



Virtual Meeting on Informed and Shared Decision-Making

Co-Chairs:

Kathy Oliver, ECO Patient Advisory
Committee

Guy Buyens, Anticancer Fund



Welcome and introduction

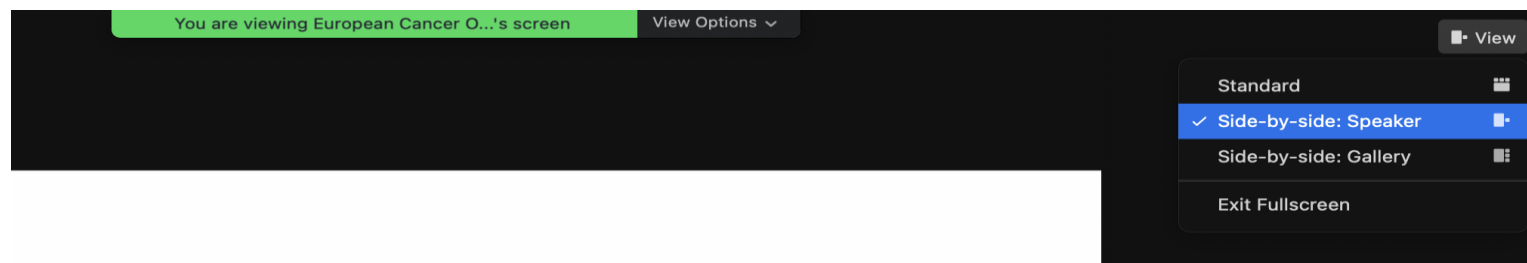
Andreas Charalambous

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

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

Session 2: Personalised Patient Information

*Chaired 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

Inequalities Network



Co-Chairs:

Nicolò Matteo Luca Battisti

International Society Of Geriatric Oncology (SIOG)

Sarah Collen

European Association Of Urology (EAU)

Inequalities Network Participants

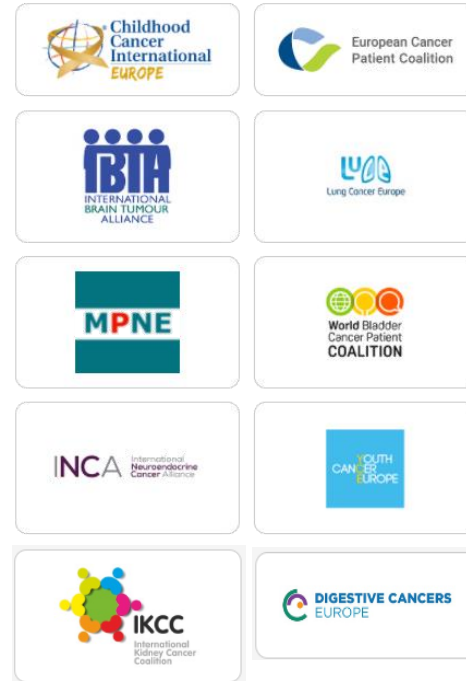
Member Societies of the European Cancer Organisation



Charities & Foundations



Patient Organisations



Invited Stakeholders



Cancer literacy in Europe - Informing patients and implementing shared decision making

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

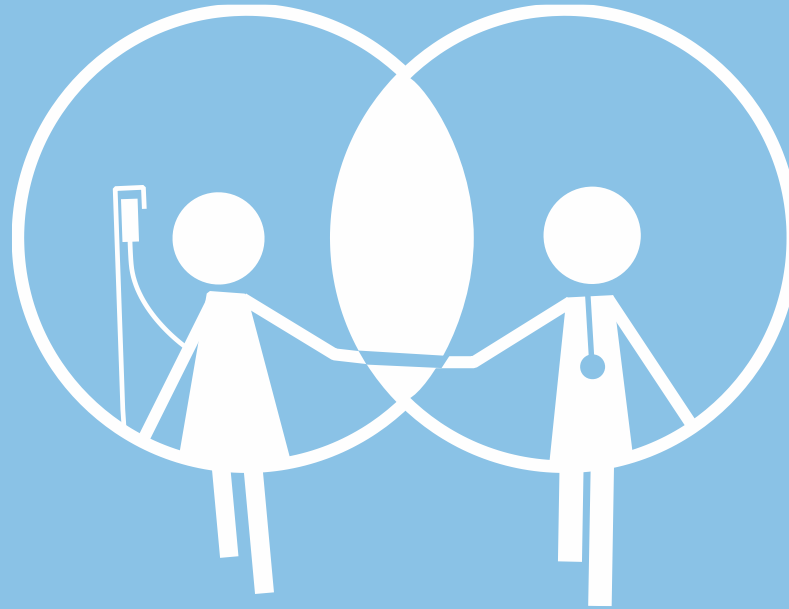
- A citizen and patient-centred statement of the **core requirements for good clinical cancer practice**, in order to improve outcomes for all of Europe's cancer patients
- Co-produced by a team of cancer professionals, cancer patients and patient advocates
- Sets out a series of **10 key overarching 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

January 18, 2023, Webinar by the
European Cancer Organisation and
The Anticancer Fund



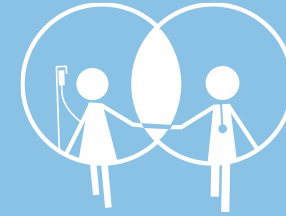
Shared-decision making process and its implementation in daily practice – experience from Denmark

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?

Will it work?

I don't have the time!

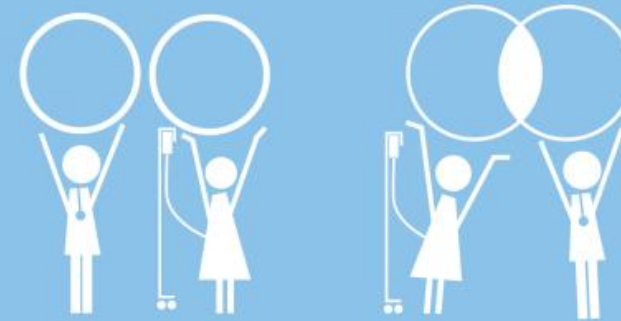
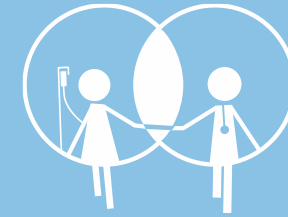
We do it already!



My patients don't want it

We are not doing it...

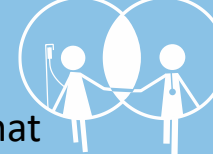
- Results from The Danish Cancer Society's National Survey of Danish Cancer Patient Experiences show that 3 out of 4 cancer patients prefer decisions about treatment to be made *together* with clinicians based on information about treatment options, possible side effects, and the patients' preferences.
- However, 1 out of 3 Danish cancer patients feel they are not sufficiently involved in decisions about treatment and care.



Clinicians often underestimate the strong wish from patients to be involved in the clinical decision making process. This makes it essential to discuss with patients in explicit terms the role they wish to have in that process.

Ref: Danish Cancer Society: Cancer patients needs and experiences through treatment and in follow-up. *Danish Cancer Society. Barometer Survey, 2013. Copenhagen, 2013*

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

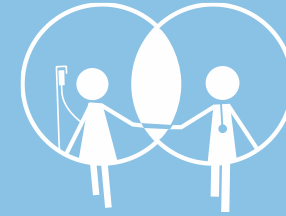
McAlpine K, Lewis KB, Trevena LJ, et al. What Is the Effectiveness of Patient Decision Aids for Cancer-Related Decisions? A Systematic Review Subanalysis. *JCO Clin Cancer Informatics*. 2018 Nov;(2):1–13.



Decision aids for people facing health treatment or screening decisions (Review)

Stacey D, Légaré F, Lewis K, Barry M, Bennett CL, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Thumason R, Trevena L

So – why don't we practice SDM?

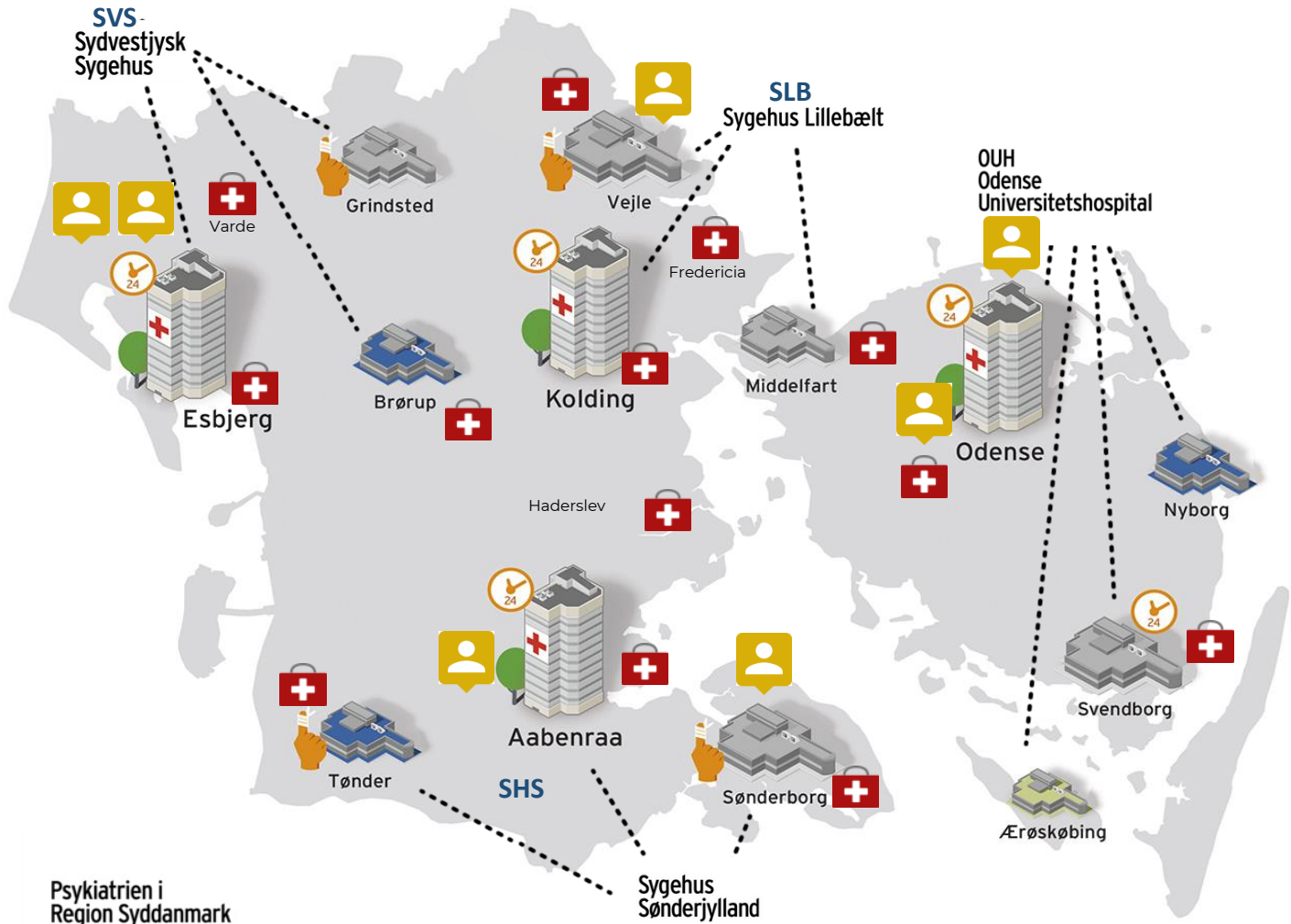


**BUZZ-words and
evidence available ...**

... Action missing



Hospital units in Region of Southern Denmark



- Acute care hospital
- Specialised hospital unit
- Outpatient hospital
- Island hospital
- Implementation consultant SDM
- Mental Health Care Hospital

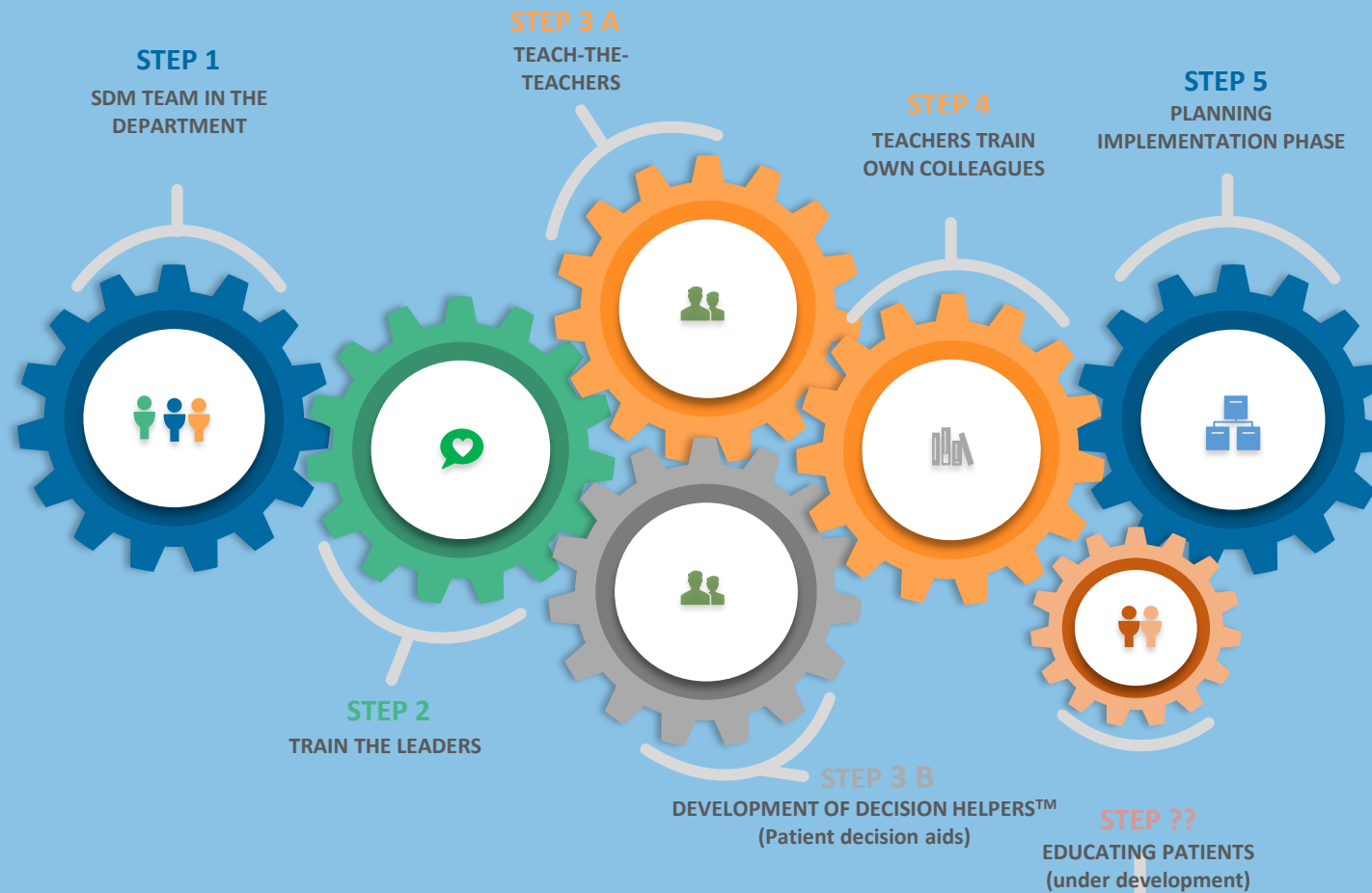
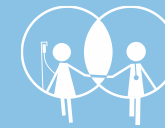
- 24-hr A&E
- A&E day and evening



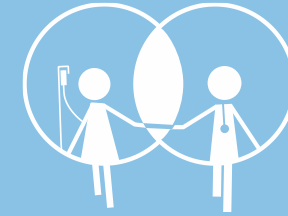
All rights reserved © Karina Dahl Steffensen, Center for Shared Decision Making, 2022.

Vejle Hospital
- a part of Lillebaelt Hospital

Elements of implementation



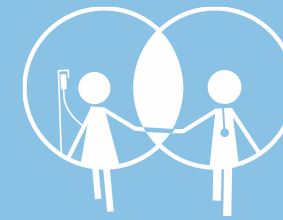
Patient Decision Aids (PtDAs)



- 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...



4 Radiotherapy

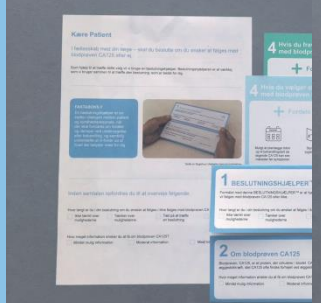
+ Benefits

- Reduces the risk of disease relapse
- Increases the chance of staying cancer free
- Taking action
- Possibility to maintain

÷ Disadvantages

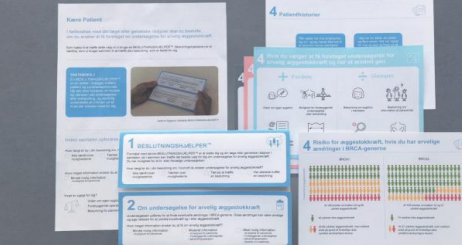
- Skin reaction
- Insomnia
- Heart and lungs
- Many hospital appointments
- Late side effects
- Body image. Solid tissue formation in the breast

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



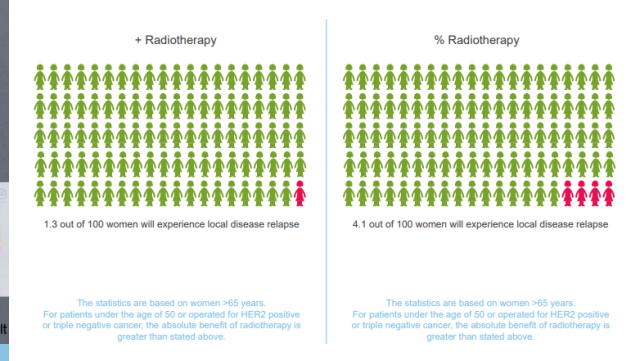
Frame: version 15 / Cards: version 16 / Preparat

Genetic testing in ovarian cancer // The final design



Frame: version 5 / Cards: version 7 / Preparation sheet: version 7

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



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

2 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

A little Moderately A lot

To avoid side effects/late adverse effects

A little Moderately A lot

Family, work, vacation e.g.

A little Moderately A lot

4 Radiotherapy



+ Benefits



Reduces the risk of disease relapse



Increases the chance of staying cancer free



Taking action

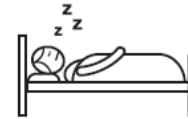


Possible to maintain daily activities

÷ 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.

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.

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?

.....

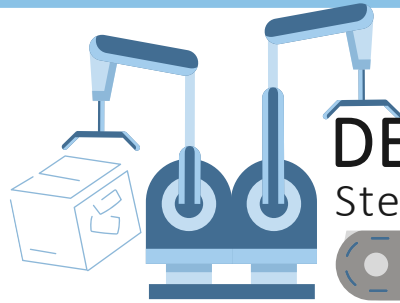
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Development of your own patient decision aid (DECISION HELPER™) from the generic template



Development (PROCES) of your own patient decision aid (DECISION HELPER™)



DECISION HELPER™

Step by step: From generic tool to concrete product

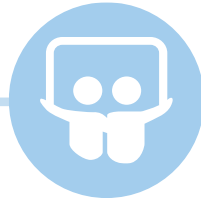


1



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

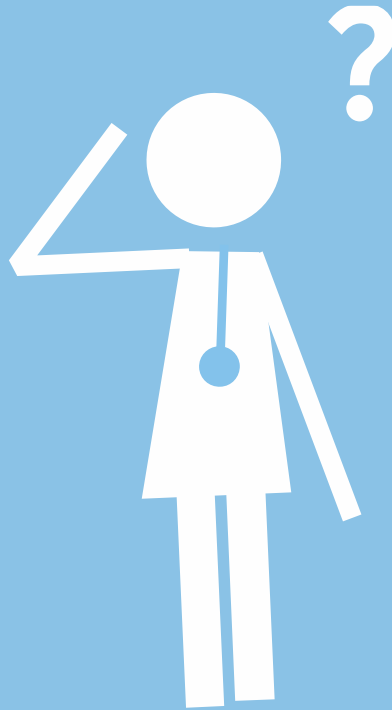


Final product in physical format

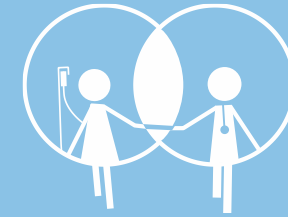
How far have we come? SDM implementation in numbers

- **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)

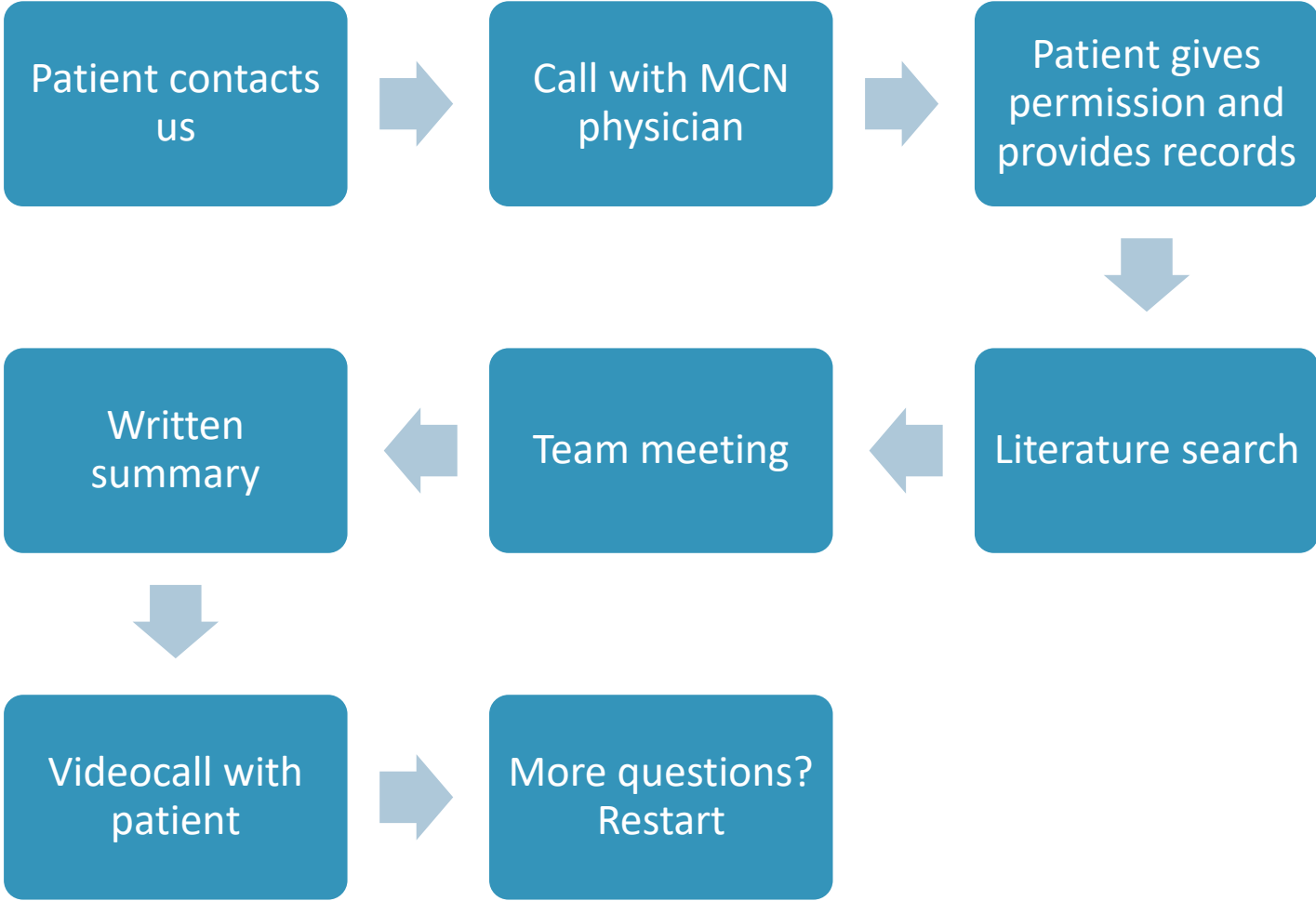
Why do people need My Cancer Navigator?

- 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



MCN in 2022

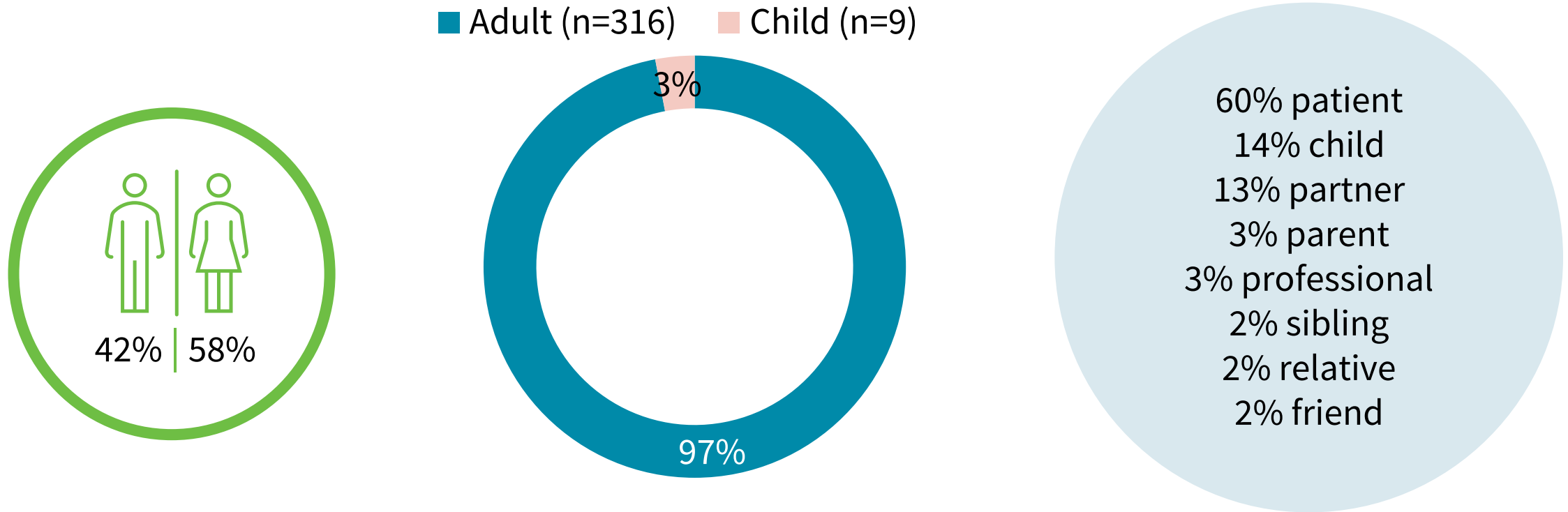




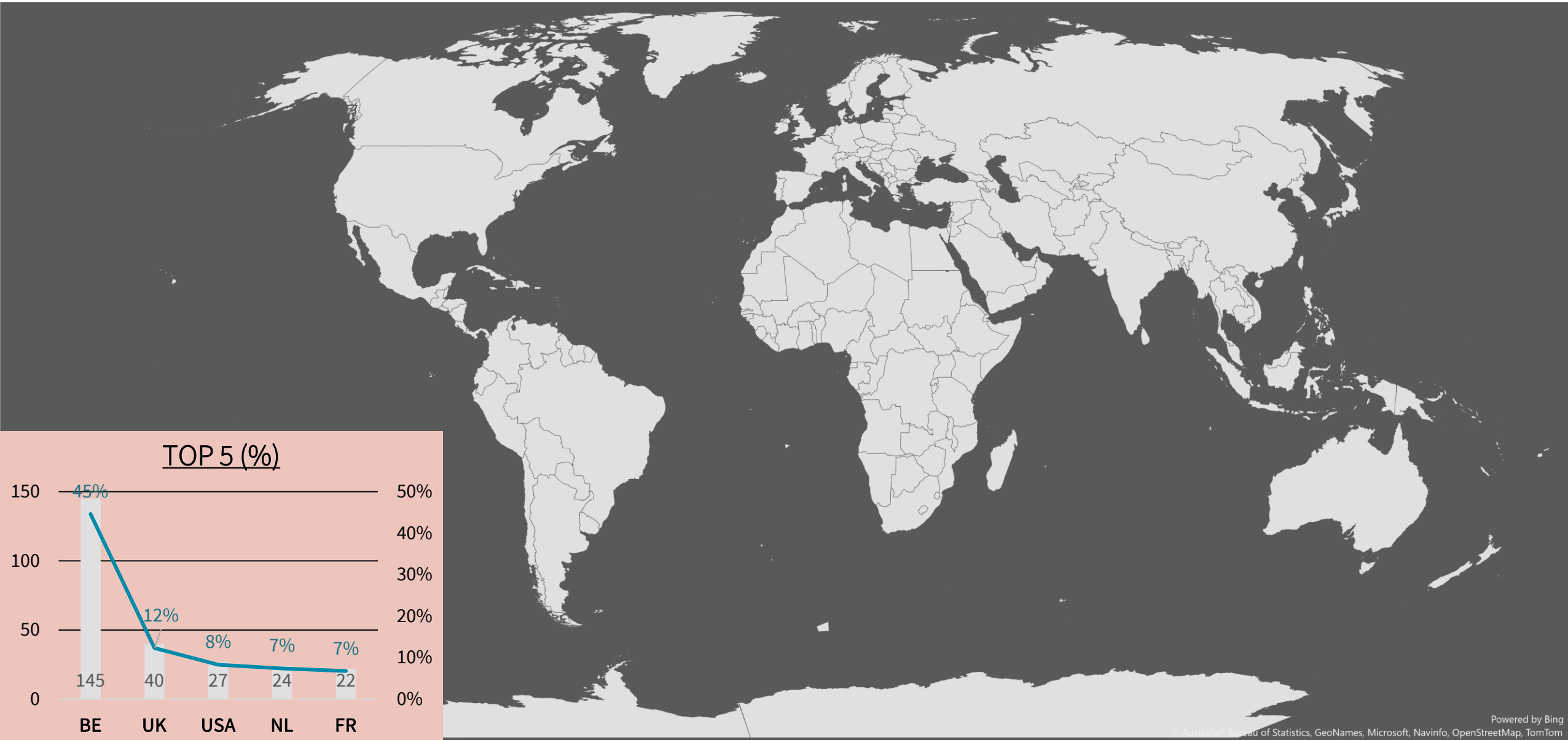
Patients we
supported in
2022

325

Gender, age and contact person (%)

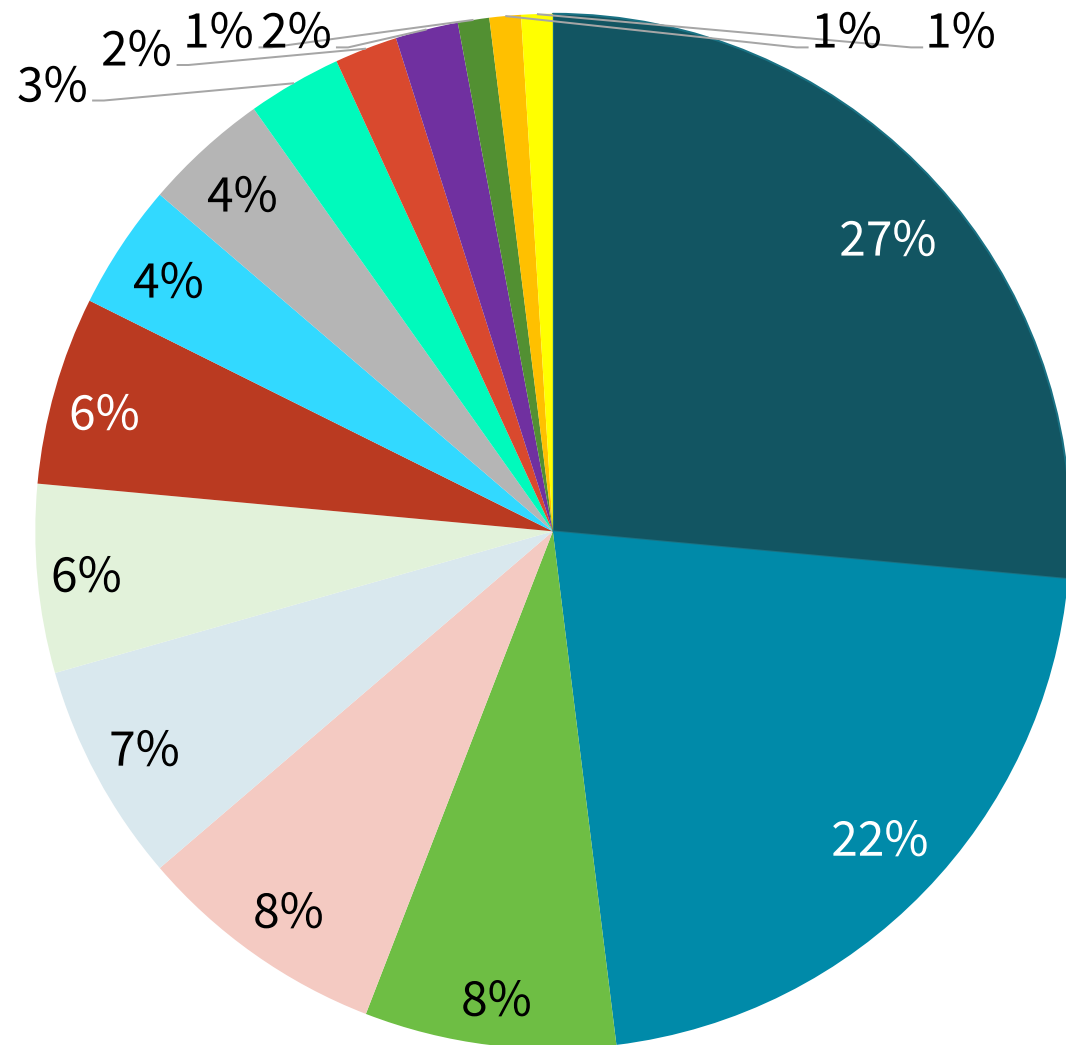


Country of residence (n)

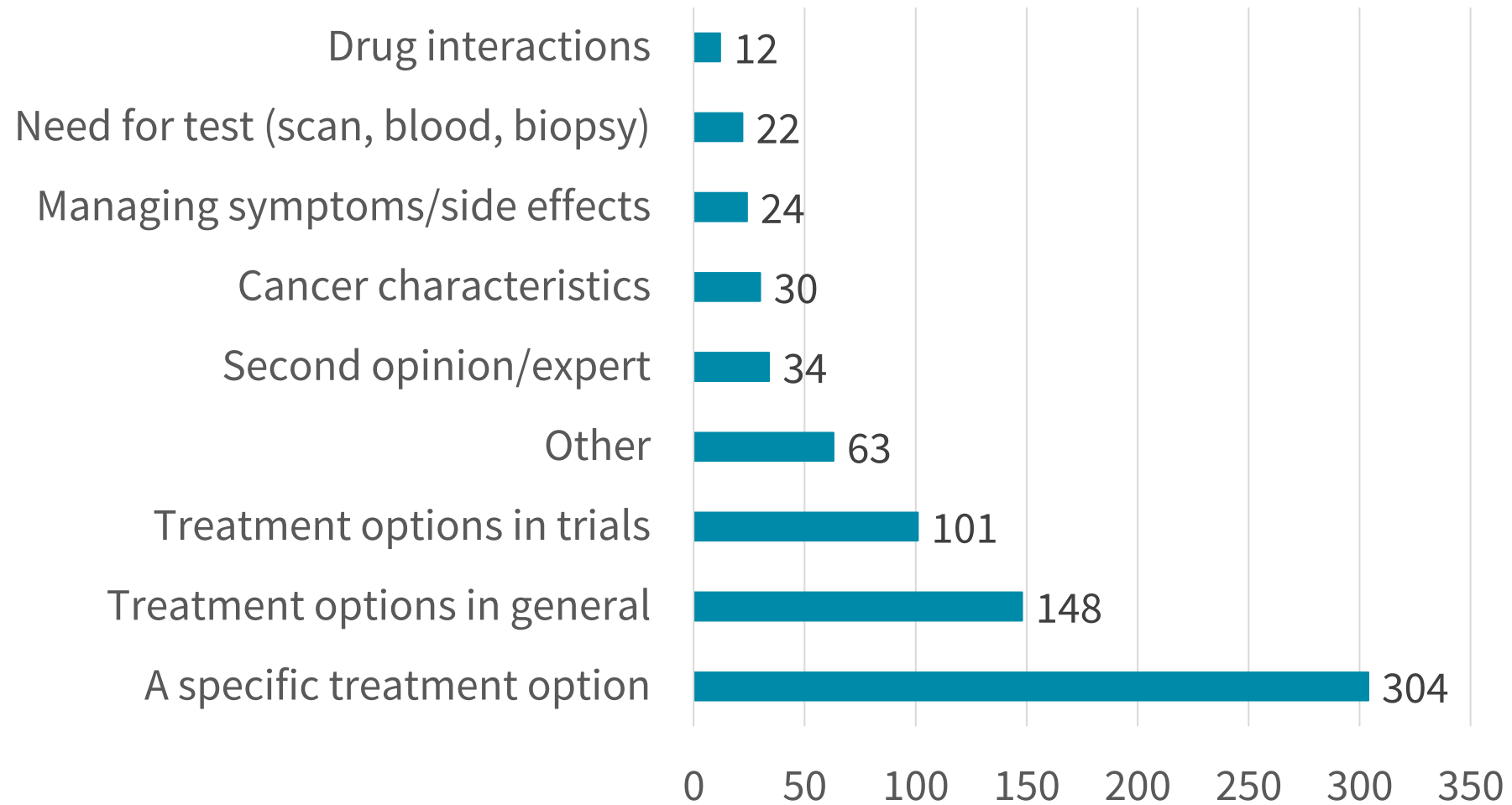


Cancer types (%)

- Gastrointestinal
- Breast
- Gynaecological
- Central Nervous System
- Sarcoma
- Urological
- Lung
- Haematologic
- Unknown
- Lymphoma
- Skin
- Endocrine
- Head and Neck
- Carcinoma of Unknown Primary



Type of questions asked (n)





Patient testimonials

Patient testimonials

Mason



THANK YOU



www.anticancerfund.org



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info@anticancerfund.org

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

vimeo

Recordings to be shared with meeting participants



The second Health Literacy article in production

NEXT: Community 365 Roundtable Meeting: 2023 - A Year of Opportunities on Pharmaceutical Access and Value

- 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.**



Community 365
Roundtable Meeting

**2023 - A YEAR OF OPPORTUNITIES
ON PHARMACEUTICAL ACCESS AND
VALUE**

27 February 2023
16:00 - 18:30 CET

Report from the Community 365 Roundtable Meeting on Cancer Care Needs in the Community Setting

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



Beating HPV Cancers in Europe: The Role of Vaccination

European Parliament

europa cancer ORGANISATION

renew europe.

 **26.01.2023**

 **17:40–20:00 CET**

 **Altiero Spinelli, Room 5G1**

 **Hosted by Alin Mituța MEP, Renew Europe**

 *Followed by a networking reception*

 giacomo.lazzaro@europeancancer.org

 Co-funded by the European Union

protect-europe.org – EU4Health project

Join our Inequalities Network!



Inequalities Network



europeancancer.org/topic-networks



Contact Nela Osmanovic

nela.osmanovic@europeancancer.org