

DEVELOPMENT OF THE OECD PARIS PATIENT SURVEY

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Does Healthcare Deliver?

Results from the Patient-Reported Indicator Surveys (PaRIS)





1970S–1980S: CONCEPTUAL FOUNDATIONS

Emergence of Patient-Centred Care

Response to limits of disease-focused medical models.

Balint's Philosophical Contribution

Enid and Michael Balint: seeing patients as whole persons beyond symptoms.

McWhinney: patient-centred rather than doctor-centred, which implied that the physician must “try to enter the patient’s world, to see the illness through the patient’s eyes.”

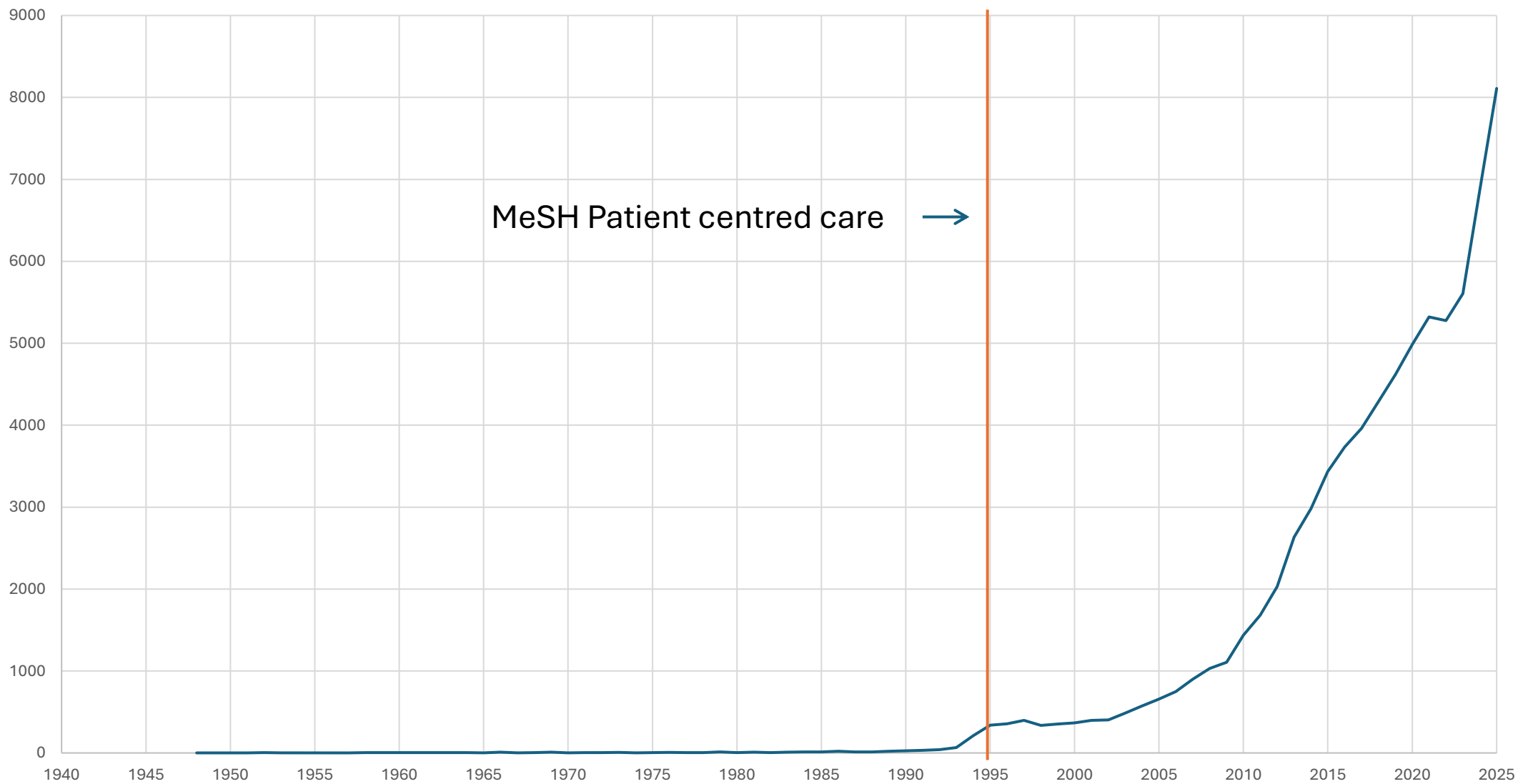
Alma-Ata Declaration

Accessible, participatory, and equitable primary health care.

Shift to Social Determinants

For more inclusive and responsive health systems.

Publications mentioning Patient-centredness BY Year





1990S–2000S: INSTITUTIONAL RECOGNITION

Institutional Endorsement

The 2001 IOM report formally recognized patient-centred care as a key aim to improve healthcare quality.

Integration into Health Systems

Healthcare systems began embedding PCC principles into policies and strategic reform agendas globally.

Focus on Patient Preferences

Care shifted to respect individual patient preferences, needs, and values in treatment decisions.

Shift to Compassionate Care

The era emphasized personalized and compassionate healthcare as a priority across systems.

2000S–2010S: OPERATIONALIZATION AND MEASUREMENT

Transition to Practical Care

Patient-centred care moved from theory to actionable healthcare practices during 2000s–2010s.

Eight Principles Framework

The Picker Institute's principles structured patient-centred care focusing on respect and coordination.

Measurement Tools Adoption

Surveys like HCAHPS)and eventually PREMs= measured patient experiences to evaluate care quality.

Technology Enhancements

Electronic health records and portals enabled patient engagement and shared decision-making.



2010S–2020S: STRATEGIC INTEGRATION

Patient-Centred Care Priority

Patient-centred care became a strategic focus in health systems.

Emergence Value-Based Care Models

Response to fee-for-service models that incentivized volume over outcomes as catalysed by rising healthcare costs and evidence of variable quality. Core Idea: Align payment with health outcomes rather than activity, emphasizing quality, efficiency, and patient experience.

Patient Involvement in Research

Organizations promoted patient input in healthcare research and policy decisions.

Global Health Policy Inclusion

International bodies incorporated PCC into health system performance frameworks worldwide.

ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT (OECD)



Health and Quality of Healthcare

- Health Care Quality Indicators (HCQI) Project – internationally comparable indicators; domains: effectiveness, safety, patient-centredness, access, responsiveness.
- Systematic Data Collection – covers primary care, acute care, cancer care, mental health, patient safety, end-of-life care.
- Conceptual Framework – links health outcomes to system-level factors and policy objectives.
- Renewed Health System Performance Assessment (HSPA) Framework – integrates resilience, people-centredness, environmental sustainability.



- Are diabetes programmes in my country making people actually feel better?
- How do people who were diagnosed with cancer in the past five years fare and does this differ from similar patients in other countries?
- How well is care organised around the needs of patients?
- Are patients with chronic heart conditions better off in some parts of the country than in others?
- How does the effectiveness of pain management vary across patient groups and geographic areas in my country?
- How well can people with multiple chronic conditions perform daily life activities?



A questionnaire to measure PROMs and PREMs for adults

- aged 45 or older
- living in the community
- with 1+ chronic conditions
- who use primary/ambulatory care (1+ registered contact in the past 6 months)

A questionnaire for care providers working in primary/ambulatory care



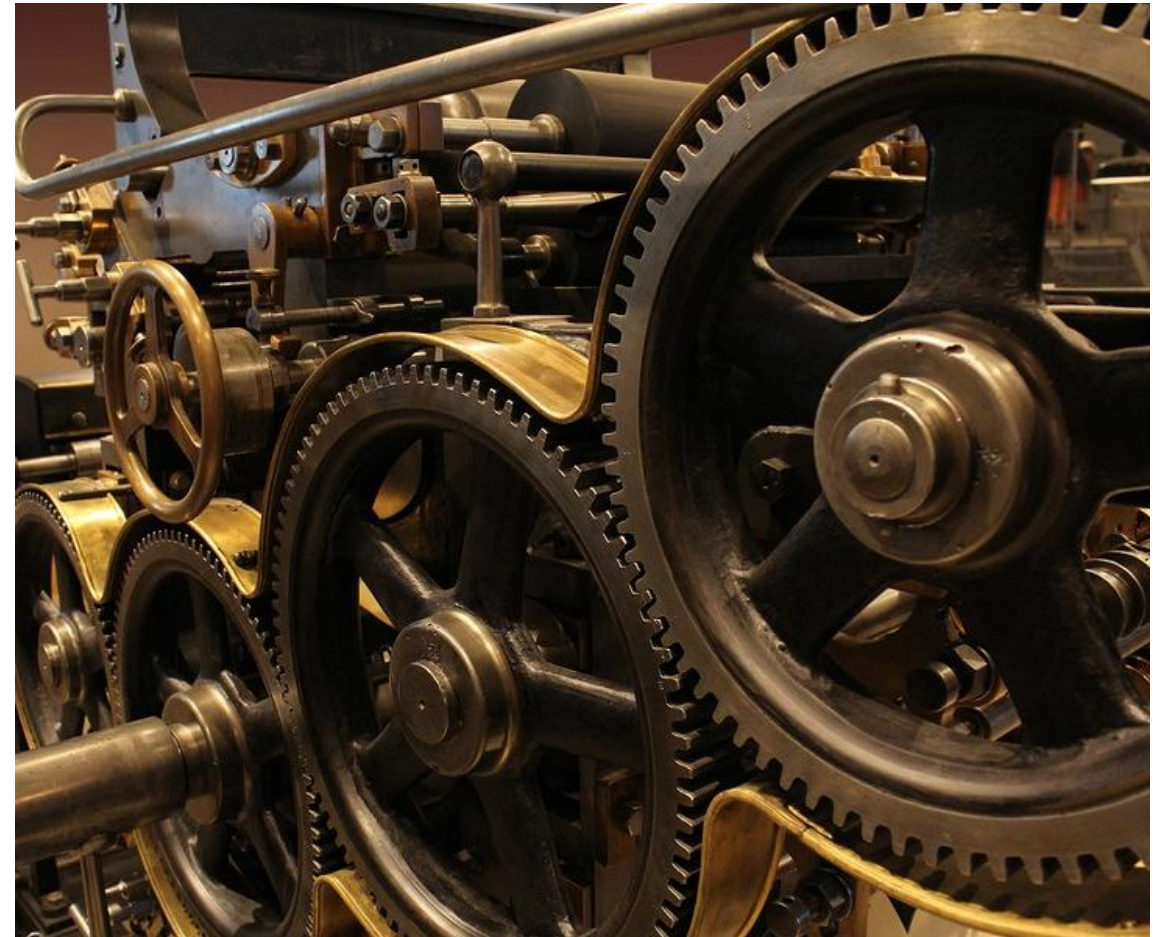


- Paris Working Party
- OECD Health Secretariat
- Country Project Leads
- Patient Advisory Panel
- Technical Advisory Community



Survey development

- Framework: WHAT to measure
- Instruments: HOW to measure
- Survey: Integration of measurement instruments in a coherent single tool



WHAT TO MEASURE: THE FRAMEWORK

Methods: framework (i)

- OECD Framework
- Set of a priori identified frameworks
- Systematic review of relevant frameworks
 - Primary care
 - Chronic Care
 - Patient Reported Outcomes
 - Health System Performance

Methods: framework (ii)

- **Narrative synthesis and comparison** of each of the domains and subdomains in the identified frameworks with consideration of:
 - part of coherent set
 - overlap
 - support in the literature
 - minimization of the number of domains (without significantly compromising comprehensiveness)
 - alignment with the previous recommendations from a taskforce

Methods: framework (iii)

- **Draft framework with iterative process**
 - **sustained engagement with**
 - International Patient Advisory Panel (PaRIS-PP)
 - International and multidisciplinary Technical Advisory Community (TAC)
 - Oversight by an international Working Party of OECD member states
 - **International virtual patient co-development workshops**
 - Revisiting the scope, identifying gaps, minimizing overlap, and ensuring consistency of terminology with patient preferences
 - 22 participants in three languages (English, Spanish, German) and seven countries (Australia, Austria, Canada, Chile, Germany, Mexico, Spain, Switzerland UK, and USA)

Results: framework (i)

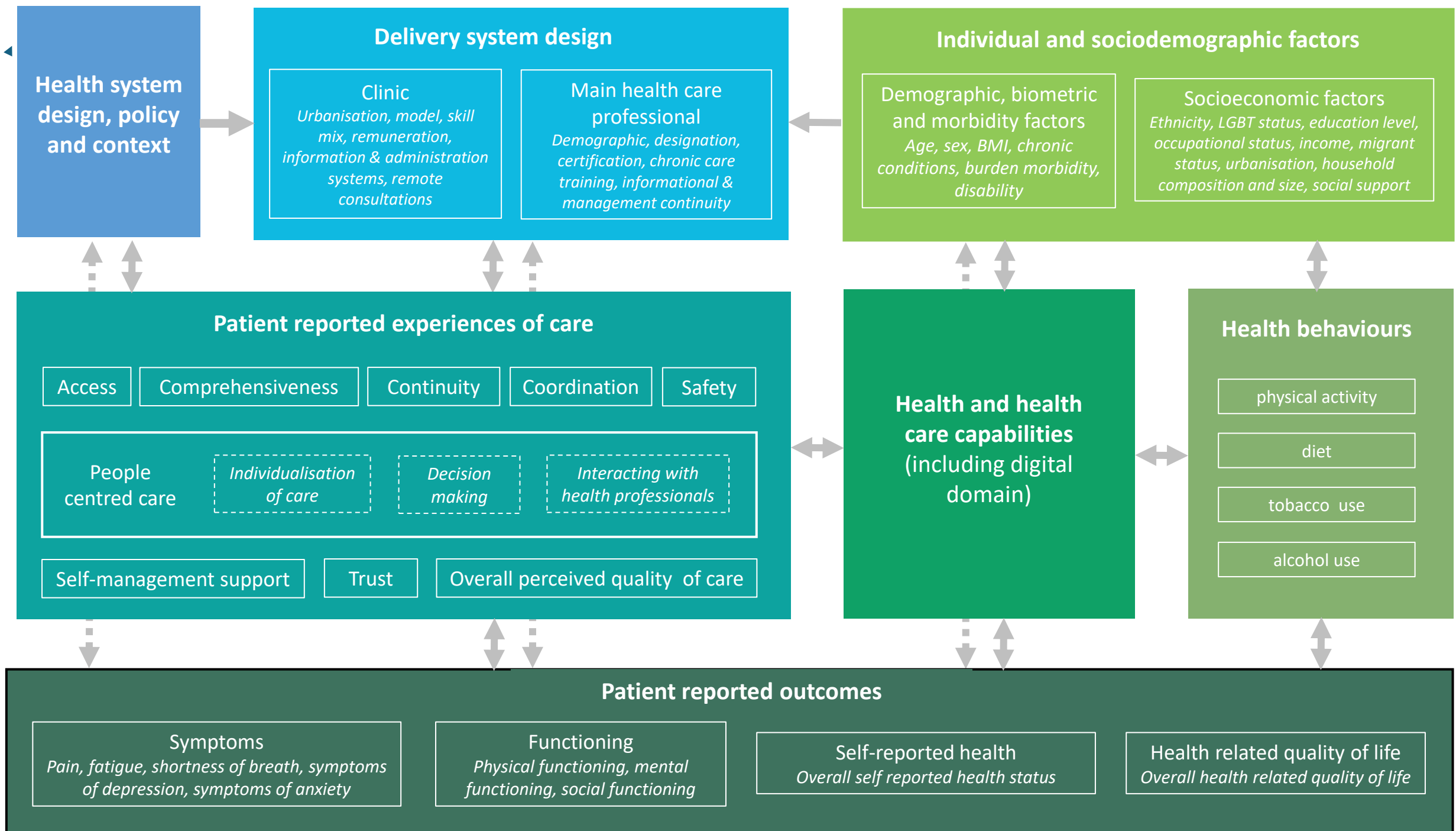
- 87 different frameworks
 - 23 a priori identified frameworks
 - 62 frameworks identified through electronic searches (from 561 initially identified aggregated records)
 - 2 more through subsequent expert input
- Draft framework
- Each iteration of feedback from PaRIS-PP and TAC resulted in changes to draft framework

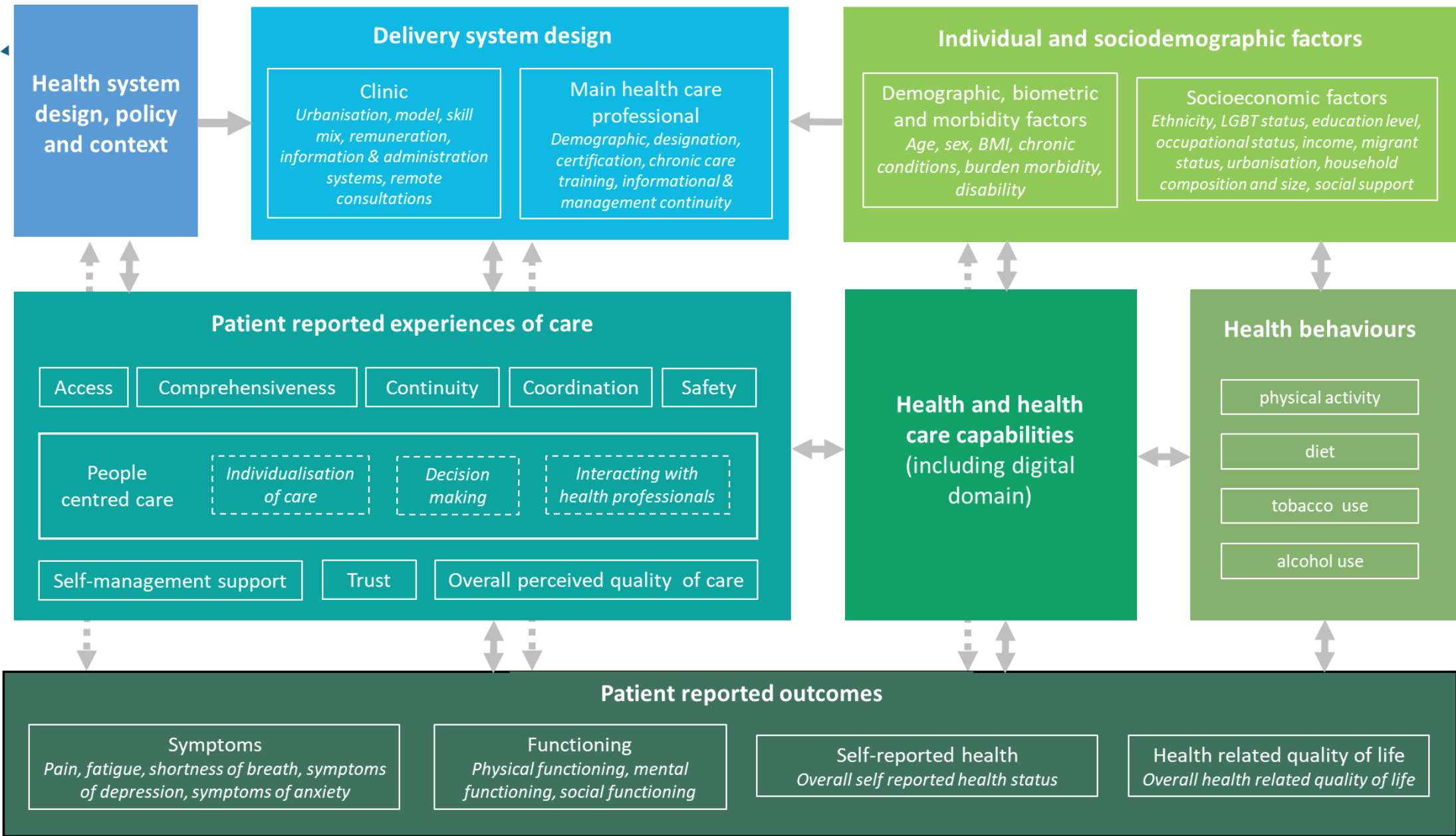


INTERNATIONAL CO-DEVELOPMENT WORKSHOPS

Key recommendations

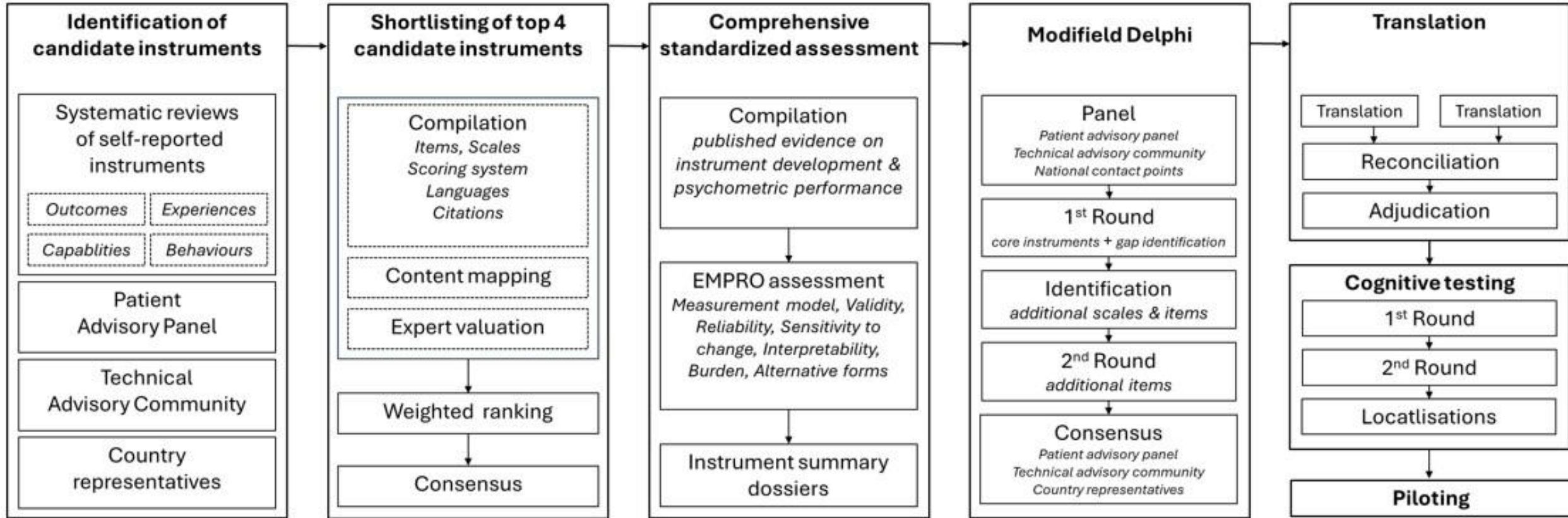
- Additional symptoms
- Financial aspects of care
- Trust in the health care professional
- Achievement of goals and expectations.
- Self-management.
- Multiplicity of ways in which interaction could take place
- Patient safety
- Impact of COVID-19 on care delivery.
- Professional skill mix





HOW TO MEASURE: INSTRUMENTS AND SURVEY

The PaRIS Patient Questionnaire



a) Comprehensive list of candidate measures

i. Patient-Reported Outcome Measures (PROMs)

- Systematic review of instruments measuring outcomes (ICHOM Overall Health Standard Set)
- Bespoke review of instruments measuring dyspnoea (PubMed; Health Measures)
- OECD PaRIS Task force

ii. Patient-Reported Experience Measures (PREMs)

- Systematic review of PREMs (update)
- OECD PaRIS Task force

iii. Measures of health and health care capabilities (health literacy, self-efficacy, patient participation, engagement, involvement, enablement, empowerment, and activation)

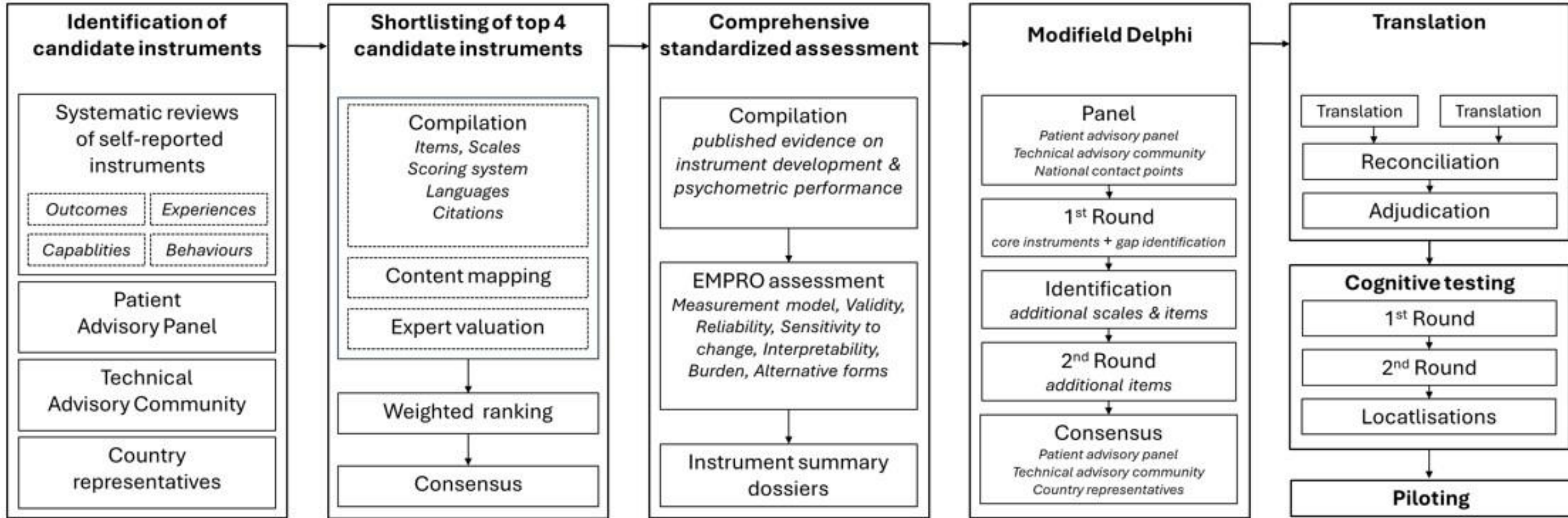
- Umbrella review
- Systematic review (last 3 years)
- OECD PaRIS Task force

iv. Measures of health behaviours and lifestyles

- Systematic review of outcomes for ICHOM Overall Health Standard Set
- OECD PaRIS Task force



The PaRIS Patient Questionnaire



b) Prioritization of instruments

i. selection of top 10% (summative weighted score):

- Number of sub-domains the instrument has been mapped onto (0.4)
- Number of items (0.2)
- Number of OECD languages the instrument is available (0.1)
- Citations in Google Scholar (0.1)
- Expert judgement (0.2)



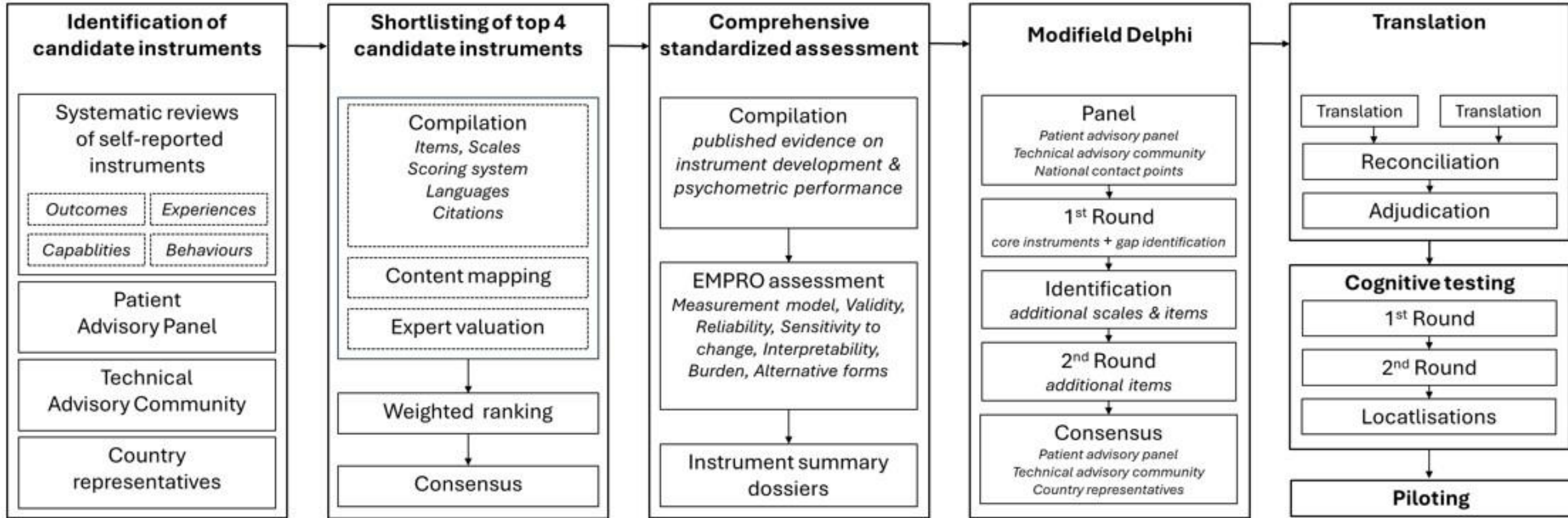
ii. top 4 ranked instruments (consensus)

- Option to replace some of them with lower-ranked instruments if deemed appropriate
- Finalised by consensus and final feedback from OECD.
- The output of this step will be up to 4 instruments measuring each broad domain in the conceptual framework.

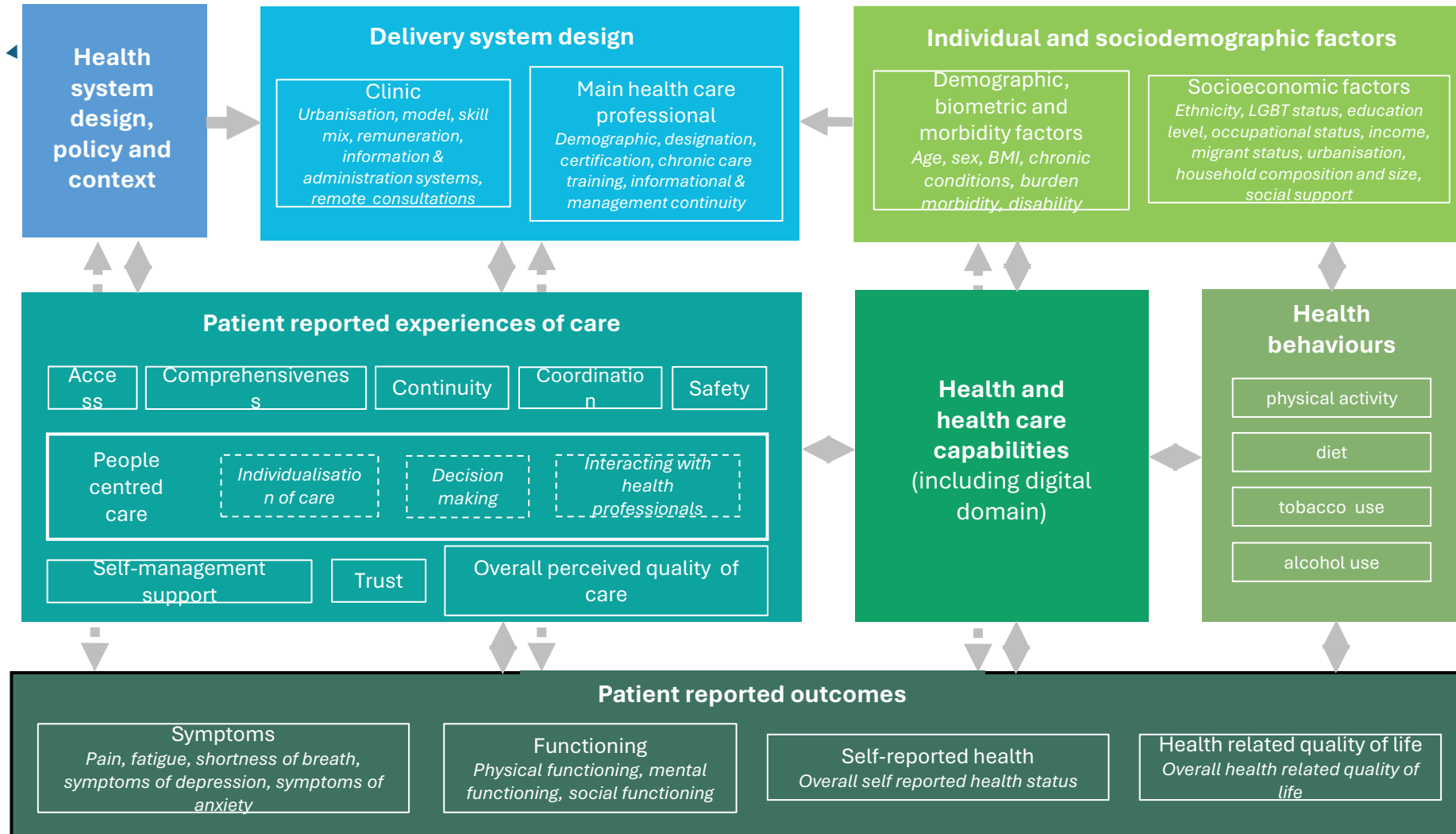
Dossier for each candidate instrument

- . Development date & country
- . Completion time
- . Whether part of family of instruments
- . Sub-domains the instrument maps onto
- . Number of items, names of scales and items per scale
- . Summary of EMPRO results
- . OECD languages
- . Versions available for administration (e.g., paper and pencil, telephone, computerized adaptive testing)
- . Seminal paper Google Scholar Citations
- . Barriers to access (e.g. fees, licensing, etc.).

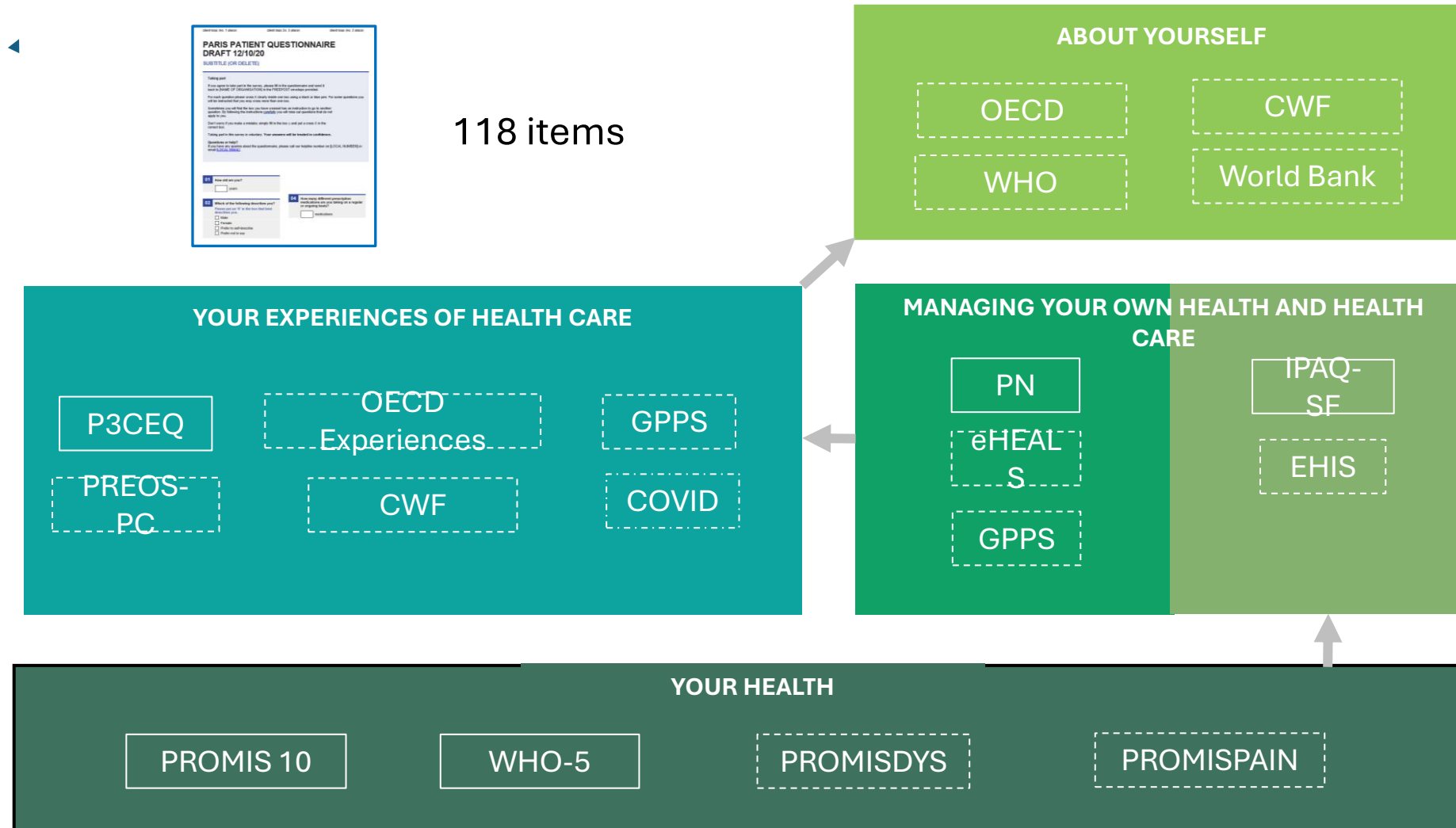
The PaRIS Patient Questionnaire



The PaRIS framework



The PaRIS Patient Questionnaire



PILOTING THE SURVEY



PILOT

- 18 countries across Europe & Australia, Canada and Saudi Arabia in 2022.
- National project managers (NPMs) worked with PaRIS-SUR Consortium, OECD & national stakeholder groups in pilot design and implementation.
 - Practices identified at random (stratified)
 - randomly selected patients aged ≥ 45 years seen in each practice
- 25 primary care practices (except 10 for Iceland)
- Sampling was conducted by
 - Primary care practices (e.g., in Belgium, Czech Republic)
 - Third parties (e.g., Australia, the Netherlands)
 - the NPM (e.g., Spain)
- 50 participating patients per participating practice (samples of 150 to 400 eligible patients per practice).



PILOT

Psychometric evaluation

- item level (missingness, distribution of responses, ceiling/floor effects)
- scale level (reliability, structure, validity)
- Previously validated scales: CFA
- For less extensively validated scales: EFA
- Refinements were also made based on feedback from NPMs and Working Party members.

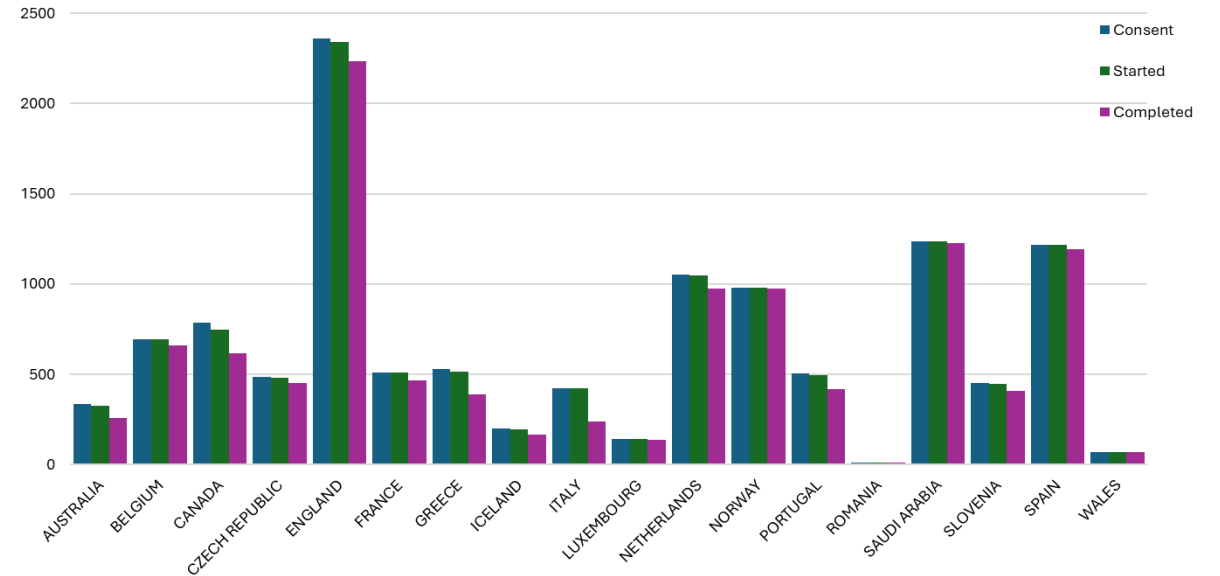
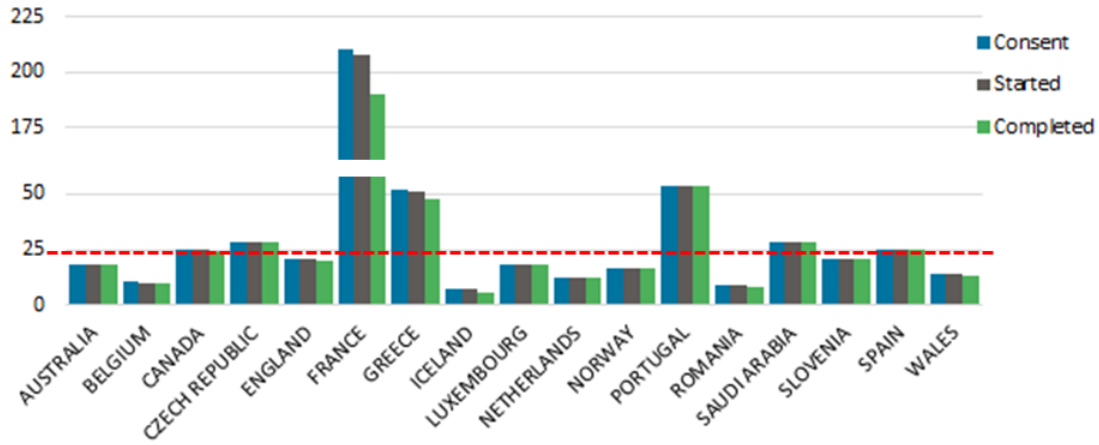


PILOT

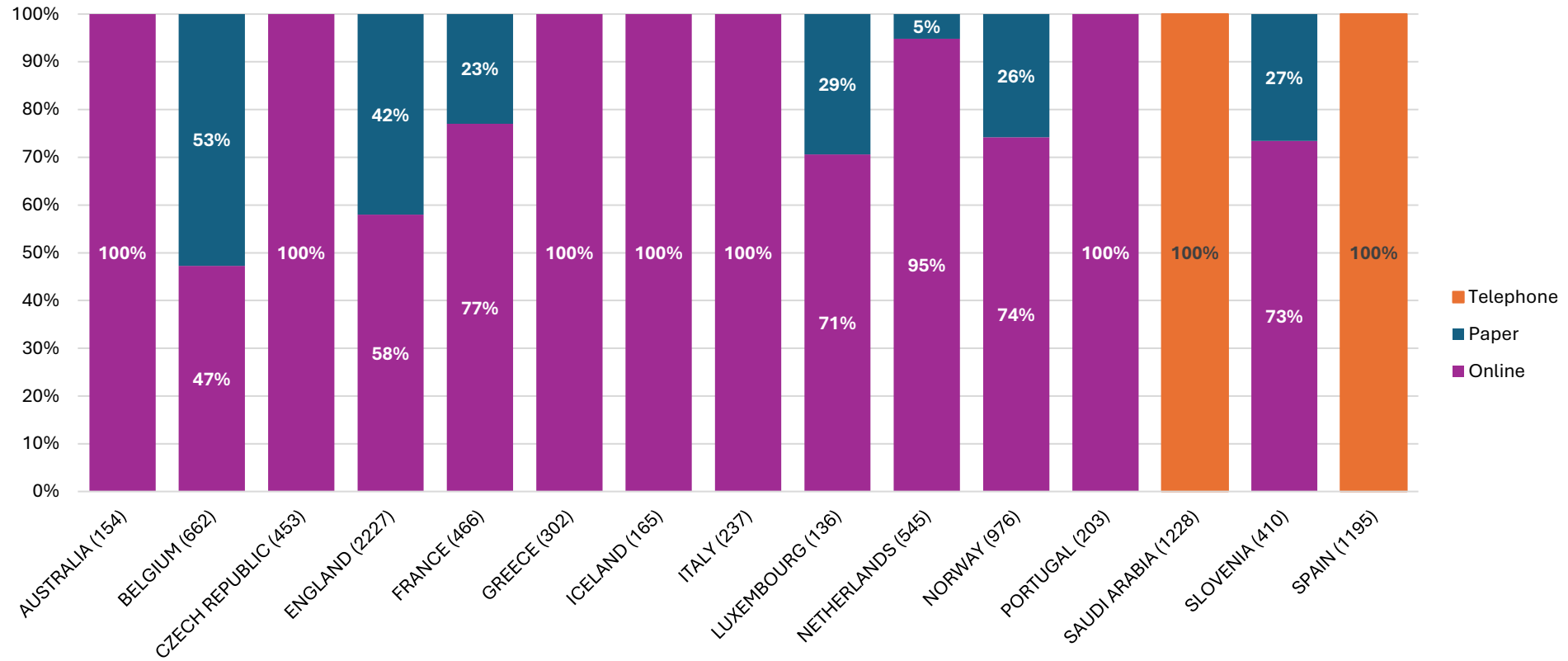
Participants

- 11,999 patients providing consent across the 18 countries
- 10,894 completed the patient questionnaire (91%)
- Median time to complete (by country): 24-33 mins

Participating practices and patients per country



Administration mode



Item level analyses

- 3 questions (out of 118) had more than 10% of answers missing (household income and composition).
- Many items with normal, bell-shaped distribution of valid answers (those that not in line with expectations for target population)
- Most items without ceiling or floor effects

Scale analyses: outcomes

Reliability

- PROMIS Global – Physical scale: 0.77
- PROMIS Global – Mental scale: 0.80
- WHO-5 Wellbeing: 0.89

Structure

- PROMIS Global – Physical scale std. factor loadings: 0.65-0.71
- PROMIS Global – Mental scale std. factor loadings : 0.58-0.71
- WHO-5 Wellbeing std. factor loadings: 0.75-0.83

Validity

- PROMs were highly correlated with each other (range: 0.47-0.82).

Scale analyses: experiences

Reliability

- P3CEQ overall score: 0.77
- P3CEQ person-centredness: 0.76
- P3CEQ care coordination: 0.70

Structure

- P3CEQ overall score: EFA single factor
- P3CEQ person-centredness: 0.39-0.67
- P3CEQ care coordination: : 0.22-0.46

Validity

- Correlations: Person-centred coordinated care experience and care coordination (0.92). Other correlations range: -0.09 and 0.72, largely in line with a priori hypotheses.

Scale analyses: health & healthcare capabilities

Reliability

- Patients' confidence in self-management (6 items): 0.78
- Reliance on health professionals (4 items): 0.68
- Active engagement (6 items): 0.73

Structure

- Patients' confidence in self-management: 0.43-0.89
- Reliance on health professionals: 0.46-0.65
- Active engagement: 0.45-0.69

Validity

- Patients health and care capabilities were correlated weakly with health/risk behaviours (range: -0.11 to 0.27).

	Chi ²	df	RMSEA	SRMR	CFI	TLI	Stand. factor loadings
PROMIS Global – Physical (N=9880)							
<i>Overall model–all countries together</i>	146.566	2	0.09	0.02	0.99	0.96	0.65 - 0.71
<i>Configural</i>	253.419	30	0.11	0.03	0.98	0.94	
<i>Metric</i>	528.382	86	0.09	0.11	0.96	0.96	
<i>Scalar</i>	2.656.717	142	0.16	0.15	0.78	0.86	
PROMIS Global – Mental (N=9884)							
<i>Overall model –all countries together</i>	312.324	2	0.13	0.03	0.98	0.93	0.58 - 0.83
<i>Configural</i>	367.526	30	0.13	0.03	0.97	0.92	
<i>Metric</i>	712.930	86	0.11	0.13	0.95	0.95	
<i>Scalar</i>	2623.839	142	0.16	0.16	0.81	0.88	
WHO5– Wellbeing Index (N=9884)							
<i>Overall model –all countries together</i>	802.221	5	0.13	0.03	0.97	0.94	0.75 - 0.83
<i>Configural</i>	1095.566	75	0.14	0.03	0.97	0.93	
<i>Metric</i>	1422.766	145	0.12	0.15	0.96	0.95	
<i>Scalar</i>	2678.324	215	0.13	0.16	0.91	0.95	

$p < 0.001$ for all models

Lessons from feed-back

- Countries provided rich feedback on their experiences and proposed several improvements:
- To intensify national efforts for engagement and recruitment
- To consider challenges of the nested design
- To further harmonise sampling and data collection
- To revise instruments
- To further develop country-specific implementation plans together with stakeholders.

Changes to the survey

- Three questions were removed either because they overlapped with other content or because scale reliability was preserved with the item removed:
- “In the past 7 days, I had a problem with my sleep”.
- “Are you offered regular follow-up for your health condition(s)? If you have more than one condition, please answer about the condition that you are seen for most regularly.”
- “Did this health professional give you an opportunity to ask questions or raise concerns about recommended treatment?”
- The response scale for one question about number medication was modified
- Four COVID-19 questions about vaccination status and concerns about care were also replaced with questions on symptoms and impact on activities.

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Thank you for your attention!

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