

Views of Individuals Concerning Research (VOICE)

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Introduction

There is a need for research institutions to develop opportunities for patient and public involvement (Fig 1) within their research themes in order to:

- 1) Provide high quality evidence in areas of importance to patients and the public;
- 2) Meet recommendations of governance guidelines;
- 3) Meet requirements of funding providers.

There is a lack of literature, however, describing how patient and public involvement (PPI) advisory groups have been developed to meet this need, and a dearth of evidence on how development has considered the needs of members in order to provide meaningful involvement.



Figure 1: Stages of the research process showing areas in which to include patients and members of the public in research.

Aim

VOICE aimed to explore the opinions of patients in the core themes of our Clinical Research Facility (chronic cough, aspergillosis, food allergy) with respect to involvement in the research process using qualitative research methods. We hoped to understand whether specific opportunities for involvement were favoured within and between disease groups and why. In doing so we aimed to develop a patient advisory group covering the areas of interest identified by patients themselves to ensure opportunities for involvement would be aligned with the interests of our patients.

Methods

A total of 14 patients were recruited to two semi-structured focus group discussions. Group discussions were dual moderated, audio recorded and later transcribed by an independent transcriptionist. The two transcripts were analysed using an interpretative phenomenological approach (Fig 2).

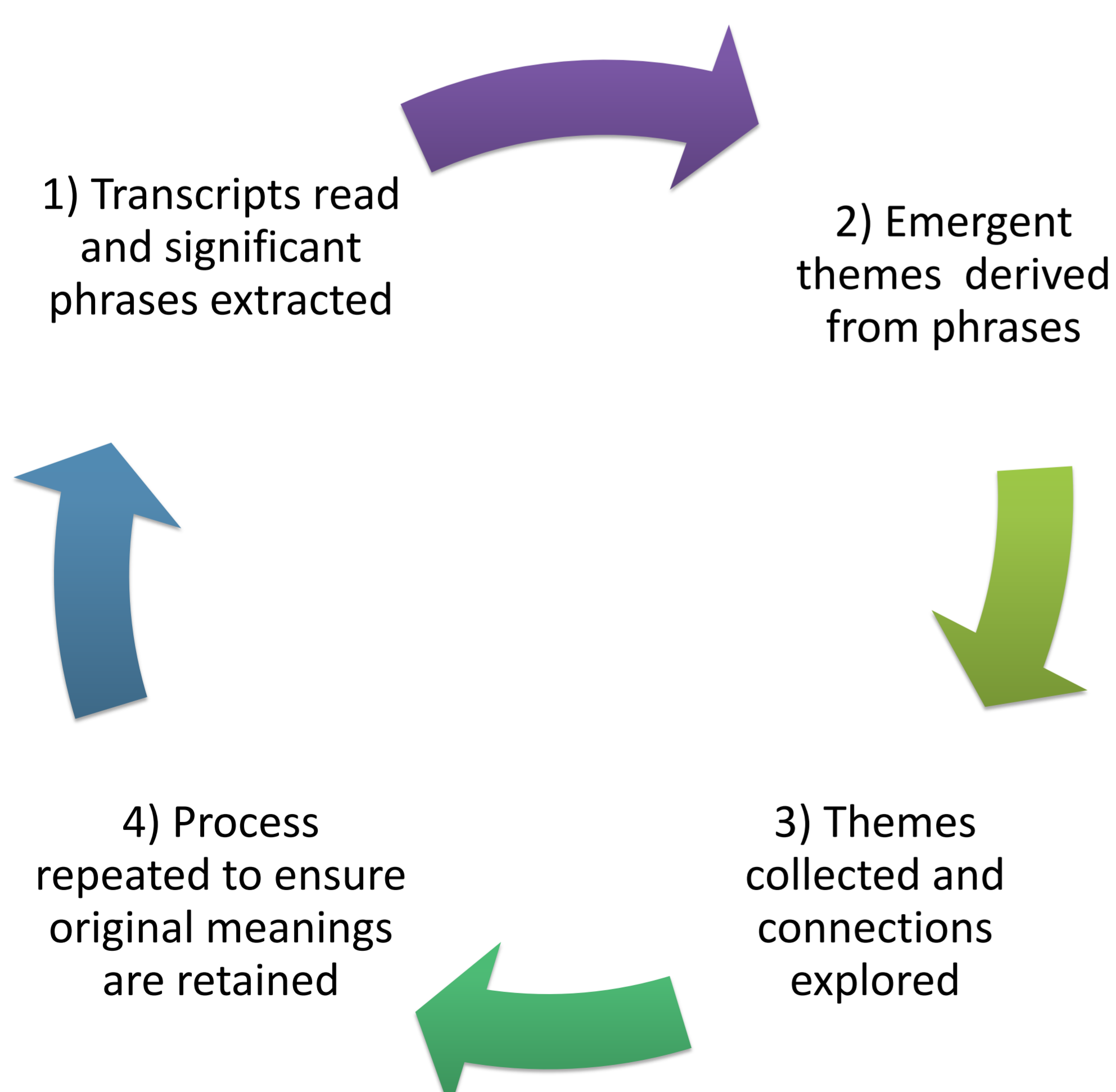


Figure 2: Interpretative phenomenological analysis technique

Results

- ✿ Although patients had no prior awareness of PPI opportunities, they felt they had a **vested interest** in all areas of the research process, often providing selfless reasons for involvement.
- ✿ Access to support networks proved important when attempting to understand motivations and reservations towards involvement in the research process. Patients with no access to support networks initially found the concept of PPI **daunting**, whereas patients who were part of an existing support network felt **comfortable** with the prospect of involvement.
- ✿ Both groups believed with **clear explanations** of involvement, and appropriate training, they could make a **meaningful contribution** to research.

In order to avoid the sense of tokenism often expressed by patients and the public who kindly donate their time to PPI, this study recommends the consultation of patients and the public in the development of PPI advisory groups.

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