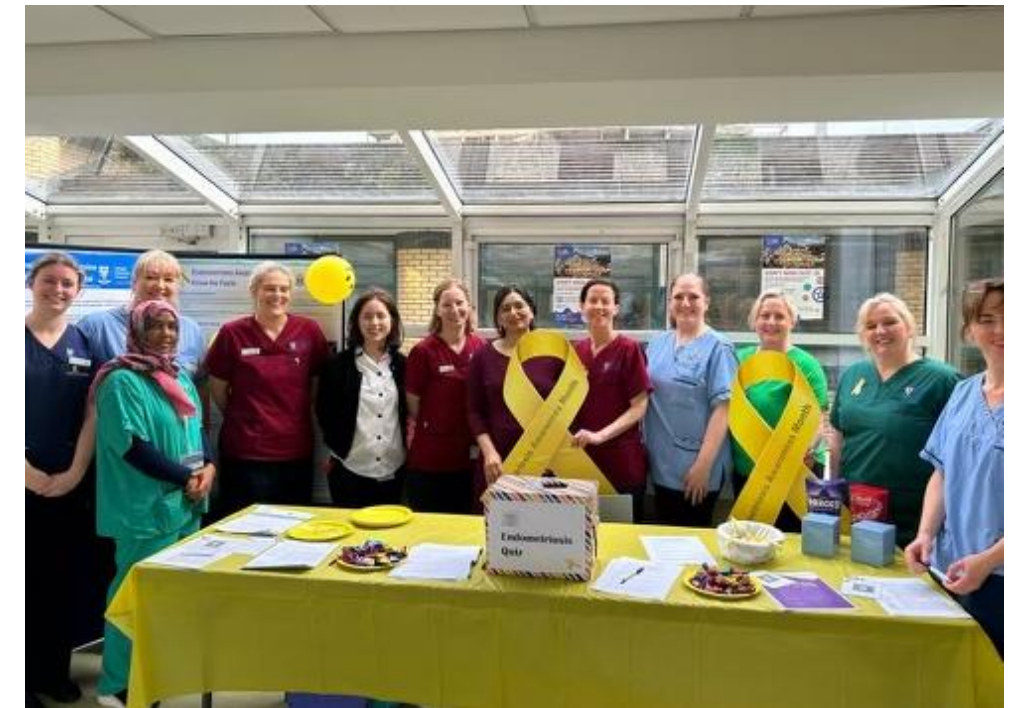


BMUS))

Endometriosis Services in Ireland

Data-Driven Care, Framework
Implementation & Service
Evolution

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Disclaimer

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Endometriosis group poised with new surgery abroad

The group are protesting outside government on the Endometriosis Surgery Abroad Interim

Endometriosis care in Ireland; End the suffering, End the silence – Senator Maria McCormack & David Cullinane TD

14 JULY 2025

Sligo woman with endometriosis who was 11 years is still waiting list for surgery

'More needs to be done' for endometriosis patients, says health minister

Teenager with horrendously painful periods

'Clear as mud' applied to endometriosis surgery process for endometriosis treatment putting women off, advocates say

unknown' - Endometriosis care in Ireland

Why Endometriosis Matters

Endometrial-like tissue outside uterine cavity

Chronic inflammatory, recurrent, hormonally mediated disease

Long delays in diagnosis 7-9 years

Repeat surgeries (30- 50% recurrence risk post surgery)

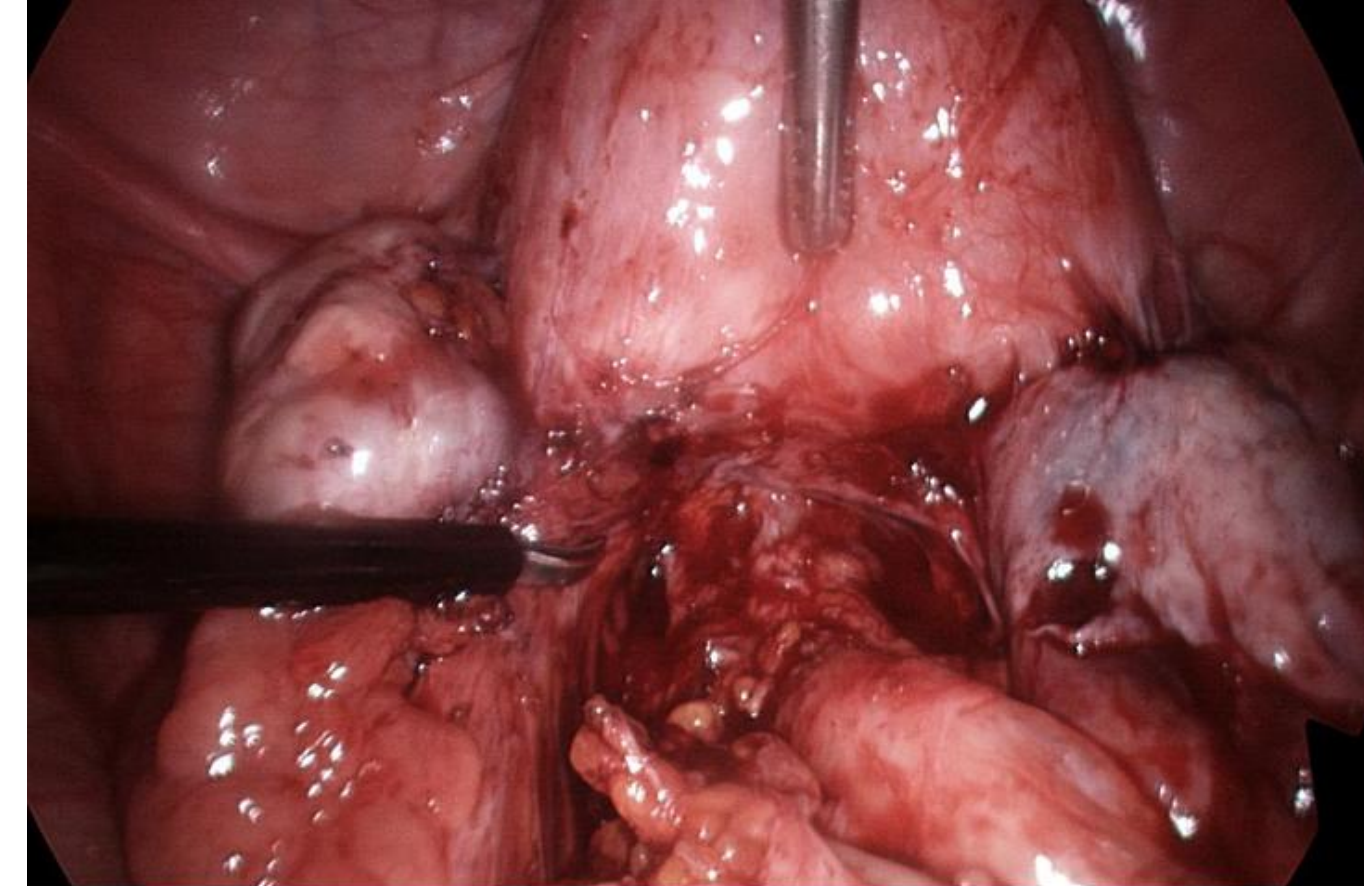
58% of women report multiple GP visits

Socio-economic burden

Personal and family impact

Disparities in access to care

Minority populations disproportionately affected



Prevalence:
3-10% of
women aged
15-45

1 in 3
women have
fertility
issues

5-30% have
severe
disease

Costs:
€9,579 per
woman per
year

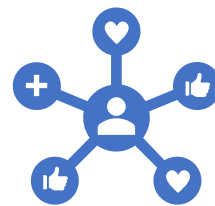
Historic Deficits in Irish Endometriosis Services



Long waiting lists



Diagnostic delay



Fragmented service
pathways



Dismissal or normalisation
of symptoms



Travelling abroad for
specialist surgery

Health System Context in Ireland: Dismissal/normalisation of symptoms

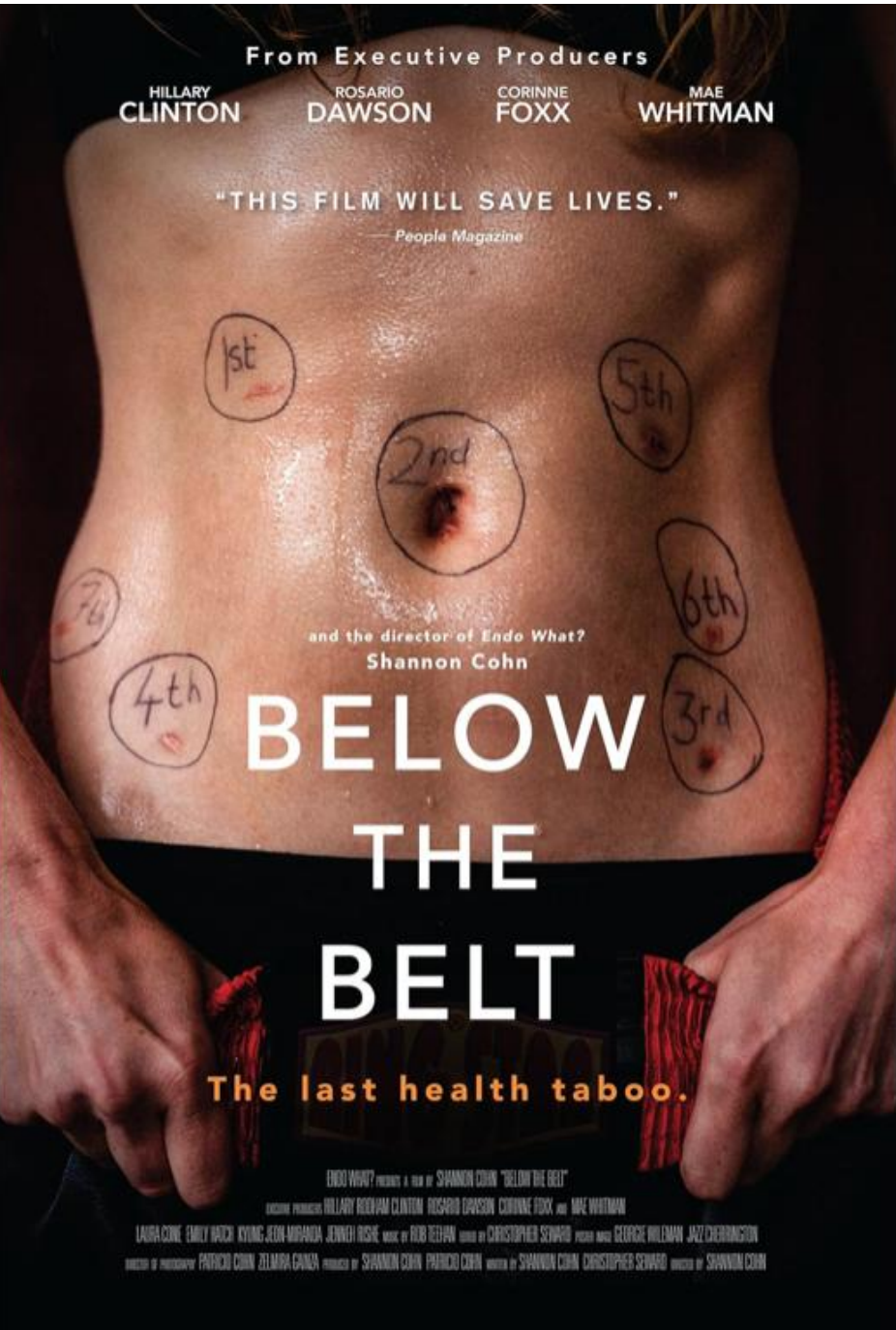


Our Health, Our Voices:
Women's Experiences of Healthcare
in Ireland Listening Forum

Report 1: Insights from General Listening
Sessions with Women



Section 5: Endometriosis Care Experiences

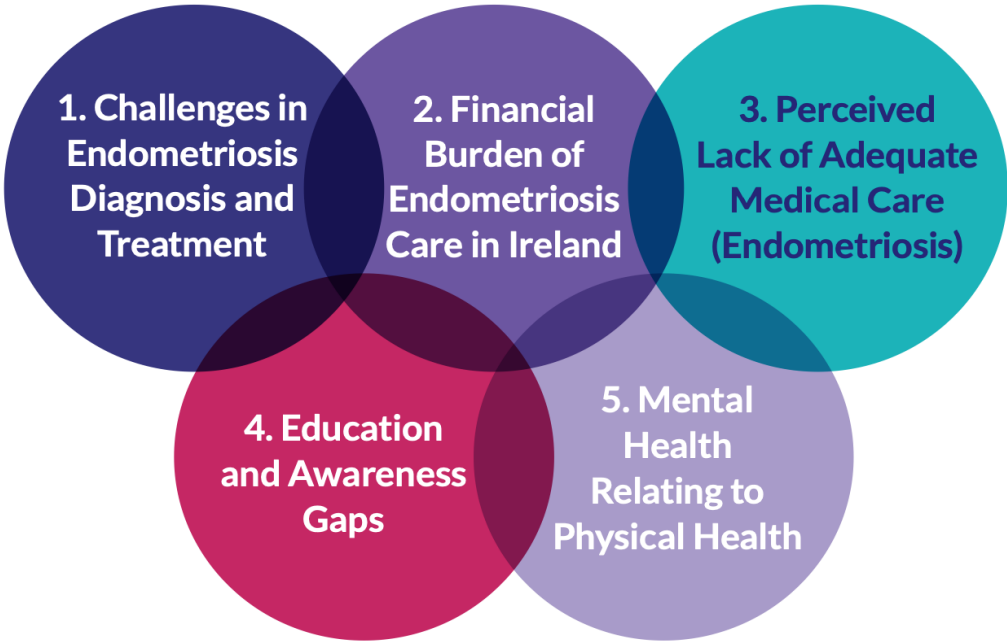


APPG on Endometriosis Inquiry Report 2020

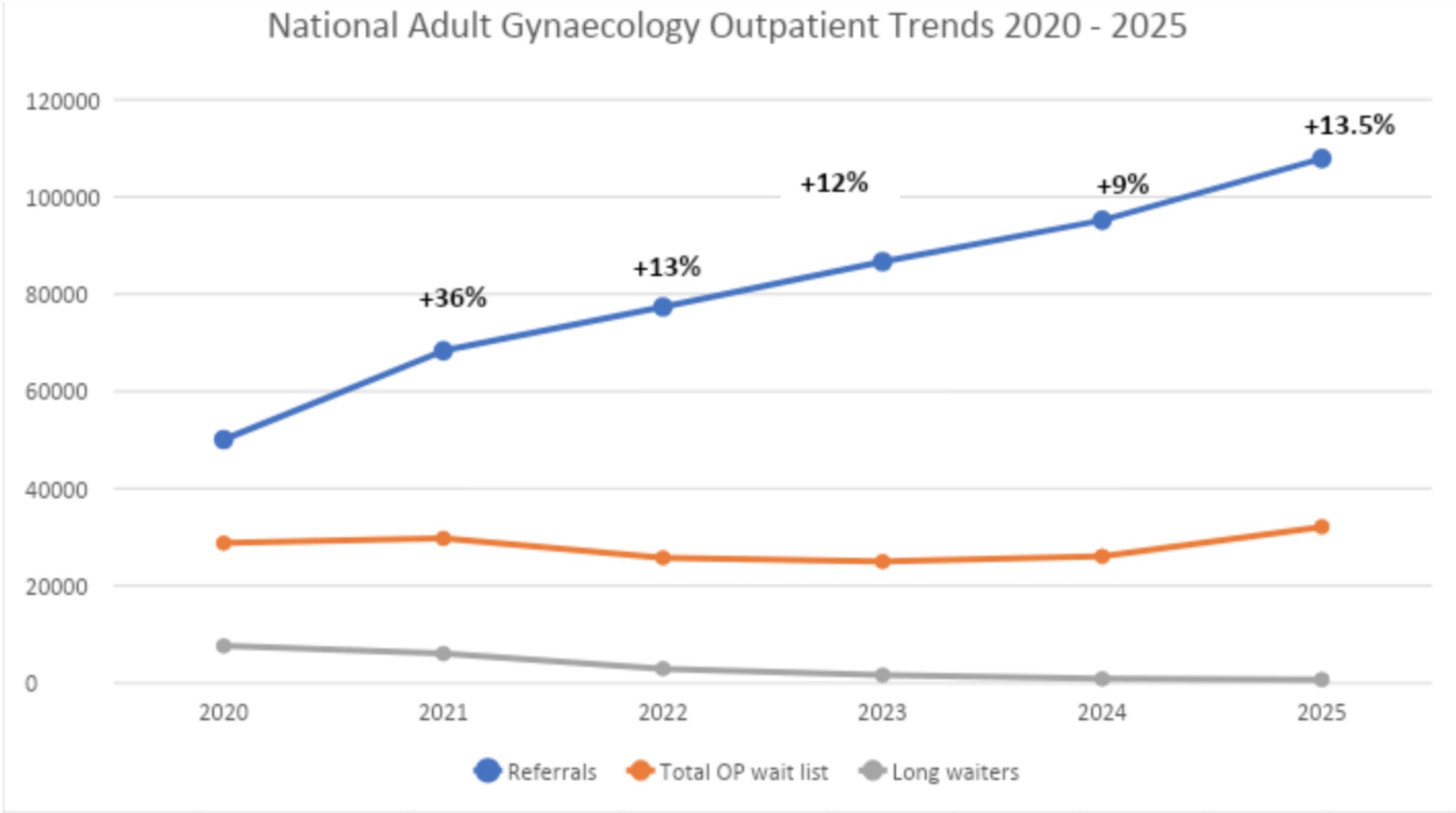
Diagnosis

It takes 8 years on average from onset of symptoms to receiving a diagnosis, the same length of time as it did a decade ago. Prior to receiving a diagnosis of endometriosis, due to their symptoms:

- **58%** visited the GP over 10 times
- **21%** visited doctors in hospital 10 times or more
- **53%** went to A&E; 27% went to A&E 3 or more times



Health System Context in Ireland: Wait Times



Health System Context in Ireland: Fragmented Service Pathways

Traditional referrals for complex pelvic surgery primarily to Gynae Oncology surgeons

Impact of National Cancer Care Programme; led to workforce shortages

Pockets of expertise in Minimally Invasive surgery; Consultant-dependent

Limited dedicated clinics for Endometriosis

No system of defined referral pathways; inequity in access to care

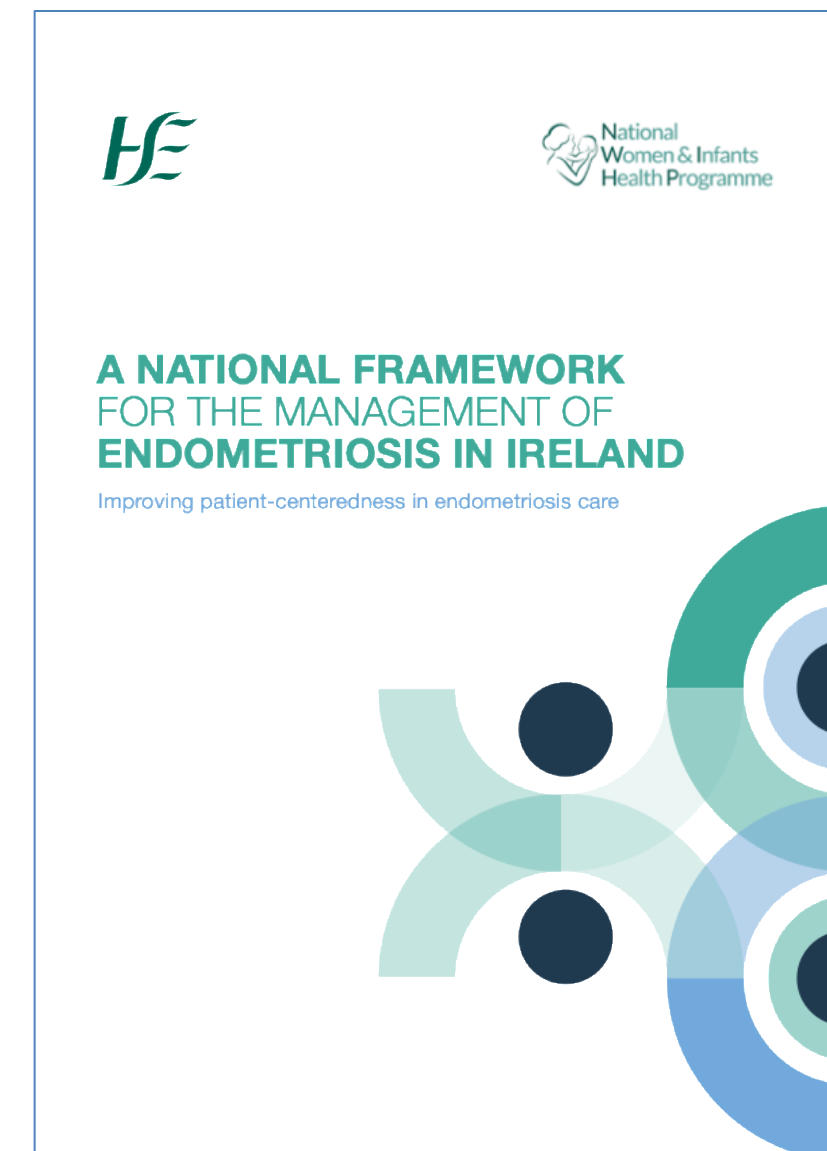
Calculating the Need

- 1,022,437 women between the ages of 15 and 45 year, (based on Census figures 2016)
- The prevalence of endometriosis is 3% - 10% of this group so:
 - The disease burden ranges from **30,600 to 102,200 endometriosis cases**
- **The prevalence of severe endometriosis ranges from 5-30% of affected patients**
 - This gives a cohort of 1,530 to 30,600 women within this 30-year age span.
 - A conservative estimate is therefore **250 women** with severe disease requiring treatment in Ireland **each year**.

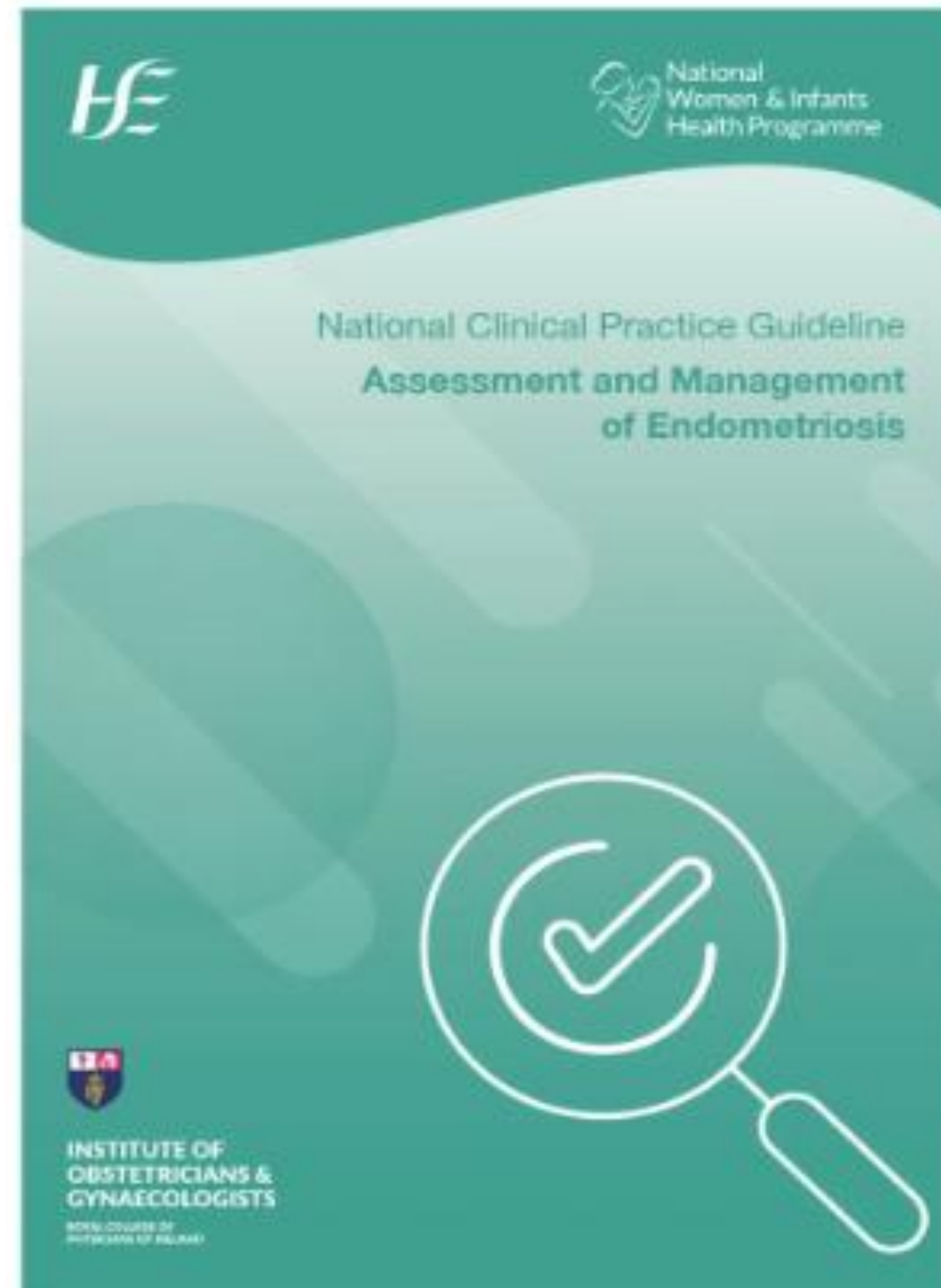
THE RESPONSE TO THE NEED

National Clinical Framework for Endometriosis Care

- Ireland's *first National Framework for the Management of Endometriosis* was launched in **October 2025**
- Developed by the **HSE National Women and Infants Health Programme (NWIHP)** with patient advocacy input



Clinical Guidelines to Support the Framework



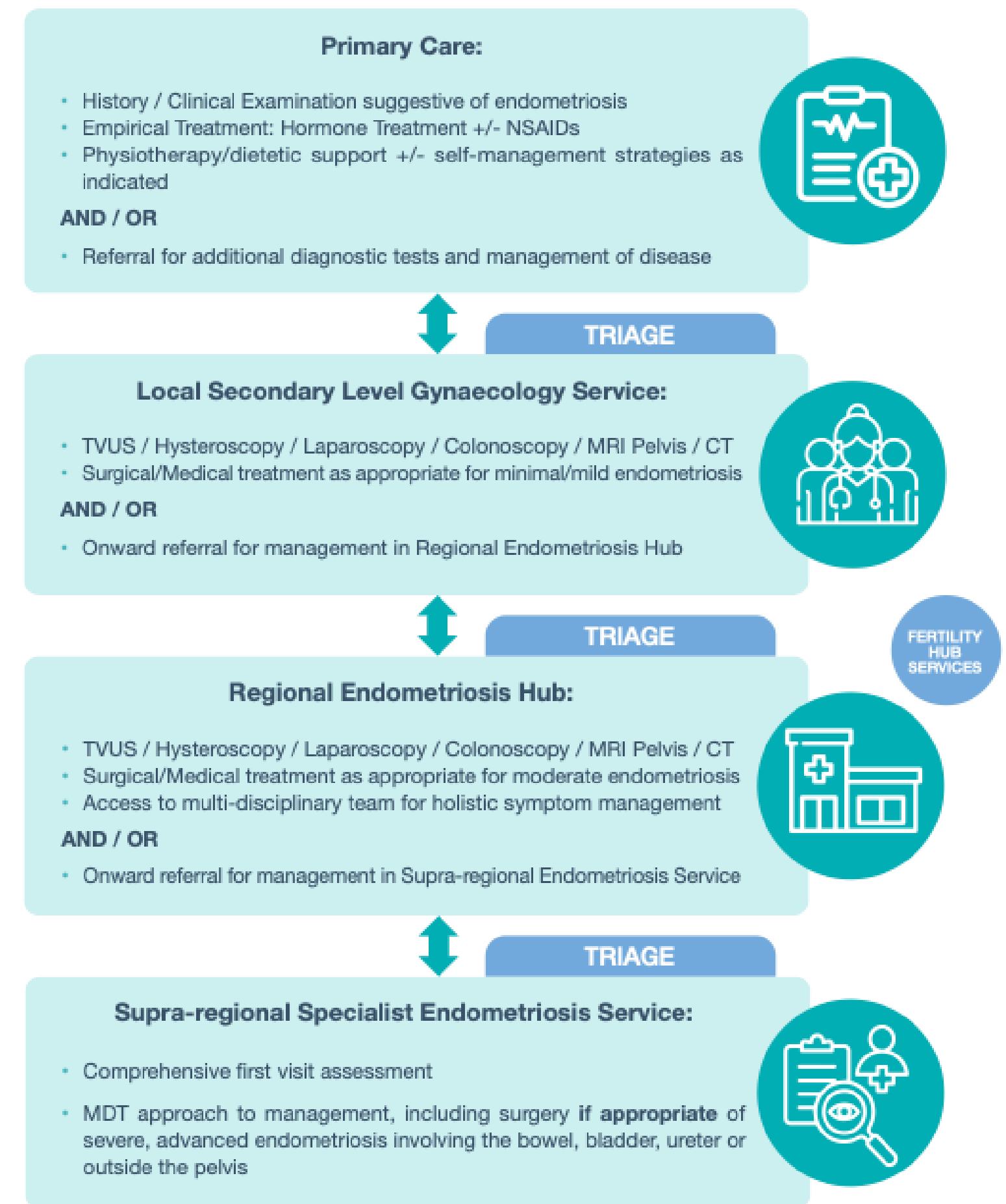
- **2025 National Clinical Practice Guideline** aligns with the Framework, guiding diagnosis and management, including endometriosis-related infertility.
- Based on international evidence (NICE, ESHRE, RANZCOG).

Core Principles of the Model of Care: What's New?

- **Presumed diagnosis:** Women presenting with symptoms treated empirically with presumption of endometriosis — intended to *reduce delays in care*
 - Move away from laparoscopy as necessary for diagnosis of endometriosis
- *Right care, right place, right time* model spanning **primary, secondary, and tertiary care**
- Structured care pathways with **regional hubs** and **supra-regional centres**
- **Multidisciplinary team development** is prioritised in recognition of complexity of endometriosis disease
- Care pathways **tailored** to the needs of individual women
- The need for Ireland to **invest** in the required multidisciplinary teams, across both primary and secondary care services

Service Structure in the Framework: Tiered Care Model

1. **Primary Care:** GPs recognising and managing initial symptoms; early referrals.
2. **Referral to Local Gynaecology Services:** involving further imaging; may include diagnostic/therapeutic laparoscopy
3. **Regional Specialist Centres (6 hubs):**
 1. The Coombe Hospital, Rotunda Hospital, University Hospital Limerick and Cork University Maternity Hospital
 2. Two more in development at Galway University Hospital & National Maternity Hospital
4. **Supra-regional Complex Centres (2 centres):**
 - Tallaght University Hospital & Cork University Maternity Hospital for complex cases



ACCESS CRITERIA

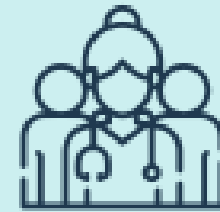
The primary aim of this Framework is to ensure timely access to the appropriate level of care at the most appropriate level for women with endometriosis. In order to facilitate this objective, it is necessary to have defined access criteria across the paradigm of care.



Primary Care

Access Criteria

- Any woman experiencing symptoms suggestive of endometriosis



Local Secondary Hospital

Access Criteria

- Referral to local Regional Fertility Service for fertility issues
- Unsuccessful disease management using hormone treatment and/or analgesia after a period of 6 months.
- Patient unwilling to attempt hormonal treatment/Pregnancy is a priority.
- Patient unable to tolerate hormonal treatment.
- Suspicion of advanced endometriosis indicating the need for further diagnostic work-up



Regional Specialist Endometriosis Service

Access Criteria

- Women with moderate diagnosed endometriosis, the management and symptoms of which require the input and care of a multi-disciplinary team available at service level including designated endometriosis consultant leads.
- Appropriate work-up completed and included as part of onwards referral



Supra-Regional Specialist Endometriosis Service

Access Criteria

- Definitive or strongly presumptive diagnosis of deep invasive endometriosis +/- bowel involvement
- Appropriate work-up completed and included as part of onwards referral from referring service.

Discharge Criteria

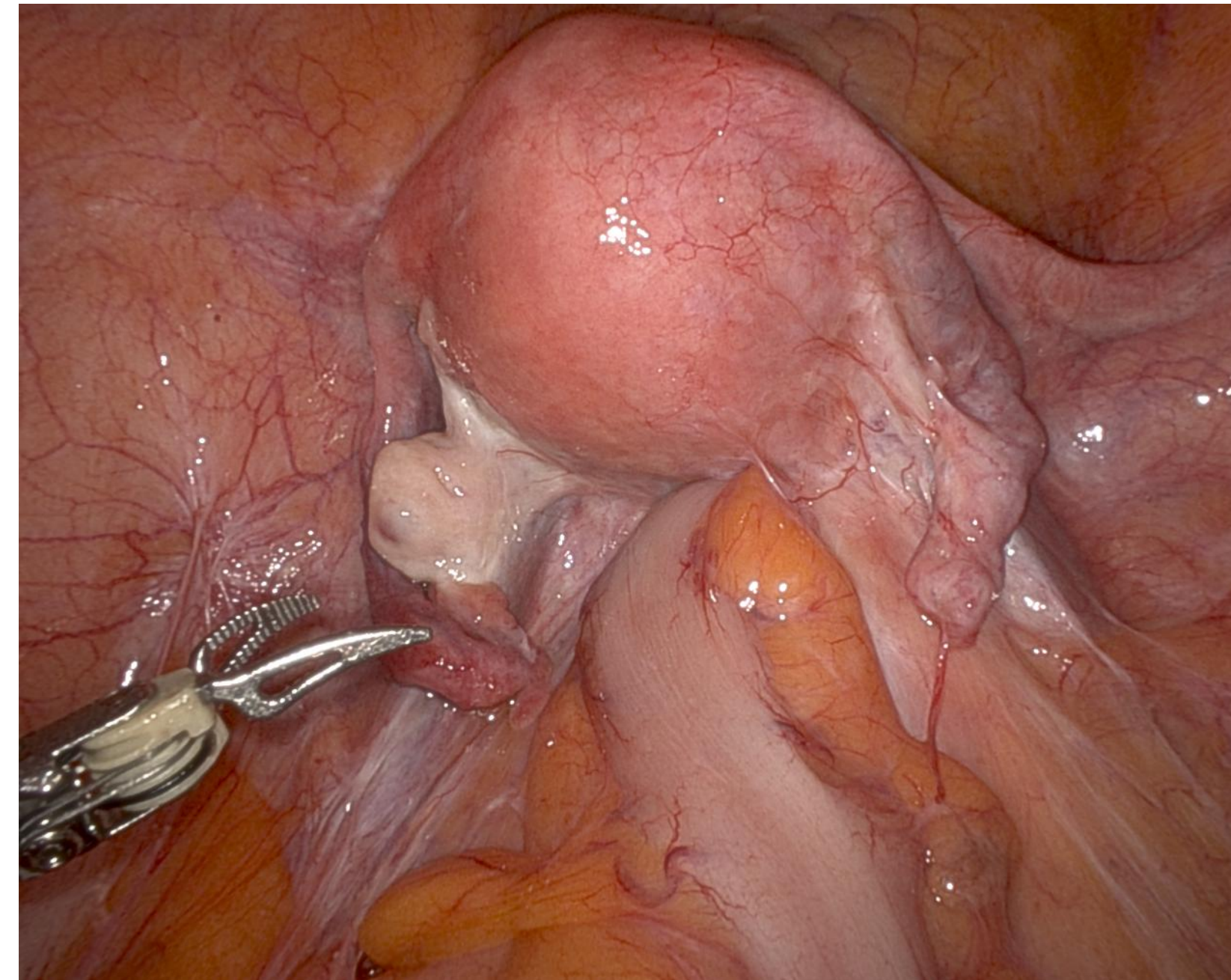
- Following satisfactory symptom reduction for 6-12 months after treatment.

Regional specialist endometriosis services

- **Coombe Hospital, Rotunda Hospital, Univ. Hospital Limerick**
- **In development: Nat'l Maternity Hospital, Univ. Hospital Galway**
- To manage moderate complexity disease
- **MDT:**
 - Clinical lead consultant
 - Clinical nurse specialist
 - Clinical specialist physiotherapist
 - Senior dietetics
 - Senior psychologist
 - Administration
- Theatre access – crucial component

Supra-regional specialist endometriosis services

- Tallaght University Hospital
- Cork Univ. Maternity Hospital
- To manage extensive, complex disease
- **MDT:**
 - Consultant gynaecologists with training in advanced laparoscopic surgical skills
 - Consultant colorectal surgeon with special interest in endometriosis
 - Consultant urologist with special interest in endometriosis
 - Consultant radiologist with training in imaging of endometriosis
 - Clinical nurse specialist(s)
 - Clinical specialist physiotherapist
 - Senior dietetics
 - Senior psychologist
 - Administration, HCA supports
- Data collection/ research
- Training, future proofing of service

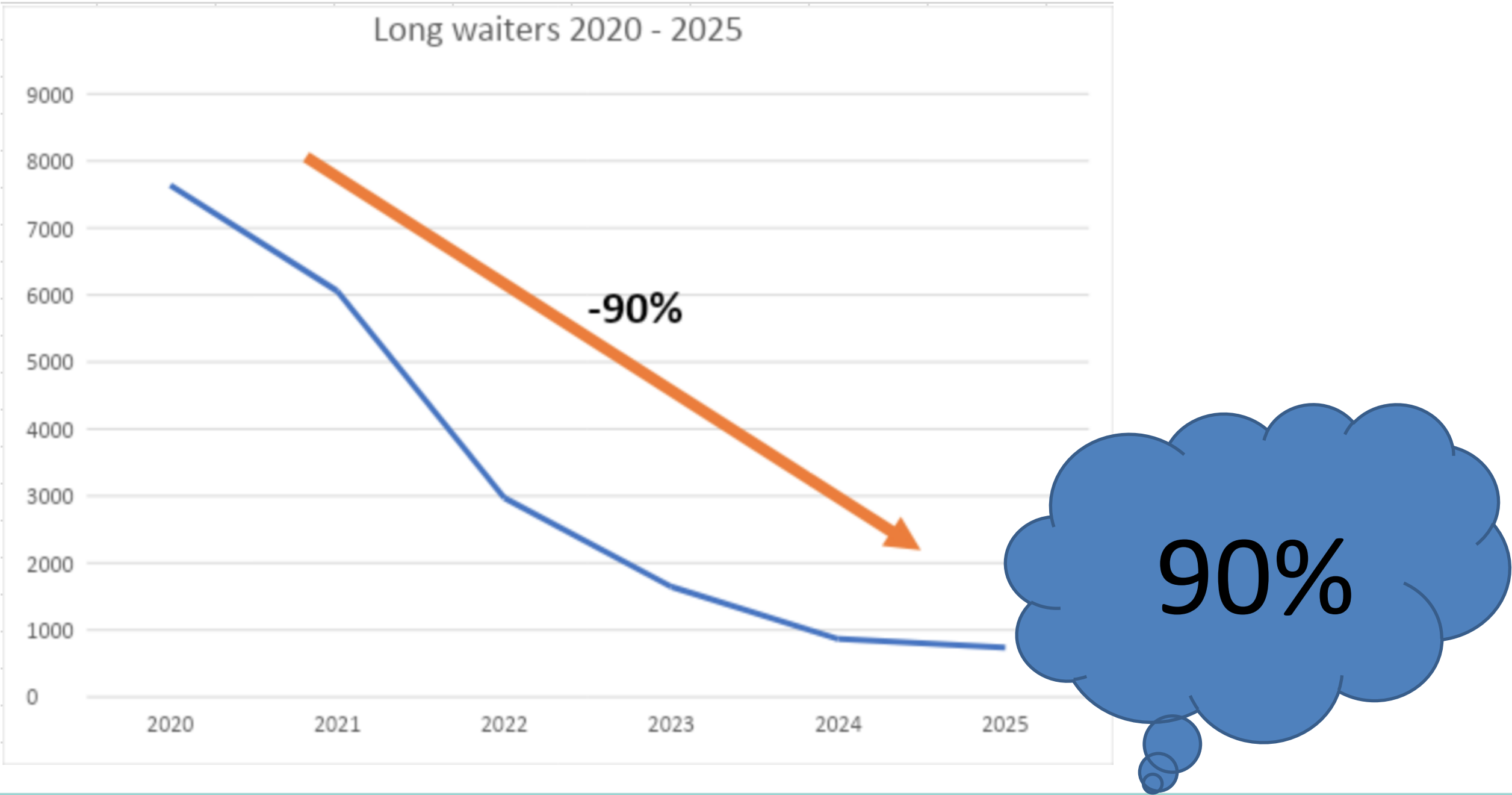


TUH Endometriosis Service: Current Structure

- Working towards **BSGE accreditation** (provisional status)
- Weekly **Endometriosis Clinics**
 - With ANP ultrasonography support
 - Prospective data collection ongoing - QoL questionnaires, dietetic surveys, physio surveys
 - Monthly clinic with colorectal surgeon
- Weekly ANP-led **Pelvic Pain Clinic** - streamline patients with suspected endometriosis for investigation
- CNS-led **Endometriosis telephone clinics**
- Fortnightly **multidisciplinary team (MDT)** meetings
- Monthly Endometriosis **team meetings** – to discuss service provision/ goals/ upcoming events
- 2+ full day **operating** lists/week
 - Access to surgical robot
 - Colorectal/urology joint cases
 - Complex cases involving 2 (or more) consultants
- 2-year **Endometriosis fellowship** between TUH and CUMH

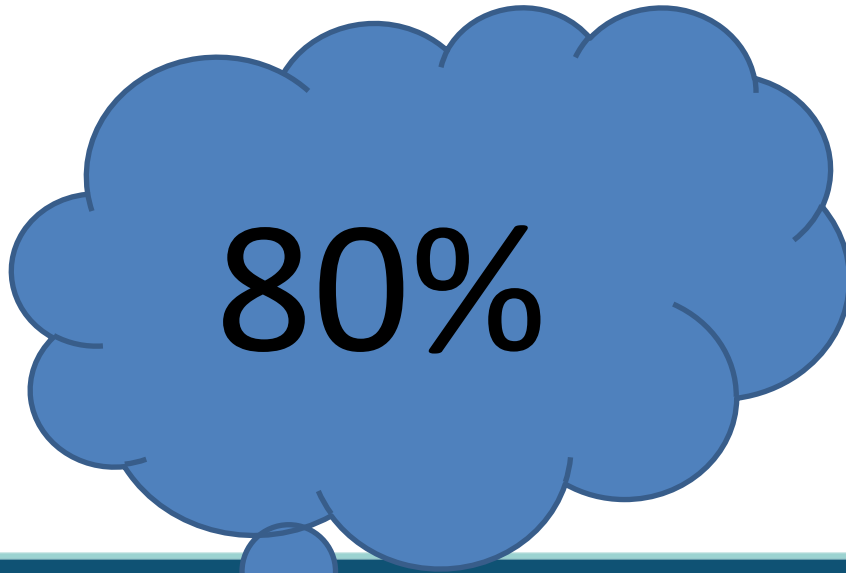


Irish Service Utilisation Data: Data Trends in National Gynaecology Out-Patient Services



Irish Service Utilisation Data: Data Trends 2025

- Almost **1,200 new patients** seen in specialist services in 2025, with continued growth expected in 2026
- >5,000 review appointments provided
- Approx **1,400 endometriosis-related surgeries** performed within designated services
- Improvements: approx **80% waiting < six months** in specialist pathways.



80%

Drivers of Change: Key Moments



Women's Health Action Plan 2026-2027

Phase 3



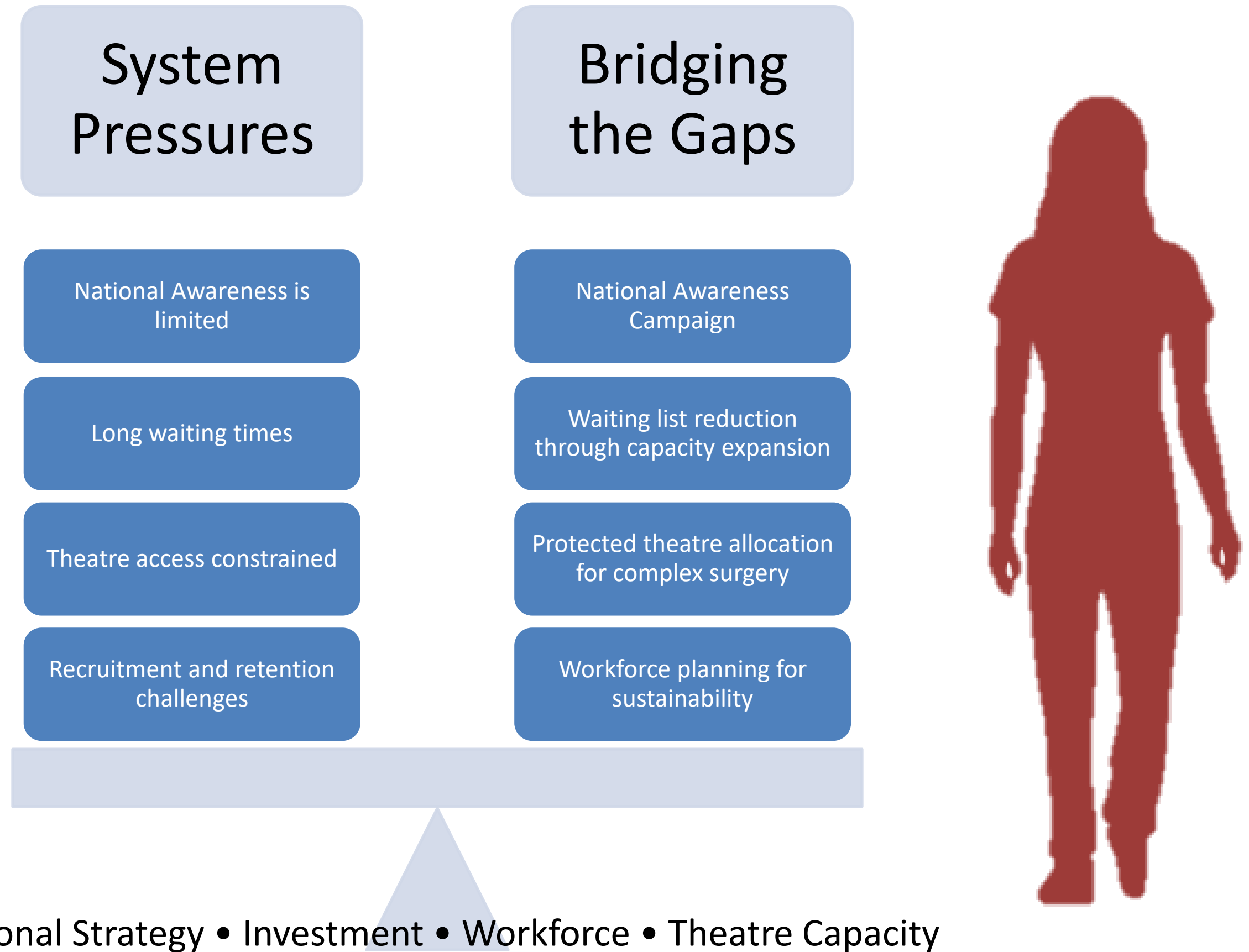
Tallaght University Hospital
Ospidéal Ollscoile Thamhlachta
An Academic Partner of Trinity College Dublin

Addressing Historic Deficits: What's Improving



- Earlier recognition in primary care and presumptive diagnosis aiming at *shortening diagnostic journey*
- Increase in specialist hubs *reducing geographic inequities*
- Recruitment of specialist surgeons ongoing, *building capacity*
- Our National Guideline promotes *evidence-based, multidisciplinary care*

Ongoing Challenges: Bridging the Gap



Likely Future Evolution: What's Next/ In progress

- Focus on **education and awareness campaigns** to support earlier recognition and appropriate care
- Continued expansion of **regional and supra-regional hubs' capacity and sustainability**
- International **collaboration and training** to build on local specialist expertise and efficiencies
- Focus on **research** for Irish-specific data
- Strengthening referral pathways for endometriosis-related infertility
- Development of adolescent endometriosis support services
- Potential **integration** of broader pain and chronic care pathways into the model of care

Conclusion

- Ireland has moved from fragmented, inequitable referral services to provision of **structured, tiered care pathways** for endometriosis care
- The *National Framework* for Endometriosis Care and supporting Clinical Practice Guidelines are major milestones
- Patients' lived experience and ongoing data collection highlight continued need for investment, multidisciplinary team-building, and **system integration**

