



# Unheard Voices: Exploring Patient and Carer Experiences in Endometrial Cancer Care in Victoria

Frances Graham – Project Manager, VICCS Optimal Care Summits Program  
Maureen O’Keeffe – Endometrial Cancer Consumer

**COSA-IPOS 2025**

12 November 2025



The Victorian Integrated Cancer Services (VICCS) are supported by the Victorian State Government

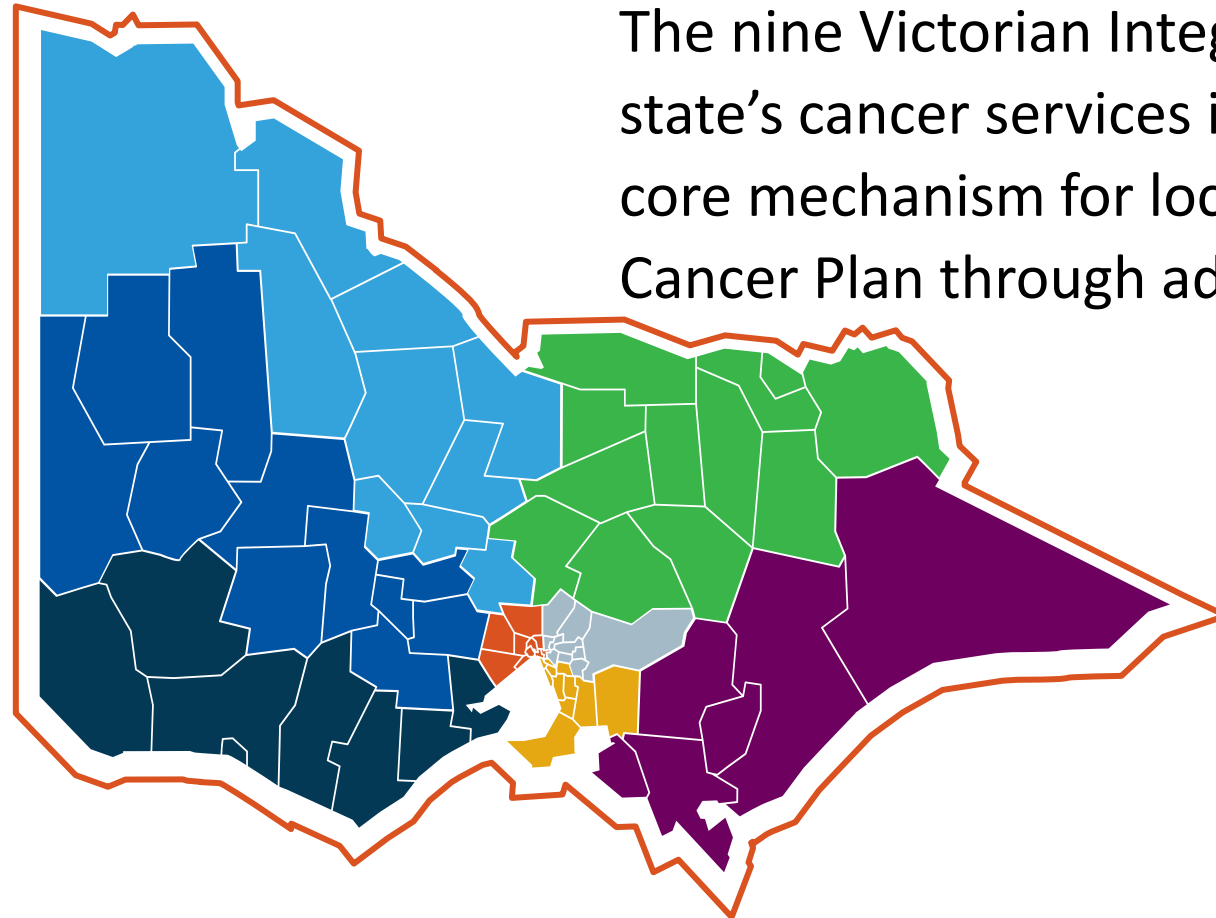
# Acknowledgements

- **Expert Advisory Group Co-chairs:** A/Prof. Simon Hyde, Dr Rosie McBain
- **Consumers/patients and carers**
- **Endometrial Cancer Expert Advisory Group**
- **Department of Health**
- **Data Analysts**
- **VICS Program Managers and Directors**
- **VICS Optimal Care Summits Team:** Linda Nolte, Helena Rodi, Nicklaus Baje, James Shirvill, Emma Bernar



# About the VICS

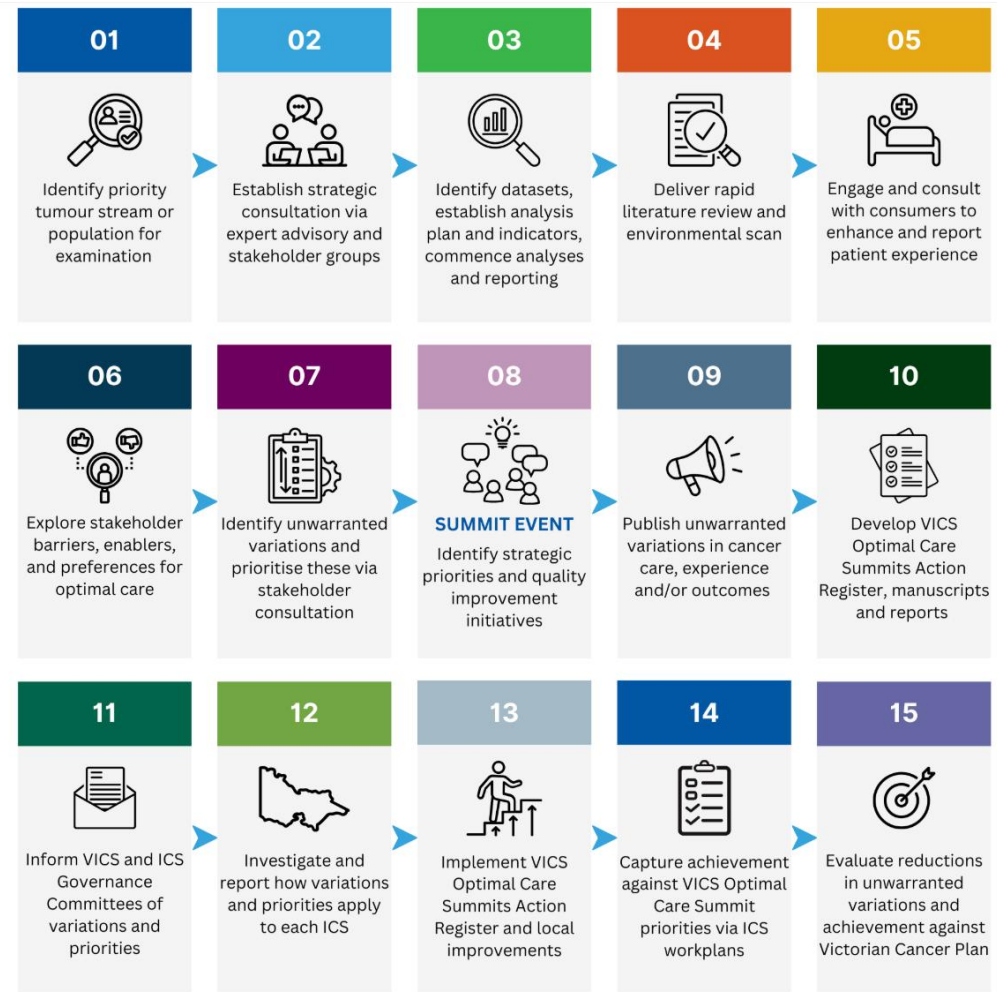
The nine Victorian Integrated Cancer Services (VICs) form the state's cancer services improvement network. They are a core mechanism for local implementation of the Victorian Cancer Plan through adoption of Optimal Care Pathways



- BSWRICS
- GICS
- GRICS
- HRICS
- LMICS
- NEMICS
- PICS (statewide)
- SMICS
- WCMICS

*The VICs Optimal Care Summits program is an initiative of the Victorian Integrated Cancer Services (VICs), administered by the North Eastern Melbourne Integrated Cancer Service (NEMICS) based at Austin Health*

# Optimal Care Summits Consultation Process



## Step 5: Consumer Engagement

- Direct engagement with patients and carers.
- Collection of qualitative insights on experiences, challenges, and gaps.
- Patient voices informed summit recommendations.
- Complements mixed-methods approach to identify and examine unwarranted variation using linked administrative datasets from the Department of Health (6,873 women  $\geq 18$  years with endometrial cancer, 2013–2022).

Data linkage performed by Centre for Victorian Data Linkage, Victorian Department of Health



# Background, Aim and Methodology

## Background

- Age-standardised incidence rate for uterine cancer (of which 95% is EC) nationally increased from 14 cases per 100,000 females in 1982 to 20 cases per 100,000 females in 2018.
- Reflects a growing health concern and underscores the importance of hearing women's voices.
- EC patients have complex care needs so understanding experiences is key to improving equity and care priorities.

## Aim

- Capture perspectives of people diagnosed with EC and their carers in Victoria

## Methodology

- **Online survey** ( $n=7$ ) via national EC support group (covered all OCP steps)
- **Focus group discussions** with EC patients and carers ( $n=9$ ; deeper insights)
- **Rapid literature review** of recent Australian EC studies (Sep–Oct 2024)



# Early detection and initial investigations



## Awareness before diagnosis

- Most patients had **no prior knowledge** of EC
- Awareness existed for general risk factors (weight, smoking, alcohol consumption) but not specific to EC

*"I'd never heard of this cancer until I actually got diagnosed."*



## Delay in seeking care

- Timelines ranged from 4 weeks to 12 months, due to tolerating bleeding or assuming was period-related pain



## Diagnostic challenges

- GPs sometime reluctant to test or misdiagnosed as perimenopause or fibroids
- Bleeding attributed to menopausal changes

*"It's one thing for us as women to understand what the science and symptoms are, but it's also a very big part for our GP and our medical students to be aware of what these symptoms are."*



# Diagnosis, staging and treatment planning

## Investigation timelines

- People with lived experience of EC reported investigations took between two weeks to 3.5 years.
- Delays were linked to access to services and GPs unwillingness to conduct tests or listen to concerns

*"I didn't feel like there was anyone to ask any questions...and I didn't know who to go to or anything like that, so my experience was not a great one."*

## Receiving their diagnosis

- Many described it as bewildering, filled with uncertainties and lack of empathy
- Two patients felt overwhelmed by the amount of information provided
- *Common theme:* lack of communication, leading to uncertainty, anxiety and delays

## Information received

- Information received was often insufficient, contradictory and confusing

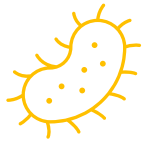


# Treatment



## Travel for treatment had a significant impact

- Most treatment was timely (within 4 weeks)



- COVID pandemic created barriers (traffic delays, no support person at treatment)



- Clinical trials and fertility implications rarely discussed

## Travelling for treatment:

*“Travel time could take up to four hours daily for radiotherapy between Geelong and Melbourne.”*

## Impact of COVID:

*“My husband wasn't allowed with me. It was really hard to walk into that hospital and do this all by yourself. But he was in the car and that is the only thing that really kept me going was knowing he was there waiting for me...”*



# Care after initial treatment and recovery



## Complications from treatment

- Hernia, bowel functioning issues, kidney stones
- Often untreated or took significant time to treat



## Communication issues

- Results were explained using overly technical/medical language
- Difficulty receiving responses or arranging tests
- Lack of discussion on implications of different clinical trial approaches
- Problems with follow-up meetings for complications and recurrence diagnosis
- Pathology results/treatment plans not delivered to primary care



## Supportive care

- Most consumers did not receive supportive or psychological support

### Communication issues:

*"I think people need to be more upfront and I think there needs to be consistency in messaging. There needs to be more care sometimes in delivering messages."*

### Supportive care:

*"Mine didn't even exist."*

*"So, to me that [Facebook support group] was where I got all that information that you talk about. That was very supportive. And we could ask each other, like who do you recommend for physio?"*



# Managing recurrence and end-of-life care



## Prognosis not communicated

- A third of patients were not told about their prognosis.



## Limited understanding of planning

- Most patients felt advance care planning and palliative care were unnecessary, highlighting a lack of knowledge.



## Language and accessibility barriers

- Approximately half of consumers expressed concern for those with English as a second language navigating the system.

*“Some standard information like handouts to be given to take home, even though people sort of tell you stuff, or they might not even tell you. Its all such a blur.”*



# Summary

- Even with a small cohort, findings highlight the need for systemic improvements in EC care
- **Key gaps:** limited GP education, inconsistent diagnostic pathways, and poor support/communication
- **Recommendations:**
  - Promote community and GP awareness of EC
  - Expand supportive care services
  - Establish an EC advocacy group
- **Call to action:** Collaboration between healthcare providers and stakeholders is essential to optimise EC care in Victoria

*“We need better information, empathy and clear points of contact so we don’t feel lost in the system.”*

*Amplifying women’s voices is critical to driving systemic change in endometrial cancer care*



# Thank you

Further information about the VICS endometrial cancer consultative process (including summit event) is located via the QR code shown below.

