

ENGAGeO⁺

EUROPEAN NETWORK
OF GYNAECOLOGICAL CANCER
ADVOCACY GROUPS

14th Patient Advocacy Seminar

February 26–28, 2026, Copenhagen, Denmark

2026



THANK YOU for supporting the 14th ENGAGe Patient Advocacy Seminar in Copenhagen! We were glad to welcome **71** participants from **36** patient advocacy groups and **25** countries.



We welcomed participants from:

- Albania
- Belgium
- Cyprus
- Czech Republic
- Denmark
- Finland
- France
- Georgia
- Germany
- Greece
- Hungary
- Ireland
- Israel
- Italy
- Norway
- Poland
- Portugal
- Romania
- Serbia
- Slovenia
- Spain
- Sweden
- The Netherlands
- Türkiye
- United Kingdom

FRIDAY, 27 February 2026

Opening remarks

SPEAKERS: **Prof. Anna Fagotti** (Fondazione Policlinico A. Gemelli, Italy)
Kim Hulscher (Olijf, The Netherlands)
Prof. Philippe Morice (Institute Gustave Roussy, France)



- ▶ On behalf of everyone, Prof. Philippe Morice thanked Prof. Anna Fagotti, past president of ESGO, for all of her achievements during her mandate for her endless support of patients. Prof. Fagotti strongly believes that patients must remain at the core of ESGO and has shown an unwavering commitment to ensuring their voices are central.
- ▶ Kim Hulscher presented the ENGAGe Award. 17 projects were nominated and the winner was The Eve Appeal's Get Lippy campaign, an annual campaign in May that works with leading brands in the beauty industry to raise awareness of the five gynae cancers: endometrial, ovarian, cervical, vulval and vaginal.
- ▶ Athena Lamnisos from The Eve Appeal accepted the award, stating that it was an honour and that they could not do the work that they do without patients being at the heart of everything. The funds raised during the campaign will be used for awareness activities and on investing in research.

SESSION 1

Prevention

Innovating Against HPV: The Science Driving the Next Generation of Vaccines

SPEAKER: Prof. Elmar A. Joura (Medical University of Vienna, Austria)



- ▶ Prof. Joura gave a brief overview of the current status of HPV vaccines, what can be expected within the next couple of years, and what to expect of future vaccines.
- ▶ Six different cancers are related to HPV, and the first generation of bivalent and quadrivalent vaccines have been extremely successful according to the data from five countries.
- ▶ However, there is a global need for new vaccines. He highlighted the progress being made by some companies in developing affordable vaccines, which is a game changer in making it possible to provide global coverage.
- ▶ As important as the vaccines themselves is the design of the coverage program – it has to be robust and school-based. When there is high coverage, those not vaccinated are protected through the herd effect.
- ▶ He emphasised the importance of gender-neutral vaccination which is now done in the majority of countries. Gender neutral vaccination potentially doubles the coverage.

SESSION 1 Prevention

Genetic Risk Beyond BRCA: What's New in Hereditary Gynaecologic Cancer

SPEAKER: Prof. Claudia Marchetti (Policlinico Universitario Agostino Gemelli, Italy)

- ▶ 20% of ovarian cancer is related to the BRCA gene and other genes related to DNA repair, therefore more needs to be done for those who have this mutation.
- ▶ NCCN guidelines recommend removing ovaries to the BRCA gene carrier starting from 45 years old, and those with Lynch syndrome genes even earlier.
- ▶ Current testing utilises several criteria including family-based criteria, personal cancer history and overall clinical criteria. But more needs to be done to avoid missing people when testing is only based on these criteria. Prof. Marchetti suggests the possibility of population-based screening in the future to avoid cancer in healthy women.
- ▶ She also advocates the use of the Pap smear to identify ovarian cancer at a very early stage and as a form of prevention.

DISCUSSION

- ▶ Prof. Joura was asked about the feasibility of achieving 90% vaccination coverage and the potential benefits of gender-neutral vaccination. He explained there are challenges to achieving high vaccination rates, with most countries struggling to get over 80% even in countries like Australia which are doing well.
- ▶ He highlighted the important role of patient organisations in spreading awareness about vaccination. If the advice is coming from doctors or the medical industry, people may be more cautious. However coming from peer groups like patient organisations, the information may be seen as being more trustworthy and acceptable.
- ▶ A question was asked about the single-dose vaccine and its effectiveness compared to multiple doses. Prof. Joura stated they now have five-year data that proves single-dose vaccines work; however, they do not have long term data. For multiple doses, data up to twenty-five years shows there is 100% efficacy.
- ▶ He highlighted the importance of high coverage, because then vaccination does not have to be perfect. When there is low coverage, every person needs the perfect protection.
- ▶ Prof. Marchetti was asked about the prevalence of sporadic ovarian cancer and the challenges of testing patients. She explained that the current literature states it is at 80%, but there are geographical variations in sporadic ovarian cancer prevalence. She highlighted the importance of cost-effective testing.
- ▶ A question was asked about the reasons for low testing rates and the potential for improving testing practices. Prof. Marchetti explained the need for population-based screening and the importance of integrating new prevention strategies into clinical practices.

SESSION 2

Symptoms & Diagnosis

Early Detection and Artificial Intelligence: The Future of Gynaecologic Cancer Diagnosis

SPEAKER: Prof. Frédéric Amant (UZ Leuven, Belgium)



- ▶ Prof. Amant explained the process of colposcopy and the role of artificial intelligence in assisting gynaecologists in biopsy decisions.

- ▶ He discussed the challenges gynaecologists face in diagnosing cervical cancer and the potential benefits of artificial intelligence. Data shows that AI can identify cervical cancer with high accuracy but struggles with early-stage lesions.

- ▶ There are also ethical considerations and data privacy issues in using AI for cancer diagnosis.

- ▶ He discussed the application of AI in vulvar pathology, noting the overlap between expert and AI-identified biopsy sites. Data shows that AI can potentially identify low and high-grade lesions in the vulva.

- ▶ In terms of breast cancer, the Maasai study on breast cancer screening with AI-supported mammography demonstrates that it can improve screening performance and reduce workload.

- ▶ AI also works with high accuracy in ultrasound for ovarian tumour differentiation. The data shows that AI can help pathologists identify areas at risk for endometrial cancer.

- ▶ A study was introduced that used pathology data to predict cancer types and prognosis, demonstrating AI's ability to identify subtle differences.

- ▶ Prof. Amant believes that AI will revolutionise cancer diagnosis and treatment, particularly in low-resource settings.

SESSION 2

Symptoms & Diagnosis

Rare Gynaecologic Cancers: The Importance of Early Detection & Communication

SPEAKER: Prof. Philippe Morice (Institute Gustave Roussy, France)



- ▶ Prof. Morice highlighted the importance of teamwork in diagnosing and treating rare gynaecological cancers, involving gynaecological oncologists, pathologists, medical oncologists and radiologists.
- ▶ European authorities play an important role in defining and managing rare diseases, including ovarian, uterine, and cervical cancers. There is a need for skilled pathologists and molecular biologists in diagnosing and treating rare gynaecological cancers.
- ▶ Data shows that the centralisation of care can increase the survival rate in patients with soft tissue sarcomas.
- ▶ It is important to have early diagnosis and fertility-sparing management in rare gynaecological cancers. The role of patient advocacy and education is also significant in improving the management of these cancers.
- ▶ Prof. Amant also discussed the potential role of AI in diagnosing and treating rare gynaecological cancers, noting the need for human expertise in rare cases.
- ▶ The role of networks and collaborations is important in improving the management of rare gynaecological cancers and there is a need for specific trials and guidelines.

SESSION 2

Symptoms & Diagnosis

Liquid Biopsy & Blood-Based Screening: The Next Step Toward Non-Invasive Diagnosis

SPEAKER: Prof. Iain McNeish (Imperial College London, United Kingdom)

- ▶ Prof. McNeish outlined the different types of liquid biopsies, including circulating tumour DNA, circulating tumour cells, and ascites.
- ▶ The advantages of liquid biopsies over traditional tissue biopsies include reduced invasiveness and the ability to monitor disease over time.
- ▶ Applications of liquid biopsies in cancer diagnosis and monitoring include the use of circulating tumour DNA to predict prognosis and guide treatment. Data shows the ability of circulating tumour DNA to identify residual disease and predict recurrence.
- ▶ Liquid biopsy tests have to be validated to ensure their accuracy and clinical utility, but they have the potential to revolutionise cancer management, particularly in gynaecological cancers.
- ▶ Prof. McNeish also highlighted the potential cost savings of using AI to reduce the need for expensive imaging and follow-up tests.

DISCUSSION

- ▶ Discussion focused on the critical need for cooperation in rare cancers between patients, patient advocates, organisations, doctors and clinicians.
- ▶ Discussion also centred around the efficacy of AI versus a doctor in diagnosis. Some argued that AI can help a doctor to make the right diagnosis and offer the best treatment possible, even for a doctor who does not have that particular expertise.
- ▶ Others argued that due to the complexity of the decision-making process, the multitude of factors that need to be considered and the data that need to be integrated, a human being is in the best position to do this over AI.
- ▶ A question was asked about ultra rare cancers and when they might become less rare. The response was that the decision-making process needs to be more integrated in ultra rare cancers, so they can be responded to with speed but without impairing the prognosis of the patients.
- ▶ A question was asked about the cost effectiveness of liquid biopsy testing and how such extremely expensive screening tests can be justified. The response was two-fold. First that the technology will become cheaper over time, and secondly, it is able to provide information that cannot be achieved in any other way, and this unfortunately makes it expensive.



SESSION 3
Treatment**Current and Future Landscape of Immunotherapy****SPEAKER: Prof. Alexandra Leary** (Gustave Roussy Institute, France)

- ▶ Prof. Leary explained the basics of immunotherapy and its effectiveness in certain gynaecological cancers. The immune system recognises and attacks foreign pathogens like bacteria and viruses. Certain cancer cells, especially those with defective repair systems, can be recognised by the immune system and treated with immunotherapy.
- ▶ She highlighted the success of immunotherapy in MSI endometrial cancer and HPV-driven cervical cancer.
- ▶ She also discussed the challenges in treating ovarian cancer with immunotherapy and the recent positive trial in platinum-resistant ovarian cancer.
- ▶ Future of immunotherapy: there is a need for newer immunotherapies and she discussed three approaches: vaccines, bispecific T-cell engagers (BiTEs), and tumor-infiltrating lymphocytes (TILs).
- ▶ An international study used an anti-tumour vaccine for ovarian cancer. BiTEs have the potential to increase the immune system's ability to kill tumour cells, while TILs, which are personalised T-cell therapies, are mainly tested in cervical cancer.

Radiotherapy Today: How New Techniques and Brachytherapy Improve Care**SPEAKER: Prof. Remi A. Nout** (Erasmus University Medical Centre Rotterdam, The Netherlands)

- ▶ Prof. Nout discussed the basics of radiotherapy and its effectiveness in cancer treatment. There are challenges in treating gynaecological cancers due to tumour motion and the importance of precision in radiotherapy.
- ▶ There have been technological advancements in radiotherapy, including intensity-modulated radiotherapy (IMRT), image guidance, and AI. In particular, he highlighted the role of AI in automating treatment planning and reducing treatment time.

SESSION 3

Treatment

Precision Markers and Biomarker Testing in Gynaecological Cancers

SPEAKER: Dr. Roman Kocián (Všeobecná fakultní nemocnice v Praze, the Czech Republic)

- ▶ Prof. Kocián explained the concept of biomarkers and their importance in making better treatment decisions. He discussed the tumour microenvironment and the need for precision diagnostics to guide treatment.
- ▶ He provided example of different biomarkers, including HRD and MMR deficiency, and their impact on treatment responses.
- ▶ There is a need for better access to biomarker testing for patients for effective care.
- ▶ A biomarker is a measurable signal coming from a tumour. It can be detected in tissue, DNA or blood.
- ▶ He explained that two patients can have the same stage of the disease and same pathology report but the tumours may behave differently due to different tumour biology.

Antibody–Drug Conjugates (ADCs): A New Era in Gynaecologic Malignancies

SPEAKER: Prof. Toon Van Gorp (University Hospital Leuven, Belgium)

- ▶ Prof. Van Gorp explained ADCs and their mechanism of action in targeting cancer cells.
- ▶ He explained the development and approval of ADCs for specific types of ovarian and cervical cancers. Some adverse events have been associated with ADCs, therefore he stressed the importance of proper targeting.
- ▶ There are ongoing clinical trials and the potential for future advancements in ADCs, the focus is on making ADCs more effective with fewer side effects.
- ▶ Every ADC has its own unique side effect profile. Payloads can be released into the bloodstream and for very toxic chemotherapy this can cause side effects. It can also have side effects on different parts of the body depending on where the target is. This can include small cysts in the eyes, blisters in the mouth, nausea and vomiting.



SESSION 3
Treatment**Treatment Planning and Perioperative Care:
Myths, Facts and Practical Applications****SPEAKER: Prof. Christina Fotopoulou** (Imperial College London, United Kingdom)

- ▶ Prof. Fotopoulou discussed the evolution of perioperative care and the importance of prehabilitation. She debunked common myths about preoperative care, such as the need for prolonged bed rest and fasting before surgery.
- ▶ Instead, we need to focus on the importance of targeted exercise programs, mental preparation and proper nutrition for patients.
- ▶ The role of enhanced recovery programs in improving patient outcomes and reducing complications was highlighted.
- ▶ Clinical nurse specialists in particular play an important role in providing patient education and support. There is also the need for global collaboration and the development of guidelines for perioperative care.
- ▶ Prof. Fotopoulou highlighted the biggest myth in perioperative care: that patients should be passive and leave it to the professionals. She emphasised that it is patients who bring healing to themselves through motivation and effort. While doctors and healthcare teams guide and support patients throughout the pathway, healing is a deeply personal process in which patients themselves play a central role.

SESSION 3

Treatment

Liquid Biopsy & Blood-Based Screening: The Next Step Toward Non-Invasive Diagnosis

SPEAKER: Dr. Andrea Rosati (Policlinico Universitario Agostino Gemelli, Italy)



- ▶ Dr. Rosati discussed the evolution of minimally invasive surgery and its impact on quality of life. He explained the different declinations of minimally invasive surgery, including laparoscopy, mini-laparoscopy, and robotic surgery.
- ▶ The benefits of minimally invasive surgery include faster recovery, less pain, and improved cosmesis.
- ▶ The tailoring of surgical approaches to individual patients and their specific needs is important, as well as patient-surgeon communication and preoperative counselling.
- ▶ There is a need for ongoing research and development to improve minimally invasive surgical techniques.
- ▶ We are currently in the third wave of surgical innovation which is robotic surgery. The full potential of robotic surgery utilises the integration of new technologies including artificial intelligence. This will be the bridge towards digital surgery, in which a truly minimally invasive experience of surgery can be given to patients.

DISCUSSION

- ▶ A question was asked about re-challenging ICI after first failure and the future of T-cell therapy in gynaecological cancers. Prof. Leary mentioned the lack of data but encouraged attendees to seek further information. She emphasised the importance of scientifically re-challenging ICI in the context of clinical trials.
- ▶ She also discussed the potential role of T-cell therapy in cervical cancer and the complex infrastructure required for its administration.
- ▶ A question was asked about quality of life innovations for radiotherapy. Prof. Nout replied that current technical innovations are aimed at decreasing side effects which will improve quality of life long term. Increasing patient comfort during treatment by decreasing the dose when possible and using radiotherapy with more precision also positively impacts on quality of life.
- ▶ A question was asked about how to manage pain and raising awareness amongst patients that they should not suffer during brachytherapy and other radiotherapy sessions. Prof. Nout responded that pain management is often a combination of anxiety and pain, so addressing the anxiety can also lessen some of the suffering. Overall, ensuring optimal pain medication and guidance by oncologists around managing pain will result in better patient quality of life.
- ▶ A question was asked about leading biomarkers in the future and efforts to make ADCs more accurate. Prof. Kocian explained that the focus is on making the next generation of ADCs more effective with fewer side effects. He also mentioned the importance of using available tools like somatic and germline mutation testing for ovarian cancer and highlighted the need for better education and access to biomarker testing for patients.
- ▶ A question was asked about how to work together to improve and reduce myths around perioperative care. Prof. Fotopoulou emphasised the importance of education and standardisation of perioperative care. She mentioned the role of clinical nurse specialists in providing patient education and support, and highlighted the need for global collaboration and the development of guidelines for perioperative care.
- ▶ A question was asked about the decision-making process for choosing between minimally invasive and open surgery. Dr. Rosati emphasised the importance of patient-surgeon communication and preoperative counselling in the decision-making process. He also mentioned the use of 3D virtual reality for preoperative planning and patient education, and the need for ongoing research and development to improve minimally invasive surgical techniques.

SESSION 4

RECURRENCE, PALLIATIVE CARE

Holding on to Hope

SPEAKER: Virág Karai, Zsuzsanna Koós (The Mallow Flower Foundation, Hungary)

- ▶ A need for understanding recurrence beyond just its clinical aspects and the concept of 'holding onto hope' in the context of end-of-life care.
- ▶ The psychological and emotional impact of recurrence needs to be recognised, including the importance of setting goals and maintaining hope. In addition, social support and meaningful engagement play an important role in maintaining hope.
- ▶ There is a correlation between anxiety, depression, and hope in advanced cancer patients. There is also a difference between major depression and demoralisation, and it is important to distinguish between the two.
- ▶ They highlighted the role of social support, meaningful employment, and identity continuity in maintaining hope. There are also reciprocal benefits of fostering hope for both patients and clinicians.

Ascites and Beyond:

Coping with the Physical and Emotional Burden of Advanced Disease

SPEAKER: Prof. Thais Baert (UZ Leuven, Belgium)

- ▶ Prof. Baert introduced the topic of ascites: its causes and symptoms, and emphasising its impact on quality of life.
- ▶ She explained the disease process behind ascites, including impaired drainage, increased filtration and inflammation.
- ▶ Treatment options for ascites include drainage, corticosteroids, shunts, and novel treatments like catumaxomab.
- ▶ She emphasised the importance of treating the underlying cancer to manage ascites.



SESSION 4

RECURRENCE, PALLIATIVE CARE

Navigating Chemotherapy: How to Look After Your Body, Mind, and Daily Life

SPEAKER: Dr. Houssein EL Hajj (Gustave Roussy Institute, France)

- ▶ Dr. El Hajj introduced the concept of 'navigating chemotherapy' and the importance of self-care and support.
- ▶ He discussed the common side effects of chemotherapy, such as nausea, fatigue, and neuropathy, and ways to manage them.
- ▶ Early intervention for side effects is important as well as the role of antiemetics and other treatments.
- ▶ In addition, maintaining a positive mindset and seeking support from healthcare providers and support groups can aid in navigating chemotherapy.

The session concluded with a discussion on the role of palliative care in improving quality of life and the need for standardised early intervention, as well as the role of patient advocacy groups in supporting patients. In addition, the role of psychologists in helping patients understand and manage their hope as well as other forms of social support. The session was a reminder of the importance of hope, support, and early interventions in cancer care.



SESSION 5

QUALITY OF LIFE

Life After Cancer: How to Monitor Safely Without Losing Peace of Mind**SPEAKER: Prof. Nadeem R. Abu-Rustum**

(Memorial Sloan Kettering Cancer Center, United States of America)

- ▶ Prof. Abu-Rustum highlighted the importance of symptom review and physical exams in follow-up care for endometrial cancer.
- ▶ He emphasised the simplicity of follow-up for endometrial cancer, avoiding unnecessary tests like pap smears and CT scans.
- ▶ Similarly, the follow up protocol for ovarian cancer include regular exams and optional CA 125 tests.
- ▶ The concept of circulating tumour DNA as a potential future biomarker for follow-up.
- ▶ He discussed the follow-up for cervical, vulvar, and vaginal cancers, emphasising the importance of symptom review and physical exams.

**Hormonal Treatment After Gynaecologic Cancer:
Managing Long-Term Toxicities and Menopause****SPEAKER: Prof. Maria Kyrgiou** (Imperial College London, United Kingdom)

- ▶ Prof. Kyrgiou discussed the importance of menopause care in gynaecological cancers, highlighting the symptoms and health risks associated with early menopause.
- ▶ Menopause is traditionally defined as not having a period for 12 months. The average age in the UK is 51 but perimenopause symptoms predate the end of the period by five to ten years.
- ▶ The different types of menopauses include natural, surgical and after chemotherapy. The symptoms include hot flashes, night sweats, sleep disturbances, mood changes, brain fog, depression, low mood, irritability, anxiety, sexual dysfunction, vaginal dryness, joint pains and exhaustion.
- ▶ Apart from the symptoms, there are health risks that are associated with early menopause such as osteoporosis, heart disease, problems with bladder function and so called 'gentle urinary syndrome'.
- ▶ Hormone replacement therapy (HRT) is a treatment that aims to replace those hormones that are not naturally produced anymore.
- ▶ There are risks and benefits of HRT, including the increased risk of breast, ovarian, and endometrial cancer. Prof. Kyrgiou discussed the various types of HRT and their respective risks and benefits, emphasising the importance of individualised treatment.

SESSION 5

QUALITY OF LIFE

Prophylactic Surgery & Quality of Life:

SPEAKER: Dr. Zoltán Novák (National Institute of Oncology, Hungary)

- ▶ Dr. Novák discussed the importance of prophylactic surgery for high-risk patients with mutations like BRCA1 and BRCA2.
- ▶ Surgical menopause induced by prophylactic oophorectomy has an impact on quality of life. Dr. Novák discussed salpingectomy with delayed oophorectomy as a potential solution to reduce the impact of surgical menopause.
- ▶ He highlighted ongoing studies investigating the safety and efficacy of salpingectomy and the potential for improved quality of life.
- ▶ He explained the process of prophylactic surgery in the treatment of ovarian cancer. The majority of ovarian cancer cases are diagnosed in an advanced stage when it is difficult to treat, therefore preventative surgery is recommended especially for those who are high-risk. Prophylactic surgery involves removing both ovaries and fallopian tubes surgically and it is known to be highly effective.



Digital Health for Survivorship: Apps, Wearables, and Tele-Monitoring

SPEAKER: Dr. Zoia Razumova (Karolinska Institutet, Sweden)



- ▶ Dr. Razumova discussed the benefits of digital health tools including symptom tracking apps, telemedicine and mental health apps.
- ▶ She emphasised the importance of evidence-based digital health tools and the need for data protection.
- ▶ There is the potential for digital health to improve communication with care teams and support mental health.
- ▶ However, there are limitations to certain digital health tools, such as food apps that divide food into 'good' and 'bad', and the importance of clinician-supported resources.

SESSION 5

QUALITY OF LIFE



DISCUSSION

- ▶ The chairs of the session mentioned that a quality of life research will be conducted later on in the year with a focus on patients' experiences.
- ▶ A discussion amongst the speakers included the challenges of monitoring patients post-treatment and the importance of shared decision-making.
- ▶ They also discussed the need for specialised menopause clinics and the availability of alternative treatments for managing menopause symptoms.
- ▶ The impact of prophylactic surgery on fertility and the potential for new surgical techniques to improve outcomes was also mentioned.
- ▶ Questions from the audience included the detection and screening of high-risk patients for prophylactic surgery. Dr. Novák explained the process of identifying high-risk patients and the role of genetic testing in determining the need for prophylactic surgery.
- ▶ An audience member raised concerns about the commodification of digital health and the potential for data misuse. Dr. Razumova acknowledged the challenges and potential benefits of digital health tools, emphasising the need for careful consideration and regulation.

ENGAGE Scientific session:

Optimising the Patient-Physician Communication in a Shared Decision and Integrative Patient Care

SPEAKERS: Annemijn Aarts, Houssein El Hajj, Kim Hulscher, Vesna Kesic

Annemijn Aarts

- ▶ Dr. Annemijn Aarts emphasised the importance of shared decision-making in patient care, stating that it should be at the core of medicine.
- ▶ She highlighted that clinicians often struggle to estimate patient preferences accurately, despite patients' desire to be actively involved in their treatment decisions.
- ▶ Doctors are medical experts who need to communicate clearly with patients, ensuring they understand the treatment options and the uncertainty of evidence. Survival is not always the only important factor in treatment decisions and providing too much information without context can be overwhelming for patients.
- ▶ Findings from a recent study in Denmark showed that patients prefer to be involved in their treatment decisions and make different trade-offs, such as prioritising less side effects over survival. Patients often want more information about the late effects of treatment, which could influence their decisions.
- ▶ The three-talk model was developed with international researchers, simplifying the shared decision-making process into three phases: tell, option, and integrate.
- ▶ Each phase aims to ensure patients understand their options, discuss the pros and cons, and make informed decisions based on their individual circumstances.
- ▶ There are positive effects of shared decision making, such as increased patient knowledge, better risk perceptions, and improved quality of life. Despite these benefits, there is still room for improvement, as the process can be complex and may require multiple consultations.
- ▶ Tools like patient-reported outcomes, patient decision aids, and the BRAND tool can aid in this process. The training of oncologists in shared decision making and communication skills was also highlighted.

SESSION 5

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Dr. Houssein El Hajj (Gustave Roussy Institute, France)

- ▶ Dr. Houssein El Hajj emphasised the importance of effective communication in managing pre-cancerous conditions. He likened pre-cancer to a 'smoke alarm', stressing the need for timely treatment to prevent progression.
- ▶ He highlighted the paradox of early detection, where patients may perceive a threat of cancer despite reassurances. Therefore, there is a need for clear, non-stigmatising language and structured communication to reduce anxiety and ensure understanding.
- ▶ The importance of tailoring treatment and follow-up plans that focus on risk reduction rather than elimination.
- ▶ Tools like the 'Ask, Tell, Ask' method and the NURSE for Emotions statement as well as visual aids can enhance patient comprehension and adherence.
- ▶ The need to adapt communication to the patients' level of education and socioeconomic status. The teach-back method is recommended to ensure patients understand their condition and treatment plan.
- ▶ The impact of pre-cancer on mental health was discussed, with studies showing high anxiety and distress associated with abnormal PAP smears and HPV results.
- ▶ Key takeaways include emphasising that pre-cancer is not cancer but a smoke alarm that requires attention, risk reduction rather than elimination, the use of simple visual aids rather than percentages to explain residual risks, and the need for a written plan and a clear sentence that patients can repeat.
- ▶ He underscored the importance of empathy, shared decision-making, and follow-up plans to manage residual risks effectively.

SESSION 5

QUALITY OF LIFE

Kim Hulscher (Olijf, The Netherlands)

- ▶ Kim Hulscher, a single parent from the Netherlands who was diagnosed with cervical cancer in 2013, shared her experiences with patient-physician communication.
- ▶ She emphasised the importance of not downplaying diagnoses and ensuring patients are informed about potential side effects and late effects of treatments.
- ▶ She discussed some of the late effects of her treatments including bleeding, bladder problems, bowel problems, and lymphedema.
- ▶ Kim stressed the need for doctors to be honest and clear about diagnoses, avoiding terms like curative that can be misinterpreted.
- ▶ Doctors need to help patients feel comfortable seeking second opinions without fear of ruining their relationship with their doctor.
- ▶ She highlighted the importance of nonverbal communication in building trust between doctors and patients, as well as the need for honesty, empathy, and shared decision-making in medical care.
- ▶ Doctors need to take patients' concerns seriously and to provide clear, repeated information about treatment options and potential outcomes.

Vesna Kesic (Medical Faculty, University of Belgrade)

- ▶ Prof. Vesna Kesic emphasised the importance of psychological support in cancer treatment from the pre-cancer stage to advanced stages, while also sharing her personal experiences both as a cancer survivor and in caring for a family member.
- ▶ Emotional challenges are faced by patients when curative treatment is no longer an option, therefore there is a need for comprehensive, multi-disciplinary palliative care to improve quality of life for patients with advanced or terminal disease, focusing on pain relief, symptom management, and addressing psychosocial and spiritual needs.
- ▶ The concept of integrative care combines palliative care, symptom management, and multi-disciplinary approaches. It emphasises the importance of communication and the need for empathetic dialogues. A focus on the patients' life and not just the disease.
- ▶ The significance of non-verbal communication was highlighted, with only 7% of communication being verbal.
- ▶ The impact of cancer on families was also noted, with divorce rates higher for affected female partners and children at risk of emotional and behavioural problems. It highlights the importance of supporting families and integrating care early to provide comfort and support.

SESSION 5

QUALITY OF LIFE

ENGAGE Scientific session:

Beyond Survival: Redefining Success Through Quality of Life in Gynaecological Oncology

SPEAKERS: Icó Tóth, Kathrin Kirchheiner, Nadeem Abu-Rustum, Philippe Morice

Prof. Nadeem R. Abu-Rustum (Memorial Sloan Kettering Cancer Center, United States of America)



- ▶ Prof. Nadeem Abu Rustum discussed the rising incidence of endometrial cancer in the US, now surpassing ovarian cancer in deaths. In the US, endometrial cancer is the fourth most common cancer in women, following breast, lung, and colon cancer.
- ▶ He emphasised the importance of quality of life (QoL) in gynaecologic oncology beyond just survival.
- ▶ QoL encompasses physical health, psychological state, independence, social relationships, personal beliefs and environment.
- ▶ Common issues affecting QoL include fatigue, sleep, pain, neuropathy, nausea, hair loss, anxiety, depression and financial toxicity.
- ▶ Quality of life is now recognized as a strong predictive and prognostic biomarker in gynaecological cancer.
- ▶ Validated quality of life tools like the FACT and EORTC questionnaires have been developed and are increasingly used in clinical trials.

- ▶ The impact of treatment such as surgery, chemotherapy, and radiation on QoL in gynaecological cancer patients are many. He noted that younger patients are more vulnerable to issues related to fertility, sexuality, and body image while older patients face challenges with comorbidities, socio-economic effects and financial toxicity.
- ▶ Sexual dysfunction is common in both younger and older patients, with menopause being a significant unaddressed issue.
- ▶ Disfiguring surgeries, chemotherapy, and radiation can worsen QoL, with patients often needing support for managing symptoms.
- ▶ Prof. Abu-Rustum stressed the need for integrating QoL assessments into clinical trials and patient care, with quality of life now being considered as important as survival.
- ▶ He also highlighted the importance of discussing patient goals and using multi-disciplinary approaches in addressing patients' QoL concerns, as well as the need for more research in underserved populations to better understand and improve QoL in gynaecological cancer patients.

SESSION 5

QUALITY OF LIFE

Prof. Kathrin Kirchheiner (Medical University Vienna, Austria)

- ▶ The discussion focused on the pathway of cancer survivorship, emphasising the transition from survival instincts to holistic recovery. The concept of holistic recovery includes physical activity, nutrition, psychosocial support, and energy management.
- ▶ Physical activity, particularly moderate exercise, is highlighted as crucial for cancer-related fatigue and overall quality of life. The importance of consistency in exercise programs with a focus on daily, non-intensive activities.
- ▶ The impact of nutrition on quality of life and physical functioning: individualised dietary counselling is recommended, with a balanced diet being more important than strict dietary restrictions. Consistency in dietary habits with a focus on common sense and high-quality food.
- ▶ The benefits of psychosocial interventions was discussed, particularly for distressed patients.
- ▶ Energy management should focus on stabilising the circadian rhythm, improving sleep hygiene, and learning relaxation and mindfulness techniques.
- ▶ Sexual dysfunctions after gynaecological cancer are multifactorial and involve physical, psychological and relationship dynamics. Besides physical therapies, psychosexual counselling was recommended to address the emotional and relational dimensions of sexuality.
- ▶ The importance of building habits to support long-term recovery was highlighted. Habits should be repetitive and occur in a stable environmental context, with small behavioural changes, such as short workouts, recommended over ambitious plans.
- ▶ She emphasised the need for cancer patients to be empowered to take action on holistic recovery, with educational material for holistic recovery made available to patients. Clinicians are encouraged to guide patients towards these resources and support their holistic recovery pathway.



SESSION 5

QUALITY OF LIFE

Ic6 T6th (The Mallow Flower Foundation, Hungary)

- ▶ The importance of quality of life (QoL) in cancer treatment, highlighting it as a core outcome rather than an add-on. QoL should be considered throughout the entire treatment pathway, including clinical trials, treatments, follow-up, survivorship and health system policies.
- ▶ QoL was often overlooked in clinical trials until recently. Studies from 2006 and 2026 revealed inconsistent reporting of QoL and the need for better long-term data.
- ▶ There should be systematic integration of QoL assessments into clinical trials, as it critically informs clinical decision-making beyond short-term outcomes.
- ▶ The significance of patient involvement in research and policy. The ENGAGe network, with over 30 countries and over 80 patient advocacy groups, was mentioned as an example of a collaborative effort to improve QoL and the role of patient advocates in pushing for changes and improvements in care.
- ▶ The use of the purple flower symbol to recognise the importance of quality of life in gynaecological cancers.
- ▶ The presentation concluded with a call to action for attendees to scan a QR code to access a survey that is part of a bigger quality of life research project and to use the purple flower in their institutions to promote quality of life care.

DISCUSSION

- ▶ The discussion focused on improving the quality of life for cancer patients, emphasising the importance of family support and integrating family aspects into treatment plans.
- ▶ It was highlighted that a standard form created by a psychologist is being used to measure and address patient concerns, including referrals for specific symptoms.
- ▶ It was noted that there is a higher divorce rate among gynaecological cancer survivors and the challenges of involving male partners in treatment was discussed.
- ▶ The need for patient experts to be included as equal partners in multidisciplinary teams was stressed.
- ▶ The session concluded with a call for increased involvement of expert patients to improve project outcomes.

SESSION 5

QUALITY OF LIFE

Stand for support in gynae cancers

SPEAKERS: Houssein El Hajj, Icó Tóth, Kim Hulscher, Maria Papageorgiou, Richard Tóth, Zoia Razumova

The session was structured in three parts: a roundtable discussion, a brief survey, and an interactive activity aimed at producing an advocacy paper.

Roundtable Discussion on Quality of Life After Gynaecological Cancer Treatment

- ▶ ENGAGe has developed a Quality of Life project and various brochures and webinars on the topic.
- ▶ Panellists were asked to define quality of life after gynaecological cancer in one sentence. Responses included the importance of living life without pain and being able to do things easily, and living life without restrictions and consequences.
- ▶ Panellists discussed challenges in clinical and health system regarding quality of life. For example, there is a lack of focus on sexual health in clinical consultations, and the need for better communication between physicians and patients about quality of life. It is important that doctors give patients the option to discuss quality of life topics at any time, and that doctors should refer patients to specialists if they are uncomfortable discussing certain topics.
- ▶ The domains of life most affected after treatment include menopause, fertility, somatic problems like incontinence, sexual health, and depression.
- ▶ In clinical practice, sexual health and symptoms of depression are the most under-discussed topics.
- ▶ Ongoing time constraints in consultations, coupled with limited resources, emphasise the importance of integrating families into the care of patients.
- ▶ Panellists discussed education and guidelines for doctors and nurses to address quality of life topics. For example, including quality of life topics in medical education, creating standards for communication initiated by patient advocacy groups, creating education materials such as podcasts for medical students, and involving younger generations in creating these education materials.

SESSION 6

Quality of Life WORKSHOP

Quick Survey

- ▶ Two quick surveys were done during the session, one for patient advocates and one for doctors. The questionnaire aimed at gauging what both clinicians and patient advocates deemed as most important for patients' quality of life. It is part of a bigger research project on quality of life that will occur later across 10+ countries.

Workshop on Writing Advocacy Policy Papers

- ▶ Participants played an interactive activity where they had to write advocacy policy papers for different institutions. Participants were divided into groups each representing a different institution, for example EU Parliament, WHO, local government, pharmaceutical companies etc.
- ▶ Each group chose a quality of life issue and wrote a policy paper for their assigned institution. Representatives from each group presented their policy papers and received feedback from the other groups. Policy papers ranged from the reintegration of patients into their lives with financial support and flexible working hours, fatigue being considered in disability calculations, the need for targeted communication and affordable access to sexual health services, the impact of cancer on women and a patient roadmap to return to work.



SESSION 7**How Can PAGs Be Involved in ENGAGE Projects****ENGAGE Projects 2026****SPEAKER: Anne De Middelaer** (Gynca's, Belgium)

- ▶ The session opened with an overview of how PAGs can engage in ENGAGE projects and upcoming initiatives in 2026.
- ▶ This was followed by updates on ENGAGE's active participation in the ESGO Congress, including two scientific sessions and representation across multiple sessions.
- ▶ Preparations for the London 2027 event are already in progress.

ENGAGE Campaigns & Patient Committees**SPEAKER: Kim Hulscher** (Olijf, The Netherlands)

- ▶ Several campaigns are planned for 2026: the cervical cancer campaign commenced in January, followed by the ovarian cancer campaign in May, the endometrial cancer campaign in June, and the rare cancer campaign in September, alongside World GO Day. Each campaign will include a range of webinars, brochures, and social media awareness activities.
- ▶ A Quality of Life survey and new brochures on caregivers, sexual health, and menopause are in development.
- ▶ Sexual health guidelines are being developed and will be published in 2027.
- ▶ Representatives of the ENGAGE clinical trials group will attend the ENGOT GCA meeting in December 2026.
- ▶ An increased involvement of patient experts within ESGO activities is planned.
- ▶ The purple flower symbol of quality of life will be promoted across all organisations.
- ▶ The ENGAGE Award will be held again next year, with more details to be shared in Q3.
- ▶ A new EEG will be formed, with a strategic meeting to develop standard operating procedures and a five-year plan.
- ▶ Elections for the Co-Chair Elect are planned for February 2027.

SESSION 7

How Can PAGs Be Involved in ENGAGE Projects

World GO Day 2026

World GO Day Working Group

- ▶ World GO Day 2026 is an initiative to inform the lay public about gynaecological cancers.
- ▶ The theme for 2026 is support for patients and will include a social media campaign and live interviews. Participants can log their initiatives on the website and receive invitations to participate.
- ▶ World GO Day 2025 was a success with 291 events in 64 countries. Delegates presented their work during this campaign for inspiration.
- ▶ Everyone was encouraged to join World GO Day by organising awareness events and engaging through social media. The importance of collaboration between doctors and patient advocacy groups was reiterated and the session concluded with a call to action for increased involvement and awareness.

ENGAGE TEENS

ENGAGE TEENS

- ▶ ENGAGE TEENS collaborate with healthcare professionals to raise awareness of HPV among the general public.
- ▶ Comprising teenagers from across multiple countries, the initiative focuses on tackling misconceptions and promoting prevention.
- ▶ To date, the group has developed HPV comic books, actively participates in the World GO Day events, interviews healthcare professionals and creates social media campaigns.
- ▶ Looking ahead, plans include school-based education programmes, expanded social media campaigns, a dedicated section on the ENGAGE website, and broader outreach efforts.

SESSION 8**Clinical trials WORKSHOP****SPEAKER:** Anne De Middelaer (Gynca's, Belgium)

- ▶ The clinical trials project currently involves 25 members from 13 countries who have completed an educational programme. The need for better funding and ongoing cooperation within local trial groups in various countries was emphasised.
- ▶ Dr Giuseppe Caruso presented on the history and the importance of clinical trials in gynaecological oncology, the difference between observational studies and experimental studies and the pros and cons of each, the phases of drug development (preclinical, phase 1-4), and the need for transparency, communication and trust in informed consent.
- ▶ Practical considerations such as time toxicity, cultural background and post-study communication in clinical trials were also highlighted.
- ▶ The session concluded with an interactive group activity related to challenges in clinical trials. Each group was given a specific task, such as describing the four phases of clinical trials or improving the informed consent form. The groups then presented their findings, discussing the importance of clear communication, ethical considerations, and patient involvement. The presentations also highlighted the need for simplified consent forms, clear explanations of study procedures, and ongoing communication with patients.

SESSION 9

Advocacy Best Practice Sharing

SPEAKERS: Kim Hulscher, Anne De Middelaer

Representing ENGAGE: Practical Presentation Tips

Kim Hulscher (Olijf, The Netherlands)

- ▶ The power of patient storytelling in educating healthcare professionals and raising awareness as well as improving healthcare communication.
- ▶ The need for safe and effective storytelling to avoid emotional or privacy risks, and the importance of teaching patients how to share their experiences without burdening them.
- ▶ Highlighted the need to connect with different audiences and avoid over-sharing to protect privacy. A workshop at Olijf teaches volunteers to learn to share their stories effectively through practice and co-presentation.
- ▶ Structured storytelling empowers patients and improves healthcare understanding.

When Data Meets Humanity: The New Role of Patient Representatives in HTA

Frédéric Martinez (Cancer Patients Europe, Belgium)

- ▶ The impact of health technology assessments (HTA) in Europe on patient access to new medicines. EU HTA regulation aims to reduce delays and disparities in accessing new medicines.
- ▶ The three main bodies involved in the HTA regulation implementation: the European Commission, the Coordination Group, and the Stakeholder Network.
- ▶ There is a process of joint scientific consultations, clinical assessments and early scanning to improve coordination and predictability.
- ▶ The importance of patients in the HTA process, ensuring that future evidence reflects real needs.
- ▶ Described the identification process for patients to participate in HTA assessments, including the selection of patient experts.
- ▶ Highlighted the need for effective patient engagement through training and capacity building. Feedback from patients involved in assessments has already led to improvements in guidance materials and timelines.

SESSION 9

Advocacy Best Practice Sharing

Social Media and Communication: The Power of Patient Voices Online

Athena Lamnisos (The Eve Appeal, UK)

- ▶ The importance of communications in patient advocacy, especially the role of social media.
- ▶ Communications have a strategic role in changing behaviour and improving outcomes.
- ▶ Social media can be used to reach patients directly and encourage meaningful action.
- ▶ The need for clear, accessible, and human-connected communications to build trust and reduce stigma.

What Does It Mean to Be Involved in the ESGO Guidelines?

Anne De Middelaer (Gynca's, Belgium)

- ▶ Including the patient perspective is important in the process of developing the ESGO guidelines.
- ▶ The guidelines development involves a systematic literature search, nomination of a multi-disciplinary international group and external evaluation.
- ▶ The literature search often lacks patient-relevant content, so the patient working group is building its own online reference library using trustworthy medical databases such as the International Journal of Gynecological Cancer and PubMed.
- ▶ The international multidisciplinary expert group usually consists of more than 20 representatives, including two patient experts. Expert contribution is important, and includes mandatory attendance at work group meetings as well as providing medical writing recommendations with references.
- ▶ The process is described as time-consuming but crucial for ensuring the patient voice is heard in the guidelines.
- ▶ It is expected to take about one year, with a possibility of extending to one and a half years.



SESSION 9

Advocacy Best Practice Sharing

Projects from ENGAGE Members

Charming You!

Małgorzata Krętowska (Eurydyki, Poland)



- ▶ The Charming Scarves project in Poland aims to provide beautiful scarves to women undergoing cancer treatment.
- ▶ Three stages of the project: collecting scarves, showing the scarves and sharing the scarves with patients.
- ▶ The project brings women together and shows solidarity and support.
- ▶ Upcoming workshop on International Women's Day to distribute scarves to women during cancer treatment.

SESSION 9

Advocacy Best Practice Sharing

Onco-Fertility Project

Ekaterine Sanikidze (GPU, Georgia)

- ▶ A new project in Georgia aimed at improving awareness, education, and prehabilitation for gynaecological cancer patients.
- ▶ This involves a collaboration with various organisations, including psycho-oncology, cardio-oncology, and rehabilitation centres.
- ▶ The creation of Community Advisor Boards to attract patients to clinical trials and the success of the onco-fertility project.
- ▶ The importance of partnerships and the need for funding to support these initiatives.

Artists in Residence

Nino Gvasalia (Vitae for Life, Georgia)

- ▶ The Healing Canvas artistic residency project in Georgia is aimed at supporting emotional strength and resilience.
- ▶ It is a collaboration with artists and cancer patients to conduct art therapy sessions.
- ▶ There is the potential for an international component, involving professional art therapists and international artists.
- ▶ The projects' focus is on raising awareness about cancer and providing patient support.

SESSION 9

Advocacy Best Practice Sharing

Free Go-Cards (Disease awareness) at cafes and cinemas

Charlotte Dybvik (KIU, Denmark)

- ▶ Charlotte Dybvik discussed their 25th anniversary campaign to raise awareness about gynaecological cancers.
- ▶ The campaign aimed to make women aware of symptoms of gynaecological cancers and encouraged early contact with healthcare professionals.
- ▶ The campaign used cards to distribute information in cafes and cinemas across four major cities and aimed at breaking taboos and encouraging early detection.
- ▶ A total of 130,000 informational cards were distributed, with 99,000 taken during the campaign period. The remaining cards were also collected, indicating a high demand for such information.
- ▶ The campaign increased KIU's visibility and demonstrated the effectiveness of placing simple, non-clinical messages in everyday environments to foster important health conversations and potentially support earlier diagnoses.
- ▶ The key learning was that simple visual messages placed in everyday environments can help start important conversations and support earlier diagnosis.

Patient - Doctor Communication

Annemijn Aarts (Amsterdam University Medical Centre, The Netherlands)

Linda Snoep (Olijf, The Netherlands)

- ▶ The project, a collaboration between a medical department and the patient organisation Alive, aimed to enhance patient-centred communication in oncology consultations.
- ▶ Four Alive volunteers, including Linda, received training in observation and feedback. Thirteen oncologists participated, with each having three consultations observed by a patient expert. Analysis of simulated consultations showed improved patient-centered behavior, with oncologists providing more tailored information and considering emotional impacts.
- ▶ Linda highlighted the initial stress for both doctors and patients but noted the positive change in doctor-patient interaction. Key takeaways included the importance of open questions, patient control, and acknowledging patient discomfort during examinations.
- ▶ The project has led to a positive change, with doctors becoming more open to learning from patients and improving patient care. They provide more adjusted information and are paying more attention to the emotional impact on patients.

SESSION 9**Advocacy Best Practice Sharing****Aktion Grüne Socke! Green Socks of Hope****Anja Dieryck** (Gynäkologische Krebserkrankungen Deutschland e. V., Germany)

- ▶ The Green Socks of Hope project provides self-knitted socks to cancer patients. The project has rapidly grown, including the establishment of an Instagram account, Facebook page, and website.
- ▶ Explained the process of collecting and distributing socks, including the involvement of a facility for people with disabilities.
- ▶ The project is successful in other countries, including Switzerland, the Netherlands, the Czech Republic and Austria.

Free Psychological Support Project**Charo Hierro** (ASACO, Spain)

- ▶ A comprehensive care project in Spain that provides free psychological and physiotherapy support to ovarian cancer patients and their families.
- ▶ There has been an increase in demand for these services, especially after the COVID-19 pandemic, and challenges in meeting these growing needs.
- ▶ Involves a collaboration with more than 20 specialised professionals to provide the best available care.
- ▶ Highlighted the financial constraints of the project and the need for continued support to ensure its sustainability.



SESSION 9

Advocacy Best Practice Sharing

Signs and Symptoms for Marginalised Communities

Sharon O'Toole (Ovacare, Ireland)

- ▶ The Inclusion Project for the Travelling Community in Ireland aims to raise awareness about gynaecological cancers among the traveling community.
- ▶ They utilised a co-design process with the traveling community to create a leaflet that was more suitable for their population.
- ▶ The new leaflet will be launched on World Cancer Day with subsequent education events.
- ▶ The project emphasises the importance of representing marginalised communities in patient advocacy and awareness campaigns.



ACKNOWLEDGEMENTS

We are grateful to our sponsors for their support!



Contact ENGAGE

Webpage: <https://engage.esgo.org/>

Email: engage@esgo.org

Facebook: <https://www.facebook.com/engage.esgo>

Instagram: <https://www.instagram.com/engage.esgo/>

LinkedIn: <https://www.linkedin.com/company/esgo-engage>

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Save the date for 2027!

See you in London!



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Webpage: <https://engage.esgo.org/>

Email: engage@esgo.org



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