

# Identifying and Prioritizing Uncertainties: Patient and Clinician Engagement in the Identification of Research Question

Elwyn et al. (2010)

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## For which topic were research priorities identified?

asthma

## In which location was the research priority setting conducted?

Europe - United Kingdom

## Why was it conducted at all?

This article describes the process and outcome of the first JLA Working Partnership (WP) between Asthma UK and the British Thoracic Society to illustrate the potential contribution of collaborations involving patients, carers and clinicians in the identification and prioritization of treatment uncertainties.

## What was the objective?

to arrive at an agreed, prioritized ranking of treatment uncertainties in asthma that need further research

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

No information provided.

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: literature review: searching for clinical and research uncertainties: explicit statements describing need for further research were identified in clinical guidelines, statements of continuing uncertainty from systematic reviews and research recommendations. Step 2: survey: participants were asked for uncertainties, 370 uncertainties submitted. Step 3: data processing: 267 raw uncertainties, a 57 further uncertainties were removed after application of 'no systematic review evidence' criteria resulting in 210 validated uncertainties, steering group refined and categorized uncertainties, agreed on set of common terms, allocated each uncertainty to the relevant categories, verified each uncertainty against existing systematic review, this resulted in list of 21 uncertainties. Step 4: interim ranking: participants of workshop asked to rank the list of 21 uncertainties in order of importance before the workshop. Step 5: final prioritization: workshop: nominal group technique used, briefing documents were circulated to participants prior to the workshop, small groups compared their prior rankings, participants then asked to agree on ranking, group results aggregated, new overall ranking obtained, new small groups formed and asked for new group rankings, in final plenary sessions consensus on top 10 research questions

## Which stakeholders took part?

Patients, carers and clinicians. Workshop: 9 individuals with asthma (Asthma UK staff and patient advocates), 3 researchers, 2 asthma nurse specialists, a research coordinator from UKCRN, 2 clinical specialists (members of British Thoracic Society), the chief executive of British Thoracic Society, the editor of DUETs and 3 facilitators from JLA.

## How were stakeholders recruited?

The survey was posted to 1146 people (120 to 'Speak Up For Asthma' volunteers, 225 to parents and children who have attended 'Kick Asthma' holidays and 801 to people with asthma and carers). The sample was taken from over 30.000 Asthma UK supporters. The survey was also placed on the Asthma UK website.

## Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.