

ENGAGe Patient Seminar
24 October 2015, Nice, France
Delegate Satisfaction Survey
Executive Summary

Held during ESGO 2015 under the theme of ‘magnifying the patient voice’, the third ENGAGe Patient Seminar attracted delegates from patient groups in 27 European countries. Responses to the satisfaction survey were received from 39 delegates, who described the primary focus of their group as:

<i>Primary focus</i>	<i>Number¹</i>
• Ovarian cancer	20
• Cervical cancer	13
• Women’s cancers	13
• Uterine cancer	9
• Other (e.g. breast cancer, all cancers)	20

Overall evaluation

The Patient Seminar was rated overall as either very good or excellent by 85% of respondents, who described the Seminar’s strengths as:

- Opportunity to interact with and learn from members of other patient advocacy groups and health professionals from ESGO
- High quality of the speakers and the range of up-to-date presentations
- Opportunity to join workshops with delegates from other advocacy groups
- Number and range of advocacy groups and countries represented at the Seminar
- Highly efficient organisation of the Seminar
- Practical, relevant, take-home digital and print information offered by ENGAGe.

Session evaluations

Respondents considered all sessions to be either very good or excellent, with no presentation scoring less than 75%²:

<i>Session</i>	<i>Very good or excellent</i>
Session 1: Setting the scene <ul style="list-style-type: none"> • John Butler: Trends in gynaecological cancer in Europe • Helga Salvesen: Hot topics in research • Usha Menon: Ovarian cancer—UKCTOCS study: the outcomes 	95% 90% 92%
Session 2: Prevention and screening <ul style="list-style-type: none"> • Helena Rundqvist: Physical activity and cancer risk • Vesna Kesic: Cervical cancer—today and tomorrow • Jan C. Oosterwijk: Management of women with a genetic predisposition • Ranjit Manchanda: Utility of a screening programme of high-risk groups 	92% 97% 90% 85%

¹ Some delegates gave more than one primary focus for their group

² Throughout this report, percentages are shown to the nearest whole number and so may not total 100

Session 3: Innovation and treatment <ul style="list-style-type: none"> • Jalid Sehoul: Surgery: when, why and how? • Remi Nout: New advances in radiation oncology for gynaecological cancer • Isabelle Ray Coquard: Improving the treatment of rare gynaecological cancers 	95% 92% 77%
Session 4: Best practice marketplace <ul style="list-style-type: none"> • Barbro Sjölander and Paz Ferrero: Setting up & building the capacity of a gynaecological cancer advocacy group. • Slavica Periskic: Communications and campaigns on a shoestring budget • Elisabeth Baugh: Gynaecological cancer campaigns with cross border initiatives • Annwen Jones: Patient involvement in research—clinical trials 	87% 85% 87% 95%
Session 4: Social media <ul style="list-style-type: none"> • Rob Music: Plenary lecture: Running a campaign and social media—experience from cervical cancer (#SmearforSmear) • Louise Horner: Social media—beginners group • Jan Geissler: Social media—advanced group 	90% 90% 92%
Session 6: Cancer in the workplace <ul style="list-style-type: none"> • Isabelle Lebrocquy: A patient's experience • Ward Rommel: The European landscape 	77% 87%
Session 7: Advocacy in action <ul style="list-style-type: none"> • Louise Bayne: Using data in health policy—how we use research findings to advocate for change • Barbro Sjölander: Zerovision for cervical cancer • Annwen Jones: The Angelina Jolie effect in the context of the health policy landscape 	87% 90% 97%

Improving the Patient Seminar

Respondents suggested that the Seminar could be improved by:

- More time for delegates to exchange ideas, including a social event such as a dinner
- Longer Marketplace sessions to enable more discussion in the workshop groups
- Greater focus on the experience of patient groups, especially their projects and practical solutions
- Free or reduced-cost access to the main ESGO congress
- More time to interact with speakers, especially during questions at the end of each presentation
- Information provided during the seminar about the groups represented, including contact information
- More structured follow-up with delegates after the Seminar.

Overall, most respondents were satisfied with the current balance between the different session topics. The exception was Advocacy: 56% of respondents

requested more focus, compared with 38% preferring the current focus and 5% less focus.

Less than one third (31%) of respondents were satisfied with the current Seminar format (one day, beginning in the morning and ending in the late afternoon). Nearly half (46%) preferred a Seminar of two full days, while 31% suggested a one-day Seminar comprising an afternoon session, following by a morning session on the following day.³

Assuming that the Patient Seminar continues to be held every two years, two thirds of respondents (67%) would be interested in taking part in regional activities in the intervening year.

ENGAGe resources and network

Respondents regarded ENGAGe resources, when applicable, as useful for the work of their patient groups:

<i>Resource</i>	<i>Useful</i>	<i>Not applicable</i>
<i>Facts and figures</i> brochure	92%	8%
Gynaecological cancer factsheets	92%	8%
<i>She needs to know</i> consensus document	87%	13%
What is a clinic trial? brochure	82%	18%
<i>How to start a gynaecology cancer patient advocacy group</i> factsheets ⁴	77%	15%
Capacity-building grants ⁵	69%	26%
Translation of resources to languages other than English ⁶	46%	46%

ENGAGe network

Just over half (51%) respondents would be interested in both individual and organisational membership of the ENGAGe network. Nearly half (49%) would be interested in organisational membership only, while very few (3%) opted for individual membership only⁷.

When asked about the value of an online gynaecological cancer advocacy community, most (85%) respondents would be interested in joining such an organisation.

[Ends]

³ Some respondents gave more than one answer

⁴ Not useful: 8%

⁵ Not useful: 5%

⁶ Not useful: 8%

⁷ Some respondents gave more than one answer