

ANNUAL NEWSLETTER 2023

Irish Society of Gynaecological Oncology Public and Patient Involvement Group (ISGOPPI)

Origins

The Irish Society of Gynaecological Oncology (ISGO) re-established in Dec 2015. The society is an all-Ireland venture encompassing all gynaecological cancers. Its members are lead clinicians, nurse specialists, scientists and allied health working in the area of Gynaecology Oncology in Ireland. They meet several times a year. The society will focus on the full continuum of cancer care; from prevention to diagnosis, treatment, survivorship and palliation.

What is PPI?

The society realised the importance of including the Patient and Public voice in the management of all aspects of Gynaecological Oncology. The term “public” refers to potential patients, significant others and people who use health and social care services as well as people from organisations that represent people who use these services. The Society would like that its PPI group would play a role in improving Patient Experiences and Clinical Research but not exclusively just these areas. Our hope is that by having a partnership with our patients, we can achieve more as a group and you have a better Patient Experience.

Commitment

The group aim to meet 3 times a year and correspondence is mainly through email. A number of our members are involved in national and international committees and further education around PPI.

ISGOPPI Co-founders

Yvonne O’Meara and Sharon O’Toole established and run the ISGOPPI. Yvonne is a Systemic Psychotherapist & Psycho-Social Oncologist. Yvonne has worked in the area of psychosocial oncology and palliative care since 2004 in teaching hospitals in Ireland and in North America. She has recently taken up a post at the University College Dublin School of Medicine as Women’s Cancer Survivorship Research Coordinator based in the Mater hospital.

Sharon is a Senior Research Fellow in Trinity College Dublin working in the area of gynaecological cancer. Her research focuses on early diagnosis and better treatments. Sharon works closely with a number of ovarian cancer charities in Ireland and coordinates the national awareness events in Ireland for gynaecological cancer.

Where can I find out more?

More information please email: isgoppi@gmail.com



[ISGO \(@isgoppi\)](#)



[Isgo Ppi | Facebook](#)



Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Welcome to our Annual Newsletter,

It has been an amazing year with largest number of research projects being run through the ISGOPPI. We extend a special welcome to our new members who have joined us this year. We have a number of exciting new projects which will require your input throughout the year so feel free to volunteer if the topic is of interest. The success of this group is all down to your active engagement and for that we are grateful.

The International Gynecological Cancer Society (IGCS) will hold its annual meeting for the first time in Dublin this year Oct 16th -18th. This will be preceded by the 2024 IGCS-IGCAN Gynecologic Cancer Survivor-Caregiver Summit on Oct 15th. Details may be found at igcsmeeting.com. The World Ovarian Cancer Coalition will also be in Dublin at this time. In addition, the [Gynecologic Cancer Intergroup](#) will hold its first ever consensus conference in cervical cancer in Dublin Castle on 14th and 15th Oct.

We thank you for your support and hope you continue working with us going forward to improve the experience for women and their families diagnosed with gynaecological cancers. We remember those who have died in the past year and offer our sincere sympathies to their families. Ar dheis De go raibh a anam.

Please feel free to pass on this newsletter to anyone who may be interested as we welcome new members.

Sharon and Yvonne.

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Activities 2023

INGO

Irish Network for
Gynaecological Oncology

1. Awareness Event: World Ovarian Cancer Day 8th May 2023

Ireland has an active gynaecological cancer support, advocacy, research and care community. In recent years this has formalised and expanded into the Irish Network for Gynaecological Oncology (INGO), [[Irish Network for Gynaecological Oncology - ISGO](#)]. ISGOPPI is a partner of INGO. The aim of the INGO is to raise awareness of gynaecological cancers across the Island of Ireland. The group are part of an international effort for 2 major awareness events: World Ovarian Cancer Day (WOCD) May 8th and World Gynaecological Oncology (GO) Day Sept 20th.

In 2023, the Network continued the work with The Reputations Agency which was another great success.

The INGO currently includes; ARC Cancer Support Centres, Dublin, Answers for Cancers podcast team, Breakthrough Cancer Research, Cancer Care West, Cancer Trials Ireland, CERVIVA, Circle of Friends Cancer Support Centre, Coombe Women and Infants University Hospital, Cork ARC Cancer Support, Cork Cancer Care Centre, East Galway and Midlands Cancer Support Centre, Emer Casey Foundation, Irish Cancer Society, Irish Society of Gynaecological Oncology Public and Patient Involvement Group, Karen Fenton Ovarian Cancer Fund, Lynch Syndrome Ireland, Marie Keating Foundation, Mater Hospital Dublin, National Cancer Control Programme, National Immunisation Office, National Women’s Council of Ireland, OvaCare, Pink Ladies Cancer Charity, Purple House Cancer Support, Sláinte an Chláir, Sligo Cancer Support Centre, SOCK, St. James’s Hospital Foundation (GynaeCancerCare), Swell Fermanagh Cancer Survivorship Group, Trinity College Dublin, Trinity St James’s Cancer Institute, University College Dublin and 221+ CervicalCheck Patient Support Group.



The Irish Network for Gynaecological Oncology (INGO) focussed their 2023 world ovarian cancer day campaign on increasing awareness of symptoms using the BEAT acronym. This followed a repeat of their 2022 survey which still highlighted that 4 out of 5 women in Ireland were not confident to recognise the symptoms of ovarian cancer. This made headline news on Morning Ireland and RTE 6 o'clock news featuring Prof Karen Cadoo and patient Deirdre O'Raw. The INGO were delighted to have the support of the Press Up hospitality group and Peter Marks who displayed specially designed BEAT stickers, kindly sponsored by CCL Label Ireland Ltd, outlining symptoms of ovarian cancer in their outlets.

The **BEAT symptoms** can be vague but if persistent, women are encouraged to contact their GP.

- Bloating that is persistent and doesn't come and go
- Eating less and feeling full more quickly
- Abdominal and pelvic pain you feel most days
- Toilet changes in urination or bowel habits

The campaign also sought to dispel the myth that cervical screening detects ovarian cancer. There is no screening for ovarian cancer. Ireland has one of the highest death rates from ovarian cancer in Europe. Approximately 400 women are diagnosed with ovarian cancer each year in Ireland and almost 300 women die every year. Early diagnosis can significantly improve survival. For more information and useful resources check out www.thisisGO.ie

Details of the World Ovarian Cancer Day Press Release can be found on the INGO page and a copy of the outputs achieved [INGO Outputs - ISGO](#).



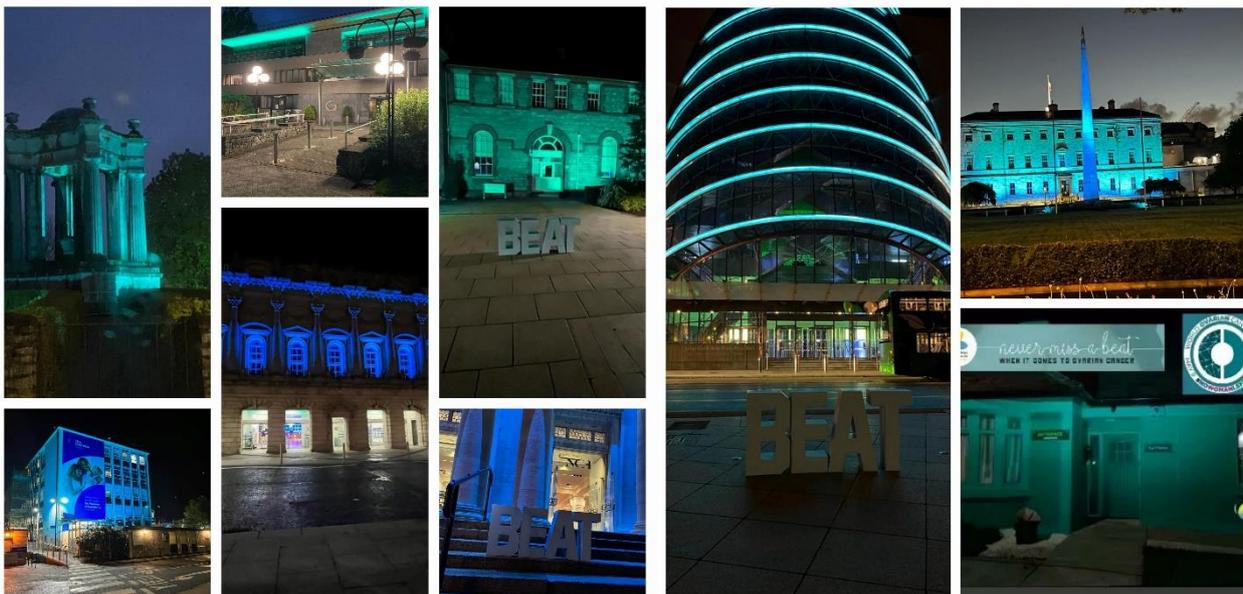
ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

The Sasha Terfous spoken word video created for the 2022 campaign was also promoted again on social media and viewings were almost double 2022 figures.



We also ran our annual buildings lighting up in TEAL (<https://drive.google.com/file/d/1-D7hosQCTuK5hdzJNnuWeUMYHOaHB9aw/view?usp=drivesdk>) as part of the campaign which was very successful. To mark World Ovarian Cancer Day, the following buildings generously agreed to participate in our campaign on 8th May by lighting up in teal, the colour associated all over the world with the fight against ovarian cancer –Bunratty Castle, Co. Clare; City Hall, Cork; The Coombe Hospital, Dublin; Cork County Hall; Donegal County Council; East Galway and Midlands Cancer Support Centre, Ballinasloe, Co. Galway; Galway City LCDC; Heuston Station, Dublin; Laois County Council; Le Poer Trench Monument, Ballinasloe, Co. Galway; Leinster House, Dublin; Limerick City Hall; Mansion House, Dublin; Monaghan County Council; National Concert Hall, Dublin; St Lukes Hospital, Rathgar, Dublin; St. James’s Hospital, Dublin; The Convention Centre Dublin, Titanic Belfast and University College Dublin Water Tower. A selection of images below.



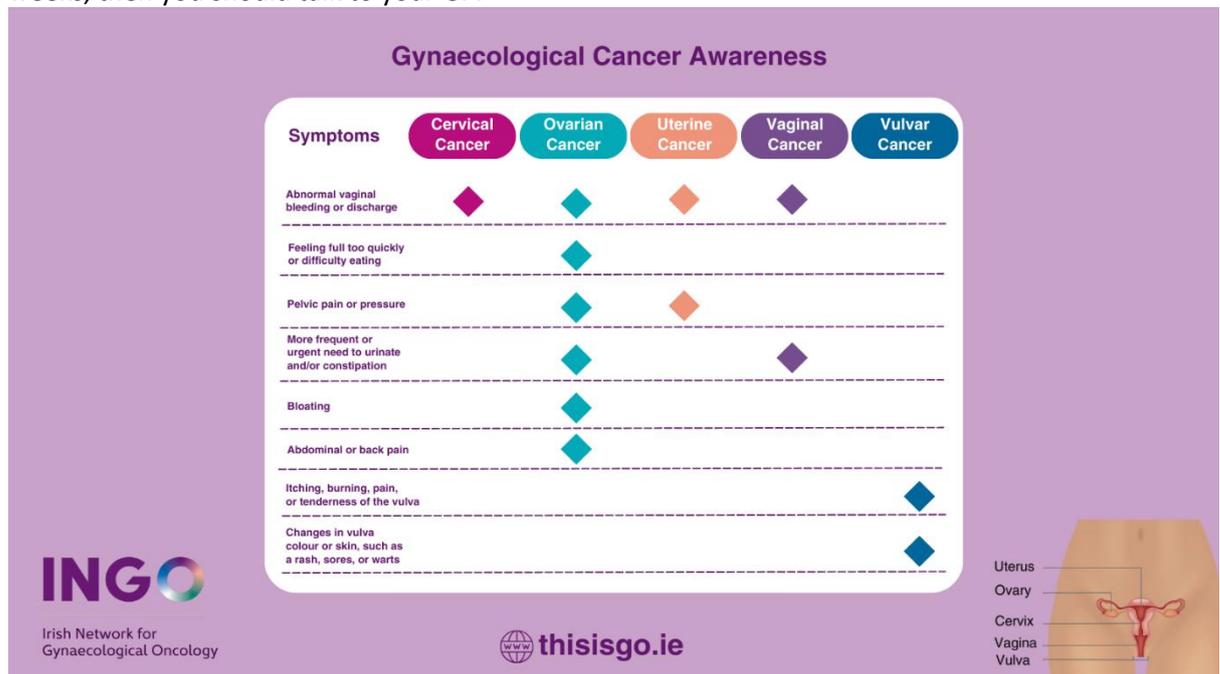
2. Awareness Event: World Gynaecological Oncology Day 20th Sept 2023

Raising awareness of gynaecological cancers

On the 20th of September the Irish Network of Gynaecological Oncology (INGO) which include thirty of Ireland’s foremost gynaecological cancer campaigners, researchers and patient advocates came together to raise awareness about all five gynaecological cancers (ovarian, cervical, uterine, vulval and vaginal) and their risk factors. World GO Day aims to educate people worldwide about the importance of sharing information in relation to prevention, screening, symptoms, early diagnosis and treatment.

Research commissioned by the Irish Network for Gynaecological Oncology (INGO), showed that one in three women in Ireland (34%) mistakenly believe that cervical screening checks for all five gynaecological cancers. The CervicalCheck Screening Programme assesses whether a woman is at risk of having cervical cancer, there is no screening for the other gynaecological cancers.

The graphic highlights the common symptoms of gynaecological cancers, but there are more symptoms that relate specifically to each type. If you have persistent symptoms for longer than two weeks, then you should talk to your GP.



To further increase awareness of the symptoms of gynaecological cancers, the INGO partnered with Riley, an Irish subscription based delivery service offering eco-friendly, toxin-free period products. A leaflet detailing the symptoms of all five gynaecological cancers was distributed to Riley’s subscribers throughout the month of September.

Details of the World GO Day Press Release and a copy of the outputs achieved can be found on the [INGO webpage](#).

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Dip or Dance

Throughout September, people were invited to take part in a Dip or Dance with HSE National Cancer Control Programme sponsored hats, to remind women that maintaining a healthy weight and staying active can reduce the risk of developing Uterine Cancer.



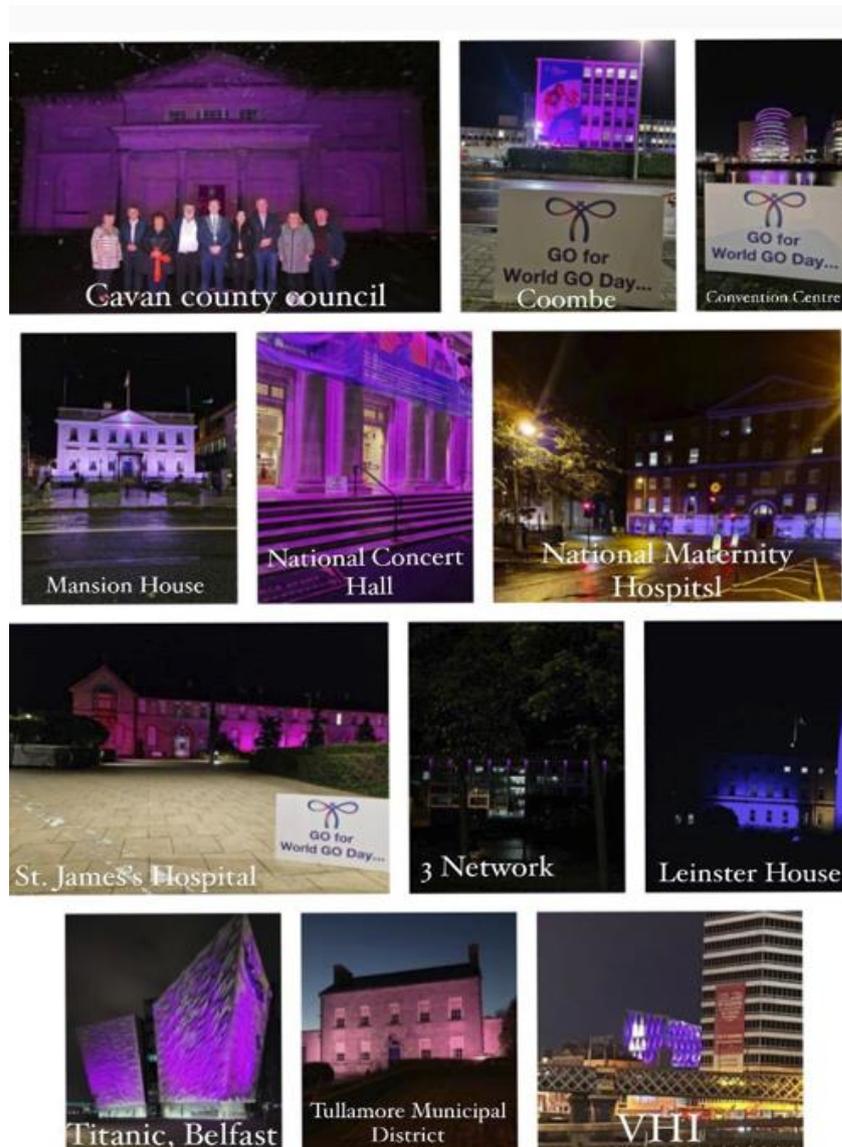
<https://www.instagram.com/reel/CxaGb-voviK/?igsh=MTE1MmNwajBndDdjcg%3D%3D>

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Light Up in Purple

To mark World GO Day 22 buildings across Ireland will light up in purple, the international campaign colour including; Cavan Court House, Convention Centre Dublin; The Coombe Hospital, Dublin; Cork County Council; Derry City Strabane City Council; East Galway and Midlands Cancer Support Centre, Ballinasloe, Co. Galway; Galway County Council; Laois County Council; Le Poer Trench Monument, Ballinasloe, Co. Galway; Leinster House, Dublin; Mansion House, Dublin; Rock of Cashel, Tipperary; Limerick City Hall; Offaly County Council; Purple House Cancer Support, Wicklow; Sligo County Council; St James's Hospital, Dublin; Titanic Belfast; Tuam Clock Tower, Co Galway; University College Cork; Wexford County Council; Wicklow County Council. A selection of images are shown below.



3. PR Award Best Healthcare Campaign



Sharon O’Toole was delighted to receive the Best Healthcare Campaign Award on behalf of the Irish Network for Gynaecological Oncology at the PRAwards 2023 in the Round Room, Mansion House. The aim of the network is to raise awareness of the 5 gynaecological cancers. The campaign “Giving gynaecological oncology a voice” focused around 2 global awareness days; World Ovarian Cancer Day on May 8th and World Gynaecological Oncology (GO) Day on Sept 20th.

Ireland has one of the highest death rates in Europe from ovarian cancer. Over 75% of patients present with late-stage disease, partly due to the vagueness of symptoms and the similarity with other conditions such as irritable bowel syndrome. The World Ovarian Cancer Day campaign focused on highlighting the BEAT (Bloating, Eating difficulties, Abdominal pain, Toilet changes) symptoms of ovarian cancer.

The Dip or Dance campaign on World GO Day for raising awareness of uterine cancer and how to reduce the risk got people swimming and dancing across the country.

The campaign surpassed all expectations with a reach of over 12 million across both awareness days. The wonderful patients who volunteered to share their story brought the human side to the campaign. The network are delighted to have started a conversation around gynaecological cancers and hope to build on our efforts annually.

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

4. National and International Meetings

ESGO Engage patient advocacy meeting Istanbul Sept 29th- Oct 1st 2023.

ISGOPPI is a member of the Engage network which is part of the European Society of Gynaecological Oncology (ESGO) and had an opportunity to highlight their work at the annual meeting in Istanbul. Yvonne O'Meara attended this in-person meeting on behalf of ISGOPPI. Details of the programme are available [here](#).

ESGO | European Network of Gynaecological
Cancer Advocacy Groups



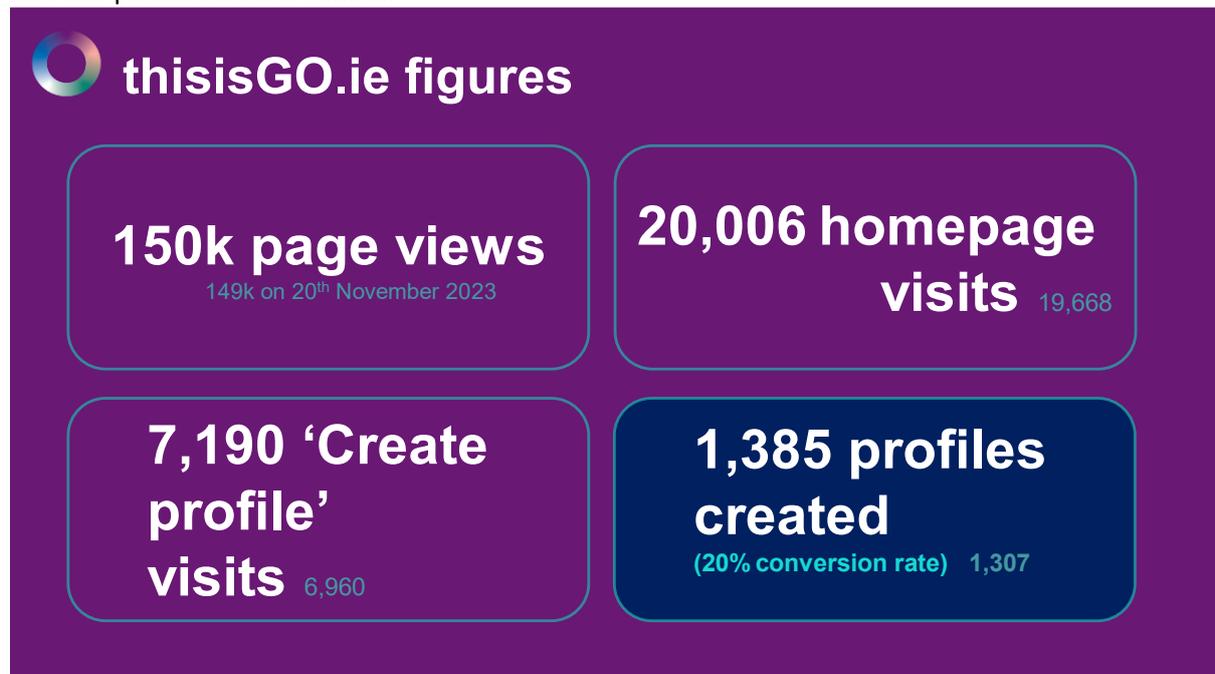
11th DATIENIT

- **Irish Society for Gynaecological Oncology Annual Meeting Belfast Dec 1st 2023**
The ISGO held a face-to-face meeting in Belfast on Dec 1st. ISGO-PPI members were able to join this meeting in person. A wonderful array of speakers demonstrating the cutting edge medicine and science happening in Ireland was organised by Dr Ian Harley. Details on [ISGO-Programme-2023-Belfast.pdf](#)
- **OvaCare Patient Day 2023**
OvaCare held its annual patient day in conjunction with the ISGO annual meeting in Belfast on Dec 2nd. ISGOPPI had a desk at this meeting. Videos of the talks are available [here](#).

5. Irish Cancer Society Women's Health Initiative

The Women's Health Initiative based in the Mater Misericordia University Hospital (MMUH) has focused on Five projects since it began in 2020.

The online personalised platform for patients, family, and health care professionals, thisisGO.ie was completed in Dec 2022. It includes all five gynecological cancers (ovarian, cervical, uterine, vulvar, and vaginal) and two genetic pathways for BRCA and Lynch Syndrome. Public and Patient Involvement (PPI) is key to it's success. We ran a number of focused groups in 2023 to continue to improve the platform and populate it with relevant and relatable material. We plan in 2024 to have a more robust directory of services, translate our most popular articles into audio and to centralise all pharmaceutical trails clinical and non pharmaceutical clinical.



In 2023 we evaluated thisisGO.ie and had a 96% satisfaction and recommendation rating. Thank you for all your helpful feedback and input into this project. If you ever wish to share your story, please get in touch with me at yvonne.omeara1@ucd.ie it is one of the most popular features on the site.

The Menopause After Cancer Study (MAC study) has been novel in its approach. There has been a dearth in addressing menopausal symptoms in the female cancer population. The MAC study was awarded the American Society of Clinical Oncology GRASP Advocate choice award 2023. Supporting the importance and relatability of the study to the PPI population. Results are helping inform the clinical management of these women. It has been an important initiative given the national conversation around menopause over the last few years.

Following on from the hugely success Menopause After Cancer Study (MAC) The Sleepio After Cancer Study (SAC Study) began in 2023 and is a randomised controlled trial examining the efficacy of digital Cognitive Behavioural Therapy for insomnia in women cancer patients. Recruitment is on target for completion at the end of 2024. If you are Women aged ≥ 18 years old have a Cancer diagnosis (current

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

or prior) and have Internet access, Fluent in written and spoken English contact Dr Teresa Treacy teresa.treacy@ucdconnect.ie

The Sleepio After Cancer (SAC) Study

Digital cognitive behavioural therapy for Insomnia (dCBT-I) in women cancer patients - A Randomised Controlled Trial

Primary Investigator Prof Donal Brennan, Co-Investigator Dr Teresa Treacy
teresa.treacy@ucdconnect.ie



The study

Participants

- Women
- ≥18 years old
- Cancer diagnosis (current or prior)
- Internet access
- Fluent in written and spoken English

Intervention

- Digital cognitive behavioural therapy for insomnia (dCBT-I) delivered on the Sleepio™ platform
- 6 x 20 minute sessions
- Fully automated
- Personalised content

Comparator

- Sleep Hygiene Education (SHE)
- Those randomised to SHE will receive access to Sleepio at the end of the Study

Primary Outcomes

- Mean Continuous Change in Sleep Condition Indicator (SCI) score at 6 months
- Proportion of women with SCI>16 at 6 months

Secondary Outcomes

- Sleep related QoL
- Anxiety
- Depression
- Fatigue
- Hot Flash Interference

Experience of Sleepio Study

Addie, 55
Thank you for allowing me to be part of this research. It has helped improve my sleep and it has helped.

Michelle, 53
It has been v helpful thank you for letting me take part

Gill, 48
I've seen a marked improvement in my sleep.

Joanne, 45
My sleep is vastly improved and I will be eternally grateful for the intervention and study. Thanks a million

Margaret, 50
Many thanks for the access to the trial. It was, and is, great to have access to the programme.

Donagh, 44
I did find the sleepio app very helpful. It has definitely had a positive impact on my sleep.

Marie, 31
It's made a huge difference to my sleep and my overall well being.

Marina, 45
I found this intervention very helpful!

We are aiming to recruit 308 women to the SAC Study
To refer please email teresa.treacy@ucdconnect.ie
Scan the QR code to take patient to patient information



Research contribution

30% of cancer patients meet DSM insomnia diagnostic criteria, which is double the prevalence compared to the non-cancer population

The SAC study aims to assess the efficacy of dCBT-I in women cancer patients, with the aim of improving sleep parameters as well as sleep related QoL measures

The availability of face to face CBT is a barrier to treatment and dCBT-I offers an exciting and potentially efficacious alternative

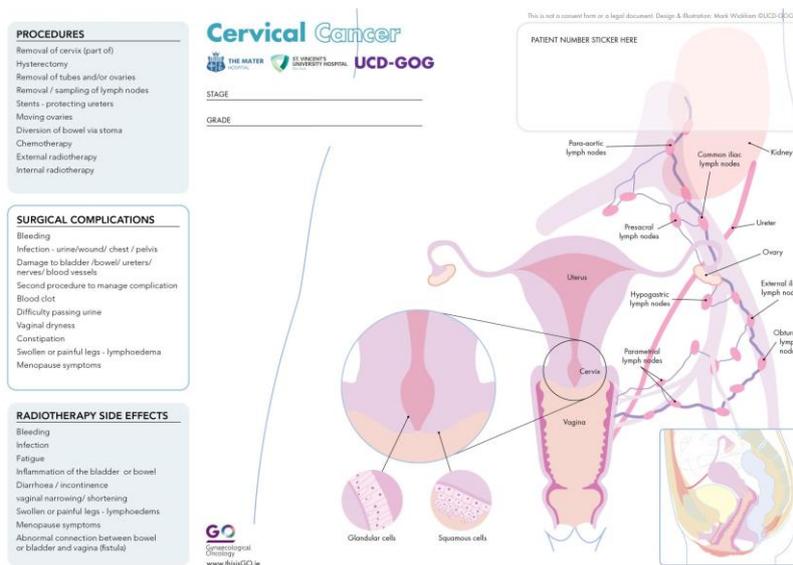


ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

The GO Cancer Centre. Nurse led, patient identified survivorship clinics were set up in 2021 in St Vincent's University Hospital and MMUH. Attendance has gone from 52% to 84% and continue to go. This will be evaluated in 2024.

The Diagnosis Delivery Project (Visual and written aids for those attending clinics) has been hugely successful and was awarded the ESGO Engage Project of 2023 and is being rolled out across Europe. We are currently working on a breast version and have had several PPI groups partake in it. If you have been diagnosed in the last year in any of the cancer centres in Ireland and did not receive an image (see sample below) please get in touch with me on yvonne.omeara1@ucd.ie. If you wish to share any feedback about receiving these images please also connect with me.



The PPI has been fundamental to all of these projects. It would have been very challenging to get them off the ground without your support. A big thank you from all the Team at UCD and the Mater Hospital (Prof Donal Brennan, Yvonne O'Meara, Dr Fionan Donohoe, Aidin Roberts and Dr Teresa Tracy)

Publications

- 1) https://ascopubs.org/doi/abs/10.1200/JCO.2023.41.16_suppl.12024
- 2) Donohoe F, O'Meara Y, Roberts A, Comerford L, Kelly CM, Walshe JM, et al. The menopause after cancer study (MACS) - A multimodal technology assisted intervention for the management of menopausal symptoms after cancer - Trial protocol of a phase II study. *Contemp Clin Trials Commun.* 2021;24:100865.
- 3) Donohoe F, O'Meara Y, Roberts A, Comerford L, Kelly CM, Walshe JM, et al. Using menopausal hormone therapy after a cancer diagnosis in Ireland. *Ir J Med Sci.* 2022.
- 4) Teresa Treacy, Yvonne O'Meara, Marie C Galligan, Alasdair L Henry, Sarah F Lensen, Michaela J Higgins, Martha Hickey, Donal J Brennan. The Sleepio after cancer (SAC) study. Digital cognitive behavioural therapy for insomnia (dCBT-I) in women cancer patients - Trial protocol of a randomised controlled trial PMID: 37741507 DOI: [10.1016/j.cct.2023.107337](https://doi.org/10.1016/j.cct.2023.107337)
- 5) Brennan DJ. Language and medicine: Breaking the barriers in gynaecological cancer. *Case Rep Womens Health.* 2021;32:e00361.

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

6. Research Projects

2023 was a busy year for the ISGOPPI group with numerous requests coming through for PPI involvement in projects. Projects are detailed below and for the first time we have now asked for a testimonial from researchers to outline how the patient involvement impacted their project and also from a patient to give their experience of being involved. We hope these testimonials will encourage others to get involved in PPI. The projects detailed below display the range of projects taking place in the area of gynaecological cancer and also the scale of involvement across Ireland.

Summary of requests for PPI Input 2023

SEXUAL INTIMACY (UCC)	SURGICAL BOOKLETS (Mater)	TREATMENT SUMMARY (Mater)	LIQUID BIOPSY (TCD)	LYNCH SYNDROME (SJH/Mater)
VULVOVAGINAL BOOKLET (Mater/UCD)	ISGO PODCAST (ISGO)	EXERCISE INTERVENTION (TCD)	RADIOTHERAPY (TCD)	ONCOLOGY DAY WARD DESIGN (DCU)
PATIENT PASSPORT (SJH)	WORLD OVARIAN CANCER DAY (INGO)	WOCD LUNCH AND LEARN (MSD)	WORLD GO DAY (INGO)	PPI CHOICE AWARD (ISGOPPI)
LAURA BRENNAN AWARD (ISGO)	SLEEP AFTER CANCER (Mater/UCD)	CLINICAL TRIALS (Mater/UCD)	NCPE SUBMISSION (ISGOPPI)	SURVEY (PRECISION ONCOLOGY IRELAND)
OVARIAN CANCER DIAGNOSIS (UCC)	AROMATHERAPY (TCD)	PATIENT INFORMATION LEAFLET GYNAE (Mater)	Dilator Project (Mater/UCD)	Ovarian Cancer Decision Aid (Mater/UCD)

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Researcher Feedback on PPI

Collaboration with PPI for the Sleepio After Cancer study has been a really invaluable asset. Consultation with PPI allowed us to tailor how best to approach women who may benefit from the intervention which we provide through our study; as well as streamlining our recruitment process.

Feedback provided to us from the PPI process has been really encouraging. Thank you ISGO-PPI

(Teresa Treacy, SAC Study)

I conducted a cross sectional study of modifiable risk factors in people with Lynch syndrome. PPI played an integral role in my study. Throughout the project, I met with representatives from Lynch syndrome Ireland to ensure it was of interest and relevance to patients. The survey that was used to collect data was piloted by a group of Irish people with Lynch syndrome, and I held a focus group to gather feedback and explore patients' views on research priorities for Lynch syndrome. This feedback was incorporated to improve the methods of data collection, and the survey itself was disseminated in part by Lynch syndrome Ireland. As a clinician, I found directly engaging with patients, through PPI, the most rewarding part of my research project. This would not have been possible without the help and guidance of Sharon O'Toole and Yvonne O'Meara from ISGOPPI.

(Robert Power SJH and Mater)

I was delighted to have participation from members of the ISGO-PPI to review our newly devised patient information surgery leaflets. These leaflets which prepare patients for what to expect in terms of their surgery have been divided into 3 leaflets:

Getting ready for surgery, After surgery (In Hospital), Going home after surgery

The feedback we received was reassuringly positive especially given that all participants of the focus group had prior surgery. Knowing that this patient information would be welcomed by women who have had surgery in the past reaffirmed the need for the initiative. All suggestions made by the group were greatly appreciated and were inputted into the leaflets. The input from the ISGO-PPI focus group ensures that we are listening to the patient's voice and ensures our information leaflets are in line with their expectations.

(Sheilah Broderick, Clinical Nurse Specialist, Mater)

PPI Feedback on Research

Our involvement is meaningful and it is very rewarding to know you have helped shape ovarian cancer research by sharing your story of your lived experience of this disease. Getting involved in PPI has been a wonderful, exciting experience and has given me some great opportunities.

Bridget Carr

I was thrilled when ISGOPPI reached out with an invitation to partner up to address the information needs of people living with genetic predisposition syndromes through the development of a new patient platform - ThisisGO.ie. As a patient rep for the lynch syndrome community I can't tell you how important it is to have someone really listen to the needs of your community and work with you to create positive change...

Now when someone newly diagnosed with Lynch syndrome is looking for information I can confidently point them to a trustworthy source of information that was designed with patient input at the heart of it. I highly recommend getting involved with ISGOPPI. It is rewarding, empowering and you'll be warmly welcomed.

Roberta Horgan, Lynch Syndrome Ireland

ISGO-PPI

Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

7. ISGO Podcast Series

'Hosted by Dr Doireann O'Leary, The ISGO podcast was launched in 2023. The aim of this podcast was to highlight womens' lived experience of gynaecological cancers.

6 episodes have been recorded so far and can be found on spotify <https://open.spotify.com/show/6186kDjcP9dCrzloBkD35n?si=7f42d6e0b8614842> and multiple media outlets have covered the podcast including the Irish Examiner <https://www.irishexaminer.com/lifestyle/healthandwellbeing/arid-41306941.html>



Thank you so much to all of the women who gave so generously of their time in preparing for and taking part in the podcast and to our sponsors Breakthrough Cancer research. We hope to create more episodes in 2024'

8. Laura Brennan Award

Laura Brennan had received the inaugural award in Belfast in 2018 for her endless campaign for the HPV vaccine. With Laura, it was decided that the Laura Brennan Award would be presented on an annual basis by the ISGO to a patient or member of the public as a recognition of outstanding achievement in the areas of gynaecological oncology patient advocacy and or patient and public involvement in research. Joan Moore was a worthy recipient of the award in 2019. Sadly Joan passed away on 2/9/22, the award was very special to Joan and this recognition was something she was extremely proud of and it was lovely to see it being presented as a symbol of her advocacy achievements on the day of her funeral.

Jacqueline Daly received the award in 2020 and worked closely with the Brennan family to continue Laura's legacy, and what a wonderful job she did and continues to do.

Kim Hanly was the recipient in 2021 and together with Jacqueline and ISGO worked with Laura's parents to advocate for the catch up programme. A testament to Laura's family and their tireless efforts to achieve this, the Laura Brennan Catch up Programme was established.

Roberta Horgan from Lynch Syndrome Ireland was the 2022 recipient of the Laura Brennan Award and is an amazing advocate across all cancers. Roberta worked with the Brennan family and used her social media skills to increase awareness around HPV vaccination.

Bridget Carr (pictured here with Bernie and Larry Brennan, Laura's parents) is the 2023 recipient of the Laura Brennan Award. Bridget Carr epitomises what it is to be a PPI advocate as she has been involved with multiple research projects, volunteering her voice to improve the quality and relevance of gynaecological cancer research since she was diagnosed herself in 2019. An active member on patient advisory committees, sharing her story with positivity and honesty (not to mention great sense of humour) while giving so freely of her time. As a patient committee member for Cancer Trials Ireland she has contributed to clinical trials in gynaecological cancer. In addition to being a member of the ISGO public and patient involvement (ISGOPPI) group, she is also involved in lab-based research in UCD offering guidance and support to those in need. Bridget has contributed to the painting by Vincent Devine *The Vitruvian: Uncovering the Layers of Cancer* for Science Week 2023 and has spoken about this at an event held in Dundrum Town Centre. She has also co-authored a publication on PPI in lab-based research and was invited to speak about this at a Patient Engagement Journal Club in Canada. In recent months she has been involved in setting up a private support group on Facebook providing a safe, secure platform for those affected by ovarian cancer.



PLANNED ACTIVITIES 2024

May 8th 2024 World Ovarian Cancer Day

May 16th 2.30-5.30pm Training Workshop Dublin

June Uterine Cancer Awareness Month (IGCS)

September 20th 2024 World Gynaecological Cancer Day

Oct 15th IGCS-IGCAN Gynecologic Cancer Survivor-Caregiver Summit Convention Centre Dublin
(Agenda to follow)



The International Gynecological Cancer Society (IGCS) will hold its annual meeting for the first time in Dublin this year Oct 16th -18th. This will be preceded by the 2024 IGCS-IGCAN Gynecologic Cancer Survivor-Caregiver Summit on Oct 15th. Details may be found at www.igcsmeeting.com

The World Ovarian Cancer Coalition will also be in Dublin at this time.

In addition, the Gynecologic Cancer Intergroup will hold its first ever consensus conference in cervical cancer in Dublin Castle on 14th and 15th Oct.



Irish Society of Gynaecological Oncology
Public and Patient Involvement Group

Acknowledgment

In 2023, we are aware that some of you due to health-related matters have had to step down from participation in ISGO-PPI. We would like to thank you for your support, lens and your expertise over the years and hope that you may be well enough to return in due course.

We would also like to remember our members who have died as a result of gynaecological malignancy. In their death, we lost some fantastic and amazing patient advocates who really wanted to make a difference in gynaecological oncology. We fondly remember them and their contributions. On behalf of ISGO-PPI we would like to thank them for their contribution and for trying to make a difference for all women with gynaecological cancer. We hope their contribution will inspire others. We offer our sincere condolences to their loved ones.

Go raibh maith agat agus ar dheis De go raibh a n-anamacha.