

Appendix 1 Example of an audit trail: Main categories (column 5) derived from the thematic content analysis, partly illustrated for the main categories ‘conference design’ and ‘skepticism’.

Text fragment	Open coding	Axial coding	Sub-categories	Main categories	
<ul style="list-style-type: none"> • “as soon as you invite a collaborator, you are on the same team” [RL] • “I felt equal to all others and I was stimulated to participate” [RH] • “as part of the team I was considered an equal co-researcher” [PG] • “I don’t remember feeling us and them” [PM] 	<ul style="list-style-type: none"> • Co-researcher • Equality 	<ul style="list-style-type: none"> • Participation ladder: partnership • Co-creation • Equality 	<ul style="list-style-type: none"> • Multi-stakeholder approach • Spirit of OMERACT • Full & equal participation • Interactive breakouts • Structural involvement 	<ul style="list-style-type: none"> STRONG LEADERSHIP SELECTION PROCEDURE CONFERENCE DESIGN MODERATION STYLE PEER SUPPORT 	FACILITATORS
<ul style="list-style-type: none"> • “New stakeholders often don’t have knowledge about clinimetry” [RE] • Clinicians who do not accept patients’ influence, are difficult to change [PI] • “there is still an undercurrent that questions the issue of the added value of patient input” [PN] 	<ul style="list-style-type: none"> • (low) expectations of patients’ contribution 	<ul style="list-style-type: none"> • Resistance to change • Perspective on potential contributions of patients 	<ul style="list-style-type: none"> • Risk of tokenism • Doubts about added value • Imperceptibility of contributions • Lack of continuity 	<ul style="list-style-type: none"> INTENSITY OF THE PROGRAM SKEPTICISM COMPOSITION PATIENT GROUP 	BARRIERS