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Emma Steele

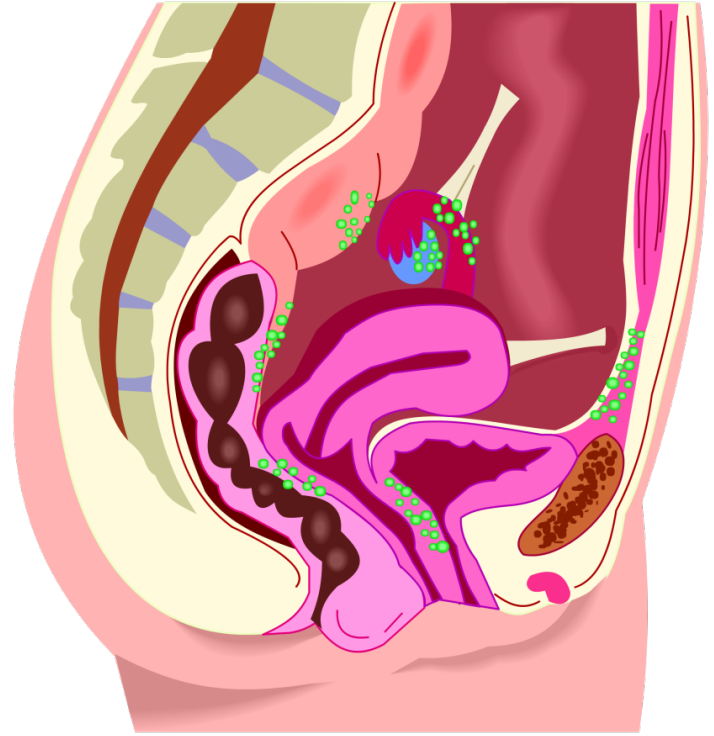
EndoNeeds

Exploring the physical, psychological and social needs of women with endometriosis



Endometriosis

- Chronic gynaecological condition
- 5-10% population prevalence¹






Symptoms:

Pain

Infertility



Diagnostic
delay

Up to 10 years to diagnosis

Diagnostic
delay

Symptoms:

Pain

Infertility

Sexuality

Diagnostic
delay

Relationships

Symptoms:

Sexuality

Pain

Infertility

Diagnostic
delay

Relationships

Normalisation

Symptoms:

Sexuality

Pain

Infertility

Diagnostic
delay

Relationships

Normalisation

Symptoms:

Sexuality

Pain

**Social
isolation**

Infertility

Diagnostic
delay

Relationships

Normalisation

Symptoms:

Sexuality

Pain

**Treatment &
recurrence**

Infertility

Social
isolation

Mental
health

Diagnostic
delay

Relationships

risk of depression

HR=1.44 (95% CI 1.25-1.65)

No

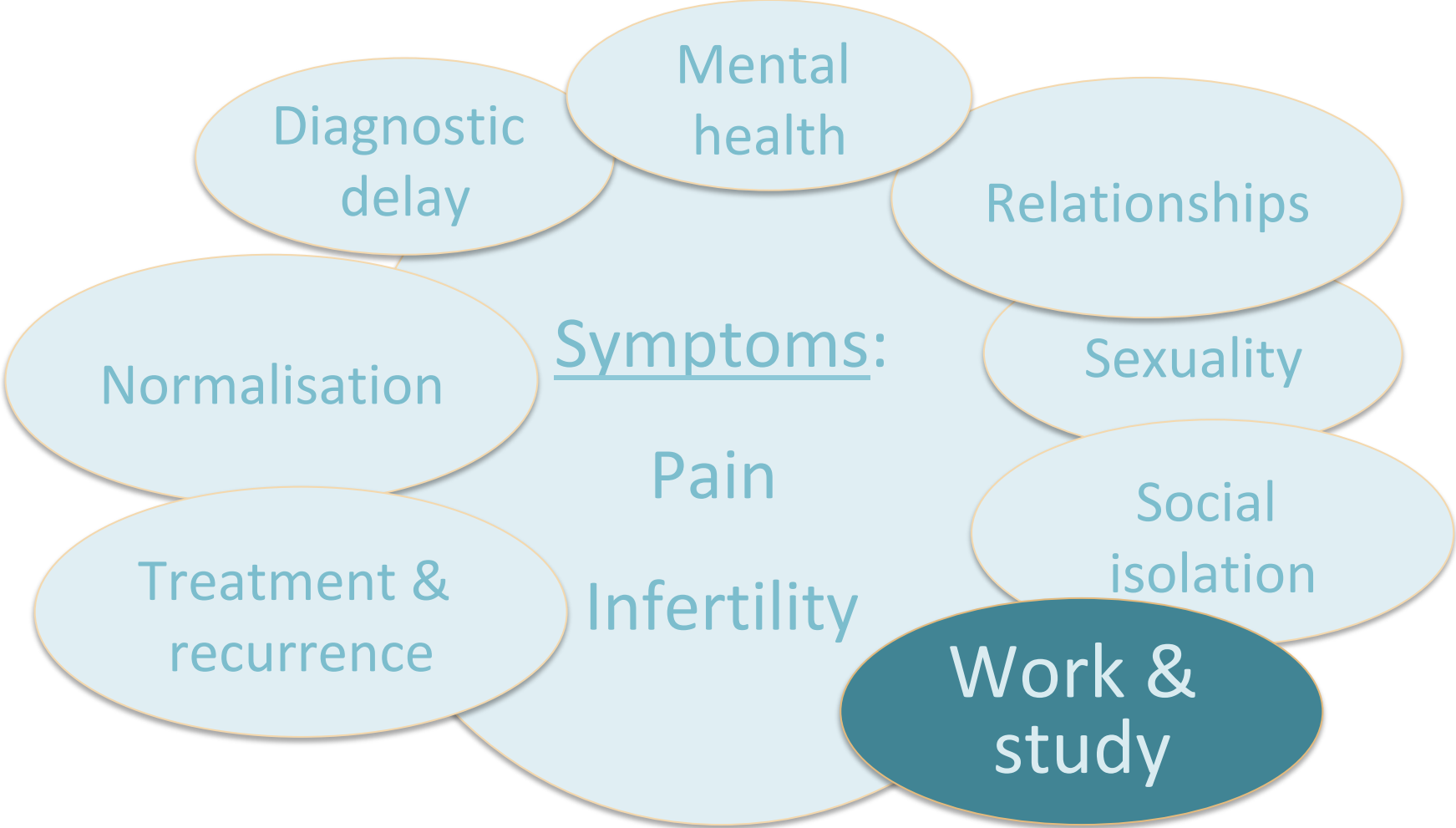
ty

Tr

on

recurrence

inefficiency



Diagnostic delay

Mental health

Relationships

Symptoms:

Sexuality

Normalisation

Pain

Social isolation

Treatment & recurrence

Infertility

Work & study

Diagnostic
delay

Mental
health

Relationships

Norm

Annual cost of €9579 per
woman

Trea
recurrence

Cost

Work &
study

Patient Reported Outcome:

“a report on the status of a patient’s health condition that comes directly from the patient, without the interpretation of the patient’s response by a clinician or anyone else.”¹

Unmet Need:

“the requirement of some action or resource that is necessary, desirable or useful to obtain optimal wellbeing.”²

1. FDA. Guidance for industry: patient-reported outcome measures: use in medical product development to support labelling claims. 2009; 74(235):65132-3

2. Sanson-Fisher R et al. The unmet supportive care needs of patients with cancer. Cancer. 2008;88(1):226-37

Systematic review

- **PROMs & UMN surveys in endometriosis**
- **Development of UMN surveys in other conditions**
- **Identification of needs from qualitative evidence**

Systematic review

Databases: Medline, PubMed, PsychINFO, CINAHL

Search term examples:

- Endometriosis
- Unmet needs, needs assessment
- Patient-reported outcome measure, quality of life
- Qualitative, focus groups, interviews

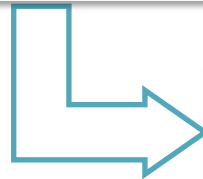
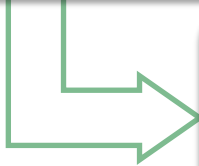
Systematic review

2148 records
identified

936 after de-
duplication

254 records
screened

113 records
included

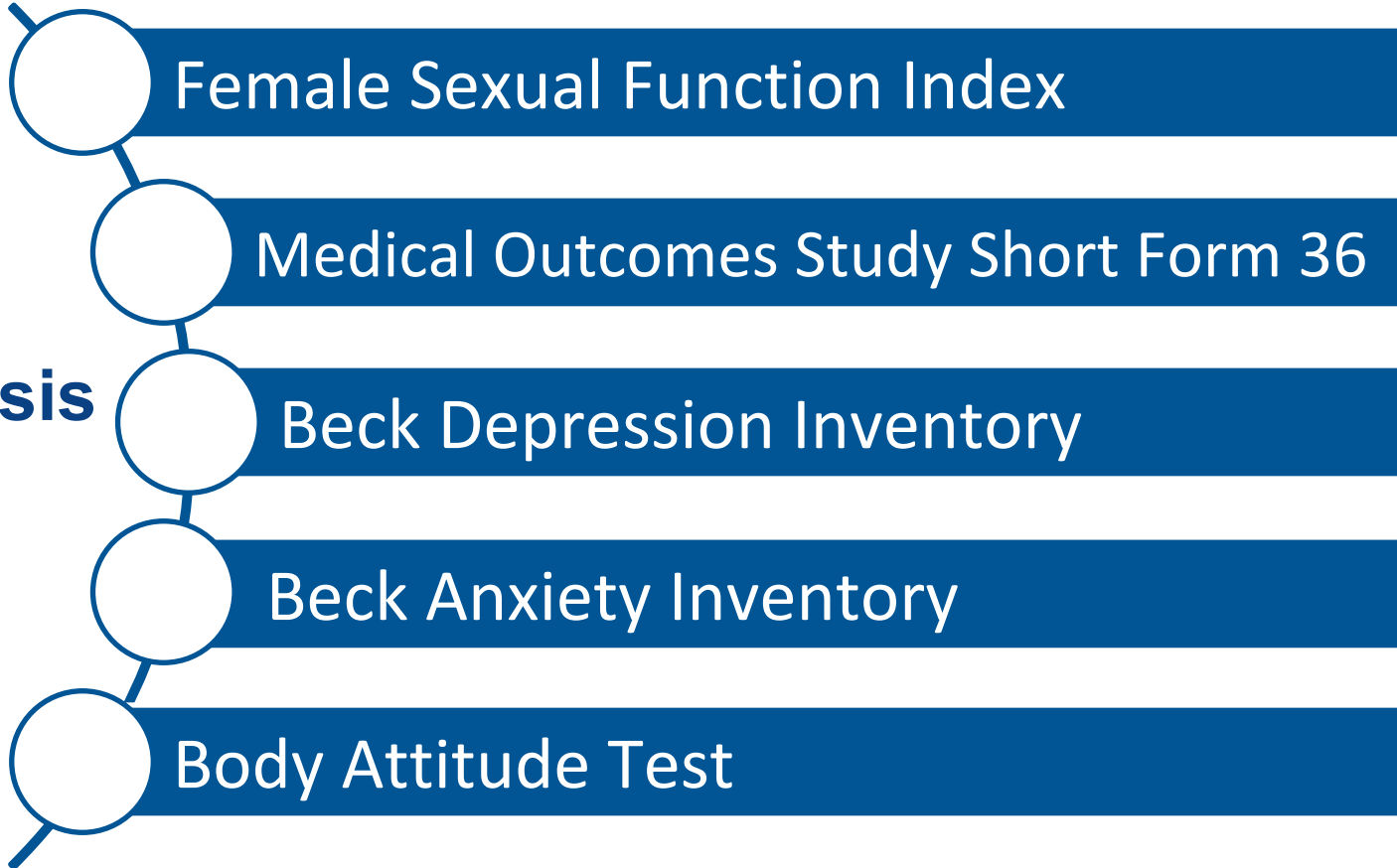


Systematic review:

- **PROMs in endometriosis(n=65)**

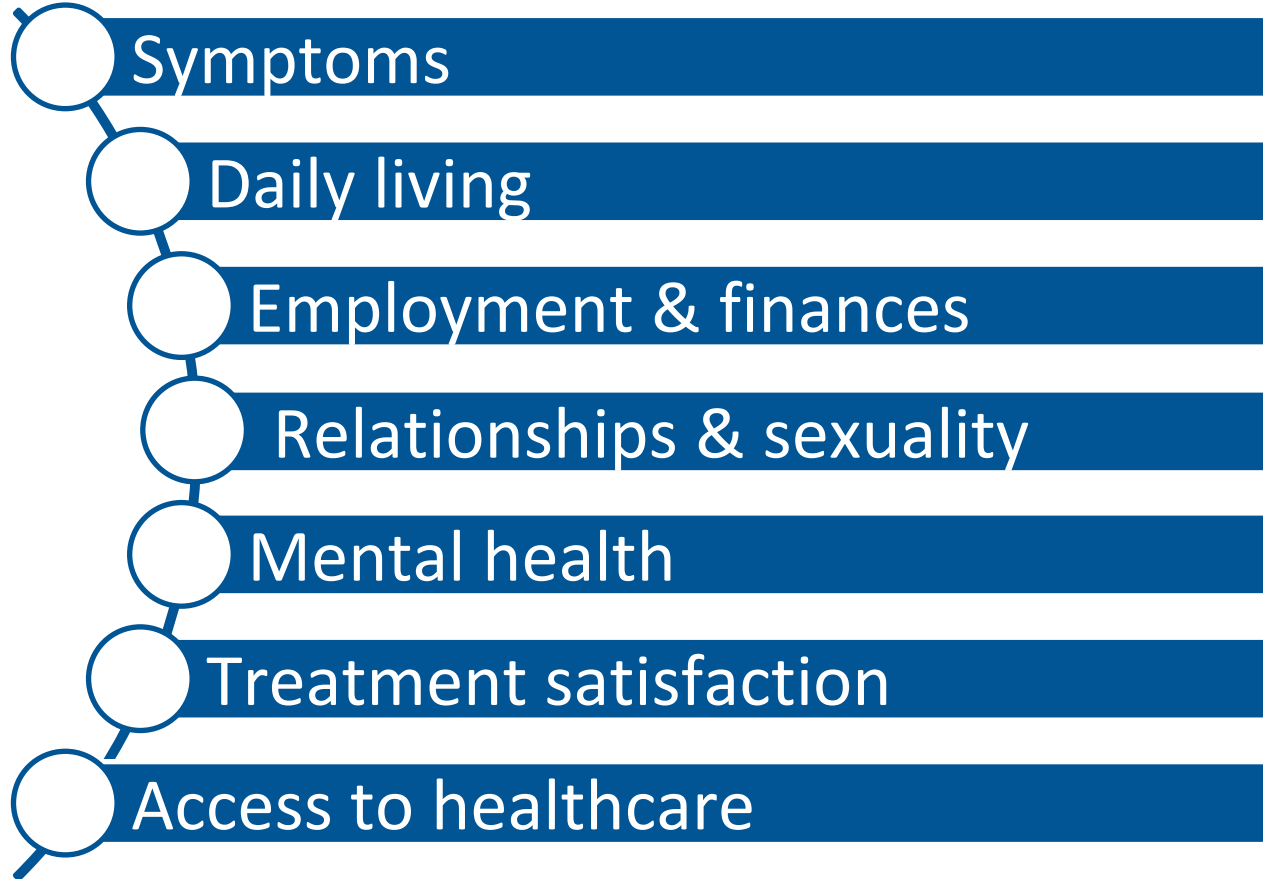
Systematic review:

- **Generic PROMs in endometriosis (n=55)**



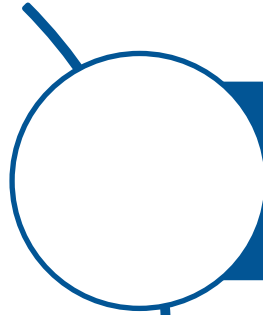
Systematic review:

- **Disease-specific PROMs in endometriosis (n=10)**

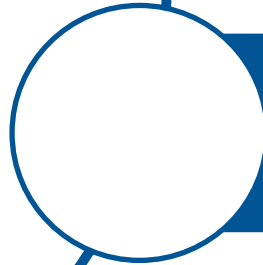


Systematic review:

- **Disease-specific PROMs that address needs (n=2)**



Unnamed Survey, Cox et al¹



Dutch Endometriosis Society Survey²

1. Cox H, Ski CF, Wood R, Sheahan M. Intl journal of consumer studies, 2003;27(3)
2. Roos-Eysbouts Y, De Bie-Rocks B, Van Dijk J, Nap AW. Gynecol Obstet Invest. 2015;79(4)

Systematic review

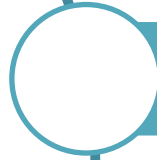
- UMN's in other conditions(n=14)

Systematic review

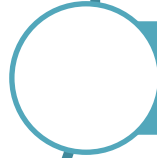
- UMN in other conditions (n=14)



Consumers



Clinicians



Qualitative research



Psychometric validation

Systematic review

- Qualitative evidence in endometriosis(n=31)

Systematic review

- Qualitative evidence in endometriosis(n=31)

He actually said to me “I don’t know this condition at all”.

Systematic review

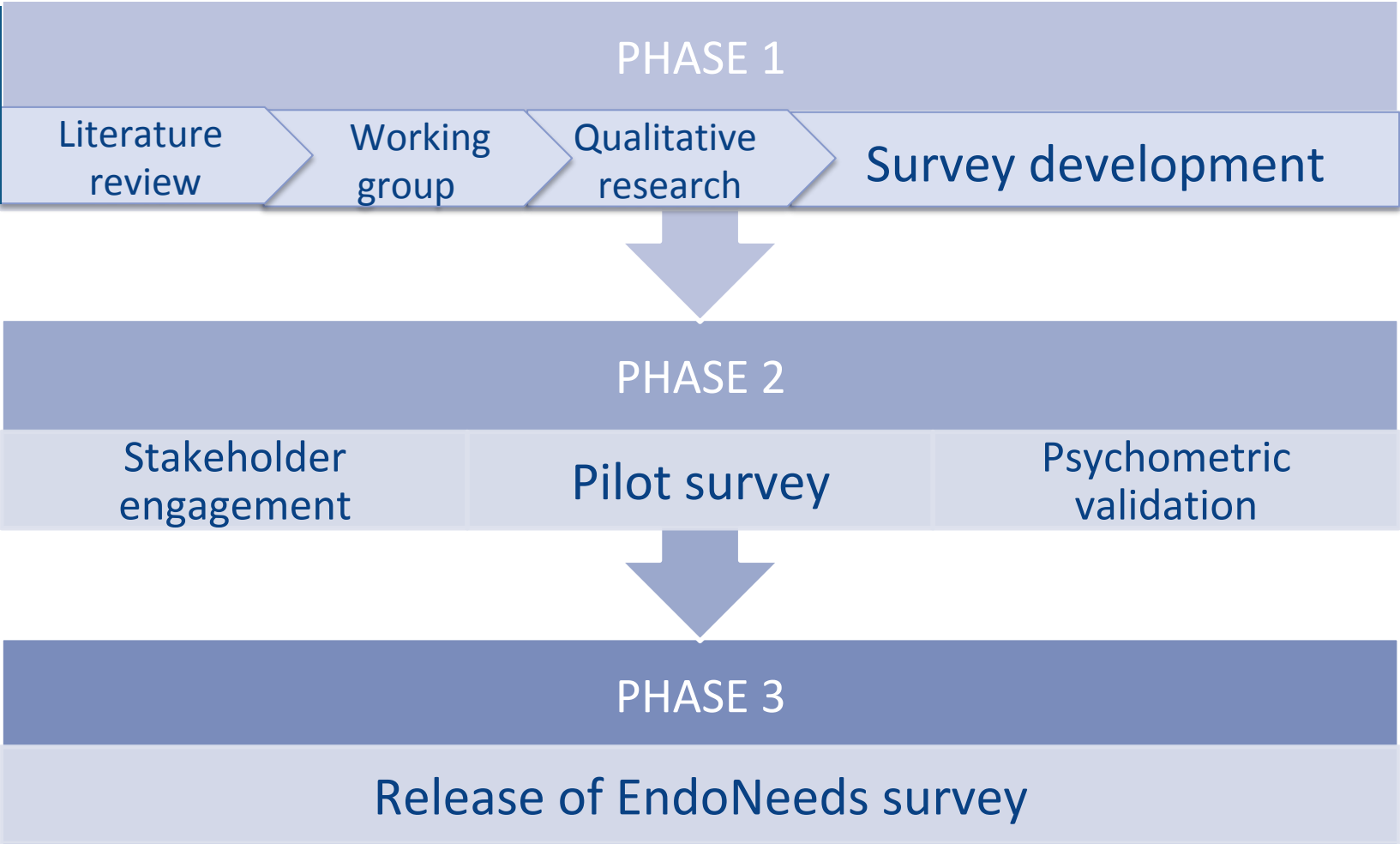
“The first one was too quick to say it was women’s problems, and the second . . . didn’t know what she was looking for and when she suggested a strained muscle I nearly fell off the chair laughing.”

Young K, Fisher J, Kirkman M. Endometriosis and fertility: women's accounts of healthcare. *Human Reproduction*. 2016;31(3):554-62.

Systematic review

“To be honest I don’t think he knew very much, but he was very nice and he did go and read all about it.”

Young K, Fisher J, Kirkman M. Endometriosis and fertility: women's accounts of healthcare. *Human Reproduction*. 2016;31(3):554-62.



Research Question:

“What are the physical, psychological and social needs of women with endometriosis?”



Research Aim:

To explore the needs of women with endometriosis through focus group discussion

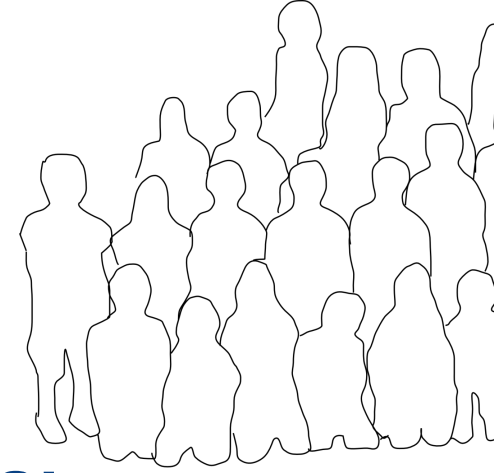
Sampling

Experience:

- Variable pain and infertility symptoms
- New diagnosis
- Varying parity
- Varying treatments
- Range of ages

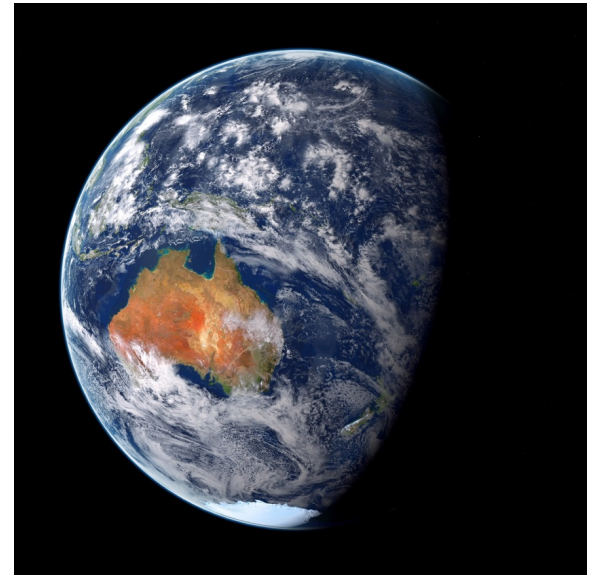
Eligibility criteria:

- 18 or over
- Surgical diagnosis of endometriosis
- English-speaking
- Able to attend focus group at RWH



Research implications

- First unmet needs survey for this population
- Potential uses of instrument:
 - Individual level
 - Health service level
 - Health system level



A graphic consisting of several yellow circles of varying sizes, arranged in a curved, descending pattern from left to right.

ENDOMETRIOSIS
AUSTRALIA

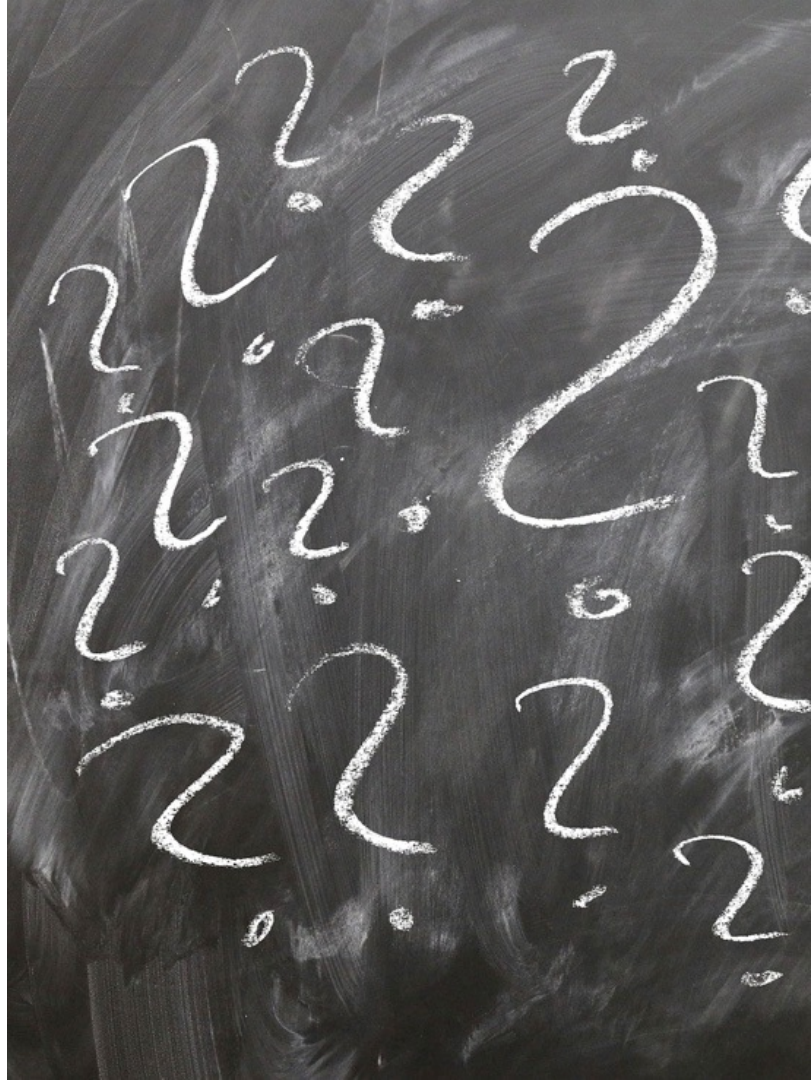
- Dr Jane Girling
- Dr Michelle Peate
- Dr Martin Healey
- Dr Uri Dior
- Dr Charlotte Reddington
- Dr Angela Chia
- Dr Karin Jones
- Dr Vanessa Ross
- Dr John McBain
- Dr Christina Bryant
- Lora Adamson
- Anne-Florence Plante
- Consumer members

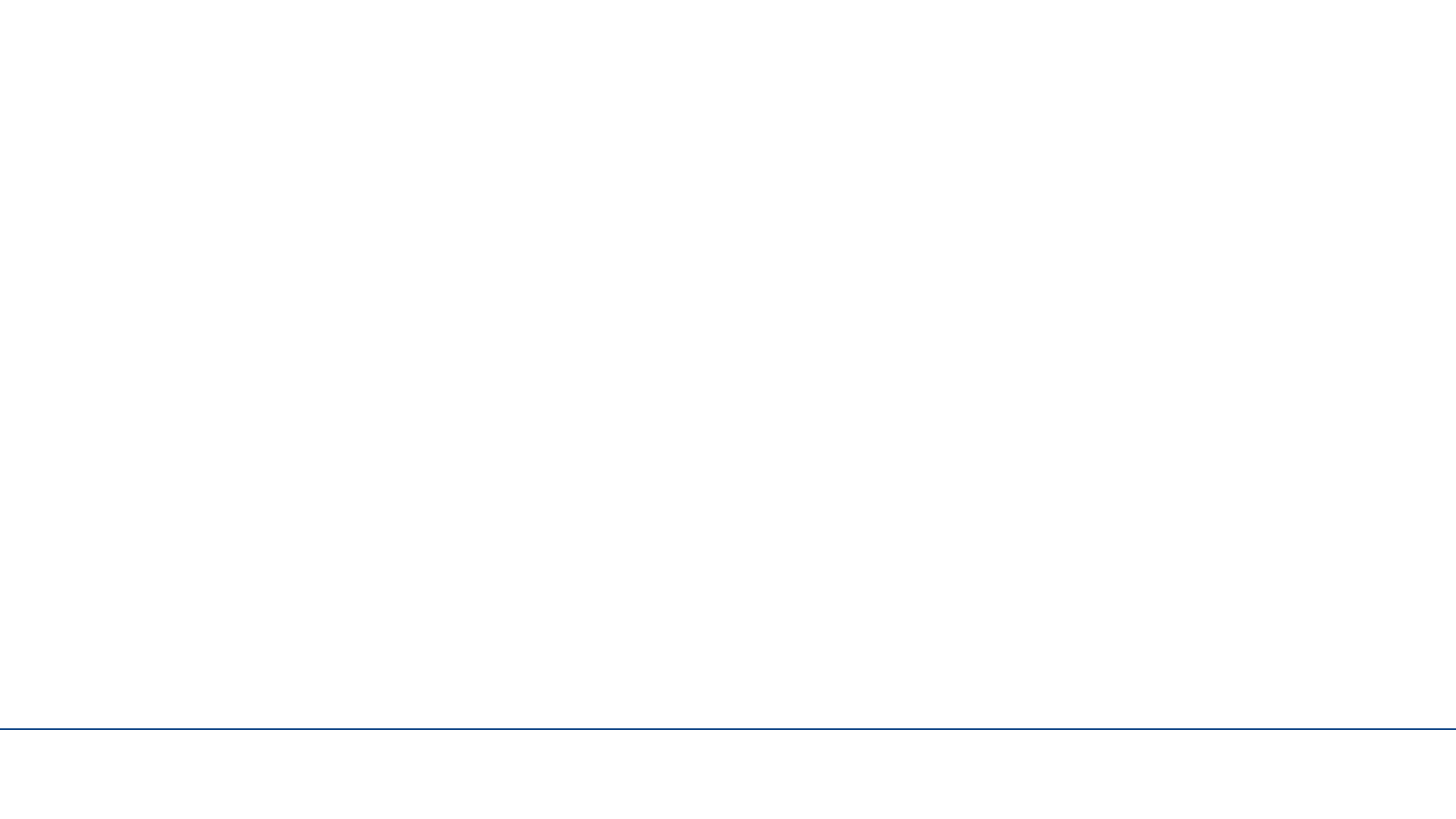


Questions?

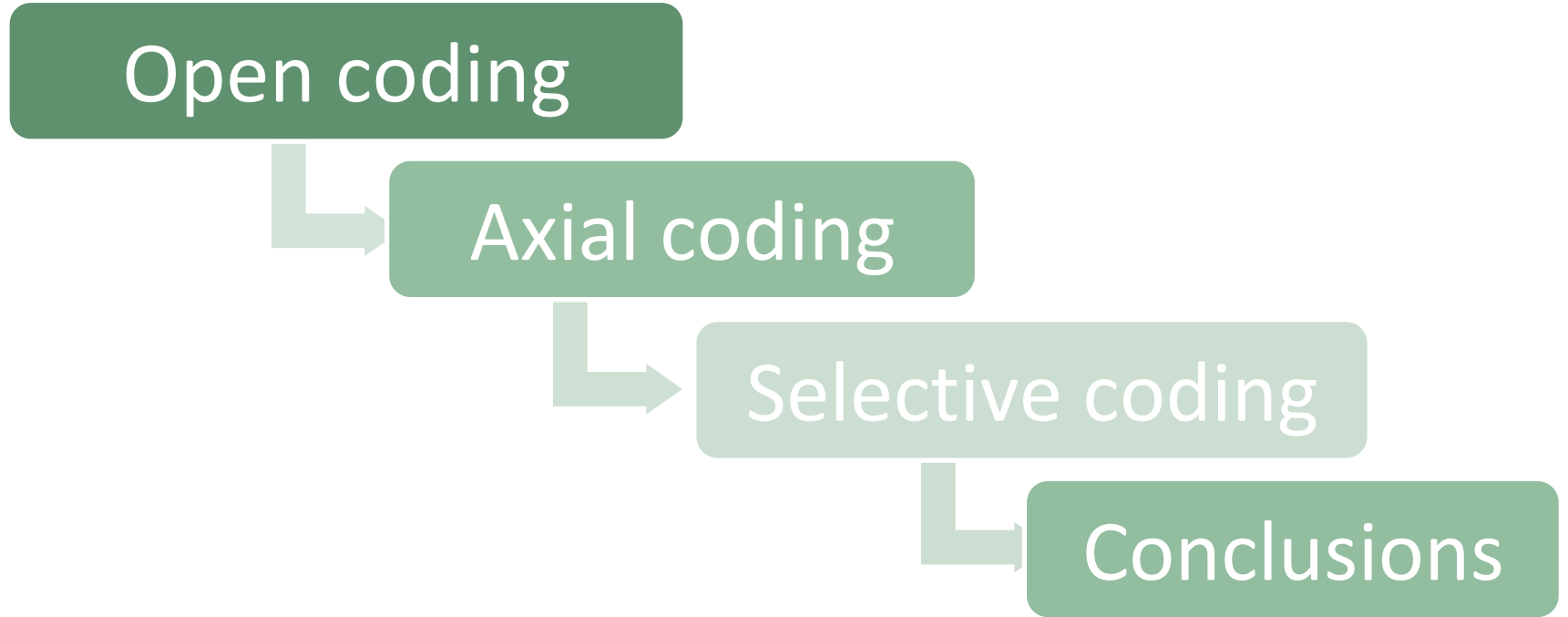


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Data analysis



Search Terms

Concept 1 - PROMs in endometriosis:

exp Endometriosis AND ("health-related quality of life"
or HR-QOL or "quality of life" or "patient reported outcome*"
or "patient satisfaction" or "screening tool*" or "psychometric
measure"
or wellbeing or psychosocial or survey* or questionnaire* or
measure*
or instrument* or experience)

Search Terms

Concept 2 – UMN's in endometriosis:

exp Endometriosis AND ("unmet need*" or "needs assessment tool*")

or "needs assessment*" or "health care need*" or "supportive care need*"

or survey* or questionnaire* or measure*)

Search Terms

Concept 3 – UMN's in other health conditions:

(cancer or "heart failure" or stroke or "chronic health" or "mental illness") AND ("unmet need*" or "needs assessment tool*")

or "needs assessment*" or "health care need*" or "supportive care need*"

or survey* or questionnaire* or measure*)

Search Terms

Concept 4 – Qualitative research in endometriosis:

endometriosis AND (experience or satisfaction or perception)
AND (qualitative or interview or "focus group*")
