

Participatory research in PREM

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NIVEL

Research for better care

Definition of patient and public involvement

Patient and public involvement (PPI):

*Research being carried out **with** or **by** members of the public rather than **to**, **about** or **for** them*

Why patient involvement in PREMs?

- The moral case of listening to and acting on people's views. Patients have a right to provide input to healthcare.
- Person-centered care
- Value-based health care
- Benefits:
 - Improving validity of PREM
 - Reducing 'development and measurement waist'



Quality indicators from patients perspective

- Structure, process, outcome indicators



PREM



PROM

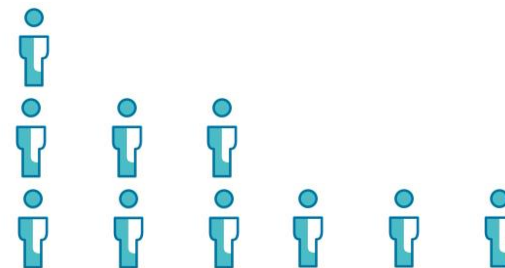
‘standardized way’

Generic **PREM** topics and questions:

- Treatment: Overall, did you feel you were treated with respect and dignity while you were in hospital?
- Communication: Did doctors talk in front of you as if you weren't there?
- Information: Did the doctors or nurses give your family or someone close to you all the information they needed to help you recover?
- Shared decision making: Did you want to be more involved in decisions made about your care and treatment?

PREMs: where to start?

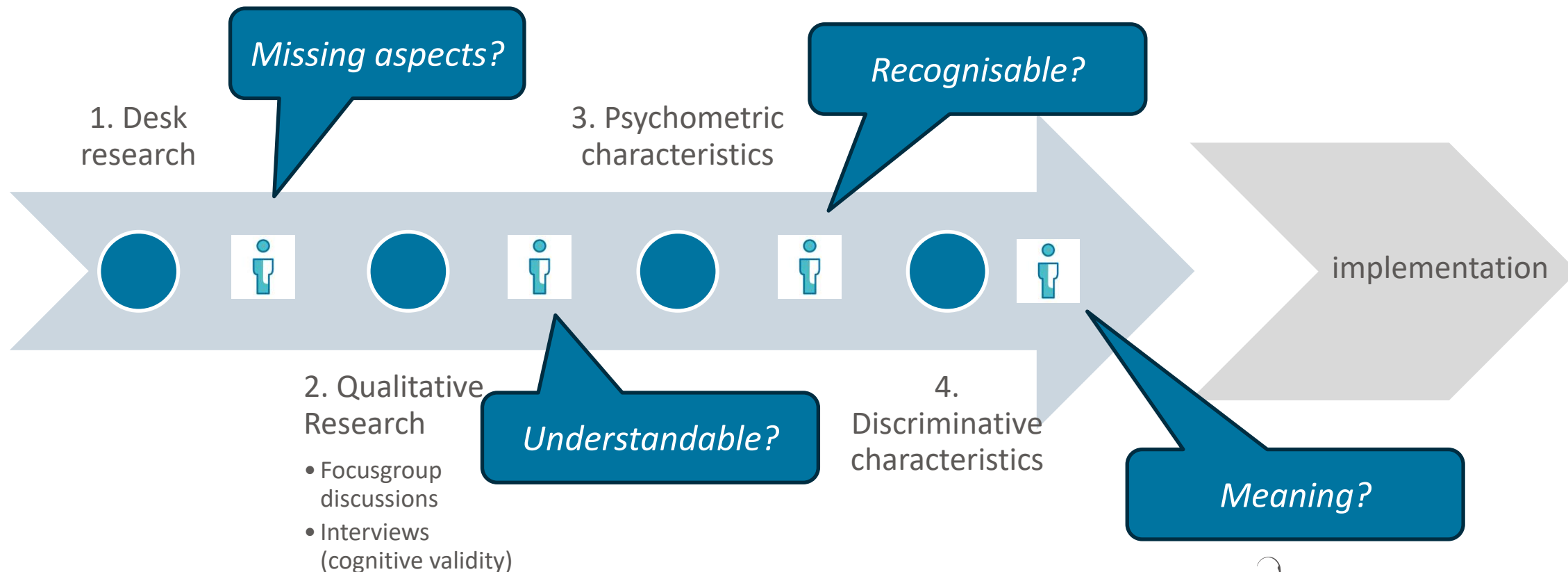
- Define goal:
 - Shared decision making and/or evaluation – individual level
 - Quality improvement and/or benchmarking – group level
 - Accountability and efficiency – population level
- Join existing initiatives:
CAHPS, CQ-index, Picker initiative (PPE-15)
- Join forces with like-minded providers
- Start from scratch?
 - Leverage existing PREM, check relevance with patients
 - Sampling, data collection and analysis → involve expertise on survey research



Involve patients in PREM development process

Phase 1 + 2: **What** kind of experiences, attitudes, opinions are present in a population?

Phase 3 + 4: **How many** of each type of experiences, attitudes, opinions are present in a population?



Example cognitive test: PREM C (Australia)

Original question	Reworded question
My tests (e.g. blood tests, X-rays and scans) were undertaken when they needed to be	In general, I did not have to wait long for my tests (e.g. blood tests, x-rays and scans)
The health professionals involved in my care coordinated my care well	The health professionals involved in my care coordinated the different aspects of my care well
The information I received about my treatment was accurate	The different health professionals involved in my care always gave me similar information

Reid C, Jones L, Janda M, Langbecker D, Stone L, Laing B, McCarthy A. Development and testing of a patient-reported experience measure for cancer: A cross-sectional survey. *J Adv Nurs*. 2024 Jan;80(1):312-327. doi: 10.1111/jan.15767. Epub 2023 Jul 11. PMID: 37432759.

Cultural adaption for international use of PREM

Example:

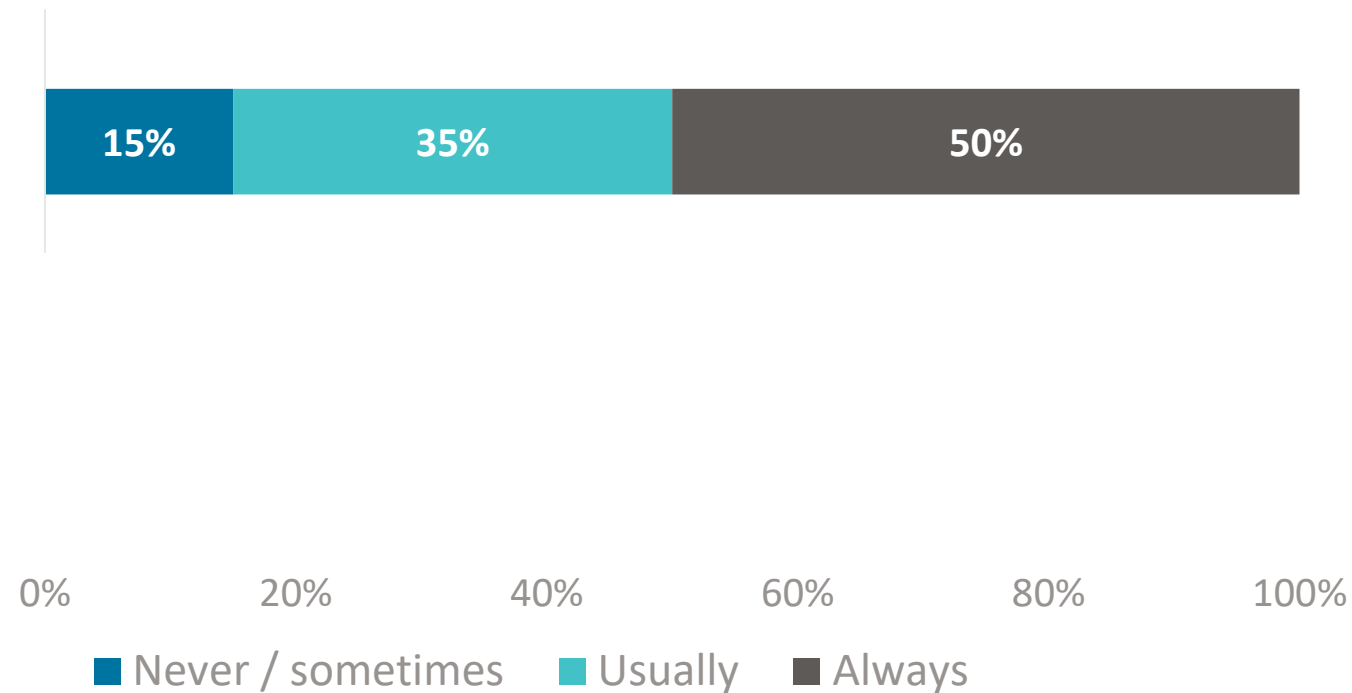
- Focus group discussions with participants with a different cultural background (N=94; 62% women)
- Consensus about important quality-of-care themes: Treatment, Communication, Expertise, Accessibility
- Some additional culture sensitive items were requested
 - Culture-differences issues:
 - The nurse (or nurse practitioner) taking care instead of the doctor
 - Shared decision making (being responsible for ones' own health)
- Questionnaire issues:
 - Order of questions, unnecessary questions, unclear introductions

Think-aloud interviews proved highly valuable in the process of questionnaire design!

And then you have data....

When you had important questions to ask a doctor, did you get questions you could understand?

Provider B



With data, you know *what* you score, not *why* you score what you score!!

From data to better care

- This really requires an additional process that must be organized and resourced



**Brainstorm with
professionals AND patients**



**Additional qualitative
methods**



**Study answers to open
questions in questionnaire**

Take home messages

- Think about the goal(s) of measuring patient experiences before you start. Is a PREM the right way to go?
- Qualitative methods can be very informative as well
- Involve patients in the development/implementation process of PREMs

Questions



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