

D.4 Information and support

Item	Details
Area in the scope	Information and support for women with endometriosis
Review question in the scope	What information and support do women with endometriosis and their families and carers need?
Review question for the guideline	What information and support do women with endometriosis and their families find helpful and what are the barriers and facilitators in the provision of these information and support needs?
Objective	<p>To discover what information and support makes a positive difference to women and their families when diagnosed with endometriosis, including women's reports of what information and/or support they would have liked.</p> <p>Tree objectives have been set up:</p> <ul style="list-style-type: none"> • To explore the areas of information and support that women and their families find helpful. • To test the effectiveness of interventions or package of care to provide additional information and support needs compared to usual care • To see how they would like to receive this information or support
Population and directness	<ul style="list-style-type: none"> • Women with endometriosis of any stage or severity. • Women with a suspected diagnosis of endometriosis (definition: suspected diagnosis based on the history of the patient, pelvic examination and other tests such as ultrasound, MRI and the CA-125 blood test) • Family or partners of women with confirmed or suspected endometriosis <p>Exclusions:</p> <ul style="list-style-type: none"> • Studies with indirect populations (such as women with dysmenorrhea, women with non-confirmed pelvic pain, or post-menopausal women) • women with chronic pelvic pain which was known to be due to causes other than endometriosis • Those suspected based solely on a CA-125 test with no other contributing factor, CA-125 should be used in combination with other evaluative measures. • Studies with mixed populations of women with pelvic pain where less than 66% of women have a diagnosis of endometriosis
Intervention – information and support (quantitative)	<ul style="list-style-type: none"> • Support groups • Volunteer supporters • Helplines • Methods of information provision (Tools to facilitate) <ul style="list-style-type: none"> ○ Verbal ○ Written ○ Online (and online networks) ○ Apps ○ In groups (peer groups) online or face or face to face ○ 1:1 advocacy support

Item	Details
	<ul style="list-style-type: none"> ○ Online health forum
Comparison	<p>Additional information and support with no comparator</p> <p>Additional information and support vs usual care</p>
Context and perspective (qualitative)	<p>Context</p> <p>Information content and type and support needs with regards to endometriosis for women confirmed or suspected of having the condition as well as their family, partner.</p> <p>Themes</p> <p>Themes will be identified from the literature, but expected themes are:</p> <ul style="list-style-type: none"> ● Methods of information provision (Tools to facilitate): <ul style="list-style-type: none"> ○ Verbal ○ Written ○ Online (and online networks) ○ Apps ○ In groups (peer groups) online or face or face to face ○ 1:1 advocacy support ○ Online health forum ● Choice and options (treatment related): <ul style="list-style-type: none"> ○ Information needs with regards to treatments for pain or fertility (pharmacological, surgical and non-pharmacological) ● Information content: <ul style="list-style-type: none"> ○ Provision of basic information: what is endometriosis, signs/symptoms, guidance for medical appointments and what to expect) ○ Impact on relationships ○ Support for husbands/partners and families ○ Sexual health/psychosexual effects ○ Support for adolescents with endometriosis ○ Misconceptions ○ Mental health
Outcomes (quantitative)	<ul style="list-style-type: none"> ● Health related quality of life ● Psychological wellbeing outcomes (any including post-traumatic stress disorder, and anxiety) ● Knowing choices available/able to make informed decisions including involvement in decision-making ● Participant satisfaction with treatment (measured as proportion of women who reported improvements and satisfaction with their treatment)
Importance of outcomes	<p>Preliminary classification of the outcomes for decision making:</p> <p>Critical (up to 3 outcomes):</p> <ul style="list-style-type: none"> ● Health related quality of life ● Psychological wellbeing ● Participant satisfaction <p>Important but not critical (up to 3 outcomes)</p> <ul style="list-style-type: none"> ● Improved decision making
Setting	All settings
Stratified, subgroup and	<p>Groups that will be reviewed and analysed separately:</p> <p>Pre-specified sub-group analyses:</p> <ul style="list-style-type: none"> ● Young women

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adjusted analyses	
Language	English
Study design	<p>Systematic reviews of RCTs or Systematic reviews of qualitative studies RCTs Comparative cohort studies Qualitative studies Cross sectional studies</p> <p>In absence of full text published RCT and Conference abstracts are being considered. RCTs with <10 participants and observational studies with <30 participants will not be considered</p>
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, CENTRAL, CDSR, DARE, HTA, Embase Limits (e.g. date, study design): Limit to English language and human-only studies where appropriate Supplementary search techniques: No supplementary search techniques will be used. See appendix for full strategies</p>
Review strategy	<p>Appraisal of methodological quality: State how this will be assessed, e.g. The methodological quality of each study should be assessed using checklists (eg AMSTAR for systematic reviews, Cochrane RoB tool for RCTs, CASP for cohort studies) and the quality of the evidence for an outcome (or a theme / review finding) across studies will be assessed using GRADE or a GRADE CERQual approach for qualitative research. Synthesis of data quantitative: State the method of analysis, e.g. meta-analysis will be conducted where appropriate. If comparative cohort studies are included, multivariable analysis evidence will be used wherever possible and only if no multivariable evidence is identified will univariate analysis be considered MIDs: default MIDs will be used: 0.8 and 1.25 for dichotomous outcomes; 0.5 times SD for continuous outcomes. Synthesis of qualitative data: Evidence will be summarised by theme and the quality of the themes will be assessed across studies using a process like GRADE but adapted for qualitative information GRADE-CERQual. A theme map may also be presented if there is sufficient information identified in the search.</p>
Equalities	<p>Women receiving information through an interpreter Adolescents are noted as a specific subgroup requiring consideration in the equalities impact assessment</p>
Notes/additional information	