

HTAI PCIG

PROJECT NAME: PATIENT AND CITIZEN INVOLVEMENT IN THE LOW- AND MIDDLE-INCOME COUNTRY (LMIC) SETTINGS

DATE – submitted 22. July 2019

Project Aims and Description



Describe the aims of the project

- *Why is it needed*

Access to quality and affordable healthcare is essential for all patients. HTA in Low- and middle-income countries (LMIC) aims to meet different stakeholder expectations and must involve stakeholders in ways that are culturally and socially meaningful, with challenges very different to those seen among high income countries. For instance, the cost of medicines can account for up to 60% or more of total healthcare expenditure in some LMICs, much of which is out-of-pocket payments. Consequently, family illness can have catastrophic consequences for families. Governments are striving for universal access for at least essential medicines. However, there is still a long way to go in some countries. Concurrent with this, there can still be heavy reliance on traditional medicines and low educational levels enhances poor adherence to medicines unless appropriately tackled.

Patient and public involvement (PPI) and engagement enriches the quality of evidence and the decisions associated with it. Consideration of values and beliefs of patients and their carers are an integral part of patient engagement. However, these values are intrinsically linked to their professional, cultural and social background. As a result, involving patients and citizens, especially in LMICs, requires careful consideration to create tools and guidance appropriate for these jurisdictions. There is a need for patient empowerment, encouraging involvement and self-determination. Examples for special reirements in LMICs include high levels of domestic violence in some LMICs enhancing mental illness, high levels of self-purchasing of antimicrobials in many LMICs, or low adherence to chronic medicines by patients with diabetes and cardiovascular diseases (CVDs). Greater patient and citizen involvement can effectively contribute towards an informed perspective improving the relevance of HTA and healthcare decisions. Consequently, it is essential for patient/patient advocates/public to better understand the mechanisms behind HTA and how they can make the biggest impact through their involvement. As a result, it is important to employ appropriate research methods to collect and value patient preferences alongside a greater understanding of current disease pathways and patient experiences in LMIC settings. In addition, there is a need to increase awareness and competence within the HTA bodies for the role of patient involvement and how this can be operationalized within the national / local processes as LMICs continue to expand their healthcare systems towards universal access.

- *What will it achieve*

We will explore the current routes of patient involvement in LMICs and collaborate with LMIC stakeholders to define LMIC-specific needs for patient involvement. Based on this, we will develop and adapt guidance and tools to support patient and citizen involvement in HTA in emerging economies.

- *Which audience it is designed for*

HTA units in emerging economies/ patient and public in these countries

- *A general description of the project (no more than 2 paragraphs)*
 - We aim to explore the current situation in a number of pilot LMIC countries through interaction with the core stakeholders in these countries. For this, team members will take the lead in their respective countries.
 - Based on these discussions, we will start to develop a landscape analysis for LMICs which eventually should help others to develop similar activities in their own countries
 - Based on the needs identified in the pilot LMIC countries, we will adapt existing tools to make their use feasible in the LMIC context or, if no useful tools can be identified, we will aim to develop such tools collaboratively.
- *(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, ...)*

Project team

i Describe those involved

- *Project leads – Jani Mueller (DC-SIG), Anke-Peggy Holtorf (PCIG)*
 - *Team members*
 - *Brian Godman*
 - *additional members to be identified. It will include interested members of both SIGs (PCIG, Developing Countries) from target areas.*
- Possible support from WHO.

Deliverables and Dissemination

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

- *Deliverable 1: Documentation on landscape analysis of the current state of PPI in emerging countries under study; publication of a whitepaper*
- *Deliverable 2: Documentation on review of existing tools and guidance and identify key issues and gaps.*
- *Deliverable 3: Operational plan*
- *Dissemination route (e.g.: HTAi PCIG resources pages, E-bulletin, peer reviewed journal, conference plenary...)*

Dissemination will take place through usual routes used in the countries under study and will conform to the key audiences. In general, the deliverables will be disseminated via infographics, publication in peer reviewed journal, resource papers.

High-Level Timeline/Schedule

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

- *Our first goal is to form a project team with representatives from LMICs who can and will engage with the local stakeholders. We aim to form such core team until the end of Q1/2020*
- *This team will then collaborate to develop a plan and timeline for further action (end of Q3/2020)*