DOCUMENTING BEST PRACTICES FOR DIGITALLY COLLECTED PATIENT–REPORTED **OUTCOME & EXPERIENCE METRICS IN LMICS**

EXECUTIVE SUMMARY

Remote collection of patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) is an emerging strategy to efficiently generate high-quality data, that can inform more person-centered health systems, particularly in low- and middle-income countries (LMICs). Mobile phone–based surveys, especially Computer-Assisted Telephone Interviewing (CATI), have shown promise for improving data access and use, especially where traditional, in-person data collection is infeasible. However, challenges related to equity, digital access, and data utilization remain.

KEY FINDINGS

- Digital approaches are most effective when aligned with national governance frameworks.
- Equity and inclusivity can be improved through human-centered design and hybrid modalities.
- 19 best practices were identified, including government co-leadership and secure data governance.
- 32 key stakeholder organizations were mapped, with 34% based in LMICs.
- Major learning gaps remain regarding government engagement, recruitment, dissemination, data use of data for policymaking, and institutionalization.

INTRODUCTION

Patient-reported data are essential for understanding and improving people's experiences as they navigate complex health systems, including in relation to the quality and equity of healthcare services. In LMICs, traditional in-person data collection can be costly, logistically complex at scale, siloed by health area, and inconsistent across care levels. Exploration of more efficient and cost-effective data collection methods, such as the digital (remote) collection of patient-reported experience and outcome measures (PREMs/PROMs), have accelerated in recent years, primarily due to expanding digital connectivity as well as the COVID-19 pandemic.[1]

Despite increasing use of remote methods, evidence on best practices in LMICs remains limited, including how to address digital access disparities, sustainability and integration into health systems, and promote data use for decision making.[2-7] While digital platforms can offer speed and cost-efficiency, their overrepresentation of urban, educated, and higher-income populations poses risks to data equity.[1]

This brief describes findings from a landscaping review conducted by PSI, with support from Endless Foundation, to assess the state of digital collection of PROMs/PREMs and identify best practices, core stakeholders, and develop a global learning agenda.

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RESEARCH OBJECTIVE

To summarize evidence on successes, challenges, best practices, key stakeholders, and learning gaps in relation to the digital (remote) collection of PREMs/ PROMs in LMICs.

METHODOLOGY

A desk review was conducted that included both peer-reviewed research and grey literature published from 2015-2025. A total of 138 resources were included in the review:

- Peer-reviewed sources (n=100): Searched using PubMed, Google Scholar, and African Index Medicus
- Grey literature (n=38): Identified via Perplexity AI queries, targeted Google Scholar searches, and the websites of global health organizations

The desk review was supplemented with key informant interviews (KIIs) conducted with nine stakeholders identified from the desk review, including implementers, funders, and digital health innovators.

Documents and KII transcripts were analyzed thematically to extract information about implementation strategies, barriers, government engagement, and innovations. Best practices and learning gaps were categorized by stage of the data lifecycle, from design to implementation to policy application. Exemplar organizations were mapped and categorized based on type and location (LMIC vs. HIC).

KEY FINDINGS

Digital collection of PREMs and PROMs is increasingly feasible and often cost-effective, especially when integrated into routine health systems. It is particularly valuable during crises (e.g., pandemics or conflict), when in-person surveys are not possible.

STANDARDIZED METRICS

The landscaping review found that many identified projects and stakeholders used novel, project-specific metrics for measuring patient outcomes and experiences, limiting ability to compare across studies and populations (8). This finding was echoed in the key informant interviews, with a lack of standardized metrics and measures emerging as a common theme. In response, a non-systematic secondary review was conducted to identify commonly used PROMs/ PREMs, overarching constructs measured by these tools, and gaps and learning opportunities. The review revealed several shared domains across commonly used PROMs, including: physical functioning, social functioning, symptomology (including mental health-specific symptoms), pain, self-care, and general health-related quality of life. The review also revealed several broad suites of PROMs, such as the International Consortium for Health Outcomes Measurement (ICHOM) and Patient-Reported Outcomes Measurement Information System (PROMIS), which include a wide variety of condition/symptom-specific and general outcome measures. This review builds off the USAID MOMENTUM Measurement of Self-Reported Experience of Care Across Sexual, Reproductive, Maternal, Newborn, and Child Health compendium,[1] refining the list to identify more cross-cutting patient experience metrics and filling in gaps with additional targeted searches. Common PREM domains included: satisfaction, communication, dignity, supportive care, social support, privacy/ confidentiality, autonomy, trust, and health facility environment.

DIGITAL MATURITY

We mapped the sources included against the Google/ BCG Digital Maturity Model, which ranges from nascent (pilot) to multi-moment (mature, data-driven, and scaled). Approximately half of sources (49%, n=67) included in the review were at the nascent (pilot) stage, while only 15% were at the pinnacle multi-moment phase.

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[1] No longer available due to funding changes

STAKEHOLDER MAPPING

32 key organizations were identified:

- One-third (n=11, 34%) are LMIC-based
- Majority are academic institutions (22%) and private sector entities (19%)
- Only 9% are national NGOs

Findings indicate opportunities to increase local leadership.

BEST PRACTICES ACROSS THE DATA LIFECYCLE

- **Government engagement:** Co-lead with government stakeholders from the outset and align with national ICT frameworks.
- **Design:** Use participatory methods (e.g., human-centered design) to promote acceptability, usability, and equity; co-develop evaluation plans with government partners.
- **Testing and recruitment:** Pilot surveys using cognitive interviews; engage trusted community actors such as Community Health Workers (CHWs).
- **Data collection:** Provide airtime/devices, pre-contact (e.g. via SMS or call), and account for gender sensitivity.
- **Data storage and monitoring:** Ensure secure, government-compliant data systems, including local storage where feasible.
- **Analysis and dissemination:** Use post-stratification weights to address bias; share results through existing government forums.
- **Policy and scale-up:** Institutionalize data review meetings; strengthen the digital health enabling environment.

PRIORITY LEARNING AREAS

Ten critical learning questions emerged across the data lifecycle, spanning topics including:

- **Government engagement:** Effective strategies for co-developing, financing, and institutionalizing digital PREM/PROM systems aligned with national ICT frameworks and health strategies.
- **Equity and design:** Methods to ensure inclusive, representative data collection across diverse populations and digital access levels.
- **Data use and governance:** Mechanisms for routine, meaningful use of patient data in decision-making and integration into existing health data systems.
- **Scalability and sustainability:** Approaches to expanding digital systems nationally, including policy advocacy, infrastructure investment, and long-term government ownership.

CONCLUSION

The remote collection of PROMs and PREMs holds significant promise for strengthening patient-centered care in LMICs, and there is a growing evidence base to support this approach. Several key best practices emerged from this review, including engaging government stakeholders from the outset, designing inclusive tools informed by user feedback, involving community health workers, and building secure, interoperable data systems aligned with national strategies. However, notable critical questions remain, including best practices for tool and survey design, institutionalization of digital data collection approaches in line with policies and regulations, and improving data utilization to inform responsive health system and policy design.

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ABOUT PSI

PSI makes it easier for people in LMICs to lead healthier lives and plan families they desire by marketing affordable products and services.

APPENDIX: BEST PRACTICES

PHASE	DOCUMENTED BEST PRACTICES
GOVERNMENT ENGAGEMENT	Ensure the digital data collection approach is government-mandated, co-led with government stakeholders, and integrated with existing governance mechanisms.
	Align with or establish a national ICT and digital health framework that defines standards, promotes interoperability, and engages cross-sector stakeholders.
	Co-develop long-term, sustainable funding models that include government cost-sharing and commitments.
DESIGN	Assess feasibility of digital approaches by reviewing national indicators on mobile phone ownership, connectivity, and digital literacy to inform mode selection and coverage expectations.
	Align with national policies and global standards by co-selecting standardized questionnaires, reviewing digital health strategies, and implementing Digital Adaptation Kits (DAKs) to ensure interoperability with HMIS.
	Co-design tools and processes with end-users and implementers using participatory methods such as human-centered design or focus groups, to ensure relevance, usability, and sustainability.
	Design for equity and inclusivity by incorporating socio-demographic questions, building offline functionality, and using representative sampling frames or methods like RDD to reduce non-response and coverage bias.
	Co-develop an evaluation plan with government and long-term partners for digital health data collection approach.
TESTING	Conduct cognitive interviewing and piloting for questionnaire design.
RECRUITMENT	Engage trusted community actors (e.g., CHWs, leaders) to support recruitment and build trust.
DATA COLLECTION	Reduce non-response and coverage bias by pre-contacting via SMS, offering airtime or devices, and collecting multiple contact numbers.
	Employ data collection practices that are sensitive to gender and sexual orientation.
DATA STORAGE / MONITORING	Ensure secure, government-led data storage and governance systems that comply with national laws and regulations.
DATA ANALYSIS	Use post-stratification weights to mitigate selection bias.
DISSEMINATION	Use existing government-led forums (such as technical working groups or advisory committees) to engage all stakeholders involved in digital health data collection and use.
DATA USE	Institutionalize routine data review meetings at all levels of the health system and develop SMART plans to address identified challenges.
ADAPTATIONS FOR SCALE-UP	Strengthen the digital health enabling environment through advocacy for policy, infrastructure, and workforce capacity.
	Improve accessibility and inclusivity through multi-platform options (e.g., USSD, AI, voice response).
DATA-INFORMED POLICY CHANGE	Use existing governance mechanisms (such as technical working groups or advisory committees) to review evidence generated from patient data and advocate for patient-informed policy development and health system design.