p. 129, Line 206: Marital quality was assessed 6 months postpartum. Therefore it should be written: At 6 months postpartum, (and not: During late pregnancy), IVF mothers of twins reported significantly lower.....<br/> p. 132, Line 319, 320: Maternal stress was assessed 6 months postpartum. Therefore it should be written: At 6 months postpartum (and not : During pregnancy), mothers of twins conceived with IVF reported significantly higher levels of maternal stress....<br/> p. 132, Line 324 : Maternal self-efficacy was assessed 6 months postpartum. Therefore it should be written:At 6 months postpartum (and not: During pregnancy), mothers of....<br/> p.133, Line 354: I would like to emphasize that indeed women conceived with IVF had higher prebirth maternal expectations. However, no association was found between these prebirth expectations and postpartum maternal stress. Nonetheless, this finding reflects the women's unwillingness to relate to the prospective birth until healthy twins are borne. In turn, it hinders their ability to prepare themselves to the expected challenging motherhood.</p> | <p>Thank you for this helpful comment. We have indeed misinterpreted the paper. As the current guideline is limited fertility treatment up to the end of the pregnancy, we should not have included your paper assessing women 6 months postpartum. We have removed all the data on the paper, and the recommendation, except for the evidence on maternal expectations, as this was assessed during pregnancy.</p>  |
| <b>Patricia E. Hershberger</b> | 1 | <p>Foremost, I would like to commend the authors of the 2014 ESHRE Psychology and Counseling Guideline Development Group for the document, "Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff." A tremendous amount of effort has gone into the preparation of this document and I anticipate that it will make a valuable contribution. I do have a two comments for the authors to consider that are specific to two sections of the document. They are:<br/> 1. RE: Section 1.1a Fertility clinic staff characteristics (p. 30, lines 80-95)<br/> While I agree the scientific evidence is limited in this area and the authors put forth appropriate recommendations (e.g., prospective studies, differentiation of previous experience with fertility treatment), my colleague (Dr. Karen Kavanaugh) and I completed a qualitative study that addresses issues of quality care in fertility clinics.[1] We found that to provide high quality care, providers should exhibit the characteristics of "being available,</p>  | <p>Thank you for your comments. We have assessed your study, but as it is a qualitative study focussing on donor oocyte recipients; it did not really fit with the PICO question. It is, however, good to see that your results are similar to the studies we refer to. We have added your last point to the recommendations for future research. Regarding your second question, again this study was not selected, as it did not focus on infertile patients. However, we believe your</p> |

|                    |         |  |  |
|--------------------|---------|--|--|
|                    |         | <p>providing communication, exhibiting compassion, demonstrating competency and promoting empowerment” - which support the references in the text in this section. Additionally, we found that if clinic professionals want to provide the highest level of care possible – it is not sufficient to have one of the characteristics such as competency – but all are needed. Research that addresses the behaviors (attributes) of health care professionals and their interaction with patients would therefore be beneficial, too.</p> <p>1.) Hershberger, P.E., &amp; Kavanaugh, K. (2008). Enhancing pregnant, donor oocyte recipient women’s health in the infertility clinic and beyond: A phenomenological investigation of caring behaviour. <i>Journal of Clinical Nursing</i>, 17(21), 2820-2828. PMID: PMC2825483</p> <p>2. RE: Section 1.1.c Psychosocial care components (Page 34-40)</p> <p>I appreciate the review of the literature in this section, however, I would like to interject support for “low-grade” evidence (p. 40) especially when our understanding is limited as in the instance of knowing how to provide high-quality psychological care for fertility patients. For instance, we found that many patients (albeit young women with cancer) did not know what questions to ask health care professionals in-order to determine their preferences.[2] Thus, when counseling patients, it is important for clinicians to anticipate questions and guide education – perhaps more so for younger patients. However, my comment for the committee to consider would be to include language in the recommendations for providers to use anticipatory guidance and take an active role in educating patients.</p> <p>2.) Hershberger, P.E., Finnegan, L., Altfeld, S., Lake, S., &amp; Hirshfeld-Cytron, J. (2013). Toward theoretical understanding of the fertility preservation decision-making process: Examining information processing among young women with cancer. <i>Research and Theory for Nursing Practice</i>, 27(4), 257-275. DOI: 10.1891/1541-6577.27.4.257. PMID - In Progress abstract</p> <p>I do thank-you for your time toward improving care for our patients worldwide and for considering these comments.</p> | <p>point is relevant, and we will take this into account when updating the guideline.</p>  |
| Chantalle Laruelle | II      | <p>P15: relational and social needs, line 9/10/11. Active confronting strategy of coping is associated with higher fertility specific marital and social distress. It is not clear how this way of coping differs from emotional expressive coping which is associated to lower infertility distress ( p19 , emotional section, line 16/17) as expressing feelings is mentioned in both cases.</p>   | <p>Thanks for your comment. We are not sure what your concern is. After a more careful analysis of the studies, we decided to remove the emotional coping. Although the effect is there it is only men who are distressed when their partners engage in this strategy.</p> |
|                    | 1       | <p>p31, line 99: the word "patients" is missing.</p>   | <p>Thank you, this was corrected.</p>  |
|                    | General | <p>I have seen nothing about patients from other cultures. These patients are sensible to the efforts of the team to take religious, cultural and language differences into account. Of course this is not specific to infertile patients but, for example, African couples value the choice of a donor not only of african origin but from the same ethny if possible.</p>  | <p>Thank you for your comment. We have decided, to limit the extend of the document, to limit the guideline to the “infertile patient”, and to exclude specific</p>  |

|                |         |  |  |
|----------------|---------|--|--|
|                |         |  | groups of patients with distinct needs. The latter can be described in further ESHRE guidelines.   |
| <b>Ma Fang</b> | I       | <p>Page 1:<br/>Title: the concept of "infertility"----can we express the points:"parenthood wish",and "long-term "</p> <p>Reason:infertility, normally seen as a private and sensitive matter, if we want to this population to see the doctor actively for psychosocial care , who just havn't the baby temporarily, which we might weaken "the concept of infertility", also, as we know having a baby needs time and patience,so, they need the long-term care."</p>  | <p>Thanks for your comment.</p> <p>We think you made a valid point. After consideration, we have decided to keep the title as it is, as we think medical staff at fertility units would relate more with it.</p> |
|                | I       | Page 6,Line 3 "offers best practice advice"--- "best" as"impactful"---more better?   | <p>Thanks for your comment.</p> <p>In general, guidelines offer best practice advice, so we have not changed this.</p>   |
|                | I       | Page 6,Line 4,5 that enables patients, "spouses (added is better?)   | <p>Thanks for your comment.</p> <p>In response to this comment, we have changed "patients" to "couples"</p>  |
|                | II      | <p>Page 12,Line 5: Staff characteristics---" Knowing the needs of the reproduction knowledge"(added is OK?)</p> <p>Page 13 Line 10:Staff and clinic characteristics--"smile service, optimistic supports(encouragement, positive case example share, personal and friendly care, long-term concern"(add ed is OK?</p> <p>Page 14, Line 17: Behvioural---"Explanation for asking the excessive medical intervention "(add ed is OK?</p> <p>Page 15, Line 20:"women whose partner has male factor infertility experience higher anxiety than women with female factor, mixed or unexplained infertility, whereas type of infertility diagnosis is not related to depression. "-----Based on our experience unexplained infertility is more depressed for the people for the no specific medical intervention to perform.</p> <p>Page 17,line 23,"actively involve both partners of the couple in the diagnosis and treatment process." --add "family"</p> <p>Page 18,line 23 "during an IVF/ICSI cycle 6 in 10 patients report treatment related absences from work and, on average, patients miss 23 hours of work." ---- "miss 23 hours of work"- a little confused to me, is that 24 hours?</p> | <p>Thank you for your comments. We have tried to incorporate them when appropriate.</p>  |
|                | General | This is a practical and detailed guideline for the clinician and staff for infertility center, also for the counsellor and social worker who make efforts to help the people who want to have the baby. Moreover, much more concerns on the comprehensive care for such this population, the guideline make it more professional and documental. On my opinion, it's useful for us combining with the local condition and social culture.  | Thank you for your comment.  |

|              |    |   |  |
|--------------|----|---|--|
| Bonnie Maher | I  | P6, L16-17 & 26: Contradictory. Who decides between 'most' and one fifth?   | Thank you. The evidence shows that only 20% experience clinical significant problems (i.e., above the clinical threshold for a mental health diagnosis.  |
|              | I  | P9, L110 & 120: Contradictory. Detailed and clear guidance IS specialised training.   | Thanks for your comment. To resolve the possible contradiction, we have added a definition of specialized training (i.e., as part of degree or post-graduation course...).   |
|              | I  | P9, L114: Is this a misprint? Clinic staff members are NOT "non-specialised mental health professionals". They are professionals in their given professions.  | Thank you for your comment; we have rewritten this section to address your comment.  |
|              | II | The summary is excellent if obvious and self-evident. It highlights what should be common practice in dealing with the care of patients. However, it also highlights the essentials role of mental health professionals. Every staff member has a duty of care within the parameters of each one's expertise.   | Thank you  |
|              | 1  | P12, L5: patients want "...services from mental health professionals..." P13, L13: "...may improve...stress..." Another misprint? A "decrease in ... stress" is reported on P48, L650. Given the range of materials and mixed results, it is unfair to dismiss complex interventions. It may be the studies were not useful. E.G., expressive writing is not a quick fix but an ongoing practice. | Thank you for your comments. The expression "improve stress" is meant as "making it better", so it is not contradictory. We have re-assessed the paragraph, but feel this should not be adapted. We agree that dismissing "complex interventions" may seem unfair, but the existing studies, which we evaluated as being of appropriate quality, conclude that the currently available interventions are not efficient; Maybe some longer- term studies on expressive writing will show benefit in the future. |
|              | 2  | P15, L20: Appendix 2 is an exhaustive list of psychological measurement tools. P16: To expect staff to have time or energy to use these ir the expertise to evaluate them is impractical and unrealistic. To expect patients to have the patience to wade through them is cruel. To then inform them of their emotional adjustment before treatment is presumptuous.                              | Thank you for your question. The goal is not to use ALL measures with ALL patients but use them as convenient. The only measure that we are advising to use in routine care is the SCREENIVF However, it should be noted that by using these measures one can actually be decreasing consultation time because they  |

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|                |         |  | can be used to identify major difficulty areas and only these will need to be explored in more depth  |
|                | 3       | There is the repeated recommendation to utilise the tools in appendix 2. These psychological tools should only be used by psychology professionals. However, this section provides good advice and sound information.  | Thank you. The tools can be used by clinicians, although interpretation is not always straightforward. We will modify this.   |
|                | 4       | There are obvious gaps in this section which is understandable for those who are 'successful'. Whatever about the need for research, it is important to emphasise the need and duty of care for clinics to maintain contact with couples post treatment. The breakdown into four areas in each of the above sections is helpful.   | Thank your for comment. The comment on clinic obligation to maintain contact with couples post treatment has no supporting evidence and is questionable due to feasibility  |
|                | General | P24-27: 1. Common sense: should be the aim of everyone who deals with the public.<br>2. Referral to mental health professionals combats the 'intense distress' of unsuccessful patients.<br>3. P25: Experienced staff members who deal with patients on a daily basis do not need questionnaires to identify those more anxious and vulnerable.<br>4. P26: Providing information should be "...fairly simple and feaisvle to implement..." So should recommendations to all staff for psychosocial care. This draft blurs the boundaries between groups. All staff should relate to patients as human beings with psychosocial needs, but the support advocated necessitates the input of mental health professionals. | Thanks for your comments. We acknowledge that some of the recommendations are known and common practice in some health care settings. The GDG is sensible to the comment about the lack of role definition. Although we consider that we cannot dictate how clinics should organize their staff in order to meet the guidelines (especially because this is also constrained by cultural, social and legal factors), we did try to address this comment in the introduction by clarifying on different issues (e.g., psychosocial care, specialized counselling, psychotherapy, specialized mental health training, etc.) |
| Yael Benyamini | 2       | Page 77, line 716: The guidelines provide very limited information on women's ways of coping with infertility and its treatment and some of the information differs from other findings in the literature (e.g., active coping has also been found to be related to MORE stress, see reference below):<br>Benyamini, Y., Gefen-Bardarian, Y., Gozlan, M., Tabiv, G., Shiloh, S., & Kokia, E. (2008). Coping specificity: The case of women coping with infertility treatments. <i>Psychology &amp; Health, 23</i> (2), 221-241. doi:10.1080/14768320601154706  | Thank you for your comment. We have assessed the paper, but it was not included in the guideline <b>because the patients are at different treatment stages. Coping strategies will differ in their effects according to the stage patients are undergoing.</b>  |
|                | 3       | The guidelines do not refer to women's perceptions of infertility, that may guide their ways of coping and are related to their well-being and distress:   | Thank you for your comment. The studies were excluded as they include patients at different treatment stages, while we  |

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|                  |          | <p>Benyamini, Y., Gozlan, M., &amp; Kokia, E. (2004). On the self-regulation of a health threat: Cognitions, coping, and affect among women undergoing treatment for infertility. <i>Cognitive Therapy and Research</i>, 28(5), 577-592. doi:10.1023/B:COTR.0000045566.97966.22</p> <p>Furthermore, when referring to couples, it is important to attend to both partners' perceptions of infertility and to their congruence - incongruent perceptions affect women's distress more than men's:</p> <p>Benyamini, Y., Gozlan, M., &amp; Kokia, E. (2009). Women's and men's perceptions of infertility and their associations with both partners' psychological adjustment. <i>British Journal of Health Psychology</i>, 14, 1-16. doi:10.1348/135910708X279288</p> | <p>included only studies looking at patients before treatment, during treatment, or after treatment.</p>   |
| General          |          | <p>1) The guidelines do not refer to the great variability among women (and probably men too) in their needs. Without awareness to this issue, professionals might form a "stereotypical" view of the needs common to women undergoing infertility treatment and be less sensitive to the unique needs of each woman, which could greatly differ from those of other women. Benyamini et al., 2005, is cited for its research instrument, not for the findings that clearly show that women so greatly differ from one another in their needs.</p> <p>2) The role of mental health professionals and their unique contribution is not clarified well enough.</p>   | <p>Thank you. We believe that the guidelines do address this issue. While the sections what are the needs... describe the common needs of patients (i.e., group variability), the sections about detecting needs address individual variability by identifying risk factors for such needs, which allows to profile more vulnerable patients. This is described in the scope of the guideline. Regarding the role of MHPs, the guidelines make it explicit that routine psychosocial care can be delivered by all staff that has contact with patients (including MHPs) and that counselling and psychotherapy should only be provided by MHPs. (see also SIMILARITIES AND DIFFERENCES WITH PREVIOUS GUIDELINES)</p> |
| Lies ter Haar    | 4        | page 136 / line 429: 2x "refers to" in stead of 1x   | <p>Thanks for your comment. This error was corrected</p>   |
|                  | Appendix | page 161 / line 105: "psychologists" in stead of "psychologist"  | <p>Thanks for your comment. These errors were corrected</p>  |
|                  | General  | Good work!   | <p>Thank you.</p>  |
| Tereza Indrielle | II       | "patience may value presence of chaperone" based on the study of Ouj et al (2011) from rural Nigeria. My first comment is on relevance of such study in the European guidelines, applicable to European countries. Also the scope of the study was perception of vaginal examinations and not preference of chaperone, nor was anything mentioned in their conclusion about chaperone.   | <p>Thanks for your comment. We agree with it. There are no studies on the preference for a chaperone in the ART setting, nor are there studies on for instance male patients preferring designated rooms. However, based on clinical experience, the GDG</p>   |

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|                          |                          | For example General Medical Council in the UK specifies: "8. When you carry out an intimate examination, you should offer the patient the option of having an impartial observer (a chaperone) present wherever possible. This applies whether or not you are the same gender as the patient. "   | decided that it would be helpful to provide such services to patients, and wrote a "clinical expertise"-based good practice point. The reference of the Ouj paper is added as this may add some indirect evidence supporting the good practice point. We did not exclude papers based on country.  |
| 2                        | line 132 Emotional needs | I found an interesting paper on other aspects of emotional needs/characteristic of the infertility subpopulation, aside the well-evidenced depression and anxiety. There is evidence that women entering IVF are more suspicious and show greater levels of guilt and hostility than fertile controls (Csemiczky, Landgren& Colling, 2000). Csemiczky G, Landgren BM, Collins A (2000). The influence of stress and state of anxiety on the outcome of IVF-treatment: Psychological and endocrinological assessment of Swedish women entering IVF treatment. Acta Obstetricia et Gynecologica Scandinavica 79(2): 113-118.  | Thank you for your comment. We limited the outcomes assessed in this guideline to psychosocial care components (emotional impact, social impact, education, ... ). There are a number of studies evaluating the impact of psychosocial aspects on the outcome of IVF treatment. These were excluded, but may be relevant to add when updating/rewriting the guideline. |
| General                  |                          | Very concise and well structured guidelines. I very much liked the uniformity of the main sections.   | Thank you.   |
| <b>Alma Linkeviciute</b> | I                        | It is explained clearly and provides a user with a good grasp of what guideline will address. My concern is the references which might be pointing out the best experts in the field like Aarts, Boivin, Gaimero, Verhaak, but for more scrupulous user it might give an impression that some kind of a monopoly of opinions is being used. For a fully informed counselling practice I would like to see a wider list of references where authors of quoted papers are not co-authors of subsequent references, just to make sure a more pluralistic view is given.  | Thank you for your comment. We have added references where appropriate.  |
|                          | II                       | CONCLUSIONS AND CONSIDERATIONS starting with page 24 has a very clear layout and is easy to read and understand while previous part LIST OF ALL RECOMMENDATIONS with a table is not user friendly at all. 'Fertility staff' notion is clear but not very elegant use of English. It is not always clear what is the recommendation for fertility staff to be aware of and what is collection of information from the literature. I would see LIST OF ALL RECOMMENDATIONS as a quick guidance manual to review the points to be aware of but as it is presented now it is more confusing when clear. Limiting the repetitive use of 'fertility staff should be aware of' could help to improve the body of this important section as it might be the only part of the guideline read my many to whose work it is relevant. | Thank you for your comment. We have tried to improve the "list of all recommendations"   |
|                          | 1                        | Line 99, the word 'patients' is missing. Recommendations are very clear and its significant strength is the level of evidence stated.   | Thanks for your comment. We have corrected this error.   |



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|                     | Tables are more harder to read and understand without reading the text in detail before hand. It could be beneficial for the future users if tables were made more 'stand alone'. However, I appreciate that tables give a good summary of the most important information.  | We agree that the tables should be “stand-alone”, we have tried to ameliorate them.   |
| 2                   | In general tables are not very clear. I had a problem understanding if they provide summary for the literature review or points to be aware of for fertility staff. Add short explanation under each table would help the reader.   | Thank you for your comment. We have tried to clarify the tables.  |
| 3                   | More concise summary of each question would be very helpful for a busy reader. For instance, a table listing psychosocial needs and shortly explaining each of them would be more accessible information than going through the text in search for relevant information. I would strongly suggest to rethink the structure how information is presented!  | Thank you for your comment. This document will be the basic document for people wanting to know how the recommendations were developed and whether they are evidence based. For the busy reader, implementation tools / summary documents will be developed.  |
| 4                   | The same as previous sections. Improve the clarity and representation of the contents.  | OK  |
| Appendix            | Page 167, line 271: 'questions important to questions', most probably should read 'questions important to patients'.<br>Appendix 2 provides an extensive list of tools found while reviewing a literature. Does guideline recommend any of them? I am very doubtful that fertility staff will find the list of tools useful overall. However, improving the clarity with more clear summaries of recommendations and also explaining what tables represent might make it more readable and hopefully beneficial for more professionals working in a field of fertility. Moreover, appendix 2 could be enriched with adding tools for ethical decision making.   | Thanks for your comment. These errors were corrected, and an introduction was added to appendix 2. Based on several comments, we have shortened the list of tools in appendix 2 to those that are specific and usable by fertility clinic staff.  |
| General             | In its present form the guideline looks more like research thesis work or awareness raising campaign than a guideline for professionals. It is repetitive and not very clear what the actual guidelines for high quality care are. Just stating that 'fertility staff should be aware of' does not mean that having awareness about certain facts will help to improve the service for patients. Guideline does not seem to offer concrete tools for fertility staff on how to implement the awareness proposed by the guideline in their clinical practice.<br>For future guidelines I would look forward to include more emphasis on ethics, ethical counselling and some mentioning of oncology patients, especially fertility preservation for children and adolescents as they are unique group and adult recommendations does not always work for counselling them. | Thank you for your comment. This document is extensive, and many parts are probably valuable to interested readers only. We will work on implementation tools to increase usability. Indeed, there is a lack of concrete tools for staff, but this is due to a lack of evidence in many areas of the guideline. |
| <b>Marja Visser</b> | I<br>L5. Preferable: Ps and social implications instead of consequences<br>L58. emotional well being etc. + loss/mourning<br>L61. Is this not the diagnostic period- pre-treatment period.<br>This is including all uncertainty etc.<br>L63. IUI is also ART and not separate next to ART   | Thank you for your comments. Based on them, we made some changes in the text. We have not changed IUI and ART, as IUI is part of MAR, but not of ART, according to the definitions of Zegers-Hochschild 2009  |

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|                  |         | L64: I don't understand why the 'after treatment' periods starts after 1 year  |  |
|                  | II      | A bit a pity that some things only seem important for IVF treated people and not for ART-total group   | Thanks for your comment.<br>The recommendations on IVF treated patients are deducted from studies that only included IVF patients. One could expect that the same recommendation can be made for non-IVF fertility treatment, but no studies have been conducted so this would be interpretation and speculation.<br>We have raised this issue in the summaries of evidence and will add it to the research recommendations. |
|                  | 2       | L28: first word; form instead of from (page 56)<br>I appreciate the recommendations for the fertility staff!<br>For me it is unclear what 'cognitive needs' are.<br>Page 63: "healthawareness"<br>Page 77: "knowledge"<br>Page 85: include knowledge<br>What are these cognitive needs?  | Thank you for your comments, we have corrected the errors.<br>Cognitive needs include knowledge and concerns. The differences you quote are because not for each section on in   |
|                  | General | Worthwhile document, a kind of overview of studies in the field of psychosocial care in ART. Systematic and carefull.<br>All in all it's a long document. When fertility staff wants to use it, they need wome time to read, though with the clean content as help.  | Thank you.   |
| <b>Steve Lui</b> | I       | The group has provided comprehensive recommendations for fertility staff providing PSC for fertility patients.   | Thank you.   |
|                  | II      | P.21 and 22 Missing descriptions in the behavioral, emotional and cognitive boxes, may require statements.<br>If the patients were unsuccessful with their IVF treatment why is there a section entitled " Pregnancy after treatment". These sections were unclear. Should line 34 read " What are the needs of patients after treatment?" Should line 39 read "How can fertility staff detect the needs of patients after treatment?" | Thank you for your comment. We have added a footnote explaining the empty boxes.<br>We have also corrected the key questions as suggested.   |
|                  | 1       | P.29 line 56 Positive attitudes from staff - please define staff group.  | Thanks for your comment.<br>We changed this to physicians' attitude.   |

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| 1 | P. 32 line 123 Provision of counselling to be consistently important - once again by who - nurses?   | Thanks for your comment.<br>This sentence is explanation of previous sentence where it is stated "counselling/emotional support by MHP"   |
| 1 | P.32 line 135 Is the word " No " correct or should it read " A number of " ?   | Thanks for your comment.<br>We have changed "no" to "none of the"   |
| 1 | P.45 line 554 RCTs were reported in table - could meta-analysis be performed on these trials. Meta-analysis might be able to provide an overall effectiveness for these interventions.   | Thanks for your comment.<br>Although a meta-analysis is not really in the scope of guideline development, it could be useful. However; in this case, the interventions are different and the outcomes are assessed differently in the RCTs making a meta-analysis complex and probably not very relevant. |
| 2 | P.60 line 169 Shindel found depression is more prevalent in male partner, line 183 Kumbak found higher state of anxiety in men and line 232 men scored significantly worse in general wellbeing. The mental health of the male partner is highlighted , however not included in the recommendations section, line 242.<br>P. 76. line 676 suggests that SCREENIVF could be used to identify emotional maladjustment. The recommendations line 712 need to state clearly which staff should carry out the SCREENIVF and how to interpret the results. Staff would require clear guidance and training on the usage and its implications upon clinical practice. | Thanks for your comment.<br>We agree with your second point. However, information on using and interpreting SCREENIVF would maybe be more relevant in an implementation tool, than within the guideline.  |
| 3 | This section omits consideration to the psychosocial care for those patients how were not pregnant 4 weeks after the pregnancy test.<br>P. 95 line 167. It will be useful to know the sample size of this study.<br>P. 96 IUI and AI terminology should be used consistently throughout the guidelines.<br>P. 97 line 222 and 223 should read "cut off " and not cuff off.<br>P.118 I think embryologists are not trained to delivery emotional support for patients. They will need to have more training.  | Thanks for your comment.<br>We have corrected the errors, and added information on miscarriage after fertility treatment in the introduction.   |
| 4 | I could see the authors rationale for not including patients immediately following treatment, however I think clinically they are the patients who need psychosocial support. The guidelines may require a more inclusive approach.<br>p.128 line 167 I think it should be "weekly" not "weakly".  | Thanks for your comment.<br>We agree with this comment. However, we have included reactions to a negative treatment in the during treatment period, and we also included pregnancy and then the unsuccessful group. Therefore, the excluded patients are those who did                                    |

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|                      |   |   | unsuccessful treatment and are considering whether to continue or stop treatment. We have corrected the second comment.  |
| Appendix             | P. 147 line 6, 38, 41, 83, and 91. Some references are incomplete. I found Appendix 5 contains important recommendations for researchers. I am unclear with the search strategy (e.g. the key words used and the boolean logic employed by this guideline).   |   | Thanks for your comment. These errors were corrected   |
| General              | I am concerned about how these guidelines would be implemented by the clinics and how would the implementation be overseen and scrutinised. These guidelines require a definition of the phrase " fertility staff". I feel the guidelines should encompass all personnel working within an infertility setting. The administrative staff are very important and they will require additional training to ensure they are able to work in a professional manner whilst ensuring they exhibit care and empathy towards patients and partners.<br>The PSC provided by embryologist cited in this report is a rare clinical occurrence in my experience. The ESHRE Embryologists Meeting 2014 and British Fertility Society Meeting in 2015 do not contain any presentations relating to psychosocial patient care therefore many embryologists are not equipped to provide PSC for fertility patients. Shenfield et al in the ESHRE Good Practice Guide suggests an ombudsman is required to monitor clinical adherence. I would suggest this guide should also suggest if clinics do not provide PCS how could their patients redress this important issue. |   | Fertility staff are defined in the section TARGET USERS OF THE GUIDELINES as follows : fertility clinic staff (doctors, nurses, midwives, counsellors, social workers, psychologists, embryologists, and administrative personnel) that have contact with patients and can deliver routine psychosocial care and/or make referrals to specialised mental health services (i.e., counselling and psychotherapy).<br>Regarding your second point, this guideline is written for fertility staff. We will write a patient version, and will consider including this information in the patient version. |
| <b>Daniela Leone</b> | General   | The document seems to collect very useful suggestions for physicians regarding difficulties the patient/couple may experience during the different phases of the clinical course in medically assisted reproduction.<br>We found a little bit vague the suggestions of the necessity of a "good communication" the clinicians should use. We would suggest to add a section – or may be more than one – regarding specific communication and relational skills physicians may find useful to manage difficult conversation as the conversations that occur in medically assisted reproduction . Only as an example, the doctor is often involved in clinical encounter in which he/she has to communicate a bad news (e.g., the transfer is not possible). Medical literature offers some precious suggestions to facilitate the patient comprehension of the news and the rapport building also in the case of a bad medical information to be communicate (think about the breaking bad news protocol by Baile et al., 2000). These practical communication strategies could be declined for the PMA context, and exemplified through real conversations transcripts in order to offer a practical guide for clinicians. We notice that this is a lacking point also in medical literature in this field: to our knowledge, only one theoretical contribution appeared (Lalos, 1999) and no one experimental study has been published | Thank you, we agree that the information on communication could benefit for more explanation and more specific recommendations. However, this is not possible to do in an evidence-based way. If there were protocols/interventions on how to deliver bad news that were tested in an infertile patient population then we would have cited and evaluate such work   |

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|               |          | <p>about doctor-patient communication in medically assisted reproduction, but it is clear the importance of having reflection and data about this issue.</p> <p>Baile, W. F., Buckman, R., Lenzi, R., Globler, G., Beale, E. A., Kudelka, A. P. (2000). SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer. <i>Oncologist</i>, 5, 302-11</p> <p>Lalos, A. (1999). Breaking bad news concerning fertility. <i>Human Reproduction</i>, 14, 581-5</p>   |   |
| Danièle Besse | I        | Very clear, very well, useful for the staff  | Thank you.  |
|               | II       | Very clear, very well for the staff. I would add maybe the notation of the studies such as it is made in the detailed guideline (A, B, C, GPP), to give the pertinence of recommendations. The recommendations of the GPP help to summarize what is important when there is too much recommendations "Fertility staff should be aware of....".<br>(Only page 28, an asterisk of excess at the end of the line 27, "relational and social")   | Thank you. We have added the levels of evidence in the summary table and corrected the mentioned error.   |
|               | 1        | Pages 35-39: summaries very (too much?) in detail ?  | Thank you for your comment. We have tried to limit the amount of information, and have added a summary to increase readability.   |
|               | 2        | Page 76: "Fertility staff should be aware that SCREENIVF is a pre-treatment infertility-specific validated tool to assess risk factors for emotional problems after treatment cycle" should be put on line 719, page 77, instead of page 76, line 712, accordingly to the summary page 16.   | Thanks for your comment.<br>This was corrected in the tables.   |
|               | 3        | Very long, and impression of repetitions due to the division BREC...but is it possible to do it differently?   | Thanks for your comment.<br>We have written each chapter as a stand-alone chapter. The summary and implementation tools should help to make the guideline more usable   |
|               | Appendix | All the appendices are useful to understand the method.<br>The tools, especially the SCREENIVF seems to be practical and useful for the staff.   | Thank you   |
|               | General  | Thank you for all this very detailed work! I am impressed!<br>First I expected a specific guideline for counsellors, as was the former guideline. But then, in ESHRE Munich, I understood the approach, and I appreciated this new guide without ulterior motive.<br>This guide is certainly very useful for the future researchers who will have from now on the criteria to make a valid study ( A ).<br>For the fertility staff and clinical, certain chapters as "Introduction and scope of the guideline", (p. 6-11)," the list of recommendations" (p.12- 23,) and the "conclusions and considerations" (p.24-27) will be especially useful. Sometimes too many recommendations... | Thank you!<br>We are aware that the summary will be used more than the rest of the extensive document. The main reason for the extensiveness is to be able to show interested readers how the recommendations were derived from the evidence, or written due to the lack of evidence. This is important to ensure the document is perceived as trustworthy and implemented. |

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|                         |    | <p>The reading may be difficult (p 28-144) due to the detailed summaries (short or long) and the quantity of recommendations...(But is it possible to do it differently?).The recommendations of the GPP help to synthesize them.</p> <p>The detailed references will be useful for other studies, and for the staff, to optimize fertility treatment and justify new management to take care of the social and psychological consequences of an infertility treatment.</p>   |  |
| <b>Lalatte Faustina</b> | I  | <p>pag.6, line 3. It is clear and well described that guidelines are for fertility staff in order to increase patient wellbeing before, during and after treatment. The relevance of psychological implications within this specific field is well described but it is stated several times with similar words. Is repetition necessary? (line 3-36-40-47..)The change of focus of the present guidelines is very clear compared to previous ones. Methodology is complex but well described.</p>   | <p>Thank you for your comment. We are aware of repetition in this document, as we aimed to have each section as a stand-alone text. We have tried to reduce the amount of repetition.</p>  |
|                         | II | <p>This section is the most useful one. I strongly support the choice which has been made to keep the same structure (what are the needs, how to detect and how to address those needs), for the different "times" of treatment. It is very clear and complete. Reader must be motivated and supported to consider every step and all the different issues.</p>   | <p>Thank you.</p>  |
|                         | 1  | <p>pg.29, line 26. The statement "The aim of identifying the clinic characteristics that are important to patients during their fertility care is to reinforce these aspects in order to enhance the quality of clinic's patient-centred care" is crucial in the perspective of quality of psychological aspects of Infertility clinic, which is not addressed everywhere. Is this aim among the recommendation of quality standards in all European countries?I am not aware of such a quality standard in Italy.</p>  | <p>Thank you for your comments. The guideline aims to set a minimum quality standard. They intend to influence practice across Europe and should provide guidance for quality standards for different countries to consider, despite socio-cultural differences.</p>   |
|                         | 1  | <p>pg 30, line 73 what patients value about staff (i.e.good attitude, meaning attention, respect, courtesy, empathy, and understanding) is universal, not only related to infertility and should be made a general requirement of Health Services which also includes Fertility Clinics where the length of treatment makes the expectations deeper.</p>  | <p>Thanks for your comment. We agree that the staff qualities that are valued are not specific for the ART setting, but as this guideline is written in general for the ESHRE audiences, this will be the people reading and using the guideline</p>   |
|                         | 1  | <p>The "clinical evidence of this section is impressive. It is impossible to evaluate and have an opinion about the numerous studies which are reported. (pg 34 and following). pg 40. Research recommendation indeed underlines these limits (dishomogeneous studies). pag 40 line 441 : very interesting to view the interventions, which are delivered by fertility staff to one or more patients in an interactive context and self-administered interventions. The section is somehow lengthy even though the conclusions are very clear and simple. I believe that one crucial point will be the staff compliance with the "heavy" structure of the clinical evidence section. Who is going to read it and make it a professional tool?</p> | <p>We agree that the guideline is extensive and probably very few people will have the time or take the effort in reading the entire paper. The aim is to provide useful recommendations accompanied with all information necessary to trust the origin of the recommendations. We will work on tools to improve implementation of this document, which will remain the "basis."</p> |

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| 2        | <p>pg 56 and following. Patients needs are presented in a very detailed and analytical manner. Maybe this section could be simplified. I believe that the fertility staff might have difficulties in getting the differences between the several categories of needs. Maybe they can be grouped. I also find too analytical the section described in pg 64 -88. It is difficult to get the real differences and similarities of the numerous sections and the information for staff is, in my opinion, too diluted and difficult to appreciate and transform into good clinical practices</p> | <p>Thank you for your valid comment. We agree that the guideline describes all the evidence in depth, and we consider this necessary to ensure that the reader sees the evidence behind each recommendation, and therefore can trust the recommendations and apply them. By making the summary tables, and adding implementation tools, we try to make the recommendations accessible.</p> |
| 3        | <p>I have no specific comment for this section. I think that, again ,the length and the meticulous division of the different aspects is perhaps too analytical. The staff could find it difficult to incorporate into clinical practice. I understand that the clinical evidence is enormous but for a practical approach it may be too fragmentary. I believe that a greater emphasis should be given to the psychiatric aspects described at pg 98 and 109 which, clinically are more relevant than the other less serious consequences of the fertility treatment.</p>                     | <p>Thank you for your comment. We agree with the large amount of information in the chapter, and will work on implementation tools to improve this. However, we disagree on your comment that we should put more emphasis on the psychiatric aspects. All aspects are important when considering a holistic approach to patient well-being.</p>  |
| 4        | <p>I found this section consistent with the previous sections. I think that many of the recommendations are the right result of clinical studies, but it is not easy to see the correlation between the references cited and the conclusion. If you consider pg 123-143, recommendations are very challenging for the staff because they suggest to monitor all the psychological and social aspects of each patient and the partner. Is it something that can be put into practice?.</p>   | <p>Thanks for your comment.<br/>The guidelines only recommend that fertility staff be aware of what are the risk factors for poorer adjustment and the areas most affected<br/>If more in depth assessments are to be made then they should be done with the tools listed<br/>The SCREEN IVF is the only tool that we recommend to use on routine basis</p>                                |
| Appendix | <p>147-149 Glossary : positive opinion<br/>150 -153 Tools : The list of tools intimidates inexperienced staff and I believe it is important to highlight the difficulty of their use in clinical practice. Very useful for research.<br/>abbreviations and guidelines experts : no comment<br/>pg 159 -160 : very useful the research hints<br/>methodology : very clear and well presented</p>   | <p>Thanks for your comment. An introduction was added to appendix 2, and the list was significantly shortened.</p>   |
| General  | <p>I was very lucky to be able to read the guidelines in their almost final version. Thank you for this opportunity. My overall impression is very positive. However, I am concerned about the complexity, length and detail of the different chapters. We must consider that the</p>   | <p>This is a very good point. This document details all the evidence that supports the</p>   |

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|                           |          | <p>psychological and social aspects of medicine in general are still little known and little studied except for some areas (oncology, genetics chronicity). The specialists and staff working in a infertility centre are aware of the difficulties of women and partners, but often do not know how to deal with these difficulties. The guidelines will help if you are able to make them more usable, more concise and less detailed. This is the opinion of a clinician who has always looked for new ways to improve the practice. This tool is great but perhaps not completely applicable. An effort could be done to separate the recommendations from all the material generated to formulate it. Thank you again</p>  | <p>recommendations and therefore has to remain extensive.<br/>However, ESHRE is committed to develop a number of additional materials and tools to facilitate the implementation of the guidelines.</p>   |
| <b>Adelheid Rigo</b>      | 2        | <p>p.57 nr.5: Patients' five most selected reasons for discontinuation during diagnosis and before initiation of treatment (based on two studies) were rejection of treatment (due to ethical objections ...</p>  | <p>Thanks for your comment. We are not sure about the issue you are trying to raise. The results reported are mainly based on a systematic review of the compliance literature that included 21 studies.</p>  |
|                           | Appendix | <p>p.160 appendix 5:<br/>Overall, there seems to be little knowledge about the relational and social needs of patients before they start treatment. These needs may differ according to patients' cultural, ethnic, and religious background but evidence about this is inexistent.<br/>comment : see infra</p>   | <p>Thanks for your comment. Your conclusion is correct.</p>   |
|                           | General  | <p>I do understand that the focus of the guidelines is psychosocial care as part of a routine care.<br/>Nevertheless I think there is too little attention for the ethical concerns of patients (and counselors). The fertility counseling is loaded by ethical issues that can cause psychosocial suffering and problems (ex. see above: rejection of treatment): what's the emotional and ethical value/meaning of loosing an (even briefly) implanted embryo, ... , conflict by a pregnancy of multiple embryo, ... .<br/>The ethical factors playing an important role in the whole proces of infertility counseling should be explicated in conversations between patient, family and counselor(s).<br/>Psychosocial care is only possible when there is (explicit) attention for a conversation about ethical issues and potential ethical conflicts.</p> | <p>Thanks for your comments. Ethical concerns were considered to the level that they were present in the evidence reviewed. For instance, regarding the behavioural need of compliance (ethical concerns are one reason for rejecting treatment) or regarding concerns (cognitive needs).</p>               |
| <b>Hana Gilaie Guinor</b> | 2        | <p>1. Page 65, line 293.<br/>In addition to the guideline's general recommendation to use the infertility specific tools listed in appendix 2 to detect the needs of patients, I would suggest including a psychosocial intake performed by a mental health professional. In addition, I would suggest it taking place before beginning the fertility treatments. To my understanding, the intake is an interpersonal process, and as such it increases the reliance of the patient upon the medical team. This might increase the patient's readiness and willingness to cooperate with specialized psychosocial support, as well.</p>   | <p>Thank you for your comment. There are no studies showing the benefit of a psychosocial intake by MHP for every patient.<br/>We have used additional and specialised as they implicate different things: additional refers to additional support from staff, although which support we cannot say due</p> |



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|                     |   | 2. Page 84, line 908.<br>Please clarify the 908 recommendation versus the 909 recommendation regarding "specialized" versus "additional" support.   | to lack of evidence, while specialised support is support from MHPs  |
| 4                   |   | Page 140, line 555.<br>The difference between "mental health" (line 555) and "maladjustment" (page 143, line 626) should be explicit. In other words, the discussion involving the risk factors that appears on page 143 should appear as well on page 140.   | Thanks for your comment. The terms mentioned are defined in the glossary of the guidelines, this should clarify on their difference. The two sections you mention also appear in different sections of the guidelines that have different goals (detect and address), therefore the recommendations will also be different.  |
| General             |   | 1. I fully support the approach and the vision of the guideline in which psychosocial care should be provided by all fertility staff members, and not exclusively by mental health professionals. However, I do believe a special role should be assigned for mental health professionals in promoting the ideas put forth in this guideline.<br>2. It is clear to me that the patients mentioned in the guideline are the people who undergo medical fertility treatments and their wellbeing is at the utmost importance. Nevertheless, the welfare of the unborn child should be taken into consideration throughout the fertility treatments. | Thanks for your comment. The GDG recognises that this is a very important question. However, the guidelines focus on how routine psychosocial care should be provided to patients. We state that all staff (including MHPs) should be involved in this task.<br><br>It is not possible to provide more precise guidance on who should do what because there is huge variability in how care is organized at clinics across different European Countries. In addition, ultimately, there is no evidence showing that task A is more effective when done by different members of staff. However, we explicitly state that counselling and psychotherapy should only be provided by MHPs.<br><br>These points are highlighted in the introduction<br><br>In addition, please note that we also do not make any specific comments about the role of other staff members within the clinic. |
| <b>Marysa Emery</b> | 3 | page 18 line 28: patients "have" a depressive "disorder ",(..) anxiety "disorder". The guideline elsewhere notes "experience more anxiety and depression" or "symptoms of depression" or "higher depression scores" or "anxiety and depression levels", ... I think we  | Thanks for your comment.<br>Some studies did assess mental health disorders, therefore, we need to leave it,   |

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|                   | <p>should avoid the word "disorder" unless it is defined in the glossary. To "have a disorder" elicits an idea of permanence, whereas to "present clinically relevant levels of depression or anxiety " may be better understood.</p> <p>p20 line 30 and page 15 line 20: "the use of avoidant coping..." on page 20 is better than "use of active avoidance coping strategies" on page 15 because of the later use of "active" and "passive" coping strategies, which is confusing. So please take out the "active" for the avoidance and confronting strategies, in every place they are used in the text.</p>   | <p>although I agree that it may cause confusion for staff that is not aware of these subtleties. We have modified the recommendations based on your second comment.</p>  |
| 4                 | <p>page 21 line 37 : "higher levels of (unrealistic) maternal expectations". I think the "unrealistic" should be removed, it has a judgemental echo. The study showed poorer coping resources and higher stress in IVF mothers. The IVF women were also significantly older. The shortcut between being an IVF mother and being more "unrealistic" doesn't reflect the poorer coping resources or higher stress or other factors.</p>  | <p>Thank you for your comment. We agree that the label unrealistic in maybe too inferential and removed it from the recommendation.</p>  |
| Appendix          | <p>p147 Glossary: Counselling should be ... "between one or more participants and a counsellor..."</p> <p>Please add to glossary: Mental health professional</p> <p>p156 Please include abbreviations: "BREC", MHP (mental health professional)</p> <p>p157 line 6, please correct because Marysa Emery is not a psychologist but a medical doctor specialised in psychosomatic and social medicine. To my knowledge, Petra Thorn is not a psychologist either? So: "The GDG is composed of 6 psychologists, one medical doctor specialised in psychosomatic and psychosocial medicine, one ..</p> <p>I think that the professional functions should be nominally listed in Appendix 4.</p> <p>p161 line 104. " The first 8 psychologists" please correct: The initial group of 6 psychologists, one medical doctor specialised in psychosomatic and psychosocial medicine and one ... was extended...</p> <p>p159 line 43. (meaning?) " Black cells indicate no low priority for future research."</p> <p>p167, line270. Please correct : "with emphasis on questions important to questions"</p> | <p>Thanks for your comments. The suggested terms se were added to the glossary and corrections were made. Regarding the comment on the profession, we have corrected this. After careful consideration we decided that the general profession and affiliation was enough and consistent with other ESHRE guidelines.</p> |
| General           | <p>This paragraph is too extreme in my opinion:</p> <p>p24 line 78 "At the behavioural level, many patients do not comply with recommended treatment. " My impression after reading the guidelines is not "many" but "some" or "a certain number". How is "many" defined?</p> <p>I also propose:</p> <p>line 79 "At the relational level, women MAY lack adequate support from significant others.."</p> <p>line 82 "patients ok experience intense distress."</p>   | <p>Thanks for your comments. We took them in considerations and edited the text accordingly.</p>   |
| Deborah Lancaster | <p>Figure 1.2 line 79 ('Address' box): I have concerns about the 'does not require specialized training' phrase as I wonder whether this can be interpreted by managers as 'does not need training' and used as a way of preventing staff from accessing training and Continuing Professional Development relating to psychosocial support of patients. All staff need CPD at</p>  | <p>Thank you for your comment. We agree that this needs to be clarified to avoid this kind of misconfusions. We added a sentence to clarify its meaning. It reads, "By specialized</p>   |

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|   | least to ensure they stay abreast of new developments and have the opportunity to reflect upon current practice and learn new concepts in best practice. Perhaps the need for education/CPD could be emphasised? Or is the proposal that the guidelines alone will be sufficient to promote such best practice?   | training we mean master or PhDs in counselling, psychology, psychiatry, or other long-term specialized training programmes.”  |
| 1 | There should be no apostrophe after patient in the subheadings on these pages (unless you change it to patients')   | Thank you. We have corrected this.  |
| 2 | Page 15 Grammatically this sentence is not clear in terms of whom the couple are differing from. I would suggest the following "couples in which the partners differ in their views of the importance of parenthood and social concerns may show lower relationship satisfaction than couples where both partners have similar views"   | Thanks for your comment.<br>We have modified the recommendation accordingly   |
| 2 | Page 16 "the SCREENIVF is a pre-treatment infertility-specific validated tool to assess risk factors for emotional problems after a treatment cycle" seems odd as it seems strange to offer a pre-treatment questionnaire after treatment. This may need expressing differently - it is expressed much more clearly at the end of page 19 and therefore makes sense at that point.  | Thank you. We have corrected this by only mentioning the SCREENIVF in the pre-treatment period.   |
| 2 | Page 17/23"The guideline development group recommends that fertility staff refer patients at risk for clinical significant psychosocial problems to specialised psychosocial support services." Will staff without specialised training be able to assess patients for this risk? Can they all refer to other services? Should it be that they follow clinic protocol for dealing with concerns about patients at risk? If the idea is that the SCREENIVF should be routinely used and the results used to make decisions about referral then this needs to be made more clear. | Thanks for your comment.<br>The aim of the section "HOW CAN FERTILITY STAFF DETECT THE NEEDS OF PATIENTS?" is written to aid clinicians in identifying patients for referral. In the section on "HOW TO ADDRESS PATIENTS NEEDS" we explicitly state that patients with problems or risk factors for problems should be referred to specialised psychosocial support services. |
| 2 | Page 52, paragraph beginning line 796 - researchers could be directed to the Glasgow et al. (1999) Re-AIM framework for guidance about the implementation of interventions into practice. This reference could be added to the reference list for this section.   | Thank you for the comment. The research recommendations are not evidence based, just a note from the guideline group to researchers endeavouring a study in the field of psychosocial care in infertility. We have not put references in any of these sections, although it may have been appropriate.  |
| 3 | Page 20/31 and elsewhere - should it not be 'clinically' significant not clinical significant?<br>Page 92 - table at top of page, line 89. It is not clear here what the tick marks refer to. Do they mean the 'presence of intimacy'? If so, this doesn't seem to work with the text that refers to women reporting 'more' intimacy at some stages of treatment than at others - esp line 96 forward - as 5 boxes are ticked in the table but the text reports women reporting   | Thanks for your comment.<br>We have corrected and updated the guideline based on your comments.   |

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|          | <p>more intimacy at 2 stages (retrieval and transfer) than at the other stages. A note under the table may help (similar observation for the remaining tables in that section).</p> <p>Line 414 - is 'students' the right word here?</p> <p>Page 115 line 775/776. In this table, are the blank cells where significant results arose or where the need was not tested? This could be clarified in a note (as was done for the table at line 833/4).</p>   |   |
| 4        | <p>Page 21/35 - It looks like there is something 'missing' from behavioural/emotional/cognitive sections. I think it would be better to say 'no evidence' or 'no recommendation' or similar.</p>   | <p>Thank you. We have added a footnote.</p>   |
| 4        | <p>Page 124. How likely is it that fertility clinic staff will be involved in the psychosocial care of patients a year or more after their final treatment? If the proposal is that staff should be thinking of preparing patients at the end of treatment for possible future issues then perhaps that could be stated at the start of this section. Or should the recommendations be passed on to those involved in obstetric care for those who become pregnant during treatment? Should fertility staff be notifying those involved in pregnancy care when a fertility patient who has become pregnant is at risk of psychosocial difficulties? Is there a duty of care in this respect or are there confidentiality issues?</p>   | <p>Thanks for your comment.</p> <p>It is true that staff will not have direct contact with patients but we do think that good care implies not only helping patients to conceive but also helping them adjusting to all possible outcomes.</p> <p>Currently there is no single intervention for people who did unsuccessful treatment. There is no more justification for this given the fact that interventions can be self-administered and made available online, etc... The point is, if patients do need support, they are informed about how to get it and it should be easily accessible</p> |
| Appendix | <p>Not reviewed</p>  | <p>OK</p>   |
| General  | <p>The guideline development group should be complimented on a very well-constructed set of guidelines which contain a wealth of valuable evidence and recommendations that will be of use to many specialising in fertility matters. There are a few matters that could be clarified for those who are new to these guidelines, which I've described above.</p> <p>One of the matters that made me pause and think is that a lot seems to hinge on the level of awareness of staff about patients who may be 'at risk' of psychological distress. Although the recommendations for the use of screening measures is contained within the document, I wonder if they are 'embedded' in the text in a way that means a busy member of clinic staff may not pick up on the importance of these recommendations (as this seems central to the likelihood of the recommendations being implemented).</p> <p>Another issue that may require more specific guidance is the practicalities of accessing and utilising the sort of interventions that may be helpful to patients, the evidence for which is discussed in excellent detail in the recommendations. Not all of these are easily available for staff who may not have easy access to a computer to search/download the relevant</p> | <p>Thanks for this useful comment.</p> <p>ESHRE is committed to supplement this document of the guidelines with additional materials and tools of the genre to facilitate its implementation.</p> <p>We will consider if the best way it to include this in the present document or not.</p>  |

information. Although the guidelines will help (for those who read and absorb the excellent advice and recommendations) I also think there is a need to emphasise that it is appropriate for staff to engage in CPD/training when it is available if it will help them to better help their patients.

There also may be a need for clinic staff to work out how they will gather information about interventions that may help their patients at key stages of treatment, how these recommendations will be disseminated within the clinic and to patients and so on.

I thought that maybe a flow chart suggesting a process for clinic staff that they can set in motion for each new patient would be useful (especially if placed as soon as possible in the guidelines). This may have great practical utility for busy clinic staff.

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| <b>Nezihe Kizilkaya<br/>Beji</b> | I  | The aim and scope of the guideline were described clearly.   | Thank you  |
|                                  | II | List of all recommendations is useful  | Thank you.   |
|                                  | 1  | Reproductive medical tourism is an increasing reality worldwide, defined as travelling of clients from their country of residence to another country in order to receive a fertility specific treatment. Those couples might have been considered as a special patient group and excluded from your review. However, those couples could have additional expectations, preferences or values. Fertility staff should be aware of their specific concerns (language, ethical and religious concerns, misinformation/uninformed consent etc) and provide transcultural care as a part of customized care. At least this issue might be mentioned in "research recommendations" in Page 40. Line 409.   | Thanks for your comment.<br>We agree that patients undergoing cross border fertility care have specific needs. Other patient subgroups (e.g., doing 3rd party reproduction) also have specific needs. For feasibility reasons, in this guideline we could not address all these groups so we only focused on them when they were reporting on issues that were common to all patients.<br>Further guidelines can be developed to focus on these specific patient populations |
|                                  | 2  | Page 60. Line 129 - About Recommendation "Fertility staff should be aware that patients starting first-line or ART treatments do not have worse marital and sexual relationships than the general population". The evidence about domestic violence against infertile women should be reviewed in this "before treatment" section and also in the sections about during and after treatment.<br>Needs: Intimate partner violence affects the lives of millions of "infertile" women worldwide regardless of their socioeconomic or educational levels. Although infrequently reported, domestic violence against infertile women is a problem that should not be ignored. There are many studies that investigated the prevalence of intimate partner violence against infertile women and found a difference between infertile and fertile women regarding the level of marital violence.<br>Detection: Major organizations including the American College of Obstetricians and Gynecologists recommend routine intimate partner violence screening as part of standard | Thank you for your comment. In the key questions and the search strategy, we did not include domestic violence, although it may have been part of marital quality/satisfaction.<br>We will consider this comment in the revision of the guideline.   |

patient care. There are many studies that include developing tools such as “Hurt, Insult, Threaten, and Scream” (HITS), “Abuse Assessment Screen” (AAS), Partner Violence Screen (PVS) and “Infertile Women’s Exposure to Violence Determination Scale” to screen abuse or violence among women by health care providers.

Fertility staff should screen and identify the abused infertile women and provide them with medical care and supportive counseling.

Page 80, Line 800-Addressing the lifestyle behavior change needs before treatment:  
Research recommendations about this section may include using health behavior change models (health belief model, transtheoretical model, etc...) as a standard theoretical frame to assess the effectiveness of interventions. Current studies usually evaluate the effects of complex behavior change programs, however the structure of the programs vary and usually rely on just giving information. Therefore studies usually have inconsistent results.

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|                        | 3        | No comment   | OK  |
|                        | 4        | No comment   | ok  |
|                        | Appendix | Tools for assessing lifestyle behaviors may be included.   | Thank you. We are not aware of tools for assessing lifestyle behaviours in an infertile population.   |
|                        | General  | This is a useful guideline for fertility clinic staff including recommendations about routine psychosocial care.   | Thank you   |
| <b>Zaira Donarelli</b> | I        | P. 8 L.63-64 Capital letters for IUI and ART;<br>p.9 L. 93 GDF is labelled but not explained (it's done after at L. 104-105)   | Thanks for your comment.<br>We have addressed these comments in the text  |
|                        | II       | P.20 In "emotional" section: the 3rd the dot is not followed by any comments   | Thanks for your comment.<br>This was corrected  |
|                        | 1        | p.35 L. 227 there is a - before .<br>p.42 - In my opinion Table 1.1. could be slipped at L 491   | Thank you, we have corrected this.  |
|                        | 2        | p.59: lines and dots in the list of the 2nd box<br>p.61. L.186 and foll: not cited Donarelli et al 2012 about state anxiety before treatment and the relational consequences within the couple<br>p.68 l.392 and segg. well-being and sexual concerns (suggesting difficulties in sexual intercourses) divergent concepts. It could be useful to explain the results...??<br>p.70 l.473-474 In men, sexual concerns were also associated with anxiety and negatively associated with sexual concerns: maybe you meant "In men, sexual concerns were also associated with anxiety and negatively associated with age?"<br>L. 692a space is necessary after 46%<br>L 921 (Hope and Rombauts, 2010) are bold marked | Thanks for your comment.<br>We have corrected the errors. The study of Donarelli 2012 is mentioned in other sections, it describes the impact of different factors on sexual concerns and anxiety, so we have mentioned it in section B on the risk factors that could help identifying patients at risk. |

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|                  | 3       | L. 391 there is a space before the last dot.  | Thanks for your comment.<br>This error was corrected.  |
|                  | General | Great job! Thank you for your effort in the psychosocial care for infertility staff.  | Thank you  |
| <b>Vera Higi</b> | 3       | <p>Clinical hypnosis found to be a useful tool during embryo transfer, and also may increase implantation rate (Levitas, 2006). It also seems that the patients' attitude to the treatment was more favorable when they used hypnosis during IVF treatment (Levitas, 2006). According to our patient's feedback, the 2 weeks waiting period after the embryo transfer is one of the most stressful period of the IVF treatment (p. 96). After taking all necessary medications during the stimulation period, having a successful egg retrieval and embryo transfer, our female patients suddenly feel that they are out of control "just" waiting for the outcome of the two weeks. They often decide to stay at home to avoid stress at work, but with this volunteer social isolation they also feel that they are left alone with their doubts whether the treatment will be successful or not, which increases the level of anxiety. That is the reason they often ask for our professional advice and a stress reducing tool to relax at home. As relaxation and medical hypnosis was already proven to be a helpful tool before, during and after the IVF treatment at our infertility clinic, our patients required to attain this method at home as well. For this reason we expanded a positive suggestion voice record for all stages of the IVF treatment, which seems to be an individual, successful tool to reduce anxiety. We would like to expand our observations to a clinical study in this year to prove the utility of this methodology. We suggest that hypnosis could take part of the treatment protocol in the different stages of IVF program.</p> <p><i>Levitas, E. et al (2006) Impact of hypnosis during embryo transfer on the outcome of in vitro fertilization-embryo transfer: a case control study. Fertil. Steril., 85 (5): 1404-1408</i></p> | Thank you for your comment. The effect of hypnosis during embryo transfer on implantation rate was not part of the scope of the guideline. Hypnosis and relaxation during the waiting period could be helpful interventions for reducing stress, but these interventions are generally not provided by clinic staff, but part of specialised support by MHP. |
|                  | 4       | <p>The risk of spontaneous first trimester abortion is estimated to be between 10 and 20% (Tummers et al, 2003). According to Blackmore et al., about 15% of the women experienced clinically significant depression and/or anxiety after miscarriage. The miscarriage rate seems to be higher among IVF patients (Simon, 1999), which could be the consequence of increased maternal age and the somatic reason of infertility as well. In our clinical experience, miscarriage after IVF treatment is one of the main crisis, so in our opinion it needs special attention within the psychological care. These women sometimes waited for years for a child to conceive spontaneously, after some of them had to go through one or more unsuccessful IVF treatment, when they finally became pregnant. According to their feedback they feel that their body "disappointed" them, so they lose their security in their body as well. According to the Guideline, pregnancy after IVF needs attention, but psychologic care should be available after the miscarriage followed by personal crisis as well.</p>  | Thank you for your comment. In this guideline we assessed the standard "infertile patient", without focussing on special patient groups. Miscarriage, although rather prevalent, as an additional problem which was not included in the guideline. We may consider including the impact of miscarriage in the update of the guideline.                       |

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|                          |         | <p>Tummers, R. et al (2003) Risk of spontaneous abortion in singleton and twin pregnancies after IVF/ICSI. Human Reproduction., 8 (8), 1720-1723.</p> <p>Simon, et al. (1999) Early pregnancy losses in in vitro fertilization and oocyte donation. Fertil. Steril., 72, 1061–1065.</p> <p>Blackmore et al. (2011) Previous prenatal loss as a predictor of perinatal depression and anxiety. British Journal of Psychiatry, 98(5):373-8</p>  |  |
| <b>Diana Guerra Diaz</b> | General | <p>The guidelines are a step forward to the clinical practice.</p> <p>The holistic scope and the process suggested is very good. In my opinion the same recurrent difficulties should be take in account: its diffusion, degree of implementation and outcome evaluation.</p> <p>The optimal way to solve these issues would be to have a register in the ESHRE field.</p> <p>My congratulations to the developers team!</p>  | Thank you.   |
| <b>Laura Salerno</b>     | I       | <p>p. 9, line 93 = The acronym GDG was not specified before</p> <p>p. 10-11, lines 145-182 = Standardise the referencing style (i.e. journals' titles sometimes are written in shorter form and sometimes in a no-abbreviate form)</p>  | <p>Thanks for your comment.</p> <p>We have addressed these comments in the text</p>                            |
|                          | II      | <p>p.12, line 5 = Standardise the graphic style in the "clinic characteristics section" (i.e. in the second bulleted list, full stops are inserted at the end of each sentence, while full stops are not used in other bulleted list)</p> <p>p.14, line 17 = It could be useful for readers detailing some examples of "lifestyle behaviours" in bracket.</p> <p>p.15, line 20 = standardise the graphic style (i.e. full stops at the end of the sentences).</p> <p>p.20, line 31 = nothing is specified in the third bullet of the "emotional section"</p>  | Thank you. We added some explanation for the different needs, and corrected the errors you mentioned.          |
|                          | 1       | <p>p.32, line 128 = remove the space between "25" and "%".</p> <p>p. 32, lines 148-149 = It could be useful give some examples of the meaning of "chaperone" in the study from Ouj et al.</p> <p>p. 35, line 227 = remove the dash after the full stop.</p> <p>p.36, line 288 = remove the second bracket (before the "1").</p> <p>p.37, line 310 = why including the age only for women? It could be useful give information about the age for both women and men in the study.</p> <p>p.37, line 314 = detail: "p=n.s." (i.e. no significant) on bracket after "explain test results" and "explain treatment option"</p> <p>p.43, line 486 = the acronym PCC was not specified before.</p> <p>p. 44, line 522 and p.53, line 820= Write the name of the author in the correct way.</p> <p>p.46, line 560 = remove "and colleagues" (Mori is the only author of the research paper mentioned).</p> <p>p.46, line 578 = remove "and colleagues" (Terzioglu is the only author of the reaserch paper mentioned).</p> | Thank you for your comments. Where appropriate, we have addressed these comments in the text of the guideline. |



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|                     | p.53-55, lines 804-900 = standardise the referencing style (i.e. journals' titles sometimes are written in shorter form and sometimes in a no-abbreviate form).  |   |
| 2                   | p.57, line 36 = remove the space between "42,3" and "%".<br>p.57, line 43 = remove the space between "9,1" and "%" and between "3"and "%".<br>p.57, line 55 = the acronym GIFT was not specified before.<br>p.58, line 75-76 = standardise the graphic style of the bullet points.<br>p.61, line 172 = write "anxiety" in capital letter.<br>p.62, line 225 = the correct acronym is "SCID" (instead of SKID).<br>p.70, lines 472-474 = the findings of the study are reported in a no correct way within this sentence: "In men, sexual concerns were also associated with anxiety and negatively associated with sexual concerns".   | Thanks for your comment.<br>We have corrected the errors in the guideline text.   |
| 3                   | p. 96, line 200 = the acronyms TESA/PESA were not specified before.  | Thanks for your comment.<br>This error was corrected  |
| 4                   | I have no comments relating to this section.   | OK  |
| Appendix            | pp. 154-155 = standardise the referencing style.   | OK  |
| General             | I think that the guidelines are clear and very interesting.  | Thank you   |
| <b>Claudia Melo</b> |  |   |
| I                   | Page 6, line 12 - language suggestion - "First, the usual treatment does not cure..."<br>Page 6, line 22 - Before the sentence "In sum...", I think that it would be important to introduce the idea that if the couples persist with the treatments, the pregnancy rates increase.  | Thanks for your comment.<br>We have rewritten the paragraph to address these comments.  |
| II                  | Page 17, Cognitive needs - It would be important to emphasize the importance of the information being clear, simple and adapted to the patients.<br>Page 20, Relational/social and Emotional - language suggestion - "The guideline development group..."<br>Page 24, line 73 - language suggestion - "support should be tailored..."<br>Page 25, Table II.1. - Emotional - I think it should be deleted the examples from the table, like "e.g. rumination, withdrawal".  | Thanks for your comments.<br>We have a general recommendation that patients value understandable and customized information (chapter 1) independent on whether this information is provided before, during or after treatment.<br>We have corrected the errors mentioned. |
| 1                   | Page 32, line 119 - language suggestion - "Further important characteristics were the provision of opportunities to establish contact with prior patients and the organization of live support groups..."<br>Page 32, line 149 - I think that it is important to specify what kind of chaperone it would be important to stay in the medical examinations.<br>Page 35, line 239 - language suggestion - "over in-person follow-up."<br>Page 36, line 288 - language suggestion - "(1, not helpful, to 7, extremely helpful)..."<br>Page 37, line 308 - language suggestion - "Dancet and colleagues (2010) investigated..."<br>Page 37, line 318 - language suggestion - More women than men (11-21% vs. 5-9% depending on option)..." | Thank you for your comments. Where appropriate, we have addressed these comments in the text of the guideline.  |

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|          | <p>Page 37, line 321 - language suggestion - "... if it would be available at the clinic."<br/> Page 37, line 324 - language suggestion - "...written information about psychosocial aspects (&lt;56%)..."<br/> Page 38, line 380 - language suggestion - "... to provide information in the preferred format."<br/> Page 39, line 398 - language suggestion - "In order to synthesise the information, it was made the assumption that studies using..."</p>  |   |
| 2        | <p>Page 57, line 54 - language suggestion - "15% of the couples undergoing IVF or GIFT..."<br/> Page 57, line 64 - language suggestion - "10% of patients that are referred to fertility clinics..."<br/> Page 57, line 71 - language correction - "Overall these data suggest..."<br/> Page 60, line 146 - language correction - "...Lintsen and colleagues found no differences..."<br/> Page 69, line 427 - language correction - "They also assessed..."<br/> Page 70, line 476 - language correction - "...the male partner's relationship quality..."</p>  | <p>Thanks for your comment.<br/> We have corrected the errors in the guideline text, except for the first 2 comments: on the start of a sentence, numbers should be written in full.</p>  |
| 3        | Nothing to declare.  | OK  |
| 4        | Nothing to declare.  | OK  |
| Appendix | Nothing to declare.  | OK  |
| General  | <p>In my opinion, this is a very clear and specific guideline to health professionals about how to provide psychosocial support to infertile couples across the different stages of treatment or at diagnosis. The literature review is exhaustive and sustain all the recommendations done, which is a crucial thing for guidelines. However, and as a psychologist, I think the role of the psychologist in the team is not well established and is undefined. Through the guideline it is said that in some cases the couple or one of the member at risk should be forward to a specialist. However I think that this is reducing the role of the psychologist in the fertility staff. Psychologist have the competence, training and skills to know how to give this support, that other professionals do not have. So, in my opinion it can not be replaced, and so it is crucial that its role is well defined.</p> | <p>Thanks for your comment.<br/> The GDG recognises that this is a very important question. However, the guidelines focus on how routine psychosocial care should be provided to patients. We state that all staff should be involved in this task because the psychosocial wellbeing of patients should not be the solely responsibility of mental health professionals. It is not possible to provide more precise guidance on who should do what because there is huge variability in how care is organized at clinics across different European Countries and this is many times constrained by cultural, social and even legal factors. In addition, ultimately, there is no evidence showing that task X (e.g., information provision) is more effective when done by different members of staff. However, we explicitly state that counselling</p> |

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|                            |    |  | <p>and psychotherapy should only be provided by MHPs.</p> <p>This approach is in line with the bio-psychosocial and patient centred models of care and has been advocated and implemented across different health conditions.</p> <p>Finally, please note that we also do not make any specific comments about the role of other staff members within the clinic. We revised the introduction to make these issues clearer.</p>   |
| <b>Stamatios Karavolos</b> | I  | <p>p.9 line108:I totally agree with this. A qualitative interview study I am undertaking at present looking at the experiences of men diagnosed with azoospermia and undergoing fertility treatment in our tertiary fertility centre highlighted the importance of addressing these issues by front line clinic staff and healthcare professionals, not necessarily qualified counselors or psychotherapists (unpublished data).</p> <p>p.9 line126:This is very useful indeed and very easy to follow.</p> <p>p.10 line 134: An area that also needs to be addressed in the future is the experiences of men diagnosed with their own (male factor) infertility.</p>  | <p>Thanks for your comment.</p> <p>We agree with your comment and our happy to see your research supports our recommendations. We have mentioned the question “What are the specific needs of men undergoing fertility treatment?” in the points for further research (appendix 5)</p>  |
|                            | II | <p>p.12 Box heading below line 2: patient'- correct to patients'</p> <p>p.12 Box below line 5: bullet point: how staff relate to them</p> <p>p.13 Box below line 13: last bullet point: consider revising content in brackets- contradicting</p> <p>p.23 Box below line 23: 1st sentence: patients at risk of clinically significant...</p> <p>p. 18 Box below line 27: consider defining 'first-line' treatment here (although definition provided later on)</p> <p>p.19 box below line 29: the sentence ' the use of emotional expressive coping...' contradicts statement above (p.15 box below line 20, which states that both avoidant coping and emotional expressive coping increase distress)- consider correcting.</p> <p>p.20 Box below line 31: extra bullet point with no text</p> <p>p.25 Consider not using a full stop at the end of sentences within table, to be consistent with rest of document</p> <p>p.26 line 145: why are qualitative interview studies considered 'low quality' methods?</p> | <p>Thank you for your comments. We have corrected the errors mentions. We have confirmed that “staff” is plural in British English.</p> <p>On page 13, we revised this content and could not identify anything contradictory so we did not do any changes.</p> <p>On page 19, after a more careful analysis we decided to remove the emotional coping. Although the effect is there, it is only men who are distressed when their partners engage in this strategy.</p> <p>On page 26, This is how it is defined in the ESHRE manual for the development of guidelines. Generally, qualitative research is considered lower quality because it lack</p> |

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|                         |   | generalization, so one cannot assume that results reported apply to all patients.  |   |
| 1                       | p.59:correct to physicians. (page 29, line 59)<br>p.35 line 227: delete -<br>p.35 line 233: appointment<br>p.36 line 289: delete underline<br>p.36 line 315: p<0.05   | Thanks for your comment.<br>These errors were corrected in the guideline.  |   |
| 2                       | Very well written section. I am in agreement with the content. Some minor typing errors.<br>p.68 lines 387-8: p<0.01<br>p.72 line 565: -0.43 and -0.56<br>p.78 line745: totally agree. This is also a finding of my current research on the experience of men with azoospermia considering treatment options (unpublished data).  | Thanks for your comment.<br>We have corrected these errors.  |   |
| 3                       | Very well written section. I am in agreement with the content.<br>p.118 line 833: patients'<br>p.120 line 888: patients'<br>p.121 line912: intention  | Thanks for your comment.<br>This error was corrected   |   |
| 4                       | Very well written section. I am in agreement with the content.<br>p.124 line 30: behaviour  | Thanks for your comment.<br>This error was corrected.  |   |
| Appendix                | None  | OK   |   |
| General                 | Thank you for allowing me to review this guideline. It is a very comprehensive and well written document, with an extensive review of the current literature and available evidence. I am in agreement of all the content. It clearly highlights the areas where there is lack of research and high quality evidence. The format and layout is easy to follow, with key recommendations highlighted clearly.<br>I have raised some minor comments and typing errors that I came across during my review. It will my pleasure to get involved with the further development of this guideline, especially as new evidence on this topic emerges.<br>Best wishes, Stam Karavolos | Thank you.   |   |
| <b>Laure Camborieux</b> | I   | Not reviewed   | OK  |
|                         | II  | Not reviewed in depth  | OK  |
|                         | 1   | Probably few patients will need psychosocial intervention during their fertility treatment. However, some of them will encounter specific issues and need a tailored approach. Thus, offering psychoeducative information and help them to identify the professional resources they could use could be more efficient than complex programs. Meeting early with a psychologist or a counselor could help to clarify the infertility issues, and to better anticipate | Thank you for your comment. The aim of this guideline is to provide evidence based assistance to clinicians to identify patients with issues that need a tailored approach (by screening tools and risk factors) and to refer these patients for psychosocial |

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|   | the potential needs of the patients, as well as propose a specific psychosocial care if necessary.  | support. It is also stated that the current available "complex interventions" are not effective.<br>There is no evidence that a compulsory meeting with a counsellor/psychologist is necessary and effective for all patients.  |
| 2 | p 59 line 120 and below. Although there is no statistical difference concerning sexual behaviour, one should be aware that some couples can have poor sexual activity, potentially decreasing their conception probabilities and/or weakening couple relationship, intimacy and emotional support. Couples at risk should be identified and appropriate counseling should be offered (at least, opportunity to discuss these issues should be offered).<br>Almost same comments about Emotional needs : one should pay attention to the patients exhibiting high level of anxiety and/or depression and to those using avoidant coping. The individual, clinical approach should be preferred to the statistical one.   | Thanks for your comment.<br>The guideline describes the common needs of most of the patients, and how to identify patients with specific needs for referral. It considers individual variability (detect section) and does recommend that more distressed patients be offered specialized mental health care.<br>The definition of clinical significant is a very complex one and most studies do not provide data that allows for that assessment. When that data was presented it was reported in the guidelines. |
| 3 | p104, line 415 : change for "...no reliable tools or predictors to identify patients ...had been identified yet" (In my experience, avoidant coping and behavior seem to be a good predictor for treatment discontinuation or delay. Specific anxious troubles such as medical phobia, blood or syringe phobia, or larger anxious problematics such as PTSD, agoraphobia, generalised anxiety often explain my patients drop out or delay in treatment. Maybe more research is needed to verify this).<br>p108lines 557, 558, 559 : change "depressive" by "anxious" ?  | Thanks for your comment.<br>We agree that clinicians may from experience know some risk factors, but these have not been formally assessed in appropriate studies.  |
| 4 | p124, l 17 : I disagree with the statement that patients in the first post-treatment year are excluded from this study and are at risk not to receive appropriate care ; I am not sure also (what sort of data ?) that it is a heterogeneous group not allowing research programs. Some of those couples are likely to experience infertility specific distress, anxiety and/or depression, marital, social and professional difficulties. They deserve tailored, specific psychological care, even at that time, more research is needed to delineate appropriate care.<br>p125, l 38. Add the comment written p135, l 401-404 : "of the participants...(n=207)"<br>Otherwise, one could conclude that non successful treatment has no consequence on the patient. | The error mentioned was corrected.<br>Thanks for your comment.<br>We agree with this comment. However, we have included reactions to a negative treatment during the treatment period, and we also included pregnancy and then the unsuccessful group. Therefore, the excluded patients are those who did not have a successful treatment and are considering whether to continue or stop treatment.  |

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|                | 4        | <p>Same comment p125, line 66 versus p 136 line 417-420.<br/>         Johansson's study delineate one specific group of patients : "unsuccessful treatment without children" : this group seems at risk to encounter several psychosocial difficulties, and fertility staff should be aware of that. cf also p 137, line 466-469<br/>         p136 l429 : repetition "refers to"</p>  | <p>The Johansson study actually shows that people without children have lower anxiety and depression, although also lower scores on other issues such as self-confidence, vitality. Overall the results are inconsistent to make a definitive conclusion.<br/>         The repetition was corrected.</p>  |
|                | Appendix | Not reviewed in deep  | OK  |
|                | General  | <p>This guideline is very interesting and should be very useful in the treatment of infertile couples. Unfortunately, due to lack of studies, many points are still unclear. Clinical experience in private practice could maybe be a useful source of hypothesis to be tested. In particular, the impact of stress and ways of coping should be investigated. The main thing this guideline shows is to my point of view that some subpopulation of infertile couples deserves specific, tailored and professional delivered psychosocial care. To identify quickly those at risk and referring them to appropriate professionals should be a great help.<br/>         My concerns with this guideline are :<br/>         *How to implement it in fertility clinics. It represents a very impressive project and will ask many efforts to the clinics, but the importance of offering psychological care to infertile patients is not appropriately highlighted to my point of view. At least in France, psychological health is not a major concern (euphemism) in fertility treatment. This guideline need to be strongly promoted.<br/>         *To my best knowledge, many of the tools proposed to assess patients needs, specifically those related to infertility, are not available in other language. There is a need of translation/validation of such tools in other languages.<br/>         *Specific issues like gamete or embryo donation, surrogate motherhood, crossborder infertility care, the transitions between different treatments, adoption or living childless should be studied in a future guideline.</p> | <p>Thank you for your comment?. We agree that psychosocial care is not major concern and hope this guideline may increase this. We have discussed this issue in the introduction.<br/>         Regarding the translation of the tools, the GDG totally agrees with this. However, as it may be easy to understand, this falls completely out of the scope of the guideline development work.<br/>         These (and many others) are things the field needs to address.<br/>         We consider that it is positive that the guidelines highlights barriers to the optimal deliverance of care.</p> |
| Tracey Chester | I        | Clear and thorough  | Thank you   |
|                | II       | P13, line 13 - It may be helpful to reference on line psycho-educational intervention for staff to use.   | In the chapter, the intervention performed by Cousineau is described, but we have decided to leave this out of the summary table.   |
|                | II       | <p>P15, line 20 - Emotional needs, ' The Guideline development group recommends . . ' Is this suggesting Nurses do the SCREENIVF or referral to counsellors/psychologists, it may be helpful to specify.<br/>         P19, line 29 - Whilst it is a good principle for staff to use tools, how might this be implemented in clinics, and who would interpret the results.</p>   | Thank you for your comment. All the tools listed can be used by staff. The guidelines offer recommendations, they are not meant to tell clinics how they should implement them, however ESHRE will work on  |

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|          |   | facilitating the dissemination and implementation of the guidelines and will try to provide information on some of these issues at a later stage.  |
| II       | P26, line 131 - There needs to be a distinction between mental health practitioner and counsellor as most clinic counsellors in the UK are not MHP.   | Thank you for your comment. We are aware there is a variation on the definition and country. We have decided to keep "MHP" and we have added it to the glossary.   |
| 1        | Good evidence based recommendations and good to see the needs of men being addressed  | Thank you  |
| 2        | P76, L 712 - It would be useful to have SCREENIVF as an appendix.<br>P 78, L 763, p83, L 877, p84, L908 - It would be helpful to add specialist infertility counselling services.   | Thanks for your comment. Adding SCREENIVF in appendix would be helpful but is not possible. ESHRE intends to continue to work on the dissemination and implementation of the guidelines and this work may address the issue you are raising. After reviewing your second comment, we have decided not to change the text according to your suggestion. |
| 3        | P115 L 758, p119 L 875 - It would be helpful to add specialist infertility counselling services.  | Thanks for your comment. This was added  |
| 4        | P142, L611 & p143, L632 - it would be helpful to add specialist infertility counselling services  | Thanks for your comment. This was done.  |
| Appendix | Very thorough   | OK   |
| General  | <p>The British Infertility Counselling Association (BICA) members felt that the document is a comprehensive guide to fertility staff on the psycho-social care provision for fertility patients.</p> <p>BICA were pleased to see the information and well backed up research. We particularly liked the emphasis on the impact all professionals can have on the 'patient's' psychological and emotional well-being. BICA also felt that it was important to provide recommendations to staff, raise awareness and inform staff about the lessons learned from the research. As counsellors we are well aware, through our 'clinical' experience, how patients can be adversely affected by the way they are treated by the system and clinical personnel - the idea that all staff can be better informed about the emotional impact of the fertility experience and routinely recognise the role they play in promoting well-being is a welcome step forward.</p> <p>The guidelines break down the stages of the journey/pathway and the impact on, as well as the needs of, 'patients' at a range of levels. This results in a comprehensive, research and</p> | Thank you  |

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|                       |          | evidence based series of guidelines, which the contributors should be congratulated on devising. The application of the Guidelines is perhaps what we look forward to, but is presumably beyond the scope of this consultation.   |   |
|                       | General  | BICA members commented that there may need to be caution about how some of the conclusions are interpreted e.g some of the material around coping, 'avoidance coping' and relational issues, may need more explanation and understanding before being used.   | Thanks for your comment.<br>The GDG agrees with this opinion.<br>Recommendations around these topics are only made at the level of awareness (Staff should be aware that). The level of evidence also provides guidance on how reliable that specific guideline is. There is no guidance on what should be done in relation to these issues in the guideline due to lack of evidence, as BICA highlights. |
|                       | General  | BICA members also felt it was important to specify 'specialist infertility counsellors' and 'specialist infertility counselling services' as this is not mentioned. Here in the UK, the majority of counsellors attached to infertility clinics are 'specialist infertility counsellors' and not mental health practitioners. BICA would like to see this addressed. Furthermore BICA would welcome more emphasis on the provision to patients at all stages of their treatment of a dedicated service to explore and assist them in managing the emotional consequences of infertility, not just to those who are seen to be most vulnerable or likely to suffer adverse consequences.<br>BICA were pleased to see the document was inclusive of the male needs and value this contribution to the provision of care.<br>We look forward to working with you on further consultation in this area. | The GDG thanks BICA for their review.   |
| <b>Herborg Holter</b> | Appendix | On page 153, other tools below service evaluation; we miss recommendations for the validated instrument Quality from the Patient's Perspective of In Vitro Fertilization (QPP-IVF). The instrument is valuable since it evaluates patients subjective experiences and perceived reality of treatment. QPP-IVF is a useable tool for IVF-clinics in improvements of services to patients. The QPP-IVF is used by all IVF clinics in Sweden and implemented in the Swedish National Quality Register of Assisted Reproduction.<br>Reference: Holter et al. Quality of care in an IVF programme from a patient's perspective: development of a validated instrument. Hum Repro vol.29, pp.534-547, 2014.   | Thank you for your comment. We have added this tool to the list.  |
|                       | General  | The guideline gives valuable information concerning the results of quantitative studies in this field so far. One limitation is that qualitative studies are not included at all and by that valuable information for fertility staff is missing. We also considered the guideline to be too detailed and extended. We think the guideline would be more accessible, for the reader, if   | Thank you. We will work on different formats to access the content.   |



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|                      |                        | the format could be more compressed and with less repeats (eg. recommendations for different stages are the same).   |   |
| <b>Cailin Jordan</b> | I                      | Comprehensive and succinct introduction.   | Thank you   |
|                      | II                     | Page 16 - Cognitive needs is blank. Is that intentional? Otherwise, comprehensive.   | Thanks for your comment.<br>We added a footnote   |
|                      | 1                      | Good review and analysis of the literature. Comprehensive guidelines.  | Thank you   |
|                      | 2                      | Excellent analysis of the literature. Page 75 (and others) discussing Active, passive, avoidance coping, active avoidance, active confronting, dependency, self-criticism, passive coping and intrusiveness are all terms that may benefit from inclusion in a glossary of terms to ensure the comprehension of the multi-disciplinary teams that may use these guidelines but may be unfamiliar with the psycho social language or terminology. | Thanks for your comment.<br>The glossary was updated.   |
|                      | 3                      | Comprehensive review. Clear guidelines.  | Thank you   |
|                      | 4                      | <i>Comprehensive review. Clear guidelines.</i>   | Thank you   |
|                      | General                | Excellent resource for clinic teams. Would benefit from explanation of some psychological terms - perhaps an introduction glossary.  | Thank you. We have extended the current glossary.   |
|                      | <b>Helena Volgsten</b> | I  | page 6 line 4; psychosocial care is defined by....add reference<br>page 7 line 40; doctors, nurses/midwives....add midwives   |
| II                   |                        | A general comment to this section is that it could also be made as a "web based course" mandatory for all staff to go through as a way to accredit the psychosocial care at the IVF-clinic.  | Thank you for the input   |
| 1                    |                        | page 42 line 472; I find it remarkably that a study with a reponse rate of 17.5% is included! When on the next page (43) it is mentioned that qualitative research was excluded due to low qualitative evidence.<br>page 47 line 611 significantly higher<br>page 51 line 754 showed to reduce...  | Thanks for your comment. We acknowledge that some studies have very low response rates. Studies were included if quality assessment indicated they were at least of level C quality. The quality criteria are described in the methods and include many other issues than response rate. The CGC took in consideration the studies strengths and limitations and overall quality when making the recommendations.<br>The mentioned errors were corrected. |
| 2                    |                        | page 60 line136; depressive symptoms<br>page 62 line 235; significantly lower...<br>page 64 line 267; how can a study with 32% in response rate be included (and if so give the reference) as a reader I can then choose if the result is representative   | Thanks for your comments. We have addressed them. Regarding your comment on page 64, we acknowledge that some studies have very low response rates.   |

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|          | <p>page 65 line 311; education level (low)<br/> page 73 line 572; depressive symptoms<br/> page 80 line 788; higher for the DVD...<br/> page 81 line 816; mention how many women were included in the study?</p>  | <p>Studies were included if quality assessment indicated they were at least of level C quality. The quality criteria are described in the methods and include many other issues than response rate. The CGC took in consideration the studies strengths, limitations, and overall quality when making the recommendations.</p> |
| 3        | <p>page 94 line 148; depressive symptoms<br/> page 95 line 157; depressive symptoms<br/> page 98 line 254; PRIME-MD clinician evaluation guide<br/> page 100 line 316; the last statement .....seem to be similiar should be removed if there is no reference.<br/> page 101 line 322; after the pregnancy test result...<br/> page 104 line 414; studies<br/> page 106 line 485; depressive symptoms<br/> page 109 line 602; Volgsten at al 2010a<br/> page 109 line 605; Volgsten et al 2010b (see references!)<br/> page 109 line 613; Volgsten et al 2010a<br/> page 111 line 684; vary<br/> page 112 line 710; add Volgsten 2008<br/> page 112 line 711; add Volgsten 2010a<br/> page 123 line 1017 add reference; Volgsten H, Ekselius L, Sundström Poromaa I, Skoog Svanberg A. Personality traits associated with depressive and anxiety disorders in infertile women and men undergoing in vitro fertilization treatment Acta Obstet Gynecol Scand. 2010;89(1):27-34</p> | <p>Thanks for your comment.<br/> We have corrected the mentioned errors,<br/> We had assessed the mentioned paper, but decided that it was not fulfilling the inclusion criteria.</p>  |
| 4        | <p>page 126 line 87; anxiety and depressive symptoms<br/> page 131 line 255; recommendations mention couples when in the study for example only men were included. Better to write women and men<br/> page 131 line 262; anxiety and depressive symptoms<br/> page 136 line 429; refers to</p>  | <p>Thanks for your comment. Regarding the second comment, the recommendation is based on 3 studies of which 2 studied women and 1 studied men. Therefore, we think it is correct to use "couples". The other comments were corrected in the text.</p>  |
| Appendix | <p>Appendix 2 tools;<br/> page 151 below psychiatric disorders add; PRIME-MD clinician evaluation guide<br/> reference; Spitzer RL, Williams JB, Kroenke K, Linzer M, deGruy FV, Hahn SR,</p>   | <p>Thank you for your comment. Based on several comments, we have shortened the list of tools in appendix 2 to those that are specific and usable by fertility clinic staff.</p>   |

Brody D, Johnson JG. Utility of a new procedure for diagnosing mental disorders in primary care. The PRIME-MD 1000 study. *JAMA* 1994;272:1749–1756.  
 page 152 below personality traits add; Swedish universities Scales of Personality (SSP) reference; Gustavsson JP, Bergman H, Edman G, Ekselius L, von Knorring L, Linder J. Swedish universities Scales of Personality (SSP): construction, internal consistency and normative data. *Acta Psychiatr Scand.* 2000;102:217–25.

General

Thank you for doing all this work with these comprehensive guidelines! The ESHRE guidelines are filling a gap by presenting the overall gathered research within the area of psychosocial care in one publication! The guidelines are both useful to me as researcher and will be useful for the staff at the fertility clinics meeting the infertile couples! However, there are a few questions; one is how some of the quantitative studies have been included. Some studies are old > 15 years (1996-99), have small samples (less than 50 subjects) and low response rates (less than 50%). If these studies are to be included it needs to be mentioned. On the other hand, qualitative studies are not included referred to as lack of credibility. But how representative are the results in the quantitative studies mentioned above? Qualitative studies, if well designed, can contribute to the research area by complementing quantitative studies by giving meaning and understanding of each individual's experience. The extent of the transferability of the findings depends on cultural and traditional similarities or differences. Another question is how emotional aspects/needs can be compared between the quantitative studies. Are we "measuring" the same when we are referring to depression, anxiety, stress/distress, psychiatric disorders/morbidity, affect, mood, grief etc. However, the most important thing was to summarize the research in the area, which has been thoroughly done.

Furthermore, I think there need to be different ways to administer the ESHRE guidelines to reach as many in the staff as possible. Therefore one suggestion is to not only to publish the guidelines in paper format but also as a "web based course" that you have to pass to have "licence"/to be certified to work at the IVF- clinic. An evaluation of the ESHRE guidelines can then be done both at the clinic and as a multi-center study to assess the level of awareness within and between IVF-teams.

However, one problem with addressing these guidelines to all the staff is that no one will take the full responsibility. There will always be factors as lack of time etc. Therefore, one suggestion is that all staff needs to take part of the guidelines (as mentioned above) but someone needs to be the one responsible for the individual couple. My suggestion is that the nurse/midwife in the IVF-team, who is the one meeting the individual couple before and after treatment, is the one responsible for the psychosocial care. A specialized midwife can be responsible for screening of emotional needs, such as previous depression or miscarriage, when the couple is entering the IVF-clinic. By screening at baseline, but also

Thank you for your comment. The criteria for quality assessment included sample size and response rate. Furthermore, it was decided not to include studies published before 1990. Although the limits are artificial, some limitations are needed as this is already a very extensive document. Qualitative studies are a valuable contribution to the field, but whether these studies can be used as a valid foundation for a recommendation for clinical practice is discussable, especially when writing recommendations for clinicians. We will work on a web-based course, website, patient version, .. to complement this guideline. Regarding the responsibility of the staff, the GDG recognises that this is a very important question. However, the guidelines focus on how routine psychosocial care should be provided to patients. We state that all staff (including MHPs) should be involved in this task.

It is not possible to provide more precise guidance on who should do what because there is huge variability

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|                   |          | after the treatment, the patients at risk for developing depression can be referred to specialized mental health professionals. This will make these ESHRE guidelines useful and supportive by giving the fertility staff an increased awareness and in incorporating psychosocial care in the routine infertility care to the individual couples. |  |
| <b>Akiko Mori</b> | I        | P7, L44-45 I would like to hope you to make reference to other area's advanced countries not only European countries.<br>P7, L57-58 I think 2-axes of the guideline (Fig.1.1) are explicit and relevant.   | Thanks for your comment.<br>The guideline recommendations were written with a focus on the European situation, but they are applicable to other advanced countries. The evidence was not selected based on origin  |
|                   | II       | This chapter is colorful and visible. I think the summary works very well.   | Thank you  |
|                   | 1        | There are many "be aware that" in recommendations of this chapter. However I think it is important that fertility staff will act something after the awareness. How describe?  | Thank you for your comment. We agree with you. Whenever there is sufficient supporting evidence we do state guidelines about what to do. However; for a lot of recommendations the evidence is very limited in quantity and quality, so we can only advise to be aware. Furthermore, the key question "what are the needs of patients' does not really imply action from clinicians, rather it aims at staff being aware of issues which can then be identified and addressed. |
|                   | 2        | P84, L908 Please explain the SCREENIVF more detail in here. I found it in P111, L671~682.  | Thanks for your comment.<br>The explanation for SCREENIVF was given in section 2.2c, when the tool was first introduced.   |
|                   | 3        | The category of patient's need and treatment period is excellent.  | Thank you  |
|                   | 4        | Some recommendations of this chapter will be useful to the staff of maternity care unit. I would like to hope you to make reference to cooperation between infertility staff and maternity staff.  | Thank you for your comment. We assume that both physician in a fertility clinic and maternity staff, as they are both caring for infertile couples, will be up to date on the evidence/guidelines referring to pregnancy .   |
|                   | Appendix | I think it is competent as appendix of guideline.  | OK   |
|                   | General  | This guideline will be strong supporter for nurse.   | Thank you.   |

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|               |    | Well-organized and evidence-based recommendations are very useful to fertility nursing care.   |   |
| Carolyn Cesta | I  | <p>Overall, the introduction would benefit from a re-writing with more clear and precise language.</p> <p>Page 6</p> <p>line 12 and line 15 - replace the word 'usually' with a word that is more precise</p> <p>line 13 - 'infertility disease' might be better described as 'cause of infertility' since it is not always a disease that causes it</p> <p>line 15 - should 'no warranties' actually 'no warranty', alternatively 'no guarantee' would sound better here</p> <p>line 15 - 'prolonged' could be changed to 'lengthy'</p> <p>line 19 - it says 'without achieving pregnancy' but what it really meant here *and in the rest of the document* is 'pregnancy resulting in a live birth'. I believe this should be made more clear, since many couples do become pregnant during the ART process but then experience a spontaneous abortion.</p> <p>line 19 - add 'most' before the final word 'experience' (most experience difficulties adjusting...)</p> <p>line 21 - start new sentence with 'Even when a ....'</p> <p>line 24 - replace 'aftermath' with a less sensational/negative word... 'impact' for example</p> <p>line 32 - add 'studies' after 'Numerous research'</p> <p>Page 7</p> <p>line 44 - connect the two sentences with 'and' (remove 'the guideline aims'... it is repetitious)</p> <p>line 45 - add 'in the ART setting' between 'psychosocial care' and 'across'</p> <p>Page 8</p> <p>line 61 - replace 'goes from' with 'begins at'</p> <p>line 67 - replace 'pregnancy' with 'live birth' - see comment about line 19 above</p> <p>line 85 - '...to be able to deliver them' doesn't really make sense. '...to be able to address them' is better</p> | <p>Thank you for these comments; In rewriting the introduction, we have addressed most of your comments.</p>  |
|               | II | <p>Page 13 Table 2 (after line 13) - 3rd bullet point - this is the first time that 'psycho-educational interventions' are mentioned in this guideline. They may be introduced and discussed in more detail in further sections, but if the intention is for this summary to stand alone, then these 'psycho-educational intervention' and similar concepts should be introduced in this summary as well.</p>  | <p>Thanks for your comment.</p> <p>We agree with your comment. However, adding the explanation of all interventions is outside the scope of the summary. We will try to provide a link to the appropriate section for the interested reader</p> |

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|                     | II      | Page 16 - although the guidelines thus far have recommended the use of specific tools listed in Appendix A, it now specifically recommends the SCREENIVF tool in a number of sections. If this is the highest recommended tool, then perhaps it should be introduced in this summary and guidelines more thoroughly?   | Thank you for your comment. We have clarified the use of the SCREENIVF, and limited the list of tools in the appendix   |
|                     | II      | Page 17 Table - 'Behavioral needs section - this is the first time in the summary, and also the last time, that these lifestyle recommendations are mentioned. They seem out of place, since they are not directly linked back to psychosocial care.   | Thank you for your comment. In writing the key questions, we have decided to include lifestyle behaviours in the BREC needs described in this guideline. An explanation for Behavioural needs was added in the summary table. |
|                     | II      | Page 17 Table - 'Emotional needs' section - what is exactly referred to by 'emotional problems' in the first bullet point? This could be clarified if the SCREENIVF tool is properly introduced, if it indeed evaluates risk of 'emotional problems'.  | Thanks for your comment. We have tried to address your comment in updating the summary table.   |
|                     | II      | Page 18 Table - 'cognitive' section - the 'desired treatment result' is pregnancy with a healthy live birth, so why not say that?  | Thanks for your comment. We agree, we have modified this according to your comment.   |
|                     | II      | Page 20 Table - 'relationship/social' section - 1) this is the first time that 'interactive complex interventions' are mentioned in this summary. This concept should be introduced. 2) what are the 'specific characteristics associated with social isolation or absence from work'??  | Thanks for your comment. We added a footnote to define complex interventions.   |
|                     | II      | Page 22 - Table2 (Pregnancy after treatment) 'emotional' section - the 2nd bullet point does not fit within the theme of this overall section of 'how can fertility staff detect the needs of patients after treatment in case of unsuccessful treatment?' since it does not comment on an unsuccessful treatment scenario.  | Thanks for your comment. Question above the table has been changed  |
|                     | II      | Page 23 - table 1 - this table of the guideline recommends that fertility staff refer patients with unsuccessful treatment who are at risk to specialized psychosocial care, but does not provide guidance on how to evaluate this risk in these patients - is there a tool to assess this risk in this special unsuccessful population? And for how long after their last treatment are the staff responsible for following up with these patients regarding this risk?   | Thanks for your comment. We agree, this is also discussed in chapter 4 and mainly due to the absence of research on patients after unsuccessful treatment   |
|                     | General | Overall, although the summary of recommendations provides items for staff to be aware of in their patients at various points in the cycle, it lacks specific actions to be taken by fertility staff. Additionally, it seems that the recommendation is encouraging the use of questionnaire evaluation tools but which one specifically (is it SCREENIVF?) and at what point in the treatment cycle this should be administered is not clearly addressed. If it is up to the fertility staff to decide when to use this, then that should be made clear as well. | Thanks for your comment. <b>We have made the recommendation about using SCREENIVF more explicit. It is only presented in the pre-treatment period (before the start of any tr cycle)</b>                                      |
| Mariana Moura Ramos | II      | Page 15, Line 20 - The expressions "infertility stress" and "infertility distress" may be difficult to distinguish, mainly for fertility clinic staff other than psychologists and mental health professionals.  | Thanks for your comment. We agree; both are mentioned in the glossary. We tried to be correct but are   |

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|               |   | aware that clinicians may not grasp the difference in concepts. It will probably not cause confusion.   |
|               | II Page 20, Line 31- It may be difficult for fertility clinical staff (other than mental health professionals) to identify patients at risk for clinical significant psychosocial problems in order to refer them to psuchosocial support services. This assessment should be performed by mental health professionals.   | Thank you for your comment. In fact, this guideline tries to give tools to fertility staff for identifying patients at risk for problems (by listing risk factors, and informing on SCREENIVF) in order to refer them for further support.  |
|               | General This guideline provides guidance to all fertility clinic staff to deliver psychosocial care in routine infertility care (by assuring high quality care and by making referral for specialized mental health professionals in situations of clinical significance). Although there are important recommendations for all professionals, I have some concerns regarding the psychological assessment of patients needs (namely emotional and relational needs). In my view, and according to several recommendations (e.g. American Psychological Association), the use of instruments for psychological assessment is of competence of mental health professionals. Therefore, I think it is important to clarify that routine assessment of emotional adjustment must be performed by a mental health professional. | <b>Thanks for your comment. This is a good and valid point. We have updated the list of tools to limit it to those tools that can be used by all fertility staff. Even though, staff may still choose to seek assistance from a mental health professional.</b>   |
| Stina Järholm | I p6, line 25,"patients" is it both men and women or just women?  | Thanks for your comment.<br>Patients refers to both men and women.  |
|               | I p7-8 It's a contradiction between target for the guidelines were mental health professional first are included in staff/guidelines p 7, line 40-41 and then p 8 86- care that only can be given by mental health prof. not is included.   | Thanks for your comment.<br>The guideline deals with care that can be delivered by all staff (including but not only MHPs)<br>We have stated that the guideline informs about psychosocial care components that do not require the presence of mental health professionals (e.g., counsellor, psychologist) or can be delivered by any member of staff without specialised training in mental health care. Interventions that can only be delivered by mental health professionals were not considered.<br>In rewriting the introduction, we tried to clarify this further. |
|               | I P 9 line 93 GDG appear at first time and first at line 105 it's explained, should be the other way around.  | Thanks for your comment.<br>This is corrected.  |

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| II | P18 first box; What do you want the reader to be aware of with "around 1 in 12 and 1 in 5 patients do not comply with first..."   | Compliance is an important aspect of psychosocial care, and we believe it is important to know that a significant proportion of patients will not comply with recommended treatment.  |
| II | P20 Second and third box; what do you want the reader to be aware of with "the currently available (interactive) complex interventions..."  | Thanks for your comment. This is a negative recommendation informing clinicians that currently none of the described interventions has shown any benefit, saying that they should not use complex interventions. The interventions are explained in the designated chapter, but especially as they show no benefit, we think it is irrelevant to add them to the summary table.                           |
| II | P22 Box relational/social why is it important to stress that it is more likely to separate without children than with?  | Thanks for your comment. This part tries to hand tools to clinicians to identify the patients that will develop psychosocial problems (emotional/relational) after treatment, so these patients can be referred for support, There are very little studies on this topic, but one of them showed that whether or not patients have children has an impact on the development of problems after treatment. |
| II | P26, line 144- I suggest that you more explain the fact surrounding psychological and social science. That is very hard to research on clinical population regarding this questions with research methods that is "best standard". "Low quality methods" could be include if they are conducted in the best possible ways. And could also contribute as well as the chosen GPP. | Thanks for your comment. We followed the ESHRE manual to assess the quality of the research reviewed and excluded what was considered low quality research, which included qualitative research. We did consider this research when writing GPPs.   |
| 1  | P41-43, Is it not valuable concerning factors about well-being to know if the patient who had been addressed with these questions are prior, during or after treatment? Different characteristics could be associated with different periods? How come that this block is separated from the 2-3-4, before, during and after?   | Thank you for your comment. We have separated this, because it does not address specific thinks that need to be done at specific time points  |



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| General | <p>It is an ambitious and important task to implement this view for all personnel at the fertility clinics, thank you for address these questions and for all your hard work.</p> <p>Comments to 2-3-4</p> <p>However it is a general problem that the guidelines focus is "routine psychosocial care" and therefore address all fertility staff and at the same time the guidelines often investigate rather complex psychological interventions who should be performed of mental health professionals. The same problem is with the outcome investigated which often are depression or anxiety which neither could be considered as routine psychosocial care.</p> | <p>We do differentiate between value attributed to these characteristics (whether patients had or not experienced them) and satisfaction (which refers to evaluation after experiencing them).</p> <p>Thank you for your comment. You make a very good point, with no easy answer. We have made the guideline more explicit about the limits of routine psychosocial care, i.e., when patients should be referred to specialized psychosocial care (infertility counselling and psychotherapy), both in the recommendations and in the introduction. In our view, the focus on anxiety and depression is justified for several reasons</p> <ul style="list-style-type: none"> <li>- if helps to differentiate which one these two approaches needs to be implemented</li> <li>- routine psychosocial care should address low levels of anxiety or depression</li> </ul> <p>these are the outcomes more commonly assessed when looking at psychosocial needs</p> |
| General | <p>I strongly disagree about the fact that all qualitative research is left out. Research done in the best possible way and with good standard have also with this kinds of methods valuable contribution to the research field of psychology and social science.</p>   | <p>Thanks for your comment. Qualitative studies are a valuable contribution to the field, but whether these studies can be used as a valid foundation for a recommendation for clinical practice is discussable. The ESHRE guidelines considers these are of low quality for recommendations and we followed this.</p>  |
| General | <p>The expert group represent just a few of the European countries. GPP in these questions could differ among countries and therefore a broader spread group would have been a better setting for make the GPP recommendation stronger</p>  | <p>Thanks for your comment. We tried to have a representative of each part of Europe in our guideline group, but are aware of limitations, especially in finding representatives of Eastern European countries.</p>   |

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| Nicky Hudson     | General | <p>These draft guidelines and the review on which they are based represent a considerable contribution to the improvement of care and support of those undergoing fertility treatment in Europe. The objective of homogenising psychosocial support across all European countries (p7, line 45) is one which will have the potential to address the variable support that users of fertility clinics report in accounts of their experiences. The robust methodology on which this guideline was based will provide assurance to those professionals at which it is aimed.</p> <p>It is disappointing however, that the review and guidelines say little about those groups for whom tailored (rather than generic) psychosocial support could be beneficial. It is no doubt partly a reflection of the state of knowledge, but also partly an omission produced by the review methodology, that the growing body of evidence which explores patient experience and support needs in, for example, minority ethnic communities, is missing. The varying ways in which infertility is understood amongst different patient groups is an important feature of any claim for treatment and any subsequent, related psychosocial support. The very idea of 'psychosocial support' is one which is firmly rooted in a very specific (western) cultural context. Related to this is the need for information-giving which is culturally and linguistically appropriate. In the context of this guideline, this is especially important in relation to adherence to treatment (p6, line 34) for those who may not speak the majority language in any particular country.</p> <p>In light of the growing numbers of people using fertility clinics who identify as gay, lesbian, bisexual or transgender, or who are seeking treatment alone, it would also seem pertinent to include reference to the increase in diverse family forms and the potential questions this raises in the nature and delivery of 'appropriate' support.</p> <p>Much of the evidence on such minority and emergent groups is necessarily drawn from smaller scale, qualitative research, which is nonetheless based on robust design and established, evidence based methods of data collection, but which seems to be largely missing from this review. It would seem problematic to discount this body of research on the basis set out on page 165-166 (lines 218-222), since this is not the only, nor necessarily a shared objective, of the wide range of qualitative studies which exist in this field.</p> <p>Despite these limitations, the guideline group are to be commended on the desire to understand support needs across the treatment trajectory and in acknowledging infertility as a relational process, rather than a static state. It is also beneficial to see the identified research gaps and to acknowledge the important work that is urgently needed to ensure representation for all patient groups in professional guideline development.</p> | <p>Thank you for your comment on ethnic groups. It is correct that for this guideline, we have focussed on the general infertile patient in Europe. As we are aware of specific needs for specific ethnic groups, we have the intention to write complementary guidelines for these specific groups. However, as evidence and knowledge is scarce, writing these guidelines requires careful composed guideline groups with appropriate patient representatives and experts, which is not an easy task. The second comment on the growing numbers of gay lesbian, bisexual or transgender or single patients is a very good point. We have now introduced a paragraph in the guidelines introduction to address issues of inclusivity.</p> <p>We do not make any specific differentiation between patients in the recommendations because these are to address the needs ALL patients experience. As explained, additional guidelines may be developed to address specific patient populations or topics.</p> |
| Charmain Russell | I       | <p>This very clear as are the two main issues within the scope of the Guideline. Page 7 - Lines 49 and 52</p>   | Thank you   |

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|                    | II       | Again, the summary is clear and leaves staff in no doubt as to how patients respond positively when they can relate to staff and the clinic itself. Page 12 Lines 5 - 6  | Thank you  |
|                    | 1        | This will serve to raise staff awareness of patients feelings towards them and assist with 'humanising' the process. Page 13 Lines 10 & 13 and text which follows.   | Thank you.   |
|                    | 2        | Emotional needs (Page 14 - Line17 onwards) Some patients appear to be anxious but many display excitement at starting a treatment for the first time hence enhancing the disappointment and the negative feelings we recognise when treatment fails.   | Thanks for your comment.<br>We agree with your comment but do not consider it requires making changes to the text.   |
|                    | 3        | I feel these concepts can be difficult for some staff to understand (Page 18 lines 27 onwards) especially those who are not trained as counsellors or psychologists. While nursing staff, especially those with experience in the field will recognise the behavioural and emotional signs in patients, many would not define these signs as in this narrative.  | Thanks for your comment.<br>We agree with your comment and have added the explanation of the BREC needs in the summary table.  |
|                    | Appendix | Appendix 2 - Tools - page 150 - if the objective of the document is to reach nurses and doctors, the tools described are very specialised and would fall into the remit of the counsellor and psychologist in most UK clinics. These make very interesting reading notwithstanding that.   | Thanks for your comment. An introduction was added to appendix 2. The number of tools was also reduced to make it more applicable.   |
|                    | General  | This is a comprehensive guide and would provide an excellent basis for teaching and learning new skills for fertility clinic staff. It would hopefully encourage clinics to engage professionals from the psychology field to assist with some of the more complex areas of treatment and for staff to understand the emotional and behavioural stresses which is perceived in some patients, and for which staff themselves need support. | Thank you.   |
| <b>Tanja Tydén</b> | I        | First I would like to say that this is a VERY important and scientifically solid document, so I congratulate the authors.<br>Page 9, line 103-136: I don't think this information is of importance for the average staff at IVF clinics. As the guidelines are extensive and filled with so much information it takes time to read it. Some parts can be shorten.  | Thank you. We agree that the current document is not very useful for clinicians and we will work on tools to implement the recommendations in clinical practice. However, a basic document with extensive description of the basis of the recommendations is needed for trustworthiness of the guideline and the implementation tools. |
|                    | II       | Page 12 -23 This summary is excellent. It is short and concise and therefor will offer a substantial support for staff involved in IVF.<br>Page 25, Table II, also very informative  | Thank you  |
|                    | General  | This guidelines will be an important reference for health care staff involved in managing infertile women and men. It is a very good document that will used in continuous training for improved care for infertile couples.   | Thank you for your comments.<br><b>The GDG recognizes the complexity of the present document. It is not possible to make it less complex because all the</b>   |

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|                           |          | <p>The guidelines will also be very useful for researchers as each chapter gives recommendations for research.</p> <p>This is a personal reflection: As many couples in this situation also may consider adoption, such a procedure should be started in parallel with treatment for IVF. I believe that fertility staff also should be prepared to discuss adoption as an alternative.</p> <p>Comment in email : One thing that I forgot to mention is that your audience group i.e the fertility staff consists of many different professionals. These have higher and lower levels of educations. Those with higher levels (PhD) will have no problems of understanding and reading this guidelines, but for those with lower education the document might be harder to read. If possible, the document would benefit with an abstract in the very beginning, explaining that.</p>   | <p>evidence to support the guidelines must be included. However, ESHRE is committed to develop all relevant materials &amp; tools to facilitate the implementation of the guidelines, so this issue should be addressed.</p>  |
| <b>Anne Meier-Credner</b> | Appendix | <p>p.160, line 60: other important topics for further research: 10, 20 years later - what would have intended parents liked to know before their decision for Third-Party Family-building?</p>  | <p>Thanks for your comment. Third party family building was not in the scope of the guideline.</p>  |
|                           | General  | <p><b>Position of the German donor offspring organisation Spenderkinder to ESHRE's draft of "Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff"</b></p> <p><b>Guidelines should not exclusively focus on the wellbeing of the intended parents, but also on that of the future children</b></p> <p>We appreciate the fact that ESHRE develops guidelines for psychosocial support in case of infertility and medically assisted reproduction (as following: the "Guidelines") and are pleased to take the opportunity of tabling our view, which is the one of humans originating from foreign gamete donations.</p> <p>Within the process of examining the Guidelines, we noticed that they exclusively aim on the well-being resp. the psychosocial needs of the intended parents. We would like to draw attention to the fact that the well-being of the emerging humans, i.e. the children, should be taken into account as well. Certainly, this depends in substantial extent on the well-being of the parents, but there are additional and important aspects.</p> <p>In the following, we refer to the founding of a family by gamete donation as Third-Party Family-Building. Donor offspring primarily need well-informed parents, who deal self-confidently and in a reflected manner with the lifelong challenges of this special family constellation.</p> <p>At the time of the unfulfilled desire to have children and the decision for Third-Party Family-Building, there is much that occupies the couples' minds: which methods there are, how promising each one is, grief over the own infertility, fears and possibly the overcoming of unsuccessful attempts to realize the wish for a child. Based on this, psychosocial aspects, which may gain in significance only in 10, 20 years, are ignored too often.</p> | <p>Thanks for your comment. We acknowledge that the guidelines are limited in scope. As we now made clearer in the introduction, we were constrained in scope so that we could ensure feasibility while complying with the evidence-based approach recommended by the Manual for ESHRE Guideline Development.</p> <p>Future ESHRE guidelines may be developed to address specific topic such as gamete donation.</p> <p>Within the scope of the current guidelines, we tried to be inclusive in the <b>characterisation of the common needs that patients experience. Therefore, we included all studies focusing on men or specific groups (e.g., lesbian couples), as long as they focused on the aspects of care that all patients experience.</b></p> |

**Psychological care for intended parents also means to inform them actively about needs of donor offspring: early disclosure and possible interest of the children in their genetic ancestry**

Providing psychosocial care for the intended parents and the developing families therefore not only means to address the intended parents' fears and concerns, but to inform them actively about any and all substantial psychosocial aspects. Only thus can the intended parents take a conscious, responsible decision for or against a Third-Party Family-Building. In order to avoid conflicts of interest, counseling should be provided by psychosocial professionals, working independently from often ideologically and economically biased reproduction centers. Nevertheless, reproductive staff should be informed about the psychosocial challenges as well, so that they can accompany intended parents more easily.

This means in concrete terms that intended parents should be informed on the fact that research results and experiences of today grown-up donor offspring recommend an early disclosure of the children's donor origination (i.e. Blyth, Langridge & Harris, 2010; Rumball & Adair, 1999). In addition, they should know that most donor offspring who know about their donor conception sooner or later develop an interest in knowing/getting to know their biological father (Beeson, Jennings & Kramer, 2011; Hertz, Nelson & Kramer, 2013; Scheib, Riordan & Rubin, 2005; Blake, Casey, Jadva & Golombok, 2013)

**Donor offspring need strong and supportive parents who are able to talk openly about their decision to chose Third Party Family Building**

Intended parents should only opt for Third-Party Family-Building when they are ready to openly hold on to/stand by their decision. Donor offspring need parents who are able to support them and whom they can talk to about their unusual and challenging family constellation. They need parents who accompany and support them if they develop an interest in the donor as unknown third. There is a certain danger of parentification as soon as children develop the feeling of being obliged to protect their parents in order to avoid a serious dispute with them or to make them unhappy, because the parents are overexerted with the challenges of the family constellation.

Other family-dynamic aspects, which should be brought up for discussion actively with intended parents, are the unequal initial position of intended parents since only the mother is biologically related to the child (Becker, Butler & Nachtigall, 2005). Regularly, parents express the fear that the social father may be rejected by the child (Lalos, Gottlieb & Lalos, 2007) or that the knowledge of infertility might be used as a hurting weapon against the biologically non-related parental unit (Kirkman, 2004). This asymmetrical relationship to the child may lead to tensions between the partners and - unfortunately - to the fact that parents do not disclose their donor origin to the offspring.

**Guidelines do not adress the already existing knowledge about the needs of the intended father**

The majority of the Guidelines is supposed to improve the backgrounding and support of the intended mothers and criticizes the lack of knowledge over the needs of the intended fathers. Therefore, at least the existing knowledge should be incorporated in the guidelines. The burden of the infertile men is frequently overlooked by men themselves and mostly becomes apparent only years later (Thorn & Wischmann, 2014; Indekeu et al., 2012). The social fathers of donor offspring only tentatively address their feelings and therefore often have serious problems with the necessary/required open interaction about their Third-Party Family-Building (Beeson, Jennigs, Kramer, 2011). The feeling of loss after being diagnosed as infertile can be so overwhelming that some intended parents initially consider a Third-Party Family-Building only a pragmatic way to become parents - before they evaluate the genetic connection anew from their future childrens' point of view (Kirkman, 2004).

The donor plays an existential role for Third-Party Family-Building and thus for the family. Even if parents try to reduce him to his function as donor, he is a man of flesh and blood the child would most probably like to become acquainted with in the course of its life.

The (ambivalent) feelings of these men should actively be addressed for discussion with the intended fathers, even if the intended fathers articulate no need for dialogue. These topics include their infertility, the humiliation by the potent donor, from whom their wife possibly expects a child, their feelings towards their genetically not related foreign child and the intended mother, who - in contrary to them - additionally is biologically connected to the child, as well as their conceptions of how they would like to take on their social father role. The problems of the men are not necessarily expressed by clinically relevant anxiety disorders or depressions. The family-dynamic coherences are more complex and become apparent/appear with some men e.g. by uncertain behaviour towards the child, indifferent emotions, which they are not able to explain by themselves - like tensions with the female partner - although they should actually feel lucky to have become father. Here, a major need of backgrounding exists for the well-being of the men and for the relationship to their wife and child.

Based on the above-mentioned reasons, it is our belief that Third-Party Family-Building is a very challenging form of family-building and should never be advised or undertaken lightheartedly. In each case, we recommend informing the intended parents thoroughly on the psychosocial implications of Third-Party Family-Building.

In many European countries as Sweden, the UK, the Netherlands, Austria, Switzerland, and, as of latest, Ireland), it goes without saying that donor offspring can get to know their biological processors. We would like to point out that we regard this right as a basic condition for respecting and addressing the needs of (grown-up) donor offspring.

We hope you will consider our remarks with regard to the Guidelines and wish you every success with your work.

Yours sincerely

Anne Meier-Credner

(Founding member of Spenderkinder, Member of BKiD)

#### References:

- Becker G, Butler A, Nachtigall R (2005) [Resemblance talk: A challenge for parents whose children were conceived with donor gametes in the US](#). *Social Science & Medicine* 61 (2005), p. 1300–1309, p. 1307.
- Beeson D, Jennings P, Kramer W (2011) [offspring searching for their sperm donors: how family type shapes the process](#). *Human Reproduction* 9 (26), p. 2415-2424, p. 2419.
- Beeson D, Jennigs P, Kramer W (2011), [Offspring searching for their sperm donors: how family type shapes the process](#). *Human Reproduction* (9) 26, p. 2415–2424, p. 2422.
- Blake L, Casey P, Jadvva V, Golombok S (2013) [‘I Was Quite Amazed’: Donor Conception and Parent–Child Relationships from the Child’s Perspective](#). *Children & Society*, p. 10.
- Blyth E, Langridge D, Harris R (2010) [Family building in donor conception: parents' experiences of sharing information](#), in: *Journal of Reproductive and Infant Psychology* (2) 28, p. 116-127, p. 124-125.
- Hertz R, Nelson M, Kramer W (2013) [Donor conceived offspring conceive of the donor: The relevance of age, awareness, and family form](#). *Social Science & Medicine* 86, p. 52-65, p. 56.
- Indekeu A et. al. (2012) [Parenthood motives, well-being and disclosure among men from couples ready to start treatment with intrauterine insemination using their own sperm or donor sperm](#). *Human Reproduction* (1) 27, p. 159–166, p. 164.
- Kirkman M (2004) [Genetic Connection And Relationships in Narratives Of Donor-Assisted Conception](#). *Australian Journal of Emerging Technologies and Society* (1) 2, p. 1-21, p. 12.
- Kirkman M (2004) [Genetic Connection And Relationships in Narratives Of Donor-Assisted Conception](#). *Australian Journal of Emerging Technologies and Society* (1) 2, p. 1-21, p. 15.
- Lalos A, Gottlieb C, Lalos O (2007) [Legislated right for donor-insemination children to know their genetic origin: a study of parental thinking](#). *Human Reproduction* (6) 22, p. 1759–1768, p. 1766.
- Rumball A, Adair V (1999) [Telling the story: parents' scripts for donor off-jump](#). *Human Reproduction* (5) 14 p.1392-1399, p. 1397.
- Scheib J, Riordan M, Rubin S (2005) [Adolescents with open-identity sperm donors: reports from 12–17 year olds](#). *Human Reproduction* (1) 20, p. 239–252, p. 248.
- Thorn P, Wischmann T (2014) [Der Mann in der Kinderwunschbehandlung \(unter besonderer Berücksichtigung der donogon Insemination\)](#). *Journal für Reproduktionsmedizin und Endokrinologie*, Pre-Publishing Online.

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| Heribert Kentenich | I | Page 7, line 40: The guideline is for the clinical staff (doctors, nurses, counsellors, social workers, psychologists, embryologists, etc..) Here (or at another place) it should be mentioned that the tasks of the staff regarding the patients care in general are the same, but in part different.   | Thanks for your comment. We have rewritten this paragraph to address your comment.   |
|                    | I | It is also depending on the socio-cultural background of countries and legal differences in Europe (line 43). But as a result: the psychosocial care is different in Europe in a substantial way. For instance, in Germany, the psychosocial care is mainly done by the physicians (when it’s done). We have guidelines what the physicians should provide within their own psychosocial care. We have no legal guidelines regarding psychosocial care done by counsellors and nurses. In the UK (from my point of view) the psychosocial care is mainly done by nurses and counsellors and regulated by HFEA. | Thank you for your comment. We are aware of social-cultural and legal differences across Europe, as describe in the section “Target users of the guideline”. For any European guideline, clinicians should apply the recommendations while taking into account their preferences and those of their patients, but also specific national policies, legal perspective, cultural issues,, costs, reimbursement, etc. |
|                    | I | One should emphasize that (following the needs of the patients) all relevant persons of the staff have to provide psychosocial care, but with a different focus.   | Thanks for your comment.   |

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|          |   | This is a reasonable inference to make but there is no data on how these should be different, at least when we are talking about general psychosocial care, so I think it is risky to venture into this.  |
| 1        | <p>Page 28, line 16: Here again: What are the key questions for doctors, counsellors, psychologists?</p> <p>Page 30, line 85: One should mention that the staff behaviours can be different regarding their position in the unit and their position regarding their care of the patients.</p> <p>Page 41, line 425: Again: What are the different needs of the different staff members.</p> | <p>Thanks for your comment.</p> <p>All recommendations are written for staff members that have routine contact with patients are meant to provide psychosocial support. Who these staff members are is dependent on how each clinic organises routine care. Psychologists/counsellors can be involved in routine care but should definitely be involved if patients are experiencing significant distress</p> <p>This first section of the guidelines focus on characteristics that ALL staff members should possess (according to patients' opinion)</p> |
| 4        | Page 124, line 3-17: In the long run (after treatment) the patients go back to their gynecologists or their GP's. In that respect these physicians should know about the treatment and what has been done in the past..   | Thanks for your comment. This comment is valid, but is a more general point about all clinical practice, not specific to the fertility clinic.  |
| Appendix | Page 148, line 91: Give a definition of staff.  | Thanks for your comment. A definition was added.  |
| General  | Very good guideline. Congratulations to those, who were involved. But my main concern is, that within the staff following the patients' needs the aims of the involved persons (doctors, nurses, etc.) are in general the same but in part different.   | <p>Thanks for your comment. This is a very good point.</p> <p>The guidelines are trying to state that providing psychosocial care that promotes quality of life during treatment should be a goal shared by all staff members (not the solely responsibility of MHPs).</p> <p>We realize there is a different between providing advice and its actual implementation at clinics. An issue for the field to address in the future. ESHRE will</p>  |



work to promote the guidelines  
dissemination and implementation.

## OTHER COMMENTS

| Reviewer                              | Chapter | Comments  | Reply  |
|---------------------------------------|---------|---|--|
| <b>Wendy Kramer</b>                   | General | <p>This guide seems to be only focused on a patient's needs while achieving pregnancy. What about the patient's/family's needs after pregnancy? This is advice that will be needed for decades to come. What about advice on openness and honesty within families? What about the research that shows that withholding the truth can be damaging to families? Pregnancy and babyhood are very short periods of time, compared to the many years of raising and dealing with the issues of donor conceived children and then adults- many who long to know about their ancestry, medical backgrounds, and genetic relatives. Many who are curious and search for, and find their genetic relatives.</p> <p>Can a section about actually parenting these children be added? Psychological care of parents should include much more than just achieving pregnancy.</p>   | <p>Thanks for your comment.</p> <p>We acknowledge that the guidelines are limited in scope. As we now made clearer in the introduction, we were constrained in scope so that we could ensure feasibility while complying with the evidence-based approach recommended by the Manual for ESHRE Guideline Development.</p> <p>Future ESHRE guidelines may be developed to address specific topics such as gamete donation, welfare of the child, etc..</p>   |
| <b>Maria Cristina Sousa Canavarro</b> | General | <p>In advance, I would like to apologize for sending this email so close to the deadline revision of the ESHRE guideline "Routine psychosocial care in infertility and medically assisted reproduction – A guide for fertility staff".</p> <p>I would like to thank you for referring me as a reviewer of this guideline, that I found to be very well structured and written, with an important review of the research about the adaptation of these couples. However, it was impossible for me to have the time needed to review this guideline as profoundly as I wanted and as I think it is needed to be part of the reviewers list.</p> <p>Nevertheless I would like to make a comment. This guideline is focused on guiding the health professionals on how to provide psychosocial care to infertile couples. However, is not this the role of the psychologists? Although the skills, the competence and the training that the psychologists have to be members of the fertility staff and to provide this kind of support, this guideline do not specified their roles. And I think that this clarification is essential in this guideline developed by the ESHRE psychology group.</p> <p>Kind regards,<br/>Cristina</p> | <p>Thanks for your comment.</p> <p>The GDG recognises that this is a very important question. However, the guidelines focus on how routine psychosocial care should be provided to patients. We state that all staff should be involved in this task because the psychosocial wellbeing of patients should not be the solely responsibility of mental health professionals.</p> <p>It is not possible to provide more precise guidance on who should do what because there is huge variability in how care is organized at clinics across different European Countries and this is many times constrained by cultural, social and even legal factors. In addition, ultimately, there is no evidence showing that task X (e.g., information provision) is more effective when done by different members of staff. However, we explicitly state that counselling</p> |

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and psychotherapy should only be provided by MHPs.

This approach is in line with the bio-psychosocial and patient centred models of care and has been advocated and implemented across different health conditions.

Finally, please note that we also do not make any specific comments about the role of other staff members within the clinic.

We revised the introduction to make these issues clearer.