IMPROVE

Framework to IMPROVE the Integration of Patient Generated Health Data to Facilitate Value Based Healthcare

D6.1: Report on Assessment of Stakeholder Requirements

Version 1.0

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Co-funded by the European Union

Document Control Sheet

Deliverable Number	D6.1
Deliverable Responsible	TiU
Work Package	WP6
Lead Editor	Linwei He
Internal Reviewer(s)	Lutz Peschke (ius), Eva Turk (STPUAS), Ernst Martin (STPUAS), Manuel Ottaviano (UPM)

History of Changes

Date	Version/Page	Change
20-05-2025	0.1	First version of the deliverable
27-05-02025	0.2	Revised version incorporating reviewers' comments
30-05-2025	1.0	New format applied and version ready for submission

Statement of Originality

This deliverable contains original unpublished work except where clearly indicated otherwise. Acknowledgement of previously published material and of the work of others has been made through appropriate citation, quotation or both.

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Abbreviations and Acronyms

DoA	Description of Action
EC	European Commission
WP	Work package
PGHD	Patient-generated health data
PROMs	Patient-reported outcome measures
PREMs	Patient-reported experience measures
PPI	Patient-preference information
UX	User experience
EHR	Electronic health records

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1. Introduction

The IMPROVE project aims to enhance the use of patient-generated health data (PGHD) - such as Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) - to improve communication and decision-making in healthcare. To ensure the resulting framework is grounded in practice and is useful for all potential users, it is crucial to involve stakeholders early on in the design process (Van Velsen et al., 2013). The overarching goal of Work Package 6 (WP6) is to ensure the IMPROVE framework is developed with a comprehensive understanding of the diverse needs of various stakeholders. To meet this goal, we took an incremental, stepwise approach, starting with stakeholder identification, categorization, and prioritization to align the platform with real-world challenges and facilitate its successful adoption within healthcare systems. As detailed in deliverable D6.4, WP6 initially identified stakeholders through literature reviews and collaborative workshops. This process resulted in categorizing stakeholders into three primary groups: *direct users*, *involved stakeholders*, and *stakeholders to be informed*. Subsequently, stakeholder prioritization was conducted to identify key stakeholders requiring focused attention during the platform's development.

Building upon these earlier activities, the present deliverable (D6.1) provides a detailed assessment of stakeholder needs and requirements gathered through qualitative interviews. Stakeholders interviewed include patients, clinicians, researchers, policy advisors, and technology providers across multiple use cases. This deliverable systematically summarizes, categorizes, and prioritizes stakeholder needs, aiming to provide structured and actionable insights for guiding the IMPROVE platform's development. Understanding these diverse requirements helps ensure the platform's alignment with stakeholders' expectations, thereby enhancing its usability, effectiveness, and acceptance within various healthcare contexts. The stakeholder requirement assessment presented in D6.1 directly informs subsequent stages of WP6, particularly the co-creation sessions that will establish functionalities and design parameters of the IMPROVE platform. A clear understanding and structured prioritization of stakeholder needs will help ensure these co-creation sessions are targeted and effective, ultimately leading to broader adoption and meaningful impact in clinical practice and health policy settings.

This deliverable is structured as follows: first, the Methods section outlines the development of materials, data collection processes, and analytic approaches. The subsequent section presents detailed findings of stakeholder requirements, organized around key communication processes relevant to IMPROVE: *Data Collection, Data Analysis and Presentation, Clinical Integration* and *Workflow, Communication and Decision-Making,* and *Technical Infrastructure and Support*. *The General Discussion* section synthesizes these findings, categorizing stakeholders according to their level of involvement and discussing implications for WP6, as well as for the broader IMPROVE project. Finally, the *Conclusion and Next Steps* section summarizes the main findings, highlighting practical implications and outlining subsequent activities, such as co-creation sessions and prototype development.

2. Methods

2.1. Interview guide

The stakeholder needs and requirements were gathered through qualitative interviews with various types of stakeholders. The interviews were structured and based on an interview guide (See Appendix A). This interview guide was developed based on a theoretical model described by de Ligt et al. (2025), which offers a systematic approach for analyzing the implementation processes of patient-generated health data (PGHD) such as Patient-Reported Outcome Measures (PROMs). The rationale for developing this structured guide is rooted in the understanding that the effective use of PGHD involves multiple distinct steps, each engaging different stakeholder groups. For example, clinicians may focus on interpreting and integrating PGHD into clinical practice, patients on the experience and ease of data provision, and technology providers on infrastructure and interoperability.

To accurately map the processes and stakeholder-specific needs related to PGHD, we drew upon the classic communication model by Lasswell (1948), which outlines communication as a sequential process comprising several key components: who says what, in which channel, to whom, and with what effect. In the context of IMPROVE and PGHD, Lasswell's model helps identify and clarify the steps involved, ranging from data collection to clinical decision-making.

Recently, researchers have begun exploring the application of the Lasswell model specifically for PROMs, uncovering various implementation challenges. De Ligt et al. (2025) highlighted issues such as data integration complexities, clinician resistance, and patient burden, suggesting that digital tools can effectively address many of these barriers across different stages. This approach aligns closely with IMPROVE's overarching goal of offering digital solutions for integrated, patient-centered healthcare. Therefore, we adopted the framework by de Ligt et al. (2025) as our foundational theoretical model. Figure 1 shows a visualized framework of the implementation processes.

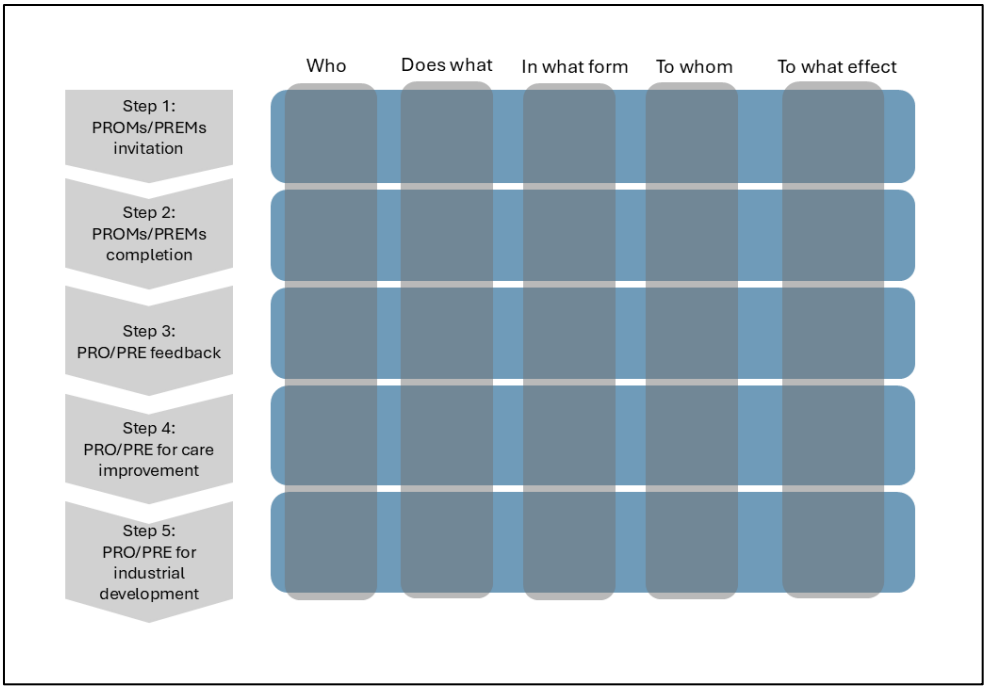

Figure 1. Visualized implementation processes of PGHD.

The interview guide itself is structured into four main sections: *Setting the Stage*, *Current Practice, Major Bottlenecks*, and *Towards Solutions*. Each section contains specific questions intended to elicit detailed responses about stakeholder practices, challenges, and potential improvements. Prompts are provided to encourage deeper discussions or clarify responses as necessary. Three versions of the guide were developed: a general version suitable for clinicians, researchers, and policymakers; one specifically tailored for patients; and another one specifically designed for technology providers. Technology providers, such as MedTech companies, were not part of the original model by Ligt et al. However, we argue that PGHD such as PROMs, PREMs, and PPI can be very useful for Medical Device manufacturers and other technology providers, as information about patient's needs and preferences can inform decisions about the design of medical equipment. As such, technology providers were added as an additional potential stakeholder. We developed the interview guide within WP6 and presented several iterations at multiple consortium meetings. Feedback gathered during these sessions was integrated into the final interview guide (see Appendix A).

2.2. Participant recruitment

Insights from deliverable D6.4 provided an initial foundation for participant selection, outlining the relevant stakeholder types. Consortium partners were invited to conduct individual interviews using their professional networks, ensuring a diverse range of stakeholder perspectives. No strict selection criteria were imposed, allowing for the inclusion of both direct users and more distantly involved stakeholders, thereby capturing a comprehensive range of requirements and insights relevant to the IMPROVE platform.

2.3. Data collection process and settings

Prior to data collection, ethics approval was obtained from the Ethics and Data Management Committee at Tilburg University. Interviews started in February, and data collection concluded by the end of March. Interviews were conducted in various formats, including video and textual communication, according to participant preference. All interviews were transcribed and anonymized for subsequent analysis, ensuring confidentiality and privacy. Given that interviews were carried out by different interviewers, there was some variability in the level of detail that was captured in the interviews.

2.4. Data analytic approach

To summarizing and present the interview findings, a narrative analytic approach was used. The process began with familiarization of all transcripts to understand the breadth and depth of collected data. A deductive structure guided the initial data extraction, based on the theoretical framework by de Ligt et al. (2025) and the structured interview guides. This ensured that key findings were capturedin accordance with the structured interview guide, with additional attention given to spontaneous insights that were not explicitly anticipated, allowing new, emergent themes to surface. Given that the majority of the interviews were not recorded verbatim, instead of line-by-line coding, data extraction was systematically recorded in an Excel spreadsheet, documenting participant characteristics, responses to the interview questions, and any additional comments provided by participants (see Appendix B). One researcher led the extraction process, and findings were then subject to iterative

discussion and agreement within the WP6 team to interpretations and ensure consistency.

3. Assessment of stakeholder requirements

3.1. Stakeholder characteristics

A total of 33 participants were interviewed as part of this needs assessment. Based on the three variations of the interview guide, these participants were categorized into three primary groups: general stakeholders (n=21), patients (n=5), and technology providers (n=7). See Table 1 below for an overview of the characteristics of the participants interviewed.

General stakeholders. The group of general stakeholders represented a wide range of professional backgrounds, including *clinicians, researchers, policy advisors, healthcare managers, and quality improvement professionals*. These individuals worked across academic and general hospitals, governmental organizations, health foundations, and private care centers, with expertise areas ranging from oncology, neurology, and cardiology to public health, mental health, and eHealth implementation. Participants were mainly based in European countries such as the Netherlands, Belgium, Germany, Italy, and Spain. For a more detailed overview of the demographic information, please see appendix B. Their involvement with PGHD varied - some engaged daily with PROMs in direct patient care, while others approached the topic from a systems, policy, or implementation perspective.

Patients. Five patients were interviewed, offering firsthand perspectives on the experience of interacting with health data in real-world clinical settings. The group was diverse in terms of age, gender, and disease diagnosis, including individuals managing chronic conditions, multiple sclerosis (MS), and various types of cancer. Patient familiarity with PROMs, PREMs, or PPIs varied. Some had direct experience filling out such questionnaires through portals or in-clinic devices; others were unfamiliar with the terminology or unsure how their responses were used. Despite this, most patients saw the potential value of such data in tracking their health status over time, contributing to shared decision-making, or enabling comparison with others. Some patients also expressed concerns about the burden and relevance of questionnaires, the risk of data misuse, and the loss of human contact in care when technology is overemphasized.

Technology providers. Seven representatives from technology companies were interviewed. Their roles included product designers, digital health managers, and marketing professionals. Participants came from both large enterprises and specialized MedTech companies. These stakeholders described the integration of PROMs and PREMs into digital health solutions as a critical component of product design, personalization, and user experience. PROMs were often collected to inform clinical decision-making or evaluate product outcomes, while PREMs guided user experience (UX) and interface choices. Some companies also used PPIs during the design phase, especially for tailoring tools to real user needs. Technology providers highlighted their use of iterative design, gamification, and validation cycles involving user feedback and clinical experts. They emphasized the importance of interoperability, data privacy, and scalability, while also noting structural challenges such as user retention, clinical validation demands, and aligning metrics across different sites.

Table 1. Characteristics of interview participants.

ID	Country	Interview partner	Role of participant	Disease area (for clinicians)/diagnosis (for patients)/expertise area (for others)	Type of organization
1	Türkiye	ius	Clinician	Ear Nose Throat	Private hospital
2	Germany	ius	Medical researcher	Endocrinology	University
3	The Netherlands	TiU	Clinician	Neurology	Hospital
4	The Netherlands	TiU	Researcher	Oncology	Hospital
5	The Netherlands	TiU	Policy advisor	Oncology	Hospital
6	Belgium	PBY	Healthcare consultant	NI	Hospital/government
7	The Netherlands	PBY	Professor	NI	University
8	Italy	Dedalus	Researcher	Clinical psychology	University
9	Italy	Dedalus	Researcher	Patient engagement, PROMs	University
10	Italy	Dedalus	Clinician	Oncology	Hospital
11	Italy	Dedalus	Psychotherapist	Oncology, psychology	Hospital
12	Italy	Dedalus	Clinician	Oncology	Hospital
13	Italy	Dedalus	Manager	Digital health specialist	Digital health company
14	Germany	UDUS	Researcher	NI	Hospital
15	Germany	UDUS	Clinician	Ear Nose Throat	Hospital
16	Germany	UDUS	Clinician	Ear Nose Throat	Hospital
17	Germany	UDUS	Clinician	Ear Nose Throat	Hospital
18	Italy	FISM	Researcher	MS	Research foundation
19	Italy	FISM	Researcher, psychologist	MS	Research foundation
20	Italy	FISM	Clinician	NI	NI
21	Spain	Medtronic	Health consultant	Cardiovascular, diabetes	Multinational company

22	Germany	ius	Patient	Breast cancer, kidney tumor	NA
23	The Netherlands	PBY	Patient	MS	NA
24	The Netherlands	PBY	Patient	MS	NA
25	The Netherlands	PBY	Patient	Breast cancer	NA
26	Italy	FISM	Patient	NI	NA
27	Italy	FISM	Technology provider	MS	NI
28	Spain	Medtronic	Digital health program manager	Digital health, digitalization of care processes, process optimization, surgery and cardiology	Large enterprise
29	The Netherlands	PMSN	Behavioral scientist	Radiology	MedTech company
30	The Netherlands	PMSN	Cardiac MR expert	Cardiovascular	MedTech company
31	The Netherlands	PMSN	MR technologist	Radiology	MedTech company
32	The Netherlands	PMSN	Neuro expert	Neurology	MedTech company
33	The Netherlands	PMSN	Marketing manager	NI	MedTech Company

3.2. Stakeholder requirements findings

To organize the findings, we followed the framework as detailed in the interview guide (see Appendix A) and integrated key insights from the interview, resulting in five key communication and process stages relevant to PGHD integration. These include *Data Collection, Data Analysis and Presentation, Clinical Integration and Workflow, Communication and Decision-Making*, and *Technical Infrastructure and Support.* Within each stage, we report current practices, identified challenges, and stakeholder recommendations for the future IMPROVE platform.

3.2.1. Data collection

The process of collecting PROMs, PREMs, and other forms of PGHD forms the first point of contact between patients and digital health tools. Across stakeholder types, there was general consensus that while PROMs and PREMs have been more widely adopted, stakeholders have less experience with PPIs and they remain underutilized or less well integrated.

Clinicians and researchers described using standardized PROMs such as the EORTC-QLQ-C30 (a

standard questionnaire developed by the European Organisation for Research and Treatment of Cancer to assess quality of life of cancer patients, covering aspects such as physical functioning, fatigue, and pain), often in research studies or specific care pathways, but data collection tended to be fragmented and lack systematicity. Patients confirmed this, showing a lack of awareness of these measures, though many saw added value and were motivated to provide data.

Technology providers echoed these concerns and stressed that data collection is often implemented in a fragmented and non-personalized way, leading to frustration, patient burden, and low response rates.

In summary, **key challenges** related to data collection include:

- Lack of clear structure and responsibility in explaining, contacting, monitoring the data collection from patients.
- Patient burden, especially when forms are too long or when digital literacy is limited.
- Lack of transparency about how the collected data are used or acted upon.

In response to these challenges and the future outlook of the IMPROVE platform, we summarized the following **stakeholder recommendations**:

- Communicate the purpose and value of data collection clearly to patients at the outset.
- Offer multiple methods for data input, including web-based tools, mobile apps, and in-clinic devices.
- Ensure the timeliness and clear interpretation of the questions (e.g., PROMs questionnaires), so that patients can provide accurate and timely data.

3.2.2. Data analysis and presentation

Once data are collected, how they are interpreted and visualized plays a crucial role in making them meaningful and actionable. While many stakeholders recognized the potential of PGHD to support clinical decision-making, they pointed to significant gaps in current tools.

Clinicians and policy advisors noted that they often receive PROM data in raw or tabular formats, which are difficult to interpret in a time-constrained consultation. Such analysis also poses extra workload to clinicians, and such burden sometimes outweigh the added value of the data. Clinicians also mentioned the challenge in data sharing, while they see great value in sharing data across sites and bench marking. In some cases, data were reviewed retrospectively for research or quality monitoring.

Patients, for their part, have little access to their own results (usually they can see their answers, but not the analyzed and/or interpreted results), resulting in a sense of detachment from the process. Technology providers expressed frustration at the lack of consistent design guidelines or standards for data visualization, particularly when working with hospitals that use their own systems.

Key challenges identified:

- Low interpretability of raw PROM/PREM scores and additional workload for clinicians.

- Absence of meaningful (trend) visualizations or benchmarks or clinically meaningful summaries.
- Lack of patient-facing feedback tools to enable reflection or tracking.

In response, we summarized the following **stakeholder recommendations**:

- Develop intuitive dashboards tailored for each user type (clinicians, patients, researchers) and individual differences (e.g., literacy level) within each type.
- Include trend tracking (at both individual and aggregated level), visual thresholds, and color-coded alerts.
- Design patient-friendly interfaces to show results over time and support self-management.
- Allow contextual interpretation, such as population benchmarks or patient-specific comparisons.

3.2.3. Clinical integration and workflow

Integration into clinical workflows was a recurring theme across interviews, particularly among clinicians and implementation experts. Many stakeholders described the current situation as fragmented, with PROMs and PREMs often "tacked on" to existing systems (e.g., Electronic Health Records) rather than embedded into routine care. Responsibilities of data integration and management differ largely across the cases, sometimes the clinician handles the data (collection and analysis and management), sometimes practice nurses are responsible, sometimes IT department plays a big role. Some clinicians and implementation experts mentioned moments where PROMs were collected but never discussed, leading to disengagement among patients.

Key challenges identified:

- Lack of integration with EHRs and consultation flows.
- Unclear roles and responsibilities for collecting, reviewing, and acting on PGHD.
- Workflow disruption, with clinicians perceiving PROMs collection as "extra work."

Stakeholder recommendations:

- Ensure interoperability across different systems and seamless presentation of PGHD at the point of care.
- Clarify role assignments (e.g., nurse vs physician) in data review and discussion.
- Provide summaries or alerts that are accessible and actionable within clinical workflows.

3.2.4. Communication and decision-making

PGHD (e.g., PROMs and PREMs) are not only data points but also tools for improving communication and enabling shared decision-making. However, stakeholders described several challenges in realizing this potential in current practice.

Clinicians noted that while PROMs can flag patient concerns, they often lack time or resources to act on them. Patients, on the other hand, frequently felt their input was not acknowledged or linked to their care plans. Implementation experts acknowledge this too and further highlight the benefit of cross-site benchmarking, which faces the challenges of data sharing and having unified measures.

Key challenges identified:

- Limited time and resources for clinicians to discuss PROM data meaningfully in consultations.
- Underutilization of cross-site comparison to inform high-level research.
- Patients not seeing the impact of their input on care decisions.

Stakeholder recommendations:

- Use PROMs and PREMs as conversation starters, not just metrics.
- Offer training or decision aids for clinicians on how to use PGHD in dialogue.
- Provide summary sheets or digital pre-consultation forms to let patients raise issues in advance.
- Improve communication across different sites, regions, and even countries, to allow for more meaningful clinical comparison.

3.2.5. Technical infrastructure and support

Finally, stakeholders pointed to a range of technological and infrastructural barriers that must be addressed to ensure the effective deployment of the IMPROVE platform. Clinicians and implementation experts described working with diverse hospital IT systems (e.g., one system for collecting PROM data, another for displaying and integration), which was echoed by technology providers, noting that interoperability, customization demands, and privacy requirements often complicate implementation.

Key challenges identified:

- Fragmented systems and lack of interoperability across sites.
- Security and privacy regulations across hospitals and countries that complicate integration.
- Digital literacy gaps among both clinicians and patients.

Stakeholder recommendations:

- Design the IMPROVE platform to be interoperable with existing systems (e.g., EHR) of the hospitals.
- Provide integration support for local hospital systems.
- Ensure accessibility for users with varying levels of digital literacy.

3.3. Cross-stakeholder insights: Aligning shared and unique needs

While many requirements identified across stakeholder interviews reflect shared wishes, it became clear that each stakeholder group expresses distinct priorities, challenges, and expectations. These differences highlight the importance of developing the IMPROVE platform not as a one-size-fits-all solution, but as a system that accounts for the needs of all actors in the PGHD communication process. In the table below, we map out both the shared and stakeholder-specific needs and recommendations across the five key PGHD process stages.

As seen in Table 2, several themes repeatedly emerge across different stages and stakeholder groups, including **the need for system interoperability, clearly defined responsibilities within clinical workflows, and the meaningful involvement of patients throughout the process**. These recurring themes highlight critical aspects for the design and implementation of the IMPROVE platform. Addressing these points will be essential for ensuring that PGHD tools are not only technically feasible but also usable, accepted, and valuable across stakeholder contexts. In the next section, we will discuss what this implies for the IMPROVE project and for broader stakeholder engagement.

Table 2. Stakeholder requirements for the IMPROVE platform.

PGHD process stage	Shared needs	Clinicians & implementation experts	Patients	Technology providers
Data collection	• Clear structure and responsibility • Communication and infrastructure improvements to increase patient engagement	• Training and shared responsibility in explaining, inviting, and monitoring patient participation • Development of consensus on questionnaires to foster cross-site comparison	• Clear and personalized explanation of benefits • Offer multi-modal tools for ease of use • Timely and clear formulation of the questions for all literacy level	• Customizable questionnaires for system-specific insights
Data analysis and presentation	• Provide access to all parties (clinician, patient, management, etc.) • Easy-to-interpret data format (e.g.,	• Easy-to-use dashboard with flagging systems for quick assessment	• Provide immediate feedback on the meaning of the scores	• Ensure interoperability with hospital systems • Define clear objectives of

	visualization, trend tracking) • Allow for contextual benchmarking	• AI-supported interpretive/predictive models • Enable data sharing across site to allow for comparison at aggregated levels	• Offer trend tracking and support self-management • Comparison with "patients like me"	analysis (e.g., for clinical experience, device improvement, patient decision support, etc.)
Clinical integration and workflow	• Establish clear processes and responsibility in collecting, reviewing, and acting on PGHD • Ensure interoperability with existing systems	• Clear processes and responsibility • Avoid additional systems	• Involve patients early • Reassurance data is acted upon • Provide feedback to encourage active participation and communication	• Improve interoperability of multiple systems • Enhance compliance and integration in terms of privacy and data sharing
Communication and decision-making	• Ensure an individualized view on PGHD rather than only metrics • Improve cross-site communication for more meaningful clinical decision-making	• Ensure easy-to-interpret data representing the individual patient • AI-supported tools for highlighting areas of concern	• Feel heard and acknowledged • Provide feedback on raw score and support in preparation for consultations	• Improve data sharing to support higher-level research and broader system integration
Technical infrastructure and support	• Avoid additional systems • Provide integration support for local hospital systems • Ensure accessibility for users with varying levels of (digital) literacy	• Ensure compatibility with existing clinical system to avoid additional workload • Prompt support from IT departments	• Create easy-to-use interface • Ensure human touch	• Develop modular, interoperable design • Address security and privacy concerns across regions/countries

3.4. Implications for IMPROVE platform development

The interview insights indicate that the process around PGHD contains interdependencies between different stakeholders: patients must be meaningfully involved early on in the process; their data must be interpreted and acted on by clinicians; these data must be supported by technology infrastructure, and the data must ultimately be used to and drive decisions at both the individual and system levels.

If just a single link in the process is missing, the platform's function and benefit is compromised. For example:

- If patients are confused or burdened during data collection, their input may be incomplete or inaccurate.
- If clinicians do not trust or understand the data, they may not use it in consultations.
- If the infrastructure is fragmented, none of the above can happen seamlessly.

Therefore, the development of IMPROVE must consider each stakeholder's position within this process**,** ensuring that:

- Patients feel respected, informed, and motivated to contribute data**.**
- Clinicians are supported with the right tools at the right moment in the care process.
- Technology providers are empowered with guidance and flexibility to implement the platform across contexts.

Only by connecting all these dots, from data collection to decision-making and feedback, can the IMPROVE platform function as intended: not just as a data tool, but as an integrated system for communication and action that supports better care, more engaged patients, and more value-based healthcare services.

4. General Discussion

4.1. Categorization of stakeholders by levels of involvement

In the previous deliverable D6.4, stakeholders were categorized into three levels based on their engagement with the IMPROVE platform: **end users** (e.g., patients, clinicians, and service providers such as hospitals and technology companies, directly interacting with the platform), **stakeholders involved** (e.g., researchers, public health entities), and **stakeholders to be informed** (e.g., policymakers and financial actors). This categorization, grounded in literature reviews and consortium discussions, served as a theoretical foundation for identifying and prioritizing stakeholder needs. The current deliverable builds on this categorization with empirical insights from stakeholder interviews. Overall, our findings align with the initial categorization but also reveal important nuances.

First, while patients were clearly positioned as a central group of end users, the interviews reveal that they are often **under-informed and under-involved** in practice. Patients reported not knowing why certain questionnaires were administered, how their data would be used, or whether their input made any difference, which was also acknowledged by clinicians and implementation experts. This highlights a critical gap between theoretical prioritization and real-world engagement. Addressing this gap will require designing features that **actively prioritize and involve patients** not only as data contributors but as engaged users who can understand and benefit from the outcomes.

Second, although technology providers were already classified as end users in D6.4, our findings confirm that they play a **critical role** in enabling the platform's functionality. Their insights on interoperability, infrastructure variability, and implementation barriers stress the importance of **involving them early and consistently** in the design and implementation of the platform. They are not merely support actors but crucial enablers of feasibility and scalability.

Finally, interviews revealed a **strong need for policy-level support** to address systemic barriers such as data privacy regulations, cross-institutional data sharing, and international standards. Stakeholders repeatedly emphasized that many of the wishes for the IMPROVE platform - such as meaningful benchmarking, seamless integration, and inter-organizational communication - are only achievable with **appropriate regulatory frameworks** in place. This highlights the relevance of maintaining dialogue with the "to-be-informed" stakeholders identified in D6.4, especially policymakers and funding bodies, as their facilitation will be essential for real-world impact.

4.2. Conclusion and next steps

The present deliverable offers practical implications for the next steps of WP6, particularly the upcoming co-creation and assessment activities. Building on the insights gathered, several implications emerge for the design, functionality, and evaluation of the IMPROVE platform.

First, the findings point to the importance of grounding platform design in realistic, day-to-day clinical workflow. Requirements related to clarity of data collection and presentation, and clear alignment with clinical responsibilities should be directly translated into user perspectives and design features. This means not only technical integration but also usability across different roles and (digital) literacy levels.

Second, the call for better communication and engagement features suggests that the platform should not simply function as a data pipeline but support two-way interaction. Findings from this deliverable

point to the limited involvement of patients in how their data is interpreted and used – highlighting the need to go beyond passive data collection. Empowering patients to see and reflect on their own data, while enabling professionals to engage with PGHD in a structured, time-efficient way, is essential.

Third, recurring references to cross-site collaboration and benchmarking - raised across stakeholder types - highlight the need to include functionalities for data aggregation and comparison, which can support both clinical improvement and research.

These insights will inform the structure and content of the co-creation sessions planned in WP6. Rather than starting from scratch, we now enter these sessions with a set of grounded user needs that can be further refined and iteratively evaluated. The stakeholder needs summarized in this deliverable serve as the foundation for building a platform that is not only technically feasible, but meaningful and actionable in practice.

Moreover, Insights from the stakeholder interviews, including internal reviews from STPUAS, has highlighted the issue of patient underinvolvement in how PGHD is currently used and communicated. In our follow-up activities, WP6 aims to address this by placing greater focus on involving patients as active contributors, not only in designing communication tools but also in defining what "value" in value-based health care means to them. Understanding how patients see value - in terms of outcomes, communication, and support - is essential to aligning digital tools with their needs and expectations. To this end, we will begin with additional in-depth interview studies in the oncology domain, exploring how stakeholder (patients and clinicians) needs and values play out in practice. In addition, we will investigate the potential of generative AI to support communication around PGHD (e.g., PROMs, PREMs, and PPI) (Hunter et al., 2022), for example by generating personalized, accessible narrative feedback of patient-reported data. These upcoming activities will help us further tailor the IMPROVE platform to real-world needs and explore innovative ways to support meaningful dialogue between patients and professionals.

5. References

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6. Appendices

Appendix A contains the interview guides used for data collection. Three versions of the guide were developed: a general version suitable for clinicians, researchers, and policymakers; one specifically tailored for patients; and another one specifically designed for technology providers. They can be found at the following online location: interview guides.

Appendix B contains the Excel spreadsheet used to document detailed interview findings, including participant characteristics, responses to the interview questions, and any additional comments provided by participants. It can be found at the following online location: Data collection sheet.

About IMPROVE

IMPROVE aims to be a dynamic, ready-to-use framework for seamlessly integrating patient-reported information. This adaptable system constantly evolves with the latest evidence, using PGHD and health system data to provide cost-effective solutions for diverse treatment conditions in real settings. The project follows Ontology, Epistemology, and Methodology principles. Ontology defines structures in patient-reported outcomes; Epistemology ensures valid knowledge; Methodology links techniques to outcomes, systematically addressed in its work.

IMPROVE optimizes patient-reported information in real settings, offering a deep understanding of patient behaviors. The project sets up ontology, epistemology, and methodology to minimize the burden on stakeholders cost-effectively. It adopts a scalable, data-driven approach with NLP-driven knowledge extraction. Real World Data is integrated into the Federated Causal Evidence module for comprehensive understanding. Evidence collected enables visualizing attributes affecting patient-reported outcomes through IMPROVE Engagement Factors and Indicators Knowledge Graphs.

IMPROVE's toolkit includes resources for decision-makers, featuring plausible scenarios via the Copenhagen Method. Patient engagement via the MULTI-ACT model ensures sustainable healthcare aligned with patient priorities. This project delivers a modular, open access strategy, providing a trustworthy ecosystem of evidence-based applications. Patient engagement and co-creation scenarios solidify its role in transforming healthcare research and care.

Funding Acknowledgement

This project is supported by the Innovative Health Initiative Joint Undertaking (IHI JU) under grant agreement No. The JU receives support from the European Union's Horizon Europe research and innovation programme and COCIR, EFPIA, EuropaBio, MedTech Europe, Vaccines Europe, and the contributing partners Universidad Politecnica de Madrid (UPM), PredictBy (PBY), Danish Medicine Agency (DKMA), Roche (ROCHE), Institute for Economic Research (IER), Copenhagen Institute for Futures Studies (CIFS), Servei Catala de la Salut (CatSalut), Philips Medical System Nederland BV (PMSN), Heinrich-Heine-Universitaet Duesseldorf (UDUS), Tilburg University (TiU), Dedalus (DEDA), Fondazione Italiana Sclerosi Multipla Fism Onlus (FISM), AReSS Puglia (ARSS), MultiMed (MM)iserundschmidt GmbH (ius), Better (BET), The Netherlands Cancer Institute (NKI), University of Applied Sciences St. Pölten (STPUAS), Eye Hospital, University Medical Centre Ljubljana (EYE), Utrecht University (UU), UDG Alliance (UDGA), Medtronic Iberica SA (MDT), Fundacio Hospital Universitari Vall D'Hebron – Institut de Recerca (VHIR), Splosna Bolnisnica Celje (SBC), ORTOPEDSKA BOLNIŠNICA VALDOLTRA (OBV), ETHNIKO KENTRO EREVNAS KAI TECHNOLOGIKIS ANAPTYXIS (CERTH).

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