856x288mm (118 x 118 DPI)

1 **LAY SUMMARY**

2 The National Endometriosis Clinical and Scientific Trials (NECST) Registry is part of

3 a national collaborative project by Australian clinicians, researchers and patient

4 advocates – the NECST Network, an Australian Government initiative.

5 The NECST Registry will be a national resource of participant data, facilitating high

6 quality research aiming to understand the causes of endometriosis, improve

7 diagnosis and treatment outcomes, and may eventually reduce the burden of

8 disease. Currently, there is limited long-term clinical data about endometriosis and a

9 delay of 7 – 12 years before a diagnosis of endometriosis is made for some people.

10 In addition, clear care management plans, that are based on high quality and strong

11 clinical trial studies, are not yet available (despite the available guidelines) due to the

12 lack of understanding of how endometriosis develops or changes during a woman's

13 lifetime.

14 The NECST Registry will collect and securely store demographic and health-related

15 information from consenting participants, who experience and/or seek management

16 for endometriosis and/or endometriosis-related symptoms or conditions (e.g.,

17 adenomyosis).

1 **Establishing the Australian National Endometriosis Clinical and Scientific**
2 **Trials (NECST) Registry: A protocol paper**

3 Cecilia H. M. Ng*[1, 2], Andrew G. Michelmore[2], Gita D. Mishra[3], Grant W.
4 Montgomery[4], Peter A. Rogers[2, 5], Jason A. Abbott[1, 6], on behalf of the NECST
5 Network.

6

7 **INSTITUTION AFFILIATIONS**

8   1. School of Clinical Medicine, Division of Obstetrics and Gynaecology, Health
9   and Medicine, UNSW, Sydney NSW 2052, Australia
10   2. Jean Hailes for Women's Health, Melbourne VIC 3002, Australia
11   3. School of Public Health, University of Queensland, Herston QLD 4006,
12   Australia
13   4. Institute of Molecular Bioscience, University of Queensland, St Lucia QLD
14   4072, Australia
15   5. University of Melbourne Department of Obstetrics and Gynaecology, Royal
16   Women's Hospital, Parkville VIC 3052, Australia
17   6. Gynaecological Research and Clinical Evaluation (GRACE) Unit, Royal
18   Hospital for Women, Randwick NSW 2031, Australia

19

20 **CORRESPONDING AUTHOR**

21 Dr Cecilia H. M. Ng
22 School of Clinical Medicine, Medicine and Health
23 Division of Obstetrics and Gynaecology
24 UNSW Sydney
25 Randwick NSW 2031
26 E: cecilia.ng@unsw.edu.au
27 ORCID: 0000-0002-8637-9861

28

29 **Short title:** The Australian NECST Registry protocol.

30

31 **Keywords:** Endometriosis, diagnosis, management, quality of life, registry

32

33 **WORD COUNT (excluding references and table and figure legends)**

34 4,590

ABSTRACT

Endometriosis is a common yet under-recognised chronic inflammatory disease,

affecting 176 million women, trans and gender diverse people globally. The National

Endometriosis Clinical and Scientific Trials (NECST) Registry is a new clinical

registry, collecting and tracking diagnostic and treatment data, and patient-reported

outcomes on people with endometriosis. The registry is a research priority action

item from the 2018 National Action Plan for Endometriosis and aims to provide,

large-scale, national and longitudinal population-based data on endometriosis.

Working groups (consisting of patients with endometriosis, clinicians and

researchers) developing the NECST Registry data dictionary and data collection

platform started in 2019. Our data dictionary was developed based on existing and

validated questionnaires, tools, meta-data and data cubes –World Endometriosis

Research Foundation (WERF) Endometriosis Phenome and Biobanking

Harmonisation Project (EPHect), endometriosis CORE outcomes set, patient-

reported outcome measures, the International Statistical Classification of Diseases-

10th Revision Australian Modification diagnosis codes, and Australian Government

datasets: Australian Institute for Health and Welfare (for sociodemographic data),

Medicare Benefits Schedule (MBS; for medical procedures) and the Pharmaceutical

Benefits Scheme (PBS; for medical therapies). The resulting NECST Registry is an

online, secure cloud-based database; prospectively collecting minimum core clinical

and health data across eight patient and clinician modules and longitudinal data

tracking disease life course. The NECST Registry has ethics approval

(HREC/62508/MonH-2020) and is registered on the Australian New Zealand Clinical

Trials Registry (ACTRN12622000987763).

59 **INTRODUCTION**

60 The Australian National Endometriosis Clinical and Scientific Trials (NECST) Registry

61 is a new, cloud-based, modular clinical registry. Recording and tracking diagnostic

62 and treatment data for patients with endometriosis, and/or associated conditions

63 (e.g., adenomyosis). This clinical and health information from the registry is capturing

64 patient-reported outcomes for endometriosis, how endometriosis affects people's

65 lives, and identifying trends in clinical management and potential gaps in health

66 service provision.

67 The NECST Registry was developed by a collaborative group of clinicians, allied

68 healthcare professionals, researchers and endometriosis patient advocates. It was

69 established as part of the Australian research framework, clinical trials network and

70 data collection infrastructure action items outlined in the National Action Plan for

71 Endometriosis (NAPE) (Commonwealth of Australia (Department of Health), 2018).

72 **National Action Plan for Endometriosis**

73 In 2018, the NAPE was published by the Australian Government following

74 consultation with consumers, clinicians, researchers and policy makers

75 (Commonwealth of Australia (Department of Health), 2018). The NAPE is Australia's

76 roadmap and blueprint to tackle endometriosis and was the first of its kind under the

77 Commonwealth Health Portfolio

78 ([https://www.health.gov.au/resources/publications?search_api_views_fulltext=nation](https://www.health.gov.au/resources/publications?search_api_views_fulltext=national+action+plan)

79 [al+action+plan](https://www.health.gov.au/resources/publications?search_api_views_fulltext=national+action+plan); accessed 29 August 2022).

80 Three key priority areas were identified – Awareness and education, Clinical

81 management and care and Research (Commonwealth of Australia (Department of

82 Health), 2018), with a number of action items, supported by objectives and

83   knowledge gaps, were outlined and defined. This was alongside implementation of

84   any action to be prioritised and coordinated to ensure any increase in demand for

85   services are able to be met. Establishment of the National Endometriosis Clinical and

86   Scientific Trials (NECST) Network falls under the Research priority.

87   **Endometriosis prevalence**

88   Endometriosis is a common yet under-recognised chronic inflammatory disease

89   (Giudice, 2010, As-Sanie et al., 2019). It is estimated that by the age of 44, one in

90   nine Australian women, trans and gender diverse (TGD) people, equating to 830,000,

91   are diagnosed with endometriosis (Rowlands et al., 2021). Globally, it is estimated

92   that endometriosis affects 176 million women and TGD people (Adamson et al.,

93   2010a). The delay in diagnosis of endometriosis is 6-8 years from symptom onset

94   (Armour et al., 2020, O'Hara et al., 2020), and has decreased from 7-12 years

95   approximately 3-5 years ago (Nnoaham et al., 2011, Agarwal et al., 2019). This

96   decrease may be attributed to the rise in education and awareness of this condition,

97   and global recognition by governments including Australia, All Party Parliamentary

98   Group on Endometriosis in the UK and European Parliament in France (All Party

99   Parliamentary Group (APPG) on Endometriosis Inquiry Report, 2020, Armour et al.,

100   2020, Committee on Women's Rights and Gender Equality, 2021). The diagnosis

101   may involve an invasive laparoscopy to determine disease presence. A clinical

102   diagnosis may also be made based on symptoms and/or imaging scans (via

103   ultrasound or MRI) (Abrão et al., 2007, Agarwal et al., 2019, Armour et al., 2022).

104   Pain and infertility significantly impacting quality of life are the most common

105   symptoms of endometriosis. Endometriosis has a high individual and societal burden

106   costing an estimated $6.5 billion USD annually (Armour et al., 2019), with poorer

107   quality of life, long-term employment, mental and emotional health, social and sexual

108   relationships (Nnoaham et al., 2011, De Graaff et al., 2013, Armour et al., 2020,

109   Rowlands et al., 2022a). It is documented that those diagnosed with endometriosis

110   experience physical reduction in quality of life similar to that of cancer patients

111   (Nnoaham et al., 2011).

112   Debilitating chronic pelvic pain and associated symptoms are the most frequent

113   presentations (approximately 71 – 87% of patients) (ACOG Committee on Practice

114   Bulletins - Gynecology, 2000). Endometriosis is as common as asthma or diabetes

115   but is much less well understood (As-Sanie et al., 2019). Multiple theories of

116   pathogenesis have been described including genetic and environmental factors,

117   retrograde menstruation, coelomic metaplasia, embryonic rests and immune

118   dysregulation (Montgomery et al., 2008, Upson, 2020, Lamceva et al., 2023). There

119   is no cure for endometriosis and treatment largely relies on medicines, surgery

120   and/or complementary and allied health practices to manage women's symptoms.

121   Medical management options are often limited due to their hormonal basis and the

122   impact this has on the menstrual cycle and fertility. Symptomatic treatments for pain

123   include hormonal medications or surgical removal of disease deposits and are

124   currently the primary choices for women with endometriosis. Despite treatments,

125   recurrence of symptoms and disease, that may require additional surgery, is

126   common, occurring in 20 – 44% of patients up to 10-years (Abbott et al., 2003, Guo,

127   2009, Bougie et al., 2021).

128   Clinical guidelines and practice standards provide a baseline for endometriosis care.

129   Current endometriosis guidelines include:

130   • The Royal Australia and New Zealand College of Obstetrician and

131   Gynaecologists (RANZCOG) Clinical Practice Guideline for the Diagnosis and

132   Management of Endometriosis (2021).

133   • The Society of Obstetricians and Gynaecologists of Canada Practice

134   Guidelines on Endometriosis: Diagnosis and Management (Leyland et al.,

135   2010).

136   • The American College of Obstetricians and Gynecologists Practice Bulletin

137   and Committee Opinion on Management of Endometriosis (2010) and

138   Dysmenorrhea and Endometriosis in the Adolescent (2018), respectively.

139   • The National Institute for Health and Care Excellence (NICE) in the UK,

140   updated (2017), and

141   • The European Society of Human Reproduction and Embryology (ESHRE)

142   (updated 2022) (Becker et al., 2022).

143   A common theme observed across all guidelines is that there still remains a paucity

144   of supportive evidence for many of the recommendations made. Inconsistent

145   reporting practices and limited prospective data collection framework for

146   endometriosis may be contributing factors to the limited data. The RANZCOG Clinical

147   Practice Guidelines makes a clear recommendation and mandate for the detailed

148   surgical documentation and data collection on the appearance and site of

149   endometriosis, in line with the NECST Registry Surgical Module data dictionary

150   (RANZCOG, 2021).

151   **Clinical registries**

152   Clinical registries are a collection of organised health data, including outcomes, using

153   observational study methods to collect a defined minimum dataset (Hoque et al.,

154   2017). Registries (condition-, disease- or procedure-specific) can play an important

155   role in monitoring or describing the natural history of disease, determine clinical

156   effectiveness or cost-effectiveness of healthcare products or services and delivery

157   patterns. The objective of registries are to measure or monitor safety and harm, to

158   measure quality of care and generate population-level evidence of the impact of

159   treatment and models of service delivery (Hoque et al., 2017, Tan et al., 2019,

160   Gliklich et al., 2020, Parums, 2021)

161   (https://www.safetyandquality.gov.au/publications-and-resources/australian-register-

162   clinical-registries; accessed 22 September 2022). They facilitate public health

163   reporting and transparency (e.g., cardiac surgery or assisted reproductive technology

164   treatments) (Bridgewater et al., 2013, Ahern et al., 2017)

165   (https://npesu.unsw.edu.au/data-collection/australian-new-zealand-assisted-

166   reproduction-database-anzard; accessed 14 October 2022). They may provide

167   evidence to improve the healthcare system, e.g. the UK National Joint Registry

168   identified specific devices (some metal-on-metal articulations) had higher-than-

169   expected revisions rates, leading to their removal from the UK market (Porter et al.,

170   2022). The Nordic arthroplasty registries collect longitudinal data, ascertaining

171   survival and causes of revisions; with the addition of patient-reported outcomes data.

172   Results are reported back to healthcare professionals providing an overall

173   assessment of the care provided (Porter et al., 2022). Additionally, registries may

174   facilitate clinical trials. The Australian Cystic Fibrosis Data Registry, publishing

175   clinical, health-economic, health service utilisation and medication use from trials as

176   an example (Ahern et al., 2018). A well-designed clinical registry, may support both

177   retrospective and prospective research – generating research hypotheses and

178   answering important research questions and do this alongside randomised clinical

179   trials (Hoque et al., 2017, Bak et al., 2021).

180   **The NECST Registry**

181   The NAPE has increased research and awareness of endometriosis nationally and

182   worldwide, with the UK (All Party Parliamentary Group (APPG) on Endometriosis

183   Inquiry Report, 2020, Scottish Government, 2021, Endometriosis UK, 2022), Canada

184   (Wahl et al., 2021, EndoAct Canada, 2022), and France (Committee on Women's

185   Rights and Gender Equality, 2021) following in Australia's example of developing

186   their own national action plans. While diagnostic delay in Australia has reduced

187   (Armour et al., 2020), the impact on and long-term health outcomes for patients (e.g.,

188   fertility, maternal, reproductive life, symptom-control and recurrence beyond 5-years),

189   remains largely unknown globally and is a substantial evidence gap that must be

190   addressed (Rowlands et al., 2021, Rowlands et al., 2022b).

191   Since 2008, the endometriosis research community has met to define research

192   priorities (Rogers et al., 2009, Rogers et al., 2013, Horne et al., 2017, Rogers et al.,

193   2017); tools to standardise research design in areas of clinical and symptom

194   presentation, phenotype recording and specimen collection (Becker et al., 2014,

195   Fassbender et al., 2014, Rahmioglu et al., 2014, Vitonis et al., 2014). A recent core

196   outcome set to facilitate and enhance comparable data between trials has been

197   published (Hirsch et al., 2016, Duffy et al., 2020).

198   Internationally, a small number of endometriosis registries exist (search performed on

199   ClinicalTrials.gov for "endometriosis" (condition or disease) and "observational –

200   patient registries" (study type) – the Canadian Endometriosis Pelvic Pain

201   Interdisciplinary Cohort Data Registry (EPPIC;

202   https://clinicaltrials.gov/ct2/show/NCT02911090; accessed 25 October 2022) (Yosef

203   et al., 2016, Yong et al., 2018, Arion et al., 2020), the French North-West Inter

204   Regional Female Cohort for Patients with Endometriosis (CIRENDO;

205   https://www.clinicaltrials.gov/ct2/show/NCT02294825; accessed 25 October 2022)

206   (Auber et al., 2011, Rozsnyai et al., 2011, Roman et al., 2013, Roman et al., 2016,

207   Saavalainen et al., 2016, Darwish et al., 2017, Roman et al., 2017, Badescu et al.,

208   2018), and French Quality of Life and Fertility Patients with Deep Surgical

209   Endometriosis: A Prospective Cohort (ENDORAA;

210   https://www.clinicaltrials.gov/ct2/show/NCT03555903; accessed 25 October 2022) .

211   The strengths of these registries include substantive numbers, expected long-term

212   follow up of the cohort and alignment of data instruments to allow pooling of results.

213   Weaknesses of existing registries include inclusion of only surgical and

214   histopathology confirmed endometriosis and data from only one clinical site that may

215   limit the external validity due to a high rate of tertiary referrals being assessed and

216   treated.

217   The aim of the Australian NECST Registry is to provide, large-scale population-

218   based data at a national level on endometriosis. Registry data will be systematically

219   and prospectively collected over time with support and funding from the Australian

220   Government.

221

222   **OBJECTIVE**

223   To develop a national clinical registry that prospectively collects core, standardised

224   health data from patients with endometriosis-related symptoms, have been

225   diagnosed with endometriosis or a related condition to investigate the long-term

226 patient outcomes, impact, prognosis, causes and treatment of endometriosis and its

227 related symptoms and conditions.

228

229 **OUTCOMES**

230 The primary outcome of the NECST Registry is to assess the overall quality of life on

231 endometriosis patients using validated patient-reported outcomes measures

232 (PROMs) tools. Our secondary outcomes are i) to detect the incidence of other

233 conditions, including adenomyosis, fibroids, and symptoms-related to endometriosis;

234 ii) incidence of diagnosis of endometriosis via imaging methods (including ultrasound

235 and/or MRI); iii) proportion of participants being managed expectantly vs medically vs

236 surgically vs allied health and/or complementary therapies; and iv) incidence of

237 adverse events.

238

239 **MATERIALS AND METHODS**

240 **Governance structure**

241 The NECST Registry is driven by patients, clinicians and researchers. A not-for-profit

242 women's health organisation oversaw the daily activities and registry's development,

243 with the NECST Advisory and Strategic Governance Committees, providing clinical,

244 scientific research and registry oversight. The next phase of management and

245 development will be managed and overseen by a university organisation.

246 **Data dictionary and minimum dataset**

247 The NECST Registry was developed sequentially: i) drafting of the data dictionary, ii)

248 formation of seven working groups (one for each module), with subject matter

249   experts to revise and refine the data dictionary, iii) a nationwide workshop presenting

250   the data to the wider endometriosis community and key external stakeholders iv)

251   commissioning IT developers to build the cloud-based NECST Registry platform, v)

252   content experts and IT developers defining the technical and functional requirements

253   of each registry module and vi) extensive user acceptance testing of the registry

254   platform prior to live launch of the registry (Figure 1).

255   To enable sustainability and compatibility, essential data items (minimum core

256   dataset) were defined (Table 1) and aligned with national and international datasets,

257   such as the World Endometriosis Research Foundation (WERF) Endometriosis

258   Phenome and Biobanking Harmonisation Project (EPHect) (Becker et al., 2014,

259   Fassbender et al., 2014, Rahmioglu et al., 2014, Vitonis et al., 2014), and

260   endometriosis CORE outcomes set for research (Hirsch et al., 2016, Duffy et al.,

261   2020). Data monitoring and quality assurance plans are in place with regular review

262   between the data custodian and NECST Governance Committees, in accordance

263   with the Australia's Framework for Clinical Quality Registries (Australian Commission

264   on Safety and Quality in Health Care, 2014).

265   The data dictionary outlines the 'data spine' to which additional items may be added

266   for time-limited collection or permanent collection depending on outcome measures

267   and approvals by the NECST Governance Committees. Existing patient

268   questionnaires, validated PROMs tools, meta-data and data cubes were used to

269   develop the first draft of the data dictionary. The reasons for using existing data items

270   were to avoid duplication of data collection, aligning with existing data collections with

271   a future view to undertake data linkage studies and national or international research

272   collaborations, to ensure data comparisons/analyses were utilising an identical set of

273   'epidemiologically sound' data.

274 The WERF EPHect is a collection of standardised phenotypic data compilation and

275 biological sample collection and storage tools (Becker et al., 2014, Fassbender et al.,

276 2014, Rahmioglu et al., 2014, Vitonis et al., 2014). The objective of these collection

277 tools is to facilitate large-scale international, multicentre trials with robust data and

278 advance endometriosis research (Casper, 2014). We used these tools to inform the

279 development of our Clinical Presentation and Medical History, Medical Management

280 and Surgical Management modules. Additionally, the Endometriosis Fertility Index

281 (EFI), which incorporates the revised American Fertility Society (rAFS)/American

282 Society for Reproductive Medicine (ASRM) endometriosis classification, is used to

283 capture endometriosis staging and predict pregnancy rates (Adamson et al., 2010b),

284 and is part of our Surgical Management module.

285 The World Health Organization (WHO) International Statistical Classification of

286 Diseases-10th Revision Australian Modification (ICD-10-AM) was used to define

287 diagnostic health information (including symptoms) captured in the Clinical

288 presentation and medical history module and all the clinician modules. ICD codes are

289 used globally and provides knowledge on extent, cause, and consequence of human

290 disease. It forms the main basis for health recording and statistics of disease across

291 all levels of the healthcare system; with the data supporting payment systems,

292 service panning, quality and safety assessments and health services research,

293 offering standardisation of diagnostic data collection, enabling large scale research

294 (Harrison et al., 2021).

295 Existing Australian Government datasets, meta-data and data cubes were also used

296 to inform NECST Registry modules. The Australian Institute for Health and Welfare

297 (AIHW) Metadata Online Registry (METEOR), is a collection of metadata standards

298 for statistics and information in a variety of areas including health, Indigenous,

299   housing and homelessness etc. METEOR was used to define our Demographics and

300   Consent module for sociodemographic data. The Medicare Benefits Schedule (MBS)

301   is a listing of all the services subsidised by the Australian Government. MBS item

302   numbers are used to inform coding of surgical procedures in the Surgical

303   Management module. Both the Australian Register of Therapeutic Goods (ARTG), a

304   public database of all the legal therapeutic goods supplied in Australia, and the

305   Pharmaceutical Benefits Scheme (PBS), details of Australian subsidised medicines,

306   are used to inform coding of medicines or therapies in the Medical Management

307   module.

308   Incorporated are two validated PROMs as part of the NECST Registry patient

309   modules. These are questionnaires allowing patients to report on outcomes relating

310   to their health and focus on varying aspects of health (such as symptoms), daily

311   functioning and quality of life (Hutchings et al., 2017, Haugstvedt et al., 2019). Use of

312   PROMs on more than two occasions allows comparisons over a period of time (van

313   der Willik et al., 2021). For the NECST Registry, a generic PROMs, which measures

314   aspects of health common to most patients and suitable for use across several

315   patient populations was selected. This was the EQ-5D-5L, which assess quality of life

316   across five dimensions: mobility, self-care, usual activities, pain/discomfort and

317   anxiety/depression. The generated health-state profile from respondents can be

318   converted to an index value (reflecting how good or bad a health state is for the

319   general population of a country/region), this index value facilitates health economic

320   analyses, informed by the calculation of quality-adjusted life years (EuroQol

321   Research Foundation, 2019). It also consists of the addition of a visual analogue

322   scale which records the patient's self-rated health on a vertical scale (Janssen et al.,

323   2013, Stolk et al., 2019).

324　A validated, condition-specific PROMs, the Endometriosis Health Profile (EHP)-30,

325　was also selected and is the only PROMs currently available that assesses the

326　impact on quality of life for those living with endometriosis (Jones et al., 2004, Jones

327　et al., 2006). The EHP-30, is a 30 item instrument (a short form, EHP-5, also exists),

328　which covers the areas of pain (11 items), control and powerlessness (6 items),

329　social support (4 items), emotional well-being (6 items) and self-image (3 items). In

330　addition to the 30 core items, we also use the six instrument supplementary modules,

331　and these cover the areas of work (5 items), relationship with child/children (2 items),

332　sexual relationship (5 items), feelings about medical profession (4 items), feelings

333　about treatment (3 items) and feelings about infertility (4 items).

334　The resulting eight modules make up the NECST Registry and are split into patient

335　and clinician modules (Figure 2). One of the objectives of the NECST Registry is to

336　understand the life course and impact of endometriosis. For this reason, a shortened

337　version of the Clinical Presentation and Medical History questionnaire was

338　developed. This in addition to both PROMs – the EQ-5D-5L and EHP-30 are

339　automatically sent to consenting participants to complete at 6-months, 12-months

340　and annually as follow up. The NECST Registry data dictionary is provided in the

341　Supplementary Materials. Currently, the NECST Registry is only available in English.

342　**Patient and public involvement**

343　Integral to the registry are the experiences and outcomes of individuals with

344　endometriosis and their families, partners and carers. To achieve these formalised

345　partnerships with major endometriosis consumer and advocacy organisations in

346　Australia were entered. The result is the NECST Registry has been endorsed by

347　Australia's leading endometriosis consumer and advocacy organisations, these

348   include Endometriosis Australia, EndoActive Australia and New Zealand, EndoHelp,

349   EndoSupport SA, Endometriosis Western Australia, Epworth Endometriosis Support

350   Group, Pelvic Pain Foundation of Australia and QENDO. Representatives from these

351   key organisations were involved in the review, evaluation and testing of the data

352   dictionary and data capture platform.

353   **NECST Registry data capture platforms**

354   Our patient modules questionnaire data are collected using the Research Electronic

355   Data Capture (REDCap) electronic data capture tool (Harris et al., 2009, Harris et al.,

356   2019). REDCap is a secure, web-based software platform designed to support data

357   capture for research studies. Participant responses are then automatically uploaded

358   onto the NECST Registry, built on the digital health management system,

359   canSCREEN™.

360   The clinician modules of the NECST Registry are built on canSCREEN™, a secure,

361   cloud-based online web platform and takes approximately 10 mins to complete. Best

362   practice security measures are embedded in the architecture. Features of the system

363   include role-based user privileges with only authorised users able to access

364   participant records, multilevel authentication of users, encryption of all data at rest

365   and in flight, and a full audit trail of all registry activity. All system users are required

366   to sign an agreement acknowledging the confidential nature of the data held on the

367   registry.

368   All aspects of the design and development of the data capture platforms of the

369   NECST Registry were in consultation with all relevant end-users – clinicians, allied

370   health professionals, researchers, and patients. Multiple workshops with online

371 presentations of the platforms, end-user testing and re-testing was conducted prior to

372 the NECST Registry going live in December 2020.

373 **Participant recruitment and eligibility criteria**

374 Participants are recruited by several complementary methods: invitation by

375 researchers and clinicians at sites (including hospital and private clinics) involved in

376 the NECST Registry, patient advocate and not-for-profit organisations (i.e.,

377 EndoActive Australia and New Zealand, Endometriosis Australia, EndoHelp, Endo

378 Support SA, Jean Hailes for Women's Health, QENDO), and through social media

379 (LinkedIn, Facebook, Instagram, Twitter, etc.).

380 Site representatives, clinicians and/or research team members, have the

381 responsibility to assess the eligibility of patients for the registry. The NECST Registry

382 uses an opt-in recruitment method, with participants invited to register and complete

383 the patient questionnaires (approximately 30 – 40 mins to complete). Participants can

384 withdraw from the registry at any time either by requesting to be fully removed from

385 the NECST Registry or requesting no further contact. Figure 3 illustrates the NECST

386 Registry recruitment and data capture pathways.

387 Eligible participants are women and people assigned female at birth, aged 18 years

388 and over, experiencing endometriosis-related symptoms (such as persistent pelvic

389 pain, problems with fertility, excessive menstrual bleeding or bleeding between

390 periods, heavy periods, dysuria, dyschezia, dyspareunia etc.) or have been

391 diagnosed with endometriosis or a related condition (e.g., adenomyosis).

392 The NECST Registry went live in December 2020 and has been piloted at sites in

393 New South Wales to test the registry infrastructure. This has been expanded to new

394 sites across five Australian states and recruitment via social media. The next phase

395 of development of the NECST Registry will involve analysing and assessing data

396 collection trends (e.g., completion rates, missing data, etc.) to further refine and

397 amend our recruitment strategies, participant questionnaires and modules.

398 **Ethical approval**

399 The NECST Registry has received National Mutual Acceptance (NMA) ethics

400 approval from Monash Health Human Research Ethics Committee (HREC), NMA

401 HREC Reference Number: HREC/62508/MonH-2020.

402 The NECST Registry has received Services Australia approval (to extract data on

403 government subsided health services and medicines) from consenting participants,

404 approval reference number: RMS1246.

405 **Study registration**

406 The NECST Registry has been registered with i) the Australian New Zealand Clinical

407 Trials Registry, registration number: ACTRN12622000987763

408 (https://www.anzctr.org.au/), ii) the Australian Register of Clinical Registries

409 (Australian Commission on Safety and Quality in Heath Care, ACSQHC), registry ID:

410 ACSQHC-ACRC-xxx (https://www.safetyandquality.gov.au/publications-and-

411 resources/australian-register-clinical-registries; ID number pending) and iii) WERF

412 EPHect (https://endometriosisfoundation.org/centres-using-ephect-tools/).

413 **Reporting and dissemination of results**

414 The investigators will submit an Annual Progress Report to ethics and funding

415 organisations in accordance with local policies. Findings utilising NECST Registry

416 data will be published in peer-reviewed journals and disseminated at national and

417 international conferences.

418   The purpose of the NECST Registry is to quantify and determine variations and

419   improve on the outcomes for those with endometriosis across the Australian health

420   care system. As the NECST Network and Registry moves towards the next phase of

421   development, initial data captured of the first 1000 participants will be analysed to

422   assess quality of the data captured, missing data and review of the data dictionary,

423   amending data elements collected as necessary. Requests to access NECST

424   Registry data by external research groups are reviewed and assessed by the

425   Governance Committees on a case-by-case basis.

426   In time, it is expected that the potential of the NECST Registry will be increased, as

427   comparisons may be drawn to identify variations across high vs low volume sites,

428   urban vs regional vs rural sites, clinical vs imaging vs surgical diagnosis, impact of

429   endometriosis during the fertile vs menopause period and other comparisons. High-

430   volume, public tertiary hospitals and clinicians have been recruited first to provide

431   solid evidence of 'best practice' and what may be realistically achievable. It is the

432   hope that the registry will provide evidence to improve care locally, nationally, and

433   globally.

434

435   **DISCUSSION**

436   Establishment of the NECST Registry responds to the action item under the

437   Research priority area of Australia's National Action Plan for Endometriosis. With

438   development driven by collaboration between clinicians, allied healthcare

439   professionals, research and endometriosis patient advocates; ensuring that the data

440   dictionary was defined based on existing and validated questionnaires, tools, meta-

441   data, and data cubes aligning with national and international guidelines and

442   standards. Data analyses from data collected at pilot sites will provide valuable

443   insights into the ability of the NECST Registry to capture supportive population-level

444   data on patterns of care and impact on quality of life from patients diagnosed with

445   endometriosis. Gynaecologists and other clinical specialities are integral to the

446   management of endometriosis and its associated conditions. Their engagement and

447   expertise are vital to the future and success of the NECST Registry. The NECST

448   Registry is a valuable resource and research infrastructure, collecting prospective

449   longitudinal data to assess current standard of care, identifying any variation that

450   may exist and how this is impacting on patient outcomes.

451

452   **DATA AVAILABILITY**

453   Deidentified data from the NECST Registry for research projects may be available

454   upon request and approval of the responsible authorities at the NECST Network.

455

456   **DECLARATION OF INTEREST**

457   CN reports grant funding from Medical Research Future Fund (MRFF) and Other

458   financial or non-financial interests with CSL Vifor as a previous employee (formerly

459   Vifor Pharma Pty. Ltd.; past employee). GDM reports grant funding from NHMRC. PR

460   reports grant funding from MRFF; Participation on a Data Safety Monitoring Board or

461   Advisory Board with Bayer; Leadership or fiduciary role in other board, society,

462   committee or advocacy group with Jean Hailes for Women's Health (Board Member);

463   and Other financial or non-financial interests with University of Melbourne and Royal

464   Women's Hospital (employee). JA reports grant funding from MRFF; honoraria for

465   lectures, presentations, speakers bureaus, manuscript writing or educational events

466   from Hologic Australia; Participation on a Data Safety Monitoring Board or Advisory

467   Board with Hologic Australia and CSL Vifor (formerly Vifor Pharma Pty. Ltd.);

468   Leadership roles with the Australasian Gynaecological Endoscopy & Surgery Society

469   (AGES; Past president), Heavy Menstrual Bleeding Clinical Care Standards 2017

470   and 2023 (Australian Government; Co-Chair), Expert Endometriosis Working Group

471   and Endometriosis Clinical Guidelines Group (RANZCOG, Chair); Endometriosis

472   Australia (Former Chair, 2021-2022); and Other financial or non-financial interests

473   with the Journal of Minimally Invasive Gynecology (Deputy Editor) and Australian and

474   New Zealand Journal of Obstetrics and Gynaecology (Associate Editor). The other

475   authors have no conflicts of interest to declare.

476

477   **FUNDING**

481

482   **AUTHOR CONTRIBUTION STATEMENT**

483   CN prepared the initial drafts of the protocol and data dictionary for this project with

484   input from the authored clinicians and researchers. JA supervised all aspects of the

485   development and implementation of the NECST Registry. CN prepared the draft of

486   this paper and was critically revised with input from all the listed authors AM, GDM,

487   GM, PR and JA. All authors have read and approved the manuscript.

488

REFERENCES

2010. ACOG Practice Bulletin No. 114: Management of Endometriosis. *Obstetrics & Gynecology,* 116**,** 223-236.

2018. ACOG Committee Opinion No. 760: Dysmenorrhea and Endometriosis in the Adolescent. *Obstetrics & Gynecology,* 132**,** e249-e258.

Abbott, JA, Hawe, J, Clayton, RD & Garry, R 2003. The effects and effectiveness of laparoscopic excision of endometriosis: A prospective study with 2-5 year follow-up. *Human Reproduction,* 18**,** 1922-1927.

Abrão, MS, Gonçalves, MODC, Dias Jr, JA, Podgaec, S, Chamie, LP & Blasbalg, R 2007. Comparison between clinical examination, transvaginal sonography and magnetic resonance imaging for the diagnosis of deep endometriosis. *Human Reproduction,* 22**,** 3092-3097.

ACOG Committee on Practice Bulletins - Gynecology 2000. ACOG practice bulletin. Medical management of endometriosis. Number 11, December 1999 (replaces Technical Bulletin Number 184, September 1993). Clinical management guidelines for obstetrician-gynecologists. *International Journal of Gynaecology & Obstetrics,* 71**,** 183-196.

Adamson, G, Kennedy, S & Hummelshoj, L 2010a. Creating solutions in endometriosis: Global collaboration through the World Endometriosis Research Foundation. *Journal of Endometriosis,* 2**,** 3-6.

Adamson, GD & Pasta, DJ 2010b. Endometriosis fertility index: The new, validated endometriosis staging system. *Fertility and Sterility,* 94**,** 1609-1615.

Agarwal, SK, Chapron, C, Giudice, LC, Laufer, MR, Leyland, N, Missmer, SA, Singh, SS & Taylor, HS 2019. Clinical diagnosis of endometriosis: A call to action. *American Journal of Obstetrics and Gynecology*.

Ahern, S, Hopper, I & Evans, SM 2017. Clinical quality registries for clinician-level reporting: strengths and limitations. *Medical Journal of Australia,* 206**,** 427-429.

Ahern, S, Sims, G, Earnest, A & S, CB 2018. Optimism, opportunities, outcomes: the Australian Cystic Fibrosis Data Registry. *Internal Medicine Journal,* 48**,** 721-723.

All Party Parliamentary Group (APPG) on Endometriosis Inquiry Report 2020. Endometriosis in the UK: time for change. UK.

Arion, K, Orr, NL, Noga, H, Allaire, C, Williams, C, Bedaiwy, MA & Yong, PJ 2020. A quantitative analysis of sleep quality in women with endometriosis. *J Womens Health (Larchmt),* 29**,** 1209-1215.

Armour, M, Lawson, K, Wood, A, Smith, CA & Abbott, J 2019. The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey. *PLoS ONE [Electronic Resource],* 14**,** e0223316.

Armour, M, Leonardi, M, Van Niekerk, L, Druitt, ML, Parker, MA, Mikocka-Walus, A, Ng, CHM, O'Hara, R, Ciccia, D, Stanley, K, Evans, S, Avery, J, Girling, J & McKinnon, B 2022. Lessons from implementing the Australian National Action Plan for Endometriosis. *Reproduction and Fertility,* 3**,** C29–C39.

Armour, M, Sinclair, J, Ng, CHM, Hyman, MS, Lawson, K, Smith, CA & Abbott, J 2020. Endometriosis and chronic pelvic pain have similar impact on women, but time to diagnosis is decreasing: An Australian survey. *Scientific Reports,* 10**,** 16253.

As-Sanie, S, Black, R, Giudice, LC, Gray Valbrun, T, Gupta, J, Jones, B, Laufer, MR, Milspaw, AT, Missmer, SA, Norman, A, Taylor, RN, Wallace, K, Williams, Z,

546   Yong, PJ & Nebel, RA 2019. Assessing research gaps and unmet needs in
547   endometriosis. *American Journal of Obstetrics and Gynecology*.
548   Auber, M, Bourdel, N, Mokdad, C, Martin, C, Diguet, A, Marpeau, L & Roman, H
549   2011. Ultrasound ovarian assessments after endometrioma ablation using
550   plasma energy. *Fertility and Sterility,* 95**,** 2621-2624.e2621.
551   Australian Commission on Safety and Quality in Health Care 2014. Framework for
552   Australian clinical quality registries. Sydney: ACSQHC.
553   Badescu, A, Roman, H, Barsan, I, Soldea, V, Nastasia, S, Aziz, M, Puscasiu, L &
554   Stolnicu, S 2018. Patterns of bowel invisible microscopic endometriosis reveal
555   the goal of surgery: Removal of visual lesions only. *Journal of Minimally*
556   *Invasive Gynecology,* 25**,** 522-527.e529.
557   Bak, JCG, Serné, EH, Kramer, MHH, Nieuwdorp, M & Verheugt, CL 2021. National
558   diabetes registries: do they make a difference? *Acta Diabetologica,* 58**,** 267-
559   278.
560   Becker, CM, Bokor, A, Heikinheimo, O, Horne, A, Jansen, F, Kiesel, L, King, K,
561   Kvaskoff, M, Nap, A, Petersen, K, Saridogan, E, Tomassetti, C, van Hanegem,
562   N, Vulliemoz, N, Vermeulen, N & Group, EEG 2022. ESHRE guideline:
563   Endometriosis. *Human Reproduction Open,* 2022.
564   Becker, CM, Laufer, MR, Stratton, P, Hummelshoj, L, Missmer, SA, Zondervan, KT,
565   Adamson, GD & Group, WEW 2014. World Endometriosis Research
566   Foundation Endometriosis Phenome and Biobanking Harmonisation Project: I.
567   Surgical phenotype data collection in endometriosis research. *Fertility and*
568   *Sterility,* 102**,** 1213-1222.
569   Bougie, O, McClintock, C, Pudwell, J, Brogly, SB & Velez, MP 2021. Long-term
570   follow-up of endometriosis surgery in Ontario: A population-based cohort
571   study. *American Journal of Obstetrics & Gynecology,* 225**,** 270.e271-
572   270.e219.
573   Bridgewater, B, Hickey, GL, Cooper, G, Deanfield, J & Roxburgh, J 2013. Publishing
574   cardiac surgery mortality rates: lessons for other specialties. *BMJ: British*
575   *Medical Journal,* 346**,** f1139.
576   Casper, RF 2014. Introduction: new tools for enhancing collaborative endometriosis
577   research. *Fertility and Sterility,* 102**,** 1211-1212.
578   Committee on Women's Rights and Gender Equality 2021. Situation of sexual and
579   reproductive health and rights in the EU, in the frame of women's health
580   (Report - A9-0169/2021). European Parliament.
581   Commonwealth of Australia (Department of Health) 2018. National Action Plan for
582   Endometriosis. Australian Government, Canberra.
583   Darwish, B, Stochino-Loi, E, Pasquier, G, Dugardin, F, Defortescu, G, Abo, C &
584   Roman, H 2017. Surgical outcomes of urinary tract deep infiltrating
585   endometriosis. *Journal of Minimally Invasive Gynecology,* 24**,** 998-1006.
586   De Graaff, AA, D'Hooghe, TM, Dunselman, GAJ, Dirksen, CD, Hummelshoj, L,
587   Consortium, WE, Simoens, S, Bokor, A, Brandes, I, Brodszky, V, Canis, M,
588   Colombo, GL, DeLeire, T, Falcone, T, Graham, B, Halis, G, Horne, AW, Kanj,
589   O, Kjer, JJ, Kristensen, J, Lebovic, DI, Müller, M, Vigano, P & Wullschleger, M
590   2013. The significant effect of endometriosis on physical, mental and social
591   wellbeing: Results from an international cross-sectional survey. *Human*
592   *Reproduction,* 28**,** 2677-2685.
593   Duffy, J, Hirsch, M, Vercoe, M, Abbott, J, Barker, C, Collura, B, Drake, R, Evers, J,
594   Hickey, M, Horne, A, Hull, M, Kolekar, S, Lensen, S, Johnson, N, Mahajan, V,
595   Mol, B, Otter, A-S, Puscasiu, L, Rodriguez, M, Rombauts, L, Vail, A, Wang, R,

Farquhar, C, Outcomes, eoaICH & Research, OMfE 2020. A core outcome set for future endometriosis research: An international consensus development study. *BJOG: An International Journal of Obstetrics & Gynaecology,* 127**,** 967-974.

EndoAct Canada 2022. Endometriosis advocacy efforts bolstered by Private Member's Motion.

Endometriosis UK 2022. Analysis of endometriosis service provision in Scotland.

EuroQol Research Foundation 2019. EQ-5D-5L User Guide.

Fassbender, A, Rahmioglu, N, Vitonis, AF, Vigano, P, Giudice, LC, D'Hooghe, TM, Hummelshoj, L, Adamson, GD, Becker, CM, Missmer, SA & Zondervan, KT 2014. World Endometriosis Research Foundation Endometriosis Phenome and Biobanking Harmonisation Project: IV. Tissue collection, processing, and storage in endometriosis research. *Fertility and Sterility,* 102**,** 1244-1253.

Giudice, LC 2010. Endometriosis. *New England Journal of Medicine,* 362**,** 2389-2398.

Gliklich, RE, Leavy, MB & Dreyer, NAse (eds.) 2020. *Registries for evaluating patient outcomes: A user's guide,* Rockville, MD: Agency for Healthcare Research and Quality (Prepared by L&M Policy Research, LLC, under Contract No. 290-2014-00004-C with partners OM1 and IQVIA) AHRQ Publication No. 19(20)-EHC020.

Guo, SW 2009. Recurrence of endometriosis and its control. *Human Reproduction Update,* 15**,** 441-461.

Harris, PA, Taylor, R, Minor, BL, Elliott, V, Fernandez, M, O'Neal, L, McLeod, L, Delacqua, G, Delacqua, F, Kirby, J & Duda, SN 2019. The REDCap consortium: Building an international community of software platform partners. *J Biomed Inform,* 95**,** 103208.

Harris, PA, Taylor, R, Thielke, R, Payne, J, Gonzalez, N & Conde, JG 2009. Research electronic data capture (REDCap)-a metadata-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Informatics,* 42**,** 377-381.

Harrison, JE, Weber, S, Jakob, R & Chute, CG 2021. ICD-11: An international classification of diseases for the twenty-first century. *BMC Medical Informatics and Decision Making,* 21**,** 206.

Haugstvedt, A, Hernar, I, Strandberg, RB, Richards, DA, Nilsen, RM, Tell, GS & Graue, M 2019. Use of patient-reported outcome measures (PROMs) in clinical diabetes consultations: Study protocol for the DiaPROM randomised controlled trial pilot study. *BMJ Open,* 9**,** e024008.

Hirsch, M, Duffy, JM, Barker, C, Hummelshoj, L, Johnson, NP, Mol, B, Khan, KS & Farquhar, C 2016. Protocol for developing, disseminating and implementing a core outcome set for endometriosis. *BMJ Open,* 6**,** e013998.

Hoque, DME, Kumari, V, Hoque, M, Ruseckaite, R, Romero, L & Evans, SM 2017. Impact of clinical registries on quality of patient care and clinical outcomes: A systematic review. *PLoS ONE [Electronic Resource],* 12**,** e0183667.

Horne, AW, Saunders, PTK, Abokhrais, IM & Hogg, L 2017. Top ten endometriosis research priorities in the UK and Ireland. *Lancet,* 389**,** 2191-2192.

Hutchings, HA & Alrubaiy, L 2017. Patient-reported outcome measures in routine clinical care: The PROMise of a better future? *Digestive Diseases and Sciences,* 62**,** 1841-1843.

Janssen, MF, Pickard, AS, Golicki, D, Gudex, C, Niewada, M, Scalone, L, Swinburn, P & Busschbach, J 2013. Measurement properties of the EQ-5D-5L compared

646   to the EQ-5D-3L across eight patient groups: A multi-country study. *Quality of*
647   *Life Research,* 22**,** 1717-1727.
648 Jones, G, Jenkinson, C & Kennedy, S 2004. Evaluating the responsiveness of the
649   Endometriosis Health Profile Questionnaire: The EHP-30. *Quality of Life*
650   *Research,* 13**,** 705-713.
651 Jones, G, Jenkinson, C, Taylor, N, Mills, A & Kennedy, S 2006. Measuring quality of
652   life in women with endometriosis: Tests of data quality, score reliability,
653   response rate and scaling assumptions of the Endometriosis Health Profile
654   Questionnaire. *Human Reproduction,* 21**,** 2686-2693.
655 Lamceva, J, Uljanovs, R & Strumfa, I 2023. The main theories on the pathogenesis
656   of endometriosis. *Int J Mol Sci,* 24.
657 Leyland, N, Casper, R, Laberge, P, Singh, SS, Allen, L, Arendas, K, Leyland, N,
658   Allaire, C, Awadalla, A, Best, C, Contestabile, E, Dunn, S, Heywood, M,
659   Leroux, N, Potestio, F, Rittenberg, DA, Singh, SS, Soucy, R, Wolfman, WL &
660   Senikas, V 2010. Endometriosis: Diagnosis and management. *Journal of*
661   *Obstetrics and Gynaecology Canada,* 32**,** S1-S3.
662 Montgomery, GW, Nyholt, DR, Zhao, ZZ, Treloar, SA, Painter, JN, Missmer, SA,
663   Kennedy, SH & Zondervan, KT 2008. The search for genes contributing to
664   endometriosis risk. *Human Reproduction Update,* 14**,** 447-457.
665 National Institute for Health Clinical Excellence 2017. Endometriosis: diagnosis and
666   management. London: National Collaborating Centre for Women's and
667   Children's Health.
668 Nnoaham, KE, Hummelshoj, L, Webster, P, d'Hooghe, T, de Cicco Nardone, F, de
669   Cicco Nardone, C, Jenkinson, C, Kennedy, SH & Zondervan, KT 2011. Impact
670   of endometriosis on quality of life and work productivity: A multicenter study
671   across ten countries. *Fertility and Sterility,* 96**,** 366.e368-373.e368.
672 O'Hara, R, Rowe, H & Fisher, J 2020. Managing endometriosis: A cross-sectional
673   survey of women in Australia. *Journal of Psychosomatic Obstetrics &*
674   *Gynecology***,** 1-8.
675 Parums, DV 2021. Editorial: Registries and Population Databases in Clinical
676   Research and Practice. *Medical Science Monitor,* 27**,** e933554.
677 Porter, M, Rolfson, O & de Steiger, R 2022. International Registries: U.K. National
678   Joint Registry, Nordic Registries, and Australian Orthopaedic Association
679   National Joint Replacement Registry (AOANJRR). *The Journal of Bone &*
680   *Joint Surgery,* 104**,** 23-27.
681 Rahmioglu, N, Fassbender, A, Vitonis, AF, Tworoger, SS, Hummelshoj, L, D'Hooghe,
682   TM, Adamson, GD, Giudice, LC, Becker, CM, Zondervan, KT & Missmer, SA
683   2014. World Endometriosis Research Foundation Endometriosis Phenome
684   and Biobanking Harmonization Project: III. Fluid biospecimen collection,
685   processing, and storage in endometriosis research. *Fertility and Sterility,* 102**,**
686   1233-1243.
687 RANZCOG 2021. Australian clinical practice guideline for the diagnosis and
688   management of endometriosis. Melbourne, Australia.
689 Rogers, P, D'Hooghe, T, Fazleabas, A, Giudice, L, Montgomery, G & Petraglia, F
690   2013. Defining future directions for endometriosis research: Workshop report
691   from the 2011 World Congress of endometriosis in Montpellier France.
692   *Reproductive Sciences,* 20.
693 Rogers, PA, Adamson, GD, Al-Jefout, M, Becker, CM, D'Hooghe, TM, Dunselman,
694   GA, Fazleabas, A, Giudice, LC, Horne, AW, Hull, ML, Hummelshoj, L,
695   Missmer, SA, Montgomery, GW, Stratton, P, Taylor, RN, Rombauts, L,

696 Saunders, PT, Vincent, K & Zondervan, KT 2017. Research priorities for
697 endometriosis: Recommendations from a global consortium of investigators in
698 endometriosis. *Reproductive Sciences,* 24**,** 202-226.
699 Rogers, PAW, D'Hooghe, TM, Fazleabas, A, Gargett, CE, Giudice, LC, Montgomery,
700 GW, Rombauts, L, Salamonsen, LA & Zondervan, KT 2009. Priorities for
701 endometriosis research: Recommendations from an international consensus
702 workshop. *Reproductive Sciences,* 16**,** 335-346.
703 Roman, H, Auber, M, Bourdel, N, Martin, C, Marpeau, L & Puscasiu, L 2013.
704 Postoperative recurrence and fertility after endometrioma ablation using
705 plasma energy: Retrospective assessment of a 3-year experience. *Journal of*
706 *Minimally Invasive Gynecology,* 20**,** 573-582.
707 Roman, H, Darwish, B, Bridoux, V, Chati, R, Kermiche, S, Coget, J, Huet, E & Tuech,
708 JJ 2017. Functional outcomes after disc excision in deep endometriosis of the
709 rectum using transanal staplers: a series of 111 consecutive patients. *Fertility*
710 *and Sterility,* 107**,** 977-986.e972.
711 Roman, H, Hennetier, C, Darwish, B, Badescu, A, Csanyi, M, Aziz, M, Tuech, JJ &
712 Abo, C 2016. Bowel occult microscopic endometriosis in resection margins in
713 deep colorectal endometriosis specimens has no impact on short-term
714 postoperative outcomes. *Fertility and Sterility,* 105**,** 423-429.e427.
715 Rowlands, I, Abbott, J, Montgomery, G, Hockey, R, Rogers, P & Mishra, G 2021.
716 Prevalence and incidence of endometriosis in Australian women: A data
717 linkage cohort study. *British Journal of Obstetrics & Gynaecology,* 128**,** 657-
718 665.
719 Rowlands, IJ, Hockey, R, Abbott, JA, Montgomery, GW & Mishra, GD 2022a.
720 Longitudinal changes in employment following a diagnosis of endometriosis:
721 Findings from an Australian cohort study. *Annals of Epidemiology,* 69**,** 1-8.
722 Rowlands, IJ, Mishra, GD & Abbott, JA 2022b. Global epidemiological data on
723 endometriosis. *In:* Oral, E (ed.) *Endometriosis and Adenomyosis.* Switzerland:
724 Springer Nature.
725 Rozsnyai, F, Roman, H, Resch, B, Dugardin, F, Berrocal, J, Descargues, G,
726 Schmied, R, Boukerrou, M & Marpeau, L 2011. Outcomes of surgical
727 management of deep infiltrating endometriosis of the ureter and urinary
728 bladder. *Journal of The Society of Laparoscopic & Robotic Surgeons,* 15**,** 439-
729 447.
730 Saavalainen, L, Heikinheimo, O, Tiitinen, A & Härkki, P 2016. Deep infiltrating
731 endometriosis affecting the urinary tract-surgical treatment and fertility
732 outcomes in 2004-2013. *Gynecological Surgery,* 13**,** 435-444.
733 Scottish Government 2021. Women's Health Plan. *In:* Public Health, WsHaS (ed.).
734 Scotland.
735 Stolk, E, Ludwig, K, Rand, K, van Hout, B & Ramos-Goñi, JM 2019. Overview,
736 update, and lessons learned from the International EQ-5D-5L valuation work:
737 Version 2 of the EQ-5D-5L valuation protocol. *Value in Health,* 22**,** 23-30.
738 Tan, JCK, Ferdi, AC, Gillies, MC & Watson, SL 2019. Clinical registries in
739 ophthalmology. *Ophthalmology,* 126**,** 655-662.
740 Upson, K 2020. Environmental risk factors for endometriosis: A critical evaluation of
741 studies and recommendations from the epidemiologic perspective. *Current*
742 *Epidemiological Reports,* 7**,** 149-170.
743 van der Willik, EM, Terwee, CB, Bos, WJW, Hemmelder, MH, Jager, KJ, Zoccali, C,
744 Dekker, FW & Meuleman, Y 2021. Patient-reported outcome measures

745   (PROMs): making sense of individual PROM scores and changes in PROM
746   scores over time. *Nephrology (Carlton),* 26**,** 391-399.
747   Vitonis, AF, Vincent, K, Rahmioglu, N, Fassbender, A, Buck Louis, GM, Hummelshoj,
748   L, Giudice, LC, Stratton, P, Adamson, GD, Becker, CM, Zondervan, KT &
749   Missmer, SA 2014. World Endometriosis Research Foundation Endometriosis
750   Phenome and Biobanking Harmonization Project: II. Clinical and covariate
751   phenotype data collection in endometriosis research. *Fertility and Sterility,*
752   102**,** 1223-1232.
753   Wahl, KJ, Yong, PJ, Bridge-Cook, P & Allaire, C 2021. Endometriosis in Canada: It is
754   time for collaboration to advance patient-oriented, evidence-based policy,
755   care, and research. *Journal of Obstetrics and Gynaecology Canada,* 43**,** 88-
756   90.
757   Yong, PJ, Williams, C, Bodmer-Roy, S, Ezeigwe, C, Zhu, S, Arion, K, Ambacher, K,
758   Yosef, A, Wong, F, Noga, H, Britnell, S, Yager, H, Bedaiwy, MA, Brotto, LA,
759   Albert, AY, Lisonkova, S & Allaire, C 2018. Prospective cohort of deep
760   dyspareunia in an interdisciplinary setting. *The Journal of Sexual Medicine,*
761   15**,** 1765-1775.
762   Yosef, A, Allaire, C, Williams, C, Ahmed, AG, Al-Hussaini, T, Abdellah, MS, Wong, F,
763   Lisonkova, S & Yong, PJ 2016. Multifactorial contributors to the severity of
764   chronic pelvic pain in women. *American Journal of Obstetrics and*
765   *Gynecology,* 215**,** 760.e761-760.e714.

766

Table 1. NECST Registry data modules and variables

Module	General variables
Patient	
Demographics	Name, DOB, Medicare number, gender, residency location, country of birth, language(s) spoken, indigenous status, education level, employment status, marital status, BMI, smoking and alcohol status
Clinical presentation and medical history	Presenting symptom(s) (primary and secondary), menstrual symptoms, pain history and symptoms, endometriosis history, reproductive and obstetric history, medication history, general medical history
PROMs – EQ-5D	Mobility, self-care, usual activities, pain/discomfort, anxiety/depression, self-rated health
PROMs – EHP-30	Pain, control and powerlessness, social support, emotional well-being, self-image Optional modules: Work, relationship with child/children, sexual relationship, feelings about medical profession, feelings about treatment, feelings about infertility
Clinician	
Diagnosis	Clinical diagnosis (primary and secondary), LMP, hormonal treatment
Imaging (US/MRI)	Date of imaging assessment, Specialist imaging service, referrer type, reason for imaging assessment, imaging finding(s) (primary and secondary), ultrasound assessment (bowel prep, uterus position, myometrium and junctional zone, fibroids, adenomyosis, endometrium, ovaries and adnexa, bladder and anterior compartment, posterior compartment, sliding sign, others)
Medical management (including list of medications)	Date of consultation, LMP, presenting symptom(s) (primary and secondary), principal diagnosis (primary and secondary), medications (hormonal, pain, other), allied and complementary therapies, adverse/side effects, reason for using, reason for ceasing/stopping
Surgical management	Date of surgery, LMP, surgeon category, assisting surgeon, other specialist, presenting symptom(s) (primary and secondary), principal diagnosis (primary and secondary), surgical summary (primary and secondary surgical diagnoses, primary and secondary surgical procedure(s), complication(s)), endometriosis summary (location, excised/removed, residual disease, photo, sample collected, reason for residual, method of removal, EFI scoring), date of discharge
Histopathology	Date of surgery, primary and secondary finding(s)
Environmental and lifestyle risk factors	Demographics, residential information, occupation, family history, ancestry, medical history, medication history, family medical history, menstruation and pregnancy, lifestyle, physical activity, diet, hazard exposure

BMI, body mass index; DOB, date of birth; EFI, Endometriosis Fertility Index; EQ-5D, Euroqol-5D-5L; EHP-30, Endometriosis Health Profile-30; LMP, last menstrual period; MRI, magnetic resonance imaging; PROMs, patient-reported outcome measures; US, ultrasound.
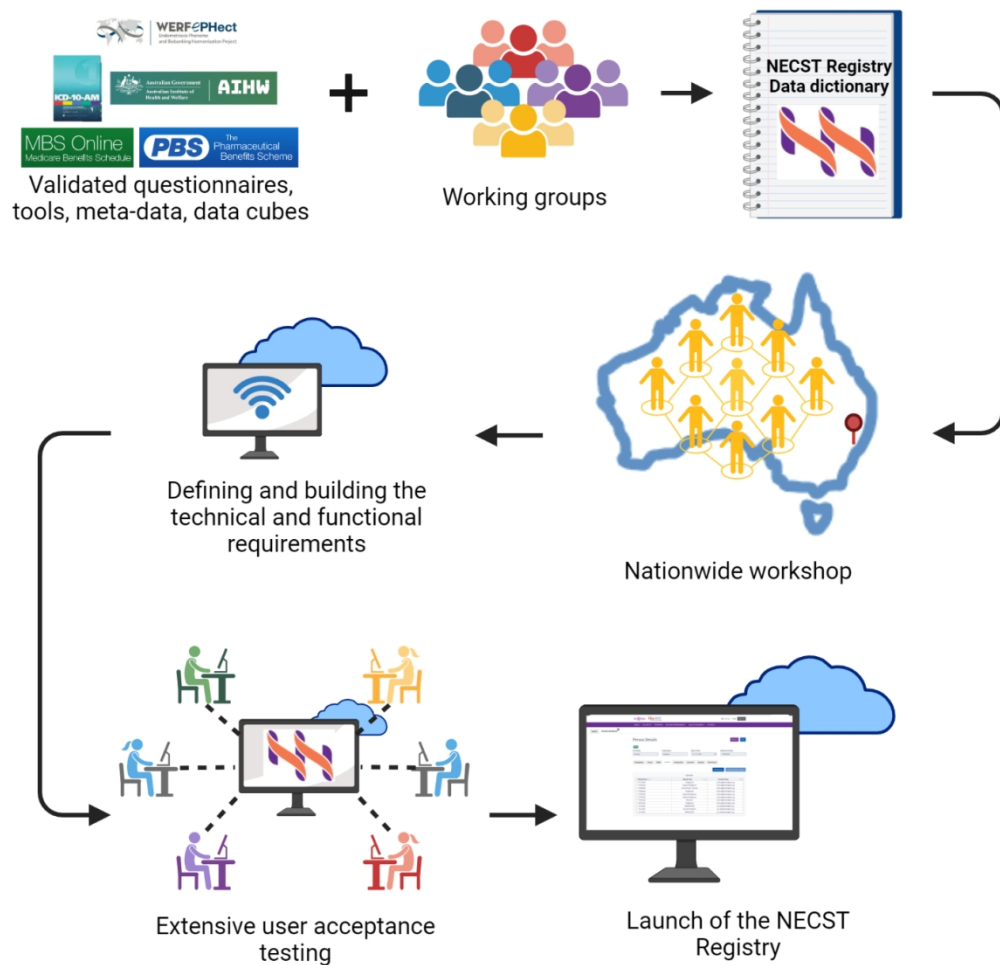
The chronological set of events in the design and development of the NECST Registry data dictionary and hosting platform.

303x291mm (118 x 118 DPI)
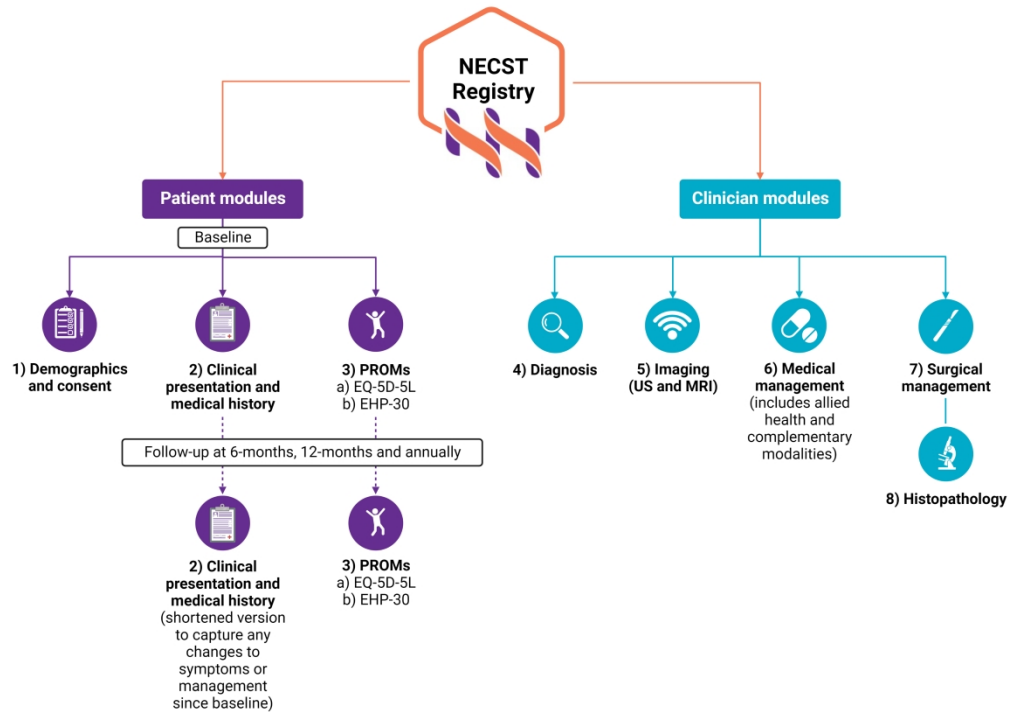
Patient and clinician modules of the NECST Registry. EHP-30, Endometriosis Health Profile-30; EQ-5D-5L, Euroqol-5D-5L; MRI, magnetic resonance imaging; NECST, National Endometriosis Clinical and Scientific Trials; PROMs, patient-reported outcome measures; US, ultrasound.

891x633mm (118 x 118 DPI)

Participating hospitals & private specialist clinics

- Standard care

A patient is identified to be eligible

Eligibility criteria:
- Be aged 18 years or over
- Have had a confirmed diagnosis (via surgery) of endometriosis (and/or adenomyosis) or
- Have any symptoms that might be caused by endometriosis (e.g., persistent pelvic pain, problems with falling pregnant, pain with bowel motions, etc.)
- Be able to speak English
- Be living in Australia

Ineligible patients

Patient is invited to participate, by the NECST Research Team using an opt-in method of recruitment

Opt-out patients

Eligible participants complete patient modules

Participant record generated and data uploaded

NECST Registry

Clinical research team upload data for the clinician modules

Participant recruitment and NECST Registry data entry process. NECST, National Endometriosis Clinical and Scientific Trials.

408x465mm (118 x 118 DPI)

The National Endometriosis Clinical and Scientific Trials (NECST) Network Registry

Minimum core dataset

DATA DICTIONARY

v2.0, 21 June 2021

Contents

Introduction and background

The aim of the National Endometriosis Clinical and Scientific Trials (NECST) Network Registry Project is to build a National endometriosis registry, housed in a contemporary for-purpose platform, that will underpin a comprehensive national program of clinical, basic science and translational research relevant to the needs of Australians with endometriosis, consistent with the research objectives in the National Action Plan for Endometriosis. The NECST Registry is a core component of the NECST Network objectives which include:

i.   Development of a national Clinical Trials Network that co-ordinates support for research organisations and conducts clinical trials for endometriosis treatments and services.

ii.   Development of an Australian Endometriosis Collaborative Research Framework to support co-ordinated patient recruitment, consistent data collection and *a national database* and bio-repository developed from clinical trials and research projects for national and international research projects specific to endometriosis.

iii.   Formation of a National Collaborative Network capable of responding to a targeted call for integrated endometriosis research focused on translational outcomes.

With the goals above in mind and ensuring the data collected in the NECST Registry is sustainable, we will define a limited series of essential data items (minimum dataset). This will form the 'data spine' to which additional items may be added for time-limited collection or permanent collection depending on outcome measures.

The NECST Network Registry will consist of a series of modules (Figure 1) that all participating sites (public and private) will use to collect an identical set of 'epidemiologically sound' data. The modules that are required include:

- Demographics and consent
- Clinical presentation and medical history (including follow-up visits)
- Patient reported outcome measures (PROMs; Quality of Life/Productivity/Lifestyle)
- Imaging
- Medical management
- Surgical management
- Histopathology and biobanking

Figure 1. Proposed NECST Network Registry and Biobank modules.
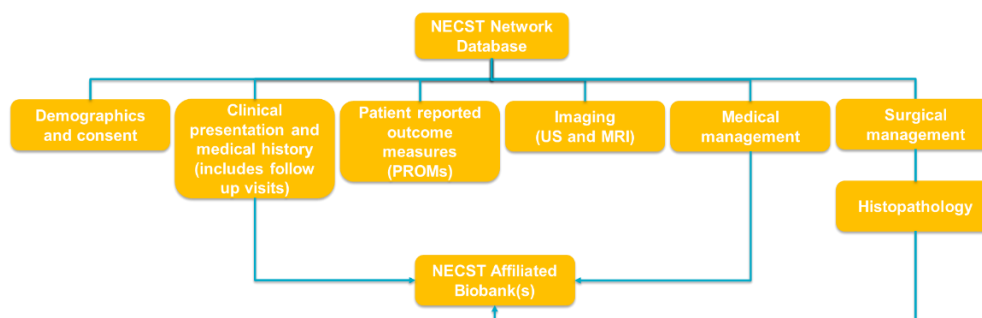
Each of these modules will contribute to the overall dataset in the NECST Registry however, not all modules will be completed for each patient, since not all patients will require all interventions.

To determine the requirements and details of each module, we have established a number of working groups of clinicians and scientists to ensure all the possibilities are covered. We have also referred to the World Endometriosis Research Foundation (WERF), EPHect Project that has SOPs and standardisation for data collection for endometriosis research.

Figure 2. Proposed outcomes and framework of the NECST Network Registry.
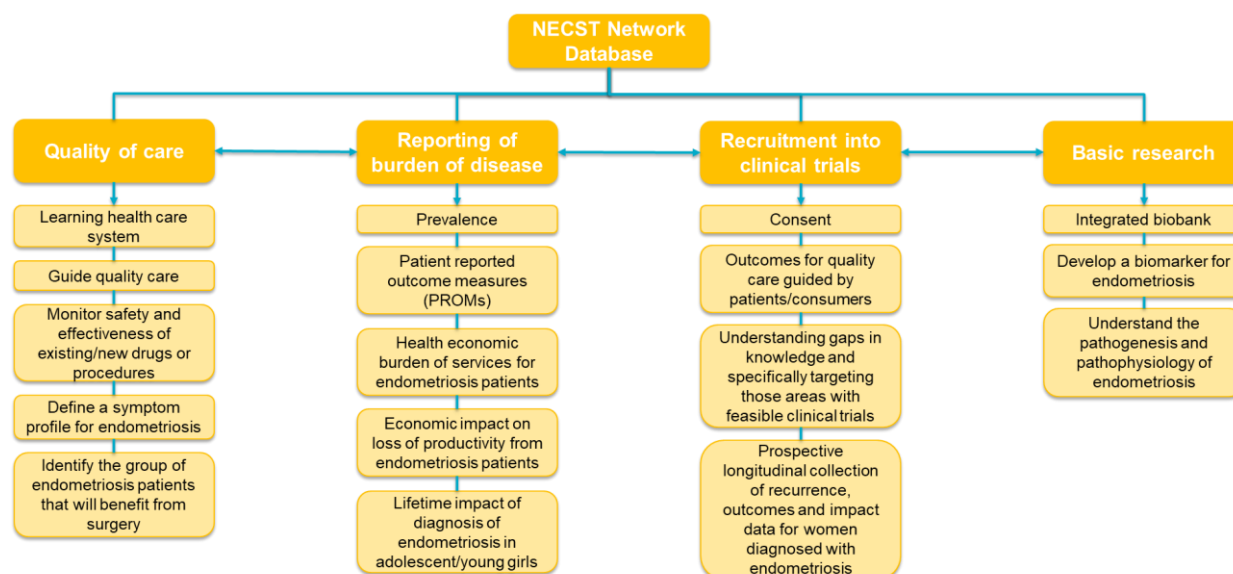
Working group members

We would like to acknowledge and thank the leads and members of each working group, listed below, for their time and continued contribution to defining and refining the draft minimum core dataset for the NECST Network Registry.

1. **Demographics and consent**

   Jason Abbott (Lead)

   Gita Mishra

   Grant Montgomery

   Peter Rogers

2. **Clinical presentation and medical history**

   Jason Abbott (Lead)

   Sonia Grover

   Louise Hull

   Luk Rombauts

   Anusch Yazdani

3. **Patient reported outcome measures (PROMs)**

   Mike Armour (Lead)

   Georgina Chambers

   Melissa Parker

   Anusch Yazdani

4. **Imaging (ultrasound and MRI)**

   Sofie Piessens (Lead)

   George Condous

   Stephen Knox

   Valeria Lanzarone

   Alexandra Stanislavsky

   Kate Stone

   Natalie Yang

5. **Medical management**

   Louise Hull (Lead)

   Jade Acton

   Rebecca Deans

   Susan Evans

   Sonia Grover

   Luk Rombauts

6. **Surgical management**

   Jason Abbott (Lead)

   Alan Lam

   Emma Readman

   Jim Tsaltas

   Michael Wynn-Williams

   Anusch Yazdani

7. **Histopathology and biobanking**

   Peter Rogers (Lead)

   Caitlin Filby

   Caroline Gargett

   Grant Montgomery

   Wayne Ng

   Luk Rombauts

1. Demographics and consent

This would include information such as consent for participation.

Participant identification number (Individual Healthcare Identifier)

Definition: This number will be automatically generated once the user enters the patient data into the system for the first time. (METeOR ID 432495)

Coding: To be decided by working group (automatically generated by registry)

Study identification number (for linkage to specific clinical trials and/or studies; process for data access to be determined by Executive Committee, to ensure data de-identification and privacy.)

Definition: This alpha-numerical number will be generated and aligned with a patient if they are part of a specific study. (METeOR ID 323304; NB: to be used for this with a more specific value domain used to construct a new data element that fits requirements)

Coding: To be decided by working group (mix of alpha and numerals, determined by specific trials and their study investigators)

PATIENT DETAILS

Given name

Definition: Patient's first name. Person and provider identification in healthcare NBPDS. (METeOR ID: 529511)

Coding: Free text field.

Last name

Definition: Patient's surname or family name. (METeOR ID: 529511)

Coding: Free text field.

Date of birth

Definition: Date of birth of the patient. (METeOR ID: 529511)

Coding: DDMMYYYY

Gender

Definition: The gender/sex of the patient. (METeOR ID 635994; ABS 2016. Standard for Sex and Gender Variables, 1200.055.012)

Coding: (1 is not being used as 1 = Male in accordance to the above metadata guidance)

2:      Female

3:      Other (please specify) [Free text field]

4:      Indeterminate/intersex/unspecified

Address

Definition: The referential description of a location where an entity is located or can be otherwise reached or found. (METeOR ID 529511, 327278, 594217)

Coding: Free text fields for the following attributes used in the formation of a full address.

- Address line (unit number/building number/house number, road name, road type, suburb/town/locality, postcode or postal delivery point identifier, State/Territory)

State

Definition: The Australian state or Territory where a person can be located, as represented by a code. (METeOR ID 529511, 327278, 594217, 286620)

Coding: [Drop down list]

1:      NSW

2:      VIC

3:      QLD

4:      SA

5:      WA

6:      TAS

7:      NT

8:      ACT

9:      Other (please specify) [Free text field] (e.g. other territories (Cocos (Keeling) Islands, Christmas Island and Jervis Bay Territory)

Postcode

Definition: The numeric descriptor for a postal delivery area, aligned with locality, suburb or place for the address of a person. (METeOR ID 529511, 327278, 594217, 286620)

Coding: A NNNN(4) representing the suburb area. To have "0000" allowed for the localities that do not have a postcode (e.g. some rural localities).

Contact number

Definition: The information of patient to enable contact via their telephone or mobile number. (METeOR ID 529511, 611164)

Coding: A 10 digit, free number/text field for entering phone number.

Email

Definition: The information of patient to enable contact via electronic mail. (METeOR ID 529511, 611164)

Coding: Free number/text field for entering email address.

Preferred contact method

Definition: The means by which the patient prefers to be contacted by. (Modelled against METeOR ID 323145)

Coding: [Drop down list]

1:      Email

2:      Phone

3:      Post

88:     Other (please specify) [Free text field]

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Medicare number (with reference number)

Definition: Person identifier, allocated by the Health Insurance Commission to eligible persons under the Medicare scheme that appears on a Medicare card. (METeOR ID 270101)

Coding:

Medicare no: A N(10) number representing the Medicare number.

Reference no: A N(1) number representing their position with the Medicare number.

Expiry date: MMYYYY

Secondary contact

Given name

Definition: Secondary contact's first name. (METeOR ID: 529511)

Coding: Free text field.

Last name

Definition: Secondary contact's surname or family name. (METeOR ID: 529511)

Coding: Free text field.

Contact number

Definition: The information of secondary contact to enable contact via their telephone or mobile number. (METeOR ID 529511, 611164)

Coding: A 10 digit, free number/text field for entering phone number.

Email

Definition: The information of secondary contact to enable contact via electronic mail. (METeOR ID 529511, 611164)

Coding: Free number/text field for entering email address.

Relationship to patient

Definition: Interpersonal relation of secondary contact to patient. (Modelled against METeOR ID 680219)

Coding: [Drop down list]

1:      Spouse/partner

2:      Mother

3:      Father

4:      Daughter

5:      Son

6:      Sister

7:      Brother

8:      Other female relative

9:      Other male relative

10:     Friend/neighbor

88:     Other (please specify) [Free text field]

ETHNICITY AND LANGUAGE

Country of birth

Definition: The country in which the patient was born. (METeOR ID: 659454; ABS 2016b, Standard

Australian Classification of Countries (SACC), 1269.0)

Coding: NNNN(4) [Drop down list]

1101:	Australia
2102:	England
1201:	New Zealand
7103:	India
3104:	Italy
5105:	Vietnam
5204:	Philippines
9225:	South Africa
2105:	Scotland
5203:	Malaysia
8102:	Canada
6101:	China (excludes SARs and Taiwan)
2304:	Germany
3207:	Greece
6102:	Hong Kong (SAR of China)
2201:	Ireland
8104:	United States of America
9:	Other (please specify) [Free text field]

How well do you speak English?

Definition: Proficiency in spoken English. This metadata item is only intended to be collected if a person has

a main language other than English spoken at home; and/or first language spoken is not English. (METeOR

ID 270203)

Coding: N [Tick box]

0:	Not applicable (persons under 5 year of age and people who speak only English)
1:	Very well
2:	Well
3:	Not well
4:	Not at all
9:	Not stated/inadequately described

Which language did you first speak as a child?

Definition: Which languages other than English are spoken by people at home. (METeOR ID 460120 and

460125; ABS 2016, Australian Standard Classification of Languages (ASCL), 1267.0)

Coding: NNNN(4)

1201:	English
7104:	Mandarin

2401:   Italian

4202:   Arabic

7101:   Cantonese

2201:   Greek

6302:   Vietnamese

2303:   Spanish

5203:   Hindi

6511:   Tagalog

99:       Other (please specify) [Free text field]

Do you speak a language other than English at home?

Definition: The language reported by a person as the main language other than English spoken by that person in his/her home (or most recent private residential setting occupied by the person) to communicate with other residents of the home or setting and regular visitors. (METeOR ID 460120 and 460125; ABS 2016, Australian Standard Classification of Languages (ASCL), 1267.0)

Coding: NNNN(4)

1201:   No, English only

7104:   Yes, Mandarin

2401:   Yes, Italian

4202:   Yes, Arabic

7101:   Yes, Cantonese

2201:   Yes, Greek

6302:   Yes, Vietnamese

2303:   Yes, Spanish

5203:   Yes, Hindi

6511:   Yes, Tagalog

88:       Other (please specify) [Free text field]

Indigenous status

Definition: Whether a person identifies as being of Aboriginal or Torres Strait Islander origin. (METeOR ID 602543; ABS National Health Survey 2014-2015, item 4363.0, released 2018)

Coding: Drop down list

1:       Aboriginal but not Torres Strait Islander origin

2:       Torres Strait Islander but not Aboriginal origin

3:       Both Aboriginal and Torres Strait Islander origin

4:       Neither Aboriginal nor Torres Strait Islander origin

99:      Not stated/Inadequately described

EDUCATION, EMPLOYMENT AND OCCUPATION STATUS

Highest education level completed

Definition: The highest level of education achieved by a person in relation to completed education. (METeOR ID 321069)

Coding: (Drop down list)

99:	Not stated/inadequately described
88:	No education
1:	Postgraduate degree
2:	Graduate diploma and graduate certificate
3:	Bachelor degree
4:	Advanced diploma and diploma
5:	Certificate (includes Certificate I-IV, Statement of Attainment, Bridging and Enabling Course I-IV)
6:	Senior secondary education
7:	Junior secondary education
8:	Primary education
9:	Pre-primary education
10:	Other education (please specify) [Free text field]

Current employment status

Definition: The person's position in relation to their employment, whether a person in paid employment is employed full-time or part-time, the nature of a person's employment in relation to her expected continuity of employment and eligibility for basic leave entitlements. (METeOR ID 269951, 269950, 314867)

Coding: [Drop down list]

99:	Not stated/inadequately described
88:	Other (please specify) [Free text field; situated after "***Employment type***"]

Status in employment

1:	Employee
2:	Employer
3:	Own account worker (a person who operates his or her own unincorporated economic enterprise or engages independently in a profession or trade, and hires no employees.)
4:	Contributing family worker (a person who works without pay in an economic enterprise operated by a relative.)

Full-time/part-time status

1:	Full-time (35 or more hours per week)
2:	Part-time (less than 35 hours per week)

Employment type

1:	Permanent
2:	Fixed term contract
3:	Casual

Occupation

Definition: The person's primary job in which they are principally engaged. (METeOR ID 350899 and ABS ANZSCO Cat. No. 1220.0)

Coding: N [Drop down list]

1:      Managers (e.g. chief executives, general managers, legislators, farmers and farm managers, specialist managers, hospitality, retail and service)

2:      Professionals (e.g. engineering, transport, scientist, doctor, registered nurse, allied health professional, education, artists and media, human resources, legal, social and welfare)

3:      Technicians and trade workers (e.g. automatic and engineering, construction, food trades, electrotechnology and telecommunications, skilled animal and horticultural)

4:      Community and personal service workers (e.g. health and welfare support, carers and aides, hospitality, protective services, sports and personal service)

5:      Clerical and administrative workers (e.g. office managers and program administrators, personal assistants and secretaries, general clerical, inquiry clerks and receptionists, numerical clerks, clerical and office support)

6:      Sales worker (e.g. sales representatives and agents, sales assistants and salespersons, sales support workers)

7:      Machinery operators and drivers (e.g. machine and stationary plant operators, mobile plant operators, road and rail drivers, storepersons)

8:      Labourers (e.g. cleaners and laundry, construction and mining, factory process, farm, forestry and garden, food preparation assistants, other)

88:     Other (please specify) [Free text field]

MARITAL STATUS AND GENERAL HEALTH

Current registered marital status

Definition: The civil status of each individual in relation to the marriage laws or customs of the country. (METeOR ID 291045; ABS National Health Survey 2014-2015, item 4363.0, released 2018)

Coding: [Drop down list]

1:      Never married

2:      Widowed

3:      Divorced

4:      Separated

5:      Married (registered and de facto)

6:      Other (please specify) [Free text field]

Height

Definition: A person's self-reported height, measured in centimetres (measurement from head to toe). (METeOR ID 270365)

Coding: A 3 digit number [NNN] representing height in centimeters.

888:    Unknown

999:    Not stated/inadequately described

Weight

Definition: A person's self-reported weight (body mass). (METeOR ID: 302365)

Coding: A 3 digit number [NNN] representing weight in kilograms.

888:     Unknown

999:     Not stated/inadequately described

BMI

Definition: A measure of an adult's weight (body mass) relative to height used to assess the extent of weight deficit or excess where at least one of the measures is self reported. (METeOR ID 270086)

Coding: [Auto-calculate from height and weight], Ratio number, NN[N].N[N], equation = weight (kgs)/height^2(meters)

888.8: Unknown

999.9: Not stated/inadequately described

Tobacco smoking status

Definition: The patient's current and past smoking behavior. (METeOR ID 270311)

Coding: [Drop down list]

99:      Unknown

0:       Never smoked

1:       Daily smoker

2   Weekly smoker

3   Irregular smoker

4   Ex-smoker

Alcohol use

Definition: The patient's current and past alcohol use behavior. (no specific METeOR item, based on METeOR ID 691052, female alcohol consumption frequency in the first 20 wks of pregnancy)

Coding: [Drop down list]

0:       Never consumed alcohol

1:       Monthly or less

2   2 – 4 times a month

3   2 – 3 times a week

4   4 or more times a week

PARTICIPANT CONSENT AND INFORMATION SHEET

Definition: Record of a participant agreeing or consent to take part and allow their health data to be recorded and stored in this national registry for endometriosis.

Coding:

- Ethics approved Participant Information and Consent Form to be available online for participants to read if they want more information and contact details.
- Consent options based on ethics approval.
- Signature capture – either electronic signature or uploaded document (pdf) with patient signature.

Electronic signature and date of consent – Participant and Primary treating clinician

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Definition: Ability to capture the electronic signature of the participant (both 1st stage and 2nd stage) and the clinician performing the 2nd stage consent. Date of consent (or data entry) participant agrees to participate in collection, record, storage and analysis of data relating to their endometriosis care to inform outlined healthcare outcomes.

Coding:

1:      Signature capture box participant: mouse pad writing or solution as defined by VCS Foundation Ltd.

    1a: Confirmation of participant informed consent with primary treating clinician.

2:      Signature capture box or verification tick box by the primary treating clinician.

3:      Date (METeOR ID: 338737) capture for each electronic signatures: DD/MM/YYYY

2. Clinical presentation and medical history

Date questionnaire was completed

Definition: The date this questionnaire was completed by patient prior to medical consultation with clinician (usually gynaecologist).

Coding: DD/MM/YYYY

Who referred you to this service?

Definition: The source of referral to the gynaecological treatment service. (Modelled against METeOR ID 269946, 607130, 607133 and 424298)

Coding:

0104:   General practitioner

0222:   Gynaecologist (including gynaecological sonographer, fertility specialist)

1:        Other medical specialist (e.g. bowel or bladder specialist, emergency care doctor, pelvic pain specialist, etc.)

  1a: Please specify [Free text field]

88:      Other (please specify) [Free text field] (e.g. nurse, physiotherapist, naturopath, yoga instructor or online patient forum)

PRESENTING SYMPTOMS

Primary presenting symptom

Definition: The main reason for patient presenting to the clinician for review and management of symptoms.

Coding: [ICD-10 diagnosis codes; only single selection allowed]

N94.4: I have monthly pain/cramps with my periods (dysmenorrhoea)

N94.1: I have pain with sexual intercourse (dyspareunia)

R19.8: I have pain with bowel motions (dyschezia)

R30.0: I have pain with urination (dysuria)

R10.2: I have other types of pelvic pain

N93.9: I have abnormal vaginal bleeding

N92.0: I have heavy menstrual bleeding

R53:   I have fatigue

N97.9: I have fertility issues

R79.9: I have been referred because of abnormal findings on a blood test

R93.8: I have been referred because of abnormal findings on an ultrasound, MRI or CT scan

88:      Other symptom (please specify) [Free text field]

Secondary symptoms

Definition: Any additional reasons for the patient presenting to the clinician for review of their symptoms and for management of said symptoms.

Coding: [Data items as per **Primary presenting symptom;** multi-selection]

MENSTRUAL SYMPTOMS

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Age of first menstrual period

Definition: How old were you when you first started to have your periods? The age, in total years, of a female at the time of her first menstrual period. (Modelled against METeOR ID: 399602)

Coding:

1:      NN(2) [Free text field; whole years only]

2:      Periods have not started yet

88:     Don't remember

How old were you when you started to experience substantial period pain?

Coding:

1:      Periods have not started yet

2:      I do not have substantial pain with my periods

3:      < 10 years

       3a: Please specify (NN(2)) [Free text field; branching logic]

4:      10 – 14 years old

5:      15 – 19 years old

6:      20 – 24 years old

7:      25 – 29 years old

8:      30 – 34 years old

9:      35 – 39 years old

10:     40 – 44 years old

11:     45 – 49 years old

12:     50 – 54 years old

13:     > 55 years

How long do your periods usually last for (in days)?

Coding: NN(2) – NN(2) [shortest number of days – longest number of days in whole days]

Guide for use: e.g. 2 – 6 means you may bleed as few as 2 days or as many as 6 days in your period.

What is the usual time between the first day of one period to the first day of the next period

Coding: NN(2) – NN(2) [shortest number of days to the first day of your next period – longest number of days to the first day of your next period in whole days]

Guide for use: e.g. 24 – 36 means sometimes you may have 24 days between the first day of one period to the first day of your next period or sometimes you may have 36 days between the first day of one period to the first day of your next period.

Do you experience any spotting outside of your periods?

Coding: (modelled against METeOR ID: 638745)

1:      Yes

2:      No

88:     Don't know

PAIN HISTORY AND SYMPTOMS

Do you experience pain with your periods?

Coding: [Matrix tick boxes; VAS scale for all the questions below] (modelled against METeOR ID: 638745)

1:     Yes [if this option is selected, show the additional questions below]

     1a: On the scale of 0 to 10, please rate the level of pain you experience with your periods.

          Where 0 = no pain and 10 = worst imaginable pain.

2:     No

The following questions ask about different types of pain with your periods (including irregular bleeding or bleeding while on hormonal treatments, but not spotting)

Do you experience pain when you have sexual intercourse?

Do you experience pain when you open your bowels (passing stool/bowel motions)?

Do you experience pain when you urinate (passing urine/urination)?

Do you experience back pain?

Do you experience any other type of pain symptoms not already mentioned? [Free text field]

Do you experience pain at times other than with your periods?

Coding: [Matrix tick boxes and the VAS scale for all the questions below] (modelled against METeOR ID: 638745)

1:     Yes [if this option is selected, show the additional questions below]

     1a: On the scale of 0 to 10, please rate the level of pain you experience at other times than with your periods. Where 0 = no pain and 10 = worst imaginable pain.

2:     No

The following questions ask about different types of pain at times other than with your periods

Do you experience pain when you have sexual intercourse?

Do you experience pain when you open your bowels (passing stool/bowel motions)?

Do you experience pain when you urinate (passing urine/urination)?

Do you experience back pain?

Do you experience any other type of pain symptoms not already mentioned? [Free text field]

Do you also experience any of these other symptoms listed below with your periods?

R51:   Headache

G43.9: Migraine

R53:   Fatigue

R11:   Nausea/vomiting

99:      Others (please specify) [Free text field]

Coding: For all options of other symptoms, they are to be answered by selecting one of the options below

[Matrix tick boxes]

1:     Never

2:     Rarely

3:     Sometimes

4:     Often

5:     Always

Have you ever received a diagnosis for the pain from a doctor?

Coding: Please tick all that apply

2:        No

K58.9: Irritable bowel syndrome

K50.9: Crohn's Disease

K51.9: Ulcerative Colitis

N80.9: Endometriosis

D25.9: Fibroid(s)

N83.2: Ovarian cyst

M79.7: Fibromyalgia

N73.9: Pelvic inflammatory disease/infection

R39.8: Painful bladder syndrome

N30.9: Interstitial cystitis

Z73.3: Stress

99:       Other (please specify) [Free text field]

ENDOMETRIOSIS HISTORY

Has a doctor or other health care provider ever diagnosed you with endometriosis?

Coding: (modelled against METeOR ID: 638745)

1:        Yes

    1a: YYYY (4 digit number representing year of diagnosis, branching logic for this and for the questions below)

2:        No [skip logic, move to "**Pregnancy and fertility history**"]

If yes, how was the diagnosis made? (modelled against METeOR ID: 431754)

Coding: Please tick all that apply

1:        Laparoscopy

2:        Ultrasound pelvis

3:        MRI pelvis

4:        CT pelvis

4:        Based on symptoms

88:      Other (please specify) [Free text field]

If you had surgery for endometriosis, during your most recent surgery, was your endometriosis treated (i.e. was it removed or burnt away)

Coding:

1:        Yes

2:        No

3:        Surgery scheduled

4:        No surgery scheduled

99:      Unsure

How old were you when you first had symptoms? (modelled against METeOR ID: 270843)

Coding: 2-digit unit of measure by total number of completed years.

1:      NN(2) years old

2:      No, you have never had symptoms [Tick box]

What symptoms, if any, prompted you to see a health care provider before your diagnosis with endometriosis?

Coding: Please tick all that apply

R10.2: Pelvic pain

N97.9: Female infertility

2:      No symptoms

88:     Other (please specify) [Free text field]

Have you ever had surgery to look for endometriosis and none was found?

Coding: (modelled against METeOR ID: 638745)

1:      Yes

    1a: **If yes, what are the symptoms prompted the surgery?**

       Coding: Please tick all that apply [Branching logic]

       R10.2: Pelvic pain [Branching logic]

          1a-1:   **If yes, did your symptoms improve after surgery?**

            1a-1a: Yes [Branching logic; matrix form]

               1a-1a-1:   **For how long did your symptoms improve after surgery?**

                   1a-1a-1a: < 6 months

                   1a-1a-1b: 6 – 12 months

                   1a-1a-1c: 1 – 2 years

                   1a-1a-1d: 2 – 5 years

                   1a-1a-1e: > 5 years

               1a-1a-2:   **By approximately how much did your pain symptoms improve?** [Matrix form]

                   1a-1a-2a: < 25 % improvement

                   1a-1a-2b: 25 – 50 % improvement

                   1a1a-2c: 50 – 75 % improvement

                   1a-1a-2d: > 75 % improvement

             2:      No

            99:      Don't know

       N97.9: Female infertility

       88:     Other (please specify) [Free text field]

2:      No

Have any of your female blood relatives been diagnosed with endometriosis?

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Have any of your female blood relatives suffered from chronic pelvic pain (i.e. "bad periods" or "periods that required some form of rest", etc)?

Coding: [Matrix tick box]

1:      Mother

2:      Sister

3:      Grandmother, aunt or cousin on mother's side

4:      Grandmother, aunt or cousin on father's side

88:     Unknown

PREGNANCY, OBSTETRIC AND FERTILITY HISTORY

Have you ever been pregnant, or attempted to get pregnant?

Coding: (modelled against METeOR ID: 638745)

1:      Yes [Branching logic to answer remaining questions in this section]

2:      No

Obstetric history

Definition: Patient's previous pregnancies and outcomes history.

Coding: A 1 – 2 digit number representing the patient's previous obstetric history.

G (Gravidity):   Total number of confirmed pregnancies.

P (Parity):   Number of births you have had after 20 weeks of gestation.

Have you ever tried to get pregnant for more than 12 months in a row without succeeding?

Coding: (modelled against METeOR ID: 638745)

1:      Yes [Branching logic]

    1a: **If yes, what was the longest amount of time that you tried, whether or not you actually got pregnant?**

        Coding: NNN(3) [numerical value in months]

2:      No

Have you or your partner ever had any tests/investigations to find out why you were not getting pregnant?

Coding: (modelled against METeOR ID: 638745)

1:      Yes

    1a: **If yes, what were the results of these tests?**

    Coding: [Tick boxes] (Select all that apply)

        N80.9: Endometriosis

        N73.6: Pelvic peritoneal adhesions

        N99.4: Postprocedural pelvic peritoneal adhesions

        N97.1: Infertility due to blocked tubes

        E28.2: Polycystic ovary syndrome

        N73.9: Pelvic inflammatory disease

        N97.0: Infertility due to no/irregular ovulation

N46:   Poor sperm count/quality

D25.9: Fibroids

2:      No cause was found

88:     Other (please specify) [Free text field]

2:      No

Did you ever seek treatment for infertility in any clinic?

Coding: (modelled against METeOR ID: 638745)

1:      Yes

1a: **If yes, please tell us about any fertility treatment you have used.**

Coding: [Tick boxes] (Select all that apply)

1:      Intercourse timed specifically to conceive

2:      Fertility drugs by pills to stimulate ovulation (e.g. clomid, clomiphene or any other drug in pill form)

3:      Fertility drugs by injection (e.g. gonadotrophin, HCG or any other drug by injection)

4:      Progesterone (vaginal or intramuscular injection)

5:      Insemination with your partner's semen

6:      Intrauterine insemination with a donor's sperm

7:      In vitro fertilization (IVF)

8:      In vitro fertilization with intracytoplasmic sperm injection (ICSI)

9:      In vitro fertilization with eggs from a donor

2:      No

MEDICATION HISTORY

Hormonal medication(s) used

Note: please see Module 5 – Medical management for data dictionary, groupings and options.

Pain medication(s) used

Note: please see Module 5 – Medical management for data dictionary, groupings and options.

Other medication(s) used

Note: please see Module 5 – Medical management for data dictionary, groupings and options.

MEDICAL HISTORY

Have you ever been diagnosed by a doctor with cancer or a malignancy of any kind?

Coding: (modelled against METeOR ID: 638745)

1:      Yes [Branching logic]

1a: **If yes, what type(s) of cancer (primary location) have you been diagnosed with, and when were you first diagnosed?**

Coding: Free text fields

1a-1:   "Type of cancer"

1a-2:   "Age first diagnosed (years)"

2:          No

Have you ever had any of the following medical conditions diagnosed by a doctor?

F41.9:   Anxiety disorder

J45.9:   Asthma

I51.5:   Cardiovascular disease

K50.9:   Crohn's Disease

G93.3:   Chronic fatigue syndrome (CFS)/myalgic encephalomyelitis (ME)

H91.9:   Deafness/difficulty hearing

F32.9:   Depression

L20.9:   Eczema/dermatitis

D25.9:   Fibroids

M79.7:   Fibromyalgia

O24.4:   Gestational diabetes mellitus

B27.9:   Glandular fever

E05.0:   Graves' Disease

E06.3:   Hashimoto's disease

I10:   High blood pressure

N30.9:   Interstitial cystitis

K58.9:   Irritable bowel syndrome

G43.9:   Migraine

I34.1:   Mitral valve prolapse

G35:   Multiple sclerosis

R39.8:   Painful bladder syndrome

N94.8:   Pelvic congestion syndrome

N73.9:   Pelvic inflammatory disease/infection

E28.2:   Polycystic ovary syndrome (PCOS)

I49.8:   Postural orthostatic tachycardia syndrome (POTS)/Neurocardiogenic syncope

M06.9:   Rheumatoid arthritis

M41.9:   Scoliosis (curvature of the spine)

M53.9:   Spine problems (excluding scoliosis)

M35.0:   Sjogren's syndrome

M32.9:   Systemic lupus erythematous (SLE; Lupus)

E07.9:   Thyroid disease

E10.9:   Type I diabetes mellitus

E11.9:   Type II diabetes mellitus

K51.9:   Ulcerative Colitis

88:      Other (please specify) [Free text field]

2:       No

Have you been told that you were born with a structural problem/birth defect of your uterus, cervix or vagina?

Coding: (modelled against METeOR ID 638745)

1:      Yes [Branching logic]

    1a: **If yes, did you have surgery for this issue?**

    Coding: (modelled against METeOR ID 638745)

      1:      Yes

      2:      No

2:      No

In the last 3 months, have you had any of the following in relation to your bowel movements?

Coding: Please tick all that apply

1:      Rectal bleeding or blood in your stool

2:      Less than 3 bowel movements per week

3:      More than 3 bowel movements per day

4:      Nausea and/or vomiting

5:      Intestinal cramping

6:      Straining during a bowel movement

7:      Urgent need to have a bowel movement

8:      Feeling of incomplete emptying with bowel movements

9:      Passing mucus at the time of bowel movements

10:     Abdominal fullness, bloating or swelling

11:     None of the above

In the last 3 months, have you experienced any of the following in relation to urination?

Coding: Please tick all that apply

1:      Loss of urine when coughing, sneezing or laughing

2:      Difficulty passing urine

3:      Frequent bladder infections

4:      Blood in the urine

5:      Still feeling full after urination

6:      Having to urinate again within minutes of urinating

7:      None of the above

TO BE COMPLETED BY GYNAECOLOGIST

Primary clinical diagnosis (only one selection allowed)

Note: Separate section, to be completed by gynaecologist only after consultation with the patient, to be shown in Module 2 Clinical presentation and medical history, Module 4 Imaging, Module 5 Medical management and Module 6 Surgical management

Definition: The principal condition, after study to be chiefly responsible for occasioning the patient's episode of care.

Coding:

N80.9: Endometriosis, unspecified [Branching logic]

    1a: Surgical diagnosis (with histopathological confirmation)

      1b: Surgical diagnosis (without histopathological confirmation)

      1c: Clinical diagnosis

      1d: Based on imaging scans

N80.0: Endometriosis of uterus (includes adenomyosis)

D25.9: Leiomyoma of uterus/fibroids

N97:   Female infertility [Branching logic]

     N97.0: Female infertility associated with anovulation

     N97.1: Female infertility of tubal origin

     N97.2: Female infertility of uterine origin

     N97.8: Female infertility of other origin

     N97.9: Female infertility, unspecified

N46:   Male infertility

N94:   Pain and other conditions associated with female genital organs and menstrual cycle [Branching logic]

     N94.0: Ovulation pain

     N94.1: Dyspareunia [Branching logic]

          N94.10: Unspecified dyspareunia

          N94.11: Superficial (introital) dyspareunia

          N94.12: Deep dyspareunia

          N94.19: Other specified dyspareunia

     N94.2: Vaginismus

     N94.3: Premenstrual tension syndrome

     N94.4: Primary dysmenorrhoea

     N94.5: Secondary dysmenorrhoea

     N94.6: Dysmenorrhoea

M54.5: Low back pain

R10:   Abdominal and pelvic pain [Branching logic]

     R10.1: Pain localized to upper abdomen

     R10.2: Pelvic pain

     R10.3: Pain localized to other parts of lower abdomen

     R10.8: Other abdominal pain

     R10.9: Unspecified abdominal pain

88:      Other (please specify) [Free text field]

Secondary clinical diagnoses (select all that apply)

Note: Similarly to "**Primary clinical diagnosis"** above, to be completed by gynaecologist only after consultation with the patient, to be shown in Module 2 Clinical presentation and medical history, Module 4 Imaging, Module 5 Medical management and Module 6 Surgical management

Definition: Any additional diagnosed condition(s), which may occasion the patient's episode of care.

Coding: [Data items as per **Primary clinical diagnosis**] (Select all that apply)

First day of last menstrual period (LMP)

Definition: Date of the first day of when the patient last experienced a menstrual bleed.

Coding: DD/MM/YYYY

Hormonal treatment?

1:      On hormonal treatment

2:      Not on hormonal treatment

88:    Don't know

FOLLOW-UP OF CLINICAL PRESENTATION AND MEDICAL HISTORY

Note: to be sent with **Module 3 PROMs** as per discussed schedule, not for index completion

Have any of your symptoms <u>improved</u> since you last answered questions on your presenting symptoms for the NECST Registry?

Coding:

1:      Yes [Branching logic]

    1a: No improvement

    1b: < 25 % improvement

    1c: 25 – 50 % improvement

    1d: 50 – 75 % improvement

    1e: > 75 % improvement

2:      No

Did you developed any <u>new</u> symptoms since you last provided answers for the NECST Registry?

Coding: [ICD-10 diagnosis codes]

1:      Yes (select all that apply) [Branching logic]

    N94.4: I have monthly pain/cramps with my periods (dysmenorrhoea)

    N94.1: I have pain with sexual intercourse (dyspareunia)

    R19.8: I have pain with bowel motions (dyschezia)

    R30.0: I have pain with urination (dysuria)

    R10.2: I have other types of pelvic pain

    N93.9: I have abnormal vaginal bleeding

    N92.0: I have heavy menstrual bleeding

    R53:   I have fatigue

    N97.9: I have fertility issues

    R79.9: I have been referred because of abnormal findings on a blood test

    R93.8: I have been referred because of abnormal findings on an ultrasound, MRI or CT scan

    88:     Other symptom (please specify) [Free text field]

2:      No

Have you needed to change or stop any of your medications (hormonal or pain or other), either since you last provided answers for the NECST Registry or when you were last prescribed a medicine (hormonal or pain or other) by your primary treating gynaecologist?

Coding:

1: Yes [if this option is selected, to bring up the table list of medications – hormonal, pain and/or other, that the participant is on from **Module 5 Medical Management**. This should also include the columns "**Adverse/side effect(s)**" and "**Reason for ceasing**" – to allow participant to select their answer(s), also allow ability of participant to add new medicine if they were then prescribed an alternative]

2: No

Have any of your contact details changed since you last provided answers for the NECST Registry?

Coding:

1: Yes [Branching logic]

  1a: Email [Free text field]

  1b: Contact number [Free text field]

  1c: Address [Free text field]

  1d: Medicare number [Free text field]

  88: Other (please specify and provide details) [Free text field]

2: No

3. Patient reported outcome measures (PROMs)

Note on the patient groups that will complete either the EQ-5D and/or EHP-30

- All patients will complete the EQ-5D, regardless their presenting symptoms and diagnosis.
- Patients who answer to having had a diagnosis of endometriosis in Module 2. Clinical Presentation and Medical History will complete the EHP-30.
- Ongoing PROMs follow up schedule post initial visit and registration to the Registry
    - 6 months → 12 month → 24 months → annually
- Patients who then undergo surgery and have endometriosis confirmed by laparoscopy and histopathology will also then start completing the EHP-30 questionnaire, in addition to the EQ-5D.
- Ongoing PROMs follow up schedule, new schedule will initiated
    - 6 months → 12 month → 24 months → annually

Date of completion of this questionnaire

Definition: The date that the patient completed this questionnaire. (METeOR ID: 338737)

Coding: DD/MM/YYYY

EQ-5D 5L

Note: to be completed by all patients, i.e. new patients, returning patients, etc.

Definition: Standardized instrument developed by the EuroQol Group. Measures of health-related quality of life across a wide range of health conditions and treatments.

Please click the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about	☐
I have slight problems in walking about	☐
I have moderate problems in walking about	☐
I have severe problems in walking about	☐
I am unable to walk about	☐

SELF-CARE

I have no problems washing or dressing myself	☐
I have slight problems washing or dressing myself	☐
I have moderate problems washing or dressing myself	☐
I have severe problems washing or dressing myself	☐
I am unable to wash or dress myself	☐

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

I have no problems doing my usual activities	☐
I have slight problems doing my usual activities	☐
I have moderate problems doing my usual activities	☐
I have severe problems doing my usual activities	☐

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

I am unable to do my usual activities ☐

PAIN / DISCOMFORT

I have no pain or discomfort ☐

I have slight pain or discomfort ☐

I have moderate pain or discomfort ☐

I have severe pain or discomfort ☐

I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION

I am not anxious or depressed ☐

I am slightly anxious or depressed ☐

I am moderately anxious or depressed ☐
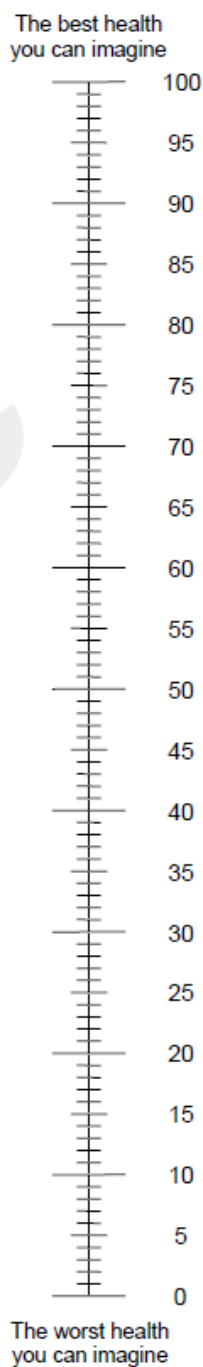
I am severely anxious or depressed ☐

I am extremely anxious or depressed ☐

Coding: [Tick box] (Select the most representative answer to your situation from each category.)

EQ-5D-5L Visual analogue scale (VAS)

Definition: EQ VAS records the patient's self-rated health on a vertical visual analogue scale.

Coding: [Sliding scale]

The best health
you can imagine

	100
	95
	90
	85
	80
	75
	70
	65
	60
	55
	50
	45
	40
	35
	30
	25
	20
	15
	10
	5
	0

The worst health
you can imagine

Guide for use: "**We would like to know how good or bad your health is TODAY. This scale is numbered from 0 to 100. 100 means the best health you can imagine. 0 means the worst health you can imagine. Mark an X on the scale to indicate how your health is TODAY. Now, please write the number you marked on the scale in the box below.**"

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Endometriosis-specific questionnaire – ENDOMETRIOSIS HEALTH PROFILE (EHP)-30

Note: Only for patients that have a "diagnosis of endometriosis". Surgical patients easily identifiable. Will need to define the group of patients that will have a clinical diagnosis of endometriosis, e.g. based on their symptom profile, with/without imaging assessment

Definition: A health related quality-of-life (HRQoL) questionnaire specifically addressing the impact of endometriosis on the physical, psychologic, and social aspects of patients' lives.

During the **last 4 weeks**, how often, because of your endometriosis, have you

1:     Been unable to go to social events because of the pain?

2:     Been unable to do jobs around the home because of the pain?

3:     Found it difficult to stand because of the pain?

4:     Found it difficult to sit because of the pain?

5:     Found it difficult to walk because of the pain?

6:     Found it difficult to exercise or do the leisure activities you would like to do because of the pain?

7:     Lost your appetite and/or been unable to eat because of the pain?

8:     Been unable to sleep properly because of the pain?

9:     Had to go to bed/lie down because of the pain?

10:     Been unable to do the things you want to do because of the pain?

11:     Felt unable to cope with the pain?

12:     Generally felt unwell?

13:     Felt frustrated because your symptoms are not getting better?

14:     Felt frustrated because you are not able to control your symptoms?

15:     Felt unable to forget your symptoms?

16:     Felt as though your symptoms are ruling your life?

17:     Felt your symptoms are taking away your life?

18:     Felt depressed?

19:     Felt weepy/tearful?

20:     Felt miserable?

21:     Had mood swings?

22:     Felt bad tempered or short tempered?

23:     Felt violent or aggressive?

24:     Felt unable to tell people how you feel?

25:     Felt others do not understand what you are going through?

26:     Felt as though others think you are moaning?

27:     Felt alone?

28:     Felt frustrated as you cannot always wear the clothes you would choose?

29:     Felt your appearance has been affected?

30:     Lacked confidence?

Coding: All 30 questions are to be answered by selecting one of the options [Tick boxes]

1:     Never

2:     Rarely

3:      Sometimes

4:      Often

5:      Always

PART 2: MODULAR QUESTIONS

Section A:

These questions concern the effect endometriosis has had on your work during the last 4 weeks. If you have

not been in paid or voluntary employment during the last 4 weeks, please tick here ☐ and move onto

Section B.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Had to take time off work because of the pain?

2.   Been unable to complete tasks at work because of the pain?

3.   Felt embarrassed about symptoms at work?

4.   Felt guilty about taking time off work?

5.   Felt worried about not being able to do your job?

Section B:

These questions concern the effect endometriosis has had on your relationship with your child/children

during the last 4 weeks. If you do not have any children, please tick here ☐ and move onto Section C.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Found it difficult to look after your child/children?

2.   Been unable to play with your child/children?

Section C:

These questions concern the effect endometriosis has had on your sexual relationships during the last 4

weeks.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Experienced pain during or after intercourse?

        If not relevant, please tick here ☐

2.   Felt worried about having intercourse because of the pain?

        If not relevant, please tick here ☐

3.   Avoided intercourse because of the pain?

        If not relevant, please tick here ☐

4.   Felt guilty about not wanting to have intercourse?

        If not relevant, please tick here ☐

5.   Felt frustrated because you cannot enjoy intercourse?

        If not relevant, please tick here ☐

Section D:

These questions concern your feelings during the last 4 weeks about the medical profession.

If this section is not relevant to you, please tick here ☐ and move onto Section E.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Felt the doctor(s) you have seen is (are) not doing anything for you?

2.   Felt the doctor(s) thinks (think) it is all in your mind?

3.   Felt frustrated at the doctor's/doctors' lack of knowledge about endometriosis?

4.   Felt like you are wasting the doctor's/doctors' time?

Section E:

These questions concern your feelings during the last 4 weeks about your treatment for endometriosis.

Treatment means any surgery or prescribed medication for your endometriosis.

If this section is not relevant to you, please tick here ☐ and move onto Section F.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Felt frustrated because treatment is not working?

2.   Found it difficult coping with the side effects of treatment?

3.   Felt annoyed at the amount of treatment you have had to have?

Section F:

These questions concern your problems conceiving during the last 4 weeks.

If this section is not relevant to you, please tick here ☐.

DURING THE LAST 4 WEEKS, HOW OFTEN, BECAUSE OF YOUR ENDOMETRIOSIS, HAVE YOU...

1.   Felt worried about the possibility of not having children/more children?

2.   Felt inadequate because you may not/have not been able to have children/more children?

3.   Felt depressed at the possibility of not having children/more children?

4.   Felt that the possibility of not conceiving/not being able to conceive has put a strain upon your personal relationship?

Coding: All Part 2 Modular Questions (Sections A – F) are to be answered by selecting one of the options

[Tick boxes]

1:      Never

2:      Rarely

3:      Sometimes

4:      Often

5:      Always

4. Imaging (Ultrasound and MRI)

US REPORT UPLOAD (PDF)

Date of imaging assessment

Definition: Date of imaging procedure performed on patient.

Coding: DD / MM / YYYY

Location of imaging service

Definition: The address of the imaging service performed on the patient to detect endometriosis.

Coding:

[Pre-populated with list of service providers]

88:    Other (please specify) [Free text field]

99:    Unknown

Imaging assessment

Definition: The type of medical imaging (i.e. radiography) used to assess internal body organs.

Coding:

1:    Ultrasound

2:    MRI

88:    Other (please specify) [Free text field]

File (pdf) upload of imaging assessment report.

Coding: [Ability to save file in accordance to the imaging assessment report number]

Primary findings

Note: as reported from the imaging (US or MRI) report

Definition: Primary finding, after imaging (US or MRI) to be chiefly responsible for the patient's episode of care in hospital.

Coding: [ICD-10 codes]

N80:   Endometriosis [Branching logic]

    N80.1: Endometriosis of ovary

    N80.2: Endometriosis of fallopian tube

    N80.3: Endometriosis of pelvic peritoneum

    N80.4: Endometriosis of rectovaginal septum and vagina

    N80.5: Endometriosis of intestine

    N80.6: Endometriosis in cutaneous scar

    N80.8: Other endometriosis

    N80.9: Endometriosis, unspecified

N80.0: Endometriosis of uterus (adenomyosis) [Branching logic]

        N80.1: Uniformly enlarged

        N80.8: Other (please specify) (Free text field enabled)

D25.9: Leiomyoma of uterus/fibroids (select all that apply) [Branching logic]

          D25.0: Submucous leiomyoma of uterus

          D25.1: Intramural leiomyoma of uterus

          D25.2: Subserosal leiomyoma of uterus

N97:   Female infertility [Branching logic]

          N97.0: Female infertility associated with anovulation

          N97.1: Female infertility of tubal origin

          N97.2: Female infertility of uterine origin

          N97.8: Female infertility of other origin

          N97.9: Female infertility, unspecified

E28.2: Polycystic ovarian syndrome

D27:   Benign neoplasm of ovary (includes cyst (colloid) (mucous) (dermoid) (ovarian twisted) (not elsewhere classified))

N70.1: Hydrosalpinx

N83.0: Follicular cyst of ovary (includes cyst of graafian follicle, haemorrhagic follicular cyst)

N83.1: Corpus luteum cyst (includes haemorrhagic corpus luteum cyst)

N83.2: Other and unspecified ovarian cysts (includes retention and simple cyst of ovary)

N83.3: Acquired atropy of ovary and fallopian tube

N83.4: Prolapse and hernia of ovaria and fallopian tube

N83.5: Torsion of ovary, ovarian pedicle and fallopian tube

N84:   Polyp of female genital tract [Branching logic]

          N84.0: Polyp of corpus uteri (includes polyp of endometrium or uterus)

          N84.1: Polyp of cervix uteri

          N84.2: Polyp of vagina

          N84.3: Polyp of vulva (includes polyp of labia)

          N84.8: Polyp of other parts of female genital tract

          N84.9: Polyp of female genital tract, unspecified

N85.0: Endometrial hyperplasia

Q51:   Congenital malformations of uterus and cervix [Branching logic]

          Q51.0: Agenesis and aplasia of uterus (Congenital absence of uterus)

          Q51.1: Doubling of uterus with doubling of cervix and vagina

          Q51.2: Other doubling of uterus (Doubling of uterus NOS)

          Q51.3: Bicornate uterus

          Q51.4: Unicornate uterus

          Q51.5: Agenesis and aplasia of cervix (Congenital absence of cervix)

          Q51.6: Embryonic cyst of cervix

          Q51.7: Congenital fistulae between uterus and digestive and urinary tracts

          Q51.8: Other congenital malformations of uterus and cervix (Hypoplasia of uterus and cervix)

          Q51.9: Congenital malformation of uterus and cervix, unspecified

88:     Other (please specify) [Free text field]

Secondary findings

Note: as reported from the imaging (US or MRI) report

Definition: Additional condition(s), findings that coexist at the time of imaging (US or MRI) that may require further management and assessment by the healthcare professional.

Coding: [Data items as per **Primary finding**; branching logic, multiple selection]

2:      No

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

ULTRASOUND DATA

Date of imaging assessment

Definition: Date of imaging procedure performed on patient.

Coding: DD / MM / YYYY

Location of imaging service

Definition: The address of the imaging service performed on the patient to detect endometriosis.

Coding:

[Pre-populated with list of service providers]

88:     Other (please specify) [Free text field]

99:     Unknown

Specialist women's imaging service

Definition: An imaging service centre provided and run by specialist women's health practitioners (i.e.

Obstetrician/Gynaecologist sonographers)?

Coding: (modelled against METeOR ID: 638745)

1:     Yes

2:     No

99:     Unknown

Sonographer details

Definition: Name of the sonologist, sonographer or radiologist that is performing the ultrasound or MRI

imaging.

Coding:

[Pre-populated with list of service providers]

88:     Other (please specify) [Free text field]

99:     Don't know

Name of referring clinician

Definition: The referring clinician that has recommended for the patient to undertake imaging assessment

based on the patients presenting symptoms and suspicion of endometriosis.

Coding:

[Pre-populated with list of service providers]

88:     Other (please specify) [Free text field]

Referred by

Definition: The source of referral to the gynaecological imaging assessment service.

Coding: (modelled against METeOR ID: 607130, 607133 and 424298)

0104:   General practitioner

0222:   Gynaecological surgeon

0222:   Gynaecologist

0237:   Reproductive endocrinology and infertility specialist (CREI)

Page 32

88:    Other (please specify) [Free text field]

99:    Unknown

Reason for imaging assessment

Coding: [Multiple selection]

1:    Suspicion of endometriosis

N80:   Endometriosis surgery planning

2:    Second opinion for possible endometriosis

R10.2: Pelvic pain

N97:   Fertility investigations

N93.9: Abnormal uterine bleeding/intermenstrual bleeding

88:    Other symptoms (please specify) [Free text field]

ULTRASOUND ASSESSMENT

Bowel prep

Definition: Documentation of whether patient had bowel prep to clean the colon to allow for thorough imaging assessment.

Coding: (modelled against METeOR ID: 638745)

1:    Yes

2:    No

88:    Don't know

Standoff pad technique

Definition: To decrease or prevent echo reverberations in the area of interest by placing it in the focal zone of the transducer.

Coding: (modelled against METeOR ID: 638745)

1:    Yes

2:    No

88:    Don't know

Menstrual cycle pattern

Definition: The regularity of a women's menstrual cycle.

Coding: [Drop down list]

1:    Regular [Branching logic]

2:    Irregular

3:    Exogenous hormones

4:    Abnormal

99:    Don't know

Time in menstrual cycle

Coding: [Drop down list]

1:    Follicular

2:      Peri-ovulatory

3:      Luteal

4:      Menstruating

5:      On exogenous hormones

88:     Other (please specify) [Free text field]

99:     Don't know

TRANSABDOMINAL (TA) ULTRASOUND

Kidney/ureter appearances

Definition: Is there renal pelvis dilatation or hydronephrosis?

Coding: (modelled against METeOR ID: 638745)

1:      Yes

2:      No

TRANSVAGINAL (TV) ULTRASOUND

Is the uterus…?

Coding:

1:      Present

2:      Absent [Skip logic, move to "Endometrial thickness"]

Position of the uterus in the pelvis

Coding: [Multiple selection]

1:      Retroverted

2:      Retroflexed

3:      Anteverted

4:      Anteflexed

5:      Rotated (anteverted and slightly retroflexed)

88:     Others (please specify) [Free text field]

MYOMETRIUM AND JUNCTIONAL ZONE

Volume of the uterus (automatic upload of the measurement)

Coding:

1:      NNN[3] (1 – 3 digit numbers representing the volume of the uterus in centimetres cubed (cm^3)).

2:      Serosal contour

   2a: Regular

   2b: Lobulated

Myometrial examination

Definition: Assessment of the myometrium, based on the MUSA consensus (van den Bosch et al., 2015;

Table 1 and 2).

Coding:

1:      Myometrial walls

1a:	Symmetrical
1b:	Asymmetrical
2:	Overall echogenicity
2a:	Homogeneous
2b:	Heterogeneous

Fibroids

Coding: (modelled against METeOR ID: 638745)

1:      Yes [Branching logic]

    1a: Number of fibroids: NNN [Free text field]

    1b: Largest fibroid: NNN in millimetres

    1c: Submucosal fibroids

        1c-1:   Yes

        1c-2:   No

2:      No

Adenomyosis

Coding: [Branching logic] (modelled against METeOR ID: 638745)

1:      Features [Multiple selection]

    1a: Lobulated serosal contour

    1b: Heterogeneity of myometrium

    1c: Asymmetrical anterior and posterior myometrium

    1d: Hyperechoic endometrial islands

    1e: Myometrial cysts

    1f: Hypoechoic irregular infiltration

    1g: Poorly defined endometrial-myometrial junction

    1h: Location

        1h-1:   Generalised

        1h-2:   Focal

            1h-2a: Anterior

            1h-2b: Posterior

        1h-3:   Adjacent to the endometrial cavity

        1h-4:   Subserosal

            1h-4a: Anterior

            1h-4b: Posterior

2:      No features

Presence of an adenomyoma [Branching logic]

Coding: (modelled against METeOR ID: 638745)

1:      Yes

2:      No

National Endometriosis Clinical and Scientific Trials Network Registry

ENDOMETRIUM

Endometrial thickness

Definition: A measured parameter on routine gynaecological ultrasound and MRI to determine the thickness of the endometrium.

Coding: 2 – 3 digit numbers representing the thickness of the endometrium in millimeters.

Endometrial characteristics

Coding: [Multiple selection]

1a: Proliferative

1b: Secretory

1c: Menstrual

2a: Atrophic

2b: Irregular appearance

3a: Evidence of polyp [Branching logic]

    3b-1:   No. of polyps [Free text field]

OVARIES AND ADNEXA

Left ovary

Coding:

1:     Present

2:     Absent [Branching logic; move to "Right ovary"]

Left ovary dimensions

Definition: Measurements taken to determine volume and size of left ovary.

Coding: NN x NN x NN mm [N = 1 – 2 digits representing measurements for volume of ovaries in millimetres]

Left ovary follicle measurements and count

Coding: N = digit representing number and size of follicles.

1:     N follicles between 2 and 9 mm in diameter and N follicles > 9 mm

2:     Dominant follicle

3:     Corpus luteum

Left ovary mobility

1:     Freely mobile

2:     Reduced mobility

3:     Immobile

    3a: Fixed to the lateral uterus

    3b   Fixed to the pelvic sidewall

    3c: Fixed to the uterosacral ligament

Left ovarian endometrioma

Definition: A cystic mass arising from ectopic endometrial tissue within the ovary. It contains thick, brown, tar-like fluid, which may be referred to as a "chocolate cyst".

Coding:

1:      Yes [Branching logic]

    1a: Size: NN in millimetres (mm)

    1b: Ground glass

        1b-1:   Yes

        1b-2:   No

    1c: Acoustic streaming

        1c-1:   Yes

        1c-2:   No

    1d: Vascularity

        1d-1:   Minimal

        1d-2:   Moderate

        1d-3:   Very vascular

2:      No

Left ovarian lesions/cysts other than suspected endometriomas

Coding: [Multiple selection] (using Timmerman et al., 2000, Ultrasound Obstet Gynecol)

1:      Cyst features

    1a: Unilocular cyst

    1b: Unilocular-solid cyst

    1c: Multilocular cyst

    1d: Multilocular-solid cyst

    1e: Solid cyst

2:      Vascularity

    2a: Minimal

    2b: Moderate

    2c: Very vascular

99:     Not classifiable

Left adnexal mass

Definition: A lump in tissue of the adnexa of uterus (structures closely related structurally and functionally to the uterus such as the ovaries, fallopian tubes, or any of the surrounding connective tissue).

Coding:

1:      Hydrosalpinx

    1a: Yes

    1b: No

2:      No

Right ovary

Coding:

1:        Present

2:        Absent [Branching logic; move to "**Urinary bladder nodule**"]

Right ovary dimensions

Definition: Measurements taken to determine volume and size of right ovary.

Coding: NN x NN x NN mm [N = 1 – 2 digits representing measurements for volume of ovaries in millimetres]

Right ovary follicle measurements and count

Coding: N = digit representing number and size of follicles.

1:        N follicles between 2 and 9 mm in diameter and N follicles > 9 mm

2:        Dominant follicle

3:        Corpus luteum

Right ovary mobility

1:        Freely mobile

2:        Reduced mobility

3:        Immobile

      3a: Fixed to the lateral uterus

      3b   Fixed to the pelvic sidewall

      3c: Fixed to the uterosacral ligament

Right ovarian endometrioma

Definition: A cystic mass arising from ectopic endometrial tissue within the ovary. It contains thick, brown, tar-like fluid, which may be referred to as a "chocolate cyst".

Coding:

0:        No

1:        Yes [Branching logic]

      1a: Size: NN in millimetres (mm)

      1b: Ground glass

            1b-1:   Yes

            1b-2:   No

      1c: Acoustic streaming

            1c-1:   Yes

            1c-2:   No

      1d: Vascularity

            1d-1:   Minimal

            1d-2:   Moderate

            1d-3:   Very vascular

Right ovarian lesions/cysts other than endometrioma

Coding: [Multiple selection] (using Timmerman et al., 2000, Ultrasound Obstet Gynecol)

1:        Cyst features

1a:	Unilocular cyst
1b:	Unilocular-solid cyst
1c:	Multilocular cyst
1d:	Multilocular-solid cyst
1e:	Solid cyst

2:    Vascularity

    2a: Minimal

    2b: Moderate

    2c: Very vascular

99:    Not classifiable

Right adnexal mass

Definition: A lump in tissue of the adnexa of uterus (structures closely related structurally and functionally to the uterus such as the ovaries, fallopian tubes, or any of the surrounding connective tissue).

Coding: (modelled against METeOR ID: 638745)

1:    Hydrosalpinx

    1a: Yes

    1b: No

2:    No

Are both ovaries kissing?

Coding: (modelled against METeOR ID: 638745)

1:    Yes

2:    No

BLADDER AND ANTERIOR COMPARTMENT

Urinary bladder nodule

Definition: Is there presence of a nodule in the bladder.

Coding: (modelled against METeOR ID: 638745)

1:    Present

    1a: Size: NN in millimetres (mm)

2:    Absent

Uterovesical region using sliding sign

Definition: Assessment of whether the posterior bladder slides freely over the anterior uterine wall.

Coding: (modelled against METeOR ID: 638745)

1:    Positive

2:    Negative [Branching logic]

    2a: Caesarean section

        2a-1:   Yes

        2a-2:   No

Is there presence of ureteric nodule(s)?

1:     Left

2:     Right

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic]

    1a: NN mm (N = 1 – 2 digits in millimetres measuring the distance from distal ureteric orifice to stricture)

2:     No

POSTERIOR COMPARTMENT

Pouch of Douglas obliteration (sliding sign)

Definition: Assessment of whether the anterior rectum and sigmoid colon glides freely across the posterior aspect of the upper uterus, cervix and vaginal wall.

Coding:

1:     Positive

2:     Negative [Branching logic]

    2a: Partial [Branching logic]

        2a-1:   Left

        2a-2:   Right

    2b: Complete

Is there a nodule present on the posterior vaginal fornix?

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic; multiple selection]

    1a: Dimension of nodule to be measured in millimetres (mm).

2:     No

Are rectovaginal nodules present?

Definition: Presence of deep infiltrating endometriosis in the anterior rectal wall and posterior vaginal fornix, located below the peritoneum of the Pouch of Douglas.

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic]

    1a: NN, 1 – 2 digits representing the dimension of the nodule to be measured in millimetres.

2:     No

Are there uterosacral ligament nodules?

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic]

    1a: Left

        1a-1:   NN, 1 – 2 digits describing the dimensions of thickening or nodule to be measured in millimetres

    1b: Right

         1b-1:   NN, 1 – 2 digits describing the dimensions of thickening or nodule to be measured in millimetres

2:     No

99:    Unknown

Is there a retrocervical nodule present?

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic]

        1a: NN, 1 – 2 digits describing the dimensions of nodule to be measured in millimetres

2:     No

99:    Unknown

Rectum and colon (IDEA consensus Guerriero et al., 2016 and Gonclaves et al., 2009)

Is there bowel deep infiltrating endometriosis seen?

Coding: (modelled against METeOR ID: 638745)

1:     Yes [Branching logic; multiple selection]

        1a: Distance from the anal verge [NN, 1 – 2 digits representing the distance of the lesion from the anal verge in centimetres]

                1a-1:   > 20 cm

        1b: Lesion type

                1b-1:   Isolated lesion

                1b-2:   Multiple lesions

                1b-3:   Curved lesion

                1b-4:   Straight lesion

        1c: Layers affected [for each lesion]

                1c-1:   Muscularis

                1c-2:   Submucosa

                1c-3:   Mucosa

        1d: Is it stuck to any structures or free lying loop?

                1d-1:   Vagina

                1d-2:   Uterus

                1d-3:   Uterosacral ligaments

                1d-4:   Ovary

2:     No

        2a: Insufficient view?

                2a-1:   Yes

                2a-2:   No

99:    Unknown

Is there evidence of tethering of the bowel?

Coding: (modelled against METeOR ID: 638745)

1:     Yes, tethered to [Branching logic]

	1a:	Uterus
	1b:	L. ovary
	1c:	R. ovary
	1d:	L. uterosacral ligament nodule
	1e:	R. uterosacral ligament nodule
2:	No	
99:	Unknown	

OTHERS

Is there site-specific tenderness?

Coding:

1:	Yes [Branching logic; multiple selection]	
	1a:	L. ovary
	1b:	R. ovary
	1c:	L. uterosacral ligaments
	1d:	R. uterosacral ligaments
	1e:	Pelvic floor (vaginal introitus)
2:	No	
88:	Other (please specify) [Free text field]	
99:	Unknown	

MRI ASSESSMENT DATA

Note: To be drafted and developed at later date. At this stage, we will only be asking to upload the MRI report of participants that have had an MRI Assessment.

5. Medical management

Date of consultation

Definition: Date of medical consultation with clinician (usually gynaecologist).

Coding: DD / MM / YYYY

Gynaecological specialty

Definition: The healthcare specialist that is responsible for prescribing the medication for endometriosis management.

Coding: [Multiple selection]

0222:   Endometriosis surgeon

0237:   Reproductive endocrinology and infertility specialist (CREI)

0222:   Gynaecologist

1:    Pain specialist

2:    Adolescent specialist

88:    Other (please specify) [Free text field]

Please list any additional health professionals involved in patients care

Definition: Any additional healthcare professionals (includes medical, dental or nursing professionals) that are currently or will be involved in the management of the patients endometriosis symptoms. (Modelled against METeOR ID: 607130)

Coding: [Multiple selection]

2:            None

0104:   General practitioner

0206:   Colorectal surgeon

021801:   Urologist

0231:   Psychiatrist

0306:   Nurse practitioner

88:            Other (please specify) [Free text field]

99:            Unknown

Please list any additional allied health professionals/practitioners involved in patients care

Definition: A broad range of health practitioners that are involved in complementary and/or specialised activities that can be used in conjunction with "mainstream therapy" in preventing and treating a range of conditions and illnesses. (Based on Allied Health Professionals Australia definition) (modelled against METeOR ID: 607130 and 607133)

Coding: [Multiple selection]

2:    None

0302:   Psychologist

0310:   Physiotherapist

0304:   Dietician

0302:   Counsellor

0399:   Sex therapist

0399:   Traditional Chinese Medicine Practitioner (includes Chinese herbalist and acupuncturist)

0303:   Chiropractor

0399:   Naturopath

88:    Other (please specify) [Free text field]

99:    Unknown

First date of last menstrual period (LMP)

Definition: Date of the first day of when the patient last experienced a menstrual bleed.

Coding: DD/MM/YYYY

SUMMARY OF PRESENTING SYMPTOMS AND PRINCIPAL DIAGNOSIS

Note: To be pre-populated from **Module 2 – Clinical presentation and medical history** and be visualised with the medical management options)

*Primary presenting symptom

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

Note 2: Allow changes to be made to Primary and Secondary symptoms above, this is to be date logged to show when the changes happened)

*Secondary symptoms

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

Note 2: Allow changes to be made to Primary and Secondary symptoms above, this is to be date logged to show when the changes happened)

*Primary clinical diagnosis

Note: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

*Secondary clinical diagnoses

Note: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

MEDICATIONS

Hormonal Medication(s)

Note: To be in a table form and date logged, current/new medications at the top, with adverse event(s), see separate data field below, added to end of column or ability to be grouped with the medication being used

Definition: Use of medicines for the treatment of disease or symptoms with synthetic or naturally derived hormones.

Coding:

Note: Need ability to add more than one medication for when medications are changed or not required. Also require ability to track the order of medications trialled.

1:      Drug group [Drop down list, branching logic and grouping "Drug brand names" with their "Drug group", with multiple selection to allow for add-back therapy with GnRH analogues]

   1-99:   Don't know

   1a: Combination hormonal contraceptives (includes COCPs and vaginal rings)

   1b: Progestogens (includes implants and intrauterine systems)

   1c: GnRH (modulators) agonist injection/shot/nasal spray

   1c-1:   GnRH with hormonal add-back therapy [to link to drug brand names listed in 2d: MHT/HRT]

   1d: Menopausal hormone/Hormonal replacement therapy (MHT/HRT)

   1e: Androgens

   1-88:   Other (please specify) [Free text field]

2:      Drug brand name [Drop down list]

Note: To be populated by commercial drug names, in-line with above drug groups → "a" = COCP, "b" = Progestogens, etc., matched to above and in alphabetical order, codes used are the ARTG IDs and PBS, if relevant, of the medicines

   2-99:   Don't know

   A: Combined hormonal contraceptives (COCP)

   42894:   Marvelon (ARTG ID; 42894; 30 mcg ethinyloestradiol + 150 mcg desogestrel; 3G)

   226238: Yasmin (ARTG ID: 226238; 30 mcg ethinyloestrodiol + 3 mg drosperinone; 4G)

   226241: Yaz (ARTG ID: 226241; 20 mcg ethinyloestrodiol + 3 mg drosperinone; 4G)

   40193:   Levlen (ARTG ID: 40193; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)

   63484:   Microgynon 20 (ARTG ID: 63484; 20 mcg ethinyloestradiol + 100 mcg levonorgestrel; 2G)

   10693:   Microgynon 30 (ARTG ID: 10693; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)

   10695:   Microgynon 50 (ARTG ID: 10695; 50 mcg ethinyloestradiol + 125 mcg levonorgestrel; 2G)

   62133:   Norimin (ARTG ID: 62133; 35 mcg ethinyloestradiol + 500 mcg norethisterone; 1G)

   62136:   Norimin 1 (ARTG ID: 62136; 35 mcg ethinyloestradiol + 1000 mcg norethisterone; 1G)

   168332: Zoely 2.5 mg (ARTG ID: 168332; 1.5 mg oestradiol + 2.5 mg nomegestrol acetate; 4G)

   33647:   Diane 35 (ARTG ID: 33647; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   55128:   Brenda 35 (ARTG ID: 55128; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   93607:   Estelle 35 (ARTG ID: 93607; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   144128: Jene 35 (ARTG ID: 144128; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   75554:   Juliet 35 (ARTG ID: 75554; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   142435: Laila 35 (ARTG ID: 142435; 35 mcg ethinylestradiol + 2 mg cyproterone; 1G)

   149319: Qlaira (ARTG ID: 149319; oestradiol valerate + dienogest, 4G)

   180561: Isabelle (ARTG ID: 180561; 30 mcg ethinyloestrodiol + 3 mg drosperinone; 4G)

   226240: Petibelle (ARTG ID: 226240; 30 mcg ethinyloestrodiol + 3 mg drosperinone; 4G)

National Endometriosis Clinical and Scientific Trials Network Registry   DATA DICTIONARY
21 JUNE 2021

170389:	Femme-Tab 20 (ARTG ID: 170389; 20 mcg ethinyloestradiol + 100 mcg levonorgestrel; 2G)
215494:	Loette (ARTG ID: 215494; 20 mcg ethinyloestradiol + 100 mcg levonorgestrel; 2G)
211154:	Micronelle 20 (ARTG ID: 211154; 20 mcg ethinyloestradiol + 100 mcg levonorgestrel; 2G)
296399:	Monofeme (ARTG ID: 296399; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)
296400:	Nordette (ARTG ID: 296400; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)
205575:	Evelyn 150/30 (ARTG ID: 205575; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)
205579:	Eleanor 150/30 (ARTG ID: 205579; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)
211155:	Micronelle 30 (ARTG ID: 211155; 30 mcg ethinyloestradiol + 150 mcg levonorgestrel; 2G)
62132:	Brevinor (ARTG ID: 62132; 35 mcg ethinyloestradiol + 500 mcg norethisterone; 1G)
62143:	Brevinor 1 (ARTG ID: 62143; 35 mcg ethinyloestradiol + 1000 mcg norethisterone; 1G)
296803:	Minulet (ARTG ID: 296803; 30 mcg ethinyloestradiol + 75 mcg gestodene; 3G)
122788:	Valette (ARTG ID: 122788; 30 mcg ethinyloestradiol + 2 mg dienogest; 4G)
40133:	Trifeme 28 (ARTG ID: 40133; ethinyloestradiol + levonorgestrel; 2G)
10419:	Triphasil (ARTG ID: 10419; ethinyloestradiol + levonorgestrel; 2G)
107722:	Triquilar ED (ARTG ID: 107722; ethinyloestradiol + levonorgestrel; 2G)
40192:	Logynon ED (ARTG ID: 40192; ethinyloestradiol + levonorgestrel; 2G)
96229:	NuvaRing (ARTG ID: 96229; 11.7 mg etonogestrel + 2.7 mg ethinylestradiol)

B: Progestogens

73027:	Mirena (IUS) (ARTG ID: 73027; 52 mg levonorgestrel intrauterine system)
198455:	Implanon (implant) (ARTG ID: 198455; 68 mg etonogestrel subcutaneous implant)
160645:	Visanne (ARTG ID: 160645; 2 mg dienogest)
42932:	Provera 2.5 (ARTG ID: 42932; 2.5 mg medroxyprogesterone acetate)
42933:	Provera 5 (ARTG ID: 42933, PBS: 2323G; 5 mg medroxyprogesterone acetate)
42934:	Provera 10 (ARTG ID: 42934, PBS: 2321E; 10 mg medroxyprogesterone acetate; ARTG ID: 42935, PBS: 2722G – 100 tabs)
12300:	Depo–Povera (injection) (ARTG ID: 12300, PBS: 3118D; 150 mg/mL medroxyprogesterone acetate injection)
143391:	Primolut N (ARTG ID: 143391; 5 mg norethisterone)
10052:	Noriday 28 (ARTG ID: 10052; 350 mcg norethisterone)
44464:	Depo-Ralovera (injection) (ARTG ID: 44464, PBS: 3118D; 150 mg medroxyprogesterone acetate injection)

C: GnRH modulators

24368:	Zoladex 3.6 mg (implant) (ARTG ID: 24368, PBS: 1454M; 3.6 mg goserelin acetate implant)

48127:   Synarel (nasal spray) (ARTG ID: 48127, PBS: 2962X; 2 mg/mL nafarelin acetate nasal spray)

D: Menopausal hormone/hormone replacement therapy (MHT/HRT)

D1:   Cyclical oestrogen + progestogen combination MHT

78654:   Femoston-Conti (ARTG ID: 78654, PBS: 10142T; 1 mg oestradiol + 5 mg dydrogesterone)

219882:   Femoston 1/10 (ARTG ID: 219882, PBS: 10146B; 1 mg oestradiol + 10 mg dydrogesterone)

75889:   Femoston 2/10 (ARTG ID: 75889, PBS: 8244X; 2 mg oestradiol + 10 mg dydrogesterone)

192476:   Trisequens (ARTG ID: 192476; oestradiol + norethisterone acetate)

131552:   Estalis Sequi (transdermal patch) (ARTG ID: 131552; oestradiol + norethisterone acetate)

D2:   Continuous oestrogen + progestogen combinations

55088:   Livial (ARTG ID: 55088; 2.5 mg tibolone)

132518:   Xyvion (ARTG ID: 132518; 2.5 mg tibolone)

114816:   Angeliq 1/2 (ARTG ID: 114816; 1 mg oestradiol + 2 mg drospirenone)

262525:   Duavive (ARTG ID: 262525; 0.45 mg conjugated oestrogens + 20 mg bazedoxifene acetate)

67440:   Kliovance (ARTG ID: 67440; 1 mg oestradiol + 0.5 mg noresthisterone acetate)

183856:   Kliogest (ARTG ID: 183856; 2 mg oestradiol + 1 mg norethisterone acetate)

70813:   Estalis Continuous 50/140 (transdermal patch) (ARTG ID: 70813, PBS: 8427M; 50 mcg/day oestradiol + 140 mcg/day norethisterone acetate)

70817:   Estalis Continuous 50/250 (transdermal patch) (ARTG ID: 70817, PBS: 8428N; 50 mcg/day oestradiol + 250 mcg/day norethisterone acetate)

D3:   Progestogen only

177673:   Premarin 0.3 mg (ARTG ID: 177673; conjugated oestrogens 0.3 mg)

177674:   Premarin 0.625 mg (ARTG ID: 177674; conjugated oestrogens 0.625 mg)

46527:   Ralovera 2.5 mg (ARTG ID: 46527; 2.5 mg medroxyprogesterone acetate)

46531:   Ralovera 5 mg (ARTG ID: 46531, PBS: 2323G; 5 mg medroxyprogesterone acetate)

46532:   Ralovera 10 mg (ARTG ID: 46532, PBS: 2321E; 10 mg medroxyprogesterone acetate; ARTG ID 46534, PBS: 2722G – bottle)

232818:   Prometrium 100 mg (ARTG ID: 232818; 100 mg progesterone)

232823:   Prometrium 200 mg (ARTG ID: 232823; 200 mg progesterone)

D4:   Oestrogen only

73962:   Climara 25 (transdermal patch) (ARTG ID: 73962, PBS: 8485N; 25 mcg/day oestradiol transdermal delivery system)

56197:   Climara 50 (transdermal patch) (ARTG ID: 56197, PBS: 8125P; 50 mcg/day oestradiol transdermal delivery system)

73963:   Climara 75 (transdermal patch) (ARTG ID: 73963, PBS: 8486P; 75 mcg/day oestradiol transdermal delivery system)

      56198:   Climara 100 (transdermal patch) (ARTG ID: 56198, PBS: 8126Q; 100 mcg/day oestradiol transdermal delivery system)

      188520:   Estrofem 1 mg (ARTG ID: 188520; 1 mg oestradiol)

      188521:   Estrofem 2 mg (ARTG ID: 188521; 2 mg oestradiol)

      10708:   Progynova 1 mg (ARTG ID: 10708, PBS: 1663M; 1 mg oestradiol valerate)

      10709:   Progynova 2 mg (ARTG ID: 10709, PBS: 1664N; 2 mg oestradiol valerate)

      75888:   Zumenon (ARTG ID: 75888, PBS: 8274L; 2 mg oestradiol)

      67089:   Estraderm MX 25 (transdermal patch) (ARTG ID: 67089, PBS: 8311K; 25 mcg/day oestradiol transdermal patch)

      76117:   Estraderm MX 75 (transdermal patch) (ARTG ID: 76117, PBS: 8486P; 75 mcg/day oestradiol transdermal patch)

      67090:   Estraderm MX 100 (transdermal patch) (ARTG ID: 67090, PBS: 8312L; 100 mcg/day oestradiol transdermal patch)

      97564:   Estradot 50 (transdermal patch) (ARTG ID: 97564, PBS: 8763F; 50 mcg/day oestradiol transdermal patch

      97565:   Estradot 75 (transdermal patch) (ARTG ID: 97565, PBS: 8764G; 75 mcg/day oestradiol transdermal patch

      97566:   Estradot 100 (transdermal patch) (ARTG ID: 97566, PBS: 8312L; 100 mcg/day oestradiol transdermal patch

      93608:   Sandrena 0.5 mg (gel) (ARTG ID: 93608; 0.5 mg oestradiol gel)

      93609:   Sandrena 1 mg (gel) (ARTG ID: 93609. PBS: 8286D; 1 mg oestradiol gel)

D5:   Oestrogen only vaginal therapy

      14515:   Ovestin 1 mg/g (cream) (ARTG ID: 14515, PBS: 1781R; 1 mg oestriol cream)

      35632:   Ovestin Ovula 0.5 mg (pessary) (ARTG ID: 35632, PBS: 1771F; 0.5 mg oestriol pessary)

      163054:   Vagifem Low 10 mcg (pessary) (ARTG ID: 163054, PBS: 10203B; 10 mcg oestradiol pessary)

E: Androgens

      97935:   Danazol 100 mg (ARTG ID: 97935, PBS: 1285P; 100 mg danazol)

      97937:   Danazol 200 mg (ARTG ID: 9793, PBS: 1287R; 200 mg danazol)

      127475:   Azol 200 mg (ARTG ID: 127475, PBS: 1287R; 200 mg danazol)

      2-88:   Other (please specify) [Free text field]

3:      Interval [Branching logic]

      3a: Continuous use

      3b: With a withdrawal bleed

            3b-1:   Not applicable

            3b-2:   1 every month

            3b-3:   1 every 2 months

            3b-4:   1 every 3 months

      3b-5:   1every 6 months

      3b-6:   Annually

4:      Current [Tick boxes]

        1:       Yes

        2:       No

        99:     NA

5:      Used prior to or in addition with [Tick boxes; multiple selection]

        1:       Surgery

        2:       Pain medication

        3:       Other medication

        4:       Allied and complementary therapies

        5:       Physiotherapy

        88:     Other (please specify) [Free text field]

Pain Medication(s)

Note: To be in a table form and date logged, current/new medications at the top, with adverse event(s), see separate data field below, added to end of column or ability to be grouped with the medication being used

Definition: Medicines that assist with pain control or relief and can range from mild through to moderate or strong relievers.

Coding:

Note: Need ability to add more than one medication for when medications are changed or not required. Also require ability to track the order of medications trialled.

1:      Drug group [Drop down list]

        1a: Paracetamol/acetaminophen

        1b: Non-steroidal anti-inflammatories

        1c: Opioids

        1d: Combination opioids

        1e: Other pain modifying preparations

        1f: Muscle relaxants (e.g. diazepam/temazepam, buscopan)

        88:     Other (please specify) [Free text field]

        99:     Don't know

2:      Drug name [Drop down list]

        A: Paracetamol/acetaminophen

        13591:   Panadol (ARTG ID: 13591; 500 mg paracetamol, 20 pack)

        15490:   Panamax (ARTG ID: 15490; 500 mg paracetamol)

        B: Non-steroidal anti-inflammatories

        2b-1:   Nurofen (ibuprofen)

        2b-2:   Advil (ibuprofen)

        2b-3:   Aspirin (acetylsalicylic acid)

        66880:   Voltaren 50 mg (ARTG ID: 66880; 50 mg diclofenac)

        42943:   Voltaren Rapid 50 mg (ARTG ID: 4293; 50 mg diclofenac)

        65247:   Naprosyn 250 mg (ARTG ID: 65247; 250 mg naproxen)

        65246:   Naprosyn 500 mg (ARTG ID: 65246; 500 mg naproxen)

        75501:   Naprogesic 275 mg (ARTG ID: 75501; 275 mg naproxen, reformulation)

        63794:   Aleve 220 mg (ARTG ID: 63794; 220 mg naproxen)

263421:	Aleve 24 Hr (ARTG ID: 263421; 660 mg naproxen modified release)
66544:	Anaprox 550 mg (ARTG ID: 66544; 550 mg naproxen)
14388:	Ponstan (ARTG ID: 14388; 250 mg mefenamic acid)
225658:	Ponstan (ARTG ID: 225658, PBS: 1824N; 250 mg mefenamic acid; primary dysmenorrhoea and/or primary menorrhagia)
301376:	Menopain 250 mg (ARTG ID: 301376; 250 mg mefenamic acid)
275277:	Femin 250 mg (ARTG ID: 275277; 250 mg mefenamic acid; ARTG ID: 301375)
67901:	Celebrex 100 mg (ARTG ID: 67901, PBS: 8439E; 100 mg celecoxib)
67902:	Celebrex 200 mg (ARTG ID: 67902; PBS: 8440F; 200 mg celecoxib)
76021:	Indocid 25 mg (ARTG ID: 76021; 25 mg indometacin)
17606:	Arthrexin 25 mg (ARTG ID: 17606; 25 mg indometacin; ARTG ID: 17586 25 mg bottle)
17587:	Aclin 100 mg (ARTG ID: 17587; 100 mg sulindac; ARTG ID: 155388 bulk)
10232:	Aclin 200 mg (ARTG ID: 10232; 100 mg sulindac; ARTG ID: 155389 bulk)
131797:	Arcoxia 30 mg (ARTG ID: 131797; 30 mg etoricoxib)
81456:	Arcoxia 60 mg (ARTG ID: 81456; 60 mg etoricoxib)
204147:	Arcoxia 90 mg (ARTG ID: 204147; 90 mg etoricoxib)
81458:	Arcoxia 120 mg (ARTG ID: 81458; 120 mg etoricoxib)

C: Opioids

2c-1:	Tramadol 50 mg
2c-2:	Tramadol 100 mg
2c-3:	Morphine
14945:	Endone 5 mg (ARTG ID: 14945, PBS: 2622B, 5195K; 5 mg oxycodone)
225335:	Mayne Pharma Oxycodone IR 5 mg (ARTG ID 225335, PBS: 2622B, 5195K; 5 mg oxycodone)
224758:	Oxycodone Aspen 5 mg (ARTG ID: 224758, PBS: 2622B, 5195K; 5 mg oxycodone)
34091:	Temgesic sublingual tablet (ARTG ID: 43091; 200 mcg buprenorphine)
116647:	Norspan 5 mcg transdermal patch (ARTG ID: 116647, PBS: 8865N; 5mcg/hr buprenorphine transdermal patch)
116648:	Norspan 10 mcg transdermal patch (ARTG ID: 116648, PBS: 8866P; 5mcg/hr buprenorphine transdermal patch)
217507:	Norspan 15 mcg transdermal patch (ARTG ID: 217507, PBS: 10770W; 5mcg/hr buprenorphine transdermal patch)
116650:	Norspan 20 mcg transdermal patch (ARTG ID: 116650, PBS: 8867Q; 5mcg/hr buprenorphine transdermal patch)
217508:	Norspan 25 mcg transdermal patch (ARTG ID: 217508, PBS: 10756D; 5mcg/hr buprenorphine transdermal patch)
217509:	Norspan 30 mcg transdermal patch (ARTG ID: 217509, PBS: 10755C; 5mcg/hr buprenorphine transdermal patch)
217510:	Norspan 40 mcg transdermal patch (ARTG ID: 217510, PBS: 10746N; 5mcg/hr buprenorphine transdermal patch)

116828:   Durogesic 12 mcg transdermal patch (ARTG ID: 116828, PBS: 8878G; 12 mcg/hr
            fentanyl transdermal patch)

112368:   Durogesic 25 mcg transdermal patch (ARTG ID: 112368, PBS: 8891Y; 25 mcg/hr
            fentanyl transdermal patch)

112369:   Durogesic 50 mcg transdermal patch (ARTG ID: 112369, PBS: 8892B; 50 mcg/hr
            fentanyl transdermal patch)

112370:   Durogesic 75 mcg transdermal patch (ARTG ID: 112370, PBS: 8893C; 75 mcg/hr
            fentanyl transdermal patch)

112371:   Durogesic 100 mcg transdermal patch (ARTG ID: 112371, PBS: 8894D; 100 mcg/hr
            fentanyl transdermal patch)

76083:   Physeptone 10 mg (ARTG ID: 76083, PBS: 1609Q; 10 mg methadone)

159750:   Physeptone 10 mg/mL inj (ARTG ID: 159750, PBS: 1606M; 10 mg/mL methadone
            injection)

49372:   Aspen Methadone Syrup (ARTG ID: 49372; 25 mg/5 mL methadone oral liquid)

152792:   Methadone Injection (ARTG ID: 152792; 10 mg/mL methadone injection)

D: Combination opioids

92203:   Panadeine (ARTG ID: 92203; 500 mg paracetamol + 8 mg codeine)

73507:   Panadeine Forte (ARTG ID: 73507; 500 mg paracetamol + 30 mg codeine)

293801:   Tramadol and paracetamol (ARTG ID: 293801; 37.5 mg tramadol + 325 mg
            paracetamol, bottle, export medicine only; ARTG ID: 152791, bulk)

59985:   Mersyndol Daystrength (ARTG ID: 59985; 500 mg paracetamol + 9.6 mg codeine)

10110:   Mersyndol (ARTG ID: 10110; 450 mg paracetamol + 9.75 mg codeine + 5 mg
            doxylamine tablets; ARTG ID: 56535 Mersyndol Caplets)

10109:   Mersyndol Forte (ARTG ID: 10109; 450 mg paracetamol + 30 mg codeine + 5 mg
            doxylamine)

E: Other pain modifying preparations

E1:   Anticonvulsants

74067:   Neurontin 100 (ARTG ID: 74067; 100 mg gabapentin capsules)

66008:   Neurontin 300 (ARTG ID: 66008; 300 mg gabapentin capsules)

66005:   Neurontin 400 (ARTG ID: 66005; 400 mg gabapentin capsules)

71793:   Neurontin 600 (ARTG ID: 71793; 600 mg gabapentin tablets)

71791:   Neurontin 800 (ARTG ID: 71793; 800 mg gabapentin tablets)

78623:   Gantin 100 (ARTG ID: 78623; 100 mg gabapentin capsules)

78624:   Gantin 300 (ARTG ID: 78624; 300 mg gabapentin capsules)

78625:   Gantin 400 (ARTG ID: 78625; 400 mg gabapentin capsules)

78626:   Gantin 800 (ARTG ID: 78626; 800 mg gabapentin tablets)

101694:   Nupentin 100 (ARTG ID: 101694; 100 mg gabapentin capsules; ARTG ID: 101695,
            bottle)

101696:   Nupentin 300 (ARTG ID: 101696; 300 mg gabapentin capsules; ARTG ID: 101697,
            bottle)

101698:   Nupentin 400 (ARTG ID: 101698; 400 mg gabapentin capsules; ARTG ID: 101699,
            bottle)

174063:	Nupentin 600 (ARTG ID: 174063; 600 mg gabapentin tablets)
174062:	Nupentin 800 (ARTG ID: 174062; 800 mg gabapentin tablets)
99469:	Lyrica 25 (ARTG ID: 99469, PBS: 2348N; 25 mg pregabalin; ARTG ID: 99478, bottle)
99479:	Lyrica 50 (ARTG ID: 99479; 50 mg pregabalin; ARTG ID: 99480, bottle)
99520:	Lyrica 75 (ARTG ID: 99520, PBS: 2335X; 75 mg pregabalin; ARTG ID: 99521, bottle)
99524:	Lyrica 100 (ARTG ID: 99524; 100 mg pregabalin; ARTG ID: 99527, bottle)
99528:	Lyrica 150 (ARTG ID: 99528, PBS: 2355Y; 150 mg pregabalin; ARTG ID: 99532, bottle)
99533:	Lyrica 200 (ARTG ID: 99533; 200 mg pregabalin; ARTG ID: 99534, bottle)
99535:	Lyrica 225 (ARTG ID: 99536; 225 mg pregabalin; ARTG ID: 99536, bottle)
99537:	Lyrica 300 (ARTG ID: 99537, PBS: 2363J; 300 mg pregabalin; ARTG ID: 99538, bottle)
235874:	Lypralin 25 (ARTG ID: 235874, PBS: 2348N; 25 mg pregabalin; ARTG ID: 235870, bottle)
235863:	Lypralin 75 (ARTG ID: 235863, PBS: 2335X; 75 mg pregabalin; ARTG ID: 235866, bottle)
235848:	Lypralin 150 (ARTG ID: 235848, PBS: 2355Y; 150 mg pregabalin; ARTG ID: 235852, bottle)
235879:	Lypralin 300 (ARTG ID: 235879, PBS: 2363J; 300 mg pregabalin; ARTG ID: 235846, bottle)
46268:	Lamictal 25 (ARTG ID: 46268, PBS: 2848X; 25 mg lamotrigine)
46267:	Lamictal 50 (ARTG ID: 46267, PBS: 2849Y; 50 mg lamotrigine)
46266:	Lamictal 100 (ARTG ID: 46266, PBS: 2850B; 100 mg lamotrigine)
46264:	Lamictal 200 (ARTG ID: 46264, PBS: 2851C; 200 mg lamotrigine)
99059:	Logem 25 (ARTG ID: 99059, PBS: 2848X; 25 mg lamotrigine)
99360:	Logem 50 (ARTG ID: 99360, PBS: 2849Y; 50 mg lamotrigine)
99062:	Logem 100 (ARTG ID: 99062, PBS: 2850B; 100 mg lamotrigine)
99064:	Logem 200 (ARTG ID: 99064, PBS: 2851C; 200 mg lamotrigine)

E2:   Cannabinoids

| E2-1: | Medicinal cannabis |
| 326240: | Eve Cannabis – Indica 140 (ARTG ID 326240; 140 mg/g cannabis sativa; export only medicine) |

F: Muscle relaxant

2f-1:	Diazepam suppository
63863:	Temaze 10 (ARTG ID: 63863, PBS: 2088X; 10 mg temazepam)
41637:	Normison 10 (ARTG ID: 41637, PBS: 2088X; 10 mg temazepam)
91058:	Temtabs 10 (ARTG ID: 91058, PBS: 2088X; 10 mg temazepam)
153123:	Apo-Temazepam 10 (ARTG ID: 153123, PBS: 2088X; 10 mg temazepam)
48256:	Buscopan 10 (ARTG ID: 48256; 10 mg hyoscine butylbromide tablet)
153552:	Buscopan Forte 20 (ARTG ID: 153552; 20 mg hyoscine butylbromide tablet)

17916:   Buscopan 20 mg/mL injection (ARTG ID: 17916, PBS: 3473T; 20 mg/mL hyoscine butylbromide injection ampoule)

48566:   Valium (ARTG ID: 48566, PBS: 3162K; 5 mg diazepam)

134472:   Apo-diazepam 2 (ARTG ID: 134472, PBS: 3161J; 2 mg diazepam)

134590:   Apo-diazepam 5 (ARTG ID: 134590, PBS: 3162K; 5 mg diazepam)

80809:   Valpam 2 (ARTG ID: 80809, PBS: 3161J; 2 mg diazepam; ARTG ID: 80810, bottle)

80811:   Valpam 5 (ARTG ID: 80811, PBS: 3162K; 5 mg diazepam; ARTG ID: 80812, bottle)

82638:   Alprax 0.25 (ARTG ID: 82638; 25 mcg alprazolam; ARTG ID: 82637, bottle)

82640:   Alprax 0.5 (ARTG ID: 82640, PBS: 11187T; 50 mcg alprazolam; ARTG ID: 82639; bottle)

82643:   Alprax 1 (ARTG ID: 82643, PBS: 11186R; 1 mg alprazolam; ARTG ID: 82641, bottle)

82644:   Alprax 2 (ARTG ID: 82644; 2 mg alprazolam bottle)

46835:   Kalma 0.25 (ARTG ID: 46835, PBS: 11205R; 25 mcg alprazolam bottle)

46837:   Kalma 0.5 (ARTG ID: 46837, PBS: 11187T; 50 mcg alprazolam bottle)

46839:   Kalma 1 (ARTG ID: 46839, PBS: 11186R; 1 mg alprazolam bottle)

63993:   Kalma 2 (ARTG ID: 63993; 2 mg alprazolam bottle)

88:    Other (please specify) [Free text field]

99:    Don't know

3:    Current (Tick boxes)

1:    Yes

2:    No

99:    NA

4:    Used prior to or in addition with [Tick boxes; multiple selection]

1:    Surgery

2:    Hormonal medication

3:    Other medication

4:    Allied and complementary therapies

5:    Physiotherapy

88:    Other (please specify) [Free text field]

Other Medication(s)

Note: To be in a table form and date logged, current/new medications at the top, with adverse event(s), see separate data field below, added to end of column or ability to be grouped with the medication being used

Definition: Additional medicines that the patient may be using to manage their endometriosis-related symptoms e.g. antidepressants, blood reducing agents, others, etc.

Coding:

Note: Need ability to add more than one medication for when medications are changed or not required. Also require ability to track the order of medications trialled.

1:    Drug group [Drop down list]

1a: Tricyclic antidepressants (TCAs)

1b: Selective serotonin reuptake inhibitors (SSRIs)

1c:	Serotonin and norepinephrine reuptake inhibitors (SNRIs)

1d: Blood reducing agents (to reduce menstrual flow)

1e: Aromatase inhibitors

1f: Botulinum toxin

1g: Triptans

1h: Creams/ointments

88:     Other (please specify) [Free text field]

99   Don't know

2:      Drug name [Drop down list]

A: Tricyclic antidepressants (TCAs)

71044:   Endep 10 (ARTG ID: 71044, PBS: 2417F; 10 mg amitriptyline)

59788:   Endep 25 (ARTG ID: 59788, PBS: 2418G; 25 mg amitriptyline)

64425:   Endep 50 (ARTG ID: 64425, PBS: 2429W; 50 mg amitriptyline)

232152:   Entrip 10 (ARTG ID: 232152, PBS: 2417F; 10 mg amitriptyline)

232154:   Entrip 25 (ARTG ID: 232154, PBS: 2418G; 25 mg amitriptyline)

232156:   Entrip 50 (ARTG ID: 232156, PBS: 2429W; 50 mg amitriptyline)

14619:   Allegron 10 (ARTG ID: 14619, PBS: 2522R; 10 mg nortriptyline)

53747:   Allegron 25 (ARTG ID: 53747, PBS: 2523T; 25 mg nortriptyline)

220998:   NortriTABS 10 (ARTG ID: 220998, PBS: 2522R; 10 mg nortriptyline)

220997:   NortriTABS 25 (ARTG ID: 220997, PBS: 2523T; 25 mg nortriptyline)

10987:   Anafranil (ARTG ID: 10987, PBS: 1561E; 25 mg clomipramine)

143879:   Placil (ARTG ID: 143879, PBS: 1561E; 25 mg clomipramine)

34419:   Dothep 25 (ARTG ID: 34419, PBS: 1357K; 25 mg dosulepin (dothiepin))

62910:   Dothep 75 (ARTG ID: 62910, PBS: 1358L; 75 mg dosulepin (dothiepin))

289783:   Dosulepin Mylan 25 (ARTG ID: 289783, PBS: 1357K; 25 mg dosulepin (dothiepin))

289784:   Dosulepin Mylan 75 (ARTG ID: 289784, PBS: 1358L; 75 mg dosulepin (dothiepin))

30899:   Deptran 10 (ARTG ID: 308899, PBS: 1011F; 10 mg doxepin)

60448:   Deptran 25 (ARTG ID: 60448, PBS: 1013H; 25 mg doxepin)

17637:   Deptran 50 (ARTG ID: 17637, PBS: 1012G; 50 mg doxepin)

42359:   Deptran 75 (ARTG ID: 42359; 75 mg doxepin)

10767:   Sinequan 10 (ARTG ID: 10767, PBS: 1011F; 10 mg doxepin)

302563:   Sinequan 25 (ARTG ID: 302563, PBS: 1013H; 25 mg doxepin)

11064:   Tofranil 10 (ARTG ID: 11064, PBS: 2420J; 10 mg imipramine)

60673:   Tofranil 25 (ARTG ID: 60673, PBS: 2421K; 25 mg imipramine)

10037:   Melipramine 25 (ARTG ID: 10037; 25 mg imipramine)

B: Selective serotonin reuptake inhibitors (SSRIs)

61164:   Cipramil (ARTG ID: 61164, PBS: 8220P; 20 mg citalopram)

93542:   Celapram 10 (ARTG ID: 93542, PBS: 8702B; 10 mg citalopram)

82904:   Celapram 20 (ARTG ID: 82904, PBS: 8220P; 20 mg citalopram)

93543:   Celapram 40 (ARTG ID: 93543, PBS: 8703C; 40 mg citalopram)

227312:   Celica (ARTG ID: 227312; 20 mg citalopram)

234594:   Talam 10 (ARTG ID: 234594, PBS: 8702B; 10 mg citalopram)

DATA DICTIONARY
21 JUNE 2021

212219:   Talam 20 (ARTG ID: 212219, PBS: 8220P; 20 mg citalopram)

234596:   Talam 40 (ARTG ID: 234596, PBS: 8703C; 40 mg citalopram)

92051:   Lexapro 10 (ARTG ID: 92051, PBS: 8700X; 10 mg escitalopram)

92053:   Lexapro 20 (ARTG ID: 92053, PBS: 8701Y; 20 mg escitalopram)

209721:   Lexapro 20 oral liquid (ARTG ID: 209721, PBS: 10181W; 20 mg/mL escitalopram

             oral liquid)

128781:   Esipram 10 (ARTG ID: 128781, PBS: 8700X; 10 mg escitalopram)

128783:   Esipram 20 (ARTG ID: 128783, PBS: 8701Y; 20 mg escitalopram)

146907:   Esitalo 10 (ARTG ID: 146907, PBS: 8700X; 10 mg escitalopram)

146908:   Esitalo 20 (ARTG ID: 146908, PBS: 8701Y; 20 mg escitalopram)

211387:   Lexam 10 (ARTG ID: 211387, PBS: 8700X; 10 mg escitalopram)

211388:   Lexam 20 (ARTG ID: 211388, PBS: 8701Y; 20 mg escitalopram)

119961:   Loxalate 5 (ARTG ID: 119961; 5 mg escitalopram)

119964:   Loxalate 10 (ARTG ID: 119964, PBS: 8700X; 10 mg escitalopram)

119966:   Loxalate 20 (ARTG ID: 119966, PBS: 8701Y; 20 mg escitalopram)

61080:   Lovan Tab (ARTG ID: 61080, PBS: 8270G; 20 mg fluoxetine tablet)

54700:   Lovan (ARTG ID: 54799, PBS: 1434L; 20 mg fluoxetine capsule)

57843:   Lovan Liquid (ARTG ID: 57843; 20 mg/5 mL fluoxetine

             escitalopram)

61081:   Prozac Tab (ARTG ID: 61081, PBS: 8270G; 20 mg fluoxetine tablet)

14653:   Prozac (ARTG ID: 14653, PBS: 1434L; 20 mg fluoxetine capsule)

43298:   Prozac Liquid (ARTG ID: 43298; 20 mg/5 mL fluoxetine)

57632:   Luvox 50 (ARTG ID: 57632, PBS: 8512B; 50 mg fluvoxamine)

57633:   Luvox 100 (ARTG ID: 57633, PBS: 8174F; 100 mg fluvoxamine)

111781:   Voxam 50 (ARTG ID: 111781, PBS: 8512B; 50 mg fluvoxamine)

111782:   Luvox 100 (ARTG ID: 111782, PBS: 8174F; 100 mg fluvoxamine)

57927:   Aropax 20 (ARTG ID: 57927, PBS: 2242B; 20 mg paroxetine)

102729:   Extine 20 (ARTG ID: 102729, PBS: 2242B; 20 mg paroxetine)

227120:   Paxtine 20 (ARTG ID: 227120, PBS: 2242B; 20 mg paroxetine)

176976:   Roxet 20 (ARTG ID: 176976, PBS: 2242B; 20 mg paroxetine)

321601:   Zoloft 50 (ARTG ID: 321601, PBS: 2236Q; 50 mg sertraline; ARTG ID: 42979)

321602:   Zoloft 100 (ARTG ID: 321602, PBS: 2237R; 100 mg sertraline; ARTG ID: 42950)

95581:   Eleva 50 (ARTG ID: 95581, PBS: 2236Q; 50 mg sertraline; ARTG ID: 95582 bottle)

95583:   Eleva 100 (ARTG ID: 95583, PBS: 2237R; 100 mg sertraline; ARTG ID: 95584)

107067:   Sertra 50 (ARTG ID: 107067, PBS: 2236Q; 50 mg sertraline)

107071:   Eleva 100 (ARTG ID: 107071, PBS: 2237R; 100 mg sertraline)

C: Serotonin-norepinephrine reuptake inhibitors (SNRIs)

120382:   Cymbalta 30 (ARTG ID: 120382, PBS: 9155W; 30 mg duloxetine)

120389:   Cymbalta 60 (ARTG ID: 120389, PBS: 9156X; 60 mg duloxetine)

179186:   Andepra 30 (ARTG ID: 179186, PBS: 9155W; 30 mg duloxetine)

179187:   Andepra 60 (ARTG ID: 179187, PBS: 9156X; 60 mg duloxetine)

170674:   Pristiq 50 (ARTG ID: 170674, PBS: 9366Y; 50 mg desvenlafaxine)

Page 55

170696:   Pristiq 100 (ARTG ID: 170696, PBS: 9367B; 100 mg desvenlafaxine)

133529:   Pristiq 200 (ARTG ID: 122529; 200 mg desvenlafaxine)

218075:   Desfax 50 (ARTG ID: 218075, PBS: 10241B; 50 mg desvenlafaxine; ARTG ID:
218079, bottle)

218061:   Desfax 100 (ARTG ID: 218061, PBS: 10231L; 100 mg desvenlafaxine; ARTG ID:
218081, bottle)

99802:   Efexor-XR 37.5 (ARTG ID: 99802, PBS: 8868R; 37.5 mg venlafaxine)

60858:   Efexor-XR 75 (ARTG ID: 60858, PBS: 8301X; 75 mg venlafaxine)

60859:   Efexor-XR 150 (ARTG ID: 60859, PBS: 8302Y; 150 mg venlafaxine)

285314:   Elaxine SR 37.5 (ARTG ID: 285314, PBS: 8868R; 37.5 mg venlafaxine)

285315:   Elaxine SR 75 (ARTG ID: 285315, PBS: 8301X; 75 mg venlafaxine)

285316:   Elaxine SR 150 (ARTG ID: 285316, PBS: 8302Y; 150 mg venlafaxine)

D: Blood reducing agents

70405:   Cykokapron (ARTG ID: 70405, PBS: 2180R; 500 mg tranexamic acid; ARTG ID:
14463, bottle)

E: Aromatase inhibitors

76369:   Aromasin 25 (ARTG ID: 76369; 25 mg exemestane)

174337:   Exemestane Sandoz 25 (ARTG ID: 174337; 25 mg exemestane)

60605:   Femara (ARTG ID: 60605; 2.5 mg letrozole)

175100:   Fera (ARTG ID: 175100; 2.5 mg letrozole)

166010:   Femolet (ARTG ID: 166010; 2.5 mg letrozole)

203379:   Gynotril (ARTG ID: 203379; 2.5 mg letrozole)

259990:   Astzol (ARTG ID: 259990; 1 mg anastrozole)

54672:   Arimidex (ARTG ID: 54672; 1 mg anastrozole)

259991:   Arianna 1 (ARTG ID: 259991; 1 mg anastrozole)

F: Botulinum toxin

195530:   Botox 50 (ARTG ID: 195530; 50U botulinum toxin, type A injection)

67311:   Botox 100 (ARTG ID: 67311; 100U botulinum toxin, type A injection)

172264:   Botox 200 (ARTG ID: 172264; 200U botulinum toxin, type A injection)

G: Triptans

52261:   Imigran 50 (ARTG ID: 52261, PBS: 8144P; 50 mg sumatriptan; PBS: 1849H (4
tabs))

106714:   Imigran FDT 50 (ARTG ID: 106714, PBS: 8885P; 50 mg sumatriptan; PBS: 10694W
(4 tabs))

38346:   Imigran 100 (ARTG ID: 38346; 100 mg sumatriptan)

106715:   Imigran FDT 100 (ARTG ID: 106715; 100 mg sumatriptan)

61565:   Imigran S 10 nasal spray (ARTG ID: 61565; 10 mg/0.1 mL sumatriptan nasal spray)

61566:   Imigran S 20 nasal spray (ARTG ID: 61566, PBS: 8341B; 20 mg/0.1 mL sumatriptan
nasal spray)

187216:   Sumatran 50 (ARTG ID: 187216, PBS: 8144P; 50 mg sumatriptan; PBS: 1849H (4
tabs))

187217:   Sumatran 100 (ARTG ID: 187217; 100 mg sumatriptan)

      124086:   Iptam 50 (ARTG ID: 124086, PBS: 8144P; 50 mg sumatriptan; PBS: 1849H (4 tabs))

      124087:   Iptam 100 (ARTG ID: 124087; 100 mg sumatriptan)

      61325:   Zomig 2.5 (ARTG ID: 61325, PBS: 8266C; 2.5 mg zolmitriptan)

      61326:   Zomig 5 (ARTG ID: 61326; 5 mg zolmitriptan)

      70175:   Zomig Rapimelt 2.5 (ARTG ID: 70175; 2.5 mg zolmitriptan)

      62900:   Naramig 2.5 (ARTG ID: 62900, PBS:8298R; 2.5 mg naratriptan; PBS: 9734H)

      69077:   Maxalt 5 mg wafer (ARTG ID: 69077; 5 mg rizatriptan wafer)

      69076:   Maxalt 10 mg wafer (ARTG ID: 69076, PBS: 9313E; 10 mg rizatriptan wafer)

      68354:   Relpax 20 (ARTG: 68354; 20 mg eletriptan; ARTG ID: 68355, bottle)

      68356:   Relpax 40 (ARTG: 68356, PBS: 5290K; 20 mg eletriptan; ARTG ID: 68357, bottle)

      68358:   Relpax 80 (ARTG: 68358, PBS: 5291L; 20 mg eletriptan; ARTG ID: 68359, bottle)

      H: Creams/ointments

      19658:   Zostrix 0.025% (ARTG ID: 19658; 0.025% w/w capsaicin)

      10344:   Zostrix HP 0.075% (ARTG ID: 10344; 0.075% w/w capsaicin)

      88:      [Free text field]

      99:      Don't know

3:      Current (Tick boxes)

      1:      Yes

      2:      No

      99:      NA

4:      Used prior to or in addition with [Tick boxes; multiple selection]

      1:      Surgery

      2:      Hormonal medication

      3:      Pain medication

      4:      Allied and complementary therapies

      5:      Physiotherapy

      88:      Other (please specify) [Free text field]

Allied and complementary therapies

Definition: Forms of treatment that are used in addition to (complementary) or instead of (alternative) standard treatments. These practices generally are not considered standard medical approaches.

Coding:

0:      None

1:      Acupuncture

2:      Aromatherapy

3:      Art therapy

4:      Ayurveda

5:      Bowen therapy

6:      Chinese herbal medicine

7:      Chiropractic

8:      Dietetics

9:      Exercise physiology

10:     Homeopathy

11:     Hypnotherapy

12:     Kinesiology

13:     Massage therapy

14:     Meditation

15:     Music therapy

16:     Naturopathy

17:     Nutrition

18:     Occupational therapy

19:     Osteopathy

20:     Physiotherapy

21:     Pilates

22:     Psychology/counselling

23:     Reflexology

24:     Remedial massage

25:     Shiatsu

26:     Tai Chi

27:     Tibetan medicine

28:     Traditional Chinese massage

29:     Traditional Thai massage

30:     Western herbal medicine

31:     Yoga

88:     Other (please specify) [Free text field]

Note: Column in all medication and CAM tables, to be next to "Used in adjunct to" column:

Adverse/side effect(s)

Definition: Any untoward medical occurrence in a patient or clinical trial subject administered a medicinal product and which does not necessarily have to have a causal relationship with this treatment. An adverse event can therefore be any unfavourable and unintended sign (e.g. an abnormal laboratory finding), symptom, or disease temporally associated with the use of a medicinal product, whether or not considered related to the medicinal product.

Coding: Select all that apply [Multiple selection and link the adverse events to the medicine/therapy that the adverse events are related to]

99:     Unknown

0:     None

1:     Breakthrough bleeding

2:     Headache

3:     Nausea

4:     Abdominal/pelvic pain

5:     Vulvovaginitis

6:     Genital discharge

7:     Increased bleeding

8:      Decreased bleeding

9:      Spotting

10:     Amenorrhoea

11:     Depression and anxiety

12:     Altered mood

13:     Altered anxiety

14:     Migraine

15:     Acne

16:     Hirsutism

17:     Back pain

18:     Upper genital infection

19:     Ovarian cyst

20:     Dysmenorrhoea

21:     Breast tenderness

22:     Breast pain

23:     IUD expulsion (partial or complete)

24:     Weight increased

88:     Other (please specify) [Free text field]

Note: Column in all medication and CAM tables, to be next to "Adverse/side effects" column:

Reason for using

Coding:

1:      Pain management

2:      Menstrual cycle management

3:      Muscle spasms support

4:      Gastrointestinal symptoms support

5:      Nerve symptoms support

6:      Mental health support

7:      General health and wellbeing

88:     Other (please specify) [Free text field]

99:     Don't know

Reason for ceasing/stopping

Coding:

1:      Adverse/side effect

2:      Symptom(s) not improving

3:      Symptom(s) worsening

4:      Too expensive

5:      Symptom(s) improved

6:      Symptoms no longer present

7:      Time constraints

88:     Other (please specify) [Free text field]

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

99:     Don't know

6. Surgical management

Date of surgery

Definition: Date of surgical procedure performed on patient.

Coding: DD / MM / YYYY

First date of last menstrual period (LMP)

Definition: Date of the first day of when the patient last experienced a menstrual bleed.

Coding: DD / MM / YYYY

Surgical hospital

Definition: The surgical hospital is where the surgeon performed the procedure on the patient to

diagnose/excise endometriosis.

Coding: [Pre-populated with list of service providers]

Primary surgeon details

Definition: The primary surgeon responsible for care of the patient.

Coding: Numeric code representing the surgeon. [Pre-populated with list of service providers]

Surgeon category

Definition: The surgeon performing the surgical procedure on the patient to diagnose/excise endometriosis.

Coding: (modelled against METeOR ID: 607130, 607133 and 424298)

0222:   RANZCOG Fellow

0222:   RANZCOG Fellow with AGES fellowship

1:    RANZCOG Advanced trainee

2:    RANZCOG Advanced trainee undergoing subspecialty training

3:    RANZCOG Advanced trainee undergoing AGES fellowship training

4:    RANZCOG Basic trainee

    4a: Which year? [Free text field]

Subspecialty [to have ability to select subspecialty and to have ability to select with all the above]

    0237:   Reproductive endocrinology and infertility (CREI)

    0238   Urogynaecology (CU)

    1:    Gynaecological Oncology (CGO)

    2:    Obstetrical and Gynaecological Ultrasound (COGU)

Support/mentorship [to have ability to select with all the above, except "RANZCOG Fellow" and "RANZCOG Fellow with AGES fellowship]

    1:    With support/mentorship

    2:    Without support/mentorship

Supervised by [to have ability to select with all the above, except "RANZCOG Fellow" and "RANZCOG Fellow with AGES fellowship]

    1:    Consultant in attendance

    2:    Consultant available

Assisting surgeon

Definition: Surgical assistant that is assisting with a surgical operation under the direction of a surgeon.

Coding: (Data items as per **Surgeon category**; modelled against METeOR ID: 607130, 607133 and 424298)

Was another specialist involved in the procedure?

Coding: (modelled against METeOR ID: 607130 and 607133)

1:        Yes [Branching logic; multiple selection]

     0206:   Colorectal

     021807:   Urology

     0206:   Upper GI

     88:        Other (please specify) [Free text field]

2:        No

SUMMARY OF PRESENTING SYMPTOMS AND PRINCIPAL CLINICAL DIAGNOSIS

Note: To be pre-populated from **Module 2 – Clinical presentation and medical history** and be visualised with the medical management options)

*Primary presenting symptom

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

Note 2: Allow changes to be made to Primary and Secondary symptoms above, this is to be date logged to show when the changes happened)

*Secondary symptoms

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

Note 2: Allow changes to be made to Primary and Secondary symptoms above, this is to be date logged to show when the changes happened)

*Primary clinical diagnosis

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

*Secondary clinical diagnoses

Note 1: Please see **Module 2 – Clinical presentation and medical history** for data dictionary, groupings and options.

MEDICATION HISTORY

Note: To be pre-populated from **Module 5 – Medical Management**

*Hormonal medication(s) used

Note: Please see **Module 5 – Medical management** for data dictionary, groupings and options.

*Pain medication(s) used

Note: Please see **Module 5 – Medical management** for data dictionary, groupings and options.

*Other medication(s) used

Note: Please see **Module 5 – Medical management** for data dictionary, groupings and options.

SURGICAL SUMMARY

Primary surgical diagnosis

Definition: The principal condition, after study/surgery to be chiefly responsible for occasioning the patient's episode of care in hospital.

Coding: [only one selection allowed; ICD-10 codes]

N80.9: Endometriosis [to show table of "**Endometriosis locations**" if this option is selected]

N80.0: Endometriosis of uterus (adenomyosis)

    N80-1: Uniformly enlarged

    N80-8: Other (please specify) [Free text field]

D25.9: Leiomyoma of uterus/fibroids (select all that apply) [Branching logic]

    D25.0: Submucous leiomyoma of uterus

    D25.1: Intramural leiomyoma of uterus

    D25.2: Subserosal leiomyoma of uterus

N97: Female infertility [Branching logic]

    N97.0: Female infertility associated with anovulation

    N97.1: Female infertility of tubal origin

    N97.2: Female infertility of uterine origin

    N97.8: Female infertility of other origin

    N97.9: Female infertility, unspecified

E28.2: Polycystic ovarian syndrome

D27: Benign neoplasm of ovary (includes cyst (colloid) (mucous) (dermoid) (ovarian twisted) (not elsewhere classified))

N70.1: Hydrosalpinx

N83.0: Follicular cyst of ovary (includes cyst of graafian follicle, haemorrhagic follicular cyst)

N83.1: Corpus luteum cyst (includes haemorrhagic corpus luteum cyst)

N83.2: Other and unspecified ovarian cysts (includes retention and simple cyst of ovary)

N83.3: Acquired atropy of ovary and fallopian tube

N83.4: Prolapse and hernia of ovaria and fallopian tube

N83.5: Torsion of ovary, ovarian pedicle and fallopian tube

N84: Polyp of female genital tract [Branching logic]

    N84.0: Polyp of corpus uteri (includes polyp of endometrium or uterus)

    N84.1: Polyp of cervix uteri

    N84.2: Polyp of vagina

    N84.3: Polyp of vulva (includes polyp of labia)

    N84.8: Polyp of other parts of female genital tract

N84.9: Polyp of female genital tract, unspecified

N85.0: Endometrial hyperplasia

Q51: Congenital malformations of uterus and cervix [Branching logic]

    Q51.0: Agenesis and aplasia of uterus (Congenital absence of uterus)

    Q51.1: Doubling of uterus with doubling of cervix and vagina

    Q51.2: Other doubling of uterus (Doubling of uterus NOS)

    Q51.3: Bicornate uterus

    Q51.4: Unicornate uterus

    Q51.5: Agenesis and aplasia of cervix (Congenital absence of cervix)

    Q51.6: Embryonic cyst of cervix

    Q51.7: Congenital fistulae between uterus and digestive and urinary tracts

    Q51.8: Other congenital malformations of uterus and cervix (Hypoplasia of uterus and cervix)

    Q51.9: Congenital malformation of uterus and cervix, unspecified

88: Other (please specify) [Free text field]

Secondary surgical diagnosis

Definition: Additional condition(s) that coexist at the time of admission, or develop subsequently, and that affect the patient care during the current episode.

Coding: [Data items as per **Primary surgical diagnosis** above; branching logic, multiple selection]

2: No

Primary surgical procedure

Definition: Minimally-invasive or invasive therapies performed as in-patient surgery, where in-patient surgery is defined as a surgical operation or procedure which is performed as a day stay or with an overnight stay in an in-patient institution.

Coding: MBS item numbers for the procedures that were performed in the surgery [only one selection allowed].

35641: ENDOMETRIOSIS LEVEL 4 OR 5, laparoscopic resection of (which requires dissection of endometriosis, or other pathology, from the ureter, one or both sides, including any associated laparoscopy, including when performed with one or more of the following procedures: salpingectomy, oophorectomy, excision of ovarian cyst, or treatment of endometriosis, not being a service to which item 35754 applies).

35638: COMPLICATED OPERATIVE LAPAROSCOPY, including use of laser when required, for 1 or more of the following procedures; oophorectomy, ovarian cystectomy, myomectomy, salpingectomy or salpingostomy, ablation of moderate or severe endometriosis requiring more than 1 hours operating time, or division of utero-sacral ligaments for significant dysmenorrhoea (not being a service associated with any other intraperitoneal or retroperitoneal procedure except item 30393).

35649: HYSTEROTOMY OR UTERINE MYOMECTOMY, abdominal

35640: UTERUS, CURETTAGE OF, with or without dilatation (including curettage for incomplete miscarriage) under general anaesthesia, or under epidural or spinal (intrathecal) nerve block, including procedures to which item 35626, 35627 or 35630 applies, if performed.

35623: HYSTEROSCOPIC RESECTION, of myoma, or myoma and uterine septum resection (where both are performed), followed by endometrial ablation by laser or diathermy.

35627: HYSTEROSCOPY WITH DILATATION OF THE CERVIX performed in the operating theatre of a hospital (not being a service associated with a service to which item 35626 or 35630 applies).

35630: HYSTEROSCOPY, with endometrial biopsy, performed in the operating theatre of a hospital (not being a service associated with a service to which item 35626 or 35627 applies).

35633: HYSTEROSCOPY with uterine adhesiolysis or polypectomy or tubal catheterisation (including for insertion of device for sterilisation) or removal of IUD which cannot be removed by other means, 1 or more of.

35635: HYSTEROSCOPY involving resection of the uterine septum.

35636: HYSTEROSCOPY, involving resection of myoma, or resection of myoma and uterine septum (where both are performed).

35754: LAPAROSCOPICALLY ASSISTED HYSTERECTOMY (which requires dissection of endometriosis, or other pathology, from the ureter, one or both sides, including any associated laparoscopy, including when performed with one or more of the following procedures: salpingectomy, oophorectomy, excision of ovarian cyst, or treatment of endometriosis, not being a service to which item 35641 applies).

35756: LAPAROSCOPICALLY ASSISTED HYSTERECTOMY (when procedure is completed by open hysterectomy, including any associated laparoscopy).

35637: LAPAROSCOPY, involving puncture of cysts, diathermy of endometriosis, ventrosuspension, division of adhesions or similar procedure - 1 or more procedures with or without biopsy - not being a service associated with any other laparoscopic procedure or hysterectomy.

35753: LAPAROSCOPICALLY ASSISTED HYSTERECTOMY with one or more of the following procedures: salpingectomy, oophorectomy, excision of ovarian cyst or treatment of moderate endometriosis, one or both sides, including any associated laparoscopy.

30393: LAPAROSCOPIC DIVISION OF ADHESIONS in association with another intra-abdominal procedure where the time taken to divide the adhesions exceeds 45 minutes.

35653: HYSTERECTOMY, ABDOMINAL, SUBTOTAL or TOTAL, with or without removal of uterine adnexae.

35657: HYSTERECTOMY, VAGINAL, with or without uterine curettage, not being a service to which item 35673 applies.

35658: UTERUS (at least equivalent in size to a 10 week gravid uterus), debulking of, prior to vaginal removal at hysterectomy.

35616: ENDOMETRIUM, endoscopic examination of and ablation of, by microwave or thermal balloon or radiofrequency electrosurgery, for chronic refractory menorrhagia including any hysteroscopy performed on the same day, with or without uterine curettage.

35622: ENDOMETRIUM, endoscopic ablation of, by laser or diathermy, for chronic refractory menorrhagia including any hysteroscopy performed on the same day, with or without uterine curettage, not being a service associated with a service to which item 30390 applies.

35730: Ovarian repositioning for one or both ovaries to preserve ovarian function, prior to gonadotoxic radiotherapy when the treatment volume and dose of radiation have a high probability of causing infertility.

32004: LARGE INTESTINE, subtotal colectomy (resection of right colon, transverse colon and splenic flexure) without anastomosis, not being a service associated with a service to which item 32000, 32003, 32005 or 32006 applies.

32005: LARGE INTESTINE, subtotal colectomy (resection of right colon, transverse colon and splenic flexure) with anastomosis, not being a service associated with a service to which item 32000, 32003, 32004 or 32006 applies.

32006: RECTUM, HIGH RESTORATIVE ANTERIOR RESECTION WITH INTRAPERITONEAL ANASTOMOSIS (of the rectum) greater than 10 centimetres from the anal verge excluding resection of sigmoid colon alone not being a service associated with a service to which item 32103, 32104 or 32106 applies.

32024: RECTUM, HIGH RESTORATIVE ANTERIOR RESECTION WITH INTRAPERITONEAL ANASTOMOSIS (of the rectum) greater than 10 centimetres from the anal verge excluding resection of sigmoid colon alone not being a service associated with a service to which item 32103, 32104 or 32106 applies.

32025: RECTUM, LOW RESTORATIVE ANTERIOR RESECTION WITH EXTRAPERITONEAL ANASTOMOSIS (of the rectum) less than 10 centimetres from the anal verge, with or without covering stoma not being a service associated with a service to which item 32103, 32104 or 32106 applies.

32026: RECTUM, ULTRA LOW RESTORATIVE RESECTION, with or without covering stoma, where the anastomosis is sited in the anorectal region and is 6cm or less from the anal verge.

32028: RECTUM, LOW OR ULTRA LOW RESTORATIVE RESECTION, with peranal sutured coloanal anastomosis, with or without covering stoma.

36615: URETEROLYSIS, with or without repositioning of the ureter, for obstruction of the ureter, evident either radiologically or by proximal ureteric dilatation at operation, secondary to retroperitoneal fibrosis, or similar condition.

37000: BLADDER, partial excision of.

30574: APPENDICECTOMY, when performed in conjunction with any other intra-abdominal procedure through the same incision.

31350: BENIGN TUMOUR of SOFT TISSUE, excluding tumours of skin, cartilage, and bone, simple lipomas covered by item 31345 and lipomata, removal of by surgical excision, where the specimen excised is sent for histological confirmation of diagnosis, on a person 10 years of age or over, not being a service to which another item in this Group applies.

88:       Other (please specify) [Free text field]

Secondary surgical procedure(s)

Definition: The main minimally-invasive or invasive therapies performed as in-patient surgery, where in-patient surgery is defined as a surgical operation or procedure which is performed as a day stay or with an overnight stay in an in-patient institution.

Coding: MBS item numbers for the procedures that were performed in the surgery [Data items as for data field above – "Primary surgical procedure"; multiple selection].

Were there any relevant intra-operative complications?

Coding:

1:        Yes [Branching logic]

    T81.8: Positional problems (please specify) [Free text field]

    T81.0: Bleeding from the vagina

    T81.0: Bleeding from the bowel

    T81.2: Perforated uterus

    T81.2: Bladder injury

    T81.2: Bowel injury

    T81.2: Ureteric injury

    T81.2: Vascular injury

    T81.0: Cervix trauma/bleed

    T81.8: Upper body emphysema

    T81.7: Gas embolus

    88:        Other (please specify) [Free text field]

2:        No

Did you have a complication following surgery?

Definition: A complication is an event or occurrence that is associated with a disease or a healthcare intervention, is a departure from the desired course of events, and may cause, or be associated with, suboptimal outcome. Based on the Clavien-Dindo classification system and the involvement of other specialists as a result of complications.

Coding: [Branching logic; multiple selections]

G1:   Any deviation from the normal postoperative course without the need for pharmacological treatment or surgical, endoscopic and radiological interventions. Allowed therapeutic regimens are: drugs as antiemetics, antipyretics, analgesics, diuretics and electrolytes and physiotherapy. This grade also includes wound infections opened at the bedside.

G2:   Requiring pharmacological treatment with drugs other than such allowed for grade I complications. Blood transfusions and total parenteral nutrition are also included.

G3:   Requiring surgical, endoscopic or radiological intervention

    G3a: Intervention not under general anaesthesia

    G3b: Intervention under general anaesthesia

G4:   Life-threatening complication (including CNS complications) requiring IC/ICU-management

    G4a: Single organ dysfunction (including dialysis)

    G4b: Multi-organ dysfunction

G5:   Death of a patient

1:        Required involvement of other specialist(s) as a result

2:        No

Date of discharge

Definition: Date of which a patient completes an episode of care.

Coding: DD / MM / YYYY

ENDOMETRIOSIS SUMMARY

Note: To have the below data fields available only if "**N80.9 Endometriosis**" is selected in either "**Primary or Secondary surgical diagnosis**"

Endometriosis locations	Observed	Excised/ Removed	Residual disease	Photo	Sample collected
0: No endometriosis visualised	☐	☐	☐	☐	☐
N80.3: Left pelvic side wall	☐	☐	☐	☐	☐
1: Left uterosacral ligament	☐	☐	☐	☐	☐
N80.1: Left ovary – serosa	☐	☐	☐	☐	☐
N80.2: Left fallopian tube – serosa	☐	☐	☐	☐	☐
N80.3: Right pelvic side wall	☐	☐	☐	☐	☐
2: Right uterosacral ligament	☐	☐	☐	☐	☐
N80.1: Right ovary – serosa	☐	☐	☐	☐	☐
N80.2: Right fallopian tube – serosa	☐	☐	☐	☐	☐
3: Uterovesical pouch / Anterior cul-de-sac	☐	☐	☐	☐	☐
N80.4: Pouch of Douglas / Posterior cul-de-sac	☐	☐	☐	☐	☐
N80.3: Uterus – serosa	☐	☐	☐	☐	☐
N80.4: Vagina	☐	☐	☐	☐	☐
4: Cervical disease	☐	☐	☐	☐	☐
N80.3: Peritoneal pouches / pockets N80.3a: Location(s) [Free text field] N80.3b: Depth [Free text field] N80.3c: Diameter [Free text field]	☐	☐	☐	☐	☐
5: Rectum	☐	☐	☐	☐	☐
N80.5: Colon – deep infiltrating	☐	☐	☐	☐	☐
N80.5: Colon – serosa	☐	☐	☐	☐	☐
6: Left paracolic	☐	☐	☐	☐	☐
7: Right paracolic	☐	☐	☐	☐	☐
8: Bladder – deep infiltrating	☐	☐	☐	☐	☐
N80.3: Bladder – serosa	☐	☐	☐	☐	☐
9: R. ureter	☐	☐	☐	☐	☐
10: L. ureter	☐	☐	☐	☐	☐
11: Appendix	☐	☐	☐	☐	☐
12: Caecum	☐	☐	☐	☐	☐
N80.5: Small bowel	☐	☐	☐	☐	☐

N80.3: Left anterior abdominal wall	☐	☐	☐	☐	☐
N80.3: Right anterior abdominal wall	☐	☐	☐	☐	☐
13: Left diaphragm	☐	☐	☐	☐	☐
14: Right diaphragm	☐	☐	☐	☐	☐
N80.8: Other (please specify) [Free text field]	☐	☐	☐	☐	☐

Reason for residual disease

Note: To only show if "**N80.9 Endometriosis**" is selected in "**Primary or Secondary surgical diagnosis**".

Definition: Any disease of endometriosis remaining following surgery.

Coding:

1a: Difficulty in access

1b: Adhesions

1c: Additional specialist required

88:      Other (please specify) [Free text field]

1d: Outcome/plan [Free text field]

2:        No

Method of removal of endometriosis

Note: To only show if "**N80.9 Endometriosis**" is selected in "**Primary or Secondary surgical diagnosis**".

Definition: Surgical modality used to remove/excise endometriosis.

Coding: [Multiple selection; drop down]

1:        Monopolar vapourisation/ablation

2:        Bipolar ablation

3:        Excision of lesions

4:        Laser excision/ablation of lesions

5:        Combination excision and ablation/vapourisation

Endometriosis fertility index (includes rAFS score)

Note: To only show if "**N80.9 Endometriosis**" is selected in "**Primary or Secondary surgical diagnosis**".

Definition: A scientifically-derived, validated and professionally recognised index that predicts pregnancy rates in endometriosis patients who want to get pregnant following surgical assessment and treatment of endometriosis, thus enabling the most informed choice from among observation, conventional or ART treatment.

Coding: Refer to endometriosiefi.com [Auto calculate EFI score]

Part 1 Patient history

Age

1:        ≤ 35

2:        36 to 39 years

3:        ≥ 40

National Endometriosis Clinical and Scientific Trials Network Registry

Years infertile:

1:      ≤ 3

2:      > 3

History of prior pregnancy

1:      Yes

2:      No

Part 2 Least function (LF) score at conclusion of surgery

Fallopian tubes (right)

0:      Absent or nonfunctional

1:      Normal

2:      Mild

3:      Moderate

4:      Severe

Fallopian tubes (left)

0:      Absent or nonfunctional

1:      Normal

2:      Mild

3:      Moderate

4:      Severe

Fimbria (right)

0:      absent or nonfunctional

1:      Normal

2:      Mild

3:      Moderate

4:      Severe

Fimbria (left)

0:      Absent or nonfunctional

1:      Normal

2:      Mild

3:      Moderate

4:      Severe

Ovaries (right)

0:      absent or nonfunctional

1:      Normal

2:      Mild

3:      Moderate

4:       Severe

Ovaries (left)

0:       Absent or nonfunctional

1:       Normal

2:       Mild

3:       Moderate

4:       Severe

Part 3 Endometriosis fertility index (EFI) points derived from rAFS/ASRM staging system

Peritoneum (superficial)

0:       None

1:       < 1 cm

2:       1 – 3 cm

3:       > 3 cm

Peritoneum (deep)

0:       None

1:       < 1 cm

2:       1 – 3 cm

3:       > 3 cm

Ovaries (right, superficial)

0:       None

1:       < 1 cm

2:       1 – 3 cm

3:       > 3 cm

Ovaries (right, deep)

0:       None

1:       < 1 cm

2:       1 – 3 cm

3:       > 3 cm

Ovaries (left, superficial)

0:       None

1:       < 1 cm

2:       1 – 3 cm

3:       > 3 cm

Ovaries (left, deep)

0:       None

National Endometriosis Clinical and Scientific Trials Network Registry

1:      < 1 cm

2:      1 – 3 cm

3:      > 3 cm

Posterior cul-de-sac obliteration

0:      None

1:      Partial

2:      Complete

Adhesions ovaries (right, filmy)

0:      None

1:      < 1/3 enclosure

2:      1/3 – 2/3 enclosure

3:      > 2/3 enclosure

Adhesions ovaries (right, dense)

0:      None

1:      < 1/3 enclosure

2:      1/3 – 2/3 enclosure

3:      > 2/3 enclosure

Adhesions ovaries (left, filmy)

0:      None

1:      < 1/3 enclosure

2:      1/3 – 2/3 enclosure

3:      > 2/3 enclosure

Adhesions ovaries (left, dense)

0:      None

1:      < 1/3 enclosure

2:      1/3 – 2/3 enclosure

3:      > 2/3 enclosure

Adhesions tubes (right, filmy)

0:      None

1:      < 1/3 enclosure

2:      1/3 – 2/3 enclosure

3:      > 2/3 enclosure

Adhesions tubes (right, dense)

0:      None

1:      < 1/3 enclosure

DATA DICTIONARY
21 JUNE 2021

2:          1/3 – 2/3 enclosure

3:          > 2/3 enclosure

4:          Complete enclosure of fimbriated end of fallopian tube

Adhesions tubes (left, filmy)

0:          None

1:          < 1/3 enclosure

2:          1/3 – 2/3 enclosure

3:          > 2/3 enclosure

Adhesions tubes (left, dense)

0:          None

1:          < 1/3 enclosure

2:          1/3 – 2/3 enclosure

3:          > 2/3 enclosure

4:          Complete enclosure of fimbriated end of fallopian tube

7. Histopathology and biobanking

HISTOPATHOLOGY REPORT UPLOAD (PDF)

***Date of surgery**

Note 1: Please see **Module 6 – Surgical Management** for data dictionary, groupings and options.

Note 2: To be linked to the appropriate **Surgical Management** episode.

***Surgical hospital**

Note 1: Please see **Module 6 – Surgical Management** for data dictionary, groupings and options.

Note 2: To be linked to the appropriate **Surgical Management** episode.

***Primary surgeon details**

Note 1: Please see **Module 6 – Surgical Management** for data dictionary, groupings and options.

Note 2: To be linked to the appropriate **Surgical Management** episode.

File (pdf) upload of histopathology report.

Coding: [Ability to save file in accordance to the histopathology report number]

Primary findings

Note: As reported from the histopathology report

Definition: Primary finding, after surgery and histopathological assessment to be chiefly responsible for the

patient's episode of care in hospital.

Coding: [Only one selection allowed; ICD-10 codes]

N80:   Endometriosis [Branching logic]

     N80.1: Endometriosis of ovary

     N80.2: Endometriosis of fallopian tube

     N80.3: Endometriosis of pelvic peritoneum

     N80.4: Endometriosis of rectovaginal septum and vagina

     N80.5: Endometriosis of intestine

     N80.6: Endometriosis in cutaneous scar

     N80.8: Other endometriosis

     N80.9: Endometriosis, unspecified

N80.0: Endometriosis of uterus (adenomyosis)

       N80-1: Uniformly enlarged

       N80-8: Other (please specify) [Free text field]

D25.9: Leiomyoma of uterus/fibroids (select all that apply) [Branching logic]

     D25.0: Submucous leiomyoma of uterus

     D25.1: Intramural leiomyoma of uterus

     D25.2: Subserosal leiomyoma of uterus

N97:   Female infertility [Branching logic]

     N97.0: Female infertility associated with anovulation

     N97.1: Female infertility of tubal origin

N97.2: Female infertility of uterine origin

N97.8: Female infertility of other origin

N97.9: Female infertility, unspecified

E28.2: Polycystic ovarian syndrome

D27: Benign neoplasm of ovary (includes cyst (colloid) (mucous) (dermoid) (ovarian twisted) (not elsewhere classified))

N70.1: Hydrosalpinx

N83.0: Follicular cyst of ovary (includes cyst of graafian follicle, haemorrhagic follicular cyst)

N83.1: Corpus luteum cyst (includes haemorrhagic corpus luteum cyst)

N83.2: Other and unspecified ovarian cysts (includes retention and simple cyst of ovary)

N83.3: Acquired atropy of ovary and fallopian tube

N83.4: Prolapse and hernia of ovaria and fallopian tube

N83.5: Torsion of ovary, ovarian pedicle and fallopian tube

N84: Polyp of female genital tract [Branching logic]

   N84.0: Polyp of corpus uteri (includes polyp of endometrium or uterus)

   N84.1: Polyp of cervix uteri

   N84.2: Polyp of vagina

   N84.3: Polyp of vulva (includes polyp of labia)

   N84.8: Polyp of other parts of female genital tract

   N84.9: Polyp of female genital tract, unspecified

N85.0: Endometrial hyperplasia

Q51: Congenital malformations of uterus and cervix [Branching logic]

   Q51.0: Agenesis and aplasia of uterus (Congenital absence of uterus)

   Q51.1: Doubling of uterus with doubling of cervix and vagina

   Q51.2: Other doubling of uterus (Doubling of uterus NOS)

   Q51.3: Bicornate uterus

   Q51.4: Unicornate uterus

   Q51.5: Agenesis and aplasia of cervix (Congenital absence of cervix)

   Q51.6: Embryonic cyst of cervix

   Q51.7: Congenital fistulae between uterus and digestive and urinary tracts

   Q51.8: Other congenital malformations of uterus and cervix (Hypoplasia of uterus and cervix)

   Q51.9: Congenital malformation of uterus and cervix, unspecified

88: Other (please specify) [Free text field]

Secondary findings

Note: As reported from the histopathology report

Definition: Additional condition(s) that coexist at the time of histopathological assessment of the primary reason resulting in a patients care.

Coding: [Data items as per **Primary findings** above; branching logic, multiple selection]

2: No

National Endometriosis Clinical and Scientific Trials Network Registry

BIOBANK

Note: To be developed following completion of initial build of the NECST Registry.

8. Environmental and lifestyle risk factors

(Note: participant questionnaire, for Royal Hospital for Women and Prince of Wales Private Hospital only)

Thank you for consenting to take part in our research project. This project aims to understand the effects that the environment, our lifestyle and behaviours have on conditions like endometriosis. This questionnaire will take you through a series of questions and should take you approximately 35 minutes to complete. All questions are voluntary and you can skip questions if you prefer not to answer them.

Before you start the questionnaire we would like to remind you that you have already provided verbal consent to participate in this project. If you would like to review the information and consent form, please email the investigator at rhwgrace@gmail.com.

As a reminder, we will collect and manage your information under the conditions in which you have provided your consent. In accordance with the Australian Privacy Principles 2014, the Australian Code of the Responsible Conduct of Research and NHMRC National Guidelines for the Ethical Conduct of Human Research (2007) - Updated 2018, this project will keep confidential your name, contact details and the answers you provide to this questionnaire. Your personal identifying information will not be given out to anyone. Any information you may disclose to us including your answers to sensitive questions (for example, your answers around drug use) will not be disclosed to anyone outside of the research team unless disclosure is required under Australian Law.

If you have decided that you no longer want to take part in this research project, that is perfectly fine. Please do not continue this questionnaire, and email the investigator (rhwgrace@gmail.com) to withdraw from this project. Withdrawal will only affect your participation in this project.

I have read the Participant Information Sheet or someone has read it to me in a language that I understand. I agree to participate and provide information about myself as required.

☐   I agree
☐   I disagree and don't want to participate in this survey

DEMOGRAPHICS
We would like to ask you some personal questions about your name, date of birth and gender so we can ensure that we accurately match the information you provide to us in this questionnaire with your clinical information.

What is your full name?   _____

What is your date of birth?   _____

Your calculated age is: _____

What is your height in centimetres (cm)?   _____

What is your current weight in kilograms (kg)?   _____

Your calculated BMI is: _____

CURRENT RESIDENTIAL INFORMATION
The following questions will ask you about the places you have lived during different periods of your life. We would like to know the postcode of the area in which you lived however if you don't know the postcode, please just write the name of the place. If you lived overseas during any of the specified periods of your life, please fill in the name of the place and the country.

Do you currently live on a farm or in a town/city dwelling?

☐   Farm
☐   Town/city dwelling
☐   Leave blank

Did you live in Australia or overseas for the majority of age 0-12?

☐   Australia
☐   Overseas
☐   Leave blank

Where did you live for the majority of your life aged 0-12?
(Australian Postcode OR name of the town/city in which you resided, leave blank if unknown)

_____

Did you live in Australia or overseas for the majority of age 13-20?
☐   Australia
☐   Overseas
☐   Leave blank

Where did you live for the majority of your life aged 13-20? (Australian Postcode OR name of the town/city in which you resided, leave blank if unknown)

_____

Did you live in Australia or overseas for the majority of age 21-45?
☐   Australia
☐   Overseas
☐   Leave blank

Where did you live for the majority of your life aged 21-45? (Australian Postcode OR name of the town/city in which you resided, leave blank if unknown)

_____

Did you live in Australia or overseas for the majority of age 45+?
☐   Australia
☐   Overseas
☐   Leave blank

Where did you live for the majority of your life aged 45+? (Australian Postcode OR name of the town/city in which you resided, leave blank if unknown)

_____

OCCUPATION
We would like to ask you some questions about the occupations you have had during your life. If you have had more than one occupation or have moved locations then please fill in one section for each different occupation you have had.

What is your current occupation or, if retired/unemployed, what was your last occupation?
☐   Legislator or Senior Official
☐   Professional (e.g., engineer; IT; medical doctor; teacher; accountant; lawyer; psychologist; librarian; other professional)
☐   Technician and Associate Professional (e.g., engineer technician; lab technician; computer assistant; ship and aircraft controller or pilot)
☐   Clerical Support Worker (e.g., office clerk; customer services clerk; secretary; cashier; travel agency clerk; receptionist)
☐   Services Worker and Shop and Market Sales Worker (e.g., travel guide; housekeeper; waiters; waitress or bartender)
☐   Skilled Agricultural, Forestry and Fishery worker (e.g., market-oriented skilled agricultural or fishery worker)
☐   Craft and related Trades Worker (e.g., extraction (mining) and building trades worker; metals worker; machinery trades worker; precision; welder)
☐   Plant and Machine Operator or Assembler (e.g., stationary-plant or related-operator; machine operator or assembler)
☐   Elementary Occupation (e.g., homemaker; street vendor; domestic helper, cleaner or launderer; garbage collector; agricultural, fishery; truck driver; bus/train driver)
☐   Armed Forces Occupation
☐   Police

☐   First Responders (e.g., paramedic; fire services; rescuers)
☐   please specify _____
☐   No answer

Please enter the Australian postcode of your current or last place of work (Leave blank if unknown or overseas)
Find a postcode here: http://auspost.com.au/postcode (http://auspost.com.au/postcode)
_____

Please enter the name of the town/city and country where your current or last place of work is located (e.g.: London, United Kingdom or Brisbane, Australia)
_____

Did you hold any other occupation for more than 5 years before your current/last occupation?
☐   Yes
☐   No
☐   Leave blank

What was your previous occupation?
☐   Legislator or Senior Official
☐   Professional (e.g., engineer; IT; medical doctor; teacher; accountant; lawyer; psychologist; librarian; other professional)
☐   Technician and Associate Professional (e.g., engineer technician; lab technician; computer assistant; ship and aircraft controller or pilot)
☐   Clerical Support Worker (e.g., office clerk; customer services clerk; secretary; cashier; travel agency clerk; receptionist)
☐   Services Worker and Shop and Market Sales Worker (e.g., travel guide; housekeeper; waiters; waitress or bartender)
☐   Skilled Agricultural, Forestry and Fishery worker (e.g., market-oriented skilled agricultural or fishery worker)
☐   Craft and related Trades Worker (e.g., extraction (mining) and building trades worker; metals worker; machinery trades worker; precision; welder)
☐   Plant and Machine Operator or Assembler (e.g., stationary-plant or related-operator; machine operator or assembler)
☐   Elementary Occupation (e.g., homemaker; street vendor; domestic helper, cleaner or launderer; garbage collector; agricultural, fishery; truck driver; bus/train driver)
☐   Armed Forces Occupation
☐   Police
☐   First Responders (e.g., paramedic; fire services; rescuers)
☐   please specify _____
☐   No answer

Please enter the Australian postcode of your previous place of work (Leave blank if unknown or overseas)
Find a postcode here: http://auspost.com.au/postcode (http://auspost.com.au/postcode)
_____

Please enter the name of the town/city and country of your previous place of work is located (e.g.: London, United Kingdom or Brisbane, Australia)
_____

Did you hold any other occupation for more than 5 years before your current/last occupation?
☐   Yes
☐   No
☐   Leave blank

What was your previous occupation?
☐   Legislator or Senior Official
☐   Professional (e.g., engineer; IT; medical doctor; teacher; accountant; lawyer; psychologist; librarian; other professional)

☐   Technician and Associate Professional (e.g., engineer technician; lab technician; computer assistant; ship and aircraft controller or pilot)
☐   Clerical Support Worker (e.g., office clerk; customer services clerk; secretary; cashier; travel agency clerk; receptionist)
☐   Services Worker and Shop and Market Sales Worker (e.g., travel guide; housekeeper; waiters; waitress or bartender)
☐   Skilled Agricultural, Forestry and Fishery worker (e.g., market-oriented skilled agricultural or fishery worker)
☐   Craft and related Trades Worker (e.g., extraction (mining) and building trades worker; metals worker; machinery trades worker; precision; welder)
☐   Plant and Machine Operator or Assembler (e.g., stationary-plant or related-operator; machine operator or assembler)
☐   Elementary Occupation (e.g., homemaker; street vendor; domestic helper, cleaner or launderer; garbage collector; agricultural, fishery; truck driver; bus/train driver)
☐   Armed Forces Occupation
☐   Police
☐   First Responders (e.g., paramedic; fire services; rescuers)
☐   please specify _____
☐   No answer

Please enter the Australian postcode of your previous place of work (Leave blank if unknown or overseas)
Find a postcode here: http://auspost.com.au/postcode (http://auspost.com.au/postcode)
_____

Please enter the name of the town/city and country where your previous place of work was located (e.g.: London, United Kingdom or Brisbane, Australia)
_____

Did you hold any other occupation for more than 5 years before your current/last occupation?
☐   Yes
☐   No
☐   Leave blank

What was your previous occupation?
☐   Legislator or Senior Official
☐   Professional (e.g., engineer; IT; medical doctor; teacher; accountant; lawyer; psychologist; librarian; other professional)
☐   Technician and Associate Professional (e.g., engineer technician; lab technician; computer assistant; ship and aircraft controller or pilot)
☐   Clerical Support Worker (e.g., office clerk; customer services clerk; secretary; cashier; travel agency clerk; receptionist)
☐   Services Worker and Shop and Market Sales Worker (e.g., travel guide; housekeeper; waiters; waitress or bartender)
☐   Skilled Agricultural, Forestry and Fishery worker (e.g., market-oriented skilled agricultural or fishery worker)
☐   Craft and related Trades Worker (e.g., extraction (mining) and building trades worker; metals worker; machinery trades worker; precision; welder)
☐   Plant and Machine Operator or Assembler (e.g., stationary-plant or related-operator; machine operator or assembler)
☐   Elementary Occupation (e.g., homemaker; street vendor; domestic helper, cleaner or launderer; garbage collector; agricultural, fishery; truck driver; bus/train driver)
☐   Armed Forces Occupation
☐   Police
☐   First Responders (e.g., paramedic; fire services; rescuers)
☐   please specify _____
☐   No answer

Please enter the Australian postcode of your previous place of work (Leave blank if unknown or overseas)
Find a postcode here: http://auspost.com.au/postcode (http://auspost.com.au/postcode)

_____

Please enter the name of the town/city and country where your previous place of work was located (e.g.: London, United Kingdom or Brisbane, Australia)

_____

Did you hold any other occupation for more than 5 years before your current/last occupation?
☐   Yes
☐   No
☐   Leave blank

What was your previous occupation?
☐   Legislator or Senior Official
☐   Professional (e.g., engineer; IT; medical doctor; teacher; accountant; lawyer; psychologist; librarian; other professional)
☐   Technician and Associate Professional (e.g., engineer technician; lab technician; computer assistant; ship and aircraft controller or pilot)
☐   Clerical Support Worker (e.g., office clerk; customer services clerk; secretary; cashier; travel agency clerk; receptionist)
☐   Services Worker and Shop and Market Sales Worker (e.g., travel guide; housekeeper; waiters; waitress or bartender)
☐   Skilled Agricultural, Forestry and Fishery worker (e.g., market-oriented skilled agricultural or fishery worker)
☐   Craft and related Trades Worker (e.g., extraction (mining) and building trades worker; metals worker; machinery trades worker; precision; welder)
☐   Plant and Machine Operator or Assembler (e.g., stationary-plant or related-operator; machine operator or assembler)
☐   Elementary Occupation (e.g., homemaker; street vendor; domestic helper, cleaner or launderer; garbage collector; agricultural, fishery; truck driver; bus/train driver)
☐   Armed Forces Occupation
☐   Police
☐   First Responders (e.g., paramedic; fire services; rescuers)
☐   please specify _____
☐   No answer

Please enter the Australian postcode of your previous place of work (Leave blank if unknown or overseas)
Find a postcode here: http://auspost.com.au/postcode (http://auspost.com.au/postcode)

_____

Please enter the name of the town/city and country where your previous place of work was located (e.g.: London, United Kingdom or Brisbane, Australia)

_____

FAMILY HISTORY
In this section we would like to ask you some questions about your immediate family including any children you may have.

For the purposes of this survey we would like to know specifically about your biological family members. For this reason, we would like to ask you about your relationship to your family members and whether your biological family members are known to you.

A biological family member is someone that is directly related to you by blood, for example your biological mother or father, full or half sibling, or biological child. A non-biological family member is not directly related to you by blood, for example adoptive parents, step parents, step siblings, adopted siblings, adoptive children, and step children. We will ask you about the biological family that is known to you, their relationship to you, and whether they are still living. Please answer as best you can.

	Yes	No	Leave blank
Biological mother	☐	☐	☐

Biological father   ☐   ☐   ☐

Is your father still living?
          ☐   Yes
          ☐   No
          ☐   Leave blank

What is your father's current age?
_____

How old was your father when he died?
_____

What was the cause of your father's death?
_____

Is your mother still living?
          ☐   Yes
          ☐   No
          ☐   Leave blank

What is your mother's current age?
_____

How old was your mother when she died?
_____

What was the cause of your mother's death?
_____

How many biological siblings do you have?
_____

How are you related to your first sibling?
          ☐   Half sibling
          ☐   Full sibling

Is your first sibling still living?
          ☐   Yes
          ☐   No
          ☐   Leave blank

What is your first sibling's current age?
_____

How old was your first sibling when they died?
_____

What was the cause of your first sibling's death?
_____

How are you related to your second sibling?
          ☐   Half sibling
          ☐   Full sibling

Is your second sibling still living?
          ☐   Yes
          ☐   No
          ☐   Leave blank

What is your second sibling's current age?

_____

How old was your second sibling when they died?
_____

What was the cause of your second sibling's death?
_____

How are you related to your third sibling?
  ☐ Half sibling
  ☐ Full sibling

Is your third sibling still living?
  ☐ Yes
  ☐ No
  ☐ Leave blank

What is your third sibling's current age?
_____

How old was your third sibling when they died?
_____

What was the cause of your third sibling's death?
_____

How are you related to your fourth sibling?
  ☐ Half sibling
  ☐ Full sibling

Is your fourth sibling still living?
  ☐ Yes
  ☐ No
  ☐ Leave blank

What is your fourth sibling's current age?
_____

How old was your fourth sibling when they died?
_____

What was the cause of your fourth sibling's death?
_____

How are you related to your fifth sibling?
  ☐ Half sibling
  ☐ Full sibling

Is your fifth sibling still living?
  ☐ Yes
  ☐ No
  ☐ Leave blank

What is your fifth sibling's current age?
_____

How old was your fifth sibling when they died?
_____

What was the cause of your fifth sibling's death?
_____

How are you related to your sixth sibling?
    ☐   Half sibling
    ☐   Full sibling

Is your sixth sibling still living?
    ☐   Yes
    ☐   No
    ☐   Leave blank

What is your sixth sibling's current age?
_____

What was the cause of your sixth sibling's death?
_____

How old was your sixth sibling when they died?
_____

How are you related to your seventh sibling?
    ☐   Half sibling
    ☐   Full sibling

Is your seventh sibling still living?
    ☐   Yes
    ☐   No
    ☐   Leave blank

What is your seventh sibling's current age?
_____

How old was your seventh sibling when they died?
_____

What was the cause of your seventh sibling's death?
_____

How are you related to your eighth sibling?
    ☐   Half sibling
    ☐   Full sibling

Is your eighth sibling still living?
    ☐   Yes
    ☐   No
    ☐   Leave blank

What is your eighth sibling's current age?
_____

How old was your eighth sibling when they died?
_____

What was the cause of your eighth sibling's death?
_____

How are you related to your ninth sibling?
    ☐   Half sibling
    ☐   Full sibling

Is your ninth sibling still living?
    ☐   Yes

☐   No
☐   Leave blank

What is your ninth sibling's current age?
_____

How old was your ninth sibling when they died?
_____

What was the cause of your ninth sibling's death?
_____

How are you related to your tenth sibling?
☐   Half sibling
☐   Full sibling

Is your tenth sibling still living?
☐   Yes
☐   No
☐   Leave blank

What is your tenth sibling's current age?
_____

How old was your tenth sibling when they died?
_____

What was the cause of your tenth sibling's death?
_____

How many biological children have you had?
_____

Is your first biological child still living?
☐   Yes
☐   No
☐   Leave blank

What is your first biological child's current age?
_____

How old was your first biological child when they died?
_____

What was the cause of your first biological child's death?
_____

Is your second biological child still living?
☐   Yes
☐   No
☐   Leave blank

What is your second biological child's current age?
_____

How old was your second biological child when they died?
_____

What was the cause of your second biological child's death?
_____

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Is your third biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your third biological child's current age?
_____

How old was your third biological child when they died?
_____

What was the cause of your third biological child's death?
_____

Is your fourth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your fourth biological child's current age?
_____

How old was your fourth biological child when they died?
_____

What was the cause of your fourth biological child's death?
_____

Is your fifth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your fifth biological child's current age?
_____

How old was your fifth biological child when they died?
_____

What was the cause of your fifth biological child's death?
_____

Is your sixth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your sixth biological child's current age?
_____

How old was your sixth biological child when they died?
_____

What was the cause of your sixth biological child's death?
_____

Is your seventh biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your seventh biological child's current age?
_____

What was the cause of your seventh biological child's death?
_____

How old was your seventh biological child when they died?
_____

Is your eighth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your eighth biological child's current age?
_____

How old was your eighth biological child when they died?
_____

What was the cause of your eighth biological child's death?
_____

Is your ninth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your ninth biological child's current age?
_____

How old was your ninth biological child when they died?
_____

What was the cause of your ninth biological child's death?
_____

Is your tenth biological child still living?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What is your tenth biological child's current age?
_____

How old was your tenth biological child when they died?
_____

What was the cause of your tenth biological child's death?
_____

ANCESTRY
Which ancestral group(s) do you most closely relate to biologically? (multiple answers possible)
- ☐ European
- ☐ Aboriginal & Torres Strait Islander
- ☐ East Asian (from China, Japan, Korea, South-East Asia)
- ☐ South Asian (from India, Pakistan, Bangladesh, Sri Lanka)
- ☐ African (African American or Afro-Caribbean)
- ☐ Middle Eastern
- ☐ South American
- ☐ Other

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

If there are any other ancestral group(s) you most closely relate to biologically, please specify.
_____

Which ancestral group(s) does your biological mother most closely relate to biologically? (multiple answers possible)
- ☐ European
- ☐ Aboriginal & Torres Strait Islander
- ☐ East Asian (from China, Japan, Korea, South-East Asia)
- ☐ South Asian (from India, Pakistan, Bangladesh, Sri Lanka)
- ☐ African (African American or Afro-Caribbean)
- ☐ Middle Eastern
- ☐ South American
- ☐ Other

If there are any other ancestral group(s) your biological mother most closely relates to biologically, please specify.

_____

Which ancestral group(s) does your biological father most closely relate to biologically? (multiple answers possible)
- ☐ European
- ☐ Aboriginal & Torres Strait Islander
- ☐ East Asian (from China, Japan, Korea, South-East Asia)
- ☐ South Asian (from India, Pakistan, Bangladesh, Sri Lanka)
- ☐ African (African American or Afro-Caribbean)
- ☐ Middle Eastern
- ☐ South American
- ☐ Other

If there are any other ancestral group(s) your biological father most closely relates to biologically, please specify.
_____

MEDICAL HISTORY
This section of questions will ask you about any other medical conditions or disorders you may have had in your lifetime. This information may be able to assist us in looking at other medical conditions that may influence the onset of diseases and disorders. If you have had one of these conditions or disorders you may be asked additional questions about this.

Have you ever had a disease that can be subdivided into one of the following categories?

	Yes	No
Infectious and parasitic diseases e.g.: hepatitis, STDs, tuberculosis, herpes, mosquito-related diseases, tick-related diseases, influenza, viral or bacterial infections	☐	☐
Cancers/Neoplasms	☐	☐
Diseases of the blood and blood-forming organs and disorders involving the immune mechanism e.g.: anaemias	☐	☐
Endocrine, nutritional and metabolic diseases e.g.: thyroid gland, diabetes, endocrine glands, malnutrition, obesity	☐	☐
Mental and behavioural disorders e.g.: depression, schizophrenia, bipolar, anxiety	☐	☐
Diseases of the nervous system e.g.: inflammatory diseases, Parkinsons, Alzheimers	☐	☐
Diseases of the eye and adnexa	☐	☐
Diseases of the ear and mastoid process	☐	☐
Diseases of the circulatory system e.g.: rheumatic, hypertensive, ischaemic heart diseases, diseases of arteries/veins/lymphatic vessels/nodes	☐	☐
Diseases of the respiratory system e.g.: lung diseases, respiratory tract diseases	☐	☐
Diseases of the digestive system e.g.: intestines, liver, pancreas, stomach, hernia	☐	☐
Diseases of the skin and subcutaneous tissue	☐	☐

Diseases of musculoskeletal system and connective tissue e.g.: diseases of muscles/joints	☐	☐
Diseases of the genitourinary system e.g.: kidney, urinary system, breasts, genital organs	☐	☐
Congenital malformations, deformations and chromosomal abnormalities e.g.: spina bifida, encephalocele, downs syndrome	☐	☐
Symptoms, signs and abnormal clinical laboratory findings, not elsewhere classified e.g.: abnormalities of heart beat, pain in throat and chest, heartburn, dysphagia, faecal incontinence, polyuria, urethral discharge, coma, senility	☐	☐
Injury, poisoning and certain other consequences of external causes e.g.: fracture, dislocation, sprain, foreign material entering body, burns, frostbite, drug poisoning, alcohol poisoning, asphyxiation, transplantation rejection	☐	☐

How old were you when you were diagnosed with an infectious and parasitic disease?

_____

What infectious and parasitic disease were you diagnosed with?

_____

You have reported in the 'infectious and parasitic diseases' question of the medical history section. Have you had any of the following bacterial infections within the last 12 months?

- ☐　Tetanus
- ☐　Whooping cough
- ☐　Streptococcal infections
- ☐　Bacterial meningitis
- ☐　Legionnaire's Disease
- ☐　Q Fever
- ☐　Diptheria
- ☐　Listeria
- ☐　Sepsis
- ☐　Other infection not included in this list
- ☐　No

Have you had any of the following parasitic or viral infections within the last 12 months?

- ☐　Influenza
- ☐　Lyme disease
- ☐　Viral meningitis
- ☐　Shingles
- ☐　Dengue Fever
- ☐　Malaria
- ☐　Gastroenteritis
- ☐　Herpes simplex 1 (HSV-1) - cold sore virus
- ☐　Other infection not included in this list
- ☐　No

Have you have one of the following sexually transmitted infections (STI, formerly known as STD) within the last 12 months?

- ☐　Chancroid
- ☐　Chlamydia
- ☐　Gonorrhoea
- ☐　Hepatitis
- ☐　Herpes simplex (HSV-2)
- ☐　HIV
- ☐　Human Papillomavirus (HPV)
- ☐　Syphilis
- ☐　Trichomoniasis
- ☐　Other STD not on this list
- ☐　No

How old were you when you were diagnosed with a cancers/neoplasm?
_____

What cancers/neoplasm were you diagnosed with?
_____

You have reported in the 'cancer/neoplasms' question of the medical history section. Do you currently have cancer?
☐   Yes
☐   No
☐   Leave blank

What kind of cancer treatment(s) did you receive/are receiving (multiple answers possible)?
☐   Radiation Therapy
☐   Surgery
☐   Chemotherapy
☐   Bone Marrow Transplant
☐   Stem Cell Treatment
☐   Other

If other treatment, please specify
_____

How old were you when you were diagnosed with a disease of the blood/blood-forming organs?
_____

What disease of the blood/blood-forming organs were you diagnosed with?
_____

How old were you when you were diagnosed with an endocrine, nutritional or metabolic disease?
_____

What endocrine, nutritional or metabolic disease were you diagnosed with?
_____

Have you been treated for diabetes within the last 12 months?
☐   Yes
☐   No

How old were you when you were diagnosed with an mental or behavioural disorder?
_____

What mental or behavioural disorder were you diagnosed with?
_____

Have you been diagnosed with any of the following within the last 12 months?
☐   Movement disorder
☐   Depression
☐   Bipolar disorder
☐   Anxiety disorder
☐   Other

Please specify other mental disorder or brain disease not mentioned above that you have been diagnosed with in the last 12 months.
_____

How old were you when you were diagnosed with a disease of the nervous system?
_____

What disease of the nervous system were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the eye/adnexa?
_____

What disease of the eye/adnexa were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the ear or mastoid process?
_____

What disease of the ear or mastoid process were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the circulatory system?
_____

What disease of the circulatory system were you diagnosed with?
_____

Which of the following have you been treated for within the last 12 months?
- ☐ High cholesterol
- ☐ High blood pressure

How old were you when you were diagnosed with a disease of the respiratory system?
_____

What disease of the respiratory system were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the digestive system?
_____

What disease of the digestive system were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the skin or subcutaneous tissue?
_____

What disease of the skin or subcutaneous tissue were you diagnosed with?
_____

How old were you when this occurred/were diagnosed with a disease of the musculoskeletal system or connective tissue?
_____

What disease of the musculoskeletal system or connective tissue were you diagnosed with?
_____

How old were you when you were diagnosed with a disease of the genitourinary system?
_____

What disease of the genitourinary system were you diagnosed with?
_____

How old were you were diagnosed with a congenital malformation, deformation or chromosomal abnormality?
_____

What congenital malformation, deformation or chromosomal abnormality were you diagnosed with?
_____

How old were you when you had a symptom/sign/abnormal clinical laboratory finding not elsewhere classified?

DATA DICTIONARY
21 JUNE 2021

_____

What symptom/sign/abnormal clinical laboratory finding not elsewhere classified occurred?
_____

How old were you when you had an injury, poisoning or other consequence of external cause?
_____

What injury, poisoning or other consequence of external cause occurred?
_____

How many times have you ever had serious trauma requiring medical care?
_____

What injury type?
- ☐ Head injury w/ concussion
- ☐ Fracture
- ☐ Contusion
- ☐ Sprain
- ☐ Strain
- ☐ Other (Specify)

If other, please specify.
_____

Age at occurrence?
_____

Circumstances of injury?
- ☐ Work
- ☐ Sport
- ☐ Leisure (other than sport)
- ☐ Traffic
- ☐ Other (specify)

If other circumstance, please specify
_____

Duration of injury?
- ☐ Temporary
- ☐ Permanent

Injured body part?
- ☐ Head
- ☐ Arm(s)
- ☐ Chest
- ☐ Abdomen
- ☐ Leg(s)
- ☐ Spine
- ☐ Other (specify)

If other body part, please specify
_____

Severity of injury?
- ☐ Mild
- ☐ Moderate
- ☐ Severe

What injury type?

- ☐ Head injury w/ concussion
- ☐ Fracture
- ☐ Contusion
- ☐ Sprain
- ☐ Strain
- ☐ Other (Specify)

If other, please specify.
_____

Age at occurrence?
_____

Circumstances of injury?
- ☐ Work
- ☐ Sport
- ☐ Leisure (other than sport)
- ☐ Traffic
- ☐ Other (specify)

If other circumstance, please specify
_____

Duration of injury?
- ☐ Temporary
- ☐ Permanent

Injured body part?
- ☐ Head
- ☐ Arm(s)
- ☐ Chest
- ☐ Abdomen
- ☐ Leg(s)
- ☐ Spine
- ☐ Other (specify)

If other body part, please specify
_____

Severity of injury?
- ☐ Mild
- ☐ Moderate
- ☐ Severe

What injury type?
- ☐ Head injury w/ concussion
- ☐ Fracture
- ☐ Contusion
- ☐ Sprain
- ☐ Strain
- ☐ Other (Specify)

If other, please specify.
_____

Age at occurrence?
_____

Circumstances of injury?

National Endometriosis Clinical and Scientific Trials Network Registry

<div style="text-align:right">DATA DICTIONARY
21 JUNE 2021</div>

□   Work
□   Sport
□   Leisure (other than sport)
□   Traffic
□   Other (specify)

If other circumstance, please specify
_____

Duration of injury?
□   Temporary
□   Permanent

Injured body part?
□   Head
□   Arm(s)
□   Chest
□   Abdomen
□   Leg(s)
□   Spine
□   Other (specify)

If other body part, please specify
_____

Severity of injury?
□   Mild
□   Moderate
□   Severe

What injury type?
□   Head injury w/ concussion
□   Fracture
□   Contusion
□   Sprain
□   Strain
□   Other (Specify)

If other, please specify.
_____

Age at occurrence?
_____

Circumstances of injury?
□   Work
□   Sport
□   Leisure (other than sport)
□   Traffic
□   Other (specify)

If other circumstance, please specify
_____

Duration of injury?
□   Temporary
□   Permanent

Injured body part?

□   Head
□   Arm(s)
□   Chest
□   Abdomen
□   Leg(s)
□   Spine
□   Other (specify)

If other body part, please specify
_____

Severity of injury?
□   Mild
□   Moderate
□   Severe

What injury type?
□   Head injury w/ concussion
□   Fracture
□   Contusion
□   Sprain
□   Strain
□   Other (Specify)

If other, please specify.
_____

Age at occurrence?
_____

Circumstances of injury?
□   Work
□   Sport
□   Leisure (other than sport)
□   Traffic
□   Other (specify)

If other circumstance, please specify
_____

Duration of injury?
□   Temporary
□   Permanent

Injured body part?
□   Head
□   Arm(s)
□   Chest
□   Abdomen
□   Leg(s)
□   Spine
□   Other (specify)

If other body part, please specify
_____

Severity of injury?
□   Mild
□   Moderate

☐   Severe

Have you ever had any major surgery?

☐   Yes
☐   No
☐   Leave blank

Please specify what major surgery/surgeries you had.

_____

MEDICATION HISTORY
We would like to ask you some questions about medications you have been prescribed for diagnosed medical conditions or disorders that you have told us about. Please fill in each section as best you can.
Did you have all childhood vaccinations according to the vaccination program of your country?

☐   Yes
☐   No
☐   Leave blank

What vaccinations did you receive?

	Yes	No
Hepatitis B	☐	☐
Diptheria	☐	☐
Tetanus	☐	☐
Whooping cough	☐	☐
Influenza	☐	☐
Polio	☐	☐
Rotavirus	☐	☐
Pneumococcal conjugate	☐	☐
Measles, Mumps, Rubella and Varicella (chickenpox)	☐	☐
Meningococcal	☐	☐
HPV	☐	☐
Tuberculosis	☐	☐
Other	☐	☐

If other, please specify.

_____

Have you ever used medications for the following?

	Yes	No
High cholesterol	☐	☐
High blood pressure	☐	☐
Diabetes	☐	☐
Anxiety/depression	☐	☐
Anti-psychotics	☐	☐

What medication did you use for high cholesterol and what year did you start taking it?

_____

What medication did you use for diabetes and what year did you start taking it?

_____

Are you currently using any of the following medications for anxiety/depression?

☐   Diazepam e.g. Valium
☐   Duloxetine e.g. Cymbalta
☐   Venlafaxine e.g. Efexor
☐   Escitalopram e.g. Lexapro, Zoloft
☐   Sertraline e.g. Lustral, Zoloft
☐   Fluoxetine e.g. Prozac
☐   Citalopram e.g. Cipramil

☐   Sodium Valproate e.g. Epilim
☐   Lamotrigine e.g. Lamictal
☐   Lofepramine e.g. Gamanil
☐   Mirtazepine e.g. Zispin, Avanza
☐   Trazodone
☐   Paroxetine e.g. Seroxat, Aropax
☐   Lithium e.g. Priadel
☐   Dothiepin e.g. Prothiaden, Dothem
☐   Trimipramine e.g. Surmontil
☐   Buproprion e.g. Zyban
☐   Nortriptyline e.g. Allegro, Nortri
☐   Oxazepam e.g. Serepax
☐   Clomipramine e.g. Placil
☐   Desvenlafaxine e.g. Desfax, Pristiq
☐   Doxepin e.g. Deptran, Sinequan

Have you ever used any of these medications for anxiety/depression?
☐   Diazepam e.g. Valium
☐   Duloxetine e.g. Cymbalta
☐   Venlafaxine e.g. Efexor
☐   Escitalopram e.g. Lexapro, Zoloft
☐   Sertraline e.g. Lustral, Zoloft
☐   Fluoxetine e.g. Prozac
☐   Citalopram e.g. Cipramil
☐   Sodium Valproate e.g. Epilim
☐   Lamotrigine e.g. Lamictal
☐   Lofepramine e.g. Gamanil
☐   Mirtazepine e.g. Zispin, Avanza
☐   Trazodone
☐   Paroxetine e.g. Seroxat, Aropax
☐   Lithium e.g. Priadel
☐   Dothiepin e.g. Prothiaden, Dothem
☐   Trimipramine e.g. Surmontil
☐   Buproprion e.g. Zyban
☐   Nortriptyline e.g. Allegro, Nortri
☐   Oxazepam e.g. Serepax
☐   Clomipramine e.g. Placil
☐   Desvenlafaxine e.g. Desfax, Pristiq
☐   Doxepin e.g. Deptran, Sinequan

Are you currently on any of these anti-psychotic medications?
☐   Trifluoperazine e.g. Stelazine
☐   Arpiprazole e.g. Abilify
☐   Chlorpromazine e.g. Largactil
☐   Clozapine e.g. Clozaril
☐   Flupenthizol e.g. Depixol
☐   Sulpiride e.g. Dolmatil
☐   Ziprasidone e.g. Geodon, Zeldox
☐   Haloperidol e.g. Haldol
☐   Fluphenazine
☐   Risperidone
☐   Quetiapine e.g. Seroquel
☐   Olanzepine e.g. Zyprexa
☐   Thioridazine e.g. Melleril
☐   Amisulpride e.g. Amisolan, Sulprix
☐   Brexpiprazole e.g. Rexul

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

☐   Paliperidone e.g. Invega
☐   Lurasidone e.g. Latuda

Have you ever used any of these anti-psychotic medications?
☐   Trifluoperazine e.g. Stelazine
☐   Arpiprazole e.g. Abilify
☐   Chlorpromazine e.g. Largactil
☐   Clozapine e.g. Clozaril
☐   Flupenthizol e.g. Depixol
☐   Sulpiride e.g. Dolmatil
☐   Ziprasidone e.g. Geodon, Zeldox
☐   Haloperidol e.g. Haldol
☐   Fluphenazine
☐   Risperidone
☐   Quetiapine e.g. Seroquel
☐   Olanzepine e.g. Zyprexa
☐   Thioridazine e.g. Melleril
☐   Amisulpride e.g. Amisolan, Sulprix
☐   Brexpiprazole e.g. Rexul
☐   Paliperidone e.g. Invega
☐   Lurasidone e.g. Latuda

Please list any other medications you have used within the last 12 months (Name of drug, reason, age started and stopped (if applicable)).
_____

FAMILY MEDICAL HISTORY
Do you have any diseases or disorders that run in your family (e.g. cardiovascular disease, cystic fibrosis, depression)?
☐   Yes
☐   No
☐   Leave blank

Please describe the disease/disorder and which family member(s) was affected. Please be reminded that you are not obliged to answer any question that makes you feel uncomfortable within this survey. You may leave this question blank if you do not wish to answer.
_____

MENSTRUATION & PREGNANCY
This section asks specifically about your health in relation to fertility and any pregnancies you may have had. If you feel uncomfortable answering any of the questions, just a reminder you don't need to answer any questions you don't want to, just leave them blank.

Has there ever been a time when your cycle was irregular for more than 3 months?
☐   Yes
☐   No
☐   Leave blank

Around what age was your cycle irregular?
_____

Are you currently using hormonal contraceptives or have you ever done so?
☐   Yes
☐   No
☐   Leave blank

In what form have you used hormonal contraceptives?

	Yes	No
Pill	☐	☐

Subcutaneous implant	☐	☐
Injection	☐	☐
Intrauterine device	☐	☐
Other	☐	☐

If other, please specify.
_____

At what age did you start using hormonal contraceptives?
_____

For how many years did you/have you been using hormonal contraceptives?
_____

If you have ever fallen pregnant, how many times have you been pregnant?
_____

Did you breastfeed any of your children for at least 6 weeks after birth?
    ☐   Yes
    ☐   No
    ☐   Leave blank

On average, how many months did you breastfeed your child/children?
    ☐   Yes
        ☐   Less than 1 month
        ☐   1-2 months
        ☐   3-5 months
        ☐   More than 5 months
        ☐   Leave blank
    ☐   No
    ☐   Leave blank

Have you had a hysterectomy? (removal of the uterus)
    ☐   Yes
    ☐   No
    ☐   Leave blank

At what age did you have a hysterectomy?
_____

Were your ovaries removed?
    ☐   Yes both
    ☐   Yes one side
    ☐   No
    ☐   Leave blank

At what age were your ovaries removed?
_____

Have you started menopause?
    ☐   Yes
    ☐   No
    ☐   Leave blank

At what age did you start menopause?
_____

LIFESTYLE
We would like to ask you some questions about your lifestyle and behaviours during your lifetime. These questions are about your alcohol and smoking habits as well as questions about performance-enhancing supplements and recreational drugs. Scientific research to date shows us that

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

consumption of these substances can influence the onset of conditions and so we feel these questions are important to ask. These questions are not compulsory and if you feel uncomfortable answering them, please just leave them blank.

Do you drink alcohol or have you ever done so?
- ☐ I drink alcohol regularly
- ☐ I drink alcohol occasionally
- ☐ I drink alcohol rarely
- ☐ I no longer drink alcohol
- ☐ I have never drunk alcohol
- ☐ Leave blank

How often do you drink alcohol?
- ☐ Daily or almost daily
- ☐ Weekly
- ☐ Monthly
- ☐ Once / couple of times (just to try it)
- ☐ Given up drinking
- ☐ Never
- ☐ Leave blank

At what age did you start drinking alcohol?
_____

At what age did you stop drinking alcohol?
_____

How many standard glasses of alcohol do you or did you drink on average per week when you were using it the most?
1 standard drink equals:
    Beer (4.8%) 270ml
    Wine (13%): 100ml
    Spirits (40%): 30 ml

_____

Has there been a period where you abstained from drinking alcohol for at least 3 months?
- ☐ Yes
- ☐ No
- ☐ Leave blank

How many times did you stop drinking alcohol for more than 3 months?
_____

What was the longest period you stopped drinking alcohol? Please specify if months or years

_____

Have you ever used drugs (e.g.: cocaine, stimulants, inhalants, sedatives, hallucinogens, opioids, party drugs)? This EXCLUDES cigarettes and vaping.
- ☐ Yes
- ☐ No
- ☐ Leave blank

In your lifetime, have you ever used any of the following drugs, and if you did, how often did you use it when you were using it the most?

	Daily or almost daily	Weekly	Monthly	Once / couple of times (just to try it)	Never	Leave blank
Cocaine e.g. coke, crack	☐	☐	☐	☐	☐	☐
Cannabis e.g. marijuana, skunk, hash, pot, weed	☐	☐	☐	☐	☐	☐

National Endometriosis Clinical and Scientific Trials Network Registry

Amphetamine-type stimulants e.g.: speed, ice, diet pills	☐	☐	☐	☐	☐	☐
Inhalants e.g.: nitrous, glue, petrol, paint thinner	☐	☐	☐	☐	☐	☐
Sedatives or sleeping pills e.g.: valium, serepax, rohypnol	☐	☐	☐	☐	☐	☐
Hallucinogens e.g.: LSD, acid, mushrooms, PCP	☐	☐	☐	☐	☐	☐
Opioids e.g.: heroin, morphine, fentanyl, methadone, codeine	☐	☐	☐	☐	☐	☐
Ecstasy, ketamine, GHB or party drugs e.g.: E, X, MDMA, K, special K, Fantasy	☐	☐	☐	☐	☐	☐

Other drug (please specify)
_____

At what age did you first use cocaine?
_____

At what age did you first use cannabis?
_____

At what age did you first use amphetamine-type stimulants?
_____

At what age did you first use inhalants?
_____

At what age did you first use sedatives?
_____

At what age did you first use hallucinogens?
_____

At what age did you first use opioids?
_____

At what age did you first use ecstasy?
_____

What other drug have you used before, and at what age did you first use it?
_____

National Endometriosis Clinical and Scientific Trials Network Registry

Which combinations did you use the most often? (e.g.: Alcohol & Cocaine or Cannabis & LSD)

	Cocaine e.g.: coke, crack	Cannabis e.g.: marijuana, skunk, hash, pot, weed	Amphetamine-type stimulants e.g.: speed, ice, diet pills	Inhalants e.g.: nitrous, glue, petrol, paint thinner	Sedatives or sleeping pills e.g.: valium, serepax, rohypnol	Hallucinogens e.g.: LSD, acid, mushrooms, PCP	Opioids e.g.: heroin, morphine, fentanyl, methadone, codeine	Ecstasy, ketamine, GHB or party drugs e.g.: E, X, MDMA, K, special K, Fantasy	Other
Combination 1	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 2	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 3	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 4	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 5	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 6	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 7	☐	☐	☐	☐	☐	☐	☐	☐	☐
Combination 8	☐	☐	☐	☐	☐	☐	☐	☐	☐

Did you ever use performance-enhancing drugs (oral) (e.g.: creatine, steroids, amphetamines, adrenaline, oxycodone, methadone etc)

☐   Yes
☐   No
☐   Leave blank

Have you ever used Intramuscular Performance Enhancing Drugs?

☐   Yes
☐   No
☐   Leave blank

What type(s) did you use?

	Yes	No	Leave blank
Creatine	☐	☐	☐
Anabolic Androgenic Steroids	☐	☐	☐
Clenbuterol, tibolone, zeranol, zilpaterol	☐	☐	☐
Amphetamines	☐	☐	☐
Adrenaline	☐	☐	☐
Heroin, fentanyl hydromorphine/hydromorphine, methadone, morphine, oxycodone, oxymorphine/oxymorphine, pentazocine, pethidine	☐	☐	☐
Erythropoietin (EPO), dEPO, CERA or hematide	☐	☐	☐
Chorionic Gonadotrophin (CG)	☐	☐	☐
Growth Hormone (GH)	☐	☐	☐
Luteinizing Hormone (LH)	☐	☐	☐
Insulin-like Growth Factor-1 (IGF-1)	☐	☐	☐
Mechano Growth Factors (MGFs)	☐	☐	☐
Platelet-Derived Growth Factors (PDGF)	☐	☐	☐
Fibroblast Growth Factors (FGFs)	☐	☐	☐
Vascular Endothelial Growth Factor (VEGF)	☐	☐	☐
Hepatocyte Growth Factor (HGF)	☐	☐	☐

At what age did you start (and stop, if applicable) using creatine?
_____

At what age did you start (and stop, if applicable) using anabolic androgenic steroids?
_____

At what age did you start (and stop, if applicable) using Clenbuterol, tibolone, zeranol or zilpaterol?
_____

At what age did you start (and stop, if applicable) using amphetamines?
_____

At what age did you start (and stop, if applicable) using adrenaline?
_____

At what age did you start (and stop, if applicable) using heroin, fentanyl hydromorphone/hydromorphine, methadone, morphine, oxycodone, oxymorphone/oxymorphine, pentazocine or pethidine?
_____

At what age did you start (and stop, if applicable) using erythropoietin (EPO), dEPO, CERA or hematide?
_____

At what age did you start (and stop, if applicable) using Chorionic Gonadotrophin (CG)?
_____

At what age did you start (and stop, if applicable) using Growth Hormone (GH)?

_____

At what age did you start (and stop, if applicable) using Luteinizing Hormone (LH)?
_____

At what age did you start (and stop, if applicable) using Insulin-like Growth Factor-1 (IGF-1)?
_____

At what age did you start (and stop, if applicable) using Mechano Growth Factors (MGFs)?
_____

At what age did you start (and stop, if applicable) using Platelet-Derived Growth Factors (PDGF)?
_____

At what age did you start (and stop, if applicable) using Vascular Endothelial Growth Factor (VEGF)?
_____

At what age did you start (and stop, if applicable) using Hepatocyte Growth Factor (HGF)?
_____

What is your current smoking status (including vaping)?
- ☐ Current smoker (daily or almost daily)
- ☐ Occasional smoker
- ☐ Quit smoking
- ☐ Never smoked
- ☐ Leave blank

What forms of tobacco have you used?

	Yes	No
Cigarettes (including self-rolled)	☐	☐
Cigars	☐	☐
Pipe	☐	☐
E-cigarettes	☐	☐
Vaping	☐	☐
Other (e.g.: menthol cigarettes, e-cigarettes, bidis, hookahs and shisha)	☐	☐

If other, please specify.
_____

At what age did you smoke for the first time?
_____

When you were smoking the heaviest how many cigarettes would you smoke in a day?
_____

At what age did you stop smoking?
_____

Has there been a period where you abstained from smoking for more than 3 months?
- ☐ Yes
- ☐ No
- ☐ Leave blank

What was the longest period you stopped smoking for?
Please specify if months or years e.g., 3M for 3 months, 1Y for 1 year
_____

PHYSICAL ACTIVITY
Physical activity is an important part of maintaining good general health. We know that regular exercise has beneficial effects for overall wellbeing and in some cases can reduce the onset or

DATA DICTIONARY
21 JUNE 2021

development of some conditions and disorders. In this section we will ask you some questions about how much physical activity you have had during periods of your lifetime.

Please describe your overall experience with physical activity during certain periods of your life below

	Light e.g.: slow walking, gentle swim, childcare	Moderate e.g.: football, tennis, jogging, golf, gardening, house cleaning, brisk walk	Strenuous e.g.: running, strength training, HIIT, road cycling, track and field, ball sports	No answer
Age 13-20 years old	☐	☐	☐	☐
Age 21-45 years old	☐	☐	☐	☐
Last 10 years	☐	☐	☐	☐

Have you ever played on a grass sports field for more than 10 hours/week for more than 2 consecutive years? (approximately)

☐ Yes
☐ No
☐ Leave blank

DIET
A balanced diet provides your body with the vital nutrients it needs to build and maintain healthy cells, tissues and organs, which are crucial for maintaining good general health. This section asks you to provide information on your current diet. Think about your diet over the last month, including supplements. (We have displayed the Australian recommended diet pyramid to help you remember. Just answer as best you can)

Do you adhere to any specific dietary practices?

☐ Organic
☐ Vegetarian
☐ Vegan
☐ Lactose Free
☐ Gluten Free
☐ I don't have any specific dietary practice
☐ Other

If any other dietary practices, please specify.
_____

Using the advised food intake as seen in the food pyramid below, how many servings of each food group would you have on an average day?

National Endometriosis Clinical and Scientific Trials Network Registry   DATA DICTIONARY
                                                                                        21 JUNE 2021
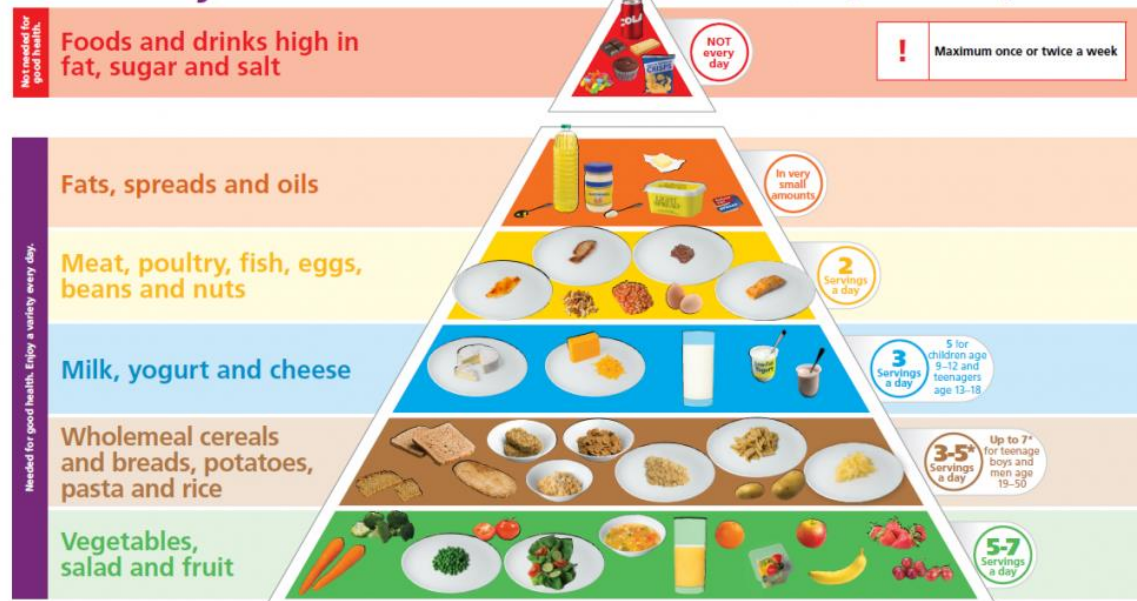
Average servings per day (0-10)

	0	1	2	3	4	5	6	7	8	9	10
Foods and drinks high in fat, sugar and salt (Recommended max. once/twice a week)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Fats, spreads and oils (Recommended daily in very small amounts)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Meat, poultry, fish, eggs, beans and nuts (Recommended 2 servings a day)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Milk, yogurt and cheese (Recommended 3 servings a day)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Wholemeal cereals and breads, potatoes, pasta and rice (Recommended 3-5 servings a day, up to 7 for men aged 12-50)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
Vegetables, salad and fruit (Recommended 5-7 servings a day)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

Have you ever taken any dietary supplements (vitamins, minerals, fish oil etc.)?
- ☐ Yes
- ☐ No
- ☐ Leave blank

Which types of dietary supplements did you take?
- ☐ Fish oil
- ☐ Multivitamins
- ☐ Vitamin D
- ☐ CoQ10
- ☐ Vitamin B
- ☐ Calcium
- ☐ Magnesium
- ☐ Probiotics
- ☐ Vitamin C
- ☐ Glucosamine
- ☐ Other

If other, please specify

_____

How often would you take these dietary supplements?
- ☐ Multiple times a day
- ☐ Once a day
- ☐ Multiple times a week
- ☐ Once a week or less
- ☐ Leave blank

Do you currently take any dietary supplements (vitamins, minerals, fish oil etc.)?
- ☐ Yes
- ☐ No
- ☐ Leave blank

Which types of dietary supplements do you currently take?
- ☐ Fish oil
- ☐ Multivitamins
- ☐ Vitamin D
- ☐ CoQ10
- ☐ Vitamin B
- ☐ Calcium
- ☐ Magnesium
- ☐ Probiotics
- ☐ Vitamin C
- ☐ Glucosamine
- ☐ Other

If other, please specify

_____

How often do you take these dietary supplements?
- ☐ Multiple times a day
- ☐ Once a day
- ☐ Multiple times a week
- ☐ Once a week or less
- ☐ Leave blank

How many calories does your diet usually contain? Within a healthy, balanced diet, a man needs around 2,500 calories a day to maintain his weight. For a woman, that figure is around 2,000 calories a day.
- ☐ Less than the advised amount of calories
- ☐ Around the advised amount of calories
- ☐ More than the advised amount of calories
- ☐ Unsure
- ☐ Leave blank

On average men need 300g of carbohydrates per day while women need around 230g. How much carbohydrate does your daily diet usually contain?
Examples of carbohydrate amounts in specific foods: 1 600+ grams cup of pasta/rice (45g), 1 medium potato (30g), 1 cup of corn or peas (30g), 1 cup of veggies (15g), small fruit (15g), 1 cup of milk/yogurt (12g), 1 slice of bread (15g)
- ☐ Less than 150 grams
- ☐ 150-249 grams
- ☐ 250-399 grams
- ☐ 400-599 grams

☐   Unsure
☐   Leave blank

Have you changed your diet within the last 12 months?
☐   Yes
☐   No
☐   Leave blank

In which way did you change your diet?
☐   More calories
☐   Less calories
☐   More supplements
☐   Less supplements
☐   More carbohydrates
☐   Less carbohydrates
☐   Other

If other, please specify.
_____

How often do you eat fish or shellfish?
☐   Daily
☐   4-6 times a week
☐   2-3 times a week
☐   Once a week
☐   2-3 times a month
☐   Once a month or less
☐   Never
☐   Leave blank

Do you have a drink containing caffeine daily or almost daily (e.g. tea, coffee, energy drinks)?
☐   Yes
☐   No
☐   Leave blank

How many drinks containing caffeine do you have on a typical day?
☐   1-2 drinks
☐   3-4 drinks
☐   5-6 drinks
☐   7-9 drinks
☐   More than 10 drinks
☐   Leave blank

Have you ever used or been excessively exposed to one of the following hazards:

	Yes	No	Uncertain
Animal and plant toxins e.g.: venom or poison, exposure through bites, stings etc.	☐	☐	☐
Drugs and pharmaceuticals e.g.: used in treatment of livestock	☐	☐	☐
Endocrine disruptors e.g.: natural hormones, natural chemicals, synthetically produced pharmaceuticals, man-made chemicals	☐	☐	☐
Neurotoxins e.g.: Botulinum toxin, Polybrominated Diphenyl Ethers (PBDEs), Isobutyronitrile, Hexachlorophene, Metaldehyde, Propoxur, Hexane, Styrene, Bifenthrin	☐	☐	☐
Pesticides e.g.: fungicides, insecticides, herbicides, rodenticides, antimicrobials	☐	☐	☐
Persistent Environmental contaminants e.g.: Dioxins (TCDD & Furans, Benzo(a)pyrene, Octachlorostyrene, Pentabromo diphenyl	☐	☐	☐

ether (PBDEs), Polybrominated hydrocarbons, Polychlorinated biphenyls (PCBs), Polycyclic aromatic hydrocarbons (PAHs, Tin) Solvents e.g.: Acetone, Ethyl Alcohol, Benzene, Carbon Disulphide, Chloroform, 1,3-Dichloropropane, Ethyl Acetate, Methyl Cellosolve, Nitrobenzene, 2-Nitropropane, Pyridine, Trichloroethylene, Vinyl Cloride, Xylene	☐	☐	☐
Acids e.g.: Sulphuric, Nitric, Hydrochloric, Citric, Acetic	☐	☐	☐
Heavy metals e.g.: Arsenic, Cadmium, Lead, Magnesium, Mercury, Plutonium, Thallium, Uranium	☐	☐	☐
Electricity / Electromagnetic Fields	☐	☐	☐
Radiation e.g.: UV, X-ray, Alpha, Beta, Gamma (Nuclear), Neutron, Microwave	☐	☐	☐

What type of animal or plant toxin?
_____

How often were you exposed to this type of animal or plant toxin?
_____

How long were you exposed to this type of animal or plant toxin? (in hours/day/weeks/months/years)
_____

What type of drug or pharmaceutical?
_____

How often were you exposed to this type of drug or pharmaceutical?
_____

How long were you exposed to this type of drug or pharmaceutical? (in hours/day/weeks/months/years)
_____

What type of endocrine disruptors?
_____

How often were you exposed to this type of endocrine disruptor?
_____

How long were you exposed to this type of endocrine disruptor? (in hours/day/weeks/months/years)
_____

What type of neurotoxins?
_____

How often were you exposed to this type of neurotoxin?
_____

How long were you exposed to this type of neurotoxin? (in hours/day/weeks/months/years)
_____

What type of pesticide?
_____

How often were you exposed to this pesticide?
_____

How long were you exposed to this pesticide? (in hours/day/weeks/months/years)
_____

What type of persistent environmental contaminants?
_____

How often were you been exposed to persistent environmental contaminants?
_____

How long were you been exposed to persistent environmental contaminants? (in hours/day/weeks/months/years)
_____

What type of solvents?
_____

How often were you exposed to solvents?
_____

How long were you exposed to solvents? (in hours/day/weeks/months/years)
_____

What type of acids?
_____

How often were you exposed to acids?
_____

How long were you exposed to acids? (in hours/day/weeks/months/years)
_____

What type of heavy metals?
_____

How often were you exposed to heavy metals?
_____

How long were you exposed to heavy metals? (in hours/day/weeks/months/years)
_____

What type of electricity or electromagnetic fields?
_____

How often were you exposed to electricity or electromagnetic fields?
_____

How long were you exposed to electricity or electromagnetic fields? (in hours/day/weeks/months/years)
_____

What type of radiation?
_____

How often were you exposed to radiation?
_____

How long were you exposed to radiation (in hours/day/weeks/months/years)?
_____

Did you ever endure severe electric shock that required treatment?
- ☐ Yes
- ☐ No
- ☐ Leave blank

On average, how many hours do you spend outside per week?
- ☐ More than 25 hours

☐   21-25 hours
☐   16-20 hours
☐   11-15 hours
☐   5-10 hours
☐   Less than 5 hours
☐   Leave blank

In which situation(s) would you put on sunscreen on a single day? (Multiple answers possible)
☐   Always
☐   Full day in swimwear outside
☐   2 hours in swimwear outside
☐   Full day of hiking
☐   2 hours cycling tour
☐   30 minute walk
☐   Never

Have you ever used tanning agents?
☐   Yes
☐   No
☐   Leave blank

How often do you use tanning agents (e.g. once a week)?
_____

Have you ever been, or are you, exposed to diesel fuel or fumes on a regular basis (i.e. at least once a week for 6 months or more), in any of the ways listed below? (multiple answers possible)
☐   Living near a major road or highway
☐   Living in an inner-city
☐   Commuting to and from work for a daily total of 2 hours or more
☐   Driving a diesel-fuelled passenger vehicle
☐   Driving a diesel fuelled light commercial vehicle
☐   Driving a bus
☐   Driving a truck
☐   Driving a land, sea or air military vehicle
☐   Using diesel-fuelled farm equipment
☐   Working on a diesel-fuelled boat or ship
☐   Operating heavy machinery
☐   Working on or at a railroad, mine, toll-booth, dock or garage/petrol station
☐   Traveling on a school bus as a child
☐   Cooking on a diesel-fuelled stove
☐   Using a diesel-fuelled heater
☐   Other

If other, please specify.
_____

YOUR PERSONAL JOURNEY
We have created this section for you to fill in with any additional information that you think may be of relevance.
It could be information about environmental exposures you have experienced that we have not asked about in this questionnaire, or information about events in your life that may have impacted on you. Examples include your responses to certain medications, any particular allergies you may have or any extensive travelling you have undertaken. You can also use this section to expand on any of your previous answers.

All information is important to us, so please fill this in.
_____

National Endometriosis Clinical and Scientific Trials Network Registry

DATA DICTIONARY
21 JUNE 2021

Thank you for completing the questionnaire. Are you still willing to provide a saliva sample?

☐ Yes
☐ No

We would like to send you a saliva sample kit. Please enter the address you would like us to send the kit to.

_____