

# Patient Input in Relative Effectiveness Assessments within EUnetHTA

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# Overall goal

- Patient input into Relative Effectiveness Assessments (REAs) based on personal experience can provide insight into what it is like to live with a disease and thus make the REAs more relevant for decision makers who use REAs in their decision making process.
- Within EUnetHTA, we developed a recommendation document that describes how assessment teams can gather and use patient input in their assessments.

# Recommendations for Patient Input

- Primarily intended for those who design and conduct EUnetHTA Relative Effectiveness Assessments but it may be informative for a wider audience for transparency of our methods
- Developed in collaboration with the Patient & Consumer/Health Care Provider Task Group in EUnetHTA
- Meeting and consultation with patient organisations
- Final version completed in May 2019

# Goals for patient input in REAs

Goals for obtaining patient input:

- to collect patient input on aspects regarding:
  - their disease/condition and their unmet needs
  - currently available treatments
  - expectations with respect to new treatments (e.g. fewer side effects)
  - identification of subgroups and possible effect modifiers
  - quality of life issues
  - Target treatment population and risks of off-label use
- gather information about outcomes that are important and relevant from a patient's point of view

Patient input can provide important insights into the disease and treatment process that can guide the assessment team's selection of relevant outcomes etc.

# Methods for Patient Involvement

## Open call

- Online and self-administered EUnetHTA Patient Group Submission Template to be completed
- Patient organization(s) should collect patient input through their own channels

## One-on-one conversation

- Allows asking more in-depth questions to one or more patients
- EUnetHTA Patient Group Submission Template can be used as a starting point
- Patients will be provided with questions in advance and participate in telephone calls

## Group conversation

- A moderator will guide the discussion
- The questions can be based on the EUnetHTA Patient Group Submission Template as a starting point

## Participation in e-meeting

- Participation in scoping e-meeting with assessment team
- Provide input to draft PICO and patient perspectives

# Presentation of patient input in REAs

Description in methods section regarding method for input and when input where gathered

Presentation of patient input:

- Separate section or chapter of patient perspectives in the report based on answers from questionnaires, one-on-one conversations or group discussions, preferably supported by quotations from the patient-validated summaries

Only status, age and/or gender (when relevant), country and organizational affiliation (if applicable) will be presented, no names

# Experiences

Patients/patient  
representatives

## Pharmaceuticals

- 2/7: one-on-one conversation
- 4/7: patient input template
- 1/7: unsuccessful

## Other Technologies

- 3/18: one-on-one conversation
- 2/18: group discussion
- 4/18: patient input template
- 3/18: other
- 4/18: unsuccessful

# Obstacles – patient involvement

- Identification of patients can be difficult and time consuming (for assessment team and patient organisations)
- No response by patient organisations or no willingness to participate
- Tight timelines of assessments
- Conflict of interest; industry funding of patient organisations not always accessible
- Conflict of interest; promotion of self-interest, desire to influence decision



## ***Example on how to develop a research question:***

- Should [intervention] vs. [comparison] be used for [health problem] in [population]

Alternatively, a more useful example could be:

- Should bariatric surgery vs. lifestyle interventions be used treat type 2 diabetes in patients with type 2 diabetes and BMI less than 35 kg/m<sup>2</sup>?
- Generate more questions like
  - “what kind of bariatric surgery?”
  - “what kind of lifestyle intervention?”
  - “how should we measure type 2 diabetes?”
  - “is there any special subgroup of patients that would benefit more than others?”
  - “are there any side effects?”



**Thank you**  
**Any questions?**