



Patient and Citizen Involvement in COVID-19 HTA

Neil Bertelsen

HTAi Patient & Citizen Involvement in HTA Interest Group

PFMD Patient Experience Data Project Co-Lead

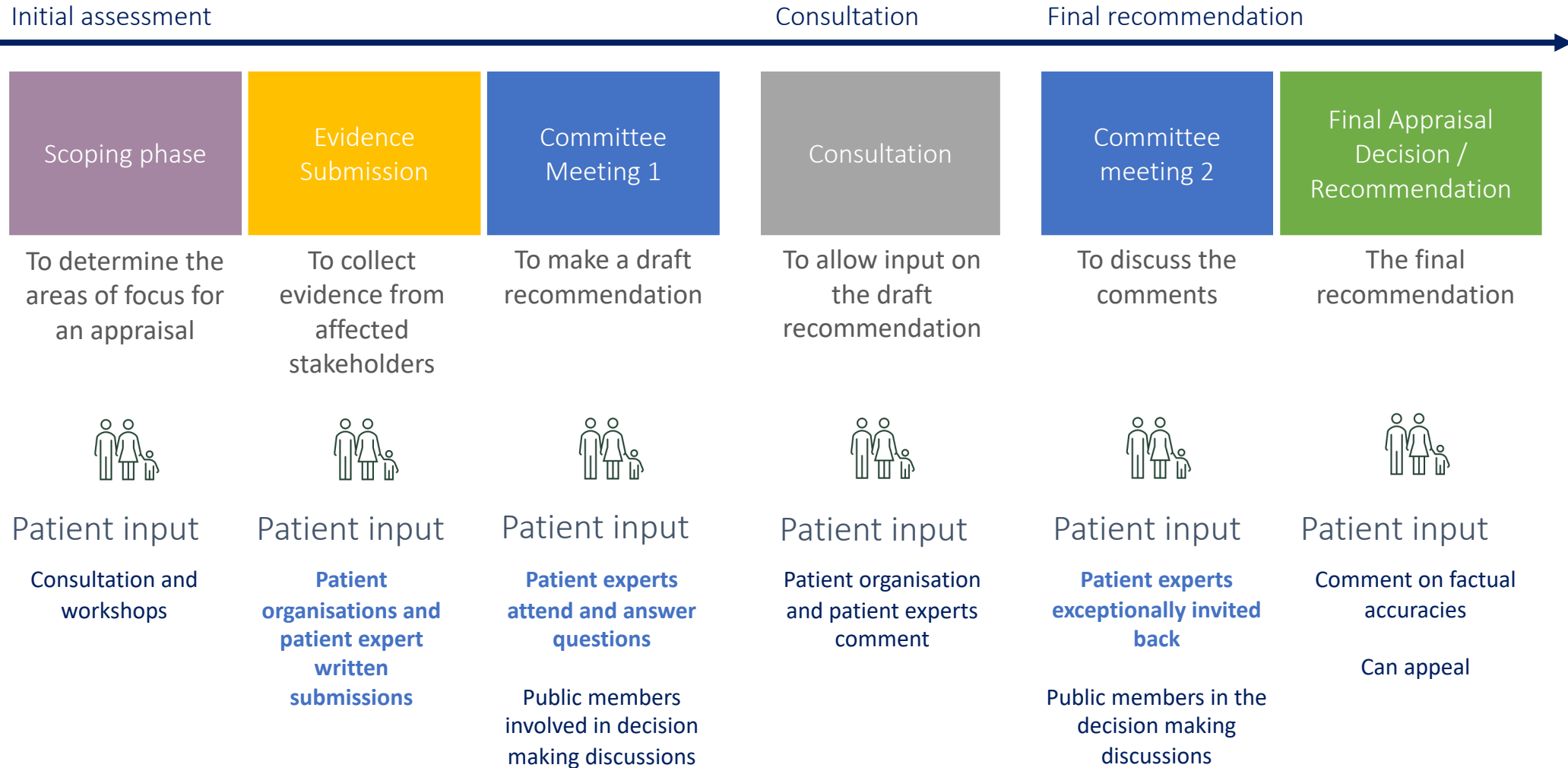
Patient involvement in HTA



Values and standards of patient involvement in HTA

- Relevance** Patients have unique relevant knowledge, perspectives and experiences to inform the decision
- Fairness** Patients have the same rights to contribute to the HTA process as others
- Equity** Balancing the needs of particular patients with all other users of the healthcare system
- Legitimacy** Patient involvement ensures those affected by a decision can participate in the process
- Capacity** Involvement processes build capacity in patient organisations and HTA bodies

A common patient involvement approach ...



But does this apply to COVID-19?

Very ill patients



Patients who experience health interventions may be too ill (or unconscious) to recollect experiences

Specific sections of society, including marginalized communities, are not organized like patient organizations

Sections of society



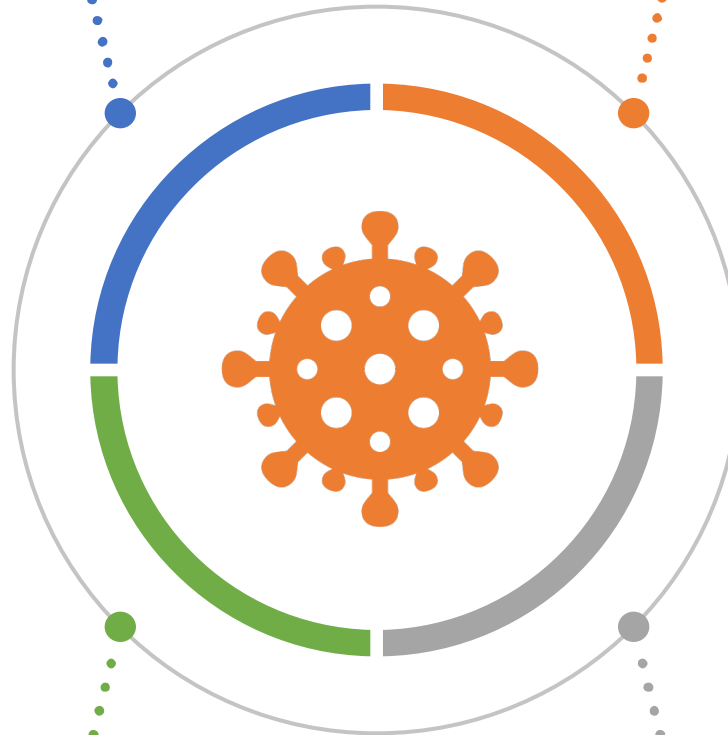
Who is a 'patient'?

Before someone becomes infected, they are not a patient. After recovery, they are not a current patient.

At-risk groups, such as those with high-risk of serious complications from COVID, are not directly COVID patients



At-risk groups



Groups we need to reach ...

EXAMPLES

RELEVANT PATIENT GROUPS¹

To gain input from those whose current conditions put them at increased risk of severe impacts

- Respiratory (e.g.: asthma, COPD, cystic fibrosis, etc.)
- Cardiovascular disease groups
- Diabetes and obesity groups
- Cancer and blood disorder groups

POPULATIONS AT RISK

Sections of society that have been shown to be at greater risk of contracting COVID or suffering worse consequences

- Associations of ethnic groups at high risk of complications²
- Unions in sectors that have a higher risk of exposure³
- Advocacy groups for the elderly¹
- Healthcare professional societies⁴

CITIZENS IN GENERAL

Those not in any 'at-risk' group that will potentially use the intervention and have insights into its use

- Citizens' rights groups
- Community associations
- Randomly selected citizens (e.g. citizen jurors)

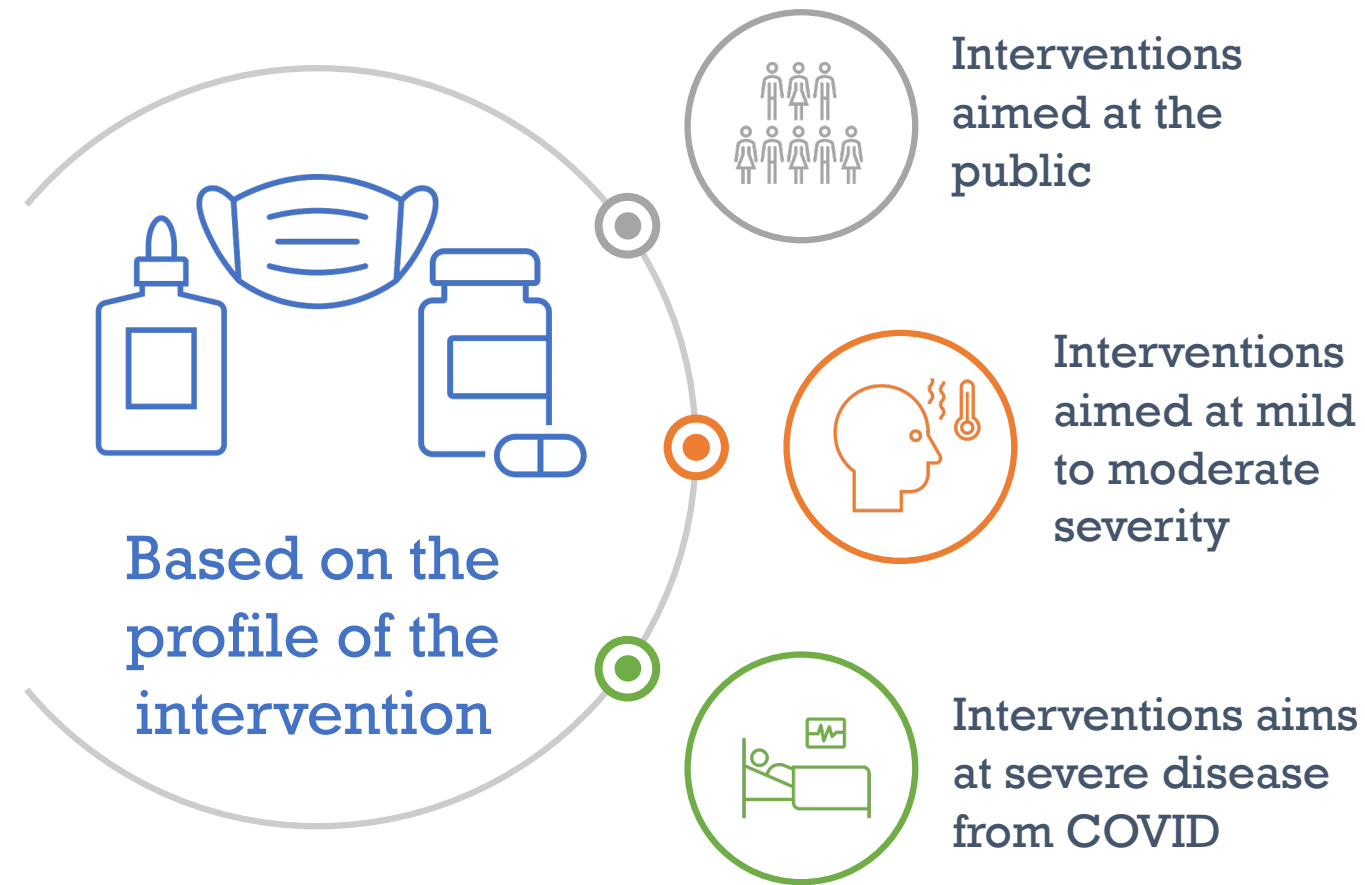
1: <https://www.mayoclinic.org/diseases-conditions/coronavirus/in-depth/coronavirus-who-is-at-risk/art-20483301>

2: Ethnicity and covid-19: BMJ 2020; 369 doi: <https://doi.org/10.1136/bmj.m2282> (Published 11 June 2020)

3: The impact of the COVID-19 pandemic on marginalized populations in the United States: A research agenda: Published online 2020 May 8. doi: 10.1016/j.jvb.2020.103439

4: Reported exposure trends among healthcare personnel COVID-19 cases, USA, March 2020–March 2021 Published: April 13, 2022 DOI: <https://doi.org/10.1016/j.ajic.2022.01.007>

We need to build a tiered approach



E.g.: Testing or prevention interventions. Citizen Rights groups, citizens and orgs that represent particular at-risk communities

People who have recent experience of COVID infections (individuals), as well as those that are care-givers (families) for those with mild/moderate disease

People who have recovered from serious disease, families and potentially nurses who can illuminate how interventions are put into practice in the ICU

Methods already exist to do this...

**Lay (citizen) members
of HTA committees**

Citizen Juries

**Individuals' input into
early dialogues**

**Population research
on needs, preferences
and attitudes**

**Use of surrogate inputs when
direct patients cannot
participate**

**Global studies on the needs of
marginalized communities**



Thank You

1-780-448-4881 | info@htai.org | htai.org
Follow us on Twitter, Facebook, Linked In @HTAiorg