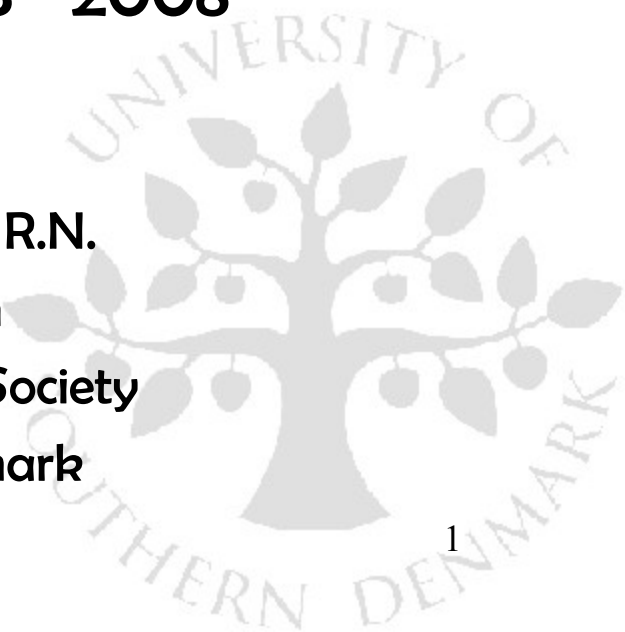


Patient/citizen related assessment in HTA – what knowledge is needed?

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The Patient

A chapter in the new Danish Health
Technology Assessment Handbook

(www.dacehta.dk)



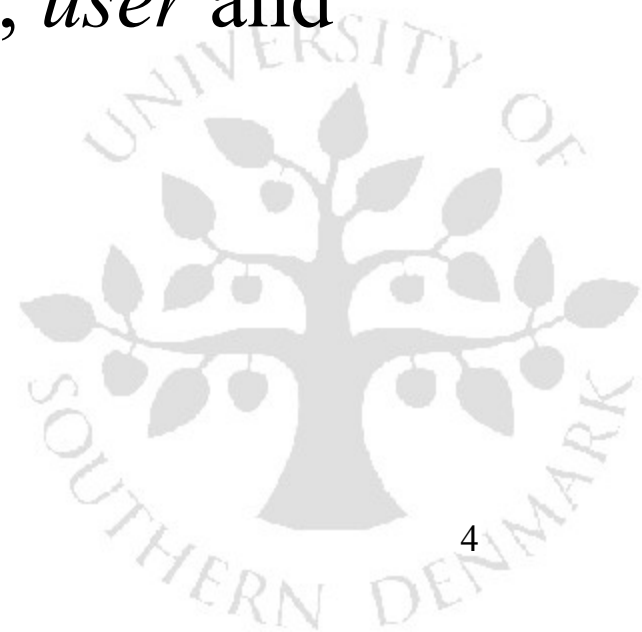
Advice and suggestions

- Patient aspects need to be explored when the respective technology, organisation and/or economic aspects concern (affect and influence) people, i.e. (nearly) always



Advice and suggestions

- In HTA contexts, the concept '*patient*' can also refer to: *citizen, customer, user and individual*



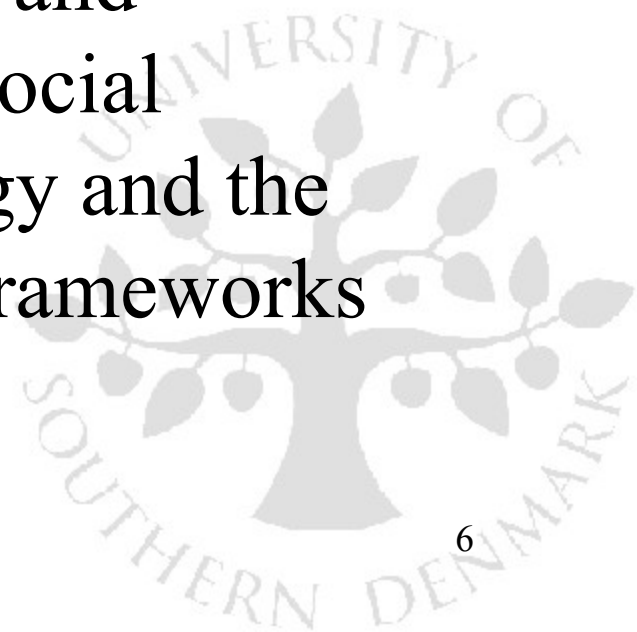
Advice and suggestions

- Reviews of the literature in the form of systematic reviews and any syntheses of qualitative research should be used in preference to primary research, if valid and usable research results are available or can be analysed
- A thorough review of the literature is needed before primary research is decided upon



Assumption 1

- It is difficult to assess health technology in isolation from the people (patients, health care professionals, researchers, politicians and decision-makers) who use and understand it, including their social understanding of the technology and the organisational and economic frameworks



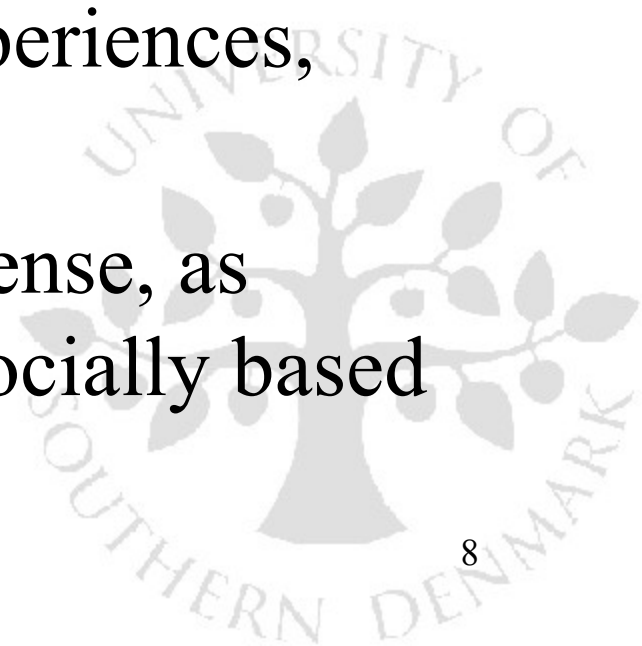
Assumption 2

- Any research result entail a specific understanding of knowledge; whether knowledge is something we *have* or it is something we *produce* and *reproduce* through different social relations and in different contexts
- This means that one's understanding of knowledge always have implications in relation to the validity and scope of the research results
- Exploring patient aspects in a specific HTA therefore entails the researcher bearing in mind that knowledge always arises from certain theoretical/analytical positions

Patient aspects is rooted in:

an understanding of the individual as:

- a biological, social and cultural being who creates and recreates meaning
- an individual with specific experiences, thoughts and feelings
- social in a very fundamental sense, as relationships are themselves socially based



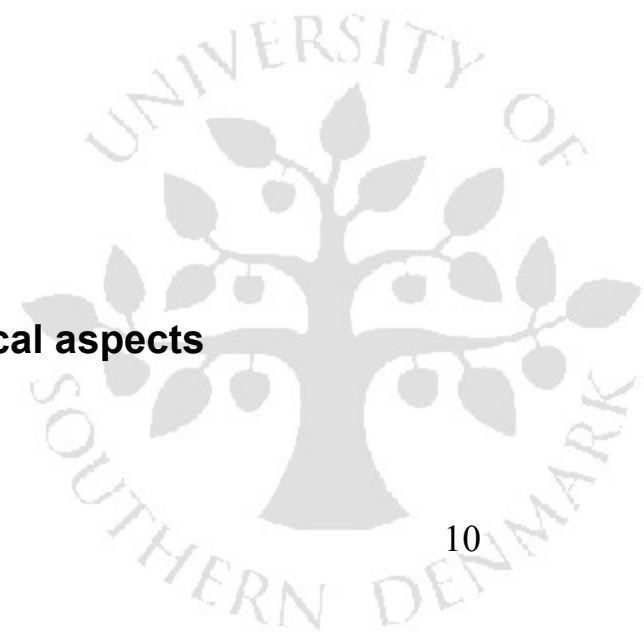
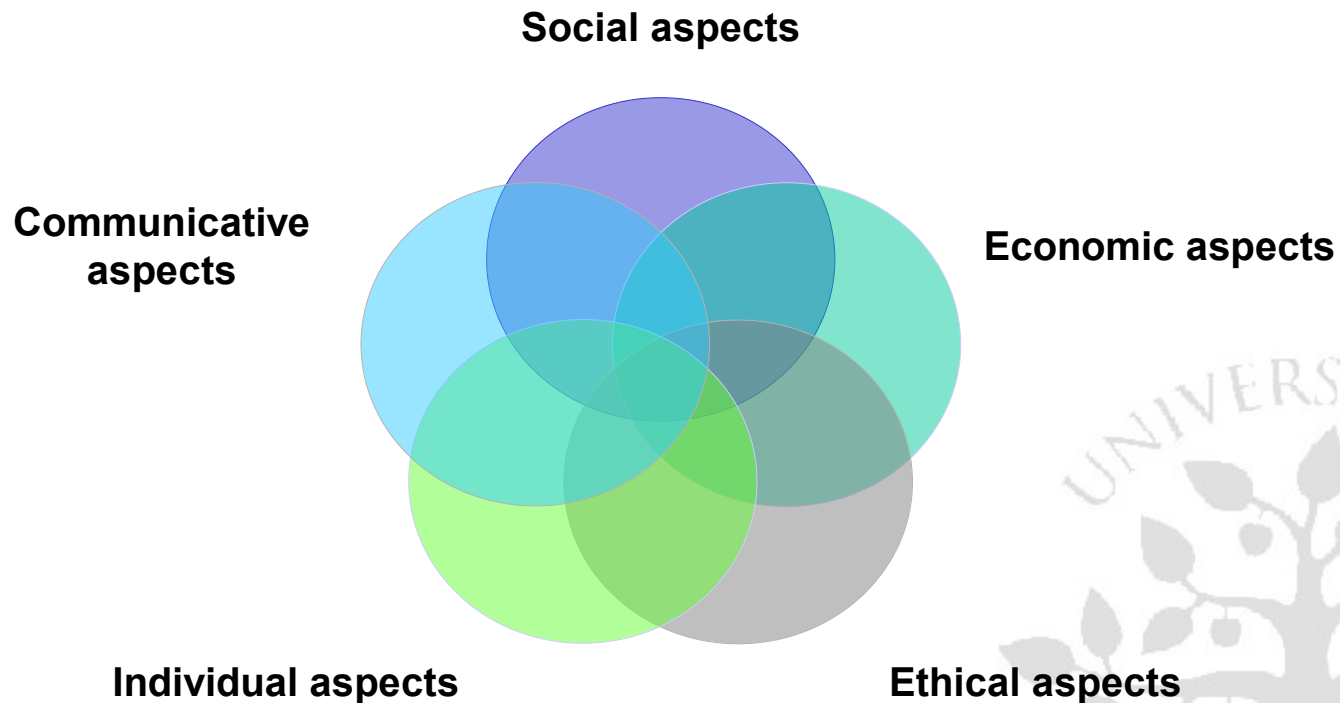
Illumination of a given technology from patients' perspectives

**This may entail gaining an understanding of
patients':**

- knowledge and experiences of a given technology
- preferences, needs and expectations of the technology
- visions and requirements concerning the technology, economy and organisation
- perspectives on the effect of the technology
- self-care and/or empowerment resources

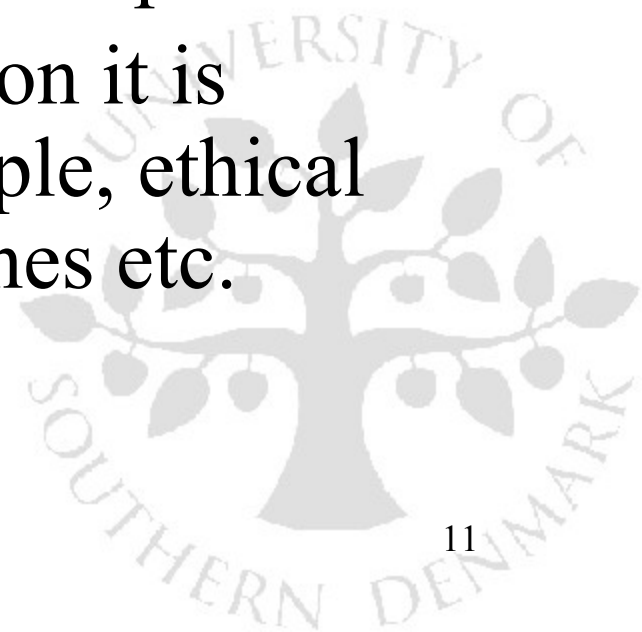


Exploration of patient aspects in HTA



The model is analytical

- The model is intended to show some areas upon which HTA practitioners can choose to focus when exploring patient aspects
- It is only in an analytical fashion it is possible to focus on, for example, ethical aspects instead of economic ones etc.



Social aspects

This covers whether, from a patient perspective, the technology will have or has, for example:

- a direct and/or indirect influence on/significance for
 - work and training
 - family life
 - leisure
 - lifestyle/quality of life



Economic aspects

This covers whether, from a patient perspective, the technology entails:

- direct and/or indirect costs in relation to
 - work
 - family life
 - leisure
 - lifestyle/quality of life



Ethical aspects

This covers whether, from a patient perspective, the technology entails:

- ethical considerations
- ethical choices
- ethical dilemmas



Individual aspects

This covers whether, from a patient perspective, the technology entails:

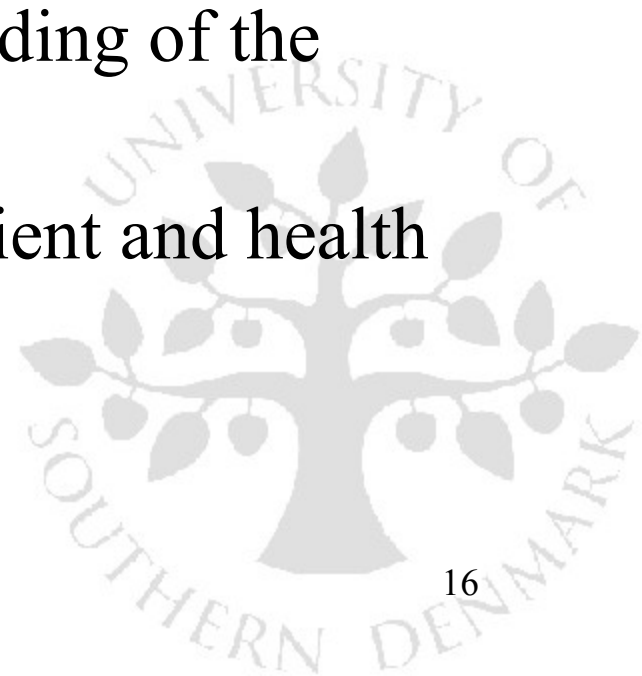
- experiences such as:
 - positive/negative/none effect of the given technology
 - insecurity/security
 - worries/hope
 - anxiety/ courage to face life
 - stigmatisation/empowerment
 - better quality of life (use of one's own resources (self-care, empowerment))



Communicative aspects

This covers whether, from a patient perspective, the technology will have or has an influence on:

- exchange of information
- patients' knowledge and understanding of the technology
- modified relations between the patient and health professionals
- involvement in decision-making



Methods to determine patients views

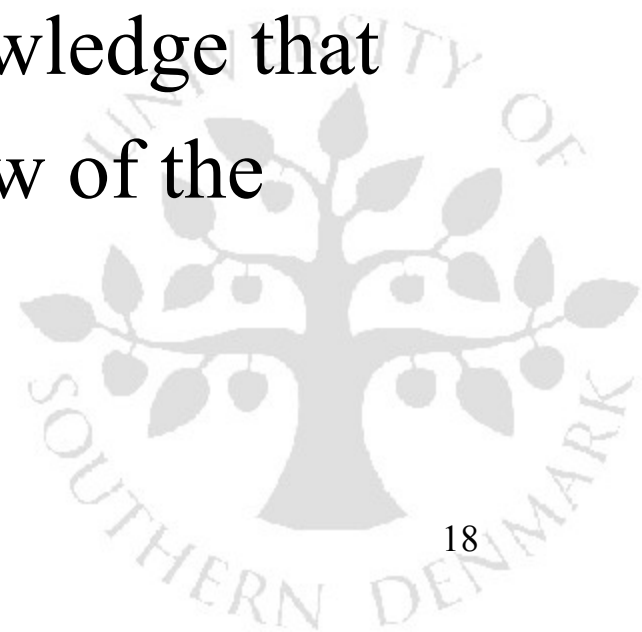
Important:

- Clarify whether the problem in relation to patient aspects is suitable for an HTA
- Do not initiate own studies before it becomes evident, that existing scientific literature does not answer the research questions of the HTA



Methodology

It is important that the initiation of primary research about patient aspects in an HTA only is considered relevant if the knowledge that can be gained from a prior review of the literature proves inadequate



Advice and suggestions in relation to literature reviews

Literature assessment of qualitative studies

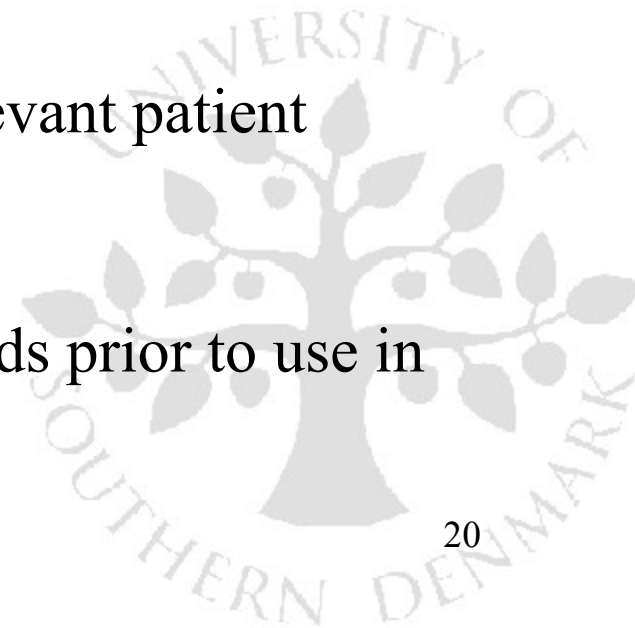
- It is important to reflect on the range and validity of the results based on qualitative methods
- It is important to decide who can/should assess the results based on qualitative methods



Advice and suggestions in relation to literature reviews

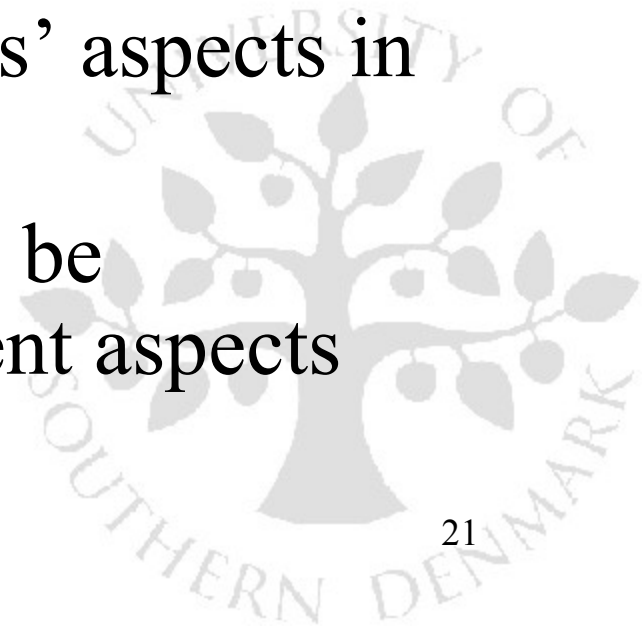
Syntheses of qualitative studies

- Can contribute to the decision-makers having the best possible evidence-based foundation to assess core patient aspects in relation to a given HTA
- Can be used to assess whether there is a need for primary research
- Can be used to gain new insight into relevant patient aspects
- Can be used to make a generalisation
- Requires in-depth insight into the methods prior to use in connection with HTA



Qualitative and/or quantitative methods

- In planning primary research, consideration should be given to whether qualitative methods are the most appropriate methods to be used in exploring patients' aspects in the HTA project.
- Qualitative methods will often be appropriate for exploring patient aspects



Qualitative methods

The main qualitative methods for generating data are:

- Individual in-depth interviews
- Focus group discussions and interviews
- Participant observation
- Fieldwork



Methods for qualitative analysis and interpretation of data

The main methods for qualitative analysis and interpretation are:

- theory-based analyses
- qualitative computer-based computer programs



Positioning

- The positioning of a person as a patient, citizen, user or consumer has an influence on the data generated and thus, in the final phase of an HTA, on the scope and validity of the results produced
- This applies both to primary research and to secondary research (reviews).
- Patients also position themselves
- HTA practitioners undertaking the generation of data are also themselves positioned, and are positioned by the participating patients



Positioning

- Merely asking questions, in certain ways and perhaps at certain times during an interview says something about the position or positions that the researcher has consciously and/or unconsciously chosen and thus also about the range of data generated
- Open questions are not open. They are asked from a particular position. Even if, for example, a researcher starts off by saying: “Will you tell me something about your experiences with ...”, a choice, and thus also a choice to omit, is made. The researcher wants to hear about certain specific experiences, and not all possible experiences.

Thank you
for listening

