

# HTAI PCIG

## PROJECT NAME: PATIENT PARTICIPATION AT THE ORGANIZATIONAL LEVEL IN HTA

Short name : PPOL-HTA

Date : April 2020

### Project Summary

**i** Summarize the project in not more than 60 words. This summary will be uploaded to the PCIG website.

- Gain better understanding of patient participation in the organizational domain: Identifying how, and on what topics, participation is occurring and the perceptions about this kind of participation.

### Project Aims and Description

**i** Describe the aims of the project

- Why is it needed
- What will it achieve
- Which audience it is designed for
- A general description of the project (no more than 2 paragraphs)
- (OPTIONAL) Special considerations – for example, listing skills that will be needed to complete this project (e.g. need involvement of team members experienced with preference studies, ...)

#### Why is it needed?

Studies of patient participation in HTA, along with PCIG guidance and tools, have tended to focus on patient participation's influence on individual HTAs (e.g. for example Menon Stafinski 2011, Berglas et al 2016, Scott Wale 2017). Such work, typically emphasises the role of patient participation in addressing gaps and uncertainties in evidence, ie providing additional information. However, its use and influence in what Gauvin et al (2010) called the organizational domain, which Facey (2017) developed as policy and HTA process participation, is less described and supported.

This participation may provide greater understanding of the value of participation in achieving those goals that Oliver et al. (2019) suggest cannot be "achieved in better ways" and remain "least well understood" such as legitimacy, relevance, credibility, feeling included and empowered and trust.

This participation beyond individual HTAs may also be important in a context where the wider adoption of rapid HTAs restricts the potential within an HTA for the two-way, dynamic and iterative communication associated with meaningful patient participation.

### **What will it achieve?**

The project will provide a better understanding of patient participation in the organizational domain by identifying how and when it occurs, the topics addressed and who is implied (patients/ citizens / patient groups...). With this improved understanding of the actual and possible participation beyond individual HTAs we could share good practice and potentially support tools or examples to support its wider implementation.

### **Which audience it is designed for?**

The audience is composed of HTA bodies, patients/patient groups/networks and citizens as the project is designed to include both perspectives and has the potential to inform tools and guidance for all.

### **General description of the project**


Patient participation has been described as a mosaic allowing for different forms and dynamics (Tritter and McCallum 2006) in not just individual HTAs, but across the organisational and policy domains (Gauvin et al. 2010). Gauvin et al. described the organizational domain as “the set of processes and procedures that affect the way that HTA agencies are directed, administered, or controlled”, including governance, prioritising assessments and commissioning research. Facey (2017) further expanded and adapted this mosaic to provide examples of the way in which patient participation could be used in HTA policy and process. So patient participation here may include activities such as evaluating patient involvement processes and methodologies, building capacities for patients to contribute, ...

The project aims to better understand the use of patient participation in the organizational domain by describing some current HTA body processes in this domain and the characteristics of the interactions between patients/ patient groups/ citizens and committees / HTA bodies. Through interviews it will consider the actual and possible role of wider participation of patients in HTA bodies, including: What was observed to change? What are the perceived difficulties? Could this kind of participation achieve more? What are the requirements?

Patient representatives and HTA bodies in different countries will be invited to answer a joint interview describing this participation. Then they will separately answer a written questionnaire to express their perspective. The representativeness of patients filling the questionnaires will be examined.

A pilot will be led with Belgium and Canada. Then the survey will include France, Québec/Canada, Wales and Scotland.

## **Project team**

 *Describe those involved*

- *Project lead*
- *Team members*

**Project lead :** Hervé Nabarette (AFM Telethon, France)

**Team members :** Ann Single (Patient Voice Initiative, Australia), Isabelle Ganache (INESSS, Québec/Canada), Jean-Claude K Dupont (AP-HP Hospital, France)

## Deliverables and Dissemination

**i** *List the final deliverable, its format and how it will be disseminated*

- *Deliverable 1: (e.g.: A word document)*
- *Deliverable 2:*
- *Dissemination route (e.g.: HTAi PCIG resources pages, E-bulletin, peer reviewed journal, conference plenary...)*

**PCIG E-bulletin** to inform about the survey

Presentations at **HTAi Congress**

**Article** published in a peer reviewed journal

## High-Level Timeline/Schedule

**i** *Outline the ball-park timeline for the project to be completed*

- *E.g. Project kick-off Q1 2019,*
- *E.g. Draft deliverables sent for consultation Q3 2019*
- *E.g. Final deliverables sent for dissemination via X and Y channels in Q4 2019*

**Project kick-off:** June 2019 (scoping, identification of interested patient groups and HTA bodies)

**Ethics committee:** February 2020

**Pilot :** beginning February 2020, end May 2020

**Preliminary report of findings to PCIG:** September 2020

**Presentation of results:** HTAi Congress

**Article written:** January 2021