

## OP35 Involving Members Of The Public In A National Screening Programme Health Technology Assessment

### AUTHORS:

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### INTRODUCTION:

Involving members of the public in the development of Health Technology Assessments (HTAs) has scientific and public value (1) but the most common form of involvement in HTA remains collection of people's views in the form of data (2). Involving members of the public in shaping the research is rare due to perceived time or resource constraints (3). Our research aimed to; (i) develop tailored meeting formats for public involvement in a lung cancer screening HTA, (ii) capture views on lung cancer screening using a community drop in format (iii) explore how different groups of public contributors, with various prior experience of involvement, participated in the HTA consultation process.

### METHODS:

The involvement included three separate public meetings and a drop-in session at a community centre. Meeting formats were specifically tailored to meet the needs of the lung cancer screening HTA while drawing on previous patient and public involvement (PPI) work in relevant disciplines. All meetings were audio recorded and observed using a structured form. This data is currently being analysed using a combination of inductive and thematic analysis.

### RESULTS:

The qualitative research data on PPI processes was collected in November 2016. The paper will present results from our full analysis. At present, we note that while limited time was available to explain HTA to participants, this did not hamper the discussions' relevance to the HTA work. Participants shared personal

stories irrespective of whether they knew each other from before. People drew on own and others' experiences when discussing outcomes of importance to this HTA.

### CONCLUSIONS:

Prior involvement in research or specific research methods training may not be necessary for public involvement in HTA. This has implications for involving diverse or "hard to reach" groups, without high levels of associated cost.

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## OP37 Can Local Ultra-Orphan Patient Evidence Shape Global Understanding?

### AUTHORS:

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### INTRODUCTION:

Written patient evidence is submitted to the National Institute for Health and Care Excellence (NICE) by patient organizations and their nominated patient experts. We reviewed the impact that patient evidence had on the

committee's decision making. This local learning can help generate global opportunities for Health Technology Assessment (HTA) bodies and patient groups to further develop their understanding and methodology about how patient evidence can support HTA decision making for ultra-orphan conditions.

## **METHODS:**

There were two phases.

Phase one was an online questionnaire about the impact of patient evidence on the committee's decision making for ultra-orphan HTA evaluations. It was sent to the committee chair, lay committee members and selected other committee members.

Phase 2 developed the initial questionnaire findings using in-depth interviews with the committee chair and the lay members. These gained further understanding of the impact of patient evidence and the themes raised.

## **RESULTS:**

Key findings showed patient evidence was helpful to understand the:

- Burden of disease
- Patient population
- Likely uptake of new medicines
- Impact on carers.

For ultra-orphan conditions, where other forms of evidence are scarcer, patient evidence is fundamental to understanding patient needs, the impact of the disease, patient population and preferences.

## **CONCLUSIONS:**

Patient evidence was useful for the committee in different ways; it provided the committee with new evidence and it helped the committee understand and interpret the evidence submitted by others. Both are key to committee decision making. It was clear that due to the very small patient population, patient groups knew the patient population, their stage of disease, and their preferences in detail.

The findings will be used to inform an updated patient submission template for ultra-orphan HTAs, and supporting guide. These will be available on the NICE website and offered to the HTAi Interest Group on Patient and Citizen Involvement so they can be shared globally.

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## **OP38 Improving The Patient Centricity Of Value Assessments: A Rubric**

### **AUTHORS:**

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### **INTRODUCTION:**

Value frameworks, analogous to Health Technology Assessment (HTA) internationally, have emerged in the United States to aid stakeholders in assessing the value of new treatments. Since patient perspectives on value may differ significantly from other stakeholders, formalized procedures to involve patients in their work have been created. Despite these efforts, concerns persist that patient involvement is insufficient or "rhetoric." To assist in this effort, the National Health Council (NHC) created a rubric to aid decision makers in improving the patient centricity of their value assessments.

### **METHODS:**

A convenience sample of twenty-eight organizations was invited to participate in a roundtable discussion. Participants discussed experiences with value frameworks; debated and thematically grouped hallmark patient-centeredness characteristics; and developed illustrative examples of the characteristics. These materials were organized into the rubric, and subsequently vetted via multi-stakeholder peer review.

### **RESULTS:**

Participants agreed upon six key domains of patient centeredness: *partnership* (patients are involved in every