Virtual Meeting on Informed and Shared Decision-Making

Co-Chairs:

Kathy Oliver, ECO Patient Advisory Committee
Guy Buyens, Anticancer Fund
Welcome and introduction

Andreas Charalambous
President, European Cancer Organisation
Board Member, European Oncology Nursing Society
Meeting Protocols

• To protect the quality of the audio for everybody please stay on “Mute” throughout the meeting

• We encourage all participants to join the interactive discussion in the Chat: ask questions, share thoughts and comments

• Please note that the meeting will be recorded

• We recommend that you connect using “Side-by-side: Speaker View” by activating it under “View” in the upper right-hand corner of the Zoom window and selecting it from the options
On our meeting agenda today!

Welcome and introduction

Session 1: Shared Decision-making

Chair by Kathy Oliver, Co-chair, Patient Advisory Committee, European Cancer Organisation

Session 2: Personalised Patient Information

Chair by Guy Buyens, Medical Director, Anticancer Fund

Summary and Closure
Inequalities Network

Our Inequalities Network dedicates itself to driving consensus, presenting policy recommendations and solutions, and sharing best practices in relation to the inequalities challenges associated to:

- The East-West Divide
- Gender
- Ethnicity
- Age
- Sexuality and Identity
- Health Literacy and Patient Education
- Other Marginalised Groups

Co-Chairs:

**Nicolò Matteo Luca Battisti**
International Society Of Geriatric Oncology (SIOG)

**Sarah Collen**
European Association Of Urology (EAU)
Inequalities Network Participants

Member Societies of the European Cancer Organisation

Patient Organisations

Charities & Foundations

Invited Stakeholders
The key topics from the article include:

• Health literacy as part of patient centred healthcare
• Cancer patients’ needs and shared decision making
• Impact on health outcomes
• Reliable information
• Misinformation in the digital era
• Helping the patient navigate
• Recommendations for improving cancer literacy in Europe

The article has been published in the Journal of Cancer Policy
SESSION I
Shared Decision-Making

Kathy Oliver
Co-Chair, Patient Advisory Committee, European Cancer Organisation
Chair and founding Co-Director, International Brain Tumour Alliance (IBTA)
European Code of Cancer Practice

YOU HAVE A RIGHT TO:

1. EQUAL ACCESS
2. INFORMATION
3. QUALITY, EXPERTISE & OUTCOMES
4. SPECIALISED MULTIDISCIPLINARY CARE
5. SHARED DECISION-MAKING
6. RESEARCH & INNOVATION
7. QUALITY OF LIFE
8. INTEGRATED SUPPORTIVE & PALLIATIVE CARE
9. SURVIVORSHIP & REHABILITATION
10. REINTEGRATION

#cancerpatientrights #codeofcancerpractice europeancancer.org/code
European Code of Cancer Practice

- A citizen and patient-centred statement of the **core requirements for good clinical cancer practice**, in order to improve outcomes for all of Europe’s cancer patients
- Co-produced by a team of cancer professionals, cancer patients and patient advocates
- Sets out a series of **10 key overarching rights**, signposting what patients should expect from their health system, in order for them to achieve the best possible outcomes
- **Empowerment tool** to ensure best available care for European citizens/patients
- **Translated** into over 20 languages
- **Endorsed** by many European and National organisations, as well as individual Cancer Centres
Shared-decision making process and its implementation in daily practice – experience from Denmark

Stine Rauff Søndergaard
Center for Shared Decision Making & Dep. of Clinical Oncology, Vejle Lillebaelt University Hospital of Southern Denmark
Shared-decision making process and its implementation in daily practice – experience from Denmark

Stine Rauff Søndergaard

M.D., PhD student.

Center for Shared Decision Making & Dep. Of Clinical Oncology
"Aren’t we already doing this?"

- What if they don’t do what I think they should do?
- We do it already!
- Will it work?
- I don’t have the time!
- My patients don’t want it
- I don’t have the time!
We are not doing it...

➢ Results from The Danish Cancer Society’s National Survey of Danish Cancer Patient Experiences show that 3 out of 4 cancer patients prefer decisions about treatment to be made together with clinicians based on information about treatment options, possible side effects, and the patients’ preferences.

➢ However, 1 out of 3 Danish cancer patients feel they are not sufficiently involved in decisions about treatment and care.

Does it work?

A systematic Review Sub analysis on Cancer-related decisions (N=46 studies) has shown that the use of patient decision aids, compared to control groups, has led to:

**Improved match between the chosen option and the features that mattered most to the patient, demonstrated by:**

- improved knowledge
- accurate risk perception
- value-choice agreement

**Improved decision-making process, demonstrated by:**

- decreased decisional conflict
- reduced clinician-controlled decision making
- fewer patients being indecisive

So – why don’t we practice SDM?

BUZZ-words and evidence available ...

... Action missing ....
Elements of implementation

STEP 1
SDM TEAM IN THE DEPARTMENT

STEP 2
TRAIN THE LEADERS

STEP 3
A
TEACH-THE-TEACHERS

STEP 3
B
DEVELOPMENT OF DECISION HELPERSTM
(Patient decision aids)

STEP 4
TEACHERS TRAIN OWN COLLEAGUES

STEP 5
PLANNING IMPLEMENTATION PHASE

STEP 6
EDUCATING PATIENTS
(under development)
Patient Decision Aids (PtDAs)

➢ A generic model “one-size-fits all”
   = a template

➢ Development together with Design School Kolding and in co-creation with patients.

➢ A template to insert data on pros and cons. Risk communication.

➢ A guide to help patients consider what matters most and the best solution for him/her.
A generic patient decision aid model....

Biomarker CA125: To monitor or not for relapse of ovarian cancer // The final design

Genetic testing in ovarian cancer // The final design

4 Radiotherapy

Benefits
- Reduces the risk of disease relapse
- Increases the chance of staying cancer free
- Possible to maintain

Disadvantages
- Skin reaction
- Insomnia
- Heart and lungs
- Many hospital appointments
- Late side effects
- Body image
- Breast tissue formation in the breast

Risk of local disease relapse up to 5 years after radiotherapy, hormone sensitive tumor

1 out of 10 women will experience local disease relapse
1 THE DECISION HELPER

The purpose of this Decision Helper is to support you and your doctor during the consultation in making the best choice concerning your possible radiotherapy for the remaining breast area. You have the choice to opt-in or opt-out of radiotherapy.

How far have you come in your decision making process, whether you want to receive radiotherapy?

☐ Have not considered the options  ☐ Considering the options  ☐ Close to making a decision  ☐ Have made a decision
About radiotherapy

After the breast-conserving surgery for breast cancer, radiotherapy is offered.

To what extent do you wish to be informed about radiotherapy to the remaining breast?

- As little as necessary E.g. - Benefits and harms
- A moderate amount of information E.g. - Benefits and harms - Consequences of disease relapse
- All available information E.g. - Benefits and harms - Consequences of disease relapse - Statistics: Late adverse effects/local recurrence
3 You as a patient

To make a shared decision about radiotherapy, it is particularly important to understand what matters to you in your daily life. When you make a decision, it will include options to add in and options to leave out, which may depend on your personal preferences. For more information see attached preparation sheet.

What is most important to you in this situation?

- To prevent recurrence of breast cancer
- To avoid side effects/late adverse effects
- Family, work, vacation e.g.

☐ A little  ☐ Moderately  ☐ A lot

☐ A little  ☐ Moderately  ☐ A lot

☐ A little  ☐ Moderately  ☐ A lot
4 Radiotherapy

**Benefits**
- Reduces the risk of disease relapse
- Increases the chance of staying cancer free
- Taking action
- Possible to maintain daily activities

**Disadvantages**
- Skin reactions
- Fatigue
- Heart and lungs
- Many hospital appointments
- Late side effects
- Body image. Solid tissue formation in the breast
4 No Radiotherapy

**Benefits**
- No side effects
- No late side effects from treatment
- Not time consuming
- Less time as a patient

**Disadvantages**
- Increases risk of disease relapse in the breast
- Decreases the chance of staying cancer free
- Patients concern of disease relapse
- Increases the risk of incurable disease relapse
4 Risk of dying from lung cancer after radiotherapy (smoker)

With Radiotherapy
+ Radiotherapy

11.8 out of 100 women will die from lung cancer before the age of 80.

No Radiotherapy
+ Radiotherapy

8.7 out of 100 women will die from lung cancer before the age of 80.

The statistics are based on a 60-year-old woman, a smoker.
Data assess the woman’s risk of dying from lung cancer before the age of 80.
4 Patient stories

The responsibility towards the family (husband/children/grand children) meant, that I chose radiotherapy.
– Patient 63 years

If my benefit of the treatment had been very small, I wouldn’t have chosen radiotherapy.
– Patient 54 years

My 88-year-old aunt chose not to get radiotherapy, because she felt “too old”.
– Relative

Radiotherapy was chosen because I was afraid that the disease would spread if I did not accept treatment.
– Patient 72 years

I chose not to get radiotherapy in fear of damaging lungs and heart and because it can be difficult to operate in irradiated tissue.
– Patient 49 years
5 Decision

Are you ready to make a decision?

☐ I want radiotherapy
☐ I do not want radiotherapy
☐ I am not ready to make a decision

What is required to enable you to make a decision?
Development of your own patient decision aid (DEcision Helper™) from the generic template
Development (PROCES) of your own patient decision aid (DECISION HELPER™)

**DECISION HELPER™**
Step by step: From generic tool to concrete product

1. **Kick off meeting w/ expert in PtDAs**
2. **Workshop w/ patients and clinicians**
3. **Data is entered into the platform, that generates the DECISION HELPER™**
4. **User test w/ patients and clinicians in consultations**
5. **Rounds of adjustment. Printing.**
6. **Final product in physical format**
How far have we come? SDM implementation in numbers

- **45** Departments/areas within the Region of Southern Denmark are in process with SDM implementation

- **139** Clinicians have been trained as trainers in SDM in the “Teach the Teachers” course – **16** in oncology

- **1181** Clinicians have been trained in SDM by these teachers

- **173** Leaders have participated in the course “Shared Decision Making for leaders”

- **41** Patient decision aids have been developed – **15** in oncology

- **14** Patient decision aids are in process

- **2** New LUP-Light (national survey on patient experiences) questions on key elements of SDM have been developed. The questions are part of 11 PREM questions that are asked to patients monthly in the Region of Southern Denmark
Thank You

Questions
Discussion
Input

LinkedIn: www.linkedin.dk/company/c-f-f-b
Homepage: www.cffb.dk

Stine Rauff Søndergaard
M.D., PhD student.
Center for Shared Decision Making & Dep. Of Clinical Oncology
Panel discussion:

Nicolò Matteo Luca Battisti
Co-Chair, Inequalities Network, European Cancer Organisation
President, International Society of Geriatric Oncology

Andreas Charalambous
President, European Cancer Organisation
Board Member, European Oncology Nursing Society

Csaba Degi
President-Elect, European Cancer Organisation
Director, International Psycho-Oncology Society

Teodora Kolarova
Member, Patient Advisory Committee, European Cancer Organisation
Executive Director, International Neuroendocrine Cancer Alliance

Patrycja Rzadkowska
Member, Patient Advisory Committee, European Cancer Organisation
Member, Pancreatic Cancer Europe
SESSION II
Personalised Patient Information

Guy Buyens
Medical Director,
Anticancer Fund
My Cancer Navigator

Gabry Kuijten
Coordinating physician of “My Cancer Navigator“, Anticancer Fund
My Cancer Navigator
Dr. Gabry Kuijten
What is My Cancer Navigator?

• An information service for patients and their relatives which is
  ▪ Independent
  ▪ Evidence-based
  ▪ Personalized
  ▪ Understandable
  ▪ Free

• Aiming to support Informed and Shared Decision Making

(Also available for healthcare professionals)
Why do people need My Cancer Navigator?

- Lack of time during consultation to address all questions
- Hesitance to “question” the doctor, power imbalance
- Some people need more information than what is provided
- Communication barriers – professional lingo, feeling overwhelmed, misunderstandings
- Confusing, conflicting and misleading information (online and elsewhere)
How do we support patients?

• We provide information on:
  ▪ Treatment options
  ▪ Clinical trials
  ▪ Centers of Excellence
  ▪ Non-regulated therapies

• Always guided by patients’ questions, and without giving advice

• Complementary to more general information services
How does it work?

Free for patients, the Anticancer Fund provides people and resources from donations.
4 medical doctors who are in contact with patients:
- Gabry Kuijten
- Henri Deckx*
- Muriel Sterckx
- Netteke Van Holthe

4 scientists performing searches:
- Annes Valckenaers
- Klara Rombauts
- Liese Vandeborne
- Rica Capistrano

5 clinical specialists who give clinical input:
- David Walker
- Nicolò Battisti
- Nina Neuendorff
- Sergio Crispino
- Yolande Lievens*

1 medical director who supervises the service:
- Guy Buyens

*not yet included in team picture
MCN in 2022
Patients we supported in 2022

325
Gender, age and contact person (%)

- Adult (n=316): 97%
- Child (n=9): 3%

- 42% male, 58% female

- 60% patient
- 14% child
- 13% partner
- 3% parent
- 3% professional
- 2% sibling
- 2% relative
- 2% friend
Country of residence (n)

TOP 5 (%)

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<tr>
<th>Country</th>
<th>Count</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>BE</td>
<td>145</td>
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<tr>
<td>UK</td>
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</tr>
<tr>
<td>USA</td>
<td>27</td>
<td>8%</td>
</tr>
<tr>
<td>NL</td>
<td>24</td>
<td>7%</td>
</tr>
<tr>
<td>FR</td>
<td>22</td>
<td>7%</td>
</tr>
</tbody>
</table>
Cancer types (%)

- Gastrointestinal: 27%
- Breast: 22%
- Gynaecological: 8%
- Central Nervous System: 8%
- Sarcoma: 7%
- Urological: 6%
- Lung: 6%
- Haematologic: 4%
- Unknown: 4%
- Lymphoma: 3%
- Skin: 2%
- Endocrine: 1%
- Head and Neck: 1%
- Carcinoma of Unknown Primary: 1%
Type of questions asked (n)

- Drug interactions: 12
- Need for test (scan, blood, biopsy): 22
- Managing symptoms/side effects: 24
- Cancer characteristics: 30
- Second opinion/expert: 34
- Other: 63
- Treatment options in trials: 101
- Treatment options in general: 148
- A specific treatment option: 304
Patient testimonials
Patient testimonials

Mason
Ciarán Nicholl
Head of the Health in Society Unit,
European Commission's Joint Research Centre
After today’s meeting!

Flash report to be shared with meeting participants

Recordings to be shared with meeting participants

The second Health Literacy article in production
We're pleased to invite you to the Community 365 Roundtable Meeting: 2023 - Year of Opportunities on Pharmaceutical Access and Value which aims to address the upcoming revisions to the EU Pharmaceutical Regulations and what it means for cancer, as well as discuss the application of the EU's HTA Regulation and its relevance to cancer.

Join Co-Chairs Matti Aapro, ECO Immediate Past-President, and Mirjam Crul, ECO Board Member and Co-Chair of both our Special Network on the Impact of Covid-19 on Cancer and our Workforce Network, on 27 February from 16:00-18:30 CET.
Our October 2022 roundtable event on cancer care needs in the community setting sought to provide a spotlight to a range of policy needs in an effort to increase survivorship and better treat patients in the community setting. We explored:

- How to achieve successful long-term management of cancer in the community setting, including ensuring suitable survivorship care planning
- Identifying and implementing the roles of primary care and allied healthcare professionals in long term management of cancer
- The experiences and learnings of those working with cancer
- New forms of treatment and care that can better support those living with cancer in the community setting

Report to be produced in late January or early February
PROTECT-EUROPE is an EU4Health Project that champions gender-neutral vaccination programme in EU Member States to provide protection for everyone against cancers caused by HPV e.g. cervical, anal, penile, vaginal, vulval and oropharyngeal.

If you are interested in attending, please contact giacomo.lazzaro@europeancancer.org
Join our Inequalities Network!

europeancancer.org/topic-networks

Contact Nela Osmanovic
nela.osmanovic@europeancancer.org