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NSGO Annual Meeting

Shared Decision Making

How to explain molecular findings to patients

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How Would You Feel If...

You were presented with **complex molecular findings** you didn't fully understand?



You faced **life-changing decisions** without knowing all the implications?

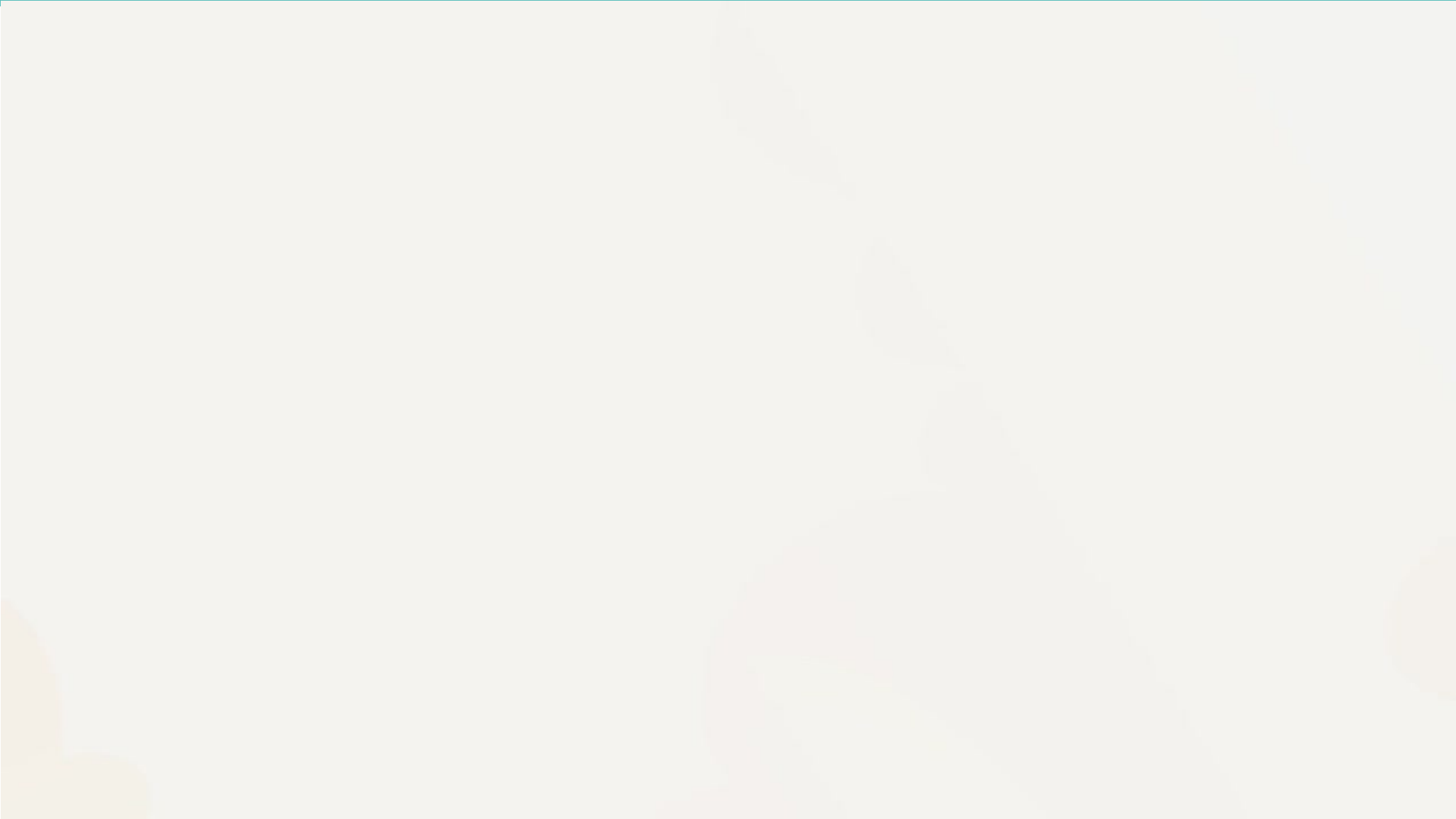
If I were the patient, how would I want this explained to me?



What is Shared Decision Making?

No decision about me - without me

Shared Decision Making (SDM) is a collaborative healthcare approach where healthcare professionals and patients work together to make informed decisions. It involves sharing medical information, discussing treatment options, and considering patients' preferences and values. SDM aims to empower patients, enhancing their active participation in their healthcare choices and ultimately improving the overall quality of care.



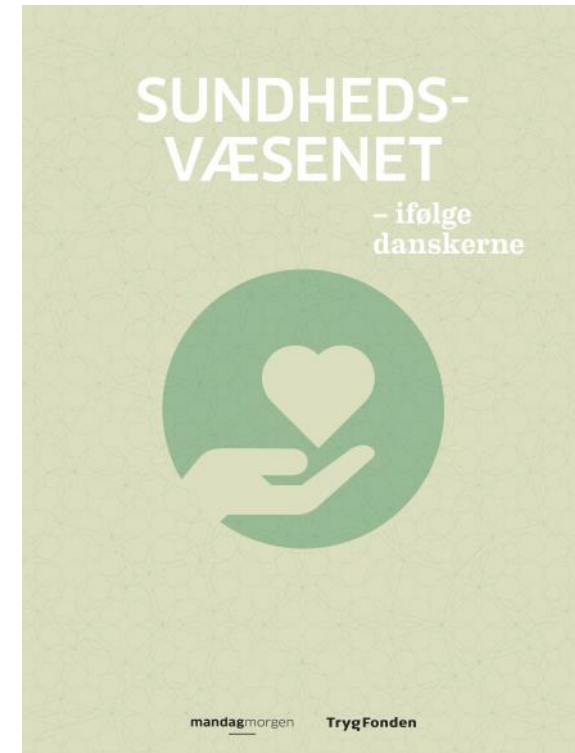
What do the patients say?



- "Health Services" – according to the Danes Mandag Morgen and TrygFonden 2016.
- More than 6.000 Danes have been asked about their overall expectations to the health services, their specific experiences and opinions to a number of change management initiatives.

Material

Ref.: Report Mandag Morgen and TrygFonden: The health Services according to the Danes, 2016

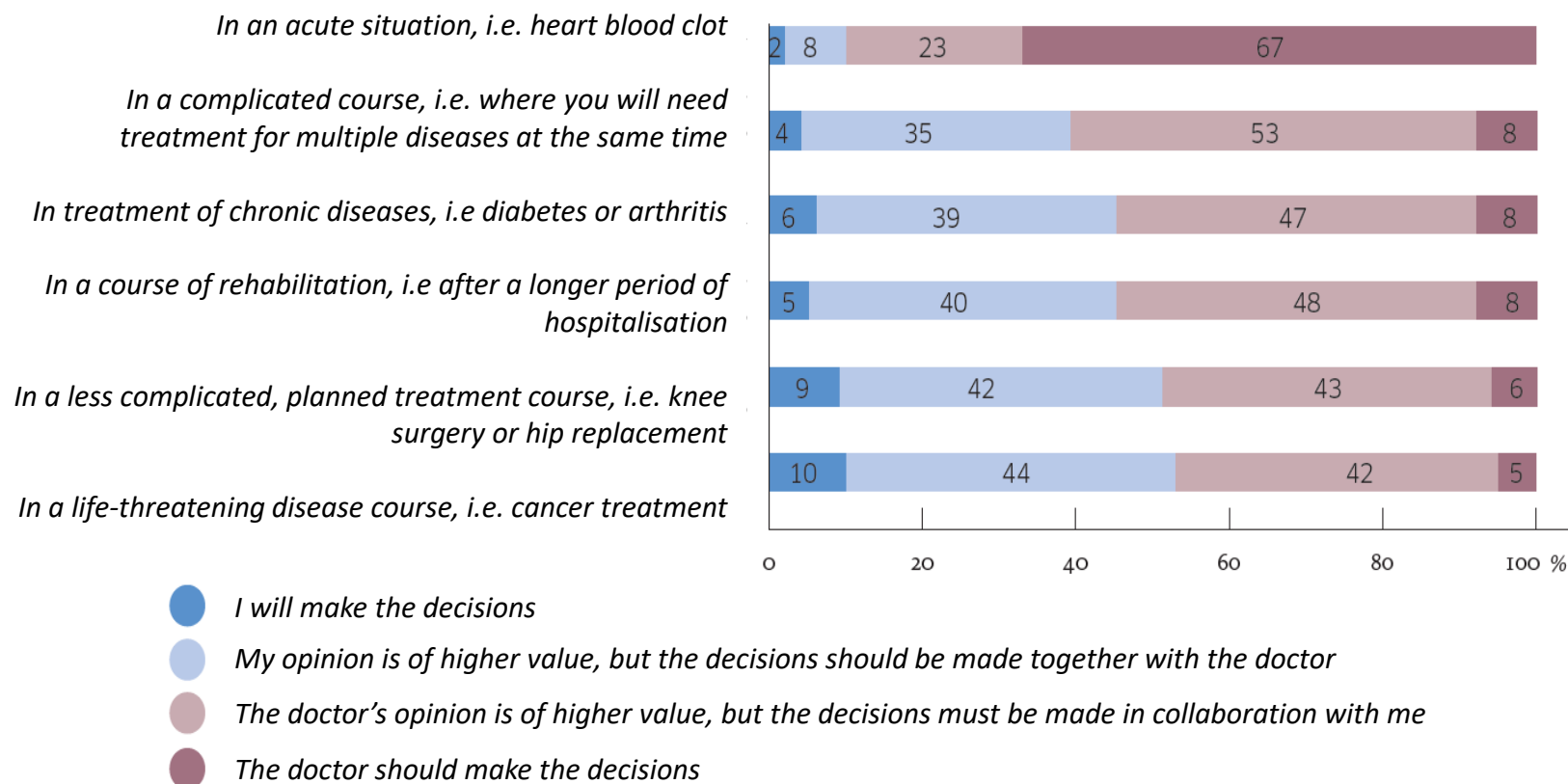


What do the patients say?



A majority wants to make shared decisions

"Who would you want to make decisions about treatment if you were in each of the following situations?"



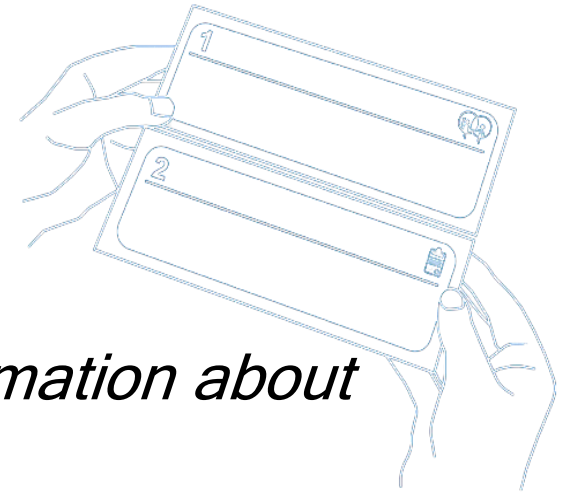
Ref.: Report Mandag Morgen and TrygFonden: The health Services according to the Danes, 2016



Definition

A patient decision aid is a tool that provides evidence-based information about healthcare options, benefits, and risks.

It helps patients clarify values and preferences, enabling them to make informed, personalized decisions in collaboration with healthcare providers.

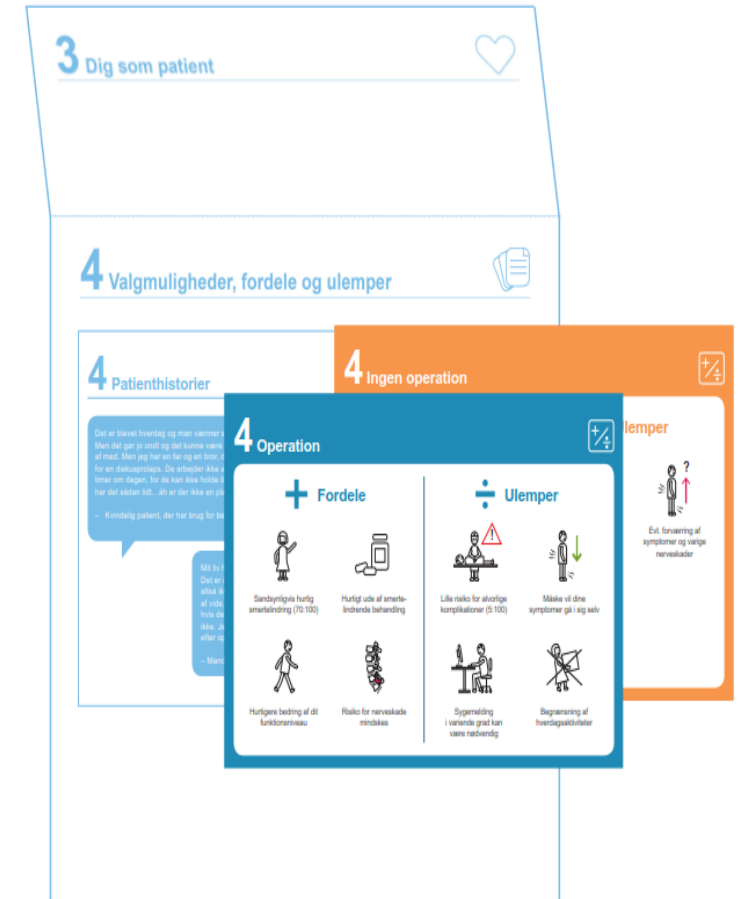


Patient decision aid

What is it?



- Clinicians and patients can use patient decision aids to support Shared Decision Making
- Can be used in the dialogue between patient and clinician when a decision is to be made
- Must provide the patients with clear, understandable information about their condition and treatment possibilities
- The tool outline results, risks and uncertainties in a clear and unbiased way
- Helps the patient to consider what is important to him/her and what solution is the best in his/her situation: "patient preferences"
- A patient decision aid cannot stand alone and cannot replace the dialogue between patient and clinician



DECISION HELPER™

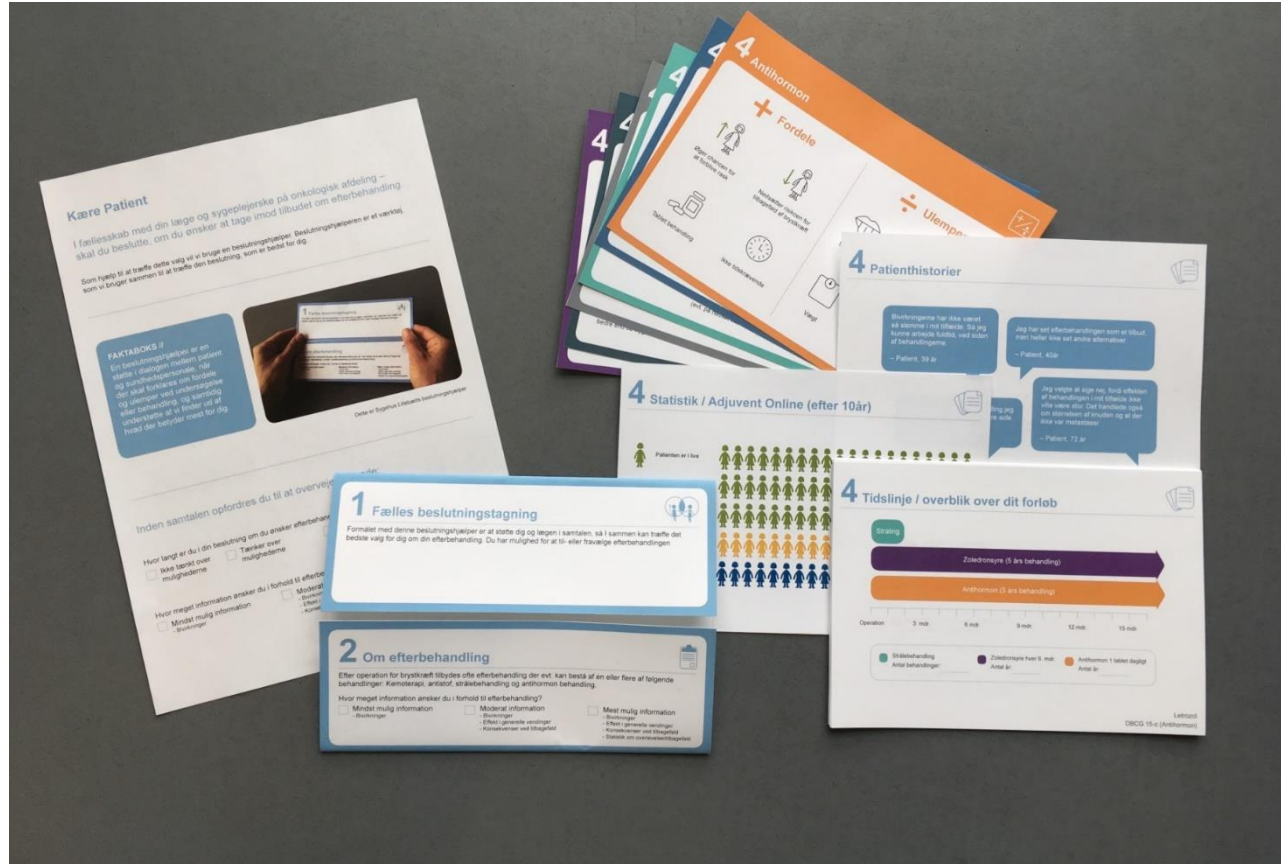
A Danish model for patient decision aids



- We have developed a template (a DECISION HELPER™) to use when working with shared decision making
- The DECISION HELPER™ has been developed in cooperation with Design School Kolding, patients and clinicians
- The DECISION HELPER™ has been tested in multiple research projects. The results show that, when the consultation is supported by when a DECISION HELPER™, the degree of shared decision making increases significantly, the patient feels more involved, is less in doubt of the decision and regrets less
- The DECISION HELPER™ is an in-consult patient decision aid tool
- The patients requested a tangible patient decision aid and not a digital solution.
(However, we do now also have an app based DECISION HELPER™)

DECISION HELPER™

A Danish model for patient decision aids

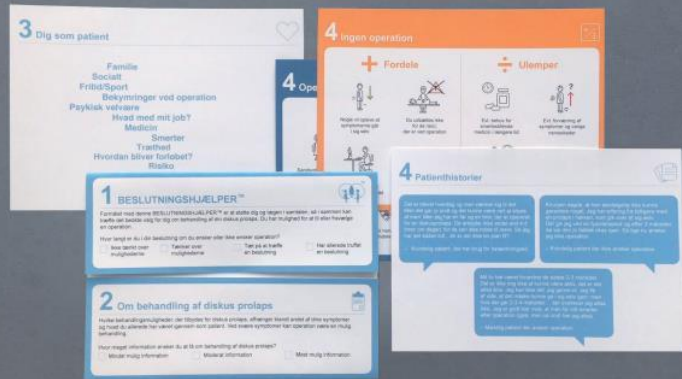


DECISION HELPER™

A generic patient decision aid model



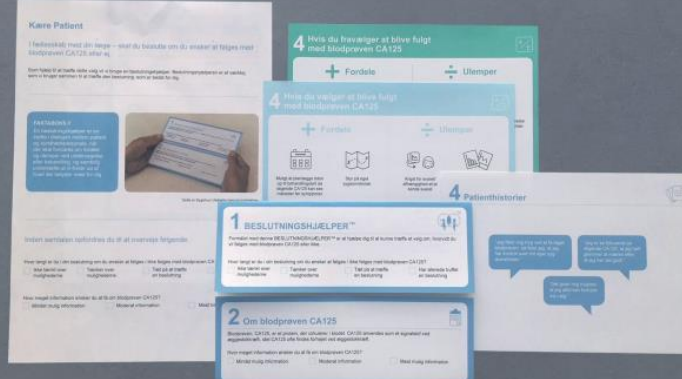
Lumbar herniated disc // The final design



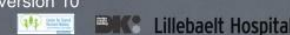
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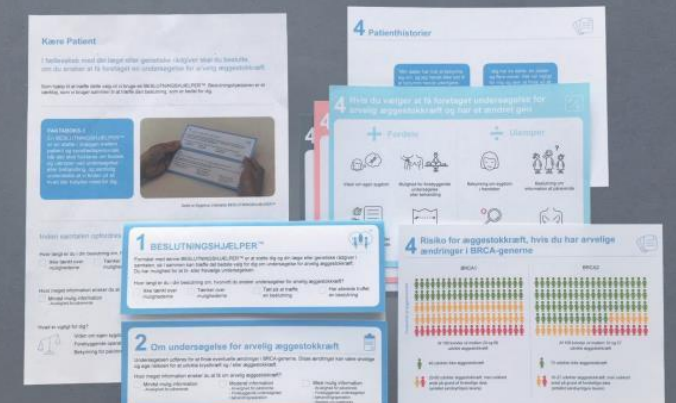
Biomarker CA125: To monitor or not for relapse of ovarian cancer // The final design



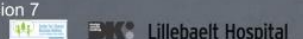
Frame: version 15 / Cards: version 16 / Preparation Sheet: version 10



Genetic testing in ovarian cancer // The final design



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







How can I explain molecular testing (and treatment) in a way that helps the patient feel informed, valued, and involved?



Step 1

Choice talk

-  Explain that a decision needs to be made, and the patient has a role in it.
-  Invite the patient: Explain that decision-making is a shared process and that the patients inputs are valued and important to consider.







How can I explain molecular testing (and treatment) in a way that helps the patient feel informed, valued, and involved?



Step 2

Option talk (Medical Options)

-  Present options neutrally, including "wait and see" – use a patient decision aid – if available
-  Discuss the pros and cons of all treatment options.
-  Use absolute numbers and explain side effects in terms of daily life.
-  Check understanding with the "teach-back" method.





How can I explain molecular testing (and treatment) in a way that helps the patient feel informed, valued, and involved?



Step 3

Patient Preferences

-  Ask about what is important to the patient now and in the future.
-  Assist the patient in linking her preferences/values to how they align with the medical options outlined before






How can I explain molecular testing (and treatment) in a way that helps the patient feel informed, valued, and involved?



Step 4

Decision talk

-  Make a shared decision based on the best match between medical options and the patient's preferences.
-  Support the patient's choice, even if it is not the best medical option.
-  Allow flexibility to revisit the decision later.

An example of a patient decision aid built from the generic patient decision aid platform



Genetic testing in ovarian cancer // The final design

Kære Patient

I fællesskab med din læge eller genetiske rådgiver skal du beslutte, om du ønsker at få foretaget en undersøgelse for arvelig æggestokkræft.

Som hjælp til at træffe dette valg vil vi bruge en BESLUTNINGSHJÆLPER™. Beslutningshjælperen er et værktøj, som vi bruger sammen til at træffe den beslutning, som er bedst for dig.

FAKTABOKS //
En BESLUTNINGSHJÆLPER™ er en støtte i dialogen mellem patient og sundhedspersonale, når der skal foretages omfangsrige og udfordrende valg omkring undersøgelse eller behandling, og samtidig undersøges, at vi finder ud af, hvad der betyder mest for dig.

Dette er Sygehus Lillebælt's BESLUTNINGSHJÆLPER™

4 Patienthistorier

"Min datter har som et barn mistet sin mor, og jeg havde ikke lyst til at bekymre hendes yndlingslærere."

"Jeg har tre døtre, en søn og flere misser! Det var vigtigt for mig og dem at have ud af."

4 Hvis du vælger at få foretaget undersøgelse for arvelig æggestokkræft og har et ændret gen

+ Fordele

- Viden om egen sygdom
- Mulighed for forebyggende undersøgelse eller behandling

÷ Ulemper

- Bekymring om sygdom i fremtiden
- Bestumning om information af pårørende

1 BESLUTNINGSHJÆLPER™

Formålet med denne BESLUTNINGSHJÆLPER™ er at støtte dig og din læge eller genetiske rådgiver i samtalen, så I sammen kan træffe det bedste valg for dig om undersøgelse for arvelig æggestokkræft. Du har mulighed for at til- eller fjerne undersøgelsen.

Hvor langt er du i din beslutning om, hvorvidt du ønsker undersøgelse for arvelig æggestokkræft?

Ikke tænkt over mulighederne Tænker over mulighederne Tænker på at træffe en beslutning Har allerede truffet en beslutning

2 Om undersøgelse for arvelig æggestokkræft

Undersøgelsen udføres for at finde eventuelle ændringer i BRCA-generne. Disse ændringer kan være arvelige og øge risikoen for at udvikle brystkræft og / eller æggestokkræft.

Hvor meget information ønsker du at få om arvelig æggestokkræft?

Mindst mulig information - Anvendt for pårørende Moderat information - Anvendt for søster/søster Mest mulig information - Anvendt for patiente / Forebyggende undersøgelser / Behandlingsoprettelse / Statistik om kræftslags

4 Risiko for æggestokkræft, hvis du har arvelige ændringer i BRCA-generne

BRCA1	BRCA2
Af 100 kvinder vil mellem 20 og 60 udvikle æggestokkræft	Af 100 kvinder vil mellem 10 og 27 udvikle æggestokkræft
40 udvikler ikke æggestokkræft	73 udvikler ikke æggestokkræft
20-60 udvikler æggestokkræft, men ukendt om de på grund af forskellige data (inkluderet udfordrende livsstil)	10-27 udvikler æggestokkræft, men ukendt om de på grund af forskellige data (inkluderet sandsynligvis livsstil)

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4 Kemoterapi - Caelyx



+ Fordele



Øger chancer for at bringe sygdommen i ro



Symptomlindring

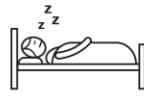


Sjældent hårtab

÷ Ulemper



Hud og slimhinde påvirkning



Træthed



Nedsat immunforsvar

4 Forsøgsbehandling



+ Fordele



Chance for at få tilbudt ny behandling



Ofte tæt kontrol af din sygdom



Kan være til gavn for dig selv og kommende patienter

÷ Ulemper



Risiko for ukendte bivirkninger



Usikker virkning



Ofte flere besøg på hospitalet



Fravalg af standardbehandling



4 Statistik // Carboplatin vs. Carboplatin/Caelyx



Carboplatin



I live efter 2 år



Ikke i live efter 2 år

Carboplatin/Caelyx



I live efter 2 år



Ikke i live efter 2 år

Platin sensitiv recidiv. Carboplatin 45% (33-45%) vs Carboplatin/Caelyx 60%



Key take aways



1 Choice talk

Present the decision to be made, emphasizing the patient's role in the process.



2 Option talk (Medical Options)

Provide clear and impartial information on the available test/treatment options, including pros and cons.



3 Patient preferences

Explore what is most important to the patient and link their preferences to the treatment options.



4 Decision talk

Support the patient in making a decision that aligns with their preferences

Does it work?



Updated Cochrane review 2024 (N=209 randomised controlled studies) has shown the use of patient decision aids in a number of clinical situations have led to:

High quality evidence

Patients gain increased knowledge about their options

Patients gain greater clarity on what is most important to them

Patients feel better informed about the benefits and drawbacks

Patients gain a more accurate perception of risk

Patients are more actively involved in the decision-making process

Moderate quality evidence

Greater alignment between preferences and the choice that was made

Low quality evidence

Fewer patients choose i.e. major elective surgery

Negative consequences in regards of health outcomes, satisfaction or other effects was not reported

Ref: Stacey D et al, Decision aids for people facing health treatment or screening decisions. Cochrane Database Systematic Reviews. 2024. Issue 1. Art. No.: CD001431.

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