



Patient and Public Involvement

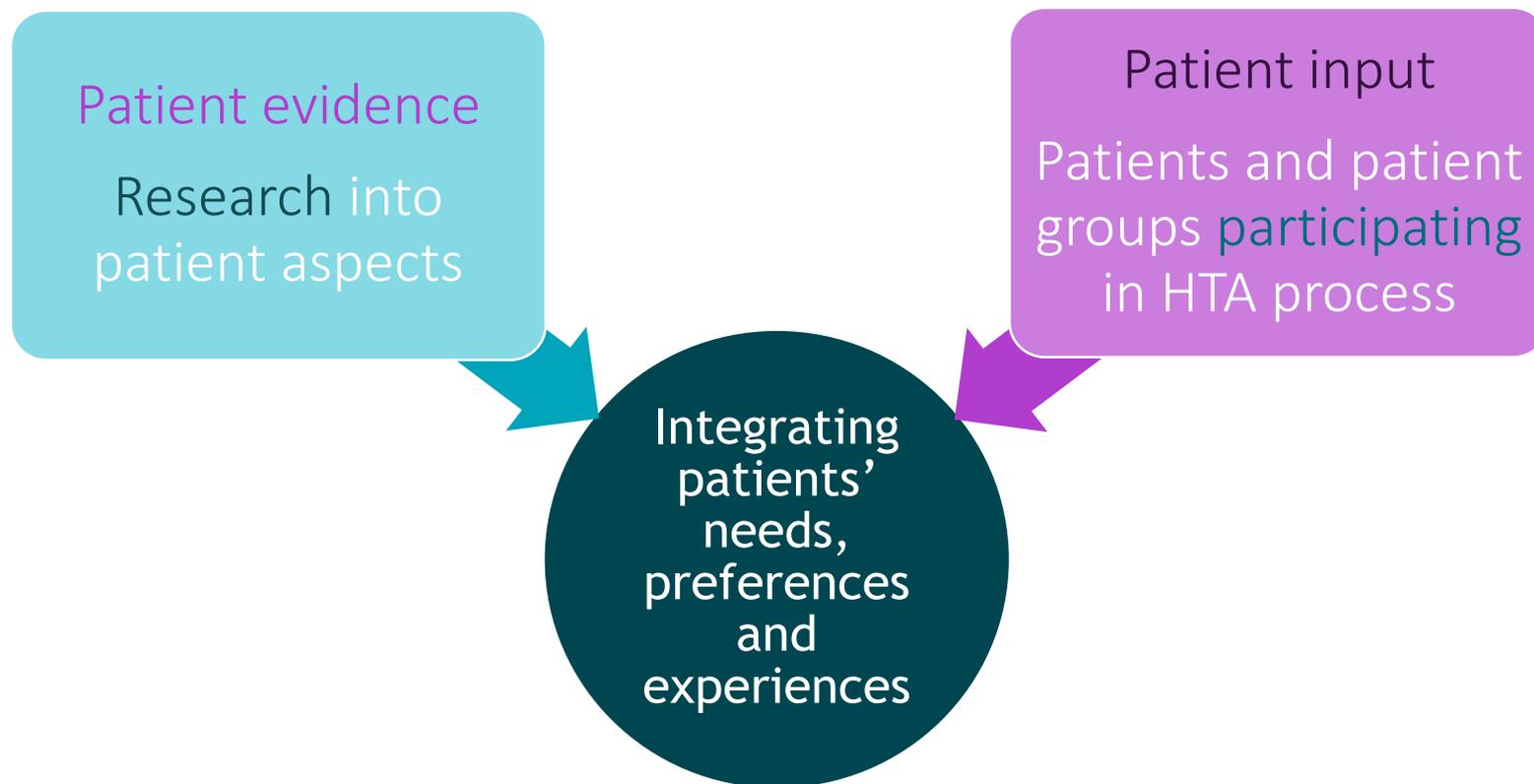
Involving the patient in HTA

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Patient involvement in HTA



Source: Patients' perspectives in HTA: a route to robust evidence and fair deliberation, *Int. J. Tech Assess Health Care*, 2010, 334-340 and Facey KM, Hansen HP & Single ANV (eds) *Patient Involvement in Health Technology Assessment*. Springer Nature Singapore



What can we learn from each other about patient perspectives and adding value?

- HTA can be considered as a bridge between **scientific evidence** and **decision making**
- Patients' perspectives can **illuminate the HTA bridge** by describing therapeutic context and added value, helping reduce uncertainty in decision making
 - **Clarifying burden** - illness, health service organisation, treatment
 - Highlighting areas of **unmet need**
 - **Identifying important outcomes**
 - benefits and disbenefits
 - **Interpreting outcomes as patient benefit**

Patient based evidence

- Research into patient aspects (needs, preferences and experiences)
- By researchers (sometimes collaboratively with patients)
- Robust scientific methodology
- Published
- Peer reviewed

Robust qualitative and quantitative research

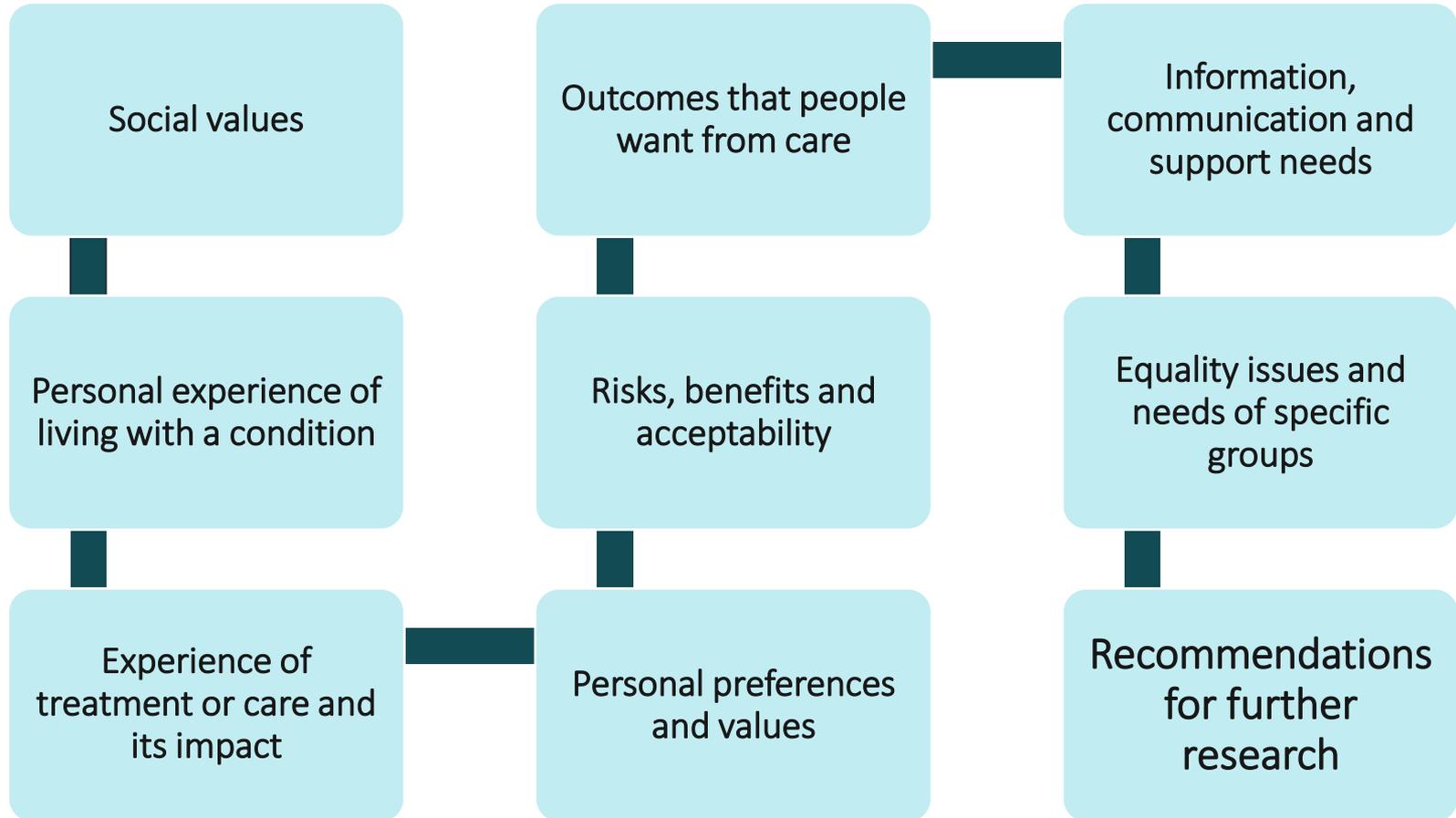


Qualitative research methods

- **Systematic** collection, organisation, interpretation of textual material derived from talk or observation
- Interviews, focus groups, participant observation
- Carefully planned with **ethical approval**
- Themes derived according to **pre-specified methods**
- Explanation of **diversity of views**
- Discussion of researcher's bias and **study limitations**
- Conclusions that are **study specific**



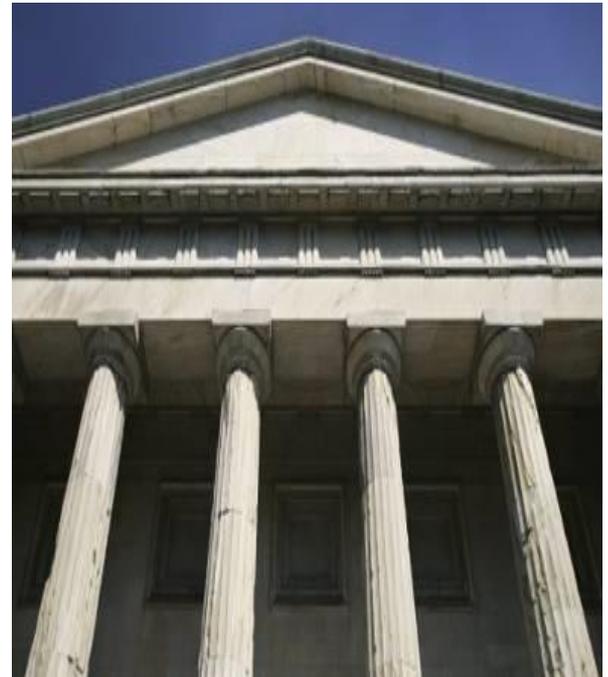
What do we get from patients and the public?



Why does NICE involve patients and the public?

Core principles of all NICE guidance

- Comprehensive evidence base
- Expert input
- Patient and carer involvement
- Independent advisory committees
- Genuine consultation
- Regular review
- Open and transparent process



What are the benefits of including the lay (patient) perspective?

'The expertise, insight and input of these lay members is essential to the development of all NICE guidance and advice, and helps us to make sure that our work reflects the needs and priorities of those who will be affected by them.'

NICE Charter

Why should we involve patients and carers?

The benefit to the HTA organisation

New evidence and information

Challenges to evidence and conventional wisdom e.g. outcomes

Qualitative context to quantitative data

Challenges to professional assumptions

Value to the patients in being involved



2 main stages for patient involvement

- Early engagement in evidence development plans:
 - Scientific advice
- Participation in HTAs
 - Scoping (setting the question)
 - written submissions
 - patient experts
 - consultation



Why do we involve patients in NICE Scientific Advice?

- Patients are the people for whom the advice that NICE Scientific advice provides will ultimately be most relevant
- Patients have the chance to influence how clinical trials are set up in order to provide the best evidence that the proposed outcomes can meet patient's needs
- We have involved patients in over 25 projects so far

Companies get powerful feedback as to the relevance of their decisions early in a product's development

Key stakeholders for NICE's HTAs



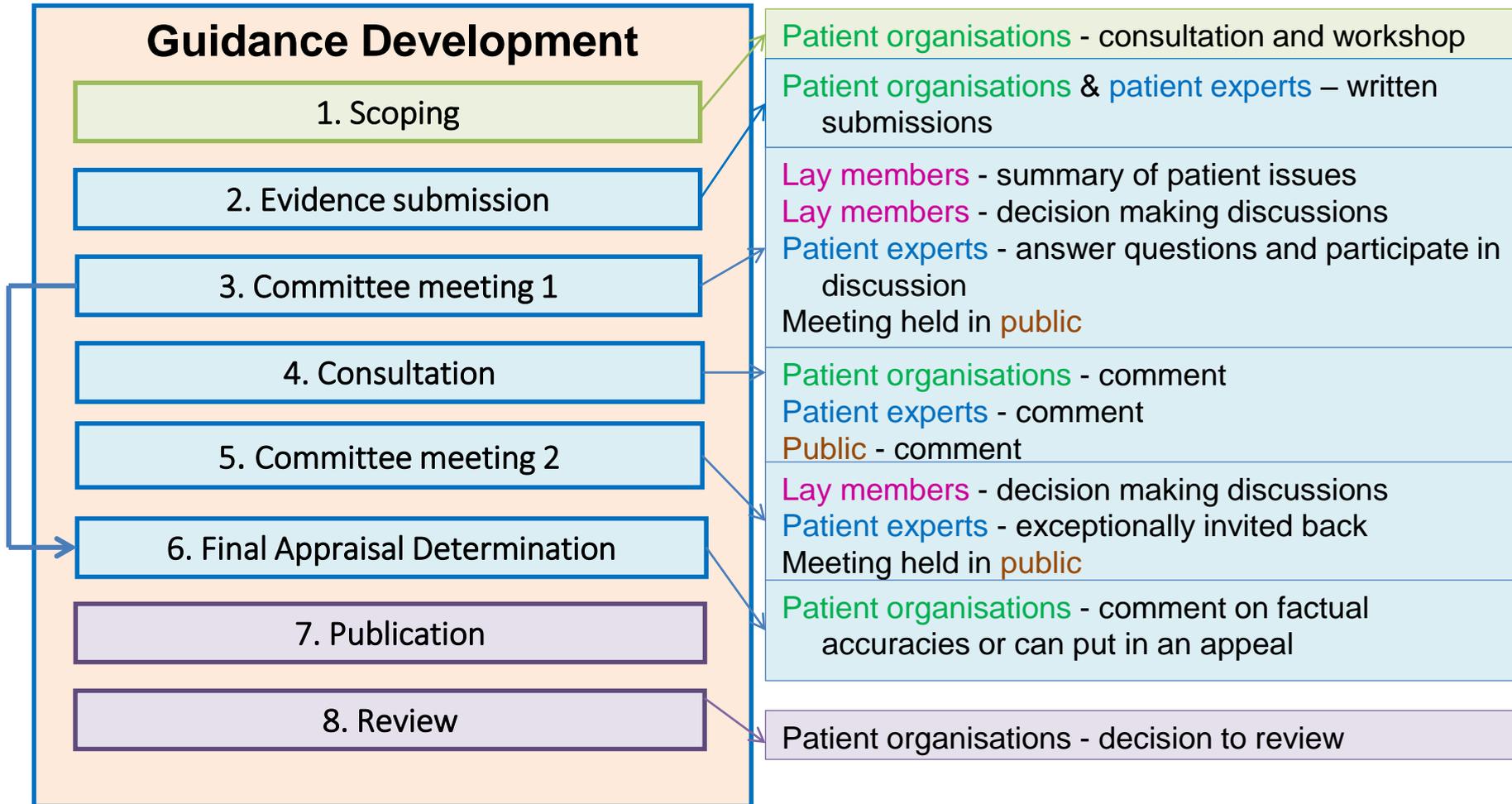
Lay members: 2 lay people on each appraisal committee

National charities: national patient organisations can comment on draft recommendations and provide submissions

Patient experts: individual patients/carers can attend meetings and provide personal statements

Public: anyone can comment on draft recommendations

Opportunities for patient involvement (medicines)

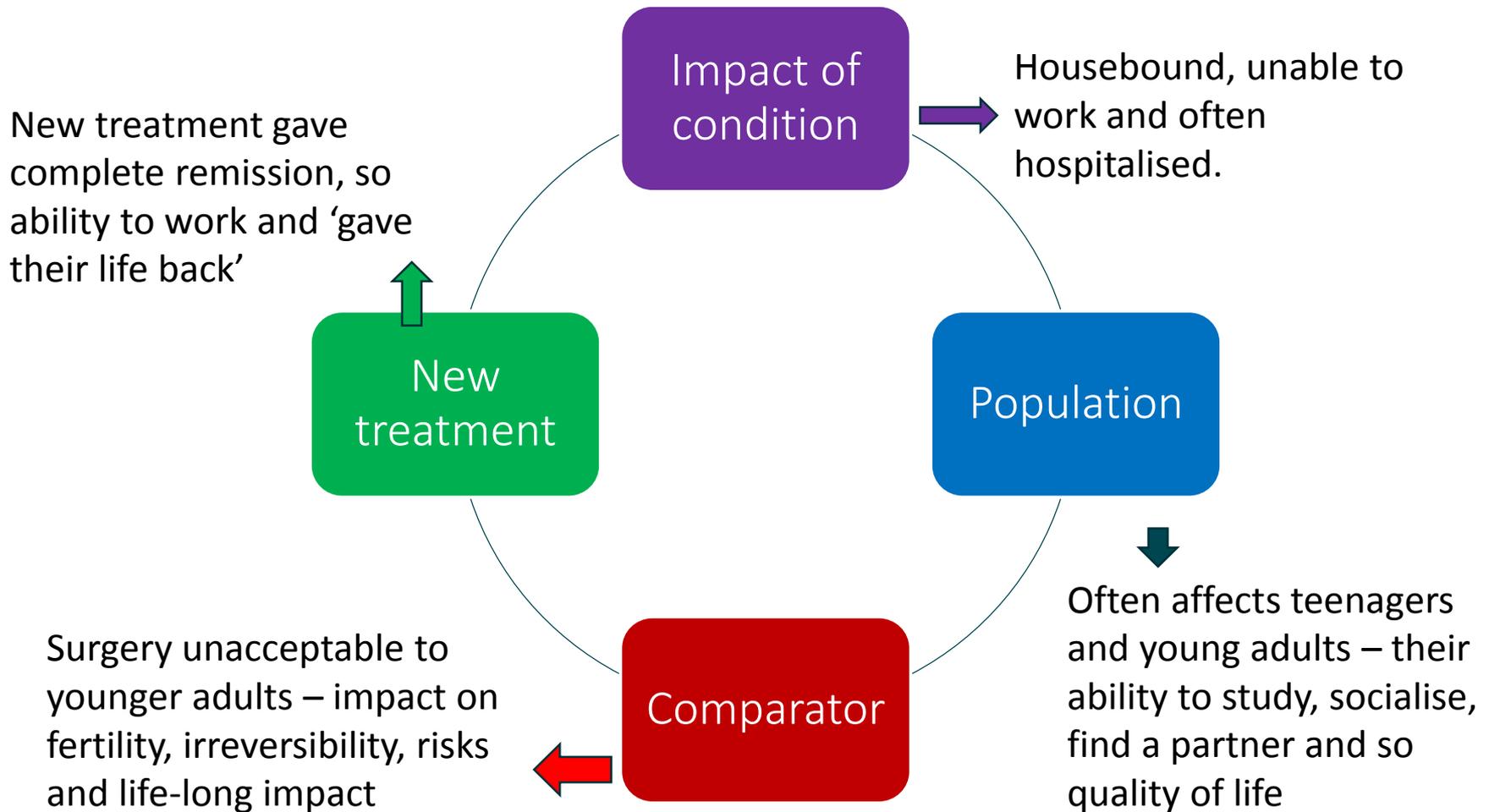


Examples of patient involvement impact

1. TA342 Ulcerative colitis – vedolizumab
2. TA 383 ankylosing spondylitis and non-radiographic axial spondyloarthritis - TNF- alpha inhibitors

1. What patients told the committee

(guidance - paragraph 4.1)



1 Committee conclusion

“Committee concluded that a drug treatment which brings disease into remission would have a major effect on quality of life, and that avoiding surgery was important to people with ulcerative colitis.”

2 How the patient organisation contributed

Submission

Survey open for 4 weeks.
608 responses

Consultation

Survey open for 8 days.
858 responses

To produce data around the two
negative areas of the consultation

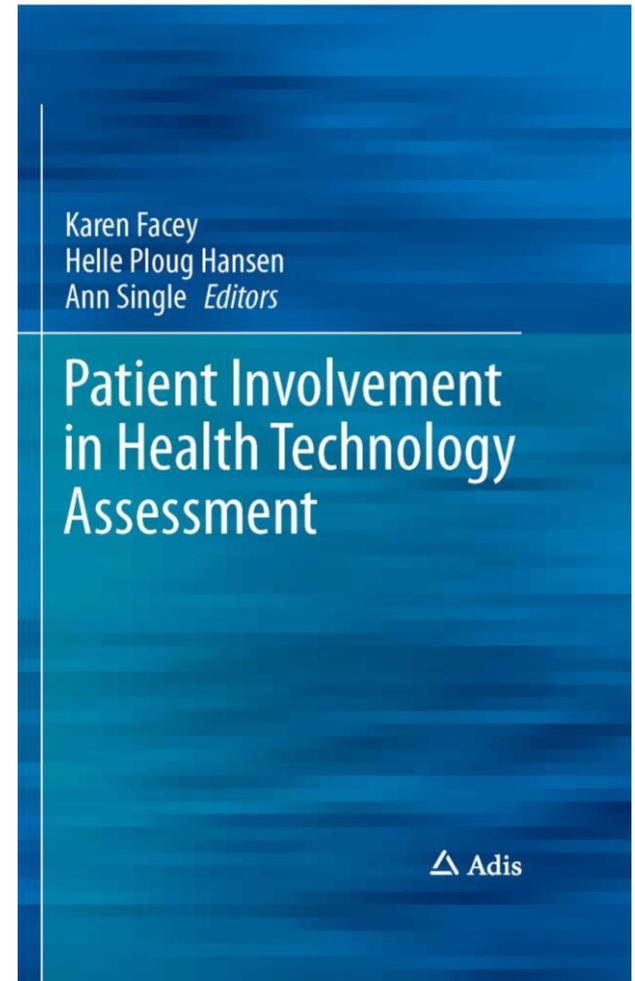
2 Guidance recommendation 1.5

“Treatment with another tumour necrosis factor (TNF) -alpha inhibitor is recommended for people who cannot tolerate, or whose disease has not responded to, treatment with the first TNF-alpha inhibitor, or whose disease has stopped responding after an initial response.”

Patient Involvement in HTA

(Facey, Hansen, Single. Springer, June 2017)

- ▶ Academic book for
 - ▶ HTA professionals,
 - ▶ policy makers and
 - ▶ Researchers
 - ▶ Industry
- ▶ More than 80 authors from a variety of disciplines



If you're not involving patients,
you're not doing HTA!...

Dr. Brian O'Rourke, President and Chief
Executive Officer, CADTH





Do you have any questions?

