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Endometriosis Toolkit for Clinicians

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DNP Project Title: **Challenges in Endometriosis Diagnosis: Development of a New Toolkit for Clinicians Caring for Women**

March 21st, 2024

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Biography

Rachel H., MSN, BSN, RN, specializes in medical and surgical care and is pursuing a DNP-FNP degree at the University of San Francisco. Her research focuses on endometriosis and women's health, advocating for holistic, evidence-based care with an emphasis on disease prevention, early screening, and effective treatment.

Disclaimer

The research presented in this academic setting is conducted independently, and there are no financial or other obligations to external parties related to the information shared.

Pre-test Survey QR Code

Pre-test Survey URL Address:

https://usfca.qualtrics.com/jfe/form/SV_cYexxV0ftymzTYG

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Purpose of this Presentation

To introduce a toolkit for early identification and management of endometriosis in women, designed for practical use by nurse practitioners in clinical practice.

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Introducing a toolkit for early identification and management of endometriosis in women, designed for practical use by nurse practitioners in clinical practice.

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Objectives for this Presentation

1) Present the endometriosis toolkit for early detection and management in women.
2) Demonstrate the toolkit's practical application for nurse practitioners in clinical settings.
3) Stress the significance of timely endometriosis recognition, diagnosis, and treatment for better patient outcomes.
4) Offer clear guidelines and strategies for integrating the toolkit into daily practice to improve patient care.

Overview of Endometriosis

What is Endometriosis?

- A disorder when endometrial tissue grows outside the uterus and other body organs
- a chronic systemic inflammatory response

How is it diagnosed?

- Gold Standard is laparoscopic surgery with biopsy and histology confirmation
- Clinical Diagnosis (History., Assessment, imaging)

Source:(WHO, 2020).

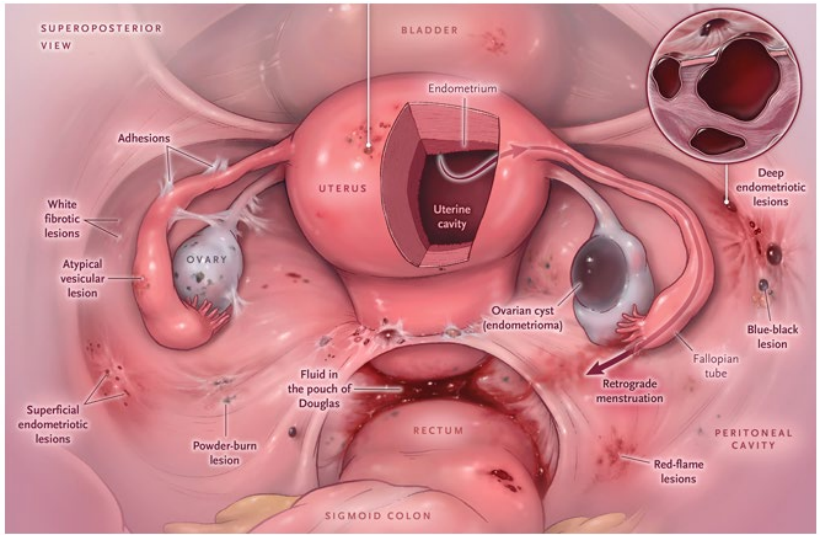


Figure 1. *Endometriosis (The New England Journal of Medicine, 2021)*

How is it treated?

- Nonsteroidal anti-inflammatory drugs
- Hormone therapy
- Laparoscopy, Surgery
- Adjunct therapies like acupuncture

Is there a cure?

- No, it is a chronic condition.

Importance of Early Diagnosis

Figure 3. Significance of Exploring if Screening Tools can Decrease Diagnostic Delays

Prevalence

Affects:

- 190 million (10%) women globally (WHO, 2023)
- 6.5 million (11%) women in the United States (OASH, 2021.)
- American women between 15-14 (OASH, 2021.)
- Common in women in their 30s and 40s (OASH, 2021.)

Cost of Endometriosis

- National cost about $78.05 billion in the United States each year
- Women pay about $12, 118 per year in The USA (Surrey et al., 2016)

Importance of Early Diagnosis

Figure 3. Significance of Exploring if Screening Tools can Decrease Diagnostic Delays

Problem

- Knowledge gaps (misdiagnosis)
- Stigma of women
- Screening challenges
- Treatment gaps
- Limited access to surgeons and specialists
- Diagnostic delays of up to 13 years

(WHO, 2023)

Possible Solutions

- Increase knowledge among patient and clinicians
- Increase access to screening, diagnostic, and treatment tools
- Increase multidisciplinary team involvement

(Agarwal et al., 2019)

- Increase Funding and Research

(WHO, 2023)

Case Study

Case Study – Jane Doe

Patient: Jane Doe
Age: 20
Gender: Female
Chief Complaint: Worsening dysmenorrhea

HPI:
- Painful periods since age 12
- Chronic sharp cramping pain in lower abdomen
- Pain with sexual activities on occasion and with bowel movement
- NSAIDs and heating pads provide
- minimal relief

PMH: No significant medical history
FH: Mother with hysterectomy

SH: Non-smoker, no alcohol or drug use
Sexual Hx: Monogamous male partner

ROS:
- Gynecological: Dysmenorrhea, menorrhagia
- GI: Bloating, constipation, pain with bowel movement hemorrhoids

PE:
- General: Discomfort and fatigue
- Abdomen: Tender in lower quadrants
- Pelvic Exam: nodule in cul de sac

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

What is you next step?

The Endometriosis Toolkit Can Help!

Formulation of an Endometriosis Toolkit

Guidelines USA	About Endo (Incidence/ Prevalence/ Etiology/ epidemiology)	Endo In adolescent	Endo and Menopause	Burden of Endo	Sequalae/ Quality of Life/ Pain/ Cancer	Delays	Risk Factors	Endo Subtypes/ Classification/ Staging/ Extrapelvic Endo	Screening Tools	Symptoms / Signs (Clinical presentation)	Diagnosis (Clinical/ Surgical)	Treatment	Tx after failed conventional care or surgery/ Recurrence	Alternative and complimentary treatment	Infertility/ Pregnancy	Multi-disciplinary support/ Follow-up	Patient Education/ support	Referral
NIH	X						X			X	X	X			X			
ACOG, 2018 (Adolescents)	X	X			X		X			X	X	X	X	X			X	
ACOG Management of Endo	X						X	X		X	X	X	X		X			
Davila et al., 2023 (Medscape)	X	X		X			X	X		X	X	X			X	X	X	X
Edi & Cheng																		
Keeler et al.	X			X		X				X	X	X		X	X			
Schrager et al.	X						X			X	X	X			X			
Guidelines International																		
ESHRE	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	
NICE, 2023								X		X	X	X		X	X	X	X	X
Allaire et al., 2023	X			X			X	X		X	X	X			X			X
Endo Toolkit for Clinicians	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**	**X**

Toolkit Content

- Endometriosis Information
- Screening Tools
- Diagnostic Tools
- Treatment Tools
- Complications
- Referrals
- Patient Education

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

About Endometriosis

Endometriosis Information

Incidence/ Prevalence

- *This chronic disease affects approximately 190 million (10%) women of childbearing age globally (WHO, 2023)*
- *Endometriosis may affect more than 11% of reproductive-aged women, in the United States of America between the ages of 15 and 44, especially in women in their 30s and 40s (OASH, 2021).*
- *Prevalence Rate of 20-50% in infertile women (ACOG, 2018).*
- *Prevalence rate can reach up to 71-87% in women experiencing chronic pelvic pain (ACOG, 2018).*
- *Prevalence rate of 45% in adolescent females with chronic pelvic pain (ACOG, 2018).*

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Screening Questionnaire

Screening Tools

Screening for Endometriosis Symptoms

Please complete the questionnaire below to learn more about common endometriosis symptoms. You can also call us at XXX-XXX-XXX if you prefer to discuss your symptoms over the phone.

1. *During your period, do you experience pelvic, abdominal, or lower back pain that limits your activities or requires medication? a. Always b. Sometimes c. Never*
2. *In between periods, do you experience pelvic, abdominal, or lower back pain that limits your activities or requires medication? a. Always b. Sometimes c. Never*
3. *Is sexual intercourse painful? a. Always b. Sometimes c. Never*
4. *Does pain ever cause you to avoid intercourse? a. Always b. Sometimes c. Never*
5. *Are bowel movements painful before or during your period? a. Always b. Sometimes c. Never*

*If you answered **always** or **sometimes** to any of the above questions, you are experiencing some of the common symptoms of endometriosis. Please provide your contact information below if you would like a member of our team to contact you about scheduling an appointment.*

Source: NYU Langone Health, n.d.

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Toolkit Content

Diagnostic Tools

FIGURE 1
Algorithm for a clinical diagnosis of endometriosis

Consistent With Endometriosis

① Evaluate Presence of Symptoms

- Persistent and/or worsening cyclic or constant pelvic pain
- Dysmenorrhea
- Deep dyspareunia
- Cyclic dyschezia
- Cyclic dysuria
- Cyclic catamenial symptoms located in other systems (eg, lung, skin)

- Severe pain, amenorrhea, or cramping without menstruation in an adolescent could indicate a reproductive tract anomaly
- Concomitant symptoms
  - Severe noncyclic constipation and diarrhea suggests irritable bowel syndrome
  - Painful voiding or flank pain could suggest urinary tract stones
  - Urinary symptoms (eg, hematuria, frequent urination) could indicate interstitial cystitis/painful bladder syndrome

② Review Patient History

- Infertility
- Dysmenorrhea in adolescence; current chronic pelvic pain
- Previous laparoscopy with diagnosis
- Dysmenorrhea unresponsive to nonsteroidal anti-inflammatory drugs
- Positive family history

- Absence of menses or other obstructive conditions in adolescence
- History of pain directly associated with surgery (eg, post-operative nerve entrapment or injury, bowel adhesions)

③ Perform Physical Examination

- Nodules in cul de sac
- Retroverted uterus
- Mass consistent with endometriosis
- Obvious endometrioma that is external (seen on speculum or on skin)

- Pelvic floor spasms
- Severe allodynia along pelvic floor/vulva or elsewhere
- Masses not consistent with endometriosis (eg, fibroids)

④ Perform/Order Imaging

- Endometrioma on ultrasound
- Presence of soft markers (eg, sliding sign)
- Nodules and masses

- Adenomyosis & fibroids (although these may be present with endometriosis)

Consider Other Diagnosis in Addition to Endometriosis*

*Alternative diagnoses indicated by symptoms on the right side of the chart may coexist with endometriosis and do not rule out the presence of endometriosis.

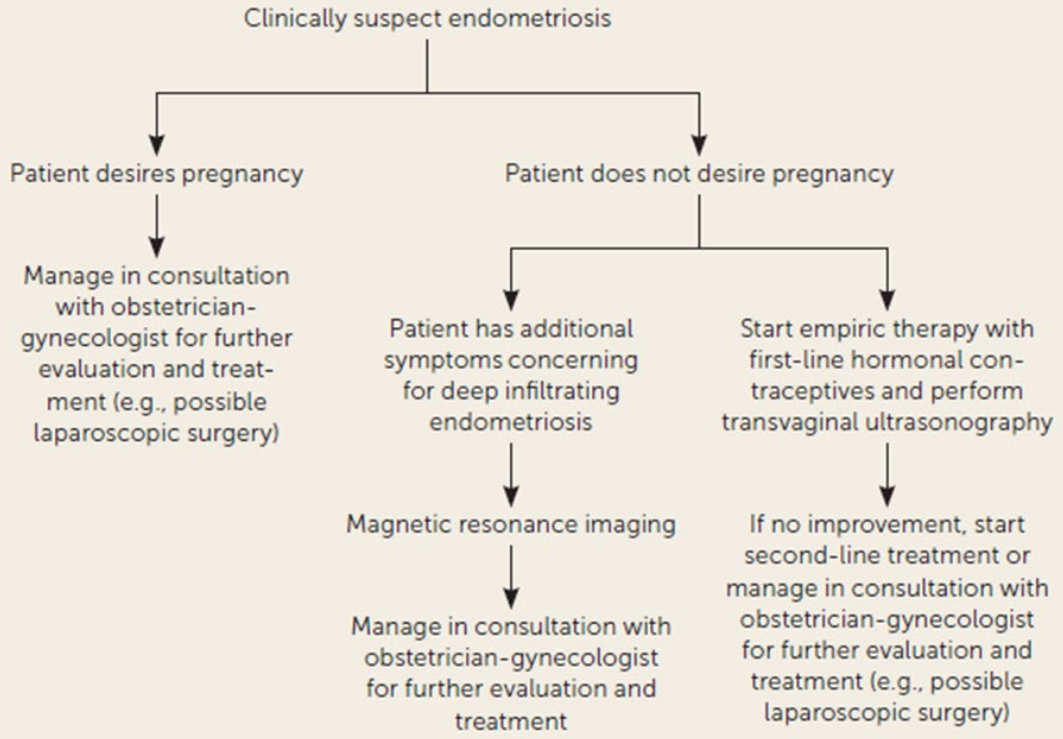
From "Clinical diagnosis of Endometriosis: A call to action" by Agarwal et al., 2019. American Journal of Obstetrics and Gynecology, 220(4), 354.e1-354.e12.

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Algorithm for Treatment

Treatment Tools

FIGURE 1



Algorithm for the treatment of endometriosis in primary care.

Information from reference 13.

From "Endometriosis: Evaluation and Treatment" by Edi, R., & Cheng, T., 2022 American Family Physician, 106(4), 397; 397-404; 404.

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Treatment Plans

Treatment Tools

TABLE 4

Medical Therapies for Endometriosis

Class	Mechanism	Drug	Characteristics	Adverse effects
First-line treatments				
Estrogen-progestin combination (combined oral contraceptives, patch, ring)	Decidualization or atrophy of lesions Inhibition of ovulation	Monophasic estrogen-progestin (continuous use daily)	Inexpensive Temporary relief Decreases pain by 52% Continual use to decrease recurrence if pain after excision	Amenorrhea, breakthrough bleeding, breast tenderness, headaches, mood changes, nausea, weight gain
Progestins (oral, depot injection, implant, intrauterine device)	Decidualization or atrophy of lesions Inhibition of angiogenesis	Norethindrone acetate (oral) Medroxyprogesterone acetate (intramuscular) Etonogestrel-releasing implant Levonorgestrel-releasing intrauterine system	Inexpensive Temporary relief Decreases deep dyspareunia	Acne, breakthrough bleeding, breast tenderness, headache, mood changes, weight gain
Second-line treatments				
GnRH receptor agonists	Inhibition of gonadotropin secretion and subsequent down-regulation of pituitary GnRH receptors causing hypoestrogenic state	Leuprolide depot (Lupron) Goserelin (Zoladex) Nafarelin (Synarel) Add-back therapy: norethindrone acetate, 5 mg, plus vitamin D plus calcium; monophasic combined oral contraceptive, conjugated equine estrogen, 0.625 mg daily; or transdermal estradiol, 25 mcg daily	Expensive Temporary relief Limited use up to one year with add-back therapy Improves pain 60% to 100%	Atrophic vaginitis, decreased bone mineral density, hot flashes, mood changes
GnRH receptor antagonists	Inhibition of gonadotropin secretion by competitive binding and subsequent down-regulation of GnRH receptors causing hypoestrogenic state	Elagolix (Orilissa; oral) Two dosing regimens: 150 mg daily up to 24 months, or 200 mg twice daily up to six months	Expensive Higher-dose therapy use limited to six months due to risk of bone density decline Contraception recommended because patients can still ovulate; contraception can also be used as add-back therapy Improves dyspareunia and dysmenorrhea	Decreased bone mineral density, hot flashes, lipid abnormalities, mood changes, vaginal dryness

From "Endometriosis: Evaluation and Treatment" by Edi, R., & Cheng, T., 2022. American Family Physician, 106(4), 397; 397-404; 404.

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Algorithm for Treatment

Treatment Tools

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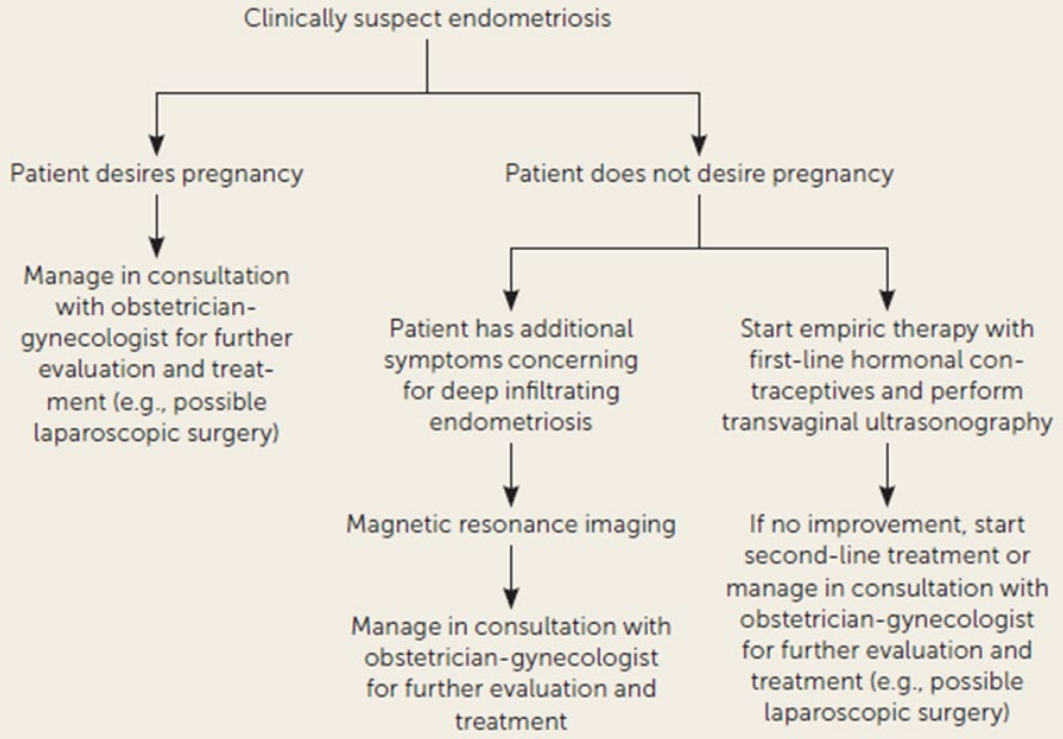

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Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Complications with Pregnancy

Complications

Infertility in Endometriosis Patients

Inflammation and tissue damage affecting the fallopian tubes and ovaries may lead to infertility in women with endometriosis (Edi & Cheng, 2022).

Pregnancy and Endometriosis

*Pregnancy **should not be promoted** solely for managing endometriosis symptoms, as its efficacy in alleviating symptoms or halting disease progression varies (Becker et al., 2022).*

Endometriomas During Pregnancy

In cases where atypical endometriomas are detected via ultrasound during pregnancy, referral to a specialized center for further evaluation is recommended (Becker et al., 2022).

Complications Related to Endometriosis in Pregnancy

Complications directly linked to pre-existing endometriosis lesions, although rare, may include issues such as decidualization, adhesion stretching, and chronic inflammation. These complications, albeit uncommon, may require surgical intervention and can pose life-threatening risks (Becker et al., 2022).

Risk Factors in Pregnancy for Women with Endometriosis

Women with endometriosis may face an increased risk of first-trimester miscarriage and ectopic pregnancy (Becker et al., 2022).

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Referrals Considerations

Referrals

Referral for women with suspected or confirmed endometriosis.

- ***Gynecology Service Referral:*** *...if women exhibit severe, persistent, or recurrent endometriosis symptoms, pelvic signs of endometriosis, or if initial management is ineffective, intolerable, or contraindicated (NICE, 2017).*
- ***Specialist Endometriosis Service Referral:*** *...if suspected or confirmed deep endometriosis involves the bowel, bladder, or ureter or if endometriosis is found outside the pelvic cavity (NICE, 2017).*

Referral for Young Women:

- *Consider referring young women aged 17 and under with suspected or confirmed endometriosis to pediatric and adolescent gynecology services, general gynecology services, or specialist endometriosis services based on local service availability (NICE, 2017).*

Criteria for Referral to a Gynecologist:

- *Identification of an endometrioma during investigations.*
- *The presence of symptoms and signs is indicative of deep endometriosis.*
- *Suspected superficial peritoneal endometriosis that does not respond to initial medical management.*
- *Contraindications to or refusal of first-line medical management options.*
- *Active attempts to conceive or experience infertility (Allaire et al., 2023).*

Source: From Medline Plus at https://medlineplus.gov/periodpain.html

Patient Education

Patient Education

Patient Education for Endometriosis:

Understanding Endometriosis Symptoms:

Educate patients about the diverse range of symptoms associated with endometriosis, including pelvic pain, dysmenorrhea, dyspareunia, gastrointestinal issues, fatigue, and infertility (SWHR,2021).

Impact on Daily Life

Discuss how endometriosis can impact various aspects of daily life, such as work productivity, physical activities, social interactions, and mental well-being. Emphasize the importance of seeking medical support and developing coping strategies (SWHR, 2021).

Diagnosis Process

Provide a comprehensive overview and rationale of the diagnostic process for endometriosis, including discussions about medical history, pelvic examinations, imaging tests (such as ultrasound and MRI), and potential diagnostic laparoscopy. (SWHR, 2021).

Treatment Options

Offer detailed information about the range of treatment options, benefits and risks, and limitations of medical treatments…surgical interventions… lifestyle modifications… and complementary therapies …. (SWHR, 2021).

ACTUAL CASE: OLIVE O.

A Brief History of Endometriosis

12

AGE: 12

- First period
- Heavy bleeding
- Severe Pain

<20

AGE: 14-19

- Heavy and painful periods
- New symptoms: Bloating and diarrhea

24

AGE: 20-24

Complained of painful periods to doctor, who prescribed birth control for one year without menstrual cycle suppression, which did not alleviate symptoms

29

AGE: 29

- Appendectomy for ruptured appendix
- Endometriosis specialists believe endometriosis should have been noted by the surgeon at this point.

ACTUAL CASE: OLIVE O.

A Brief History of Endometriosis

30s

AGE: 30+

- Worsening menstrual pains
- Increased usage on NSAIDs
- Start of acyclic pain and daily fatigue.
- Attempting to get pregnant

33

AGE: 33

- Ongoing infertility
- Interstitial Cystitis and Vulvodynia.
- Patient requested referral to Endometriosis Specialist.
- MRI revealing endometrioma, deep infiltrating endometriosis (DIE), and fibroids.
- Laparoscopy was performed, confirming stage 4 endometriosis.
- Experienced continued infertility, with blocked tube discovered during surgery

34

POST SURGERY: 34

- Took one year to recover.
- Treatment with Pelvic Physical Therapy and gabapentin.
- Birth control was not pursued due to desire to conceive.
- Developed chronic constipation post-surgery, with unresolved causes.
- Fatigue returned

36

AGE: 35

- Miscarriage 2024
- Fertility treatment recommended
- Recent MRI suggests possible recurrence of endometriosis three years post-surgery

Summary of Toolkit

Recommended Use		Other Uses
Clinical Practice	Practical information for In-Office Use	Review details and links as a reference resource
Categories and Sections (7)	Evidence based research on endometriosis screening, diagnosis, treatment, complications, referrals	Provide patient educational tools, apps and resources
Integrated Research into other Guidelines	Toolkit is based on 11 main evidence-based guidelines	Provides national and international guidelines
Appendices	Eight appendices with algorithms and charts to help with screening diagnosis and management of endometriosis	Conduct further research

Implication for Practice

- Comprehensive Guidance
- Standardized Approach
- Improved Accuracy
- Enhanced Patient Education
- Efficient Referrals
- Quality Improvement
- Patient-Centered Care
- Evidence-Based Decision Making
- Continuing Education

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Q&A

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Thank you

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