# File S1: Systematic review search strategy

# Medline/Emcare/Embase

- 1. Chronic Pain/
- 2. ((chronic or persist\*) adj3 pain).mp.
- 3. 1 or 2
- 4. exp Pelvic Pain/
- 5. (pelvi\* adj3 pain).mp.
- 6. (pelvi\* adj3 (pain management)).mp.
- 7. exp Cystitis/
- 8. exp Vulvitis/
- 9. Endometriosis/
- 10. Vulvodynia/
- 11. Dyspareunia/
- 12. Dysmenorrhea/
- 13. exp Ovarian Cysts/
- 14. Vaginismus/
- 15. Adenomyosis/
- 16. Pudendal Neuralgia/
- 17. Varicocele/
- 18. Prostatitis/
- 19. Orchitis/
- 20. Fissure in Ano/
- 21. Epididymitis/
- 22. exp Inflammatory Bowel Diseases/
- 23. Irritable Bowel Syndrome/
- 24. (cystitis or interstitial cystitis or (pain\* adj3 bladder) or pyelocystitis).mp.
- 25. (vulvitis or vulv\* vestibulitis or vulvovaginitis or vestibulodynia or vulvodynia or (vulv\* adj3 pain)).mp.
- 26. ((pain\* adj3 ovulation) or mittelschmerz or (pain\* adj3 ovulationmittelschmerz)).mp.
- 27. endometriosis.mp.
- 28. (dyspareunia or dysmenorrh?ea).mp.
- 29. ((ovar\* adj3 cyst\*) or (polycyst\* adj3 ovar\*)).mp.
- 30. vaginismus.mp.
- 31. adenomyosis.mp.
- 32. (pelvi\* adj3 congest\*).mp.
- 33. ((cycl\* pelvi\* adj3 pain) or (noncycl\* pelvi\* adj3 pain) or (genit\* adj3 pain)).mp.
- 34. (perineal adj3 pain).mp.
- 35. fibriod\*.mp.
- 36. (prostatitis or (prostate adj3 pain) or chronic pelvic pain syndrome of the male or prostatodynia).mp.
- 37. (orchitis or (testic\* adj3 pain) or orchalgia or orchiodynia).mp.
- 38. ((anal adj3 pain) or proctalgia fugax).mp.
- 39. (epididymitis or (epididym\* adj3 pain)).mp.
- 40. ((pelvi\* floor adj3 pain) or (pelvi\* girdle adj3 pain) or (pelvi\* muscle adj3 pain)).mp.
- 41. (peni\* adj3 pain).mp.
- 42. Pudendal Neuralgia.mp.

- 43. (scrot\* adj3 pain).mp.
- 44. (urethra\* adj3 pain).mp.
- 45. Varicocele.mp.
- 46. (fissure in ano or (anal adj3 fissure)).mp.
- 47. (inflammatory bowel disease or crohn\* disease or ulcerative colitis).mp.
- 48. (irritable adj2 bowel).mp.
- 49. 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49
- 50. guideline/ or practice guideline/
- 51. consensus/
- 52. ((clinic\* or practi\$e) adj3 guideline\*).mp.
- 53. guideline\*.mp.
- 54. consensus.mp.
- 55. (consensus adj3 statement).mp.
- 56. (clinic\* adj3 (recommend\* or protocol)).mp.
- 57. 51 or 52 or 53 or 54 or 55 or 56 or 57
- 58. 3 and 50 and 58

# Web of Science

TOPIC:((chronic or persistent) near/3 pain) AND TOPIC: ((pelvi\* near/3 pain) or cystitis or 'interstitial cystitis' or (pain\* near/3 bladder) or pyelocystitis or vulvitis or 'vulv\* vestibulitis' or vulvovaginitis or vestibulodynia or vulvodynia or (vulv\* near/3 pain) or (pain\* near/3 ovulation) or mittelschmerz or (pain\* near/3 ovulationmittelschmerz) or endometriosis or dyspareunia or dysmenorth?ea or (ovar\* near/3 cyst\*) or (polycyst\* near/3 ovar\*) or vaginismus or adenomyosis or (pelvi\* near/3 congest\*) or (cycl\* pelvi\* near/3 pain) or (noncycl\* pelvi\* near/3 pain) or (genit\* near/3 pain) or (perineal near/3 pain) or fibroid\* or prostatitis or (prostate near/3 pain) or 'chronic pelvic pain syndrome of the male' or prostatodynia or orchitis or (testic\* near/3 pain) or orchalgia or orchiodynia or (anal near/3 pain) or 'proctalgia fugax' or epididymitis or (epididym\* near/3 pain) or ('pelvi\* floor' near/3 pain) or ('pelvi\* girdle' near/3 pain) or ('pelvi\* muscle' near/3 pain) or (peni\* near/3 pain) or 'Pudendal Neuralgia' or (scrot\* near/3 pain) or (urethra\* near/3 pain) or Varicocele or 'fissure in ano' or (anal near/3 fissure) or 'inflammatory bowel disease' or 'crohn\* disease' or 'ulcerative colitis' or (irritable near/2 bowel)) AND TOPIC: (guideline or (clinic\* near/3 guideline) or consensus or (consensus near/3 statement) or (clinic\* near/3 (recommend\* or protocol))(clinical near/2 guideline))

**Refined by:** [excluding] **Databases:** (MEDLINE)

Timespan: All years. Databases: WOS, CCC, KJD, MEDLINE, RSCI, SCIELO.

# **Scopus**

(TITLE-ABS-KEY ((chronic OR persist\*) W/3 pain) AND TITLE-ABS-KEY ((pelvi\* W/3 pain ) OR cystitis OR "interstitial cystitis" OR (pain\* W/3 bladder ) OR pyelocystitis OR vulvitis OR "vulv\* vestibulitis" OR vulvovaginitis OR vestibulodynia OR vulvodynia OR ( vulv\* W/3 pain ) OR (pain\* W/3 ovulation)) OR TITLE-ABS-KEY (mittelschmerz OR ( pain\* W/3 ovulationmittelschmerz) OR endometriosis OR dyspareunia OR dysmenorrh?ea OR (ovar\* W/3 cyst\*) OR (polycyst\* W/3 ovar\*) OR vaginismus OR adenomyosis OR (pelvi\* W/3 congest\*)) OR TITLE-ABS-KEY (("cyclic pelvic" W/3 pain) OR ("noncyclic pelvic" W/3 pain ) OR (genital W/3 pain ) OR (perineal W/3 pain ) OR fibroid\* OR prostatitis OR (prostate W/3 pain) OR "chronic pelvic pain syndrome of the male" OR prostatodynia OR orchitis ) OR TITLE-ABS-KEY ( (testic\* W/3 pain ) OR orchalgia OR orchiodynia OR (anal W/3 pain ) OR "proctalgia fugax" OR epididymitis OR (epididym\* W/3 pain ) OR ("pelvic floor" W/3 pain ) OR ("pelvic girdle" W/3 pain ) OR ("pelvic muscle" W/3 pain ) OR (penile W/3 pain)) OR TITLE-ABS-KEY ("Pudendal Neuralgia" OR (scrot\* W/3 pain) OR ( urethra\* W/3 pain ) OR varicocele OR "fissure in ano" OR (anal W/3 fissure ) OR "inflammatory bowel disease" OR "crohn? disease" OR "ulcerative colitis" OR (irritable W/2 bowel)) AND TITLE-ABS-KEY (guideline OR (clinic\* W/3 guideline) OR consensus OR ( consensus W/3 statement) OR (clinic\* W/3 (recommend\* OR protocol))))

### The Cochrane Library

- #1 MeSH descriptor: [Chronic Pain] explode all trees #2 ((chronic or persist\*) near/3 pain)
- #3 #1 OR #2
- #4 MeSH descriptor: [Pelvic Pain] explode all trees
- #5 (pelvi\* near/3 pain) OR (pelvi\* near/3 (pain management)).
- #6 MeSH descriptor: [Cystitis] explode all trees
- #7 MeSH descriptor: [Vulvitis] explode all trees
- #8 MeSH descriptor: [Endometriosis] this term only
- #9 MeSH descriptor: [Vulvodynia] this term only
- #10 MeSH descriptor: [Dyspareunia] explode all trees
- #11 MeSH descriptor: [Dysmenorrhea] explode all trees
- #12 MeSH descriptor: [Ovarian Cysts] explode all trees
- #13 MeSH descriptor: [Vaginismus] explode all trees
- #14 MeSH descriptor: [Adenomyosis] explode all trees
- #15 MeSH descriptor: [Pudendal Neuralgia] this term only
- #16 MeSH descriptor: [Varicocele] this term only
- #17 MeSH descriptor: [Prostatism] explode all trees
- #18 MeSH descriptor: [Orchitis] this term only
- #19 MeSH descriptor: [Fissure in Ano] this term only
- #20 MeSH descriptor: [Epididymitis] this term only
- #21 MeSH descriptor: [Inflammatory Bowel Diseases] explode all trees
- #22 MeSH descriptor: [Irritable Bowel Syndrome] this term only
- #23 cystitis or "interstitial cystitis" or (pain\* near/3 bladder) or pyelocystitis
- #24 vulvitis or "vulv\* vestibulitis" or vulvovaginitis or vestibulodynia or vulvodynia or (vulv\* near/3 pain)
- #25 (pain\* near/3 ovulation) or mittelschmerz or (pain\* near/3 ovulationmittelschmerz)
- #26 endometriosis
- #27 dyspareunia or dysmenorrh?ea
- #28 (ovar\* near/3 cyst\*) or (polycyst\* near/3 ovar\*)
- #29 vaginismus
- #30 adenomyosis
- #31 (pelvi\* near/3 congest\*)
- #32 ("cycl\* pelvi\*" near/3 pain) or ("noncycl\* pelvi\*" near/3 pain) or (genit\* near/3 pain)
- #33 (perineal near/3 pain)
- #34 prostatitis or (prostate near/3 pain) or "chronic pelvic pain syndrome of the male" or prostatodynia
- #35 orchitis or (testic\* near/3 pain) or orchalgia or orchiodynia
- #36 (anal near/3 pain) or "proctalgia fugax"
- #37 epididymitis or (epididym\* near/3 pain)
- #38 (pelvi\* floor near/3 pain) or (pelvi\* girdle near/3 pain) or (pelvi\* muscle near/3 pain)
- #39 (peni\* near/3 pain)
- #40 "Pudendal Neuralgia"
- #41 (scrot\* near/3 pain)
- #42 (urethra\* near/3 pain)
- #43 Varicocele
- "fissure in ano" or (anal near/3 fissure)

- "inflammatory bowel disease" or "crohn\* disease" or "ulcerative colitis" #45 #46 #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 #47 MeSH descriptor: [Consensus] this term only MeSH descriptor: [Practice Guidelines as Topic] explode all trees #48 #49 (clinic\* or practice) near/3 guideline\* #50 consensus
- #51 (consensus near/3 statement)
- clinic\* near/3 (recommend\* or protocol) #52
- #47 OR #48 OR #49 #50 OR #51 OR #52 #53
- #54 #3 AND #46 AND #53

Note: Removed Fibriod\*, (irritable adj2 bowel) = no hits

#### **Guideline databases**

Australian Clinical Practice Guidelines,<sup>1</sup> Scottish Intercollegiate Guidelines Network,<sup>2</sup> The Guidelines International Network,<sup>3</sup> the National Institute for Health and Care Excellence,<sup>4</sup> the World Health Organisation,<sup>5</sup> the New Zealand Guidelines Group,<sup>6</sup> BCGuidelines,<sup>7</sup> eGuidelines,<sup>8</sup> and The Royal Women's Hospital.<sup>9</sup>

- 1. Government A. Australian Clinical Practice Guidelines. 2020 [cited 2020 15 June]; Available from: <a href="https://www.clinicalguidelines.gov.au/">https://www.clinicalguidelines.gov.au/</a>
- 2. Network SIG. Improving patient care through evidence-based guidelines. 2020 [cited 2020 15 June]; Available from: <a href="https://www.sign.ac.uk/">https://www.sign.ac.uk/</a>
- 3. Network GI. The Guidelines International Network. 2020 [cited 2020 15 June]; Available from: <a href="https://g-i-n.net/home">https://g-i-n.net/home</a>
- 4. Excellence NIfHaC. National Institute for Health and Care Excellence. 2020 [cited 2020 15 June]; Available from: <a href="https://www.nice.org.uk/">https://www.nice.org.uk/</a>
- 5. Organisation WH. WHO guidelines approved by the Guidelines Review Committee. 2020 [cited 2020 15 June]; Available from: <a href="https://www.who.int/publications/guidelines/en/">https://www.who.int/publications/guidelines/en/</a>
- 6. Government NZ. New Zealand Guidelines Group. 2015 [cited 2020 15 June]; Available from: <a href="https://www.health.govt.nz/about-ministry/ministry-health-websites/new-zealand-guidelines-group">https://www.health.govt.nz/about-ministry/ministry-health-websites/new-zealand-guidelines-group</a>
- 7. Columbia GoB. BC Guidelines. 2020 [cited 2020 15 June]; Available from: https://www2.gov.bc.ca/gov/content/health/practitioner-professional-resources/bc-guidelines
- 8. eGuidelines. Guidelines. 2020 [cited 2020 15 June]; Available from: <a href="https://www.guidelines.co.uk/">https://www.guidelines.co.uk/</a>
- 9. Hospital TRWs. Clinical Guidelines. 2020 [cited 2020 15 June]; Available from: <a href="https://www.thewomens.org.au/health-professionals/clinical-resources/clinical-guidelines-gps">https://www.thewomens.org.au/health-professionals/clinical-resources/clinical-guidelines-gps</a>

# Google Scholar/Google search

Clinical guideline OR consensus

AND chronic pelvic pain

**AND Cystitis** 

AND Painful bladder

AND Vulvitis

AND vulvovaginitis

AND vestibulodynia

**AND** Endometriosis

AND Vulvodynia

AND Vulvar pain

AND Painful ovulation

AND mittelschmerz

AND Dyspareunia

AND Dysmenorrhea

AND Ovarian Cyst

AND Vaginismus

AND Adenomyosis

AND pelvic congestion

AND cyclic pelvic pain

AND non-cyclic pelvic pain

AND genital pain

AND perineal pain

AND fibroid

AND Pudendal Neuralgia

AND Varicocele

**AND Prostatitis** 

AND 'chronic pelvic pain syndrome of the male'

AND prostatodynia

**AND** Orchitis

AND testicular pain

AND orchalgia

AND anal pain

AND 'proctalgia fugax'

AND Pelvic floor pain

AND Pelvic girdle pain

AND Penile pain

AND scrotum pain

AND urethra pain

AND "Fissure in Ano"

AND Epididymitis

AND Inflammatory Bowel Disease

AND crohns disease

AND ulcerative colitis

AND Irritable Bowel Syndrome

 ${\bf Table~S1:~Classification~of~overall~score~for~guideline~AGREE-II~quality~appraisal}$ 

Overall score	Classification	Quality	Recommendation for use
1.0	<50% score of domain 3, <70% score of domain 6, maximum 2 satisfactory domains, no excellent domains Poor		No
2.0	<50% score of domain 3 and <70% score of domain 6, minimum 1 excellent domain		
3.0	>50% score of domain 3 OR >70% score of domain 6, minimum 3 poor domains	Satisfactory	Yes, with
4.0	>50% score of domain 3 OR >70% of domain 6, maximum 2 poor domains		modifications
5.0	>50% score of domain 3, >70% score of domain 6, minimum 3 excellent, maximum 2 poor domains		
6.0	>50% score of domain 3, >70% score of domain 6, maximum 2 satisfactory domains OR maximum 1 poor domain	Excellent	Yes
7.0	>50% score of domain 3, >70% score of domain 6, maximum 1 satisfactory domain, no poor domains		

AGREE, Appraisal of Guidelines for Research and Evaluation.

Table S2: Classification of recommendation grades, definition, and examples of grading system terminology from guidelines

Recommendation grade classification	Definition	Examples of grading system terminology from guidelines
"High"	"High" grade recommendations were those that were strongly recommended or supported by high levels of evidence by the CPG.	GoR "A" – Evidence derived from meta-analysis <sup>31</sup> or RCT, good quality and consistency addressing recommendation. <sup>46</sup> LoE 1-1/2, 1a/b, 4 crosses – High quality meta-analyses, systematic reviews, RCTs with high risk of bias, high quality evidence. <sup>40,44</sup>
"Moderate"	"Moderate" grade recommendations were those that were recommended to be fair or supported by evidence of well-designed studies by the CPG.	GoR "B" – Meta-analysis or multiple randomized trials of moderate quality, <sup>33</sup> recommendations based on limited or inconsistent scientific evidence. <sup>46</sup> LoE 11-1/2, 3 crosses – Well-designed, non-randomized controlled trials, <sup>30</sup> well-designed cohort or case-controlled studies. <sup>29</sup>
"Low"	"Low" grade recommendations were those that could be recommended or supported by low quality, conflicting evidence in the CPG.	GoR "C" – Insufficient and/or conflicting evidence to support recommendation. <sup>40,43</sup> LoE 11-3, 3, 1/2 crosses – Non-analytical studies, <sup>29</sup> evidence obtained from multiple time series with or without the intervention. <sup>44,45</sup>
"Expert opinion"	"Expert opinion" recommendations are those provided in the guidelines at the discretion of the author's views/clinical experience with no direct evidence to support its use in the CPG.	GoR "D", "E", "Expert consensus" – Evidence from expert committee reports or opinions, clinical experience of respected authorities. <sup>42,44</sup> LoE 3 – Opinions of respected authorities, based on clinical experience. <sup>37,45</sup>
"Not provided"	Recommendations included in the CPG not supported with a relevant GoR or LoE.	GoR/LoE not provided. <sup>28,35,41</sup>

CPG, clinical practice guideline; GoR, Grade of recommendation; LoE, Level of evidence; RCT, randomized controlled trial

**Table S3: Excluded articles** 

Study	Reasons for exclusion
Ramahi & Richardson 1990 <sup>10</sup>	Could not access full text
ACOG Committee on Practice Bulletins-Gynecology 2004 <sup>11</sup>	Outdated
Maturen et al. 2018 <sup>12</sup>	Only specifies one diagnostic/treatment strategy
Cek et al. 2017 <sup>13</sup>	Not a guideline
Ali et al. 2018 <sup>14</sup>	Retracted
As-Sanie et al. 2019 <sup>15</sup>	Not a guideline
Hanno et al. 2010 <sup>16</sup>	Other
Irwin 2010 <sup>17</sup>	Not a guideline
Forrest et al. 2009 <sup>18</sup>	Not a guideline
Siedentopf & Rauchfuss 2010 <sup>19</sup>	Publication not in English
Wesselmann 2003 <sup>20</sup>	Not a guideline
Hartmann & Sarton 2014 <sup>21</sup>	Not a guideline
ACOG 2004 <sup>22</sup>	Outdated
Kuznetsova 2013 <sup>23</sup>	Could not access full text
Varma & Gupta 2005 <sup>24</sup>	Not a guideline
Moormann 2015 <sup>25</sup>	Not a guideline
Clere 2010 <sup>26</sup>	Publication not in English
Ramsden et al. 2018 <sup>27</sup>	Not a guideline
Daniels & Khan 2010 <sup>28</sup>	Not a guideline
Howard 2001 <sup>29</sup>	Not a guideline
Zermann 2001 <sup>30</sup>	Publication not in English
Rees et al. 2015 <sup>31</sup>	Guideline for pelvic infection
Schaeffer 2006 <sup>32</sup>	Not a guideline
Jarrell et al. 2005 <sup>33</sup>	Outdated
Perez-Medina et al. 2010 <sup>34</sup>	Publication not in English
Gambone et al. 2002 <sup>35</sup>	Guideline not endorsed by relevant organisation or society
Wattier 2018 <sup>36</sup>	Not a guideline
Candiani 2005 <sup>37</sup>	Not a guideline
Bourdel et al. 2018 <sup>38</sup>	Publication not in English
Graziottin et al. 2000 <sup>39</sup>	Could not access full text

Fall et al. 2010 <sup>40</sup>	Outdated
Fall et al. 2004 <sup>41</sup>	Outdated
Renner et al. 2013 <sup>42</sup>	Publication not in English
Dohle et al. 2012 <sup>43</sup>	Guideline not for the management of persistent pelvic pain
Ross et al. 2007 <sup>44</sup>	Outdated
Scialli 1999 <sup>45</sup>	Guideline for pelvic infection
Ah-Kit et al. 2019 <sup>46</sup>	Guideline not for the management of persistent pelvic pain
Antignani et al. 2012 <sup>47</sup>	Could not access full text
Roman & Puscasiu 2008 <sup>48</sup>	Publication not in English
Roman 2007 <sup>49</sup>	Publication not in English
Kentenich & Rauchfuss 2001 <sup>50</sup>	Not a guideline
Weyhe et al. 2018 <sup>51</sup>	Only specifies one diagnostic/treatment strategy
Sofianos et al. 2015 <sup>52</sup>	Could not access full text
Niro & Panel 2018 <sup>53</sup>	Publication not in English
Payne et al. 2019 <sup>54</sup>	Guideline not for the management of persistent pelvic pain
Simons et al. 2018 <sup>55</sup>	Guideline not for the management of persistent pelvic pain
Alfieri et al. 2011 <sup>56</sup>	Guideline not endorsed by relevant organisation or society
Scheiner et al. 2015 <sup>57</sup>	Not a guideline
Watier et al. 2010 <sup>58</sup>	Publication not in English
Ueda 2010 <sup>59</sup>	Not a guideline
Capogrosso et al. 2019 <sup>60</sup>	Only specifies one diagnostic/treatment strategy
Baranowski et al. 2013 <sup>61</sup>	Not a guideline
Anderson 2002 <sup>62</sup>	Guideline for pelvic infection
Nickel et al. 2013 <sup>63</sup>	Not a guideline
Kahn et al. 2005 <sup>64</sup>	Not a guideline
Nasir & Bope 2004 <sup>65</sup>	Not a guideline
Graesslin et al. 2019 <sup>66</sup>	Publication not in English
Andresen & Layer 2018 <sup>67</sup>	Not a guideline
Sauvan et al. 2018 <sup>68</sup>	Publication not in English
Ploteau et al. 2018 <sup>69</sup>	Publication not in English

Campo & Campo <sup>70</sup>	Publication not in English
Magri et al. 2018 <sup>71</sup>	Publication not in English
Possover & Forman 2014 <sup>72</sup>	Not a guideline
Tenke et al. 1999 <sup>73</sup>	Publication not in English
Schaeffer 2004 <sup>74</sup>	Not a guideline
Lefebvre et al. 2018 <sup>75</sup>	Not a guideline
Rey et al. 2017 <sup>76</sup>	Only specifies one diagnostic/treatment strategy
Locke et al. 2019 <sup>77</sup>	Not a guideline
Lazarashvili et al. 2016 <sup>78</sup>	Could not access full text
Almeida et al. 2019 <sup>79</sup>	Only specifies one diagnostic/treatment strategy
Verguts et al. 2007 <sup>80</sup>	Publication not in English
Ross 2010 <sup>81</sup>	Not a guideline
Ross 2014 <sup>82</sup>	Not a guideline
Ault & Faro 1993 <sup>83</sup>	Not a guideline
Baranowski et al. 2014 <sup>84</sup>	Not a guideline
Mais et al. 2011 <sup>85</sup>	Publication not in English
Kyriazis et al. 2014 <sup>86</sup>	Publication not in English
Jaiyeoba et al. 20187	Not a guideline
Nickel et al. 1999 <sup>88</sup>	Guideline for pelvic infection
Khilnani et al. 2019 <sup>89</sup>	Not a guideline
정혜경 2018 <sup>90</sup>	Publication not in English
Dohle et al. 2005 <sup>91</sup>	Publication not in English
Bourreille et al. 2009 <sup>92</sup>	Only specifies one diagnostic/treatment strategy
Bezhenar 2014 <sup>93</sup>	Not a guideline
Siedentopf & Hausteiner-Wiehle 2013 <sup>94</sup>	Publication not in English
Lefebvre et al. 2002 <sup>95</sup>	Only specifies one diagnostic/treatment strategy
Huchon et al. 2018 <sup>96</sup>	Publication not in English
Locke et al. 2018 <sup>97</sup>	Not a guideline
Schaeffer et al. 2003 <sup>98</sup>	Guideline for pelvic infection
Engeler et al. 2013 <sup>99</sup>	Not a guideline
Botoman 2002 <sup>100</sup>	Could not access full text

Berger et al. 2011 <sup>101</sup>	Publication not in English
Krieger et al. 2002 <sup>102</sup>	Not a guideline
Adehossi et al. 2002 <sup>103</sup>	Publication not in English
조문경 2010 <sup>104</sup>	Publication not in English
Bachnamm et al. 2006 <sup>105</sup>	Not a guideline
Moyal-Barracco & Labat 2010 <sup>106</sup>	Not a guideline
Johannesson & Bohm-Starke <sup>107</sup>	Not a guideline
Stockdale & Lawson 2014 <sup>108</sup>	Guideline not endorsed by relevant organisation or society
Centers for Disease Control and Prevention 2015 <sup>109</sup>	Guideline not for the management of persistent pelvic pain
Centers for Disease Control and Prevention 2015 <sup>110</sup>	Guideline not for the management of persistent pelvic pain
Lukacz et al. 2011 <sup>111</sup>	Guideline not for the management of persistent pelvic pain
Lamb et al. 2019 <sup>112112</sup>	Guideline not for the management of persistent pelvic pain
Farquhar et al. 2001 <sup>113</sup>	Guideline not for the management of persistent pelvic pain
The Mayo Clinic 2019 <sup>114</sup>	Not a guideline
Homma et al. 2009 <sup>115</sup>	Guideline not for the management of persistent pelvic pain
Stewart et al. 2017 <sup>116</sup>	Guideline not for the management of persistent pelvic pain
Collège National des Gynécologues et Obstétriciens Français 2006 <sup>117</sup>	Outdated
Ouyang et al. 2008 <sup>118</sup>	Not supported with relevant evidence
Douglas-Moore & Goddard 2017 <sup>119</sup>	Not a guideline
Hanno et al. 2015 <sup>120</sup>	Other
Lightner et al. 2019 <sup>121</sup>	Guideline not for the management of persistent pelvic pain
Antignani et al. 2019 <sup>122</sup>	Not a guideline
Australian Sexual Health Alliance 2018 <sup>123</sup>	Guideline not for the management of persistent pelvic pain
Ross 2001 <sup>124</sup>	Outdated
Vleeming et al. 2008 <sup>125</sup>	Pregnancy related
Kroon et al. 2011 <sup>126</sup>	Guideline not for the management of persistent pelvic pain
Ommer et al. 2017 <sup>127</sup>	Guideline not endorsed by relevant organisation or society
Taneja et al. 2017 <sup>128</sup>	Not supported by relevant evidence

Duncan & Scott-Barrett 2020 <sup>129</sup>	Guideline not endorsed by relevant organisation or society
The Digestive Health Foundation 2006 <sup>130</sup>	Not supported by relevant evidence
Doiron & Nickel 2018 <sup>131</sup>	Not a guideline
AGMMSSVD 1999 <sup>132</sup>	Outdated
Lamont et al. 2017 <sup>133</sup>	Guideline not for the management of
Lefebvre et al. 2005 <sup>134</sup>	persistent pelvic pain Outdated
Dickson 2013 <sup>135</sup>	Guideline not for the management of persistent pelvic pain
The Rotterdam ESHRE/ASRM-sponsored PCOS	Guideline not for the management of
consensus workshop group 2004 <sup>136</sup>	persistent pelvic pain
Gomollon et al. 2013 <sup>137</sup>	Guideline not endorsed by relevant
	organisation or society
Mehasseb et al. 2016 <sup>138</sup>	Guideline not for the management of
	persistent pelvic pain
Carranza-Mamane & Hemmings 2015 <sup>139</sup>	Guideline not for the management of
	persistent pelvic pain
Haefner et al. 2005 <sup>140</sup>	Guideline not endorsed by relevant
	organisation or society
Arroyo et al. 2018 <sup>141</sup>	Guideline not for the management of
	persistent pelvic pain
Andresen et al. 2013 <sup>142</sup>	Publication not in English
Street et al. 2011 <sup>143</sup>	Guideline not for the management of
	persistent pelvic pain
Lacey et al. 2013 <sup>144</sup>	Guideline for GIT conditions
Ross et al. 2018 <sup>145</sup>	Guideline for pelvic infection
Ross et al. 2018 <sup>146</sup>	Guideline for pelvic infection
Quigley et al. 2012 <sup>147</sup>	Not a guideline
ACOG 2006 <sup>148</sup>	Outdated
Homma et al. 2016 <sup>149</sup>	Guideline not endorsed by relevant
	organisation or society
Hoffmann et al. 2008 <sup>150</sup>	Publication not in English
Negrín Pérez 2010 <sup>151</sup>	Publication not in English
Kirtschig et al. 2015 <sup>152</sup>	Guideline not endorsed by relevant
	organisation or society
Bschleipfer et al. 2019 <sup>153</sup>	Publication not in English
Street et al. 2017 <sup>154</sup>	Guideline not for the management of
	persistent pelvic pain
Kranz et al. 2018 <sup>155</sup>	Guideline for pelvic infection

German Society for Digestive and Metabolic Diseases 2019 <sup>156</sup>	Publication not in English
Preiß et al. 2014 <sup>157</sup>	Not English
University of Wisconsin Hospitals and Clinics Authority <sup>158</sup>	Guideline for pelvic infection
Wagner & Tostain 2007 <sup>159</sup>	Guideline for male pelvic pain
Van Schalkwyk & Yudin 2015 <sup>160</sup>	Guideline not for the management of persistent pelvic pain
Nehra et al. 2015 <sup>161</sup>	Guideline for male pelvic pain
Engeler et al. 2020 <sup>162</sup>	Guideline for male pelvic pain
Cox et al. 2016 <sup>163</sup>	Guideline for male pelvic pain
Gomollon et al. 2017 <sup>164</sup>	Guideline for GIT conditions
Gionchetti et al. 2017 <sup>165</sup>	Guideline for GIT conditions
Rubin et al. 2019 <sup>166</sup>	Guideline for GIT conditions
Wald et al. 2014 <sup>167</sup>	Guideline for GIT conditions
Lichtenstein et al. 2018 <sup>168</sup>	Guideline for GIT conditions
Jones et al. 2000 <sup>169</sup>	Guideline for GIT conditions
Feuerstein et al. 2020 <sup>170</sup>	Guideline for GIT conditions
Bressler et al. 2015 <sup>171</sup>	Guideline for GIT conditions
Panaccione et al. 2019 <sup>172</sup>	Guideline for GIT conditions
Mearin et al. 2016 <sup>173</sup>	Guideline for GIT conditions
Song et al. 2018 <sup>174</sup>	Guideline for GIT conditions
Torres et al. 2020 <sup>175</sup>	Guideline for GIT conditions
Adamina et al. 2020 <sup>176</sup>	Guideline for GIT conditions
Amato 2015 <sup>177</sup>	Guideline for GIT conditions
Ueno et al. 2013 <sup>178</sup>	Guideline for GIT conditions
NICE 2018 <sup>179</sup>	Guideline for GIT conditions
Alex et al. 2018 <sup>180</sup>	Guideline for GIT conditions
NCCNSC 2008 <sup>181</sup>	Guideline for GIT conditions
Wei et al. 2017 <sup>182</sup>	Guideline for GIT conditions
Harbord et al. 2017 <sup>183</sup>	Guideline for GIT conditions
Clinton et al. 2017 <sup>184</sup>	Pregnancy related
Wisawasukmongchol et al. 2022 <sup>185</sup>	Guideline not endorsed by relevant organisation or society
van der Meijden et al. 2021 <sup>186</sup>	Guideline not endorsed by relevant organisation or society

Andreeva et al. 2021 <sup>187</sup>	Publication not in English
Candiani 2005 <sup>188</sup>	Could not access
Parsons et al. 2022 189	Not a guideline
Geoffrion & Larouche 2021 <sup>190</sup>	Only specifies one diagnostic/treatment strategy
Tapilskaya et al. 2021 <sup>191</sup>	Publication not in English
Sauvan et al. 2018 <sup>192</sup>	Publication not in English
Touboul et al. 2021 <sup>193</sup>	Publication not in English
Engeler et al. 2013 <sup>99</sup>	Not a guideline
Wattier 2018 <sup>194</sup>	Publication not in English
Björk et al. 2020 <sup>195</sup>	Publication not in English
Garzon et al. 2020 <sup>196</sup>	Not a guideline
Kocak et al. 2021 <sup>197</sup>	Male pelvic pain
Speer et al. 2016 <sup>198</sup>	Guideline not endorsed by relevant organisation or society
Osayande et al. 2014 <sup>199</sup>	Guideline not endorsed by relevant organisation or society
Rahnamai et al. 2020 <sup>200</sup>	Not a guideline
Jarvi et al. 2018 <sup>201</sup>	Male
Fukudo et al. 2021 <sup>202</sup>	Guideline for GIT conditions
Legro et al. 2013 <sup>203</sup>	Guideline for PCOS
ACOG 2018 <sup>204</sup>	Guideline for PCOS
Teede et al. 2018 <sup>205</sup>	Guideline for PCOS

AGMMSSVD, Association of Genitourinary Medicine and the Medical Society for the Study of Venereal Diseases; NICE, National Institute for Health and Care Excellence; ACOG, American College of Obstetricians and Gynecologists; PCOS, polycystic ovarian syndrome

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Table S4: Inter-rater agreement for AGREE-II quality appraisal

Domain	ICC (95% CI)
Scope and purpose	0.90 (0.61-0.97)
Stakeholder involvement	0.98 (0.95-0.99)
Rigour of development	0.99 (0.98-1.0)
Clarity of presentation	0.91 (0.51-0.97)
Applicability	0.98 (0.96-0.99)
Editorial independence	0.99 (0.98-1.0)

AGREE, Appraisal of Guidelines for Research and Evaluation; CI, confidence interval; ICC, intraclass correlation

Table S5: Descriptive synthesis of patient education recommendations within persistent pelvic pain guidelines

Patient education recommendation	Descriptive synthesis
Content	
Pelvic pain diagnosis	Endometriosis  NICE – "Provide information and support for women with suspected or confirmed endometriosis, which should include: what endometriosis is, endometriosis symptoms and signs, how endometriosis is diagnosed, treatment options, local support groups, online forums and national charities, and how to access them."  RANZCOG – "Provide comprehensive and ongoing information and support to people with suspected or confirmed endometriosis, to promote their active participation in care and self-management. For example, provide information on: what endometriosis is, endometriosis signs and symptoms, how endometriosis is diagnosed, treatment options including care, follow-up, anticipated waiting times and out of-pocket expenses, national and local support groups or networks, and resources (hard copy and online)."  Vulvodynia  Mandal et al "Recommendation 6: Patients should be given an adequate explanation of their diagnosis, relevant written information and suggested contact information."  ACOG – "It is important to begin any treatment approach with a detailed discussion, including an explanation of the diagnosis and determination of realistic treatment goals."
Treatment strategies	Endometriosis  NICE – "Provide information and support for women with suspected or confirmed endometriosis, which should include: what endometriosis is, endometriosis symptoms and signs, how endometriosis is diagnosed, treatment options, local support groups, online forums and national charities, and how to access them."  "Advise women that the available evidence does not support the use of traditional Chinese medicine or other Chinese herbal medicines or supplements for treating endometriosis."  Collinet et al "When endometriosis of the lower rectum is treated surgically, temporary bowel diversion to reduce the complications associated with fistula formation must be discussed and the patient must be informed and receive appropriate preoperative education."

"At the time the treatment is chosen, it is recommended that patients be informed about the treatment options, the expected benefits and risks of each treatment and the risk of recurrence, and that the patient's expectations and preferences be taken into account. Before surgery, additional information should be provided about what will happen during the procedure, the aim of surgery, the expected inconveniences and benefits, possible complications, her scars, the postoperative period and convalescence (Grade C)."

RANZCOG - "Provide comprehensive and ongoing information and support to people with suspected or confirmed endometriosis, to promote their active participation in care and self-management. For example, provide information on: what endometriosis is, endometriosis signs and symptoms, how endometriosis is diagnosed, treatment options including care, follow-up, anticipated waiting times and out of-pocket expenses, national and local support groups or networks, and resources (hard copy and online)."

"Advise people contemplating excisional or ablative surgery for the treatment of adenomyosis that there is no evidence for or against such surgery in the treatment of adenomyosis."

"Advise people contemplating a hysterectomy for the treatment of endometriosis that there is no evidence for or against the effectiveness of hysterectomy for endometriosis. If hysterectomy is indicated (for example, if the person has adenomyosis or heavy menstrual bleeding that has not responded to other treatments), all visible endometriotic lesions should be excised at the time of the hysterectomy."

"Advise people there is no evidence for Chinese herbs/medicine, supplements, and acupuncture."

ESHRE - "The GDG recommends that patients undergoing surgery particularly for deep endometriosis are informed on potential risks, benefits, and long-term effect on quality of life."

"Women should be informed that hysterectomy will not necessarily cure the symptoms or the disease."

"Clinicians should reassure women with endometriosis about the risk of malignancy associated with the use of hormonal contraceptives."

"The GDG recommends that clinicians discuss non-medical strategies to address quality of life and psychological well-being in women managing symptoms of endometriosis. However, no recommendations can be made for any specific non-medical intervention (Chinese medicine, nutrition, electrotherapy, acupuncture, physiotherapy, exercise, and psychological interventions) to reduce pain or improve quality of life measures in women with endometriosis, as the potential benefits and harms are unclear."

# <u>Vulvodynia</u>

Mandal et al. - "When prescribing treatments, clear instruction should be given on how to take medication."

	Endometriosis
	NICE – "Be aware that endometriosis can be a long-term condition, and can have a significant physical, sexual,
	psychological and social impact. Women may have complex needs and require long-term support."
	RANZCOG – "Be aware that endometriosis can be a long-term condition, and can have a significant physical, sexual,
Comorbidities	psychosocial, emotional and social impact. People with endometriosis may have complex needs and require long-term support."
Comorbidities	ESHRE – "Clinicians should inform women with endometriosis requesting information on their risk of developing cancer that endometriosis is not associated with a significantly higher risk of cancer overall."
	"The GDG recommends that clinicians reassure women with endometriosis with regards to their cancer risk and
	address their concern to reduce their risk by recommending general cancer prevention measures (avoiding smoking,
	maintaining a healthy weight, exercising regularly, having a balanced diet with high intakes of fruits and vegetables and low intakes of alcohol, and using sun protection)."
	ESHRE – "Although there is no direct evidence in preventing endometriosis in the future, women can be advised of aiming for a healthy lifestyle and diet, with reduced alcohol intake and regular physical activity."
	"The GDG recommends that clinicians reassure women with endometriosis with regards to their cancer risk and
	address their concern to reduce their risk by recommending general cancer prevention measures (avoiding smoking,
	maintaining a healthy weight, exercising regularly, having a balanced diet with high intakes of fruits and vegetables
	and low intakes of alcohol, and using sun protection)."
Lifestyle counselling	<u>Vulvodynia</u>
	Mandal et al. – "Minimizing exposure to contact irritants from everyday products will help, and use of inappropriate
	topical agents, e.g. antifungal creams, should be discouraged."
	<u>GPPPD</u>
	ACOG – "Self-care counselling should include elimination of common vulvovaginal contact irritants, including soaps,
	douches, wipes, scented products, and undergarment pads. Pointing out inflammatory skin changes to the patient around the vulva and anus may help motivate elimination of wipes or other irritants."
Self-help techniques (e.g. Pelvic	<u>Vulvodynia</u>
floor exercises, bladder training,	Mandal et al "Patients can be taught a variety of self-help techniques including pelvic floor exercises, external and
etc.)	internal soft tissue self-massage, trigger point pressure, biofeedback and use of vaginal trainers."

Interstitial cystitis/painful bladder syndrome
Homma et al. – "Behavioural therapy including timed voiding, controlled fluid intake, pelvic floor muscle training and bladder training improved symptoms in more than a half of the patients."
<u>GPPPD</u>
ACOG – "active pelvic floor retraining, bladder and bowel retraining"
<u>Chronic pelvic pain</u> Jarrell et al. – "Patient education on pelvic floor function is vital to successful physical therapy."
<u>GPPPD</u>
ACOG – "Education about the vulvovaginal anatomy and pelvic floor can help women understand the mechanisms and etiology of genito–pelvic pain and penetration disorder symptoms."
Endometriosis  Collinet et al. – "Physicians are invited to fully inform women with endometriosis about fertility."
ESHRE – "It is acknowledged that for some women with endometriosis, fertility preservation may increase their future chances of pregnancy, but there is no evidence on criteria to select those women. Based on these considerations, the GDG formulated a strong recommendation for counselling and information provision."
Chronic pelvic pain  Jarrell et al. – "Patient education on pelvic floor function is vital to successful physical therapy."
<u>Vulvodynia</u> Mandal et al. – "Patients can be taught a variety of self-help techniques including pelvic floor exercises, external and
internal soft tissue self-massage, trigger point pressure, biofeedback and use of vaginal trainers."

Nurses	Endometriosis  NICE - "In the clinical setting, specialist nursing staff are a key source of information and support."
Support groups	Endometriosis  NICE – "Provide information and support for women with suspected or confirmed endometriosis, which should include: what endometriosis is, endometriosis symptoms and signs, how endometriosis is diagnosed, treatment options, local support groups, online forums and national charities, and how to access them."  Collinet et al "The ability to interact with other women with endometriosis, through patient organizations or health service initiatives, is useful for obtaining additional information and making them feel less alone."  RANZCOG – "Provide comprehensive and ongoing information and support to people with suspected or confirmed endometriosis, to promote their active participation in care and self-management. For example, provide information on: what endometriosis is, endometriosis signs and symptoms, how endometriosis is diagnosed, treatment options including care, follow-up, anticipated waiting times and out of-pocket expenses, national and local support groups or networks, and resources (hard copy and online)."  ESHRE – "This highlights the importance of giving the woman the opportunity to gain information about nonmedical strategies in specialist pain management services with the expertise in managing complex abdomino-pelvic pain, and the potential benefits of local support groups which is also recommended by NICE (2017)."
Charities, foundations, and/or organisations	IC/PBS  Homma et al. – "Join support groups or educational programs."  Endometriosis  NICE – "Provide information and support for women with suspected or confirmed endometriosis, which should include: what endometriosis is, endometriosis symptoms and signs, how endometriosis is diagnosed, treatment options, local support groups, online forums and national charities, and how to access them."
	Chronic pelvic pain  Moore & Kennedy – "Voluntary organisations such as Endometriosis UK can be an important source of information and support for some patients."

	IC/PBS  Tirlapur et al. – "Patients should be given written information about patient organisations that provide evidence based information."
Patient-tailored education	Endometriosis  NICE – "Assess the individual information and support needs of women with suspected or confirmed endometriosis, taking into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs."  RANZCOG – "Assess the individual information and support needs of women with suspected or confirmed endometriosis, taking into account their circumstances, symptoms, priorities, desire for fertility, aspects of daily living, work and study, cultural background, and their physical, psychosexual and emotional needs."
Written/printed materials	Endometriosis  Collinet et al. – "The production of printed information is encouraged. It should contain essential information for patients and their partners, be validated by health professionals, and given to patients during the consultation, then explained in terms appropriate to the patient."  RANZCOG – "Provide comprehensive and ongoing information and support to people with suspected or confirmed endometriosis, to promote their active participation in care and self-management. For example, provide information on: what endometriosis is, endometriosis signs and symptoms, how endometriosis is diagnosed, treatment options including care, follow-up, anticipated waiting times and out of-pocket expenses, national and local support groups or networks, and resources (hard copy and online)."
	<u>Vulvodynia</u> Mandal et al. – "Recommendation 6: Patients should be given an adequate explanation of their diagnosis, relevant written information and suggested contact information."
	IC/PBS Homma et al "Patient education using a text- or video-based m-health system is useful for managing symptom flare-up."

	Tirlapur et al. – "Patients should be given written information about patient organisations that provide evidence based information."
Involvement of partner and/or family members	Endometriosis  NICE – "If women agree, involve their partner (and/or other family members or people important to them) and include them in discussions."  Collinet et al. – "The production of printed information is encouraged. It should contain essential information for patients and their partners, be validated by health professionals, and given to patients during the consultation, then explained in terms appropriate to the patient."  RANZCOG – "If the person agrees inc. family or partner"
Online resources	Endometriosis  NICE – "Provide information and support for women with suspected or confirmed endometriosis, which should include: what endometriosis is, endometriosis symptoms and signs, how endometriosis is diagnosed, treatment options, local support groups, online forums and national charities, and how to access them."  Collinet et al "The information available on the internet varies greatly in quality and is often substandard from a scientific point of view."  RANZCOG – "Provide comprehensive and ongoing information and support to people with suspected or confirmed endometriosis, to promote their active participation in care and self-management. For example, provide information on: what endometriosis is, endometriosis signs and symptoms, how endometriosis is diagnosed, treatment options including care, follow-up, anticipated waiting times and out of-pocket expenses, national and local support groups or networks, and resources (hard copy and online)."
	Homma et al "Patient education using a text- or video-based m-health system is useful for managing symptom flare-up."

Educational programs

IC/PBS

Homma et al. - "Join support groups or educational programs."