

IMPROVE

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

D6.2 – Fit assessment between stakeholders and framework

Version 0.2

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Document Control Sheet

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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This deliverable contains original unpublished work except where clearly indicated otherwise.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. Generative AI (Chat GPT 5.2) has been used for phrasing and structure.

Legal Disclaimer

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Executive summary

This deliverable presents the methodology and results of Task 6.3, which evaluates the alignment, or “fit”, between stakeholder needs and the tools, methods, and models developed within the IMPROVE project. The assessment combines a quantitative survey using a matrix-based approach with a qualitative co-creation workshop, ensuring both analytical rigor and participatory validation. Stakeholder needs identified in Deliverable 6.1 were operationalized into survey items and rated on a six-point Likert scale, producing traffic-light classifications (green/yellow/red) for each tool. Results indicate strong fit for infrastructure components (e.g., storage, interoperability, data quality) and patient-facing telehealth tools, while areas such as implementation readiness and local configuration require further attention. The follow-up focus group highlighted visibility gaps between front-end and backend tools and recommended multi-level evaluation and improved communication strategies. Findings inform actionable recommendations for tool refinement, integration, and governance, supporting IMPROVE’s goal of creating a scalable, stakeholder-centered ecosystem for patient-generated health data. These insights will feed into Deliverable 6.3 and Task 6.4 and the final synthesis of WP6.

Keywords: Fit-Assessment, Tools, stakeholder needs, co-creation, participatory design, needs assessment

Abbreviations and Acronyms

| | |
|-----------------------|---|
| AI | Artificial Intelligence |
| AQL | Archetype Query Language |
| API | Application Programming Interface |
| ASReview | Active learning for Systematic Reviews |
| AWS | Amazon Web Services |
| CKP | Clinical Knowledge Platform |
| EHR | Electronic Health Record |
| ETL | Extract–Transform–Load |
| FHIR | Fast Healthcare Interoperability Resources |
| GDPR | General Data Protection Regulation |
| HL7 | Health Level Seven |
| IQR | Interquartile Range |
| JSON | JavaScript Object Notation |
| KPI | Key Performance Indicator |
| Likert (scale) | Ordinal rating scale for subjective assessments |
| MVP | Minimum Viable Product |
| PGHD | Patient-Generated Health Data |
| PROM | Patient-Reported Outcome Measure |
| SD | Standard Deviation |
| SME | Small and Medium-sized Enterprise |
| UU | Utrecht University |
| UPM | Universidad Politécnica de Madrid |
| WP | Work Package |

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1. Introduction

This deliverable sets out the methodology and results framework of Task 6.3, which assesses the alignment (“fit”) between stakeholder needs and the tools, methods, and models developed within the IMPROVE project. Fit is not treated as a purely technical matchmaking exercise; instead, it is approached as an iterative, participatory evaluation and co-design process. Building on the consolidated needs from D6.1, these needs are operationalised into stakeholder-specific survey items for each tool, quantitatively rated on a six-point Likert scale (1–6, without a neutral midpoint), translated into a traffic-light classification (red/yellow/green), and then jointly interpreted in a co-creation workshop with WP2, WP3, and WP6 to agree targeted improvements.

Task 6.3 pursues three complementary aims. First, it analyses the extent of alignment between existing tools and real stakeholder needs spanning clinicians and implementation experts, patients and caregivers, technology providers, researchers and public-health experts, and policymakers or payors. Second, it derives evidence-based recommendations through participatory validation, using variance-aware, item-level results to focus discussion on gaps and priorities for action. Third, it enhances stakeholder legitimacy and acceptance of project outputs by making the process transparent, role-sensitive, and responsive to operational realities.

The assessment covers both commercial and non-commercial/research components contributed by partners across WP2 and WP3. Each tool is introduced with the same short description used in the LimeSurvey instrument (online survey tool) to ensure a shared understanding of purpose, functionality, target users, and status. For each tool, stakeholder-specific needs from D6.1 are mapped to concrete survey items and aggregated as fit matrices reporting central tendency (median, mean) and dispersion (IQR, SD), accompanied by the traffic-light classification. Items with high dispersion (e.g., $IQR \geq 2$) are flagged for discussion, enabling the workshop to explain misfits (usability, interoperability, workflow, or governance issues) and to agree actionable remediation steps with accountable owners.

All activities used in this deliverable (online survey via LimeSurvey and the co-creation workshop) adhere to Horizon Europe ethics and GDPR: informed consent is obtained on the first survey page; participation is voluntary; no directly identifying data are collected; and outputs are reported in aggregated form within secure institutional environments.

Section 2 details the methodological approach. Section 3 summarises stakeholder needs from D6.1 as the analytical backbone for assessing fit. Section 4 presents the survey-based fit matrices (one figure/table per tool) with traffic-light visualisation. Section 6 integrates the quantitative and workshop insights into tool-wise interpretations and actionable recommendations for refinement and scale-up within the IMPROVE framework.

2. Methodological Approach

2.1. Overall methodological concept

This methodological concept outlines a stepwise, mixed-methods approach to assess and enhance the alignment between stakeholder needs and the tools, methods, and platforms available within IMPROVE. The approach combines quantitative evaluation and qualitative co-creation to achieve both analytical precision and actionable outcomes. The steps are described below.

a) Compilation of Stakeholder Needs (from D6.1)

The purpose of this step was to establish a validated baseline of what different stakeholder groups require in terms of functionalities, usability, integration, and outcomes.

The Needs were extracted and consolidated from Deliverable 6.1, which synthesised insights across healthcare professionals, patients, technical partners, researchers, implementation experts, and policymakers. These needs were then grouped into overarching need categories, including interoperability and integration, usability and accessibility, data quality and security, workflow and process fit, evidence and transparency, scalability and sustainability, communication and collaboration, and empowerment and engagement (where applicable).

This consolidated framework served as the conceptual foundation for assessing how well each IMPROVE tool meets its intended user requirements.

b) Tool Inventory (WP2 & WP3 Catalogue)

The purpose of this step was to provide a structured overview of the tools developed or deployed within WP2 and WP3, including their features, intended use cases, and technical specifications.

Together with partners from WP2 and WP3, a comprehensive tool catalogue was compiled, covering both commercial and non-commercial components. Each tool was described in terms of its purpose, main functionalities, primary stakeholders, and development status. We requested a list of tools and methods developed and used in the work packages by the involved consortium partners.

This inventory formed the basis for the creation of fit matrices that map each tool's functionalities to specific stakeholder needs. The resulting overview ensured transparency across the consortium regarding how individual tools contribute to the overall IMPROVE ecosystem.

c) Matrix-Based Quantitative Fit Assessment (Survey)

In this step we quantitatively measured the degree of alignment between stakeholder needs and tool capabilities.

For each tool, a fit matrix was developed linking stakeholder-specific needs to the tool's functionalities. Each matrix cell represented a concrete tool \times stakeholder-need relation, which was translated into one or more Likert-scale survey items.

The consortium survey was implemented using LimeSurvey (online survey platform) and distributed to all partners involved in the IMPROVE consortium. Respondents could select multiple stakeholder roles and provide open text about their areas of expertise. Each participant rated the perceived fit of the tools from their perspective using a 6-point Likert scale (1 = Not at all fits ... 6 = Fully fits), deliberately omitting a neutral midpoint to maximise discriminability.

Quantitative analysis was based on median and dispersion measures (interquartile range IQR and standard deviation SD) per cell. To enhance interpretability, results were converted into a traffic-light classification:

1. *Green*: high fit (median ≥ 5)
2. *Yellow*: moderate/partial fit (median = 3–4)
3. *Red*: low fit (median ≤ 2)

Cells with high variance were flagged for further discussion, even when the median indicated a positive fit. The aggregated results of this assessment are presented in Section 4.

d) Qualitative Exploration of Low-Fit Areas (Co-Creation-Workshop)

Within this step of the procedure, the purpose was to interpret low- and medium-fit results, identify root causes, and jointly formulate improvement actions.

Instead of conducting individual interviews, an online co-creation workshop was organised via Microsoft Teams on the 21st of November 2025 with representatives from WP2, WP3, and WP6. The session focused on all *red* and *yellow* areas of the traffic light system of the fit matrices derived from the quantitative online survey part (step c). Participants discussed potential causes of low alignment, such as usability challenges, interoperability constraints, workflow mismatches, or governance issues.

Through guided group discussions, the workshop produced shared explanations and feasible improvement measures. The ideas for improvement were recorded in a document, specifying responsible partners and follow-up actions.

This qualitative phase thus complemented the quantitative survey by adding interpretative depth and practical relevance.

e) Integration and Synthesis

In this step, we combined insights from the quantitative fit assessment and the qualitative workshop into a unified understanding of tool-stakeholder alignment.

Results from both phases were triangulated to produce an integrated interpretation per tool and a set of cross-cutting observations. The synthesis identifies areas of strong alignment, partial gaps, and structural challenges common to multiple tools.

Based on these insights, targeted recommendations were derived to guide further development, integration, and stakeholder engagement. The consolidated findings are summarised in Sections 6.1–6.3.

2.2. Survey Design and Data Collection

The LimeSurvey instrument included all tools developed or used within the project, covering both commercial and non-commercial solutions. Each tool was introduced with a concise description to ensure shared understanding among participants. Respondents rated the fit of each tool relative to their stakeholder needs using the six-point Likert scale described above.

The stakeholder groups included healthcare professionals, patients, researchers, technical partners, implementation experts, and policymakers.

The survey dataset, therefore, captures multiple perspectives on the usability, interoperability, and sustainability of the IMPROVE ecosystem.

Data handling followed Horizon Europe standards. Participation was voluntary, informed consent was obtained on the first survey page, and all data were processed anonymously. No personally identifying information was collected. Aggregated results were stored and analysed within a secure institutional environment.

2.3. Tools included in the LimeSurvey Fit Assessment

In the following subsections, tools are listed by commercial status and partner institution, while their functional role corresponds to one or more of the three categories outlined above.

To clarify the rationale behind the selection of tools included in the LimeSurvey fit assessment, the tools were conceptually grouped into three functional categories reflecting their role in the IMPROVE research design rather than their technical similarity.

First, the assessment includes patient- and clinician-facing tools for PGHD collection and use, i.e. tools that directly interact with patients or healthcare professionals and actively generate or display patient-generated health data (PGHD). These tools are central to evaluating perceived usefulness, usability, empowerment, and workflow fit from clinical and patient perspectives.

Second, the assessment covers core infrastructure and integration services that enable secure storage, transformation, interoperability, and scalable operation of PGHD across the IMPROVE ecosystem. Although these tools are largely invisible to end-users, they are essential for data quality, governance, and system sustainability, and therefore need to be assessed from a technical and implementation perspective.

Third, the survey includes project-specific methods, formats, and research tools that were developed or adapted within IMPROVE to support evidence generation, analysis, and evaluation workflows (e.g. screening tools and participatory formats). These tools primarily address the needs of researchers, methodologists, and decision-makers rather than clinical end-users.

All three categories were intentionally included in a single fit assessment to capture the full PGHD lifecycle addressed by IMPROVE, from data generation and patient interaction, through backend processing and integration, to evidence synthesis and evaluation. The fit ratings, therefore, do not imply that each tool is expected to meet the needs of all stakeholder groups equally, but rather assess whether each tool adequately fulfils the needs of its primary intended stakeholders within the overall IMPROVE ecosystem.

To capture a comprehensive picture of how well the IMPROVE ecosystem meets stakeholder needs, the LimeSurvey instrument included all tools developed, adapted, or deployed within the project.

The following subsections reproduce the tool descriptions that were presented to participants in the survey. These short summaries ensured a common understanding of each tool's purpose, key functionalities, target users, and development status.

2.3.1. Commercial Tools

Better

Better Platform

The Better Platform provides a digital health environment to store structured clinical and patient data using the openEHR format. It includes an openEHR Clinical Data Repository, an Archetype Designer, an AQL (archetype query language) editor, and an ETL (Extract–Transform–Load) tool for data transfer to other systems. Within IMPROVE, it allows integration and data exchange with consortium partners through APIs or ETL connections. The platform visualization can be found in Graphic 1-4.

Main stakeholders: clinicians, healthcare providers

Development status: Ready-made product; requires deployment and integration with local partners.

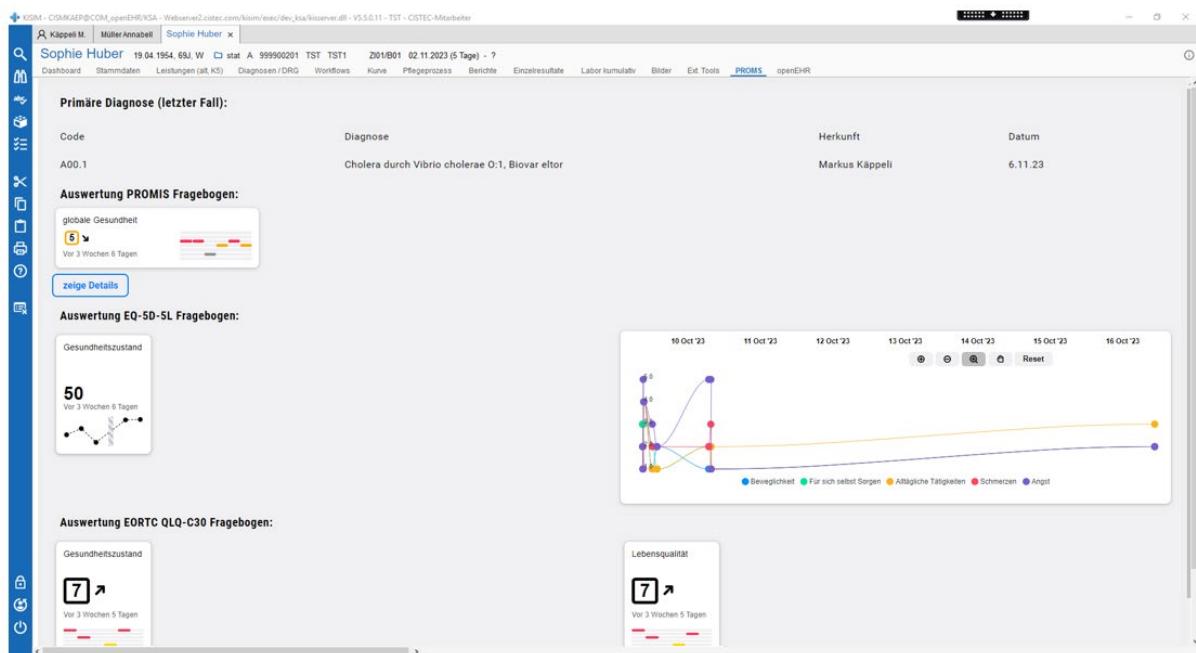
Better PROM Framework

The Better PROM Framework offers a structured solution for building and configuring patient-reported outcome measures (PROMs) on top of the Better Platform. It enables low-code PROM creation, definition of protocols for PROM distribution, individual PROM entry and tracking, and patient dashboards for visual feedback.

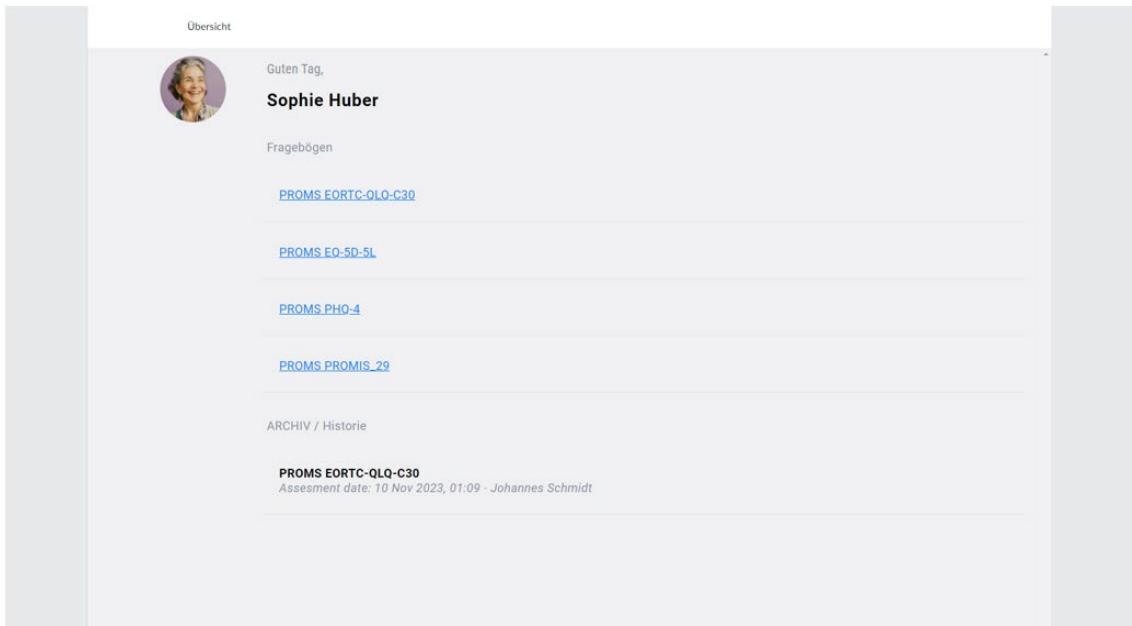
Main stakeholders: UDUS.

Development status: Ready-made product; requires configuration and adaptation to local clinical contexts.

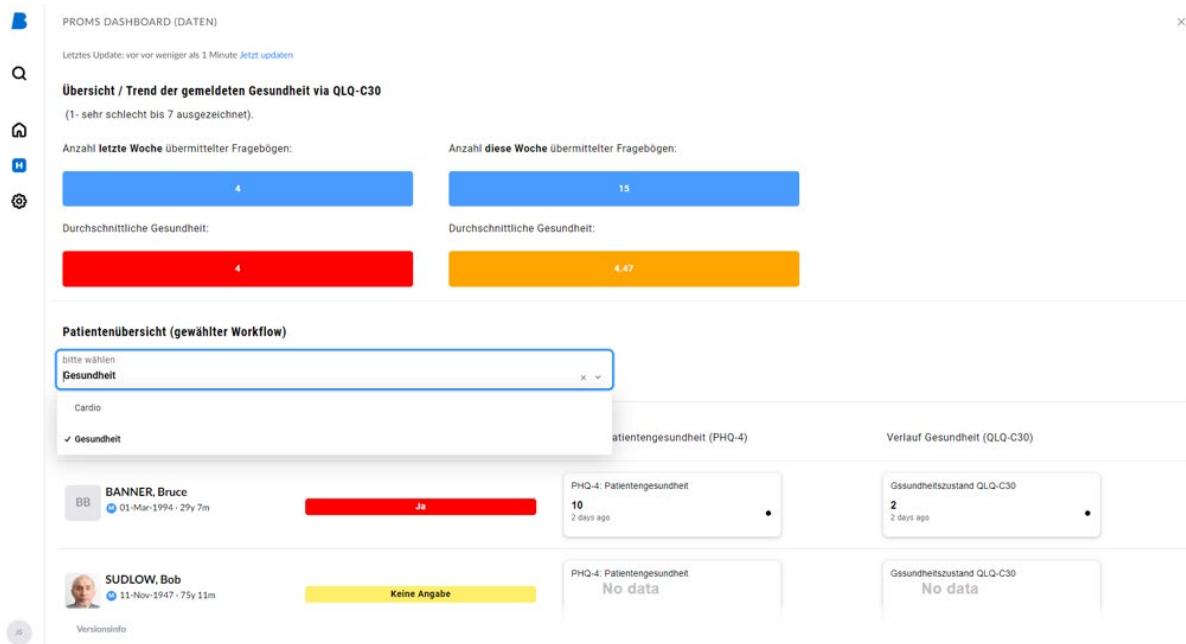
Graphic 1 Better Platform Questionnaire Section



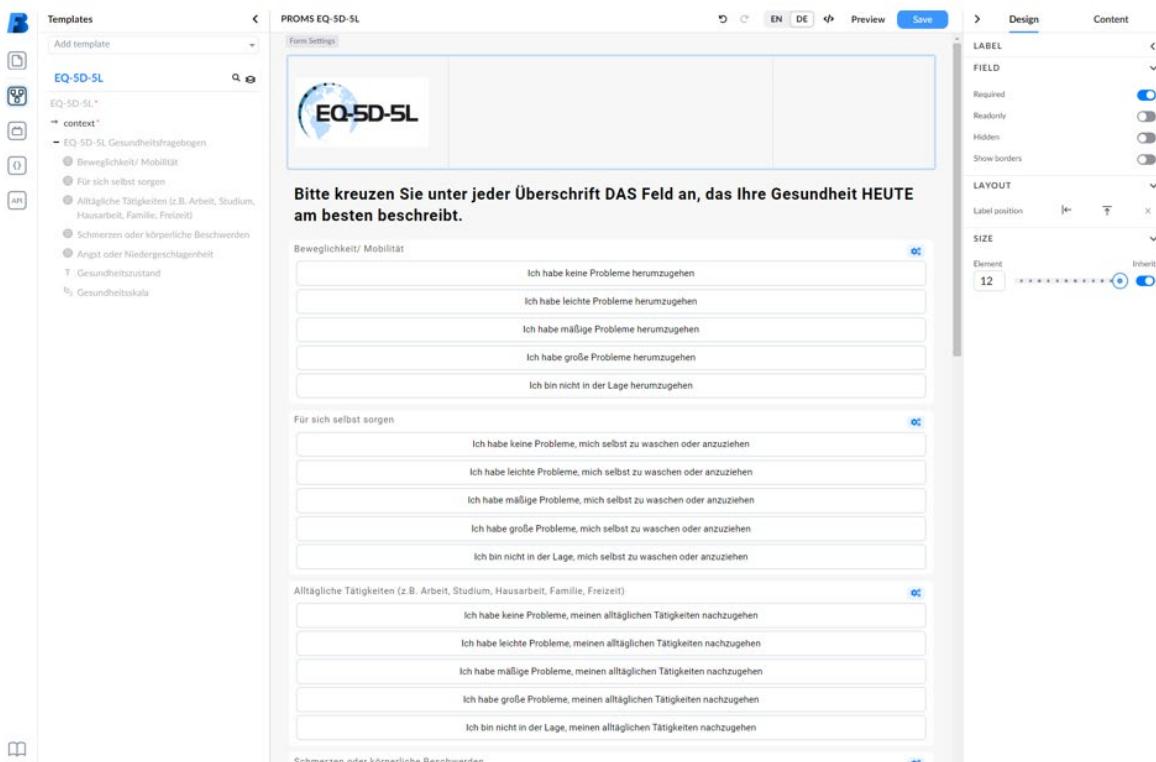
Graphic 2 Better Platform Patient Profile



Graphic 3 Better Platform Dashboard



Graphic 4 Better Platform Exemplary Questionnaire



The questionnaire editor shows the following structure:

- Templates:** EQ-5D-5L (selected), EQ-5D-5L*, context*.
- PROMS EQ-5D-5L:**
 - Form Settings:** EN, DE, Preview, Save.
 - Header:** Bitte kreuzen Sie unter jeder Überschrift DAS Feld an, das Ihre Gesundheit HEUTE am besten beschreibt.
 - Sections:**
 - Beweglichkeit/ Mobilität:** Ich habe keine Probleme herumzugehen, Ich habe leichte Probleme herumzugehen, Ich habe mäßige Probleme herumzugehen, Ich habe große Probleme herumzugehen, Ich bin nicht in der Lage herumzugehen.
 - Für sich selbst sorgen:** Ich habe keine Probleme, mich selbst zu waschen oder anzuziehen, Ich habe leichte Probleme, mich selbst zu waschen oder anzuziehen, Ich habe mäßige Probleme, mich selbst zu waschen oder anzuziehen, Ich habe große Probleme, mich selbst zu waschen oder anzuziehen, Ich bin nicht in der Lage, mich selbst zu waschen oder anzuziehen.
 - Alltägliche Tätigkeiten (z. B. Arbeit, Studium, Hausarbeit, Familie, Freizeit):** Ich habe keine Probleme, meinen alltäglichen Tätigkeiten nachzugehen, Ich habe leichte Probleme, meinen alltäglichen Tätigkeiten nachzugehen, Ich habe mäßige Probleme, meinen alltäglichen Tätigkeiten nachzugehen, Ich habe große Probleme, meinen alltäglichen Tätigkeiten nachzugehen, Ich bin nicht in der Lage, meinen alltäglichen Tätigkeiten nachzugehen.
 - Notes:** Schmerzen oder körperliche Beschwerden.
- Design and Content:** Shows settings for labels, fields, required status, and layout.

Dedalus

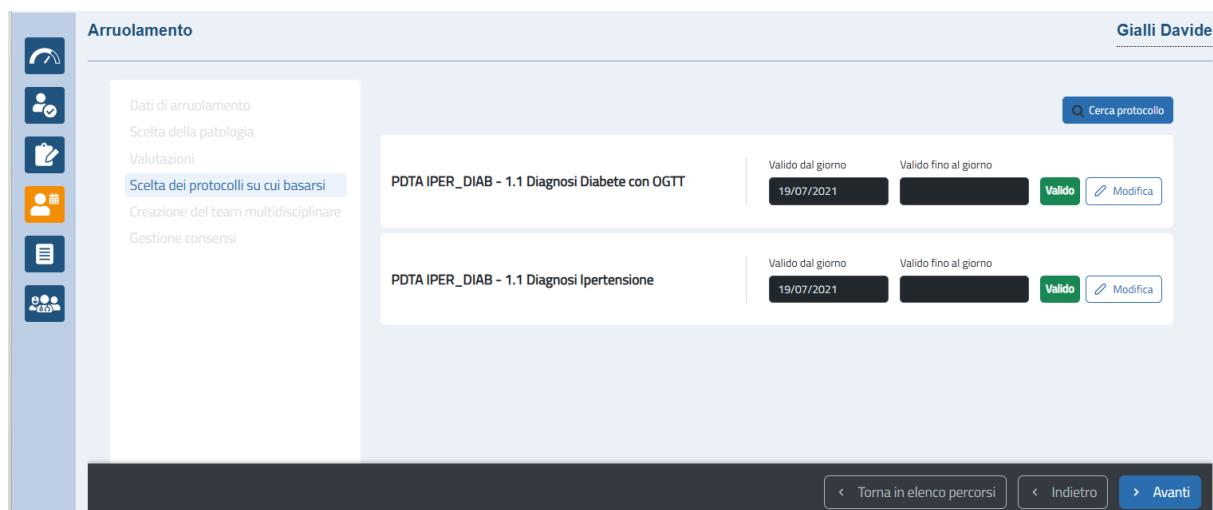
Corehealth Platform

A telemedicine platform for chronic-care management that connects patients, specialists, practitioners, and telemonitoring units. It supports remote patient monitoring, secure communication, and process digitalisation to improve coordination and continuity of care. The platform visualization can be found in Graphic 5-7.

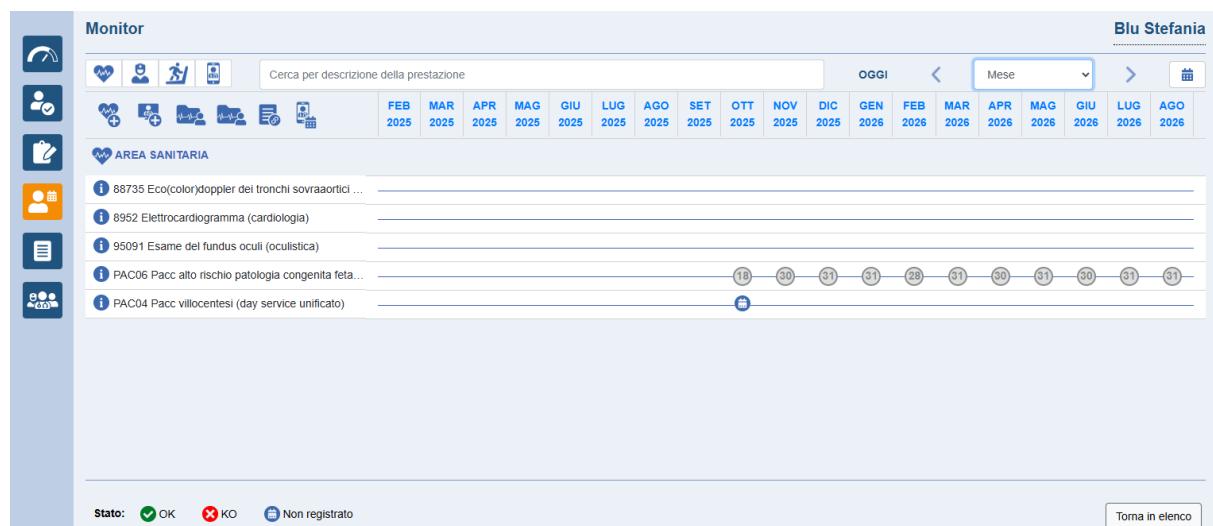
Main stakeholders: Patients, healthcare professionals, system administrators.

Development status: Commercial product integrated within the Dedalus ecosystem.

Graphic 5 Corehealth Platform Intake Section

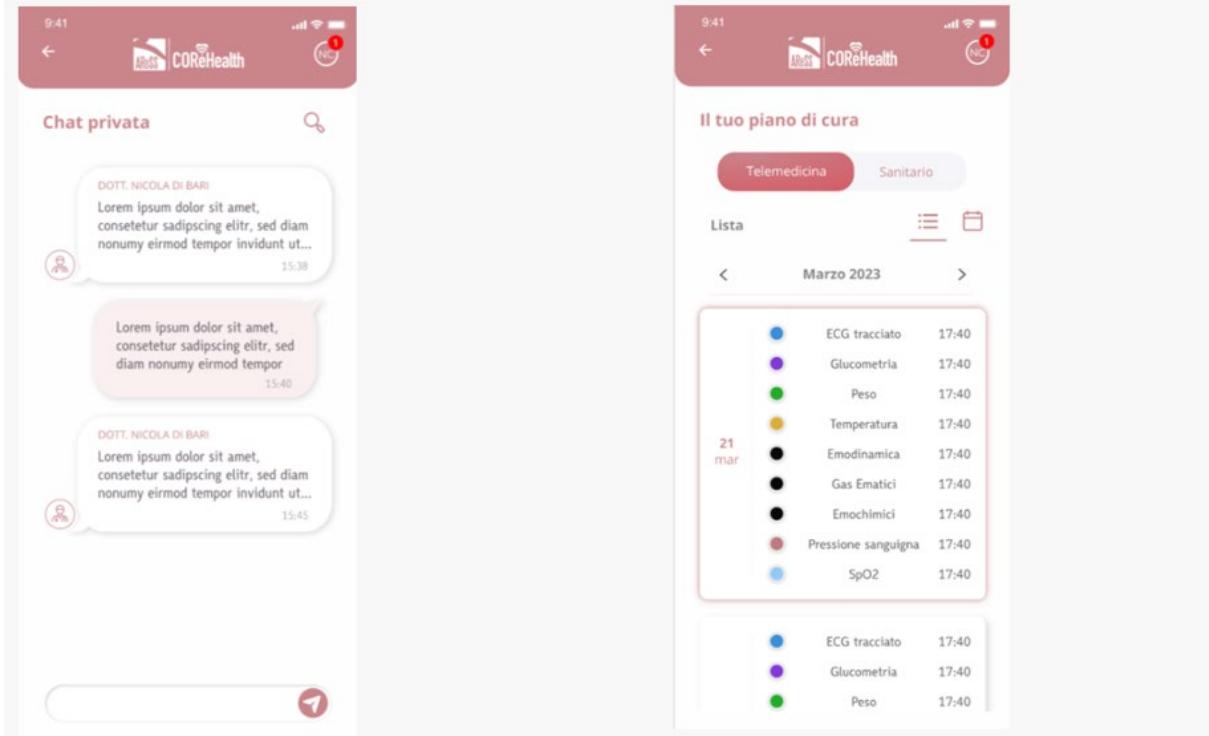


Graphic 6 Corehealth Platform Planning Section



Graphic 7 Corehealth Platform User interface (mobile app) Questionnaire Collection & Telemonitoring

User interface (mobile app) - Questionnaire Collection User interface (mobile app) - Telemonitoring



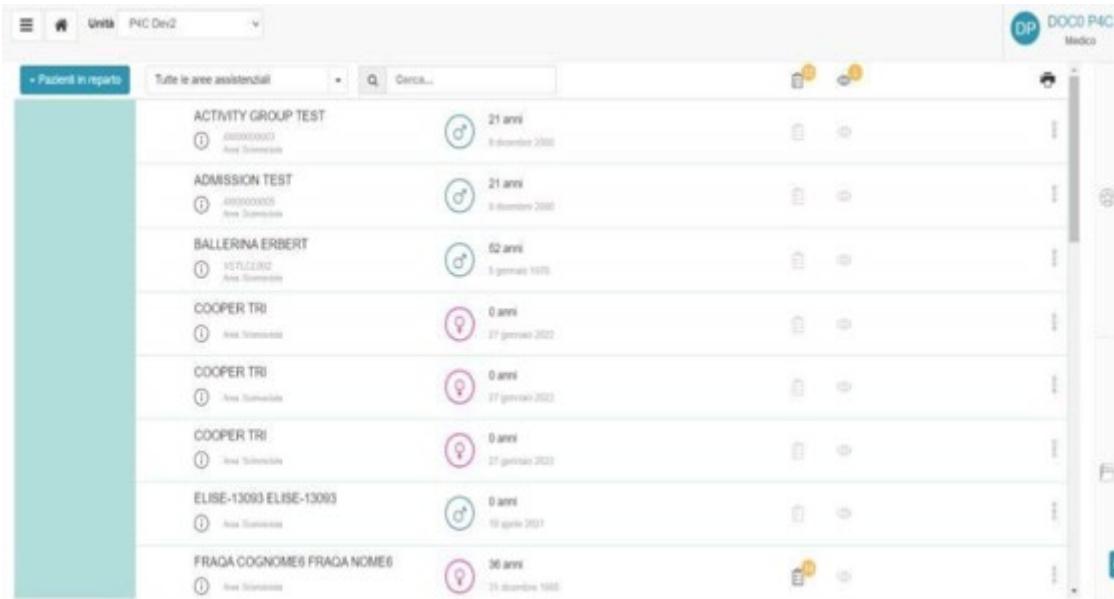
4C (EHR System)

A configurable electronic health-record system that supports structured data entry, documentation, and integration with telemedicine solutions. It enhances clinical data quality, supports interoperability, and streamlines clinical workflows. The platform visualization can be found in Graphic 8-10.

Main stakeholders: Clinicians, FISM partner.

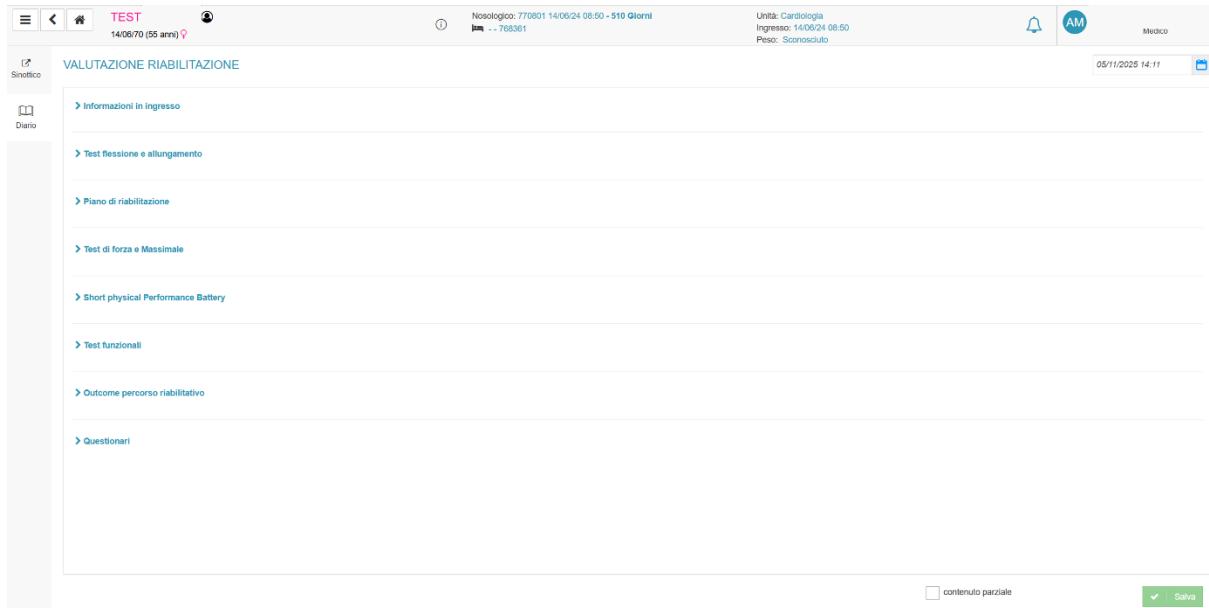
Development status: Commercial solution in active use within IMPROVE.

Graphic 8 4C Patient List Page



| Patienti in reparto | | Nome | Età | Giorno |
|----------------------------|------------|---------|------------------|--------|
| ACTIVITY GROUP TEST | 4000000003 | 21 anni | 01 dicembre 2020 | |
| ADMISSION TEST | 4000000005 | 21 anni | 01 dicembre 2020 | |
| BALLERINA ERBERT | 4000000002 | 62 anni | 01 gennaio 1959 | |
| COOPER TRI | 4000000004 | 0 anni | 27 gennaio 2023 | |
| COOPER TRI | 4000000006 | 0 anni | 27 gennaio 2023 | |
| COOPER TRI | 4000000008 | 0 anni | 27 gennaio 2023 | |
| ELISE-13093 ELISE-13093 | 4000000009 | 0 anni | 19 aprile 2021 | |
| FRAQA COGNOMES FRAQA NOME6 | 4000000010 | 36 anni | 21 dicembre 1985 | |

Graphic 9 Assessment List



TEST
14/05/70 (55 anni) ♀

Nostologico: 770801 14/06/24 08:50 - 510 Giorni
Unità: Cardiologia
Ingresso: 14/06/24 08:50
Peso: Sconosciuto

05/11/2025 14:11

VALUTAZIONE RIABILITAZIONE

- Informazioni in ingresso
- Test flessione e allungamento
- Piano di riabilitazione
- Test di forza e Massimale
- Short physical Performance Battery
- Test funzionali
- Outcome percorso riabilitativo
- Questionari

contenuto parziale

Salva

Graphic 10 Questionnaire Details

Picasso

A data-transformation and interoperability component that enables exchange and harmonisation of information across different systems. It normalises heterogeneous datasets and ensures consistent data exchange between Dedalus and other project tools.

Main stakeholders: System integrators, software engineers.

Development status: Commercial solution deployed within Dedalus architecture.

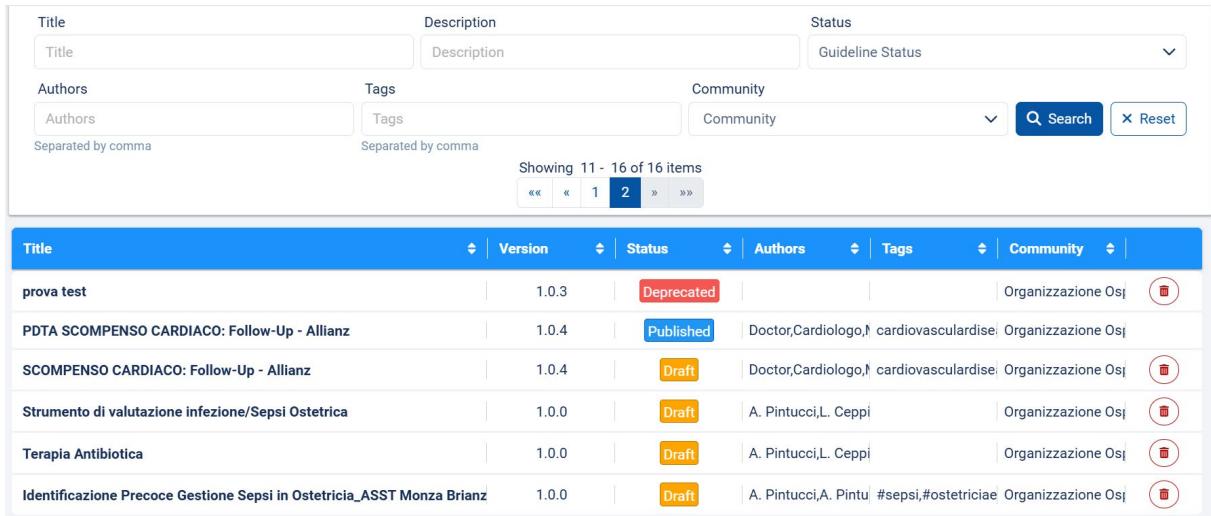
CKP (Clinical Knowledge Platform)

A platform for defining, maintaining, and sharing standardised clinical pathways and guidelines. CKP supports evidence-based workflow design and ensures alignment of clinical processes across institutions. The platform visualization can be found in Graphic 11-14.

Main stakeholders: Clinical informatics experts, healthcare professionals.

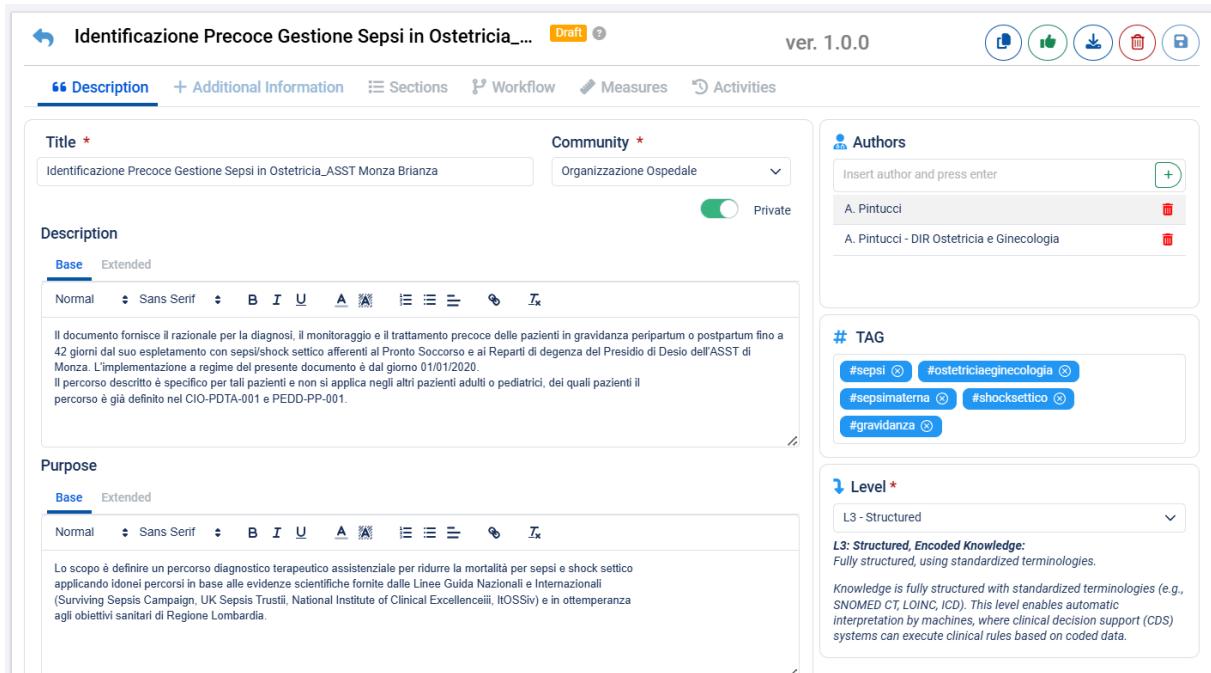
Development status: Commercial tool actively used in clinical and R&D settings.

Graphic 11 CKP Dashboard: showing the list of all formalized guidelines or best practices, along with their progress status



| Title | Version | Status | Authors | Tags | Community |
|--|---------|------------|--------------------------|------------------------|-------------------------|
| prova test | 1.0.3 | Deprecated | | | Organizzazione Ospedale |
| PDTA SCOMPENSO CARDIACO: Follow-Up - Allianz | 1.0.4 | Published | Doctor, Cardiologo, N | cardiovascular disease | Organizzazione Ospedale |
| SCOMPENSO CARDIACO: Follow-Up - Allianz | 1.0.4 | Draft | Doctor, Cardiologo, N | cardiovascular disease | Organizzazione Ospedale |
| Strumento di valutazione infezione/Sepsis Ostetrica | 1.0.0 | Draft | A. Pintucci, L. Ceppi | | Organizzazione Ospedale |
| Terapia Antibiotica | 1.0.0 | Draft | A. Pintucci, L. Ceppi | | Organizzazione Ospedale |
| Identificazione Precoce Gestione Sepsis in Ostetricia_ASST Monza Brianza | 1.0.0 | Draft | A. Pintucci, A. Pintucci | #sepsi, #ostetricia | Organizzazione Ospedale |

Graphic 12 CKP Description: containing the description of each guideline



Identificazione Precoce Gestione Sepsis in Ostetricia... Draft ver. 1.0.0

Description **Additional Information** **Sections** **Workflow** **Measures** **Activities**

Title * Identificazione Precoce Gestione Sepsis in Ostetricia_ASST Monza Brianza **Community *** Organizzazione Ospedale **Private**

Description **Base** **Extended**

Il documento fornisce il ragionale per la diagnosi, il monitoraggio e il trattamento precoce delle pazienti in gravidanza peripartum o postpartum fino a 42 giorni dal suo esploramento con sepsi/shock settico afferenti al Pronto Soccorso e ai Reparti di degenza del Presidio di Desio dell'ASST di Monza. L'implementazione a regime del presente documento è dal giorno 01/01/2020. Il percorso descritto è specifico per tali pazienti e non si applica negli altri pazienti adulti o pediatrici, dei quali pazienti il percorso è già definito nel CIO-PDTA-001 e PEDD-PP-001.

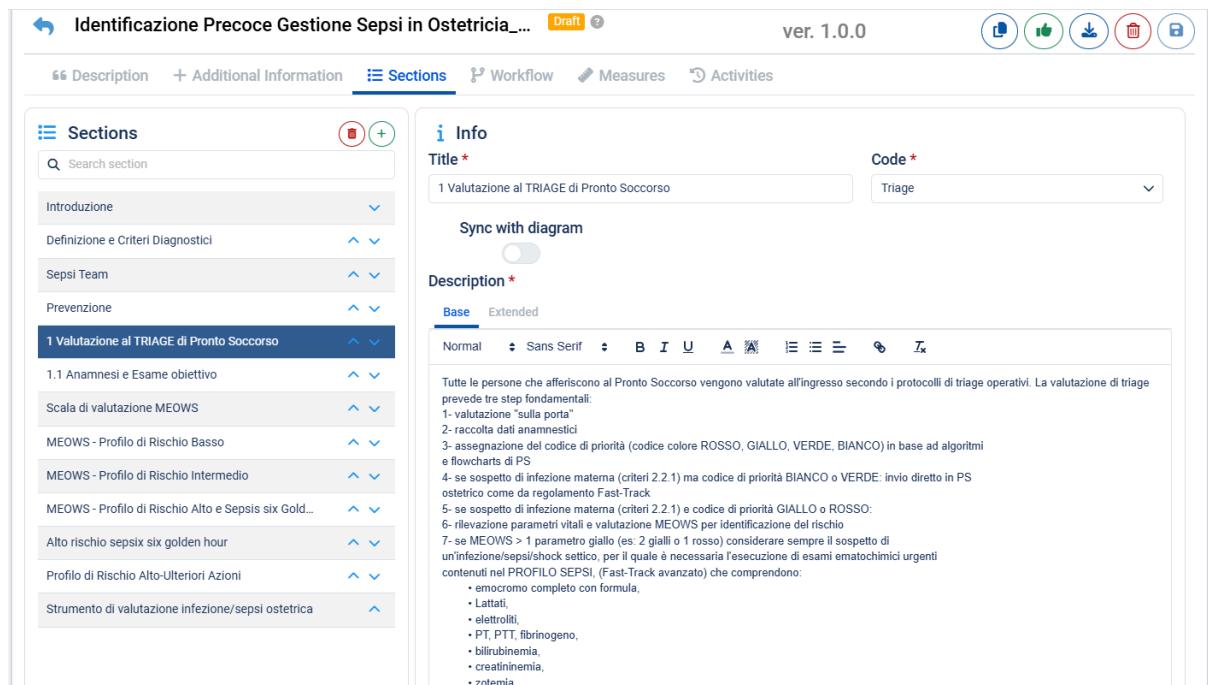
Purpose **Base** **Extended**

Lo scopo è definire un percorso diagnostico terapeutico assistenziale per ridurre la mortalità per sepsi e shock settico applicando idonei percorsi in base alle evidenze scientifiche fornite dalle Linee Guida Nazionali e Internazionali (Surviving Sepsis Campaign, UK Sepsis Trust, National Institute of Clinical Excellence, iTOSSiv) e in ottemperanza agli obiettivi sanitari di Regione Lombardia.

Authors Insert author and press enter **Tags** #sepsi, #ostetricia e ginecologia, #sepsimaterna, #shocksettico, #gravida

Level * L3 - Structured **Level Description** Fully structured, using standardized terminologies. Knowledge is fully structured with standardized terminologies (e.g., SNOMED CT, LOINC, ICD). This level enables automatic interpretation by machines, where clinical decision support (CDS) systems can execute clinical rules based on coded data.

Graphic 13 CKP Sections: where you can find all the different sections of each guideline



Info

Title * 1 Valutazione al TRIAGE di Pronto Soccorso

Code * Triage

Description *

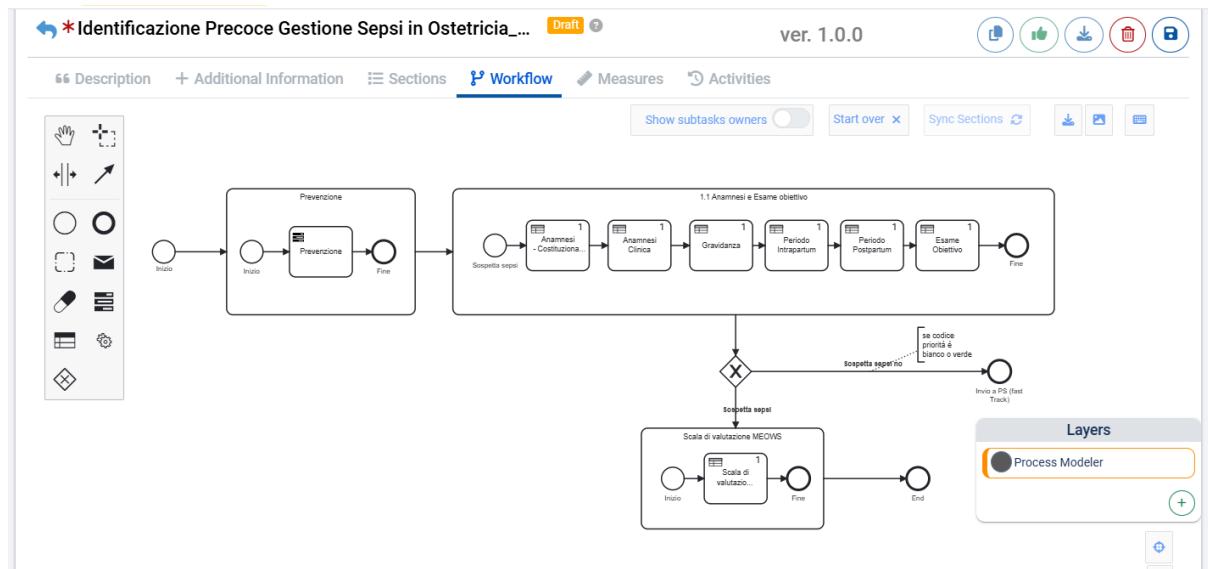
Base Extended

Normal Sans Serif B I U A \mathbb{E} \mathbb{E} \mathbb{E} \mathbb{E} \mathbb{E} \mathbb{E}

Tutte le persone che affluiscono al Pronto Soccorso vengono valutate all'ingresso secondo i protocolli di triage operativi. La valutazione di triage prevede tre step fondamentali:
 1- valutazione "sulla porta"
 2- raccolta dati anamnestici
 3- assegnazione del codice di priorità (codice colore ROSSO, GIALLO, VERDE, BIANCO) in base ad algoritmi e flowcharts di PS
 4- se sospetto di infezione materna (criteri 2.2.1) ma codice di priorità BIANCO o VERDE: invio diretto in PS ostetrico come da regolamento Fast-Track
 5- se sospetto di infezione materna (criteri 2.2.1) e codice di priorità GIALLO o ROSSO:
 6- rilevazione parametri vitali e valutazione MEOWS per identificazione del rischio
 7- se MEOWS > 1 parametru giallo (es: 2 gialli o 1 rosso) considerare sempre il sospetto di un'infezione/sepsi/shock settico, per il quale è necessaria l'esecuzione di esami ematochimici urgenti contenuti nel PROFILO SEPSI, (Fast-Track avanzato) che comprendono:

- emocromo completo con formula,
- Lattati,
- lettolti,
- PT, PTT, fibrinogeno,
- bilirubinemia,
- creatininemia,
- protoemina

Graphic 14 CKP Workflow: representing the final output of the application



AWS Services

A secure and scalable cloud environment used to host, process, and store IMPROVE-related data. It supports reliable computing, deployment of analytics and AI services, and ensures system stability and reproducibility.

Main stakeholders: Technical partners, researchers.

Development status: Commercial cloud service integrated by Dedalus.

Kafka (Event Broker)

An open-source middleware component that enables real-time, event-based data exchange between IMPROVE systems. It ensures reliable message streaming with high throughput and low latency, forming the backbone of the integration architecture.

Main stakeholders: Technical partners.

Development status: Open-source technology maintained by Dedalus for the project.

Medtronic

GetReady

A remote patient-monitoring and engagement platform that allows clinicians to collect, view, and track patient data. It supports follow-up management, communication, and patient empowerment in daily care routines. The platform visualization can be found in Graphic 15.

Main stakeholders: Healthcare professionals, patients, implementation experts.

Development status: Commercial product in pilot integration.

Graphic 15 GetReady Mobile Interfaces



Patient Questionnaire

15:15 Atmás PROMS score post IQ Si

1/6

MOVILIDAD. Indique el número que mejor describe su salud HOY. *

- 1. No tengo problemas para caminar
- 2. Tengo problemas leves para caminar
- 3. Tengo problemas moderados para caminar
- 4. Tengo problemas graves para caminar
- 5. No puedo caminar

SIGUIE... >

Tareas Cronograma Compartir Biblioteca Archivos

Educational Content

15:15 Atmás Mi hospitalización

Esta sección le ofrecerá un breve resumen de lo que ocurrirá durante su estancia en el hospital

Si tiene alguna pregunta, no dude en consultarnos. Le recordamos que a través del canal de intercambio de mensajes puede contactar con su equipo médico.

Antes de la intervención

- Podrá comer alimentos sólidos hasta 24 horas antes de la operación, y no podrá beber líquidos hasta 12 horas

Tareas Cronograma Compartir Biblioteca Archivos

HCP-Patient Contact

15:09 Atmás

Compartir

- Compartir un documento o imagen
- Contactos
- Solicitar una llamada

Mis conversaciones

Estancia en el hospital 28/4/2025 8:38

Se quedara ingresado 24hs

anticoagulacion 28/4/2025 8:26

Debe dejar de tomarla el dia previo a la cirugía

Tareas Cronograma Compartir Biblioteca Archivos

Educational Content Library

15:08 Atmás

Biblioteca

- Mi enfermedad 10/11 documentos leídos
- Mi proceso 17/26 documentos leídos
- Estilo de vida 23/23 documentos leídos
- Información general 3/4 documentos leídos

Tareas Cronograma Compartir Biblioteca Archivos

2.3.2. Non-Commercial Tools

UPM

IMPROVE Storage Service

A data-storage component for long-term and secure persistence of information within the IMPROVE Data Model. It supports HL7® FHIR® standards for clinical data (conditions, observations, diagnostic reports) as well as non-clinical data such as experience or health-economic indicators.

Main stakeholders: Technical partners.

Development status: Research infrastructure developed by UPM; adaptable for project needs.

Excel/CSV IMPROVE Parser

A data-conversion tool that maps Excel or CSV files into the JSON format compatible with the IMPROVE database. It automates data validation and preprocessing, reducing manual workload and ensuring consistency across datasets.

Main stakeholders: Technical partners.

Development status: Functional component maintained by UPM.

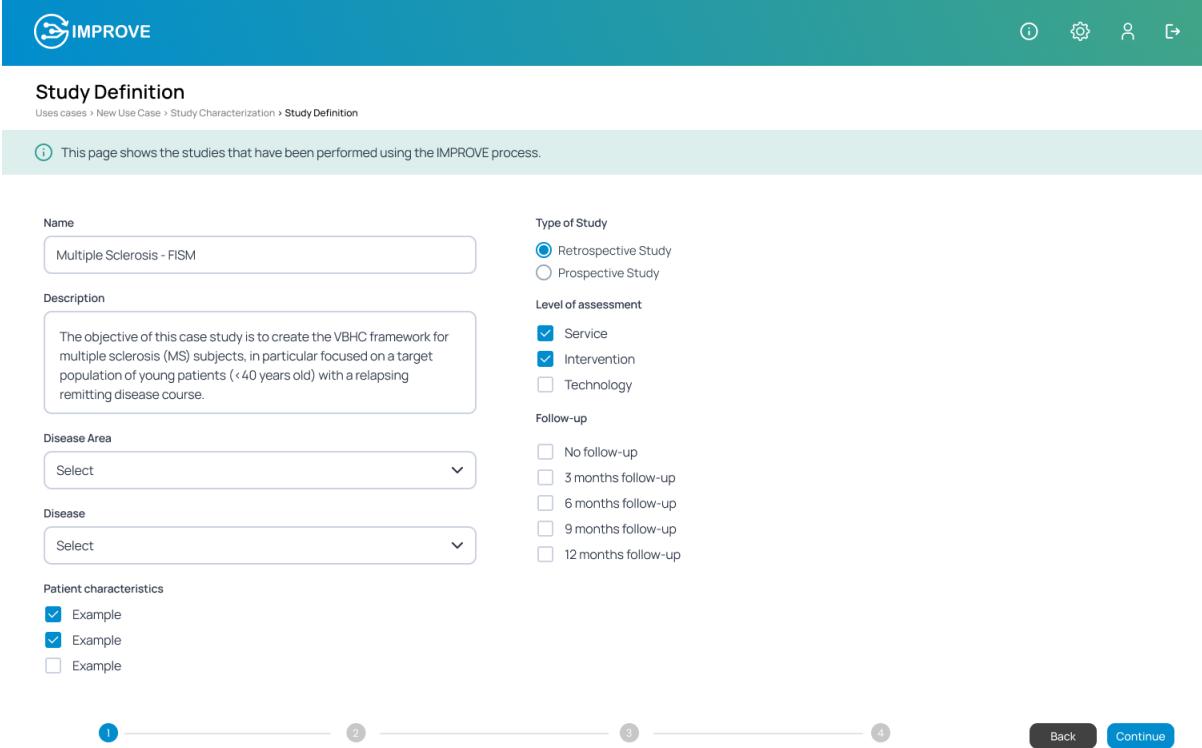
IMPROVE Dashboard

An interactive dashboard that visualises data and progress within IMPROVE. It allows multi-perspective exploration, study tracking, and the creation of configurable visual reports for different stakeholder groups. The dashboard visualization can be found in Graphic 16-18.

Main stakeholders: Researchers, healthcare professionals, technical partners.

Development status: MVP version available; additional visualisation features under development.

Graphic 16 IMPROVE Dashboard Study Definition Section

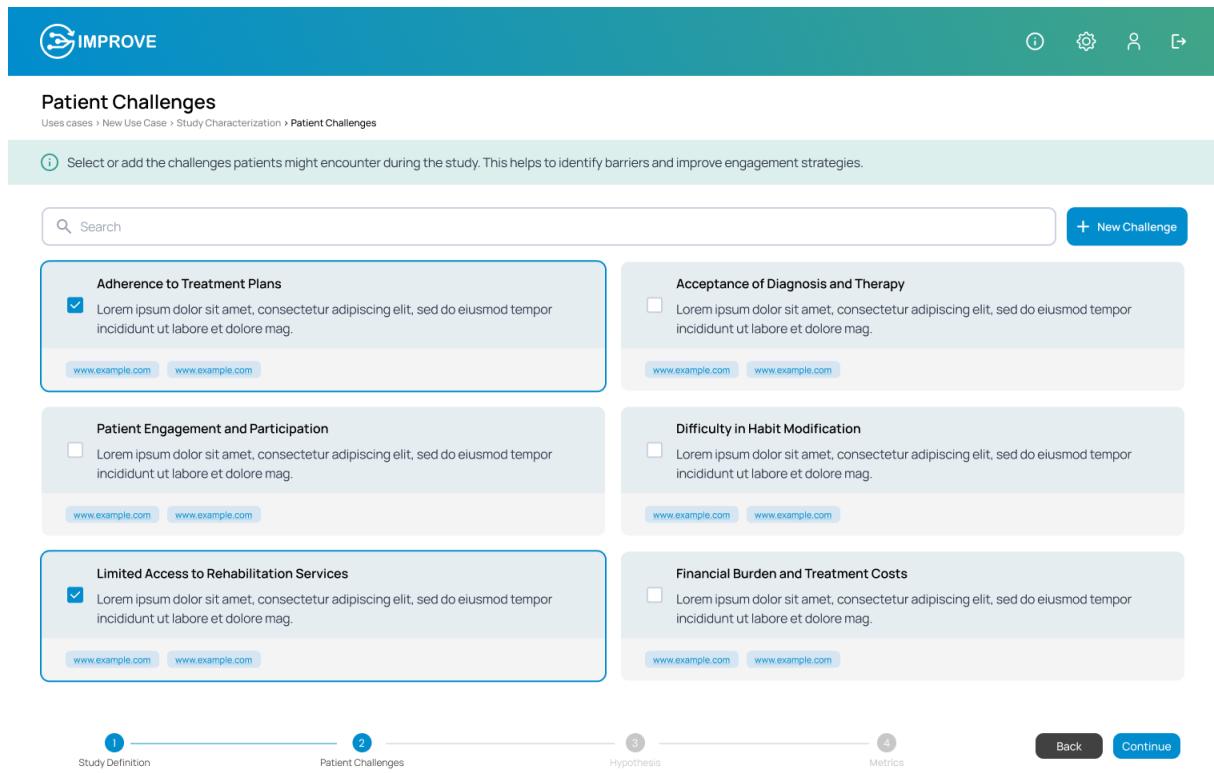


The screenshot shows the 'Study Definition' section of the IMPROVE Dashboard. The top navigation bar includes the IMPROVE logo, a search bar, and user icons for profile and logout. The main content area is titled 'Study Definition' and shows the following fields:

- Name:** Multiple Sclerosis - FISM
- Type of Study:** Retrospective Study (selected)
- Description:** The objective of this case study is to create the VBHC framework for multiple sclerosis (MS) subjects, in particular focused on a target population of young patients (< 40 years old) with a relapsing remitting disease course.
- Level of assessment:**
 - Service (checked)
 - Intervention (checked)
 - Technology (unchecked)
- Follow-up:**
 - No follow-up (unchecked)
 - 3 months follow-up (unchecked)
 - 6 months follow-up (unchecked)
 - 9 months follow-up (unchecked)
 - 12 months follow-up (unchecked)
- Disease Area:** Select
- Disease:** Select
- Patient characteristics:**
 - Example (checked)
 - Example (checked)
 - Example (unchecked)

At the bottom, a progress bar shows the user is on step 1 of 4, with labels: 'Study Definition', 'Patient Challenges', 'Hypothesis', and 'Metrics'. Buttons for 'Back' and 'Continue' are available.

Graphic 17 IMPROVE Dashboard Patient Challenges Section



Patient Challenges

Uses cases > New Use Case > Study Characterization > Patient Challenges

ⓘ Select or add the challenges patients might encounter during the study. This helps to identify barriers and improve engagement strategies.

Search

ⓘ New Challenge

Adherence to Treatment Plans

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

Acceptance of Diagnosis and Therapy

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

Patient Engagement and Participation

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

Difficulty in Habit Modification

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

Limited Access to Rehabilitation Services

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

Financial Burden and Treatment Costs

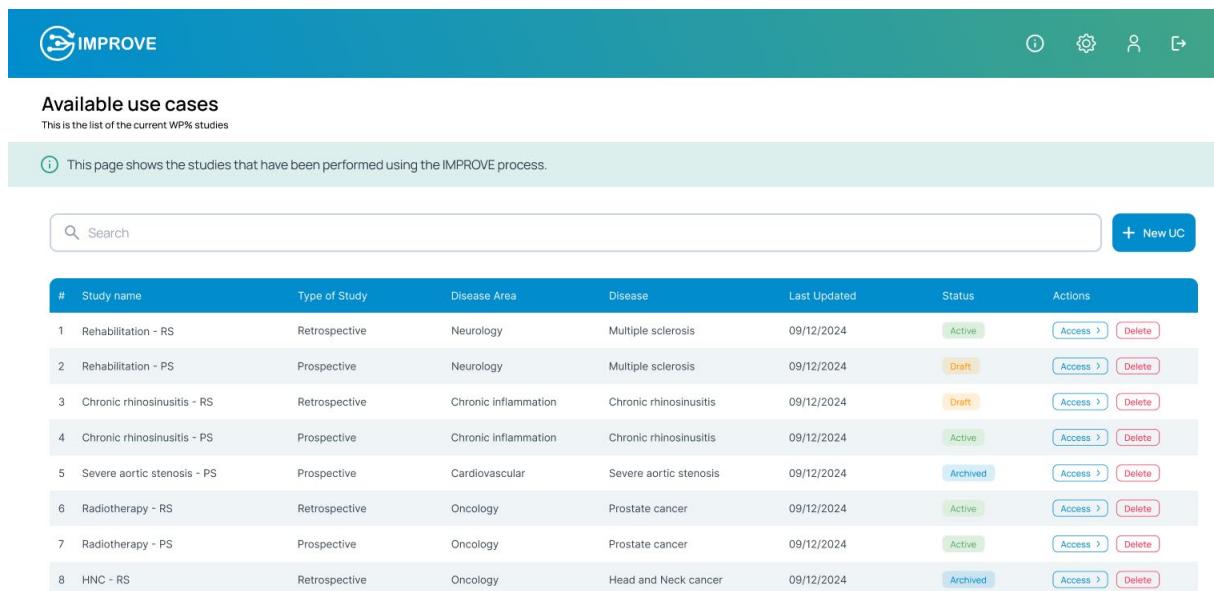
Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore mag.

<www.example.com> <www.example.com>

1 Study Definition
2 Patient Challenges
3 Hypothesis
4 Metrics

Back
Continue

Graphic 18 IMPROVE Dashboard Use Cases Section



Available use cases

This is the list of the current WP% studies

ⓘ This page shows the studies that have been performed using the IMPROVE process.

Search

ⓘ New UC

| # | Study name | Type of Study | Disease Area | Disease | Last Updated | Status | Actions |
|---|-----------------------------|---------------|----------------------|------------------------|--------------|----------|--|
| 1 | Rehabilitation - RS | Retrospective | Neurology | Multiple sclerosis | 09/12/2024 | Active | Access > Delete |
| 2 | Rehabilitation - PS | Prospective | Neurology | Multiple sclerosis | 09/12/2024 | Draft | Access > Delete |
| 3 | Chronic rhinosinusitis - RS | Retrospective | Chronic inflammation | Chronic rhinosinusitis | 09/12/2024 | Draft | Access > Delete |
| 4 | Chronic rhinosinusitis - PS | Prospective | Chronic inflammation | Chronic rhinosinusitis | 09/12/2024 | Active | Access > Delete |
| 5 | Severe aortic stenosis - PS | Prospective | Cardiovascular | Severe aortic stenosis | 09/12/2024 | Archived | Access > Delete |
| 6 | Radiotherapy - RS | Retrospective | Oncology | Prostate cancer | 09/12/2024 | Active | Access > Delete |
| 7 | Radiotherapy - PS | Prospective | Oncology | Prostate cancer | 09/12/2024 | Active | Access > Delete |
| 8 | HNC - RS | Retrospective | Oncology | Head and Neck cancer | 09/12/2024 | Archived | Access > Delete |

Utrecht University (UU)

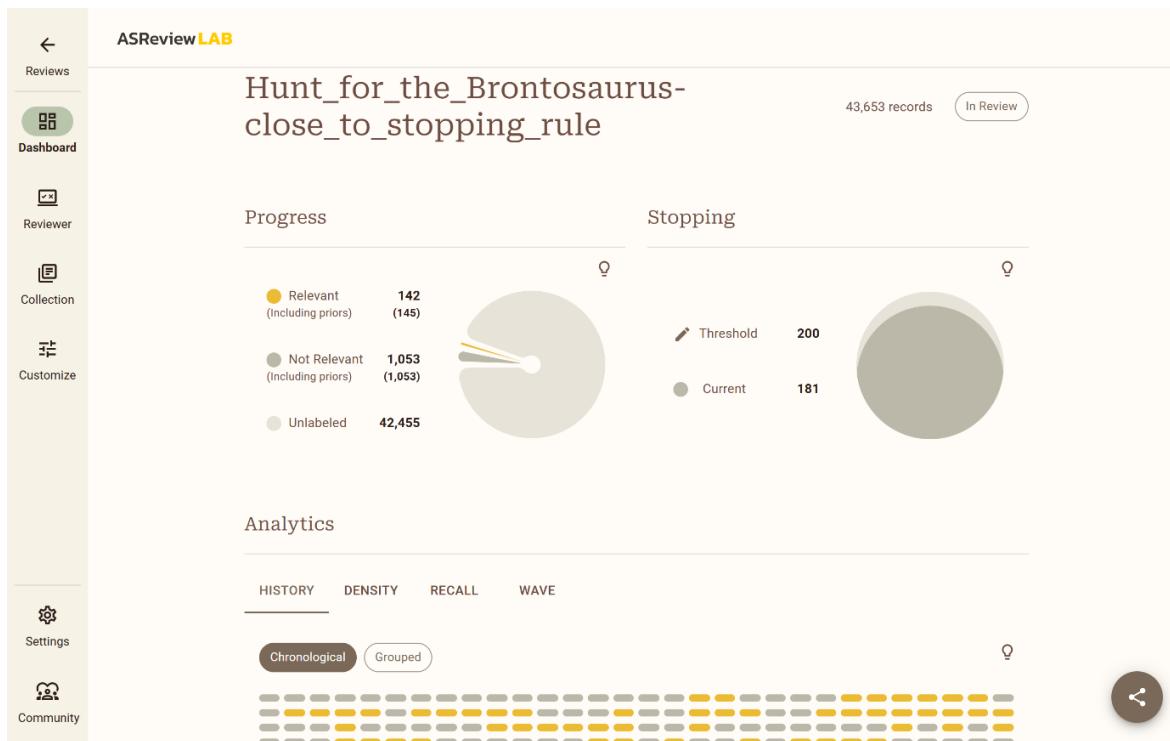
ASReview v2

An open-source, machine-learning tool for semi-automated evidence screening. It uses active learning to prioritise likely relevant studies, combining efficiency with transparency and reproducibility in systematic reviews. The ASReview interface can be seen in Graphic 19.

Main stakeholders: Researchers, clinicians, data scientists.

Development status: Open-source research software maintained by Utrecht University.

Graphic 19 ASReview v2 screening Lab interface



Screenathon

A collaborative screening event format/method developed within the project and therefore regarded as tool. The Screenathon format supports structured and team-based literature screening. It enables consistent decision-making, shared engagement, and transparent documentation of review progress.

Main stakeholders: Consortium members, researchers.

Development status: Participatory methodology developed by Utrecht University.

All these tools and methods constitute the full ecosystem evaluated through the LimeSurvey-based fit assessment. They represent a diverse portfolio of commercial and open-source components addressing complementary dimensions of the IMPROVE framework, from clinical data management and telehealth integration to research analytics and machine-learning-assisted review processes.

3. Summary of Stakeholder Needs & Groups (derived from Deliverable 6.1)

This section distils the needs landscape established in D6.1 into a coherent frame for interpreting the quantitative fit assessment that follows. We synthesised requirements across the consortium and organised them into five thematic clusters that mirror both the data lifecycle and service-delivery logic in IMPROVE: data collection, analysis, integration, communication, and infrastructure. To anchor the discussion in the project's data logic, we reference the patient-generated health data (PGHD) process, spanning capture and transfer through storage, preparation, analysis, interpretation and feedback, under the umbrella of governance and security.

3.1. Overview of identified stakeholder groups

The needs analysis embraces five groups whose roles intersect in distinct ways. Clinicians and implementation experts are concerned with tools that help them deliver care efficiently and safely, and with implementations that fit existing pathways without adding burden. Patients and caregivers sit at the origin and destination of PGHD flows; they need accessible interactions, clear benefits, and control over consent and privacy. Technology providers, including integrators and engineers, carry responsibility for interoperability, data quality, scalability and maintainability across heterogeneous systems. Researchers and public health experts depend on transparent, reproducible data access and on outputs that are valid both at patient and population level. Finally, policymakers and payors look for credible evidence of value, implementation readiness at scale, and robust governance to ensure safety, equity, and compliance.

3.2. Consolidated needs and priorities

Across groups, needs coalesce into five higher-level clusters, which subsume the more granular need categories used in the fit matrices presented below and map directly onto the patient-generated health data (PGHD) lifecycle implemented in IMPROVE. Data collection refers to the structured and low-burden capture of clinical data and PROMs at the point of care and in home settings (e.g., via telehealth solutions such as GetReady or Corehealth), including transparent consent management and GDPR-compliant access control. Analysis concerns the transformation of these raw inputs into clinically and scientifically interpretable indicators and evidence, supported by traceable preprocessing, reproducible analytics, and evidence-generation workflows (e.g., through the IMPROVE Dashboard, ASReview, and Screenathon). Integration covers both the technical coupling of components, via standards such as HL7® FHIR®, openEHR, APIs, and event streaming (e.g., Kafka and Picasso), and their procedural fit with clinical pathways, EHR workflows (4C), and local organisational policies. Communication addresses timely and role-appropriate feedback loops between patients, clinicians, and multidisciplinary teams, including dashboards, telemonitoring views, and pathway-based decision support (CKP). Infrastructure spans the underlying services required for safe and sustainable operation across pilots, including secure storage, scalability, monitoring, reliability, and lifecycle governance (e.g., the IMPROVE Storage Service and AWS), which together enable IMPROVE to function as an integrated ecosystem rather than a collection of isolated tools.

Based on the consolidated findings from Task 6.1 (Assessment of gathered stakeholder requirements), each stakeholder group brings a characteristic emphasis that maps to specific PGHD stages. Clinicians and implementation experts prioritise low-friction documentation and dashboards that surface clinically meaningful indicators, linking the capture and preparation stages to rapid interpretation. They require seamless fit with existing EHRs and telemedicine routines, so that transfer and storage occur without friction and align with established pathways. Decision support must be explainable and auditable, connecting analysis to guideline-conform interpretation, while reliable alerting and follow-up workflows ensure feedback loops are actionable across teams. Minimal training needs and stable performance anchor these requirements in infrastructure concerns.

Patients and caregivers need simple, accessible touchpoints for entering and viewing information at the capture stage, and they expect understandable feedback about status and next steps at the feedback stage. Privacy and consent control are non-negotiable and sit squarely within governance, while burden-aware capture, through reminders, automation or device integration, reduces friction at capture and transfer. Trust is reinforced when communication channels to clinicians are clear and when the provenance of advice is transparent, bridging analysis with everyday interpretation.

For technology providers, the centre of gravity is interoperability by design, open standards such as FHIR or openEHR, stable APIs and event streaming, to ensure robust transfer and integration across components. They require data-quality pipelines with validation and lineage from preparation through analysis, together with scalable, secure deployments that guarantee reliable storage and operation. Maintainable configurations, versioned forms, models and pathways, reduce life-cycle risk, and clearly defined component boundaries and service levels (including monitoring and incident response) support governance and cross-team communication.

Researchers and public health experts require transparent, reproducible datasets with well-defined metadata and access controls, tying storage and preparation to defensible analysis. They value export and reuse for secondary analyses and triangulation, and they need robust outcome indicators with appropriate uncertainty reporting to support interpretation in both clinical and population contexts. Cohort comparability across pilots and regions is essential for valid cross-tool inference, while ethical compliance and bias minimisation remain overarching governance priorities.

Finally, policymakers and payors look for interpretable evidence of value, clinical, patient-centred and economic, that links analysis to system-level interpretation and decision-making. They emphasise implementation readiness and scalability across regions and providers, where infrastructure and integration converge. Safety, equity and GDPR-compliant governance are foundational, and measurable KPIs enable monitoring, auditing and financing decisions, closing the loop through feedback. Clear ownership and accountability across stakeholders ensure that governance structures are enforceable rather than merely nominal.

In sum, the cross-cutting priorities that recur most strongly across groups are standards-based integration, usability with minimal burden, transparent evidence generation, and secure, scalable infrastructure. Reading through the PGHD lens, tensions concentrate at two interfaces:

1. Between capture and transfer, where burden, consent and data quality must be balanced;

2. Between analysis, interpretation and feedback, where explainability and accountability determine whether insights translate into trustworthy action.

These consolidated needs provide the analytical backbone for the matrix-based fit assessment in Section 4 and for the tool-wise interpretations and recommendations in Section 6.

3.3. Need-Tool Mapping and Survey Items

To translate the consolidated stakeholder needs from Deliverable 6.1 into an assessable format, we operationalised each need cluster into a set of concrete, tool-specific survey questions. The guiding principle was to move from abstract requirements (e.g. interoperability, usability, transparency) to observable perceptions of fit, phrased in a way that respondents could plausibly judge based on their role and experience.

The question design followed three consecutive steps. First, for each tool, we identified which need clusters from D6.1 were conceptually relevant given the tool's primary function and position in the PGHD lifecycle (e.g. data capture, transfer, storage, analysis, interpretation, feedback). Not all need categories were applied to all tools; instead, questions were restricted to those dimensions where a meaningful assessment of fit could reasonably be expected. This avoided artificial ratings on dimensions that lie outside a tool's intended scope.

Second, each selected need cluster was translated into one or more plain-language statements describing a concrete capability or outcome (e.g. "enables seamless data exchange", "supports efficient clinical workflows", "provides transparent and reproducible processes"). These statements were deliberately phrased as fit judgements rather than feature checklists. The aim was not to verify technical specifications, but to capture whether stakeholders perceive that a given tool meets the underlying need in practice, within the IMPROVE context.

Third, the items were aligned with the expected insight logic of the fit assessment. Questions on data quality, security and interoperability were designed to reveal whether backbone components provide a trustworthy and standards-based infrastructure. Items on usability, workflow fit and communication targeted day-to-day operational alignment for clinicians, patients and implementation experts. Questions addressing transparency, evidence and traceability were intended to assess whether tools support reproducible analysis, auditability and guideline-conform interpretation. Finally, items on scalability and implementation readiness were included to surface uncertainties related to deployment effort, local configuration and sustainability beyond pilot settings.

All items were rated on a six-point Likert scale without a neutral midpoint, complemented by a "no expertise" option. This design choice reflects the expectation that not all respondents can judge all tools equally well and allows uncertainty or lack of exposure to be analytically separated from negative fit. Taken together, the item set enables a structured comparison of perceived alignment across tools and need categories, while preserving sensitivity to stakeholder role, tool visibility and maturity. The full list of operationalised items and their mapping to need categories is provided in Table 1 for transparency and replicability.

Table 1 Operationalisation of Items per tool to assess the fit between needs and the tools used in the IMPROVE ecosystem

| Tool | Items with Question Text | Need Category | Rationale |
|------------------------------|---|--------------------------------|--|
| Better Platform | The Better Platform provides a reliable and secure environment for storing structured health data in openEHR format. | Data Quality & Security | Ensures standardized and compliant storage of clinical/PGHD using openEHR. |
| | The platform enables seamless data exchange with other consortium tools through APIs or ETL functions. | Interoperability & Integration | Supports cross-system connectivity and avoids data silos. |
| | The archetype designer and AQL editor facilitate efficient configuration and data querying. | Workflow Fit & Usability | Low-code configuration and query tooling reduce engineering overhead. |
| | The platform scales effectively to handle different project datasets and institutional contexts. | Scalability & Sustainability | Addresses deployment across pilots and growth in data volume/users. |
| | The system is ready for deployment but requires integration support for local partners. | Implementation Readiness | Reflects feasibility and the need for partner integration effort. |
| Better PROM Framework | The PROM framework allows creation and configuration of patient-reported outcome measures (PROMs) tailored to clinical needs. | Workflow Fit & Usability | Aligns PROM authoring with care pathways and clinical routines. |

| Tool | Items with Question Text | Need Category | Rationale |
|--------------------------------|---|---|---|
| IMPROVE Platform | The tool enables secure entry, storage, and tracking of PROMs for individual patients. | Data Quality & Security | Supports accurate, longitudinal capture of patient-reported data. |
| | Patient dashboards visualize PROM results in a clear and actionable way. | Transparency & Empowerment | Provides understandable feedback that supports patient involvement. |
| | The framework integrates seamlessly with the Better Platform and openEHR data model. | Interoperability & Integration | Ensures compatibility within the IMPROVE data ecosystem. |
| | The product is ready for use but requires configuration support to tailor PROMs to specific contexts. | Implementation Readiness & Sustainability | Emphasises local adaptation and maintainability over time. |
| IMPROVE Storage Service | The storage service ensures reliable and long-term data persistence. | Data Quality & Sustainability | Addresses requirement for robust and persistent data storage across pilots. |
| | The interoperability functions (e.g., HL7® FHIR®) meet the integration requirements across systems. | Interoperability & Integration | Meets D6.3 value “seamless data exchange between systems.” |
| | The tool allows transparent data traceability for debugging or auditing. | Evidence & Transparency | Supports reproducibility and |

| Tool | Items with Question Text | Need Category | Rationale |
|---------------------------------|---|-------------------------------|---|
| Excel/Csv IMPROVE Parser | | | accountability of data handling. |
| | The architecture scales effectively across different use cases and data volumes. | Scalability & Sustainability | Reflects scalability requirement across pilot contexts. |
| | Data access and security controls meet project standards. | Data Security | Ensures compliance with GDPR and project-level data protection needs. |
| | The parser accurately maps Excel/CSV data into the standardized IMPROVE Data Model. | Interoperability | Responds to stakeholder need for harmonized data ingestion. |
| | Automated validation reduces data inconsistencies and manual errors. | Data Quality | Improves accuracy and consistency in data preparation. |
| | The parser integrates seamlessly with the storage service and dashboard. | Workflow & Process Fit | Enables efficient inter-tool communication. |
| | The conversion process is transparent and reproducible. | Evidence & Transparency | Supports auditing and traceability of preprocessing. |
| | The parser improves efficiency in preparing datasets for analysis. | Sustainability & Workflow Fit | Optimizes technical effort in repeated analyses. |

| Tool | Items with Question Text | Need Category | Rationale |
|----------------------|--|-----------------------------|---|
| IMPROVE Dashboard | The dashboard presents clinically meaningful indicators in an intuitive layout. | Usability & Accessibility | Matches clinician need for intuitive visual tools. |
| | The visualizations help me interpret complex data quickly and accurately. | Transparency & Workflow Fit | Supports fast decision-making in clinical context. |
| | The tool supports ongoing monitoring of patients or project outcomes. | Sustainability | Meets need for longitudinal monitoring capability. |
| | The dashboard enables multi-perspective analysis across studies and pilots. | Evidence & Transparency | Fulfils research need for comparative visualization. |
| | The export and comparison functions meet research documentation needs. | Workflow & Integration | Allows data reuse and meta-analysis. |
| | The dashboard's modular architecture allows efficient configuration and maintenance. | Scalability & Technical Fit | Meets IT need for modular, maintainable architecture. |
| GetReady | The platform provides timely and accurate patient data for decision-making. | Data Quality | Ensures data reliability for care coordination. |
| | Remote monitoring functions improve coordination and continuity of care. | Workflow Fit | Addresses need for integrated follow-up systems. |

| Tool | Items with Question Text | Need Category | Rationale |
|----------------------------|--|-------------------------------|---|
| Corehealth Platform | The system integrates securely into existing electronic health records. | Interoperability | Supports EHR linkage. |
| | The tool is easy to use and supports active self-management. | Usability & Empowerment | Empowers patients to manage health. |
| | Communication and feedback features make me feel engaged in my care. | Engagement & Communication | Reflects D6.3 value “patient involvement and feedback.” |
| | The platform demonstrates technical reliability and usability suitable for large-scale deployment. | Scalability & Sustainability | Fits need for scalable telehealth implementation. |
| | The platform makes it easier to communicate with doctors and specialists. | Communication & Collaboration | Supports continuity of care. |
| | Remote monitoring features help me feel supported and informed. | Engagement | Enhances sense of security and participation. |
| | The system is simple to use, even without technical expertise. | Usability | Lowers entry barrier for patients. |
| Telecare System | Integrated telemonitoring reduces administrative workload and improves coordination. | Workflow Fit | Improves process efficiency. |
| | The system supports data sharing across care levels. | Interoperability | Fulfils data-exchange requirement. |
| | The architecture enables secure, scalable operation of telemedicine services. | Scalability & Security | Ensures technical sustainability. |

| Tool | Items with Question Text | Need Category | Rationale |
|----------------|---|---------------------------------|--|
| Picasso | Picasso ensures consistent and accurate data transformation across heterogeneous systems. | Interoperability & Data Quality | Core technical need for data-exchange consistency. |
| | The normalization process meets technical performance expectations. | Workflow Fit | Supports real-time processing requirements. |
| | The tool provides transparent documentation for data mappings. | Transparency | Enables auditability of mappings. |
| | Picasso enhances efficiency in system integration tasks. | Sustainability | Supports sustainable integration workflows. |
| CKP | CKP facilitates creation and maintenance of standardized clinical pathways. | Workflow Fit | Responds to process-standardization need. |
| | The tool enables effective collaboration between clinical and technical experts. | Communication & Collaboration | Encourages interdisciplinary co-creation. |
| | Pathways defined with CKP align with evidence-based clinical guidelines. | Evidence & Transparency | Links digital tools to guideline evidence. |
| | Integration with other IMPROVE tools supports consistent implementation. | Interoperability | Connects CKP outputs with the ecosystem. |
| Kafka | Kafka provides stable, real-time data streaming across IMPROVE components. | Interoperability | Enables continuous information flow. |

| Tool | Items with Question Text | Need Category | Rationale |
|-----------------|---|-------------------------|---|
| | The tool meets system performance needs in terms of throughput and latency. | Data Quality & Workflow | Satisfies performance and reliability requirements. |
| | Event handling between modules is reliable and fault-tolerant. | Sustainability | Ensures resilient infrastructure. |
| | Integration with storage and parser services is seamless. | Workflow Fit | Maintains efficient data pipeline. |
| AWS Services | The AWS environment provides secure and scalable computing capacity. | Scalability & Security | Supports high-performance computing need. |
| | The infrastructure supports fast data processing and reliable storage. | Workflow Fit | Enhances project data workflows. |
| | System monitoring and deployment functions are transparent and stable. | Transparency | Ensures accountability and traceability. |
| | The environment supports reproducible analysis workflows and data access control. | Evidence & Data Quality | Meets need for reproducibility. |
| 4C (EHR System) | The EHR system supports accurate and efficient clinical documentation. | Data Quality | Ensures reliable clinical records. |
| | Customizable data forms align with specific clinical workflows. | Workflow Fit | Adapts to local processes. |
| | Integration with telemonitoring improves patient data continuity. | Interoperability | Links data streams. |
| | The tool contributes to sustainable management of clinical information. | Sustainability | Ensures long-term usability. |

| Tool | Items with Question Text | Need Category | Rationale |
|--------------------|---|------------------------------|--|
| ASReview v2 | The AI-assisted screening accelerates literature review without reducing quality. | Efficiency & Data Quality | Addresses speed–accuracy balance. |
| | The interface is intuitive for both novice and experienced reviewers. | Usability | Simplifies learning curve. |
| | The tool ensures transparent, reproducible screening decisions. | Evidence & Transparency | Meets open-science requirements. |
| | Collaborative features support multi-user workflows. | Communication & Workflow Fit | Enables team-based screening. |
| Screenathon | The Screenathon format enables efficient, coordinated screening across reviewers. | Workflow Fit & Collaboration | Supports teamwork efficiency. |
| | The structured procedure increases consistency and transparency of results. | Evidence & Transparency | Ensures auditability of the screening process. |
| | The collaborative format promotes motivation and engagement among participants. | Engagement & Communication | Builds shared ownership. |
| | The process supports timely, high-quality screening outcomes. | Efficiency & Sustainability | Meets project timelines sustainably. |

4. Results of the Quantitative Fit Assessment (Survey)

This section provides the survey results. It includes (i) a participation overview, and (ii) one fit matrix per tool with median/mean and dispersion, plus a traffic-light classification column.

4.1. Survey participation and response overview

The consortium-wide survey captured ratings of tool–need fit from multiple stakeholder perspectives. Participation spanned all major partner types and roles as defined in D6.1.

4.1.1. Respondents by stakeholder group

| Stakeholder group | n respondents |
|--|---------------|
| Technical partners | 2 |
| Healthcare professional | 1 |
| Researcher or academic expert | 14 |
| Implementation expert/innovation manager | 1 |
| Communication and Dissemination Manager | 1 |
| Policy or decision.maker | 0 |
| Patient or patient representative | 0 |
| Industry or SME partner | 4 |
| Data scientist or AI specialist | 3 |

Total exceeds n = 17 as participants could choose several roles

4.1.2. Expertise areas of respondents

Across the 17 respondents, a wide range of professional backgrounds was reported, with each area of expertise represented by one individual (n = 1; 5.9%). Several participants indicated technical and data-driven expertise, including biomedical engineering and clinical engineering (n = 1), biomedicine and innovation (n = 1), data analysis (n = 1), digital health innovation with AI and machine learning (n = 1), software engineering (n = 1), digital health combined with data analysis and PROMs (n = 1), and digital health with value-based healthcare (n = 1). Additional technical profiles included MRI science (n = 1).

Respondents also represented several health sciences and clinical domains, such as rehabilitation, multiple sclerosis, neuroplasticity, mobility research, and work with patient-reported outcomes (n = 1). A substantial subset reported behavioral and social science backgrounds, including psychology (n = 1), psychology combined with sociology and health economics (n = 1), and psychology combined with AI-assisted systematic reviewing (n = 1). One respondent specialized in health communication (n = 1), and another in stakeholder engagement processes (n = 1). Other roles included law (n = 1), project management (n = 1), and coordination (n = 1). Overall, each expertise area was reported by exactly one respondent, highlighting the highly interdisciplinary composition of the sample, spanning technical, clinical, behavioral, and organizational domains without dominance of any single field.

4.1.3. Responses per countries & partner institutions

A total of 17 respondents provided information about their country and organizational affiliation. Two participants were based in Austria, one listing only the country (n = 1; 5.9%) and one specifying the University of Applied Sciences St. Pölten (n = 1; 5.9%). Three respondents were affiliated with institutions in Germany, including a generic entry “Germany” (n = 1; 5.9%), the Institute for Legal Studies (ius) (n = 1; 5.9%), and Heinrich-Heine-University Düsseldorf (n = 1; 5.9%). One respondent was affiliated with the Italian Multiple Sclerosis Foundation (n = 1; 5.9%), and one with Valdoltra Orthopaedic Hospital in Slovenia (n = 1; 5.9%). Participants from Spain included two entries specifying only the country (n = 2; 11.8%) and one from Universidad Politécnica de Madrid (UPM) (n = 1; 5.9%). One additional respondent represented Medtronic Spain (n = 1; 5.9%). The Netherlands was represented by a total of six entries: three respondents listing “Netherlands” without further specification (n = 3; 17.6%), one affiliated with Philips (n = 1; 5.9%), one with “Netherlands, Philips” (n = 1; 5.9%), and one with Utrecht University (UU) (n = 1; 5.9%). Overall, the sample reflects a broad geographic and organizational spread across Austria, Germany, Italy, Spain, Slovenia, and the Netherlands, with no single institution dominating the distribution.

4.2. Fit matrix per tool with traffic light visualization

Computation & thresholds (fixed): For each tool × stakeholder group, the median is computed as the primary fit indicator and IQR/SD as dispersion. Traffic lights are classified as: Red = median 1–2, Yellow = median 3–4, Green = median 5–6. High dispersion is flagged when $IQR \geq 2$. We also report the share of “No expertise” selections.

4.2.1 Better Platform

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|--------------------------------|----|--------|-----|------|------|------------------|---|
| The Better Platform provides a reliable and secure environment for storing structured health data in openEHR format. | Data Quality & Security | 9 | 5 | 1 | 4.44 | 1.51 | 47.1 % |  |
| The platform enables seamless data exchange with other consortium tools through APIs or ETL functions. | Interoperability & Integration | 8 | 4.5 | 2 | 4.00 | 1.60 | 52.9 % |  |
| The archetype designer and AQL editor facilitate efficient configuration and data querying. | Workflow Fit & Usability | 9 | 4 | 0 | 3.78 | 1.72 | 47.1 % |  |
| The platform scales effectively to handle different project datasets and institutional contexts. | Scalability & Sustainability | 9 | 5 | 1 | 4.33 | 1.41 | 47.1 % |  |
| The system is ready for deployment but requires integration support for local partners. | Implementation Readiness | 10 | 3.5 | 1 | 3.40 | 1.58 | 41.2 % |  |

4.2.2 Better PROM Framework

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|---|----|--------|-----|------|------|------------------|---|
| The PROM framework allows creation and configuration of PROMs tailored to clinical needs. | Workflow Fit & Usability | 10 | 4 | 2 | 3.90 | 1.80 | 41.2 % |  |
| The tool enables secure entry, storage, and tracking of PROMs for individual patients. | Data Quality & Security | 6 | 4 | 3 | 4.00 | 1.90 | 64.7 % |  |
| Patient dashboards visualize PROM results in a clear and actionable way. | Transparency & Empowerment | 11 | 4 | 2 | 3.82 | 1.72 | 35.3 % |  |
| The framework integrates seamlessly with the Better Platform and openEHR data model. | Interoperability & Integration | 9 | 4 | 2 | 3.89 | 1.45 | 47.1 % |  |
| The product is ready for use but requires configuration support to tailor PROMs to specific contexts. | Implementation Readiness & Sustainability | 9 | 4 | 1 | 3.44 | 1.67 | 47.1 % |  |

4.2.3 IMPROVE Storage Service (UPM)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|--------------------------------|---|--------|-----|------|------|------------------|---|
| The storage service ensures reliable and long-term data persistence. | Data Quality & Sustainability | 8 | 5 | 2 | 4.88 | 1.13 | 52.9% |  |
| The interoperability functions (e.g., HL7® FHIR®) meet the integration requirements across systems. | Interoperability & Integration | 6 | 5.5 | 1 | 5.17 | 1.17 | 64.7% |  |
| The tool allows transparent data traceability for debugging or auditing. | Evidence & Transparency | 7 | 5 | 2 | 4.57 | 1.40 | 58.8% |  |
| The architecture scales effectively across different use cases and data volumes. | Scalability & Sustainability | 8 | 5 | 0 | 4.75 | 0.87 | 52.9% |  |
| Data access and security controls meet project standards. | Data Security | 8 | 5 | 1 | 4.88 | 0.99 | 52.9% |  |

4.2.4 Excel/CSV IMPROVE Parser (UPM)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-------------------------------|----|--------|-----|------|------|------------------|---|
| The parser accurately maps Excel/CSV data into the standardized IMPROVE Data Model. | Interoperability | 10 | 5 | 1 | 5.1 | 0.99 | 41.2% |  |
| Automated validation reduces data inconsistencies and manual errors. | Data Quality | 11 | 5 | 1 | 4.64 | 0.81 | 35.3% |  |
| The parser integrates seamlessly with the storage service and dashboard. | Workflow & Process Fit | 10 | 5 | 2 | 5.0 | 1.05 | 41.2% |  |
| The conversion process is transparent and reproducible. | Evidence & Transparency | 10 | 5 | 0 | 4.9 | 0.88 | 41.2% |  |
| The parser improves efficiency in preparing datasets for analysis. | Sustainability & Workflow Fit | 12 | 5 | 2 | 5.0 | 0.95 | 29.4% |  |

4.2.5 IMPROVE Dashboard (UPM)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|---------------------------|----|--------|-----|------|------|------------------|---|
| The dashboard presents clinically meaningful | Usability & Accessibility | 14 | 5 | 1 | 4.57 | 0.85 | 17.6% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-----------------------------|----|--------|-----|------|------|------------------|---|
| indicators in an intuitive layout. | | | | | | | | |
| The visualizations help me interpret complex data quickly and accurately. | Transparency & Workflow Fit | 15 | 5 | 2 | 4.73 | 0.96 | 11.8% |  |
| The tool supports ongoing monitoring of patients or project outcomes. | Sustainability | 13 | 4 | 1 | 4.62 | 0.77 | 23.5% |  |
| The dashboard enables multi-perspective analysis across studies and pilots. | Evidence & Transparency | 13 | 5 | 2 | 4.69 | 1.25 | 23.5% |  |
| The export and comparison functions meet research documentation needs. | Workflow & Integration | 10 | 5 | 2 | 4.90 | 0.88 | 41.2% |  |

4.2.6 GetReady (Medtronic)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|---------------|----|--------|-----|------|------|------------------|---|
| The platform provides timely and accurate patient data for decision-making. | Data Quality | 14 | 5 | 2 | 4.86 | 0.95 | 17.6% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|----------------------------|----|--------|-----|------|------|------------------|---|
| Remote monitoring functions improve coordination and continuity of care. | Workflow Fit | 14 | 5 | 2 | 5.21 | 0.80 | 17.6% |  |
| The system integrates securely into existing electronic health records. | Interoperability | 12 | 5 | 1.5 | 4.75 | 1.29 | 29.4% |  |
| The tool is easy to use and supports active self-management. | Usability & Empowerment | 14 | 5 | 2 | 5 | 0.88 | 17.6% |  |
| Communication and feedback features make me feel engaged in my care. | Engagement & Communication | 11 | 5 | 1.5 | 5.09 | 1.04 | 35.3% |  |

4.2.7 Corehealth Platform (Dedalus)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-------------------------------|----|--------|-----|------|------|------------------|---|
| The platform makes it easier to communicate with doctors and specialists. | Communication & Collaboration | 13 | 5 | 0.5 | 4.92 | 0.64 | 23.5% |  |
| Remote monitoring | Engagement | 15 | 5 | 1 | 4.73 | 0.70 | 11.8% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|------------------|----|--------|-----|------|------|------------------|---|
| features help me feel supported and informed. | | | | | | | | |
| The system is simple to use, even without technical expertise. | Usability | 10 | 5 | 1 | 4.80 | 1.14 | 41.2% |  |
| Integrated telemonitoring reduces administrative workload and improves coordination. | Workflow Fit | 13 | 5 | 1 | 4.54 | 1.05 | 23.5% |  |
| The system supports data sharing across care levels. | Interoperability | 10 | 5 | 1 | 4.80 | 1.03 | 41.2% |  |

4.2.8 Picasso (Dedalus)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|---------------------------------|---|--------|-----|------|------|------------------|---|
| Picasso ensures consistent and accurate data transformation across heterogeneous systems. | Interoperability & Data Quality | 6 | 5 | 2 | 4.83 | 1.17 | 64.7% |  |
| The normalization process meets | Workflow Fit | 6 | 5 | 2 | 4.83 | 1.17 | 64.7% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|---------------------------------|---|--------|-----|------|------|------------------|---|
| technical performance expectations. | | | | | | | | |
| The tool provides transparent documentation for data mappings. | Transparency | 6 | 5 | 1 | 4.67 | 1.03 | 35.3 % |  |
| Picasso enhances efficiency in system integration tasks. | Sustainability | 6 | 5 | 2 | 4.83 | 1.17 | 64.7 % |  |
| Picasso ensures consistent and accurate data transformation across heterogeneous systems. | Interoperability & Data Quality | 6 | 5 | 2 | 4.83 | 1.17 | 64.7% |  |

4.2.9 CKP – Clinical Knowledge Platform (Dedalus)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-------------------------------|----|--------|-----|------|------|------------------|---|
| CKP facilitates creation and maintenance of standardized clinical pathways. | Workflow Fit | 11 | 5 | 1 | 5.09 | 0.54 | 35.3% |  |
| The tool enables effective collaboration between clinical | Communication & Collaboration | 13 | 5 | 1 | 4.77 | 0.73 | 23.5% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-------------------------|----|--------|-----|------|------|------------------|---|
| and technical experts. | | | | | | | | |
| Pathways defined with CKP align with evidence-based clinical guidelines. | Evidence & Transparency | 11 | 5 | 1 | 5.18 | 0.75 | 35.3% |  |
| Integration with other IMPROVE tools supports consistent implementation | Interoperability | 8 | 5.5 | 1 | 5.13 | 1.13 | 52.9% |  |
| CKP facilitates creation and maintenance of standardized clinical pathways. | Workflow Fit | 11 | 5 | 1 | 5.09 | 0.54 | 35.3% |  |

4.2.10 Kafka (Dedalus; open-source)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|-------------------------|---|--------|-----|------|------|------------------|---|
| Kafka provides stable, real-time data streaming across IMPROVE components. | Interoperability | 7 | 5 | 1 | 5.14 | 1.07 | 58.8% |  |
| The tool meets system performance needs in terms of throughput and latency. | Data Quality & Workflow | 8 | 5 | 1 | 5.00 | 0.93 | 52.9% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|------------------|---|--------|-----|------|------|------------------|---|
| Event handling between modules is reliable and fault-tolerant. | Sustainability | 6 | 5.5 | 1 | 5.33 | 0.82 | 64.7% |  |
| Integration with storage and parser services is seamless. | Workflow Fit | 6 | 5 | 0 | 5.00 | 0.63 | 64.7% |  |
| Kafka provides stable, real-time data streaming across IMPROVE components. | Interoperability | 7 | 5 | 1 | 5.14 | 1.07 | 58.8% |  |

4.2.11 AWS Services (Dedalus)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|-------------------------|---|--------|-----|-------|------|------------------|---|
| The AWS environment provides secure and scalable computing capacity. | Scalability & Security | 6 | 4.5 | 2 | 4.833 | 0.98 | 64.7% |  |
| The infrastructure supports fast data processing and reliable storage. | Workflow Fit | 7 | 5 | 2 | 4.86 | 0.90 | 58.8% |  |
| System monitoring and deployment functions are transparent and stable. | Transparency | 6 | 5 | 2 | 5.00 | 1.10 | 64.7% |  |
| The environment supports | Evidence & Data Quality | 7 | 5 | 2 | 5.00 | 1.00 | 58.8% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|------------------------|---|--------|-----|-------|------|------------------|---|
| reproducible analysis workflows and data access control. | | | | | | | | |
| The AWS environment provides secure and scalable computing capacity. | Scalability & Security | 6 | 4.5 | 2 | 4.833 | 0.98 | 64.7% |  |

4.2.12 4C (EHR System, Dedalus/FISM)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|------------------|----|--------|-----|------|------|------------------|---|
| The EHR system supports accurate and efficient clinical documentation. | Data Quality | 11 | 5 | 1 | 4.91 | 0.83 | 35.3% |  |
| Customizable data forms align with specific clinical workflows. | Workflow Fit | 9 | 5 | 1 | 5.33 | 0.71 | 47.1% |  |
| Integration with telemonitoring improves patient data continuity. | Interoperability | 10 | 5 | 1 | 5.00 | 0.67 | 41.2% |  |
| The tool contributes to sustainable management of clinical information. | Sustainability | 11 | 5 | 2 | 4.73 | 1.01 | 35.3% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|--|---------------|----|--------|-----|------|------|------------------|---|
| The EHR system supports accurate and efficient clinical documentation. | Data Quality | 11 | 5 | 1 | 4.91 | 0.83 | 35.3% |  |

4.2.13 ASReview v2 (UU)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|------------------------------|----|--------|-----|------|------|------------------|---|
| The AI-assisted screening accelerates literature review without reducing quality. | Efficiency & Data Quality | 16 | 5.5 | 1 | 5.31 | 0.79 | 5.9% |  |
| The interface is intuitive for both novice and experienced reviewers. | Usability | 15 | 5 | 1 | 5.20 | 0.78 | 11.8% |  |
| The tool ensures transparent, reproducible screening decisions. | Evidence & Transparency | 15 | 6 | 2 | 5.20 | 1.10 | 11.8% |  |
| Collaborative features support multi-user workflows. | Communication & Workflow Fit | 14 | 5.5 | 1 | 5.36 | 0.75 | 17.6% |  |
| The AI-assisted screening accelerates literature review | Efficiency & Data Quality | 16 | 5.5 | 1 | 5.31 | 0.79 | 5.9% |  |

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---------------------------|---------------|---|--------|-----|------|----|------------------|---------------|
| without reducing quality. | | | | | | | | |

4.2.14 Screenathon (UU)

| Item (Question Text) | Need Category | n | Median | IQR | Mean | SD | % "No expertise" | Traffic light |
|---|------------------------------|----|--------|-----|------|------|------------------|---|
| The Screenathon format enables efficient, coordinated screening across reviewers. | Workflow Fit & Collaboration | 17 | 6 | 1 | 5.47 | 0.72 | 0 % |  |
| The structured procedure increases consistency and transparency of results. | Evidence & Transparency | 16 | 5 | 1 | 5.06 | 1.00 | 5.9% |  |
| The collaborative format promotes motivation and engagement among participants. | Engagement & Communication | 17 | 6 | 1.5 | 5.24 | 1.15 | 0 % |  |
| The process supports timely, high-quality screening outcomes. | Efficiency & Sustainability | 17 | 5 | 1.5 | 5.18 | 0.81 | 0 % |  |
| The Screenathon format enables efficient, coordinated screening across reviewers. | Workflow Fit & Collaboration | 17 | 6 | 1 | 5.47 | 0.72 | 0 % |  |

5. Qualitative Results from the Participatory Follow-up Focus Group

5.1. Focus Group Design and Procedure

Following the survey-based fit assessment, we organised an online focus group with representatives of the main tool-owning partners (Dedalus, Medtronic, Better, UPM, UU, and WP leads). The session was conceived as a qualitative follow-up to: (a) explore tools and dimensions that had been rated “yellow” or had low response numbers, and (b) discuss how tool visibility within the consortium could be improved.

Participants were invited to work on a shared Miro board with two tasks: (1) review the traffic-light ratings for their own tools, focusing on flagged (yellow or low-N) items, and (2) collect ideas on how to make tools more visible and easier to understand. Technical problems with Miro access limited the planned sticky-note exercise; as a result, the session evolved into a structured group discussion, with the facilitator documenting key points on the Miro board (e.g. “Need 2 level assessment”, “Increasing tool visibility”).

Rather than going tool-by-tool, the group primarily reflected on why some tools had been difficult to rate in the survey and what this implies for future assessment and communication of the IMPROVE tool ecosystem.

5.2. Perceived reasons for low or uncertain fit

Two “levels” of tools: visible front-ends vs. invisible backend services

Several participants stressed that the tools included in the survey operate on very different levels. They distinguished:

1. Tools that are visible in the platform, such as dashboards and patient- or clinician-facing applications; and
2. Backend services, such as storage, transformation or streaming components, which are essential but largely invisible for end-users.

Backend services (e.g. storage service, Kafka, data transformation tools) were described as “invisible” for clinicians and patients, and even for some non-technical consortium partners. Participants noted that it was therefore “normal” that only a small number of respondents felt able to rate these tools in the survey or selected “no expertise”.

This structural invisibility was seen as a major reason why some tools received yellow ratings or very low response numbers: the issue was less a poor *fit* and more a limited ability of non-technical stakeholders to judge these components.

Ambiguity about which stakeholders and use-cases the ratings refer to

A recurring theme was confusion about which *stakeholders* and *contexts* the tools should be assessed against. Participants highlighted at least two additional distinctions:

- **Use-case level vs. overall IMPROVE level:**
Some partners filled in the survey from the perspective of a specific clinical case study (e.g. a tool used for one disease area), whereas others considered the broader role of tools in the IMPROVE ecosystem and stakeholder engagement “in general”. This led to uncertainty about whether tools are expected to fully meet the needs of a single case study, or to support the project’s wider advocacy and research agenda.
- **Stakeholders in the case studies vs. stakeholders in the whole project:**
The term “stakeholder” was interpreted differently (e.g. limited to clinicians and patients in pilots vs. including technical partners, advocacy organisations and researchers across IMPROVE). In the survey, WP6 had defined stakeholder groups more broadly, but this was not always transparent for respondents.

Participants agreed that these ambiguities likely contributed to heterogeneous or cautious ratings, especially in borderline “yellow” areas. Several partners suggested that the existing traffic-light classifications should be cross-checked with case-study owners, who can best judge whether a tool is fit-for-purpose in their context.

Tool maturity and ongoing development

For some technical services (e.g. the storage service), participants noted that development was still ongoing at the time of the survey. In such cases, respondents found it difficult to say whether all required features (e.g. security, scalability, monitoring) were already fully implemented, leading to cautious or incomplete answers.

Overall, the group agreed that many “yellow” ratings reflected uncertainty and limited visibility, rather than clearly negative experiences with the tools themselves.

5.3. Suggestions for adaptation and integration

Despite the methodological challenges, the discussion generated several concrete suggestions on how to adapt and better integrate the tools within IMPROVE.

1. Different evaluation approaches for different tool types

- a. For front-end tools that are visible to clinicians and patients (e.g. dashboards, telehealth platforms), participants recommended participatory evaluations with representatives from each use case. These should explicitly link tool functionalities to the needs identified in D6.1 and in the case-study protocols.
- b. For backend and technical services, a separate, technically focused assessment by the technical partners was proposed. This could systematically check whether

infrastructure requirements (e.g. interoperability, scalability, logging, traceability) are met, without expecting clinicians or advocacy partners to rate low-level architecture details.

2. Closer alignment between tools and use-case needs

Participants emphasised that the perceived fit of a tool depends heavily on how clearly its role in the use-case workflow is defined. In some cases, a complex platform is only used for a small subset of its capabilities to address a specific clinical need. Making these design decisions explicit would help stakeholders understand why a given tool was chosen and how it contributes to the case study.

3. Iterative validation with case-study owners

As a follow-up to the focus group, partners recommended verifying the traffic-light classifications directly with case-study leads. This would allow corrections where survey ratings do not reflect current implementation status (e.g. due to provider delays or configuration issues) and ensure that recommendations in the deliverable are acceptable to those responsible for running the pilots.

5.4. Increasing tool visibility within the IMPROVE ecosystem

The Miro board and the ensuing discussion generated several converging ideas on how to improve visibility and understanding of the tools.

- **Demos, videos and short presentations for each tool**

Participants suggested preparing concise demos or video walkthroughs for all major tools, highlighting what the tool does, which stakeholders it is for, and how it connects to the IMPROVE data flow. For use-case-specific tools, it was considered “clear” that such demos should be shown directly in the platform context so that partners can see real data and workflows.

- **Two “tracks” of educational material**

Consistent with the earlier distinction between levels, the group proposed:

- A *high-level* track for the whole consortium, focusing on user-facing functions and how the ecosystem works end-to-end; and
- A *technical* track for engineers and data scientists, going into greater depth on APIs, security, deployment, and performance.

- **Embedding educational content in the IMPROVE dashboard**

One idea was to include an open “educational” section within the dashboard, providing accessible information about patient-generated health data, the role of different tools, and why data collection and sharing matter for clinicians and patients. This could also be used to engage patient organisations and other non-technical stakeholders.

Collectively, these suggestions aim to reduce survey drop-outs, make “yellow” ratings more interpretable in future assessments, and support a shared mental model of the IMPROVE tool landscape.

5.5. Illustrative quotes

The following excerpts illustrate key themes from the discussion:

On the invisibility of backend tools:

“There are some services that for the users are invisible... For a clinician it is not important to know how Kafka works or Picasso, because they are behind the dashboard.”

On the need for multiple levels of assessment:

“We have two different levels of tools... tools that are visible in the platform and tools in the backend. And we also need to distinguish use-case level from the general IMPROVE level.”

On improving visibility through demos:

“It would be useful to have sessions to present the tools to the whole consortium... for me it helped a lot when we had a video for GetReady, with some slides showing what information is collected.”

On linking tools, use cases and stakeholder needs:

“To understand if a tool really fits stakeholder needs, we need to understand the purpose of the use cases – it is all very linked.”

Overall, the focus group confirmed that the quantitative survey results are useful but must be interpreted in light of tool visibility, stakeholder scope and maturity. The session produced concrete recommendations for a two-level (and in practice multi-level) assessment approach and for strengthening communication and educational materials around the IMPROVE tools.

6. Interpretation and Recommendations

6.1. Integrated interpretation per tool

The fit assessment confirms that the IMPROVE ecosystem is composed of several complementary clusters rather than a single “all-in-one” solution. Each cluster responds to a distinct part of the PGHD lifecycle and to specific stakeholder needs identified in D6.1, and the qualitative focus group helps explain why some components appear as only partially fitting despite strong technical capabilities.

The data and integration backbone – comprising the IMPROVE Storage Service, the Excel/CSV Parser, Kafka, Picasso, AWS and, in a more clinically oriented role, the 4C EHR and Better Platform – shows consistently high quantitative ratings for data quality, interoperability, scalability and transparency. These tools directly address technology- and research-oriented needs such as standards-based integration, long-term storage, traceability and resilient infrastructure. The focus group discussion clarified that the relatively high proportion of “no expertise” responses is not a sign of low fit, but rather of structural invisibility: for clinicians, patients and some implementation partners these tools remain hidden behind dashboards and telehealth front-ends, even though they underpin the entire IMPROVE architecture. In other words, they fit their primary stakeholders (technical partners, data scientists, some researchers) very well, but they are not yet part of the mental model of non-technical users.

The clinical and patient-facing telehealth cluster – including GetReady, Corehealth and the 4C EHR – emerges as highly aligned with the needs of clinicians, patients and implementation experts. Quantitatively, these tools receive green ratings across usability, workflow fit, communication, engagement and scalability. They operationalise several D6.1 priorities at the capture, transfer and feedback stages of the PGHD process: low-burden documentation, continuity of care, patient empowerment and clear communication channels. The focus group confirmed that these tools are easier to rate because partners have seen demos or pilots, and can link them to concrete use cases. The strong ratings thus reflect both intrinsic fit and the fact that these tools are “visible” in daily work and in project communication.

The knowledge and pathway management cluster – comprising CKP and the IMPROVE Dashboard, and prospectively the Better PROM Framework – focuses on aligning data flows with evidence-based clinical pathways and rendering them interpretable for different stakeholder groups. CKP is perceived as a central instrument for encoding and maintaining guideline-conform pathways, while the Dashboard translates complex datasets into multi-perspective visualisations. This directly supports D6.1 needs around evidence and transparency, communication across professions, and pathway-conform decision-making. The only yellow cell in this cluster concerns the Dashboard’s role in ongoing monitoring, where stakeholders experience current capabilities as promising but not yet fully embedded into routine follow-up or longitudinal evaluation. The PROM Framework, in turn, is rated consistently yellow: stakeholders see clear potential for patient-reported outcomes and dashboards but are aware that configuration, local adaptation and training are still required before PROMs can fully support empowerment, feedback and communication at scale.

Finally, the evidence generation and review cluster – ASReview v2 and the Screenathon format – shows very strong performance for efficiency, transparency, collaboration and engagement. These tools map

directly onto the needs of researchers, public-health experts and, indirectly, policymakers: rapid but auditable evidence generation, reproducible workflows and team-based screening. The focus group discussion reinforced that these components are among the most mature and well-understood within the consortium, having already been used in several reviews. They therefore form a robust bridge between IMPROVE's internal data flows and the external evidence base needed for guideline development, policy decisions and value demonstration.

Taken together, the quantitative and qualitative findings indicate that the IMPROVE ecosystem provides end-to-end coverage of D6.1 needs when tools are viewed as clusters rather than individually. The main interpretative challenge lies less in gaps of functionality and more in questions of visibility, configuration and role clarity: some tools are technically well aligned but not yet fully anchored in specific use cases or stakeholder narratives, leading to cautious or heterogeneous ratings in the survey.

6.2. Cross-cutting observations

Across tool clusters, several cross-cutting themes emerge that explain common “yellow” areas and point towards systemic improvements rather than tool-specific fixes.

First, implementation readiness and configuration support appear as the most consistent weak spots. This is most visible for the Better Platform and PROM Framework, where medians cluster around 3–4 despite substantial technical capabilities. In the focus group, partners highlighted that these platforms can only unfold their potential once archetypes, PROM instruments and workflows are jointly configured for specific clinical contexts. Until such configuration is complete and tested, respondents are reluctant to rate fit as “fully achieved”, particularly for implementation readiness and sustainability. Similar dynamics can be seen in the Dashboard’s monitoring item and in the slightly more cautious rating for AWS scalability and security: stakeholders are aware that the underlying technologies are powerful, but they are also sensitive to open questions around governance, performance in production and the division of responsibilities for operation and support.

Second, the distinction between “visible” front-end tools and “invisible” backbone services is crucial for interpreting both fit and response patterns. Tools that clinicians, patients and researchers directly interact with – such as telehealth platforms, dashboards and screening interfaces – received more ratings, lower “no expertise” shares, and more nuanced comments in the workshop. In contrast, the storage, streaming and transformation services are primarily evaluated by the technical partners who operate them. The focus group participants explicitly described this as “two levels” of tools. This structural layering is essential for a resilient ecosystem, but it also means that standardised survey instruments may systematically under-represent the perceived value of backend tools for non-technical stakeholders.

Third, there is a cross-cutting need for clearer mapping between tools, case studies and stakeholder groups. Several partners reported uncertainty about whether they should rate tools in relation to a specific use case (e.g. a disease-focused pilot) or in relation to IMPROVE as a whole, including advocacy and research activities. This ambiguity is most pronounced for multi-purpose platforms that can serve different roles across contexts. As a result, some yellow ratings may reflect variation in the reference frame rather than genuine disagreement about tool quality. The focus group therefore recommended

triangulating the traffic-light classifications with case-study owners, who have the clearest view of whether a given tool is fit-for-purpose in their setting.

Fourth, training, documentation and accessibility of knowledge emerged as a shared concern. Even when tools are technically mature, stakeholders emphasised the need for succinct demos, walkthroughs and explainer materials tailored to different audiences. These are particularly important for promoting understanding of PGHD flows, governance responsibilities, and the interplay between platforms and services. The idea of producing “two tracks” of educational content – a high-level track for the wider consortium and a technical track for engineers – reflects this insight.

Finally, there are clear synergies between tools that could be leveraged more systematically. Examples repeatedly mentioned in the workshop include the combination of CKP and the Dashboard for making guideline-based pathways visible and monitorable; the coupling of GetReady and Corehealth with 4C and the backend infrastructure for end-to-end telehealth; and the use of ASReview and Screenathon outputs within the Dashboard or other visual tools to communicate evidence to clinical and policy audiences. At present, these synergies are partly implicit; making them more explicit in communication and design could strengthen the perceived coherence of the IMPROVE framework and help stakeholders understand how individual components contribute to a shared value proposition.

6.3. Recommendations

The findings point to a layered set of recommendations that operate on different time horizons. Short-term actions focus on improving the usability and visibility of current prototypes; mid-term actions aim at more systematic integration and communication across work packages; long-term actions address policy and sustainability questions that extend beyond the project runtime.

Short-term: improving current prototypes and assessments

In the short term, priority should be given to concrete, implementable steps that increase the perceived fit of tools without requiring major architectural changes. For front-end tools such as GetReady, Corehealth, the Dashboard and emerging PROM dashboards, this includes targeted usability refinements based on existing pilot feedback, clearer alignment of interface elements with the stakeholder needs from D6.1, and small adjustments that make longitudinal monitoring and follow-up more prominent and actionable. For the PROM Framework in particular, co-design sessions with clinicians and patients from selected case studies should be used to configure a small number of high-value PROMs, with corresponding dashboards and workflows, to demonstrate the added value of tailored patient-reported outcomes.

For backend and infrastructure components, short-term actions centre on clarifying and documenting their role within the ecosystem. This could include concise one-page descriptions for each tool, short video demos (where applicable) and a shared “tool-to-need” map illustrating how storage, parsing, streaming and cloud services support clinical, research and governance requirements. At the same time, a technically focused assessment of infrastructure requirements – conducted among the relevant

engineers and architects – should complement the general survey, so that backbone services are evaluated against appropriate criteria and by appropriate stakeholders.

Finally, the interpretation of the existing traffic-light classifications should be validated with case-study owners. This can be done through brief structured feedback rounds in which leads confirm, nuance or correct the current colour codes for the tools relevant to their pilots. This step will help ensure that the recommendations in D6.3 accurately reflect on-the-ground implementation realities and are acceptable to those responsible for delivery.

Mid-term: integration and communication pathways across WPs

In the mid-term, the focus shifts to strengthening integration and communication pathways across work packages, with the aim of making the ecosystem more coherent and legible to all stakeholder groups. On the technical side, this involves consolidating the data and integration backbone into a clearly described reference architecture, showing how PGHD flows from capture (telehealth and EHR front-ends) through transfer and storage (Kafka, Storage Service, Parser, Better Platform) to analysis, interpretation and feedback (Dashboard, CKP, PROM dashboards, ASReview/Screenathon and other analytical components). Such a reference architecture should explicitly link each component to one or more need categories from D6.1, thereby turning the abstract needs framework into a concrete design map.

On the organisational side, mid-term efforts should aim at routine cross-WP exchange formats that keep tool owners, case-study leads and WP6 aligned. Regular “tool visibility” sessions, integrated into consortium meetings or dedicated webinars, can be used to showcase concrete use-case implementations, share lessons learned and discuss how tools can be reused or combined across pilots. Embedding educational content directly into the Dashboard – for example, a section that explains PGHD concepts, data flows and the role of different tools in accessible language – can help extend this communication beyond the core consortium to patient organisations, advocacy groups and other external stakeholders.

In addition, the mid-term horizon should be used to refine the assessment methodology itself. Building on the experience of Task 6.3, future evaluations could adopt an explicit multi-level approach that distinguishes between case-study fit, ecosystem-level contributions and infrastructure compliance. This would reduce ambiguity for respondents and produce more targeted recommendations: some tools may be “over-dimensioned” for a given pilot but critical for the overall framework, while others may be perfectly suited to a narrow use case but less central to the platform as a whole.

Long-term: policy and sustainability implications

Looking beyond the project timeline, the fit assessment carries several implications for policy, governance and sustainability. The consistently strong ratings for data quality, interoperability and evidence generation suggest that IMPROVE can serve as a reference model for standards-based PGHD ecosystems in European health systems. To translate this into lasting impact, the consortium should work towards clear governance models that specify ownership, responsibilities and service levels for

key components once project funding ends. This includes questions of who will maintain and host the Storage Service, Parser, Kafka infrastructure, dashboards and telehealth front-ends, under what agreements, and with which safeguards for security and privacy.

From a policy perspective, the combination of ASReview, Screenathon and the Dashboard provides a promising mechanism for producing and communicating evidence that is both rapid and transparent. This can support decision-makers in evaluating the value of PGHD-based interventions, defining reimbursement pathways and integrating patient-centred indicators into quality and performance frameworks. To maximise this potential, long-term plans should explore how the IMPROVE toolset can interface with existing national and European infrastructures (e.g. health data spaces, registries, guideline platforms) and how co-creation with patient and professional organisations can be sustained beyond the consortium.

Finally, the concentration of empowerment and engagement features in a few tools highlights an opportunity to strengthen user-centred design as a transversal principle. Over the long term, sustainability will depend not only on technical robustness but also on the lived experience of patients, clinicians and other users. Embedding participatory design cycles, feedback loops and training structures into the governance of the ecosystem can help ensure that tools remain aligned with evolving needs and that PGHD flows contribute meaningfully to person-centred, equitable and trusted care.

7. Summary and Outlook

7.1. Main conclusions from the fit assessment

The fit assessment shows that IMPROVE has successfully assembled a coherent, end-to-end ecosystem for working with patient-generated health data, but that the perceived fit of individual tools is strongly shaped by visibility, configuration status and role clarity. When viewed in isolation, several components receive mixed (yellow) ratings, particularly in relation to implementation readiness and long-term sustainability. When viewed as functional clusters, however – data and integration backbone, clinical and patient-facing telehealth tools, knowledge and pathway management, and evidence generation – the ecosystem offers comprehensive coverage of the stakeholder needs identified in D6.1 across data capture, transfer, storage, analysis, feedback and governance.

The combination of quantitative survey data and qualitative insights from the participatory focus group indicates that most “gaps” are not structural absences of functionality, but rather reflect open questions about configuration, use-case alignment and governance. Backend tools are technically mature and highly rated by those who operate them, but remain largely invisible to clinicians and patients. Front-end tools and evidence-oriented services, by contrast, are well understood and receive strong ratings where pilots or demonstrations exist, yet their full potential is still contingent on further integration and local adaptation. As a result, the main conclusion of Task 6.3 is that IMPROVE should prioritise making tool roles and synergies explicit, anchoring key components in concrete case-study workflows, and clarifying responsibilities for operation, training and support.

7.2. Added value for the IMPROVE framework

Beyond evaluating individual tools, the fit assessment adds several layers of value to the IMPROVE framework as a whole. First, it operationalises the abstract stakeholder needs from D6.1 into a concrete assessment lens: tools are no longer viewed only as technical artefacts, but as contributors to empowerment, communication, evidence generation and governance. This strengthens the conceptual backbone of IMPROVE by showing how PGHD-related values can be translated into design and evaluation criteria.

Second, the work in Task 6.3 makes the ecosystem more legible to internal and external audiences. By mapping tools into functional clusters, highlighting cross-cutting themes, and documenting perceived synergies (e.g. between CKP and the Dashboard, or between telehealth platforms and the data backbone), the deliverable helps partners and stakeholders understand how their local use cases fit into a broader architecture. This, in turn, supports more strategic decisions about reuse, scalability and generalisation across case studies and health-system contexts.

Third, the mixed-methods approach piloted here provides a template for future fit assessments in other digital-health projects. Combining a traffic-light survey with a participatory follow-up focus group has proven effective for distinguishing between genuine misfit and issues of visibility, maturity or communication. Applied iteratively, such an approach can guide ongoing refinement of the IMPROVE ecosystem, inform WP4 and WP5 evaluation work, and support future initiatives that seek to build on or extend the IMPROVE infrastructure.

In outlook, the findings from D6.2 position IMPROVE well for the next phase of work: consolidating the reference architecture, formalising governance and sustainability models, and deepening collaboration with clinical, patient and policy stakeholders. If these next steps are taken, IMPROVE can evolve from a project-specific toolset into a reusable framework for PGHD-driven, evidence-based and person-centred digital health across European health systems.

7.3. Next steps – Integration into Task 6.4 and final synthesis of WP6

The results of the fit assessment in D6.3, including the tool-stakeholder matrix, the traffic-light classifications and the integrated interpretations, will form the empirical starting point for Task 6.4, which applies a design science approach. In T6.4, this matrix will be further analysed and validated through two international workshops with experts and stakeholders from different countries and regions. Partners will nominate participants from their own ecosystems, ensuring representation of clinical, patient, research, industry and policy perspectives. Within these workshops, participants will jointly discuss the matrix, agree on which tools, methods and models are particularly relevant, and articulate key benefits and challenges for their applicability in different regional, national and international settings. This work will be closely coordinated with WP8 (Tasks 8.2, 8.3, 8.4) to align methodological refinement with dissemination, uptake and stakeholder engagement activities.

The outputs of 6.4 – shared agreements on relevance and applicability, refined tool profiles and region-sensitive recommendations – will then be fed back into the final synthesis of WP6. Together with the needs analysis from D6.1 and the ecosystem-level interpretation from D6.3, they will underpin a consolidated stakeholder-oriented framework that links PGHD-related values, concrete tools and implementation scenarios. This final synthesis will provide actionable guidance for how the IMPROVE ecosystem can be adopted, adapted and sustained across diverse health-system contexts beyond the project lifetime.

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.

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