



GCIG London 2013

Expression III

**What do primary and recurrent ovarian cancer (OC)
patients expect from their doctors and therapy
management?
(NOGGO/ENGOT-ov4 study).**

NOGGO
e.v.

Nord-Ostdeutsche Gesellschaft
für Gynäkologische Onkologie e.V.

ESGO
European Society of
Gynaecological Oncology



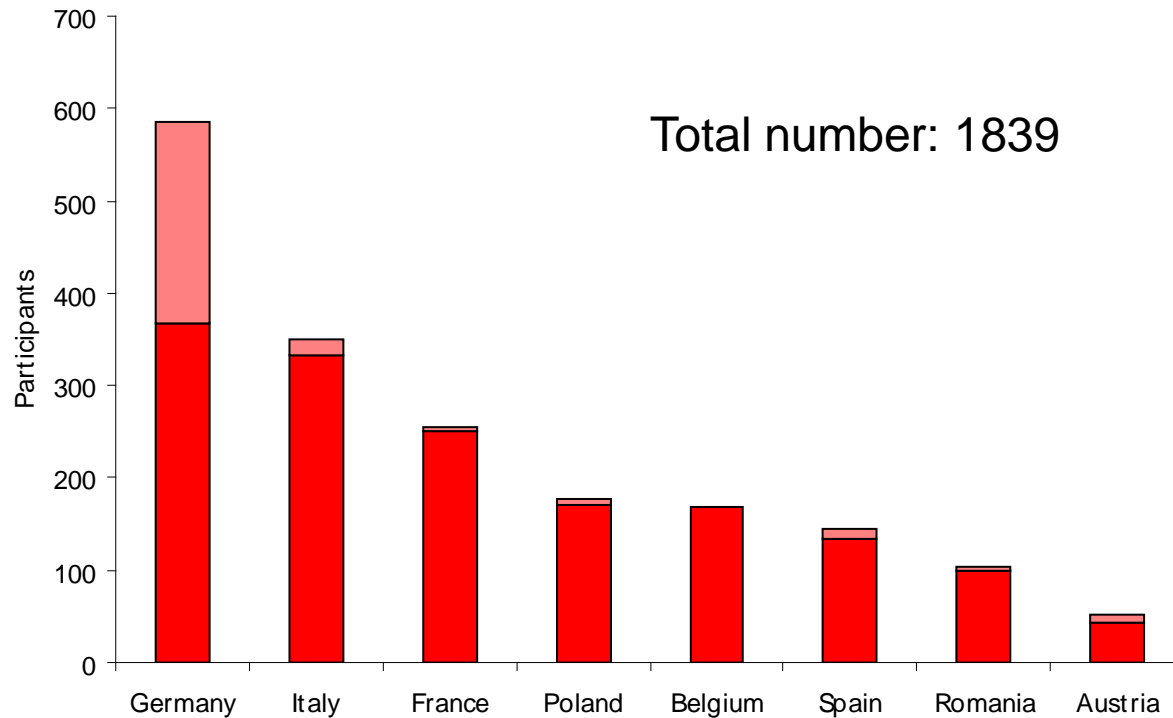
Why it can be important to know the expectations of ovarian cancer patients?

- Patients preference is important for the adjuvant and palliative setting
- Dissatisfaction is associated with Non-Compliance (*Coulter et al., 1999, Elwyn et al., 2003*)
- Compliance and Non-Compliance correlate with quality of life and survival
- Expectations and preferences from patients and physicians are different (*Oskay-Oezcelik, 2006*)

Results

- Survey runs from December 2009 to October 2012
- a total of 1839 patients with ovarian cancer from 8 European countries participated in the survey
- The median age was 58 years (range 16–89)
- 96.3% had a primary surgery and a first-line chemotherapy (91.5%)
- About 423 (25.7%) patients were included in a clinical trial
- Most of the patients in each country were pleased with the completeness and understandability of the explanations about the therapies from their doctors
- About 68 % of patients would be interested in having the opportunity to have a second opinion.
- The three most important aspects, which were proposed by patients to improve therapy against ovarian cancer were: “the therapy should not induce alopecia” (42%), “there must be more done to counter fatigue” (34%), and “the therapy should be more effective” (29%).

Results



Numbers of participants in each country, light red columns represents online survey, dark red print survey

Patient characteristics

No. of pts.	1743
Online Group.....	269 (15%)
Paper Group	1474 (85%)

Internet access

Yes.....	984 (58%)
No.....	697 (42%)

Profession

Academics.....	311 (18%)
Non academics.....	892 (51%)
Not classified.....	540 (31%)

Median age, years (range)	58 (16–89)
Online.....	52 (20–89)
Paper.....	59 (16–87)

Stage of disease

Primary ovarian cancer.....	858 (52%)
Relapsed ovarian cancer.....	693 (42%)
Unknown.....	99 (6%)

Current treatment

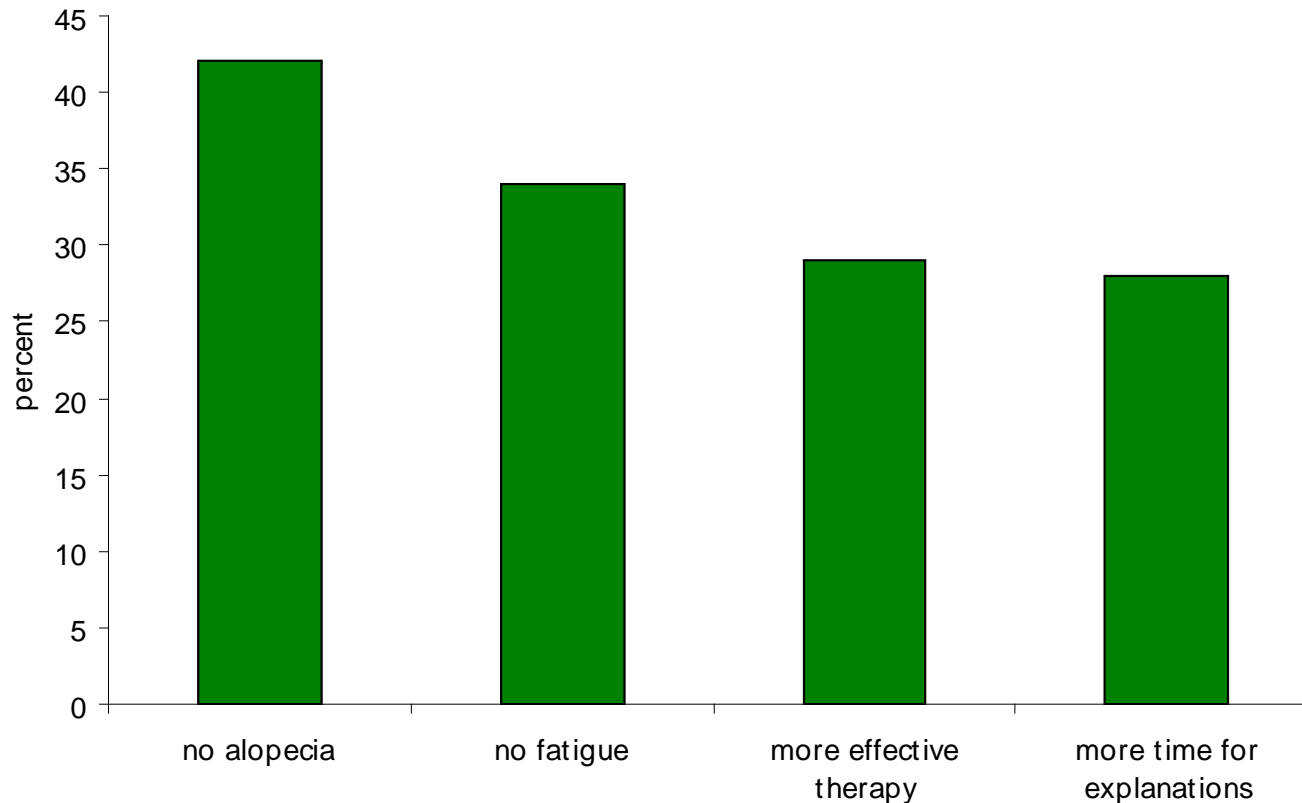
Yes.....	936 (56%)
No.....	713 (43%)
Unknown.....	12 (1%)

FIGO Stage

I-II.....	274 (17%)
III-IV.....	125 (8%)
Unknown.....	681 (43%)

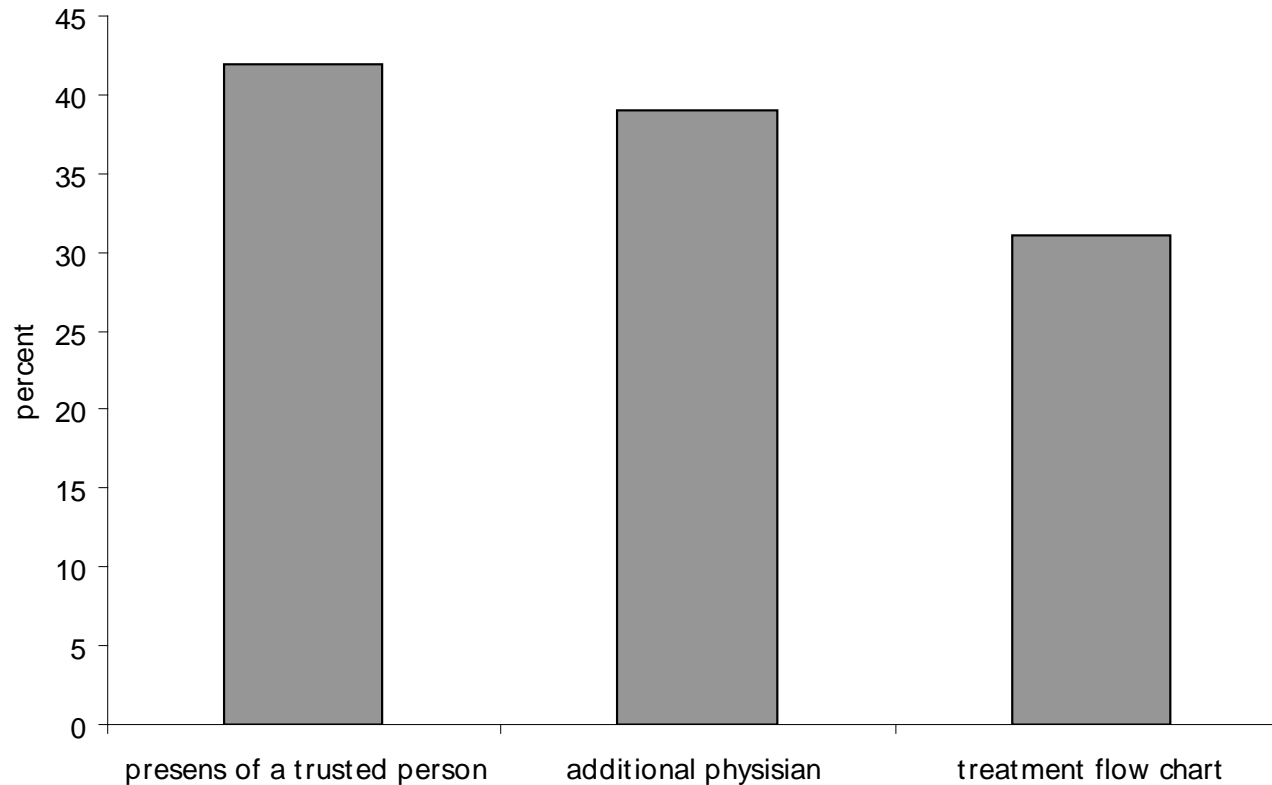
Distant metastasis	519 (29%)
Bone.....	5 (2%)
Brain.....	2 (1%)
Liver.....	56 (25%)
Lung.....	14 (6%)
Other.....	151 (66%)
Surgery	1663 (96%)
Chemotherapy	1571 (92%)
Suggestion for trials	609 (37%)
Inclusion in an other trial	423 (26%)
Wish of a second opinion	966 (69%)

Results



If there would be things you could do to improve the treatment of ovarian cancer, which of them would you say would be the most important?

Results



Which method do you think is most effective for an adequate patient information and patient participation in a therapy?

Conclusions

- This study underlines the high need of ovarian cancer patients to discuss all details concerning treatment options and clinical management with only minor difference between the countries.
- Patients also need more information about side effects of cancer therapies and second opinion opportunities.
- Besides effectiveness of therapy, alopecia and fatigue are the most important side effects bothering the patients.

Final analysis regarding intercultural aspects until the end of the year

EXPRESSION IV-Ovar
**What do primary and recurrent
ovarian cancer (OC) patients
expect from maintenance therapy?**
ENGOT-ov22

Objective

NOGGO
e.V.

Nord-Ostdeutsche Gesellschaft
für Gynäkologische Onkologie e.V.

ESGO
European Society of
Gynaecological Oncology

European Network of
ENGOT
Gynaecological
Oncology Trial Groups

current available drugs for maintenance therapy have

- different side effects
- administration forms
- schedules



identification of information needs and preferences regarding maintenance therapy among patients with ovarian cancer



Aim and design

Aim:

current available drugs for maintenance therapy have:

- different side effects
- administration forms
- schedules

identification of information needs and preferences regarding maintenance therapy among patients with ovarian cancer

Design:

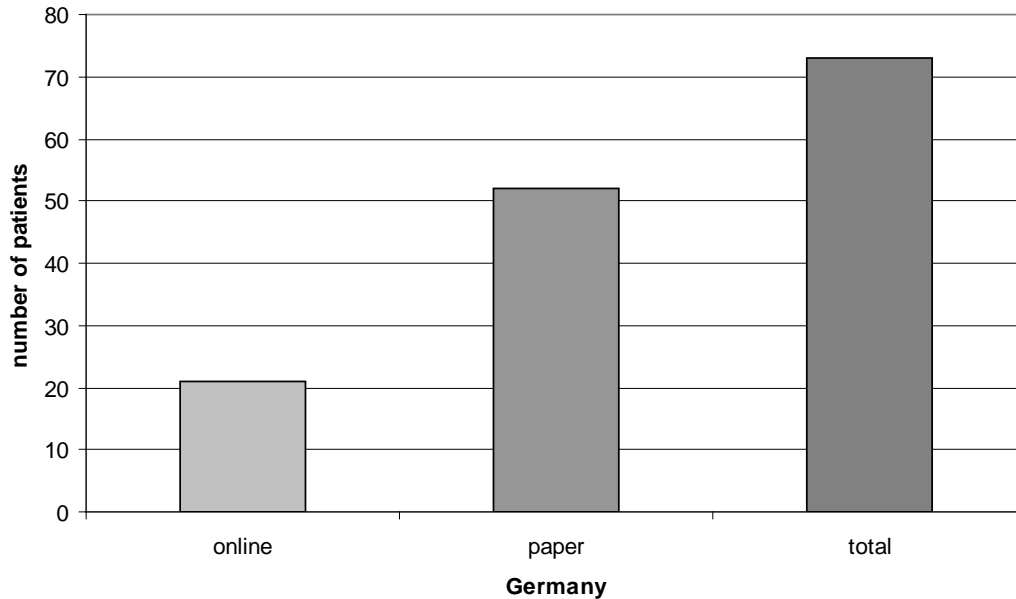
European survey (10-12 countries)

- 200-300 patients / country (all groups of ENGOT intent their participation)
- Internet version and hard copy version

Examples questions

- questions related to demography
 - e.g. Age, marital status, education level, professional status
- Questions related to disease
 - FIGO Stage, metastasis, Chemotherapy, relapse
- Questions related to maintenance therapy
 - administration type, personal incentive to choose MT, most important goal, maximum duration

Results and timeline



06-11-2013:
total 73 patients
(only Germany)

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Timeline:

May 2013

Sep

Nov

2014 autumn



Ethic approval

Start Germany

Start European survey
with Romania

coming soon: France, Belgium, Italy, Austria, Spain, Serbia, Turkey, Slovenia