



Virtual Meeting on Informed and Shared Decision-Making

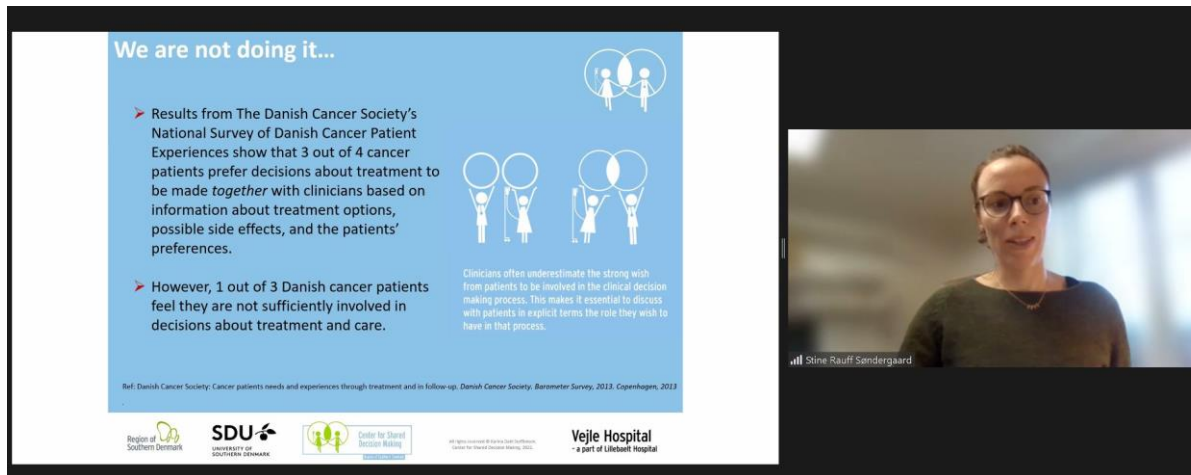
Wednesday 18 January 2023: Flash Report

The meeting was held in conjunction with the recent publication of a new open access article in the Journal of Cancer Policy "[Cancer literacy – Informing patients and implementing shared decision making](#)". The article, co-authored by healthcare professional and patient organisations, draws forward reflections, best practice examples and recommendations on how informed and shared decision-making can be better achieved in cancer care across Europe.

Session 1: Shared Decision-making - Chaired by Kathy Oliver

In her keynote presentation, **Stine Rauff Søndergaard**, from the Center for Shared Decision Making & Dep. of Clinical Oncology, Vejle Lillebaelt University Hospital of Southern Denmark emphasised the importance of improving patient knowledge, pointing out that most of those who participated in her research prefer to make decisions with physicians and be asked what matters to them. However, not all patients experience share decision-making, so a systematic approach is needed to introduce and extend it. In this respect, elements of implementation of the share decision making process includes involving a team in the department, trainings to clinicians, development and use of Patient Decision Aids (PtDAs) and educating patients. Professor Søndergaard emphasised the following points:

- **Patient decision aids** - provide a structured guide to help shift the focus in patient care more towards matters that are of highest value to them and the solutions that will best achieve this.
- It is important to present the advantages and disadvantages of available options, relative to the patient's situation. In addition, sharing the stories of patients who have made the same choice can be assistive.
- 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.



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, 2023. Copenhagen, 2023

Region of Southern Denmark | SDU UNIVERSITY OF SOUTHERN DENMARK | Center for Shared Decision Making | Vejle Hospital - a part of Lillebaelt Hospital

Stine Rauff Søndergaard

Stine Rauff Søndergaard, the Center for Shared Decision Making & Dep. of Clinical Oncology, Vejle Lillebaelt University Hospital of Southern Denmark

During the panel discussion, matters raised included:

- **Csaba Degi**, Director of the International Psycho-Oncology Society and President-Elect of the European Cancer Organisation, highlighted the need to actively remove some of the common barriers to achieving which can include anxiety, depression, fear, and cultural and language barriers. Better inclusion of psycho-oncology support in standard cancer care could help in this regard, as well as achieving stronger inclusion of patient family members within meetings and decisions.
- **Teodora Kolarova**, Executive Director of the International Neuroendocrine Cancer Alliance and member of ECO Patient Advisory Committee, raised the point that for many patients, depending on their perspective and condition, greater priority might be placed on the quality of their life above duration. The patient's main wishes, may not be what providers usually imagine. This underlines why shared decision-making is so important.
- **Patrycja Rzadkowska**, a pancreatic cancer survivor and ECO Patient Advisory Committee member, emphasizes the need to always inform and involve patients, but also remembering that patients will rarely have medical training. This matters in respect to language and terminology used. Healthcare professionals must aim to converse privately and respectfully with patients, answer questions, and solve doubts. On the patient's side, preparing in advance of meetings, including considering in advance their key questions, is recommended as well as involving family members. Recording the meetings so that they can be listened to again later could also be considered.
- **Andreas Charalambous**, ECO President, emphasized the role of nurses in supporting shared decision-making, reflecting upon their close relationship with patients and family members. The term "decision-making coaches" has been developed to describe this process. Nurses' education in the nurse-patient relationship emphasizes the patient's needs and personal care.




- **Nicolò Matteo Luca Battisti**, International Society of Geriatric Oncology and chair of ECO Inequalities Network, described shared decision-making as an unmet need of the health care system. Time is one of the most precious commodities in cancer care. If there isn't sufficient time for full discussions with patients, the achievement of shared decision-making can suffer. Training and education also has a significant role to play in providing health professionals with the skills to support shared decision-making.

Session 2: Personalised Patient Information - Chaired by Guy Buyens

In her keynote presentation, **Gabry Kuijten**, coordinating physician of "[My Cancer Navigator](#)" brought attention to the importance of information services for patients, their relatives and healthcare professionals. She highlighted, as a best practice example, the ACF My Cancer Navigator as one such evidence-based information tool tailored for patients. The service supports hundreds of patients to better navigate their care, understand their options and take more active and empowered roles in their cancer care.

- Patients and relatives may need this type of service for the following reasons:
 - 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.
 - Confusing, conflicting and misleading information (online and elsewhere).
- The team of My Cancer Navigator is composed of medical doctors, scientists, clinical specialists, and a medical director.
- My Cancer Navigator supports patients by providing information on treatment options; clinical trials (if patients might qualify); centres of excellence; and non-regulated therapies.
- The work is always guided by the patients' questions, without providing any advice but only information.
- The service supports patients from all over the world, but it is based in Belgium.


How does it work?



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graph TD
    A[Patient contacts us] --> B[Call with MCN physician]
    B --> C[Patient gives permission and provides records]
    C --> D[Literature search]
    D --> E[Team meeting]
    E --> F[Written summary]
    F --> G[Videocall with patient]
    G --> H[More questions? Restart]
    H --> A
  
```

Free for patients, the Anticancer Fund provides people and resources from donations



Gabry Kuijten

Gabry Kuijten, coordinating physician of [“My Cancer Navigator”](#)

During the panel discussion, matters raised included (look at slides for names and roles):

- **Nicolò Matteo Luca Battisti**, International Society of Geriatric Oncology and chair of ECO Inequalities Network, mentioned that healthcare professionals should always provide patients with a full set of information, translating the evidence available in words that patients can process and understand.
- **Andreas Charalambous**, President of the European Cancer Organisation, pointed to key findings from a number of systematic reviews in the scientific literature. This included the way in which under-resourcing and under-staffing in cancer care directly impacts and threatens the achievement of shared decision-making and the provision of personalised patient information.
- **Patrycja Rzadkowska**, a pancreatic cancer survivor and member of the ECO Patient Advisory Committee, underlined the core value of patients’ organisations in helping patients and families to navigate to trustworthy information. It is important to transmit to patients and their families the importance of checking sources of information. Much very good information is available but often only in English and not the many languages of Europe.
- **Teodora Kolarova**, Executive Director of the International Neuroendocrine Cancer Alliance and member of ECO Patient Advisory Committee, stressed the importance of empathy and human dialogue between the medical professional and the patient.
- **Csaba Degi**, Director of the International Psycho-Oncology Society and President-Elect of the European Cancer Organisation, emphasised that ensuring the autonomy and independence of patients is key. Psychosocial support also helps patients to be in a better position to absorb and process information together with the medical team.



Session closing and interventions

In the final part of the programme **Ciarán Nicholl**, Head of the Health in Society Unit, European Commission's Joint Research Centre highlighted ways in which the EU's cancer policy agenda is seeking to support the achievement of shared decision-making including through initiatives such as [the European Commission Initiative on Breast Cancer](#).

Romilda Baldacchino Zarb, a member of the Maltese Parliament, a pharmacist and active member of [National and European Parliamentarians for Cancer Action](#), contributed a statement to the event expressing her personal support for the shared decision-making agenda. She also called for acknowledgement of the kind of personal and specific difficulties that any individual patient may experience, as well as respect for the fact that preferences may have root in ethical and religious values.

Helpful resources and additional information

[Cancer literacy – Informing patients and implementing shared decision making.](#)

[The European Code of Cancer Practice](#)

[The ACF My Cancer Navigator](#)