

REPORT

Patient Seminar

Magnifying the patient voice
24 October 2015



Held during the 19th International Meeting of the
European Society of Gynaecological Oncology (ESGO)
24-27 October 2015, Nice, France



CONTENTS

Foreword	3
Programme	4
Summary of sessions	
Session 1: Setting the scene - trends and hot topics in research	5
Session 2: Prevention and screening	7
Session 3: Innovation and treatment	9
Session 4: Best practice market place	10
Session 5: Social media - securing a gynaecological cancer patient voice using social media	11
Session 6: Cancer in the workplace - do employment discrimination laws protect employees with cancer?.....	13
Session 7: 'Advocacy in action' panel - influencing health policy	14
Session 8: Meeting close	15

ABOUT ESGO AND ENGAGE: The European Voice of Gynaecological Oncology!

The European Society of Gynaecological Oncology (ESGO) is the principal European society of gynaecological oncology contributing to the study, prevention and treatment of gynaecological cancer. Today, ESGO has members in over 40 countries in Europe.



ESGO's mission:

ESGO strives to improve the health and well-being of European women with gynaecological (genital and breast) cancer through prevention, excellence in care, high quality research and education.



What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups in Europe is a network of European patient advocacy groups established by ESGO representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe.
- Patients are not adequately informed about gynaecological cancers and their management.
- Survivorship issues are not adequately addressed and psychosocial support in general is poor.

The ENGAGe objectives are to:

- Facilitate the development of national gynaecological cancer patient groups in Europe and to facilitate networking and collaboration between them.
- Disseminate information and share best practices to empower patient groups and improve the quality of care across Europe.
- To increase patient representation in ESGO activities by education on current research and health policy.
- To advocate patient care policies, practices and access to appropriate care at both national and European levels.
- To educate patient groups, health professionals, the public and health decision makers.



The European Voice of Gynaecological Oncology

FOREWORD

John Green, Seminar Chair
Isabel Mortara, ENGAGe Co-ordinator
Seminar Co-Chairs



■ John Green

Welcome to the third patient seminar organised under the name of the European Network of Gynaecological Cancer Advocacy Groups in Europe (ENGAGe). We have all achieved a great deal since 2012 when ENGAGe was established after a resolution from the first ESGO Patient Seminar held in Milan during the 17th International Meeting of the European Society of Gynaecological Oncology (ESGO 2011). The theme of this seminar is Magnifying the Patient Voice, and ENGAGe's voice has been heard loud and clear since the last meeting in 2013.

A key objective when ENGAGe was established was to be active at the European level to raise awareness of gynaecological oncology among European institutions. Since 2014, ENGAGe has been one of three patient groups on the European Commission Cancer Expert Committee. This has opened the door to policy makers and given us the opportunity to comment on policy documents on, for example, rare cancers and palliative care. Our opinions have also been sought by large medical societies, including ESGO, the European Society of Medical Oncology (ESMO), the European CanCer Organisation (ECCO) and the European Organisation for Research and Treatment of Cancer (EORTC).



■ Isabel Mortara

Our second objective was to build a network of local gynaecological cancer advocacy groups. ENGAGe now includes 80 groups from 30 countries, but that is not enough. We invite applications for capacity-building grants for new groups, and are very grateful to Barbro Sjölander and Paz Ferraro for helping to produce the guidelines on starting a gynaecological cancer advocacy group.

ENGAGe members are now supported by a range of educational materials. *Gynaecological Cancer in Europe* includes facts and figures on the incidence, prevalence and survival of women with gynaecological cancer in each country. We thank Dr John Butler for updating this very important advocacy tool, which is launched at this meeting and is available in print and from the ENGAGe website.¹ We were also very pleased to collaborate with ESGO, especially the Network of Gynaecological Oncological Trial Groups (ENGOT)² on a guide for patients on clinical trials, *What is a clinical trial?*,³ which has been translated and disseminated in several countries.

We are very active on social media, and in September 2015 you joined us in creating a buzz on Facebook and Twitter during European Gynaecological Cancer Awareness Month. This year our focus was ovarian cancer, and we published *She Needs to Know*.⁴ Developed by a multidisciplinary team of health professionals and patient advocates, this consensus document on the signs, symptoms and genetic risk of ovarian cancer has been widely translated and is a resource for you to use with your national media

We are delighted to open this seminar under the theme of Magnifying the Patient Voice. We hope you will use the day to network and share your successes with gynaecological cancer advocacy groups throughout Europe.



John Green
Liverpool Gynaecological Cancer Group, UK
Co-Chair
3rd Patient Seminar



Isabel Mortara
ENGAGe Coordinator
Co-Chair
3rd Patient Seminar

1. <http://engage.esgo.org/en>
2. www.esgo.org/engot/Pages/AboutENGOT.aspx
3. <http://engage.esgo.org/en/i>
4. <http://engage.esgo.org/en/actualite/launch-she-needs-know-consensus-statement>

Session 1: setting the scene: trends & hot topics in research

Chair: John Green, ENGAGe Chair

Trends in gynaecological cancer in Europe

John Butler (International Cancer Benchmarking Partnership, Gynaecological Oncology Consultant, St Bartholomew's and Royal Marsden Hospitals, UK)

Hot topics in research

Helga Salvesen (Centre for Cancer Biomarkers CCBIO, Bergen University, Norway)

Ovarian cancer - UKTOCS study: the outcomes

Usha Menon (UCL Elizabeth Garrett Anderson Institute of Women's Health, UK)

Session 2: Prevention and screening

Chair: Denis Querleu (Institut Claudius Regaud, France)

Physical activity and cancer risk

Helene Rundqvist (Karolinska Institute, Sweden)

Cervical cancer - today and tomorrow

Vesna Kesic (Department of Obstetrics and Gynaecology Clinical Centre of Serbia, Serbia)

Management of women with a genetic predisposition

Jan C. Oostervijk (Department of Genetics, University Medical Centre Groningen, The Netherlands)

Utility of a screening programme of high-risk groups

Ranjit Manchanda (Barts Health NHS Trust, Royal London Hospital, UK)

Session 3: Innovation and treatment

Chair: Nicoletta Colombo, European Institute of Oncology, Italy

Surgery: when, why and how?

Jalid Sehouli (Charité—Universitätsmedizin Berlin Campus Virchow Medical Centre, Department of Gynaecology, Germany)

New advances in radiation oncology for gynaecological cancer

Remi Nout (Radiation Oncologist, Leiden University Medical Centre [LUMC], The Netherlands)

Improving the treatment of rare gynaecological cancers

Isabelle Ray Coquard (Centre Léon Bérard, Centre de Lutte Contre le Cancer [CLCC], France)

Session 4: Best practice marketplace

Chair: Jan Geissler, Patvocates, Germany

Setting up and building the capacity of a gynaecological cancer advocacy group

Barbro Sjölander (Nätverket mot gynekologisk cancer, Sweden), Paz Ferrero (ASACO, Spain)

Communications and campaigns on a shoestring budget

Slavica Periskic (Anti-Cancer Society Sombor, Serbia)

Gynaecological cancer campaigns with crossborder initiatives

Elisabeth Baugh (Ovarian Cancer Canada)

Patient involvement in research - clinical trials

Annwen Jones (Target Ovarian Cancer, UK)

Session 5: Social media: securing a gynaecological cancer patient voice using social media

Chair: Jan Geissler, Patvocates, Germany

Plenary lecture: running a campaign and social media - experience from cervical cancer (#SmearforSmear)

Rob Music (Jo's Cervical Cancer Trust, UK)

Breakout groups: beginners and advanced social media session

Louise Horner (Target Ovarian Cancer, UK), Jan Geissler (Patvocates, Germany)

Session 6: Cancer in the workplace: do employment discrimination laws protect employees with cancer?

Chair: Isabel Mortara, ENGAGe Coordinator

A patient experience

Isabelle Lebrocqy (oPuce, The Netherlands)

The European landscape

Ward Rommel (Kom op tegen Kanker, Belgium)

Session 7: 'Advocacy in Action' Panel: influencing health policy

Chair: Jan Geissler, Patvocates, Germany

Using data in health policy: how we use research findings to advocate for change

Louise Bayne (Ovacome, UK)

Zerovision for Cervical Cancer

Speaker: Barbro Sjölander (Nätverket mot gynekologisk cancer, Sweden)

The Angelina Jolie effect in the context of the health policy landscape

Annwen Jones (Target Ovarian Cancer, UK)

Session 8: Meeting close

Chair: John Green, ENGAGe Chair

SUMMARY OF SESSIONS

SESSION 1

Setting the scene: trends and hot topics in research



■ John Butler

John Butler:

Trends in gynaecological cancer in Europe

Improved outcomes in gynaecological cancers depend on reducing its incidence, improving survival and improving the quality of life of women during and beyond their cancer. Measures such as cervical screening, HPV vaccination, risk-reducing surgery for women with inherited breast and ovarian cancers, and a healthy lifestyle will help to reduce the incidence of these cancers, while earlier diagnosis, and better availability and delivery of treatment will improve women's survival.

“Four years ago, we estimated that 1 in 3 people would develop cancer in their lifetime. Now it's 1 in 2 due to the ageing population and obesity epidemic. Cancer registries are essential for accurate data to guide policy makers.”

There are major disparities between European countries in, for example, the provision of cervical screening and HPV vaccination; indeed, the women who are least likely to have access to these proven preventive measures live in the countries of Eastern Europe with the highest rates of cervical cancer. Some countries have also not yet produced data to demonstrate the effectiveness of their cancer prevention programmes.

Cancer is a key indicator of the effectiveness of a healthcare system, and national cancer registries have played a key role in

highlighting unwarranted variation in outcomes of gynaecological and other cancers within Europe. It is encouraging that registries are being established in Eastern European countries, and these are likely to highlight the need for national policies on cancer prevention and treatment. In the current economic climate, however, patients and physicians must work together to influence policy makers to maintain investment in and awareness of cancer as national priorities.

Helga Salvesen:

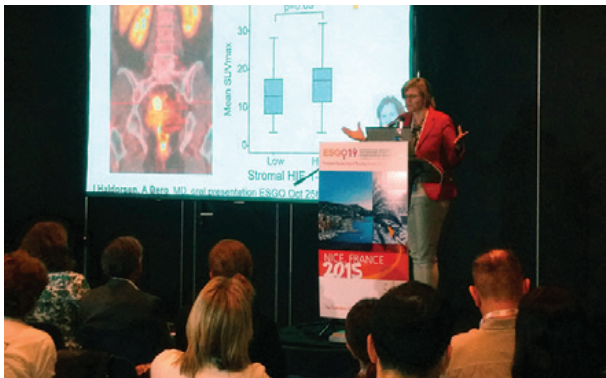
Hot topics in research - understanding cancer in context with precision medicine

Precision medicine is an emerging approach to disease that takes into account individual variations in genes, environment and lifestyle. Genes are important for precision medicine because cancer is a disease of the genome in that it is caused by errors in DNA. Understanding genetic changes in cancer cells is leading to more effective treatments that are targeted to the genetic profile of each patient's cancer. The *Cancer Genome Atlas*⁵ has, for example, revealed that serous endometrial cancers share gene patterns with serous ovarian and basal-like breast cancer,⁶ which promises to bring precision medicine to the treatment of these aggressive gynaecological cancers.

5. <http://cancergenome.nih.gov>
6. Nature 2013;497:67-73

SUMMARY OF SESSIONS

The identification of biomarkers - naturally occurring molecules, genes or characteristics that identify a normal (physiological) or abnormal (pathological) process - is also key to precision medicine. Biomarkers can be prognostic, helping to avoid over- or under-treatment, and improving the design of clinical trials, or they can be predictive, identifying patients most likely to benefit from a new treatment.



■ Helga Salvesen

Precision medicine is not a new concept; doctors must match blood types for a transfusion. However, sequencing of the human genome, improved techniques for biomedical analysis and new analytical tools mean that it is now possible to design clinical trials for innovative, targeted cancer drugs, more precise combination therapies, and strategies that may overcome the development of drug resistance in a cancer.

Usha Menon: Ovarian cancer - UKCTOS study: the outcomes

The United Kingdom Collaborative Trial of Ovarian Cancer Screening (UKTOCS) recruited 202,638 low-risk postmenopausal women aged 50 and above from England, Wales and Northern Ireland in 2001-2005.⁷ The women, who do not have a strong family history of ovarian or young-onset breast cancer, were randomly assigned to either the control group (101,359 women) who receive no screening, or a screen group who received annual screening till December 2011. The multimodal screen group (50,640 women) had a blood test for CA125, a protein that is raised in ovarian cancer and which was interpreted using the Risk of Ovarian Cancer (ROCA) algorithm.

Based on the result, women with an intermediate or elevated risk underwent repeat blood tests or a scan. The ultrasound screen group (50,639 women) had an internal (transvaginal) ultrasound scan of the ovaries, which was repeated if any abnormality was seen.

Results on performance of screening in UKTOCS showed that in the multimodal arm, about 84% of invasive epithelial ovarian/tubal cancers (iEOC) that were diagnosed within a year of screening were detected by screening compared with about 73% in the ultrasound arm. During incidence screening in the multimodal arm, about one of five operations resulted in a diagnosis of iEOC compared to one of 12 in the screening arm. As a result of screening, over 2000 women underwent unnecessary surgery where benign pathology or normal ovaries/tubes were found, 3% of whom had a major complication. Screening did not, however, increase anxiety - in fact women were less anxious with each year spent in the study. The main outcome of UKTOCS - whether fewer women died from ovarian cancer in the screen group than in control group - will be announced on 17th December 2015. Only then will we know if ovarian cancer screening should be offered to low-risk women.

UKTOCS: final results

Screening may reduce the risk of death from ovarian cancer by an estimated 20% after follow-up of up to 14 years, according to final results of UKTOCS.

From the start of the study (Year 0) and Year 14, compared with no screening:

- Multimodal screening (MMS) reduced risk of death due to ovarian cancer by 15% ($p=0.10$)
- Ultrasound screening (USS) reduced risk of death due to ovarian cancer by 11% ($p=0.21$)

This effect on mortality comprised:

- In the MMS group, a relative reduction in risk of death of 8% and 23% during respectively years 0-7 and 7-14
- In the USS group, a relative reduction in risk of death of 2% and 21% during respectively years 0-7 and 7-14.

After excluding women with undiagnosed ovarian cancer when they joined the trial, MSS significantly reduced the overall risk of death due to ovarian cancer ($p=0.021$) by:

- 8% in years 0-7
- 28% in years 7-14.

This is the first evidence to suggest that screening can prevent death from ovarian cancer. However, the researchers conclude that further follow-up of up to three years is needed to confirm UKTOCS results to date. These future outcomes, together with health economic analyses, will determine whether to introduce ovarian cancer screening.

UKTOCS results were published online in the Lancet on 17 December 2015: [http://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)01224-6/abstract](http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)01224-6/abstract)

7. BMJ 2008;337:a2079

SUMMARY OF SESSIONS

SESSION 2

Prevention and screening

Helene Rundqvist:

Physical activity and cancer risk

There is evidence from observational studies that physical activity can reduce the risk of several cancers, including some gynaecological cancers. In endometrial cancer, a statistically significant reduction in risk is seen with all intensity (but especially moderate intensity) recreational and occupational activity. Optimal effects are in adulthood and old age and the greatest risk reduction is in postmenopausal and overweight women.⁸ There is less evidence for other gynaecological cancers, but prolonged sitting time is associated with a higher risk of cervical intraepithelial neoplasia and ovarian cancer.^{9,10,11} Physical activity may protect against the risk of cancer through a variety of mechanisms, including weight control, lowering levels of oestrogen and growth factors, enhancing the immune defences, and promoting DNA repair.



■ Helene Rundqvist

Following a diagnosis of cancer, clinical experience shows that physical activity improves quality of life, and reduces cancer-related fatigue and the side effects of treatment. Group exercise helps to promote motivation and coping skills, with resistance training recommended for balance, stability and strength, and to improve muscle function. Physical activity is also associated with a reduced risk of recurrence and improved survival, including in women with ovarian cancer.¹² More studies are needed to provide more convincing evidence and find mechanisms for the beneficial effects of exercise in cancer patients.

Vesna Kesic:

Cervical cancer - today and tomorrow

Cervical cancer is caused by human papilloma virus (HPV) infection. About half of women are infected by the age of 25,¹³ but most HPV infections disappear spontaneously so that only 5% of women remain infected with the virus.¹⁴ Although they are at high risk, these women will not inevitably develop cervical cancer, since immunodeficiency, smoking, other infections, and hormonal and nutritional factors must also be present.

Cervical cancer can be prevented by vaccination against HPV infection and by cervical screening during the years that it takes for precancerous changes to progress to cancer. However, it is a disease of disparity. While HPV vaccination is offered for women in most Western European countries, it is unavailable for Eastern European women who are at higher risk of cervical cancer. In addition, only 16 European countries currently offer guideline-recommended, organised screening programmes that invite women at regular intervals.^{15,16} Organised screening is more effective and cost-effective than opportunistic screening when women consult a gynaecologist for other reasons, and its introduction has been associated with declining cervical cancer incidence and mortality (for example, in Finland¹⁷).

Today, one woman dies every two minutes because of cervical cancer - a disease that can be prevented. In the future, HPV vaccination may eliminate the disease, but this will take many years. We must raise awareness of the importance of prevention among women, especially those in higher-risk, socially disadvantaged groups, and educate politicians throughout Europe that the incidence of cervical cancer indicates how much the whole society takes care of its women.

8. Schmid P, et al. Eur J Epidemiol 2015;397-412
9. Chih H, et al. Health Promot J Austr 2013;24:219-23
10. Zhang M, et al. Cancer Causes Control 2004;15:83-9
11. Patel AV, et al. Am J Epidemiol 2006;163:709-16

12. Moorman PG, et al. Ann Epidemiol 2011;21:178-87
13. Wheeler CM, et al. Int J Cancer 2013;132:198-207
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15. Kesic V, et al. Epidemiol Biomarkers Prev 2012;12:1423-33

16. Arbyn M, et al. Ann Oncol 2010;21:448-58
17. Anttila & Nieminen. Coll Antropol 2007;31(Suppl 2):17-22

SUMMARY OF SESSIONS



■ Jan C. Oosterwijk

Jan C. Oosterwijk: Management of women with a genetic predisposition¹⁸

Cancer is always a genetic disease in that it occurs through adverse changes in DNA. Most often this is a chance occurrence. Cancer may be familial due to chance occurrence, but also because of common risk factors such as lifestyle, or because of a hereditary predisposition. The latter is responsible for 10-15% of ovarian and endometrial cancers. Hereditary cancer arises because DNA is more vulnerable to mutations, or because there is a lower capacity for DNA repair. This usually means that cancer risk is (much) higher and that it occurs at a somewhat younger age.

Some gynaecological cancers may be hereditary: this is more important for endometrial cancer and ovarian cancer, but much less important for cervical cancer. Endometrial cancer may be part of Lynch syndrome, a disorder that is mainly characterised by colon cancer, endometrial cancer and ovarian cancer, and which is caused by mutations in mismatch repair genes such as MLH1, MSH2, MSH6 and PMS2. It can also be part of Cowden syndrome (PHTS), in which breast and thyroid cancers also occur (PTEN mutations). Ovarian cancer, when hereditary, is most often related to BRCA1 and BRCA2 mutations, which also increase breast cancer risk. The second hereditary cause of ovarian cancer is Lynch syndrome.

The stronger the family history, the greater the chance of finding a genetic mutation. Referral criteria for possible genetic counselling differ between countries, but generally depend on the age at diagnosis, the number of cases in the family, degree of the relationship (i.e. first- or second-degree relative), and type of cancers that occur in the family. DNA testing is currently

performed on a blood sample, and preferably starts with the index case (the person with cancer). If she or he is unavailable, healthy first-degree relatives can be tested. DNA testing on tumour tissue is now being developed and will become more important. Women who carry a pathogenetic BRCA mutation can be offered breast screening or prophylactic mastectomy, as well as bilateral salpingo-oophorectomy. The latter should be performed at age 35-45 years and will virtually abolish the risk of hereditary ovarian cancers.¹⁹ For endometrial cancer risk, screening and preventive surgery are available options. However, challenges remain to ensure effective communication within affected families, and to optimise DNA testing, screening and prevention.

Ranjit Manchanda: Utility of a screening programme for high-risk groups

At present, women are identified for BRCA1/2 mutation testing based on their family history. However this approach misses a significant proportion of people at risk. This can be overcome by a population-based approach to genetic testing. It may be more appropriate to screen populations who are at particularly high risk of inherited cancers for BRCA1/BRCA2 mutations. Before introducing screening, however, it is essential to show that it is feasible, reliable, its benefits outweigh its risks and that it is cost-effective when compared to current practice.

A randomised trial including 1034 Ashkenazi Jewish people in the UK compared BRCA1/2 gene-mutation testing in every individual (population screening) with testing participants based on standard family-history criteria. Overall 60% of carriers would not have been offered genetic testing based on their family history and were identified by population testing alone. Screening had no adverse impact on psychological health or quality of life, and was highly cost effective.^{20,21} A non-randomised Norwegian study similarly found BRCA1/2 testing in newly diagnosed breast and ovarian cancer patients to be acceptable with no adverse effects on anxiety/depression; 23% of women with ovarian cancer were found to have a BRCA1/2 mutation in the study.²²

The current approach to genetic testing based on family history has important limitations in high-risk populations. Based on current evidence, it is time to offer population-based genetic testing to the Ashkenazi Jewish population unselected by family history as well as to women who have been recently diagnosed with ovarian cancer.

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19. Stewart BW, Wild CF (eds). *World Cancer Report 2014*. International Agency for Research on Cancer/World Health Organization. Lyon, France 2014

20. Manchanda R, et al. *J Natl Cancer Inst* 2014;107:379

21. Manchanda R, et al. *J Natl Cancer Inst* 2014;107:380

22. Hoberg-Vetti H, et al. *Eur J Hum Genet* 2015; epub September 9

SESSION 3

Innovation and treatment

Jalid Sehouli:

Surgery - when, why and how?

The role of surgery in cancer treatment depends on each patient's diagnosis, the pattern and type of the tumour, the risk of recurrence and whether tumour should be resected (removed) or debulked (reduced). Surgery must be incorporated within each patient's individualised treatment plan, and may be performed before chemotherapy, or to resect or debulk tumours between cycles of chemotherapy. To maintain high standards of surgery, cancer centres must measure and report quality indicators such as safety, morbidity, mortality and clinical outcomes, and share their data with colleagues by contributing to cancer registries.

The results of surgery reported in a single-centre case series may not be reproduced when a technique is used at other centres. So multicentre clinical trials are essential to confirm the efficacy, safety and the benefits for patients' quality of life of any surgical approach. Involvement in clinical trials is also increasingly recognised as a marker of the quality of a cancer centre's care. Women with gynaecological cancers, even if they are not recruited to a clinical trial, are more likely to receive evidence-based, guideline-recommended care. Ovarian cancer patients are, for example, more likely to undergo optimal staging in early-stage disease and receive the recommended combination of surgical debulking and combination chemotherapy in advanced disease.²³

Remi Nout:

New advances in radiation oncology for gynaecological cancer

Over half (55%) of all cancer patients are treated with radiotherapy, either with the aim of curing the cancer (60%) or relieving symptoms (40%). It has a major role in the treatment of cervical and endometrial cancer, either alone or in combination with chemotherapy or surgery. Radiotherapy treats cancer by targeting ionising radiation to the affected area of the body. It is an effective treatment for cancer because radiation damages DNA, impairing the process of cell renewal and causing cell death. Radiotherapy may be delivered as an external beam from a linear accelerator or internally through a radioactive seed or source placed in or near the tumour (brachytherapy).

Although tumour cells are more sensitive to radiation than normal cells, radiotherapy is a balance between tumour control

and side effects. It is, however, increasingly targeted to the individual patient. Treatment planning using three-dimensional computed tomography (CT) or magnetic resonance imaging (MRI) enables more precise mapping of the radiotherapy field and a low risk of side effects.^{24,25,26} Four-dimensional MRI or CT can take pelvic organ movement into account and additional improvement of side effects is expected by adapting radiotherapy treatment to exact organ positions in the individual. In future proton therapy and novel intrauterine brachytherapy systems may further refine radiotherapy for gynaecological cancers.

Isabelle Ray-Coquard:

Improving the treatment of rare gynaecological cancers

In Europe, a rare cancer is currently defined as one with a prevalence of fewer than five cases in a population of 10,000.²⁷ There are many types of rare gynaecological cancer, which differ in their clinical presentation and prognosis, but all share challenges with other rare diseases. The evidence base is lacking, there are no clinical trials due to a lack of financial support or interest from industry and research organisations, leading to a lack of innovation in treatment or improvements in survival.

Cancer networks offer an important means of improving outcomes and raising awareness of rare gynaecological cancers among health professionals and women themselves. The French national network for rare gynaecological cancers²⁸, for example, offers expert review of diagnosis, recommendations on management, education for health professionals and information for patients, families and advocacy groups. The network also takes part in clinical research, such as ENGOT-OV7, a randomised, open-label trial to investigate the role of bevacizumab in relapsed ovarian sex-cord stromal tumours.²⁹

Larger clinical trials in rare gynaecological cancers depend on pan-European co-operation and international co-operation (for example, the International Rare Cancers Initiative [IRCI]³⁰ and the Gynecologic Cancer Intergroup [GCIg]³¹). European Reference Networks for Rare Diseases are designed to share expert knowledge across national borders,³² but do not currently include gynaecological cancers. Patient advocacy at national and Europe levels is essential to ensure that a European network will be dedicated to these rare cancers.



■ Isabelle Ray Coquard

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26. Barillot I, et al. *Radiother Oncol* 2014;111:138-43

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28. L'Observatoire des Tumeurs Malignes Rares Gynécologiques: http://www.ovaire-rare.org/TMRG/public/accueil_public.aspx

29. www.esgo.org/ENGOT/Pages/ENGOTTrials.aspx

30. www.irci.info

31. www.gcig.igcs.org

32. http://ec.europa.eu/health/rare_diseases/european_reference_networks/

SESSION 4

Best practice marketplace

Barbrö Sjölander and Paz Ferrero: Setting up and building the capacity of a gynaecological cancer advocacy group

Patient groups can support people throughout their cancer journey and act as advocates in discussions with health professionals, researchers, the healthcare system, and local and national government. Many countries already have cancer advocacy groups, but these often include people diagnosed with many different types of cancer. Women with gynaecological cancers have specific advocacy needs and may not want to share their experiences in general cancer groups, especially in countries where these cancers still evoke shame, embarrassment or stigma.



■ Paz Ferrero & Barbro Sjölander

To support anyone who wants to start an advocacy group for women with gynaecological cancers, ENGAGE has created a practical toolkit of 14 factsheets.³³ The toolkit begins by explaining how to establish the key facts and challenges in your country and hold your first meeting, and then shows you how to grow and sustain your group. The toolkit is also relevant to established groups, helping them identify and address challenges in key areas such as:

- Recruiting and managing volunteers
- Membership models
- Strategy for growth and impact
- Evaluation and sustainability.

Asking questions is an important step in the development of your group. It generates discussion among your board members and helps you to focus and make good decisions. Your questions might include:

- How do you work to achieve a stronger group?
- How do you recruit, manage, take care of and retain volunteers?
- How do you choose your membership model: free of charge or subscription?
- How do you grow your impact?
- How do you evaluate your work?

Starting or growing a patient group is exciting and fulfilling but, like any pioneering work, the road ahead will not always be straightforward. But remember, the gynaecological cancer advocacy groups that are now large and successful organisations began just like you and your supporters: a few people inspired by the common vision of improving the lives of women with gynaecological cancer and their families.

Slavica Periskic: Communications and campaigns on a shoestring budget

The Anti-Cancer Society Sombor was established 46 years ago. The greatest problems faced by cancer patients in Serbia are lack of information, poor co-ordination of care and the absence of psychological support. In response, Anti-Cancer Society Sombor has created a website and print information to educate cancer patients and their families about their condition and inform them about treatment pathways, and organises individual and group psychological support. The Society has around 150 active members and runs 200 activities a year, of which 70% are voluntary and 30% funded by donors. These activities include fund-raising concerts, a monthly slot on the radio programme Knowledge for Health, publicity in the Sombor newspaper, and a book Live as Before containing 52 stories written by women treated for gynaecological cancer.



■ Slavica Periskic

33. <http://engage.esgo.org/en/supporting/starting-gynaecological-cancer-advocacy-patient-group>

SUMMARY OF SESSIONS

Elisabeth Baugh:

Gynaecological cancer campaigns with crossborder initiatives

World Ovarian Cancer Day takes place on 8th May each year. It was challenging to organise the first of these events in 2013, because of the many organisations involved, each with their own local cultures, languages and resources. However, these potential barriers were overcome by the compelling need to raise awareness of ovarian cancer. Elements critical to success included simple, achievable and measurable goals; effective branding; sensitivity to local cultures; effective communication within the core organising group; and lack of competition because of the deliberate omission of fund-raising from the global programme. Plans are now being put in place for the next five years to extend global advocacy beyond World Ovarian Cancer Day awareness.

Annwen Jones

Patient involvement in research—clinical trials

Clinical trials are essential to test the efficacy and safety of new therapies for gynaecological cancers. Participation in a clinical trial not only enables access to novel therapies but has also been shown to improve outcomes in ovarian cancer regardless of the randomised treatment.³⁴ However, only 30% of women in the UK had been asked if they would like to participate in a clinical trial, yet 90% would be interested in doing so.³⁵ This lack of information is a barrier for women themselves and for the doctors hoping to organise a clinical trial of a novel treatment. In response, Target Ovarian Cancer has set up an online Clinical Trials information Centre³⁶ to enable women to find ovarian cancer trials near their UK location. This initiative, together with the ENGAGE's guide *What is a Clinical Trial?*³⁷ is designed to give more women the opportunity to take part in this research.

SESSION 5

Social media: securing a gynaecological cancer patient voice using social media

Rob Music

Running a campaign and social media: experience from cervical cancer (#SmearforSmear)

In the UK, cervical screening coverage in women aged 25-29 years has fallen from 78% in 1999 to 66.3% in 2014, while the incidence of cervical cancer in this age group has doubled since 2005. #SmearforSmear is an innovative, award-winning social media campaign organised by Jo's Cervical Cancer Trust, the UK's only cervical cancer charity. The campaign asked younger women to support cervical screening by sharing a lipstick-smear selfie on social media, while nominating friends to do the same. Launched during Cervical Cancer Prevention Week in January 2015, #SmearforSmear ran across traditional print media, digital and social media. There was also a poster campaign that followed the lipstick-smear format in washrooms at health clubs and other social settings.

#SmearforSmear has been a record-breaking campaign for Jo's Cervical Trust, resulting in around 500 pieces of global print coverage, most mentioning the charity or the campaign in the headline or first paragraph. The number of visitors to the charity's website in January 2015 was 49% higher than

in the previous year and the highest in the charity's history. There have also been anecdotal reports that more women are attending cervical screening. Key drivers of the success of #SmearforSmear include the simple message, its launch during Cervical Cancer Prevention Week, and the charity's persistence in gaining support from celebrities and influencers (bloggers and vloggers) with a high social media profile that appeals to the target group of women. ENGAGE members are invited to take part in the next #SmearforSmear campaign during Cervical Cancer Prevention Week 2016 (24-30 January).³⁹

Louise Horner and Jan Geissler

Social media for beginners and advanced users

Today, social media is a key tool for advocacy groups wanting to build support and ongoing relationships. When establishing a social media profile, it is helpful to remember that each channel has different purposes. As an established format, discussion forums still play an important role in patient support activities, but need to be monitored regularly. Facebook allows you to build an interactive community that enables your peers to share news, information and individual experience, but patients may

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SUMMARY OF SESSIONS



■ Jan Geissler

not always be willing to mix their private Facebook profile and their cancer identity. Twitter is a method of spreading news and comments widely as soon as they happen. YouTube and Vimeo enable you to share video and Instagram is for sharing photographs. LinkedIn is a professional network that can help you to connect with potential opinion leaders. Other ways to use social media include posting or amending a Wikipedia entry, creating and sharing your slide presentations on SlideShare and authorSTREAM, and using Wiggio to create virtual group workspaces.⁴⁰

At the ENGAgE meeting, the CML Advocates Network shared various examples⁴¹ on its practical use of these channels in patient advocacy. Social media is also a very important part of Target Ovarian Cancer's advocacy efforts and political action, in order to inform, educate and mobilise women with cancer, health professionals, policy makers and the general public. Examples of Target Ovarian Cancer's digital efforts can be found on the charity's website, Facebook and Twitter.⁴²

Each patient advocacy group uses social media channels in different ways, but your social media strategy should always follow your group's objectives. You do not need to involve a large group of people to effectively use social media for advocacy. Plan a calendar of content, and agree on a process how you will respond to challenging posts - for example, it is preferable to take a conversation offline temporarily rather than delete negative feedback. Empower your staff and volunteers to use social media and to update your content, but keep control of your posting schedule. It is much better to share significant updates a few times a week or month than to bombard your followers with less important information that overwhelms the most important news. Last but not least, always take care that any medical information you post or share is accurate and balanced.

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SUMMARY OF SESSIONS

SESSION 6

Cancer in the workplace: do employment discrimination laws protect employees with cancer?

Isabelle Lebrocquy

A patient's experience

In 2011, I was diagnosed with colon cancer. Although I survived cancer, I lost my job. I lost it for two reasons: the stigma we have because of cancer and the financial risk we are for Dutch employers, who must pay 70% of a salary for the first two years of illness. Based on an online survey I set up, one quarter of cancer survivors lost their job during or shortly after their illness. The survey results motivated me to improve employment after cancer. I founded oPuce, a social enterprise to help create jobs for people who are recovered from cancer, and to inspire employers and society to look differently at cancer and cancer survivors. The Netherlands is now one of the first countries addressing the burdens of cancer survivorship. Also the Dutch Government is adapting social legislation to install a no-risk insurance for unemployed cancer survivors. At a European level, EORTC has established a Cancer Survivorship Taskforce to identify the needs of cancer survivors and provide guidance on their management,⁴³ with the second Cancer Survivorship Summit being held in spring 2016.⁴⁴

Ward Rommel

The European landscape

Although about two thirds of cancer survivors are able to return to work,⁴⁵ only about two fifths are in employment. Since 2000, grounds for protection against discrimination at work under

EU Directive 2000/78/EC⁴⁶ have included disability; employers must provide 'reasonable accommodations' to enable a person with a disability to participate in work.⁴⁶ However, there is no European definition of 'disability' and it remains unclear whether cancer is included.

At a national level, the UK's Equality Act (2000) automatically includes cancer in its definition of a disability as a physical or mental impairment that has a substantial and long-term (12 months or more) adverse effect on the person's ability to perform normal day-to-day activities.⁴⁷ In general, national labour laws aim to promote equal treatment and prevent discrimination against people with disabilities or health problems. Some European countries have quotas for the employment of people with disabilities and grants to enable employers to adjust workplaces for people with health problems.

Throughout Europe, we must change the perspective to focus on cancer survivors' capabilities rather than their reduced performance at work. We need tailored policies that enable people with chronic disease to adapt their workloads without loss of social benefits, with education and training to raise awareness among employers and co-workers. Finally, we must ensure that European equality legislation is amended to add chronic diseases such as cancer to the grounds for employment protection

CANCER IN THE WORKPLACE

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44. <http://www.eortc.org/survivorship2016/>

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SUMMARY OF SESSIONS

SESSION 7

'Advocacy in action' panel - influencing health policy

Louise Bayne:

Using data in health policy: how we use research findings to advocate for change

The UK National Cancer Patient Experience Survey (NPES) is an example of a source of data that can be used to advocate for change.⁴⁸ The Survey was sent to all 116,000 cancer inpatient and day-case patients who were treated between 1 September and 30 November 2012 in all NHS hospital trusts in England. According to NPES 2013, almost 30% of women with gynaecological cancers (including ovarian cancer) had to see their general practitioner more than twice before being referred to hospital, compared to 8% women with breast cancer.

Late diagnosis is an important factor in the low survival rates for women with ovarian cancer in the UK: over 32% of ovarian cancer patients were diagnosed in an emergency setting in England in 2006-2008.⁴⁹ Ovacom used the NPES 2013 data to advocate for action to improve early diagnosis of ovarian cancer.⁵⁰ Since the NPES provides data for each acute trust, Ovacom was able to produce a report on ovarian cancer outcomes for each constituency. This resulted in campaigns by Members of Parliament that led to improvements in local ovarian cancer services such as a GP helpline to enable rapid-access for diagnostic tests. Following Ovacom's campaign and other initiatives, improvements have been reported in the diagnosis of ovarian cancer in the UK.

Barbrö Sjölander:

Zerovision for cervical cancer

Since 2012, the Swedish Network Against Gynaecological Cancer has been concerned with all these tumours, but when it began in 2007 it was a network against only cervical cancer. The goals were to include HPV vaccination within the school vaccination programme and to replace Pap smears with HPV testing during cervical cancer screening. These goals have been in part achieved, since schoolgirls have been offered HPV vaccination since 2009 and HPV testing will begin in 2016. The Network is now campaigning for HPV vaccination for boys, a better HPV testing programme and the introduction of free-of-charge cervical screening.

The achievements of the Network for Gynaecological Cancer have been based on education of women through awareness days, social media, the network's website⁵¹ and electronic newsletter, and advocacy and partnership with health authorities and professionals. Everyone who works for the Network is a volunteer

and the 920 members do not pay membership fees. Costs are kept to the minimum by using social media, free conference calls and web-based mailing services. Annual running costs of €1100.00 are met through donations and earnings from the network's webshop, with financial support from the Swedish Cancer Society. Specific occasions such as the annual Gynaecological Cancer Day are supported by the Swedish Cancer Society, regional cancer centres and industry.

Annwen Jones:

The Angelina Jolie effect in the context of the health policy landscape

Celebrities have the power to transform the issues that they champion by raising awareness, influencing behaviour and, in some cases, achieving policy change. The bigger the celebrity, the greater the impact and few women are more famous than Angelina Jolie. Already well known for her work as a Special Envoy for the United Nations High Commission for Refugees, Angelina Jolie hit the headlines in 2013 when she had a double mastectomy to reduce her high risk of breast cancer as a BRCA1 mutation carrier, followed by removal of her ovaries and fallopian tubes in 2015.

The publicity - or media storm - that followed the announcement of these decisions put both BRCA1 genetic testing and risk-reducing surgery in the spotlight. Six months after her double mastectomy, the Angelina Jolie effect was seen in the UK and Canada in the two-fold increase in women's awareness and health-seeking behaviour. In the UK, for example, there were 4,847 referrals to genetic services in June and July 2013 - over twice the number compared with the same months in 2012 - and referrals were still two-fold higher in October 2013 with no increase in inappropriate referrals. Demand for BRCA1/2 testing almost doubled and there were also many more enquiries about risk-reducing mastectomy.⁵² While the long-term impact on health policy of the Angelina Jolie effect is not yet clear, patient advocacy continues to play a key role in securing policy change, as has been seen in the introduction of new policies on access to BRCA1/2 genetic testing in the UK, Sweden and the Lombardy region of Italy.



48. www.quality-health.co.uk/surveys/national-cancer-patient-experience-survey

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SUMMARY OF SESSIONS

SESSION 8

Meeting close

John Green, ENGAGe Chair

Thank you to all speakers and audience members for participating in this ENGAGe Patient Seminar with the theme Magnifying the Patient Voice.

Our speakers have given us the latest information on exciting new developments in the prevention, diagnosis and treatment of gynaecological cancers. We have also shared inspiring news about the achievements of advocacy groups from all over Europe, but common threads link all cancers. The benefits of a healthy lifestyle are a key take-home message, in particular the way that exercise not only reduces a woman's risk of gynaecological and other cancers, but may also reduce the risk of future recurrence.

We face continuing challenges in a time of economic austerity in many European countries. One of the many strengths of ENGAGe is that we include so many patient advocacy groups working to improve outcomes for women with gynaecological cancers across Europe. We look forward to your feedback on this seminar and on our plans for the future.



■ John Green



■ Q&A session with the Session 3 speakers & chair Nicoletta Colombo



■ Isabel Mortara - Opening the 2015 Patient Seminar

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The European Voice of Gynaecological Oncology