IMPROVE

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

D3.3: Scientific, policies and practices development

Version 1.0

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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This deliverable contains original unpublished work except where clearly indicated otherwise.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.

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Abbreviations and Acronyms

EC	European Commission
KPI	Key Performance Indicator
PGHD	Patient Generated Health Data
PPI	Patient Preference Information
PREMs	Patient-Reported Experience Measures
PROMs	Patient-Reported Outcome Measures
VBHC	Value-Based Health Care
WP	Work Package

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Executive Summary

This deliverable serves as a starting point and guidance in outlining of the development, execution and creation of the scientific, policies and practices tracker (T3.2). In upcoming deliverables of this series of deliverable we will provide more details on the technological aspects of the trackers and how the work can and will be automated. The outcomes of Task 3.2, which is related to the development of the scientific, policies, and practices tracker that will be integrated in the IMPROVE platform will be designed as a tool using Artificial Intelligence and Machine Learning, based on Language Learning Models, to trace updated state-of-the-art scientific methodologies, outcomes, and policies across the world and select the most important outcome on the predetermined Key Performance Indicators (KPIs) to feed WP4 and WP5. Existing data from the regions included in the consortium (in WP4) (e.g., Catalunya, Slovenia, Puglia, the Netherlands) will feed the first versions of the system in order to validate its functionalities. The tool will allow to make comparisons between regions and countries in order to identify differences across them. Data coming from WP2 will be integrated into the tracker and automatically analysed using Natural Language Processing. In addition, other Project Managers from other projects will be targeted in order to collect additional Real World Data to reinforce the development of the tool, if these project managers are allowed to share the information and data. Specifically, the development of the tracker will be based on the data collected in T2.1, T2.2, T2.3 and T2.4. as well as following the integration principles and requirements defined. A beta version of the tracker will be delivered at M12 to end users. This beta version will be refined based on users' feedback following the UCD iterative cycles, during the update and maintenance process.

Keywords: Scientific; Policy; Practices; Tracker; Artificial Intelligence; Machine Learning

1. Introduction

1.1. IMPROVE approach

The IMPROVE project is dedicated to harnessing the potential of Patient Generated Health Data (PGHD) through the use of m-health and e-health technologies. This initiative aims to bridge the current gaps in data utility and fragmentation by integrating and enhancing insights into the daily lives and challenges of patients across all ages who suffer from complex, chronic diseases and comorbidities. The scientific, policy, and practice trackers will be integrated into the platform to ensure a comprehensive analysis of existing activities and work done. By doing so, IMPROVE seeks to extend the capabilities of existing platforms and approaches to Patient-Centered Outcome Measures, enriching them with real-world data that reflect true patient experiences and preferences.

At the core of IMPROVE is the development of a robust platform designed to enable the intelligent use of patient input and generated evidence. This platform will facilitate three key advancements:

- **Enhancing treatment selection**: By advancing the role of patient preferences and experiences in choosing treatments, thereby personalizing healthcare to meet individual needs more effectively.
- **Medical device design improvement**: By incorporating patient feedback directly into the design process, ensuring that new medical devices are more aligned with user expectations and experiences.
- **Accelerating market entry**: By speeding up the introduction of patient-centric and cost-effective advanced integrated care solutions, thus enhancing the accessibility of innovative treatments.

The project will demonstrate the improved clinical adoption of Value-Based Health Care (VBHC) and a higher return on research and innovation investments across various European care settings. With 10 use cases spanning at least five different disease areas, including ophthalmology, oncology, cardiovascular disease, chronic inflammation, and neurology; IMPROVE will employ a diverse range of implementation strategies. These strategies are founded on a design thinking approach, which is essential for testing this innovative framework of data collection and its translation into actionable insights and controlled change.

A substantial contribution from implementation science is also anticipated, aiming to engage all relevant stakeholders to maximize the impact of the IMPROVE initiative on healthcare provision. The project's vision to integrate in-clinic and out-of-clinic PGHD and experiences to harness VBHC will be realized through improved use of Patient-Reported Outcome Measures (PROMs), Patient-Reported Experience Measures (PREMs), Patient Preference Information (PPI), and other PGHD sources. This integration will enable accelerated innovation of cost-effective and personalized patient journeys, offering accurate insights into health conditions, treatment options, and foreseeable outcomes, thus facilitating informed decision-making by patients, their families, and healthcare professionals.

1.2. Document scope and objective

The integration of PGHD into healthcare systems holds great promise for enhancing patient care and outcomes. Ongoing advancements in technology, supportive policies, and practical implementation strategies are crucial for maximizing the potential of PGHD. As the field evolves, continuous

collaboration among scientists, policymakers, and healthcare practitioners will be key to overcoming challenges and leveraging PGHD to its fullest extent. Therefore, the IMPROVE project, and in particular Task 3.2 will establish the scientific, policies and practices tracker to keep updated on scientific, political and practical developments.

More specific, we have seen that in scientific research several advancements in PGHD collection and utilization have been shown to be prevalent. For example,

1. **Technological Innovations:**
    - Wearable devices (e.g., smartwatches, fitness trackers) and mobile health applications have significantly advanced, providing continuous, real-time health monitoring.
    - Innovations in sensors and data analytics enhance the accuracy and reliability of PGHD, enabling the tracking of vital signs, physical activity, and even mental health metrics.
2. **PHGD as evidence:**
    - Studies show that PGHD can improve chronic disease management by providing clinicians with comprehensive patient health data outside clinical settings.
    - Research indicates that PGHD enhances patient engagement and self-management, leading to better health outcomes, especially in managing conditions like diabetes, hypertension, and heart disease.
3. **Integration with Electronic Health Records (EHR):**
    - Efforts are ongoing to seamlessly integrate PGHD with EHR systems, facilitating a holistic view of patient health for providers.
    - Interoperability standards, such as HL7 and FHIR, are being developed and refined to support the integration of PGHD.

Furthermore, we have seen that several Regulatory Frameworks and Guidelines have been developed the last few years in order to protect EU-citizens, and in the United States, and support the effective collection and usage of PGHD. More specific concerning,

1. **Data Privacy and Security:**
    - The General Data Protection Regulation (GDPR) in Europe sets stringent requirements for data privacy, impacting how PGHD is collected, stored, and shared.
    - Regulations like the Health Insurance Portability and Accountability Act (HIPAA) in the U.S. govern the use and protection of PGHD.
2. **Standardization and Interoperability:**
    - Policymakers are promoting standards to ensure interoperability between PGHD sources and healthcare systems.
    - Organizations such as the Office of the National Coordinator for Health Information Technology (ONC) are developing guidelines to standardize data formats and communication protocols.

3. **Reimbursement and financial incentives:**
    - Policy efforts are underway to include PGHD in reimbursement models. For example, the Centers for Medicare & Medicaid Services (CMS) in the U.S. is exploring ways to incorporate remote patient monitoring into value-based care programs.
    - Incentive programs, such as Meaningful Use, encourage healthcare providers to adopt technologies that support PGHD integration.

Finally, several practical implementations of PGHD are under development in order to make healthcare more efficient and effective. For example,

Implementation in Healthcare Settings:

1. **Clinical Workflows:**
    - Healthcare providers are incorporating PGHD into clinical workflows to enhance decision-making and personalize patient care.
    - Best practices include establishing protocols for the review and action on PGHD, training staff on new technologies, and ensuring clear communication channels between patients and providers.
2. **Patient Engagement:**
    - Strategies to increase patient engagement with PGHD include education on the benefits of data sharing, simplifying data entry processes, and providing feedback on how their data impacts care decisions.
    - Providers are using PGHD to empower patients in self-management programs, leveraging data to set personalized health goals and track progress.
3. **Challenges and Solutions:**
    - Common challenges include data overload for providers, ensuring data accuracy, and addressing privacy concerns.
    - Solutions involve deploying advanced data analytics to filter and highlight relevant data, implementing robust verification processes, and maintaining transparent privacy practices to build patient trust.

In order to have, and keep, an overarching overview of the different scientific, policy and practice developments in the area of PGHD and the implementation of PGHD in healthcare, we will build trackers in our shared environment to keep all developments in direct reach of our consortium partners.

2. Methodology

During Phase 1 Conceptualising (M1-M12) of IMPROVE, the first activity of the journey is an extensive combination of desk research, systematic review, and meta-reviews (see also WP2) to identify and collect the state-of-the-art evidence and existing frameworks and models that are published, categorize it in an open-access, searchable database, using traditional (statistical analysis) and advanced analytics (AI, NLP, ML) in the Data Lab in WP3. This will allow us to build an annotated "corpus" and extract the relevant knowledge *(WP3)*. By setting up a Data Lab using AI, NLP, and ML we are able to screen and include more information than the traditional way of screening; we can feed the framework with all state-of-the-art findings and therefore better integrate the outcome, resulting in an eclectic overview of the findings in this field.

More specifically, withing *Task 2.1 – Systematic search and creating a database* we have developed a search strategy to support an analytical framework and methodology to assess the scientific evidence on patient reported inputs and health delivery services in an iterative process to balance recall and precision. We included as many potentially relevant studies as possible, while at the same time limiting the total number of search results. We have created a **Knowledge Warehouse** with several **Chambers**, completed with a database of potentially relevant documents. A pre-trained deep learning model with a multi-language feature extractor has been developed and tested in a series of simulation studies.
The outcomes of the **Knowledge Warehouse** and its **Chambers** (1: Oncology - 1.1: Prostate cancer, 1.2: Cervical cancer, 1.3: Neck and neck cancer, 1.4: Breast cancer; 2. Ophthalmology - 2.1: Macular degeneration; 3: Cardiovascular, 3.1: Heart failure, 3.2: Coronary artery diseases, 3.3: Atrial fibrillation, 3.4: Severe aortic stenosis; 4: Neurology, 4.1: Multiple sclerosis and 5: Chronic inflammation - 5.1: Chronic rhinosinusitis), will be used to inform development of the methodologies (e.g., use cases) in the other WPs (4,5), and to build guidelines and recommendations (WP7). Based on these outcomes we will establish the experimental studies (WP4), case studies (WP5) and design science methodology (WP6).

Subsequently, we will extract the most relevant data and we will prioritize the relative significance of the different dimensions, factors and indicators (including their relative importance) for PGHD and their related concepts in Task 2.2 – Data extraction and synthesis. Furthermore, we will evaluate available models' methodologies, assessing strengths and weaknesses of selected models (1) to understand the most significant factors and indicators; (2) to profile and cluster stakeholders that are involved; and (3) to identify the context of use of the models and methodologies and their effects. As a result, we will be able to have a better overview of the effect sizes of the relationship and causality between the different patient reported inputs that will feed the development of a new methodology.
Next, in *Task 2.3 - Conducting systematic reviews, desk research and potentially meta-analyses* a series of systematic reviews, desk researches and meta-analyses using the Knowledge Warehouse and its Chamber that we constructed in 2.1 and 2.2. Depending on the exact research questions that we will answer after having collected the state-of-the-art of scientific evidence (T2.1) and consultation with the consortium and other stakeholders (WP6), we will define in more detail how many systematic reviews will be conducted. Because we will use the AS Review - AI-aided tool, and Large Language Models we can easily update the search adding newly published literature and we will publish systematic reviews and meta-analyses.

For IMPROVE, this means that we can achieve a higher quality and accuracy than traditional approaches and immediately prioritize findings as well as incorporate new evidence. This process will allow us to identify and assess the available models, methods and their potential biases and how we

can IMPROVE them, for example FDA guidances for Patient Focused Drug Development[1]and Medical Device Development[2], several IMI projects such as PREFER[3]SISAQOL[4], and PARADIGM[5]. Next, we will conduct consultation with relevant stakeholders (e.g., patients, support network of formal and informal caregivers, associations, researchers, healthcare professionals, healthcare system regulators, and industry) in a co-creation and living lab approach, in order to create consensus about these findings, including the relevance of the current models and definitions, and factors driving effective and efficient use of PGHD, to elicit stakeholder needs and capabilities in situations, contexts of use, etc *(WP3)*. This will facilitate the identification of the knowledge gaps, strengths, and weaknesses, including the need to incorporate additional data *(WP3)*, see also Figure 1.

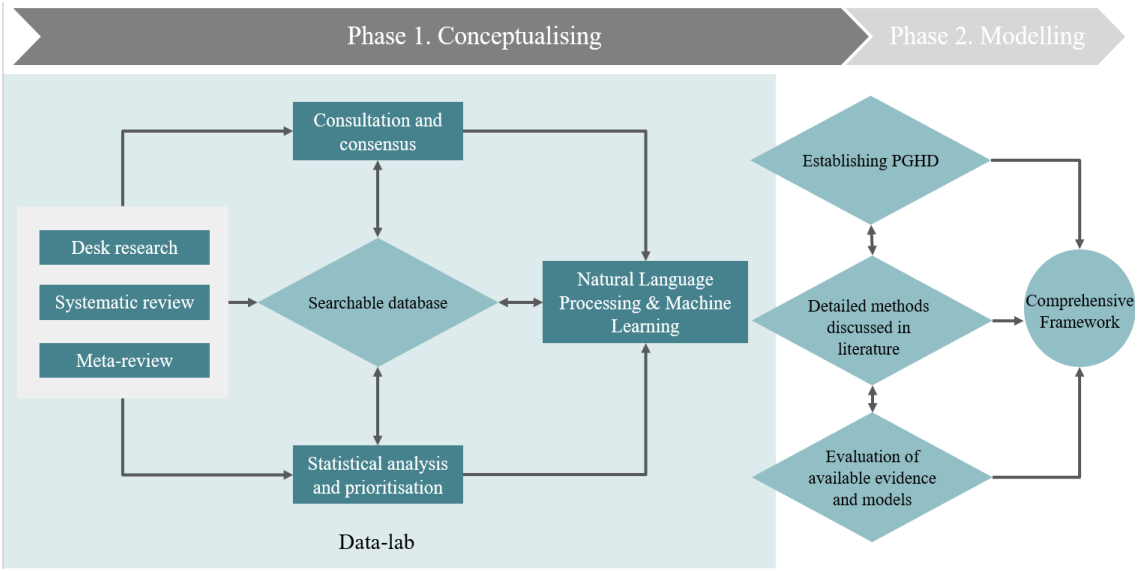

Figure 1. From conceptualization to modelling

IMPROVE's conceptual model framework approach will emerge from the consensus achieved during this process and represents the starting point of Phase Modelling (M9 – M34) *(WP3 – T3.1).* Following the consensual definition and approach, traditional statistical analyses and advanced analytics (AI, ML, NLP) will be deployed to prioritize relevant factors that have a reciprocal relation with the database, allowing the insights gained in one task to automatically feed the other tasks. Automatic learning procedures can make use of statistical inference algorithms to produce robust models from unfamiliar or irrelevant input at a split-second, while manually conducting this work would be impossible. As a result of these exercises, a comprehensive understanding of existing frameworks will be developed, independently from the therapeutic area in a real-world context and to identify, categorize, quantify, and assess the most significant theories, models and frameworks explaining the usage of patient reported outcomes in healthcare delivery. This will also incorporate the scientific, policy and practice tracker. As a result of Phase 1, an IMPROVE framework conceptual approach will be delivered,

[1] https://www.fda.gov/drugs/developmentapproval-process-drugs/fda-patient-focused-drug-development-guidance-series-enhancing-incorporationpatients-voice-medical
[2] Patient Preference Information (PPI) in Medical Device Decision-Making | FDA
[3] https://www.imi.europa.eu/projects-results/project-factsheets/prefer
[4] https://www.imi.europa.eu/projects-results/project-factsheets/sisaqol-imi
[5] https://imi-paradigm.eu/

including the main components of the AI/ML model design, development, and validation process as described in the next paragraph (see Figure 2).

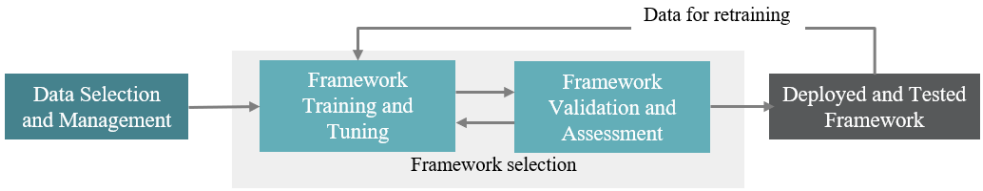

Figure 2. The main components of the AI/ML model design, development and validation processes

Data selection and management concerns the curation of measurement and data collection issues (e.g., estimation of missing values), aiming at ensuring the quality of the training set, and standard data pre-processing tasks, (e.g., aggregation, sampling, feature creation, dimensionality reduction, feature selection, discretization, and variable transformation). Model selection is the core building block of an AI/NLP/ML strategy; given a class of AI/ML models, (e.g., a kernel-based method or an expert system), its parameters are leant by proper optimization algorithms applied on the training set, treating, in parallel, the tuning of model hyperparameters via rigid approaches, and, evaluating subsequently the model's performance on the test set using suitable performance metrics (e.g., sensitivity, specificity, positive predictive value, area under the ROC curve).

Important to mention is that this deliverable is the first of its series and will provide the basic set up and main ideas; in upcoming deliverables and throughout the project we will establish the technological needs to implement the automatization of the data collection and analyses.

3. Science, Policy and Practice Trackers

3.1 Science Tracker

As described in the methodology, within WP2 we will conduct several systematic reviews and desk research to collect the necessary information. The outcomes of the first extensive systematic umbrella review is published in D2.1 and we will not repeat the main outcomes here. See below the training sessions for the first Screenathon where >12,000 titles and abstracts were screened to build the **Knowledge Warehouse.** Based on this Knowledge Warehouse, we have trained artificial intelligence models to identify relevant publications, a crucial step towards changes in healthcare. This is part of the Science tracker that will be built with the Large Language Models that will automatically analyze the scientific articles that will be included in the Knowledge Warehouse and its chambers. The next steps will be to evaluate the outputs and insights from these scientific papers to establish the needs for more detailed systematic reviews (e.g., focusing on randomized clinical trials, clinical trials) to define the use case studies in more detail. Subsequently the Large Language Models that have been developed will automatically analyze the most relevant outcomes to support the project.

3.2 Policy Tracker

In order to collect the necessary legislative measures and policy actions that have been put in place by the European Commission and European Parliament that are relevant for the IMPROVE project, we make use of the Bruegel dataset (see here for more information - A dataset on EU legislation for the digital world (bruegel.org)) that provides a comprehensive overview of mandated (by May 2024) 1) legislative measures relevant to digitalisation that were enacted in the past; measures that have been enacted during the current legislative session (2019-2024); 2) ongoing EU policy initiatives that might well lead to new legislation in the foreseeable future (see Table 1 – Overview of EU Legislations in the Digital Sector); and 3) governmental and non-governmental bodies at EU level that contribute to the implementation and enforcement of legislative measures related to digitalisation (Table 2 – Overview of EU Governance Mechanisms and Agencies in the Digital Sector).

Table 1: Overview of EU Legislations in the Digital Sector

Applicable law	Published in the Official Journal of the European Union.
In negotiation	Proposal by the European Commission entered the legislative process.
Planed initiative	Mentioned by the European Commission as potential legislative initiative.

Research & Innovation	Industrial Policy	Connectivity	Data & Privacy	IPR	Cybersecurity	Law Enforcement	Trust & Safety	E-commerce & Consumer Protection	Competition	Media	Finance
Digital Europe Programme Regulation, (EU) 2021/694	Recovery and Resilience Facility Regulation, (EU) 2021/241	Frequency Bands Directive, (EC) 1987/372	ePrivacy Directive, (EC) 2002/58, 2017/0003(COD)	Database Directive, (EC) 1996/9	Regulation for a Cybersecurity Act, (EU) 2019/881, 2023/0108(COD)	Law Enforcement Directive, (EU) 2016/680	Product Liability Directive (PLD), (EC) 1985/374, 2022/0302(COD)	Unfair Contract Terms Directive (UCTD), (EC) 1993/13	EC Merger regulation, (EC) 2004/139	Satellite and Cable Directive, (EC) 1993/83	Common VAT system, (EC) 2006/112, 2022/0407(CNS)
Horizon Europe Regulation, (EU) 2021/695, (EU) 2021/764	InvestEU Programme Regulation, (EU) 2021/523	Radio Spectrum Decision, (EC) 2002/676	European Statistics, (EC) 2009/223, 2023/0237(COD)	Community Design Directive, (EC) 2002/6, 2022/0391(COD)	Regulation to establish a European Cybersecurity Competence Centre, (EU) 2021/887	Directive on combating fraud and counterfeiting of non-cash means of payment, (EU) 2019/713	Toys Regulation, (EC) 2009/48, 2023/0290(COD)	Price Indication Directive, (EC) 1998/6	Technology Transfer Block Exemption, (EU) 2014/316	Information Society Directive, (EC) 2001/29	Administrative cooperation in the field of taxation, (EU) 2011/16
Regulation on a pilot regime for distributed ledger technology, (EU) 2022/858	Connecting Europe Facility Regulation, (EU) 2021/1153	Open Internet Access Regulation, (EU) 2015/2120	General Data Protection Regulation (GDPR), (EU) 2016/679	Enforcement Directive (IPR), (EC) 2004/48	NIS 2 Directive, (EU) 2022/2555	Regulation on interoperability between EU information systems in the field of borders and visa, (EU) 2019/817	European Standardization Regulation, (EU) 2012/1025	E-commerce Directive, (EC) 2000/31	Company Law Directive, (EU) 2017/1132, 2023/0089(COD)	Audio-visual Media Services Directive (AVMSD), (EU) 2018/13	Payment Service Directive 2 (PSD2), (EU) 2015/2366, 2023/0210(COD)
	Regulation on High Performance Computing Joint Undertaking, (EU) 2021/1173, 2024/0161(NLE)	European Electronic Communications Code Directive (EECC), (EU) 2018/1972	Regulation to protect personal data processed by EU institutions, bodies, offices and agencies, (EU) 2018/1725	Directive on the protection of trade secrets, (EU) 2016/943	Cybersecurity Regulation, (EU) 2023/2841	Regulation on terrorist content online, (EU) 2021/784	Radio Equipment Directive (RED), (EU) 2014/53	Unfair Commercial Practices Directive (UCPD), (EC) 2005/29	Market Surveillance Regulation, (EU) 2019/1020	Portability Regulation, (EU) 2017/1128	Digital Operational Resilience Act (DORA Regulation), (EU) 2022/2554
	Regulation on Joint Undertakings under Horizon Europe, (EU) 2021/2085, 2022/0033(NLE)	.eu top-level domain Regulation, (EU) 2019/517	Regulation on the free flow of non-personal data, (EU) 2018/1807	Design Directive, 2022/0392(COD)	Information Security Regulation, 2022/0084(COD)	Temporary CSAM Regulation, (EU) 2021/1232, 2022/0155(COD)	eIDAS Regulation (European Digital Identity Framework), (EU) 2014/910	Directive on Consumer Rights (CRD), (EU) 2011/83	P2B Regulation, (EU) 2019/1150	Satellite and Cable II Directive, (EU) 2019/789	Crypto-assets Regulation (MiCA), (EU) 2023/1114
	Decision on a path to the Digital Decade, (EU) 2022/2481	Roaming Regulation, (EU) 2022/612	Open Data Directive (PSI), (EU) 2019/1024	Compulsory licensing of patents, 2023/0129(COD)	Cyber Resilience Act, 2022/0272(COD)	E-evidence Regulation, (EU) 2023/1543	Regulation for a Single Digital Gateway, (EU) 2018/1724	e-invoicing Directive, (EU) 2014/55	Single Market Programme, (EU) 2021/690	Copyright Directive, (EU) 2019/790	Financial Data Access Regulation, 2023/0205(COD)
	European Chips Act (Regulation), (EU) 2023/1781	Union Secure Connectivity Programme, (EU) 2023/588	Data Governance Act (DGA Regulation), (EU) 2022/868	Standard essential patents, 2023/0133(COD)	Cyber Solidarity Act (Regulation), 2023/0109(COD)	Digitalisation of cross-border judicial cooperation, (EU) 2023/2844	General Product Safety Regulation, (EU) 2023/988	Regulation on cooperation for the enforcement of consumer protection laws, (EU) 2017/2394	Vertical Block Exemption Regulation (VBER), (EU) 2022/720	European Media Freedom Act, (EU) 2024/1083	Payment Services Regulation, 2023/0210(COD)
	Establishing the Strategic Technologies for Europe Platform (STEP), (EU) 2024/795	Gigabit Infrastructure Act, (EU) 2024/1309	European Data Act (Regulation), (EU) 2023/2854			Directive on combating violence against women, 2022/0066(COD)	Machinery Regulation, (EU) 2023/1230	Geo-Blocking Regulation, (EU) 2018/302	Digital Market Act (DMA Regulation), (EU) 2022/1925	Remuneration of musicians from their countries for reconect music played in the EU	Digital euro, 2023/0212(COD)
	European critical raw materials act (Regulation), (EU) 2024/1252	New radio spectrum policy programme (RSPP 2.0)	Interoperable Europe Act, (EU) 2024/903			Directive for combating sexual abuse and child sexual abuse material, 2024/0035(COD)	AI Act (Regulation), 2021/0106(COD)	Digital content Directive, (EU) 2019/770	Regulation on distortive foreign subsidies, (EU) 2022/2560		Regulation on combating late payment, 2023/0323(COD)
	Net Zero Industry Act, 2023/0081(COD)	Digital Networks Act	Regulation on data collection for short-term rental, (EU) 2024/1028			Digitalisation of travel documents	Eco-design Regulation, 2022/0095(COD)	Directive on certain aspects concerning contracts for the sale of goods, (EU) 2019/771	Horizontal Block Exemption Regulations (HBER), (EU) 2023/1066, (EU) 2023/1067		
	EU Space Law		European Health Data Space (Regulation), 2022/0140(COD)				AI Liability Directive, 2022/0303(COD)	Digital Services Act (DSA Regulation), (EU) 2022/2065	Platform Work Directive, 2021/0414(COD)		
			Harmonisation of GDPR enforcement procedures, 2023/0202(COD)					Political Advertising Regulation, (EU) 2024/900	Single Market Emergency Instrument (SMEI), 2022/0278(COD)		
			Access to vehicle data, functions and resources					Right to repair Directive, 2023/0083(COD)			
			FreeFlow of data					Consumer protection: strengthened enforcement cooperation			

Table 1: Overview of EU legislation in the Digital sector

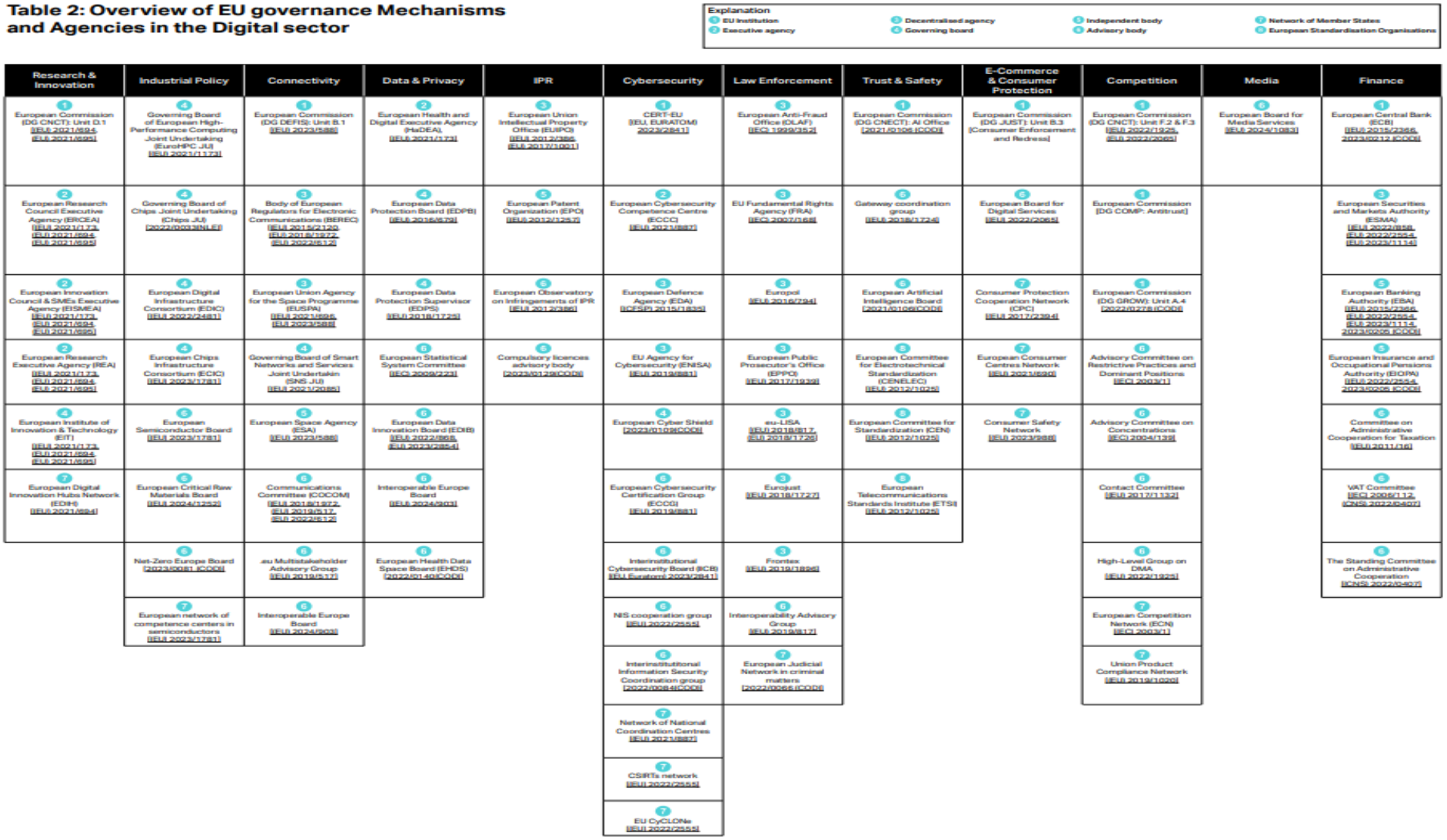

Table 2: Overview of EU governance mechanisms and agencies in the Digital sector

During the last few years, many digital laws were enacted, mostly under the EU's Digital Agenda and Digital Single Market (DSM) programmes. In the current legislative term, which is coming to an end, important new measures relevant to digitalisation such as the Digital Markets Act (DMA), the Digital Services Act (DSA), the Data Act, the Artificial Intelligence Act (AI Act), the Data Governance Act (DGA), the European Health Data Space (EHDS), an update to the regulation on electronic identification and trust services (eIDAS 2) and a measure to strengthen the cybersecurity of critical infrastructure (NIS2) have been enacted, and most have already been published. For the current project we will follow the publications in the official outlet of the European Commission and European Parliament and keep the figures updated. The information presented in the tables, especially information about measures that have already been enacted, is based on standard, publicly available sources, based on official pronouncements of the European institutions, such as European Commission work programmes or State of the European Union addresses.

In sum, Table 1 provides an overview of legislative measures enacted, during the current legislative session, roughly following the taxonomy of de Streel and Hocepied (2019). We classify the measures depending on whether they primarily relate to (1) research and innovation; (2) industrial policy; (3) connectivity; (4) data and privacy; (5) intellectual property rights (IPR); (6) cybersecurity; (7) law enforcement; (8) trust and safety; (9) e-commerce and consumer protection; (10) competition, (11) media; and (12) finance. We distinguish among (a) measures that have been enacted, versus (b) those that are in the legislative process, versus (c) initiatives that have been announced, but that are not yet formally in the legislative process.

Table 2 provides a list and taxonomy of the governmental and non-governmental bodies that in one way or another contribute to the implementation and enforcement of EU legislative measures that relate to digitalisation. The thematic taxonomy is the same as that used in Table 1, beginning with research and innovation, and continuing with industrial policy. Only EU bodies that have a role in implementing EU law relevant to digital services are included. Member state implementation bodies are not shown, nor are any expert groups that serve solely to provide the European Commission with high-level input and advice with the drafting of delegated or implementing acts. In Table 2, we distinguish between (1) EU institutions, (2) Executive agencies, (3) Decentralised agencies, (4) Governing boards, (5) Independent bodies, (6) Advisory bodies, (7) Networks of Member States, and (8) European Standardisation Organisations (ESOs).

3.3 Practice Tracker

For the practice tracker we will identify practices across countries and regions, in order to develop a knowledge base of the existing practices that are conducted to develop methods or frameworks for collecting and using patient reported outcomes. Subsequently, data gathering will be done in existing repositories of good practices in different fields and with direct contacts with a wide range of leading regional and national ecosystems. Together with the project manager of these programs we will monitor the practices for a set of predefined and agreed indicators, analyse and assess the effects and efficiencies of the practices implemented that we have identified. Several European (e.g., H2020s, IHI, Horizon Europe's) and national projects and partners have already been identified, see Appendix A for the overview of recent EU-projects and beyond, associations that are linked to IMPROVE and other organizations that work in similar areas. In the upcoming months we will approach these organizations and projects to start collaborations and improve the way we work by having open conversations.

4 Conclusion

This deliverable summarizes the first steps in establishing and building the Scientific, Policies and Practices tracker and is a starting point and guiding outlining of the development, execution and creation of the three trackers to collect the necessary insights for the successful execution of the project, mainly feeding WP4 and WP5. First, scientific data that will be collected as a result of the systematic literature reviews and desk research we are conducting have been stored in the **Knowledge Warehouse** and are being analyzed. Data coming from WP2 will be integrated into the tracker and automatically analysed using Large Language Models, implementing NLP automatization procedures. Second, in addition, other Project Managers from other projects will be targeted (see Appendix A for a tentative list) in order to collect additional Real World Data to reinforce the development of the tool. Specifically, the development of the tracker will be based on the data collected in T2.1, T2.2. and T2.3. as well as following the integration principles and requirements defined. A beta version of the tracker will be delivered at M12 to end users. This beta version will be refined based on users' feedback following the UCD iterative cycles, during the update and maintenance process.

Appendix A

Project or stakeholder working on PGHD	Contact details	Sort of project
DREAM Dynamic Regulation of photosynthEsis in light-Acclimated organisMs: Improving plant cultivation through disruptive technologies.	DREAM Project	Horizon Europe
SMELLODI Smart Electronic Olfaction for Body Odor Diagnostics: Advancing digitization of olfaction for disease detection and more.	SMELLODI Project	Horizon Europe
EOSC4Cancer A European-wide foundation to accelerate Data-driven Cancer Research: Integrating research data across Europe for cancer advancements.	EOSC4Cancer Project	Horizon Europe
BioExcel-3 BioExcel Centre of Excellence for Computational Biomolecular Research: Leading in data-driven life science research.	BioExcel-3 Project	Horizon Europe
vera.ai vera.ai: VERification Assisted by Artificial Intelligence: Combating online disinformation with AI-powered verification.	vera.ai Project	Horizon Europe
HACID Hybrid Human Artificial Collective Intelligence in Open-Ended Decision Making: Developing a hybrid collective intelligence for decision support.	HACID Project	Horizon Europe
BY-COVID Beyond COVID: Providing comprehensive open data on infectious diseases for monitoring and analysis.	BY-COVID Project	Horizon Europe
TargetBRCA To develop a new targeted therapy for the treatment of naive and PARP inhibitor-resistant BRCA1/2-mutated tumors: Developing targeted therapy for aggressive tumors.	TargetBRCA Project	Horizon Europe
4.UNCAN.eu A Coordination and Support Action to prepare UNCAN.eu platform: Generating a strategic agenda for cancer research initiative UNCAN.eu.	4.UNCAN.eu Project	Horizon Europe
SafeHabitus STRENGTHENING FARM HEALTH AND SAFETY KNOWLEDGE AND INNOVATION SYSTEMS: Making farming safer through innovation and knowledge systems.	SafeHabitus Project	Horizon Europe
microTOUCH Transmission of the human microbiome and its impact on health: Understanding the human microbiome's impact on health.	microTOUCH Project	Horizon Europe
NEXTNANO NEXT GENERATION NANOPARTICLE-BASED ANTIBACTERIAL TREATMENT FOR INFECTED WOUNDS:	NEXTNANO Project	Horizon Europe

Developing nanoparticle-based treatment for infected wounds.		
CanceRusolution A NEW DRUG TO TREAT TRIPLE NEGATIVE BREAST CANCER: Developing a new drug for Triple Negative Breast Cancer treatment.	CanceRusolution Project	Horizon Europe
SPAC MRI Spacious and accurate MRI machines of the future: Pioneering the next generation of MRI machines for improved accessibility and accuracy.	SPAC MRI Project	Horizon Europe
FRONTIERS Fellowship Residencies Offering science News professionals Tools and training for Independent and Ethical Reporting on Science: Establishing a program supporting science journalists' residencies in European research institutions.	FRONTIERS Project	Horizon Europe
FOODITY FOod and nutritiOn Data-driven innovation respectful of citizen's Data SovereIgnTY: Promoting data-driven innovation in the food and nutrition domain while respecting data sovereignty.	FOODITY Project	Horizon Europe
MDDB Molecular Dynamics Data Bank. The European Repository for Biosimulation Data: Establishing a European repository for biosimulation data.	MDDB Project	Horizon Europe
CANCER-ID	CANCER-ID Project	IMI
DO->IT	DO->IT Project	IMI
DRIVE-AB	DRIVE-AB Project	IMI
EHR4CR	EHR4CR Project	IMI
MOPEAD	MOPEAD Project	IMI
ROADMAP	ROADMAP Project	IMI
VALUE-Dx	VALUE-Dx Project	IMI
WEB-RADR	WEB-RADR Project	IMI
MACUSTAR	MACUSTAR Project	IMI
PRO-active	PRO-active Project	IMI
ADVANCE	ADVANCE Project	IMI
BD4BO	BD4BO Project	IMI
COMPACT	COMPACT Project	IMI
ConcePTION	ConcePTION Project	IMI
Ebola+	Ebola+ Project	IMI
EMIF	EMIF Project	IMI
eTRIKS	eTRIKS Project	IMI
EUROPAIN	EUROPAIN Project	IMI
GETREAL	GETREAL Project	IMI
INNODIA	INNODIA Project	IMI
MIP-DILI	MIP-DILI Project	IMI

Onco Track	Onco Track Project	IMI
PARADIGM	PARADIGM Project	IMI
Predect	Predect Project	IMI
PreDiCT-TB	PreDiCT-TB Project	IMI
PRISM	PRISM Project	IMI
SAFE-T	SAFE-T Project	IMI
SUMMIT	SUMMIT Project	IMI
ULTRA-DD	ULTRA-DD Project	IMI
VSV-EBOVAC	VSV-EBOVAC Project	IMI
STRONG-AYA	STRONG-AYA Project	HORIZON
EHAB	EHAB Project	HORIZON
IMPROVE	IMPROVE Project	HORIZON
LEAP	LEAP Project	HORIZON
VELES	VELES Project	HORIZON
Add4Kids	Add4Kids Project	HORIZON
PeekMedAuto	PeekMedAuto Project	HORIZON
RETINA	RETINA Project	HORIZON
ONCOVALUE	ONCOVALUE Project	HORIZON
DEDALUS	DEDALUS Project	HORIZON
NANOWOUND	NANOWOUND Project	HORIZON
Real4Reg	Real4Reg Project	HORIZON
AI-CARE	AI-CARE Project	HORIZON
ASCERTAIN	ASCERTAIN Project	HORIZON
GEMINI	GEMINI Project	HORIZON
LucidWave	LucidWave Project	HORIZON
XpanDH	XpanDH Project	HORIZON
Procure4Health	Procure4Health Project	HORIZON
SUSTRONICS	SUSTRONICS Project	HORIZON
RaRe2	RaRe2 Project	HORIZON
AI4CMR	AI4CMR Project	HORIZON
SYNTHEMA	SYNTHEMA Project	HORIZON
B-specific	B-specific Project	HORIZON
Med-IPUT	Med-IPUT Project	HORIZON
DECIPHER	DECIPHER Project	HORIZON
AlkaBurst2.0	AlkaBurst2.0 Project	HORIZON
LiverPRO	LiverPRO Project	HORIZON
SoftDesign_Orthotic	SoftDesign_Orthotic Project	HORIZON
HILIGHT	HILIGHT Project	HORIZON
AISN	AISN Project	HORIZON
PHOTONGATE	PHOTONGATE Project	HORIZON
iMAClung	iMAClung Project	HORIZON
ASSESS-DHT	ASSESS-DHT Project	HORIZON
POINT	POINT Project	HORIZON
SAFIR-Ready	SAFIR-Ready Project	HORIZON
G2B-002	G2B-002 Project	HORIZON

RadioVal	RadioVal Project	HORIZON
CLAIMS	CLAIMS Project	HORIZON
U-BiomarCARE	U-BiomarCARE Project	HORIZON
IDERHA	IDERHA Project	HORIZON
SIMPLI-DEMO	SIMPLI-DEMO Project	HORIZON
greenerRPP	greenerRPP Project	HORIZON
TransPharm	TransPharm Project	HORIZON
GenHumCap	GenHumCap Project	HORIZON
CONNECTINGHEALTH	CONNECTing the dots withIN diGItal HEALTH Innovation Ecosystems Project	HORIZON
SMILE	SMILE Project	HORIZON
PAINS	PAINS Project	HORIZON
MULTI-SOFT	MULTI-SOFT Project	HORIZON
SAFIRE	SAFIRE Project	HORIZON
HD-BRECA Integrating longitudinal multi-modal profiling of metastatic breast cancer patients for high-definition oncology		HORIZON
EndoTheranostics Multi-sensor Eversion Robot Towards Intelligent Endoscopic Diagnosis and Therapy	Link	HORIZON
SyMPaBiome Development of a synbiotic product to modulate the Parkinson's disease associated microbiome	Link	HORIZON
TARAF Taxonomy and azole resistance in Aspergillus section Flavi	Link	HORIZON
MAESTRO Novel machine learning techniques to improve the forecasting of stroke post-interventive outcomes	Link	HORIZON
PROTECT PReparing for Optimal Phase III/IV maTErnal Group B StreptococCal vaccine Trials in Africa (PROTECT)	Link	HORIZON
TLSaRNA Artificial induction of tertiary lymphoid structures (TLS) in tumors using intratumoral mRNAs to evaluate its synergy with immune checkpoint inhibitors	Link	HORIZON
POINT Preventing non-communicable diseases caused by the post-acute phase of cOvid-19 INfecTion	Link	HORIZON
xShare Expanding the European EHRxF to share and effectively use health data within the EHDS	Link	HORIZON
CVDLINK A federated paradigm of real-world data sources utilization for the empowerment of diagnosis, prognosis and risk assessment of cardiovascular conditions	Link	HORIZON

MONALISA A SIOPEN pragmatic clinical trial to MOnitor NeuroblastomA relapse with LIquid biopsy Sensitive Analysis	Link	HORIZON
LIMORD Longitudinal Integrative Models for Online Relapse Detection	Link	HORIZON
PaLaDIn Patient Lifestyle and Disease Data Interactium	Link	HORIZON
SASICU Improving patient outcomes and reducing cognitive load of clinical staff in intensive care through medical-device interoperability and an open and secure IT ecosystem	Link	HORIZON
BRCA-RLT Impact of BRCA2 deficiency one the DNA damage response and Immunogenicity of Prostate cancer after Radioligand therapy	Link	HORIZON
MPX-RESPONSE A clinical research network to improve the management of Monkeypox virus disease	Link	HORIZON
CARE1 First line randomized study platform to optimize treatment in patients with metastatic renal cell carcinoma	Link	HORIZON
CompSURG Computational Methods to Analyse Intra-operative Adverse Events in Surgery at Scale	Link	HORIZON
IMPACT- AML Master Framework and Pragmatic Clinical Trial for Relapse or Refractory Acute Myeloid Leukemia	Link	HORIZON
Murnia Prevention of Radiotherapy and Chemotherapy Induced Oromucosal Wounds Using an Oral Application Gel: Murnia® Mouth Gel	Link	HORIZON
CCI4EU COMPREHENSIVE CANCER INFRASTRUCTURES 4 EUROPE	Link	HORIZON
LIVERATION Unravelling the impact of Radiofrequency in liver surgery: the key to decrease local recurrence?	Link	HORIZON
CO-CAPTAIN CANCER PREVENTION AMONG INDIVIDUALS WITH MENTAL ILL-HEALTH: CO-ADAPTING AND IMPLEMENTING PATIENT NAVIGATION FOR PRIMARY CANCER PREVENTION	Link	HORIZON
EXHEUSVITAL ECONOMIC, LEGAL AND IP FEASIBILITY STUDIES OF EXHEUS VITAL TEST	Link	HORIZON
Sagittarius A PRECISION MEDICINE TRIAL LEVERAGING BLOOD-BASED TUMOR GENOMICS TO OPTIMIZE TREATMENT IN	Link	HORIZON

OPERABLE STAGE III AND HIGH-RISK STAGE II COLON CANCER PATIENTS - THE SAGITTARIUS TRIAL		
ELGN-GI A first-in-class therapy for intestinal malabsorption in premature newborns	Link	HORIZON
TRUSTroke TRUSTWORTHY AI FOR IMPROVEMENT OF STROKE OUTCOMES	Link	HORIZON
CLAIMS CLinical impact through AI-assisted MS care	Link	HORIZON
IDERHA Integration of heterogeneous Data and Evidence towards Regulatory and HTA Acceptance	Link	HORIZON
InDx CMC Implant The InDx CMC Implant. A new treatment for thumb base joint arthritis.	Link	HORIZON
ERA4Health Fostering a European Research Area for Health Research	Link	HORIZON
MAGIC Minimally invasive reliAble Glucose monitoring in Intensive Care	Link	HORIZON
PAT4CGT Automated online monitoring & control to improve processes and decision making in cell and gene therapy manufacturing	Link	HORIZON
UNDINE The human genetic and immunological determinants of the clinical manifestations of SARS-CoV-2 infection: Towards personalised medicine	Link	HORIZON
EOSC4Cancer A European-wide foundation to accelerate Data-driven Cancer Research	Link	HORIZON
PRIME Prime editing to Repair Inherited Metabolic Errors: in vivo gene correction for human genetic disease	Link	HORIZON
VEMOtion Assistive Medical Robotics for Very Early Mobilization of Critical Care Patients	Link	HORIZON
aortoseal A minimally invasive and durable endograft fastening solution for Abdominal Aortic Aneurysm (AAA)	Link	HORIZON
EUonQoL Quality of Life in Oncology: measuring what matters for cancer patients and survivors in Europe	Link	HORIZON
ONCOVALUE Implementing value-based oncology care at European cancer hospitals: An AI-based framework for assessing real-life effectiveness of novel cancer therapies in real-time	Link	HORIZON
SBMP-microcarrier SBMP - disrupting the manufacturing of biological drugs through a	Link	HORIZON

ground-breaking nanotechnology-based microcarrier		
SYNTHEMA Synthetic generation of hematological data over federated computing frameworks	Link	HORIZON
AI CUrES AI to predict Cancer metastasis using Ultra-Echo-Sono imaging	Link	HORIZON
EChiLiBRiST Development and validation of a quantitative point-of-care test for the measurement of severity biomarkers to improve risk stratification of fever syndromes and enhance child survival	Link	HORIZON
TRUMPET TRUstworthy Multi-site Privacy Enhancing Technologies	Link	HORIZON
MyPath Developing and implementing innovative Patient-Centred Care Pathways for cancer patients	Link	HORIZON
SafePolyMed Improve Safety in Polymedication by Managing Drug-Drug-Gene Interactions	Link	HORIZON
MitoSen Detection and elimination of senescent cells targeting Cyclophilin D	Link	HORIZON
END-VOC ENDING COVID 19 VARIANTS OF CONCERN THROUGH COHORT STUDIES: END-VOC	Link	HORIZON
X-MiND Next generation X-ray/H+ Micro and Nano Scintillating Detectors	Link	HORIZON
STEPUPIORS TWINNING FOR A EUROPEAN CONSORTIUM OF RECTAL CANCER RESEARCH INSTITUTIONS THROUGH STEPPING UP SCIENTIFIC, TECHNOLOGICAL AND INNOVATION EXCELLENCE OF IORS	Project Link	HORIZON
RE-SHIFT Dismantling, REdialing, personalizing, and implementing task SHIFTing psychosocial interventions to treat and prevent common mental disorders in low-resource settings	Project Link	HORIZON
AMICAS Adaptive Multi-Drug Infusion Control System for General Anesthesia in Major Surgery	Project Link	HORIZON
Ganymed Next-generation surgical robotics to set a new standard of care in orthopaedic surgery	Project Link	HORIZON
HyperProbe Transforming brain surgery by advancing functional-guided neuronavigational imaging	Project Link	HORIZON
EPIVINF Epigenetic regulation of host factors in viral infections (EPIVINF)	Project Link	HORIZON

StrokeAlert- WomenEU Striking Stroke-enhancing and expanding StrokeAlert's business skills	Project Link	HORIZON
RMCmplxPheno Recurrent miscarriage as a complex phenotype: Harnessing large-scale clinical data to uncover underlying biological pathways	Project Link	HORIZON
MINIGRAPH Minimally Invasive Neuromodulation Implant and implantation procedure based on ground-breaking GRAPHene technology for treating brain disorders	Project Link	HORIZON
XTremedy Medical Developing a surgical infection treatment to reduce amputations, healing times and hospital stays for diabetic foot patients	Project Link	HORIZON
MEETMUSA Accelerating the iMpact of microsurgEry by upscaling production of thE world's first microsurgical roboT: MUSA	Project Link	HORIZON
HyperCollar4D Radical Improvement of Cancer Treatment without Additional Negative Side Effects	Project Link	HORIZON
RNhale Dry Powder Formulation of RNA Nanoparticles for Inhalation and Improved Storage and Transport Conditions	Project Link	HORIZON
ResisCHIP Rapid chip-based detection of antibiotic resistances	Project Link	HORIZON
CANDY Therapeutic discovery for cholangiocellular carcinoma	Project Link	HORIZON
HIPPOX The mechanobiology of hypoxia during bone regeneration	Project Link	HORIZON
RESEMBLE Long-read sequencing to resolve the missing heritability in patients suspected of PTEN hamartoma tumour syndrome	Project Link	HORIZON
HERVCOV SARS-CoV-2-induced activation of pathogenic endogenous retrovirus envelope HERV-W: towards personalized treatment of COVID-19 patients	Project Link	HORIZON
eCREAM enabling Clinical Research in Emergency and Acute care Medicine through automated data extraction	Project Link	HORIZON
TransPharm Transforming into a sustainable European pharmaceutical sector	Project Link	HORIZON
STRONG-AYA THE STRONG-AYA INITIATIVE: IMPROVING THE FUTURE OF YOUNG ADULTS WITH CANCER	Project Link	HORIZON

eCAP eCAP - Ehealth CAPsule for digestive disease diagnostics and therapy	Project Link	HORIZON
SAFEST Improving quality and patient SAFEty in surgical care through STandardisation and harmonisation of perioperative care in Europe	Project Link	HORIZON
D-SOLVE Understanding the individual host response against Hepatitis D Virus to develop a personalized approach for the management of hepatitis D	Project Link	HORIZON
ebeam4therapy Very High Energy Electrons Beam for Radiotherapy	Project Link	HORIZON
IDEAHL Improving Digital Empowerment for Active Healthy Living	Project Link	HORIZON
TROPHY ulTRafast hOlograPHic FTIR microscopY	Project Link	HORIZON
Edit-SMM EARLY DETECTION AND INTERVENTION IN SMOLDERING MULTIPLE MYELOMA: POPULATION-BASED SCREENING AND TREATMENT	Project Link	HORIZON
IMPROVING-GT Innovative strategies to increase engraftment of engineered hematopoietic stem cells and bypass genotoxic conditioning, toward the next-generation gene therapy		HORIZON
Dermatology and Venereology	UEMS-EBDV European Board of Dermato-Venereology	
Emergency Medicine		
Endocrinology	uems-endocrinology – Informational website for UEMS-Endocrinology members	
Gastroenterology & Hepatology	EBGH (eubogh.org)	
Geriatrics	Geriatric Medicine - Section of the UEMS (uemsgeriatricmedicine.org)	
Gynaecology & Obstetrics	EBCOG - European Board & College of Obstetrics and Gynaecology Home	
Infectious Diseases		
Internal Medicine		
Laboratory Medicine	-UEMS SLM | News (uems-slm.org)	
Medical Biopathology		

Medical Genetics	UEMS - Section of Medical Genetics - Home (uems-genetics.org)	
Medical Microbiology	Home | UEMS Section of Medical Microbiology (uems-smm.eu)	
Medical Oncology		
Nephrology		
Neurology	UEMS Section of Neurology - Home (uems-neuroboard.org)	
Neurosurgery		
Nuclear Medicine	uems.eanm.org	
Occupational Medicine	UEMS | Occupational Medicine (uems-occupationalmedicine.org)	
Ophthalmology	UEMS - Section of Ophthalmology - Welcome to our Website (uems-ophtalmologie.org)	
Oro-Maxillo-Facial Surgery	OMFSUEMS	
Orthopaedics & Traumatology	UEMS Specialist Section of Orthopaedics and Traumatology (uems-ortho.org)	
Otorhinolaryngology	UEMS ORL SECTION - (orluems.com)	
Paediatric Surgery	UEMS - Section of Paediatric Surgery (uemspaedsurg.org)	
Paediatrics	EAP - European Academy of Paediatrics | EAP - European Academy of Paediatrics (eapaediatrics.eu)	
Pathology	About | UEMS – Section of Pathology (wordpress.com)	
Pharmacology	UEMS Section of Pharmacology (uems-pharmacology.eu)	
Physical and Rehabilitation Medicine	The European Union of Medical Specialists UEMS PRM Section and Board (uems-prm.eu)	
Plastic, Reconstructive and Aesthetic Surgery	Welcome to EBOPRAS	
Pneumology		
Psychiatry	UEMS Section of Psychiatry (uemspsychiatry.org)	

Public Health Medicine		
Radiology	Homepage - European Union of Medical Specialists (uemsradiology.eu)	
Radiation Oncology and Radiotherapy		
Rheumatology	Rheumatology - Home (uemsrheumatology.eu)	
Surgery	UEMS Section of Surgery (uemssurg.org)	
Thoracic Surgery	Thoracic Surgery - Home (uemsthorax.eu)	
Urology	EBU | EBU	
Vascular Surgery	UEMS – Section and Board of Vascular Surgery (uemsvascular.com)	
Column 2: Specialist Divisions		
Reproductive Medicine		
Angiology/Vascular medicine	UEMS - Vas-Int Angiology Vascular Medicine	
Neuroradiology	Homepage - European Union of Medical Specialists (uemsradiology.eu)	
Interventional Radiology	UEMS | Division of Interventional Radiology - UEMS | Division of Interventional Radiology (uemsir.eu)	
Abdominal wall surgery (working group)	Abdominal Wall Surgery – UEMS Section of Surgery (uemssurg.org)	
Breast surgery	Breast Surgery – UEMS Section of Surgery (uemssurg.org)	
Coloproctology	Coloproctology – UEMS Section of Surgery (uemssurg.org)	
Emergency surgery	Emergency Surgery – UEMS Section of Surgery (uemssurg.org)	
Endocrine surgery	Endocrine Surgery – UEMS Section of Surgery (uemssurg.org)	
General surgery	General Surgery EBSQ Exam – UEMS Section of Surgery (uemssurg.org)	

Hepato-pancreato-biliary surgery	HPB Surgery – UEMS Section of Surgery (uemssurg.org)	
Minimal invasive surgery (working group)		
Surgical oncology	Surgical Oncology – UEMS Section of Surgery (uemssurg.org)	
Transplant surgery	Transplant Surgery – UEMS Section of Surgery (uemssurg.org)	
Transplant coordination		
Transplant immunology		
Transplant medicine		
Trauma surgery	Trauma Surgery – UEMS Section of Surgery (uemssurg.org)	
Column 3: Multidisciplinary Joint Committees		
Adolescent Medicine		
Breast Care		
Hand Surgery	European Board of Hand Surgery (ebhs.info)	
Immune Mediated Disease		
Infection Control		
Intensive Care Medicine	The European Board of Intensive Care Medicine » EBICM (esicm.org)	
Manual Medicine		
Network of Accredited Skills Centers in Europe (NASCE)	NASCE - Home (nascenet.org)	
Oncology		
Pain Medicine		
Paediatric Urology	EBPU/MJC-PU/EAPU - ESPU | European Society for Paediatric Urology	
Phlebology		
Rare & Undiagnosed Diseases	U.E.M.S. - Multidisciplinary Joint Committee - Rare and Undiagnosed Diseases | U.E.M.S. - Multidisciplinary Joint Committee - Rare and Undiagnosed Diseases (pte.hu)	
Sexual Medicine	MJCSM – Multidisciplinary Committee of Sexual Medicine	
Spine Surgery		
Sports Medicine		

Upper gastro-intestinal surgery	Upper Gastrointestinal Surgery – UEMS Section of Surgery (uemssurg.org)	
Wound Healing	mjcwoundhealing.org	
Column 4: Thematic Federations		
CESMA (Council for European Specialists Medical Assessment)	Main UEMS - CESMA	
EDI - Equality, Diversity, Inclusivity		
Green and Sustainable Medical Practice		
Hypertension		
Legal and Forensic Medicine		
Medical Ethics		
Vertigo		

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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