



# Empowering People who are Patients to move from testers to co-creators

The value and approaches to the successful development of  
eHealth solutions with people who are patients

🏠 Rütliweg 40, Arlesheim  
Basel-Land, CH-4144,  
Switzerland

✉ [Steve@personalpulse.com](mailto:Steve@personalpulse.com)  
☎ 0041 (0) 79 961 13 36  
🌐 [www.personalpulse.com](http://www.personalpulse.com)



# **From Testers to Co-Creators**

## **The Value and Approaches to Successful Patient Engagement in the Development of eHealth Solutions**

March 2023

### **Authors**

**Steve Bourke, MPhil MSc**

PersonalPulse GmbH  
Basel, Switzerland

**Christine Jacob, PhD**

University of Applied Sciences and Arts  
Northwestern Switzerland FHNW  
Basel, Switzerland

### **Collaborator**

**Sabina Heuss, PhD, Prof. Dr.**

University of Applied Sciences and Arts  
Northwestern Switzerland FHNW  
Basel, Switzerland



[www.personalpulse.com](http://www.personalpulse.com)

Copyright © 2023 All rights reserved

©Christine Jacob, Steven Bourke, Sabina Heuss. Originally published in JMIR Human Factors ([www.humanfactors.jmir.org](http://www.humanfactors.jmir.org)), 06.10.2022.

The results communicated in this white paper were initially published in an open-access article distributed under the terms of the Creative Commons Attribution License ([www.creativecommons.org/licenses/by/4.0](http://www.creativecommons.org/licenses/by/4.0)), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Human Factors, is properly cited.

Jacob C, Bourke S, Heuss S. From Testers to Cocreators—the Value of and Approaches to Successful Patient Engagement in the Development of eHealth Solutions: Qualitative Expert Interview Study. JMIR Hum Factors 2022;9(4):e41481. URL: [www.humanfactors.jmir.org/2022/4/e41481](http://www.humanfactors.jmir.org/2022/4/e41481)



# About this Project

The content of this whitepaper reflects the work done in partnership between PersonalPulse GmbH and the University of Applied Sciences Northwestern Switzerland (FHNW) and funded by Innosuisse (the Swiss Innovation Agency).

Innosuisse financially supports science-based innovation projects conducted by practice partners – such as PersonalPulse GmbH – jointly with a research partner – such as the FHNW – to develop new types of products, services or processes together.

# About the Authors



## **Steve Bourke**

Steven (Steve) Bourke is a dynamic advocate for Empowering People who are Patients. CEO of PersonalPulse GmbH is passionate about driving transformation in citizen-led healthcare innovation, working with stakeholders across the healthcare ecosystem to co-create relevant, usable, and sustainable results. PersonalPulse guides partners in developing mutual value-based pillars through co-creation with patients in digital health. Co-creates with ecosystem partners, including European Patient Forum, global and regional patient advocacy groups and pharma partners. He has also been instrumental in developing the DayOne HealthHack, Switzerland's first patient-centred hackathon. Coordinator of the patient advisory group for the multistakeholder IMI Pharmaledger project. He is a co-founder RheumaCura Foundation, EUPATI CH member and EUPATI fellow and a core member of the Institute for Human-Centered Health Innovation (IHCHI) Basel.



## **Dr. Christine Jacob**

With over 20 years of industry experience, Christine is a seasoned healthcare executive with several leading international positions in major Pharma companies such as Roche and Novartis. Her career encompassed several Digital Strategy roles where she aimed to help her stakeholders adopt creative and innovative user engagement strategies, successfully connecting with their key customers to create relevant and sustainable digital health solutions and implementation strategies. She also acts as a senior business consultant and strategy advisor to several major players in the healthcare industry, in addition to her work with Digital Health start-ups. Her research focuses on Healthcare Technology adoption, looking into the social, organisational, and technical factors impacting user acceptance of novel digital health tools. She led several research projects involving Pharma, digital health start-ups, and various European clinics and hospitals.

# About the Collaborator



## **Prof. Dr. Sabina Heuss**

Sabina Heuss is an anthropologist and scientist in communication and media studies. After senior positions in marketing and communication, she is currently working as a lecturer with a teaching and research assignment at the Institute of Competitiveness and Communication. She also gives lectures at the universities of Bern and Basel in the field of health care. Her research interests include communication in health care, robots and self-learning systems in physician-patient communication, communication campaigns in hospital settings, change communication, crisis communication.

# Expert Acknowledgement (in alphabetical order)

We are very grateful to the 20 industry experts that shared their expertise and contributed to this work. The 14 following experts agreed to be named, while the other six preferred to stay anonymous.

- [Dr Belinda von Niederhäusern](#): Patient Partnership Expert & Chief Product Officer
- [Cécile Tardy-Srinivasan](#): Digital Health Expert and Patient Expert
- [Christian Pfeuffer](#): Patient advocate
- [Daria Cantù](#): Service Designer and User Research expert
- [Emily Bridges](#): Co-founder & COO
- [Jenny Camaradou](#): EUPATI Patient Fellow, EU & UK Grants Knowledge Exchange & Research Associate
- [Dr Maren Schinz](#): Digital Health Expert & Patient Expert
- [Maria Rigoroso-Brandt](#): Global Patient Advocate
- [Marie Ennis O'Connor](#): Healthcare Communications Consultant
- [Roman Sauter](#): Digital Health Economist
- [Sam Krukliis](#): Cloud Architect for Healthcare and Life Sciences
- [Seb Tucknott](#): Patient Expert
- [Sunjoy Mathieu](#): Healthcare communications & digital health expert
- [Ursula Costa PhD, MBA](#): Manager patient experiences at DayOne



From top left to bottom right: Dr Belinda von Niederhäusern, Cécile Tardy-Srinivasan, Christian Pfeuffer, Daria Cantù, Emily Bridges, Jenny Camaradou, Dr Maren Schinz, Maria Rigoroso-Brandt, Marie Ennis O'Connor, Roman Sauter, Sam Krukliis, Seb Tucknott, Sunjoy Mathieu, and Ursula Costa.

# Table of Content

Title page	1
Copyright page	2
About this project	3
About the authors	4
About the Collaborator	5
Expert acknowledgement	6
Foreword	9
Executive summary	10
How to use this work to optimise your eHealth development efforts?	10
Main body	12
1. From Testers to Cocreators: the what and the why	12
1.1 An opportunity for change	12
1.2 The outlook for inclusion of People who are patients	13
1.3 Scope and aims	14
2. Defining what “good looks like” for engaging with people who are patients	15
2.1 How our experts defined good patient engagement in eHealth development	15
3. The value of including people who are patients	16
3.1 Identifying unmet needs and achieving better adoption	17
3.2 Better usability and desirability	17
3.3 Better health outcomes	17
3.4 Sense of purpose	17
3.5 Advocacy and trust	17
3.6 Better health equity and access	17
4. Challenges to the inclusion of People who are patients in eHealth	18
4.1 Compliance is the most prominent barrier	19
4.2 Patient-related factors	19
4.3 Power dynamics	19
4.4 Other barriers	19

5.	Practical recommendations to overcome the barriers and achieve better inclusion of people who are patients in eHealth development	20
5.1	Education and awareness	21
5.2	Measurement frameworks	21
5.3	Regulatory clarity and patient incentivisation	21
5.4	Patient access and identification	22
5.5	Transparency and trust	22
5.6	Mindset shift	22
6.	From theory to practice: a blueprint for inclusion of people who are patients at all stages of human-centred design	23
6.1	The current state of maturity	24
6.2	Sample considerations	24
6.3	Potential engagement strategies and approaches	25
7.	How can PersonalPulse help?	27
7.1	The organisation	27
7.2	The offering	28
Notes		29
A.	Use of language and terminology	29
B.	Funding for the original research	30
C.	Ethical considerations	30
D.	Methodology	30
E.	Data and anonymity	31
F.	Glossary of terms	31



# Foreword

Technology is rapidly changing the landscape of healthcare, impacting patient care in unprecedented ways. Advances in eHealth solutions, such as telemedicine, digital health records, and mobile health apps, are transforming the way healthcare is delivered, managed, and accessed.

While the intersection of technology and medicine presents a unique opportunity to revolutionize healthcare delivery and improve health outcomes, we should never lose sight of the fact that technology must ultimately serve patients in real-world settings. People who are patients must be seen as an equal partner in this digital transformation.

Despite this, patients are often excluded from eHealth development or involved only in tokenistic ways with little influence on the outcome. In turn, this can lead to suboptimal solutions that fail to meet the needs of patients, resulting in low user engagement and acceptance. We miss opportunities to deliver mutual benefit and importantly improve patient care and quality of life

The digital health ecosystem is undergoing a significant mindset shift. They struggle in how to recognize people who are patients as experts in their health and well-being and actively involved in the development process. The change is facilitated by creating partnership in every stage of the digital health innovation process, from ideation and design to testing and implementation.

The value of patients as partners and co-creators lies in their unique perspective and real-world experience ensuring solutions are genuinely patient-centered and meet the unmet needs of individuals managing diseases on a day-to-day basis. Moreover, co-creation fosters a sense of trust and transparency between stakeholders, thereby increasing patient engagement and satisfaction. Patients are more likely to feel invested in the process when they feel that their voices are being heard.

This white paper is essential reading for anyone responsible for creating and implementing eHealth solutions, from designers and developers to healthcare providers,

researchers, patients, and policymakers. It serves as a call to action for all stakeholders in the healthcare ecosystem to prioritize patient engagement and co-creation in the digital transformation of healthcare. The insights presented here can be used to develop a culture of inclusion of patients as valued partners in ways that are meaningful and sustained throughout all stages of eHealth development.

At this transformation point in medicine's history, it is more pertinent than ever to prioritize patient participation. Ultimately, the goal should be to make patient inclusion and co-creation standard operating procedure across the digital health ecosystem. By adopting the recommendations presented here, we can move towards a more human-centered approach to healthcare technology and empower patients as co-creators of solutions that truly meet their needs. Unlocking the full potential of eHealth technologies and improving healthcare outcomes and the experience of patients.

**Marie Ennis O'Connor**

*-Healthcare Communications Consultant*

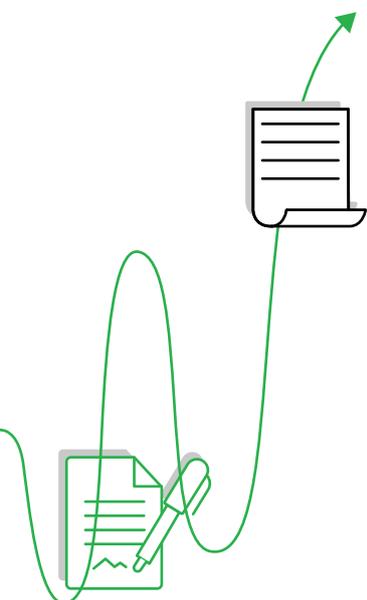
# Executive Summary

Developing successful and value-creating electronic health (eHealth) solutions is complex and requires input from expert stakeholders across the health and technology ecosystem. Many organisations struggle with the fundamental questions of how, when, and identifying individuals or communities to bring the voice of people who are patients into their development process and define and measure success. The discussion quickly turns to the value of that interaction for the companies and less the value for the patient. On the other side, people who are patients are requesting and have a more significant role to play in the development and co-creations of the impactful eHealth tools. Rather than the all too often tick-box lip service, sales and marketing-driven interaction in an attempt to gain the required mass adoption of solutions. To date, the role of the patients has mainly been as beta testers in the final stages or, more recently, at the ideation stage. Rarely as key decision-makers hence one of the reasons unmet needs can be diluted as a project develops, and when it reaches a community, the solution provided needs to be revised. Revisions at the pre-launch stage are not possible and only aesthetic.

To maintain the mutual value, we provide the blueprint for including patients at all stages of human-centred development (HCD). We advocate for a paradigm shift, looking to move the patient from the role of the tester to that of the co-creator.

## How to use this work to optimise your eHealth development efforts?

- We offer an in-depth understanding of the challenges and opportunities in including patients in developing eHealth technologies and discuss strategic approaches and practical steps to address the identified challenges and capitalise on the opportunities.
- We present an evidence-based tool for overcoming the identified gaps and creating an end-to-end practical blueprint that can guide the relevant stakeholders to successfully engage people who are patients as co-creators in all HCD phases rather than mere testers of preplanned prototypes.



It was essential to gather a balanced understanding of the current state of engagement, barriers, and facilitators in developing tools that bring impact and value, moving patients from testers to co-creators. Discussions with 20 experts from six European countries and across the health ecosystem, including patient experts, eHealth experts, health technology providers, clinicians, pharma executives, and health insurance experts, helped us generate the required science-based findings and recommendations.

Overcoming the current gaps in patient engagement in eHealth development requires consolidated efforts from all stakeholders in the complex healthcare ecosystem. The shift towards more human-centred eHealth development requires education and awareness, frameworks to monitor and evaluate the value of patient engagement, regulatory clarity and simplification, platforms to facilitate patient access and identification, patient incentivisation, transparency and trust, and a mindset shift towards value-based healthcare. By switching the role of patients from testers to co-creators, eHealth can lead the way in empowering people who are patients and help unlock the ultimate potential of these novel technologies.

The practical insights presented in this work can be used for a

project level in eHealth but are also applicable to developing a culture of inclusion of people who are patients as valued and trusted partners in the development of any type of digital health solutions. We outline seven recommendations to overcome perceived and actual gaps in eHealth development. Education and awareness, measurement frameworks, regulatory clarity and simplification, patient access and identification, patient incentivisation, transparency and trust, and mindset shift; each, in turn, should be addressed to move towards a more human-centred approach to eHealth development.

*“The people developing or thinking of building a solution if they feel somehow identified with the patient, there’s an energy in the team which you have not seen before...it’s really identifying with the goal to find a solution for this problem”*

*–Health Insurance Expert*

Our proposed blueprint outlines the end-to-end, which facilitates the inclusion of people who are patients in delivering mutual value to the

relevant stakeholders across the stages of HCD. It is designed to break down barriers and move past the current state where patients are usually engaged too late in the development process, mostly assuming a sounding role in testing a ready-made prototype. Addressing the five phases of HCD and adding the critical aspect of lifecycle management, the blueprint acts as a guide for organisations to make actionable changes to include patients as key stakeholders across the HCD. It provides insight into the current state of maturity of the inclusion of patients’ voice at each stage, considerations of the sample selection, and potential approaches for strategic engagement with diverse patient populations.

In conclusion, this white paper is designed to drive towards successful outcomes and allow all partners in the eHealth development ecosystem to understand and address the value of genuine patient engagement, barriers, and facilitators that impact moving people who are patients from testers to co-creators, and discusses strategies and approaches to overcome these barriers.



# 1. From Testers to Cocreators: the what and the why

There is a paradigm shift within health care; people who are patients are asked to take an active role in the design, delivery and development of solutions. Combined with the extraordinary pace of digitisation of all aspects of health, the role of the patient is changing. A patient who is better informed and empowered to take ownership of the management of their disease is more likely to understand and commit to treatment plans, prepare for future eventualities of life and capture their individual quality of life as it relates to health or lack thereof.

*“I think their involvement is always crucial because that should always be the overall objective, really improving patient life”*

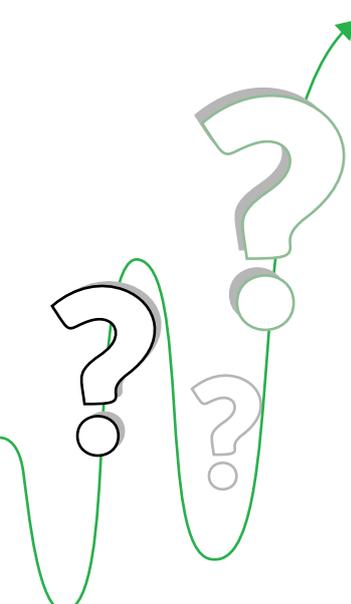
*-eHealth Expert*

## 1.1 An opportunity for change

This change requires the traditional and new players in health care to change how they and the system interact with people who are patients. This shift in value and role is no more evident than in developing eHealth tools and solutions.

*“I don't see patient engagement as—I do my project, and now I send you a questionnaire. And now I ask you, do you like it?—That's for me, not patient engagement. Patient engagement is having them all the way.”*

*-eHealth and Patient Expert*





The inclusion of patients' voices has undergone an impressive change over the past decades. This has been most evident in traditional therapeutic development. This is not yet the case in eHealth and digital health, where the inclusion and understanding of the ecosystem for patient inclusion is less mature. To drive impact and understanding, there is a need to support the discussion with science-based research. It will go towards strengthening the argument and making the shift from testers to co-creators standard operating procedure across the industry. This white paper discusses the findings of our peer-reviewed paper that was published in September 2022 [“From Testers to Cocreators—the Value of and Approaches to Successful Patient Engagement in the Development of eHealth Solutions: Qualitative Expert Interview Study”](#), in the JMIR Human Factors. All of the work presented in the white paper has its foundation in the expert opinions provided and research published in the peer-reviewed paper.

## 1.2 The outlook for inclusion of People who are patients

The future is where the value of patients as partners and co-creators is the norm, and people are no longer seen as subjects or testers. Continued innovation in eHealth requires meaningful insight adoption of solutions that are conscious and address the unmet needs of the individuals managing disease as part of their lives.

*“I think it’s really about partnering, right? We’re partnering at eye level with another expert, let’s say, in what this person has gone through or is experiencing in their daily life”*

*–Pharma Expert*

The current status quo for many is to engage with patients for validation at the delivery of a solution to “tick the box” of patient inclusion. There was a universal acceptance among all the experts we spoke with that patient involvement is most commonly done at the beginning of research or to test readily available prototypes; the patient is not involved at all stages of the development resulting in solutions that offer far-from ideal outcomes to address the management of disease on a day to day basis, leading to extremely [low adoption and high attrition rates](#).

The perceived business case does not consider the individual's needs. The balance of power is towards the solution's owner, the payers, and the clinicians who make the treatment decisions, with patients undertaking late-stage consultation rather than equal stakeholders with a decision-making role. Nonetheless, true patient empowerment necessitates a shift from a patients-as-testers mentality to patients as equal partners and cocreators, which can be achieved by involving them in every step of the human-centred design (HCD) process.

*“In order to build solutions that solve real-world problems for patients, then you need to use this really deep insight into the person behind the disease and in the context of their daily life. And honestly, you can’t do that without working very closely with the patient”*

*-Patient Expert*

### **1.3 Scope and aims**

The scope of this work focuses on patient-facing eHealth tools, including self-management tools and remote eHealth solutions, and excludes tools with no patient interface, such as those used within and between care providers (e.g., health care provider videoconferences or electronic health record integration) or health data analytics systems used at the population level.

*“Ideally, you co-develop things with them, not just you just get their perspective, and that’s it because it’s also at the same time, you’re also changing their behaviour...it’s more sustainable”*

*-Clinician and Pharma Expert*

This white paper aims to support the key stakeholders across the healthcare ecosystem to systematically cocreate with patients and assist in developing eHealth solutions tailored for people in specific contexts and with specific needs. It is a tool to help bring supporting, rigorous science-based research to life in a practical and impactful manner. This allows for ethical designs that respect privacy and quality of life, leading to the creation of more relevant and safer tools that are more likely to be adopted by their intended users for better health outcomes through the empowerment of people who are patients.



## 2. Defining what “good looks like” for engaging with people who are patients

Successful delivery of an eHealth solution requires a variety of expert knowledge, as demonstrated by the cross-functional expert panel interviewed. Building a greater understanding of the value of the inclusion of patients required gathering the individual definition of what “good looks like” across the ecosystem. Two aspects can address this question: the meaning of patient engagement and the value of that engagement. Even with the diverse background of the expert panel, there were several consistent themes when they considered the meaning of patient engagement.

*“Good patient engagement, it’s putting the patient at the—give them a seat on the table at the same level as everyone else”*

—eHealth and Patient Expert

### 2.1 How our experts defined good patient engagement in eHealth development

- Bringing patients’ voices to the process
- Cocreation and partnership
- Empowering people who are patients to make a change in their quality of life
- Engaging them from A to Z
- Integrating people who are patients as equal partners in health care

*“A much greater focus on getting the patient voice and really not even just the patient voice, but the diversity of the input and running everything by getting everything prototyped in a designed way before we go into writing a line of code”*

—Clinician and eHealth Provider



### 3. The value of including people who are patients

To include patients in the developments actively requires an understanding of the value to their partners both internally and externally. Figure 1 below outlines those values and reflects their frequencies in the expert interviews; the larger the section, the more of our more experts who mentioned a particular value. This is not to imply that one value is more significant than another but only to signal the frequency of its occurrence in our sample.

When reviewing each of the occurrences of values as mentioned by our expert panel, there is a tendency to focus on those which are mentioned most often. However, all should be observed as mutually valuable. The onus is on organisations to identify which is best suited to their situation and assist in discussions with the decision makers internally to drive a more holistic approach to the engagement with people who are patients. You can then express these values to the patient communities you look to partner with and seek alignment. Identification of mutual value proposition will aid in a differing discussion. Below we delve deeper into individual values.



**Figure 1:** Value of including people who are patients in eHealth development (adapted from [www.doi.org/10.2196/41481](http://www.doi.org/10.2196/41481))

### 3.1 Identifying unmet needs and achieving better adoption

One of the most prominent values is the ability to identify unmet needs, better usability and desirability of the tools, which typically result in better adoption and stickiness, and a more holistic view that better fits into the overall patient journey. These values are self-evident for those who have had the opportunity of working closely with people who are patients.

*“The most important thing is that you are sure that there’s an acceptance of what you’re doing, that patients, in the end of the day, take your product, your concept, your whatever because they want to use it”*

*–Clinician and eHealth Expert*

### 3.2 Better usability and desirability

Engaging people who are patients in the development of these tools also [safeguards their usability and safety](#). This is reflected in how institutions such as the Food and Drug Administration [demand evidence of end-user engagement](#) in health technology design when reviewing market presubmissions.

*“You get really a feeling of is this really something the patient would use afterwards, or need in their life, in their daily living, and in their world”*

*–eHealth and Patient Expert*

### 3.3 Better health outcomes

The tools’ better adoption and stickiness implies better health outcomes mainly because of adherence, which enables the least technically capable patients to still use those tools, resulting in better health equity and access.

### 3.4 Sense of purpose

The possibility also arises that you may have yet to consider the value of a sense of purpose for including the patient’s voice. It gives an additional and extremely meaningful purpose to the developing teams. Many may not have had the advantage of gathering in previous projects, and they can relate better to the patient’s needs and pain points.

*“Having that engagement creates a more powerful purpose for the team”*

*–Technology Provider and Pharma Expert*

### 3.5 Advocacy and trust

This value may expand and change as a project moves forward; however, taking the time to understand and maintain the value is necessary to assist in the continued development of trust from patients in our eHealth solutions.

*“If you have contributed to developing and you see that this has been developed by also patients like you, then you are more also prone to use it”*

*–eHealth and Patient Expert*

### 3.6 Better health equity and access

The inclusion of diverse profiles of patients with different skill sets and capabilities may contribute to creating more inclusive designs that lead to better equity and access to health care.

# 4. Challenges to the inclusion of people who are patients in eHealth

To develop a blueprint which offers real-world solutions for stakeholders across the entire eHealth ecosystem in having people who are patients genuinely included at each stage of the human-centred design process, it was necessary to gain a more comprehensive

understanding of both the barriers and facilitators.

Figure 2 below summarises the challenges facing the engagement of people who are patients in eHealth development and reflects their frequencies in the expert interviews.



Figure 2: Challenges of engaging people who are patients in eHealth development (adapted from [www.doi.org/10.2196/41481](http://www.doi.org/10.2196/41481))



**4.1 Compliance is the most prominent barrier**, with participants mentioning the complexity of regulatory processes as a critical hurdle. Participants pointed out that this may also be partly a perception issue in that some stakeholders may perceive compliance as more complex than it actually is.

*“There’s a lot of question marks about how you engage with patients and how you get their feedback in a compliant manner.”*

–eHealth Provider

**4.2 Some patient-related factors** may also make engaging patients in eHealth development difficult. Specifically, not only are patient identification and patient access a key hurdle, but also, some health-related constraints may render it difficult for some patients to engage, or some patients lack the needed skills to engage efficiently.

**4.3 Power dynamics** in the healthcare sector may also hinder patient engagement. Patients not being seen as equal partners, conflict of interests among the stakeholders, the economic model that gives more power to the payers, patients not being given a safe space to express their needs and pain points, and the lack of decision power in many cases can negatively impact patients’ involvement.

*“For some of the players, it starts with, unfortunately, the mentality which was developed, regulations are there, and they’re perfectly fine. We need guardrails, but it drove, unfortunately, this mentality that if you’re within a research organisation or pharma, you actually never get to speak or talk to a patient.”*

–Technology Provider  
and Pharma Expert

**4.4 Other barriers** included patient engagement being considered a marketing activity or lip service by some stakeholders, the lack of clarity on the value that patient engagement may bring, resource constraints, mistrust between patients and other stakeholders, and sometimes a mere inflexibility of some eHealth providers.

*“There is an access issue, I think. So, a lot of companies, although they claim to be experts in the disease area, actually aren’t embedded in the patient community. So, they’re having to go through maybe doctors or charities to gain access to those patients. And it adds like a wall for them that they don’t have that direct conversation.”*

–eHealth Provider

# 5. Practical recommendations to overcome the barriers and achieve better inclusion of people who are patients in eHealth development

Through detailed analysis of the insights provided by our expert panel, and discussions around potential opportunities for genuine

patient engagement, we arrived at seven practical implications for the inclusion of people who are patients in a more human-centred

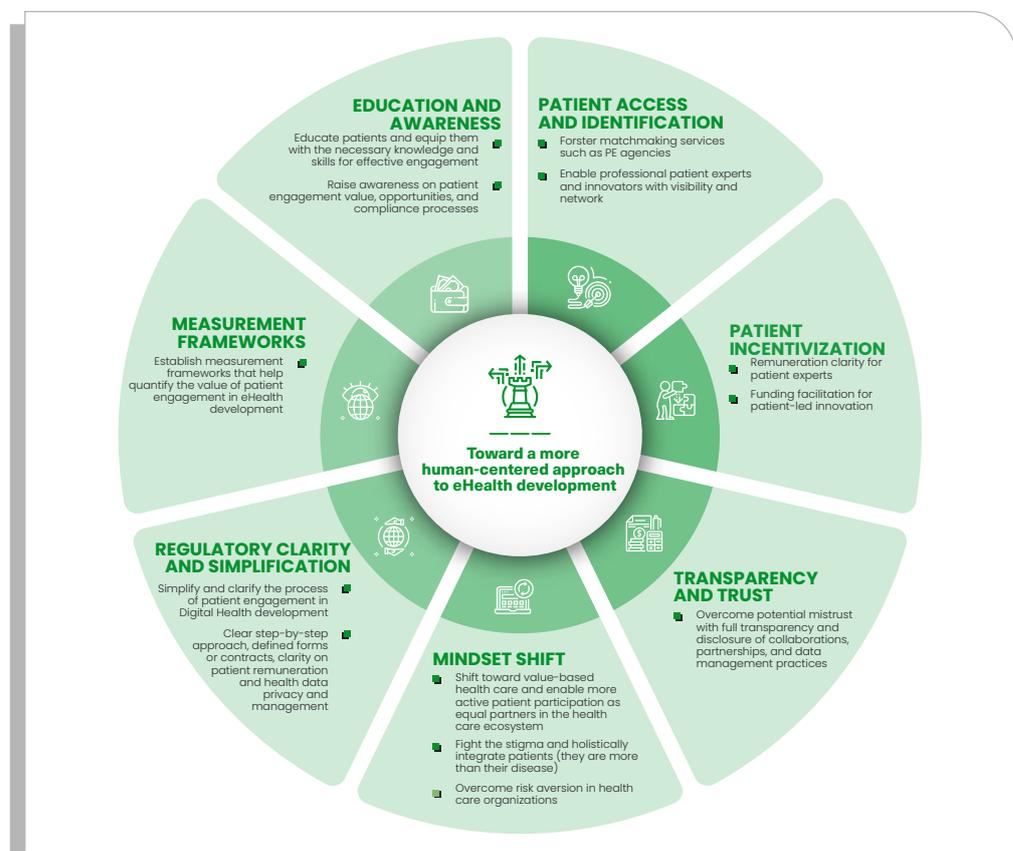


Figure 3: Recommendations for more patient-driven eHealth development (adapted from [www.doi.org/10.2196/41481](http://www.doi.org/10.2196/41481))



approach to eHealth development. Figure 3 below demonstrates the seven recommendations that can be actively implemented to tap into meaningful opportunities, drive change and create an impact for a more patient-driven eHealth development.

The recommendations are presented to assist in understanding and facilitating discussions on overcoming the current gaps in patient engagement. They require a multistakeholder approach to allow for a co-creation resulting in a future where patients are included as partners. Do not consider each as an independent recommendation. Policymakers, clinicians, eHealth providers, pharmaceutical companies, insurance companies, patient organisations, advocacy groups, and healthcare innovation incubators must work hand in hand to induce change and harness the potential value that true co-creation with patients can bring. The intertwined nature of these recommendations is expected to grow, expand over time and bring lasting value to organisations.

### **5.1 Education and awareness**

are vital to improving the meaningful involvement of patients. On the one hand, it involves educating patients and equipping them with the necessary knowledge and skills for effective engagement and contribution. There are examples of organisations providing patient education programs; however, more efforts are needed in eHealth and all that it entails from

specific technical skills. On the other hand, it is crucial to raise awareness of the value that the inclusion of patients can bring, provide platforms that may help promote opportunities to bring insights and expert knowledge from patients and provide more information about relevant compliance processes.

### **5.2 There is also a need for measurement frameworks**

that can help quantify the impact of the involvement of patients to shed light on the business case for it and overcome the value perception barrier. Some organisations are digging deeper into this issue in attempts to create tools that may help evaluate patient engagement. For instance, the citizen-led organisation Patient-Focused Medicines Development (PFMD) offers the [PEM suite](#). The PARADIGM project developed [a toolbox](#) to help better monitor and evaluate patient engagement.

### **5.3 Regulatory clarity and patient incentivisation**

As compliance was identified as a significant challenge by almost all participants, working on making it more accessible would also be central in facilitating this type of engagement. A straightforward step-by-step approach, templates for agreements and contracts, clarity on patient remuneration, and health data privacy and management would encourage the relevant stakeholders to involve and co-create with patients compliantly and transparently, which can reduce compliance risks.



The lack of globally accepted guiding principles around this topic pushed organisations such as Patient-Focused Medicines Development to create resources, such as [sample agreement templates](#), to facilitate compliant engagement and collaboration between patients and providers of medical technologies. The Workgroup of the European Cancer Patient Advocacy Networks (WECAN) has also issued similar [guiding principles](#) on reasonable legal agreements between patient advocates and pharmaceutical companies.

*“I think it’s important to incentivise people in some way because most people can’t be bothered to give their feedback or—yeah, give a real motivation as to why people should get involved.”*

*–Patient Expert and eHealth Provider*

#### **5.4 Barriers such as patient access and identification**

could be overcome by working with partners and promoting novel approaches to empower professional patient experts and innovators with visibility and networks. The rise of [matchmaking services](#) can also play a positive role in overcoming these barriers; agencies that focus on identifying patient experts to match them with suitable opportunities are a good example.

#### **5.5 Transparency and trust**

Potential mistrust between different stakeholders can be overcome with complete transparency, disclosure of collaborations and partnerships, and more clarity on data management practices.

*“Because participation is also built on trust and so everything has to be very transparent and clear.”*

*–eHealth Expert*

#### **5.6 Mindset shift**

This change would also require a mindset shift toward more value-based health care, as [research](#) has shown that only once patients are allowed to participate in managing their health actively, they take ownership of their disease management, thus improving health outcomes. This would help overcome the current imbalance in power dynamics, reinforce a more active role for patients, fight the stigma around disease and being a patient, empower patients, and encourage them to speak up.

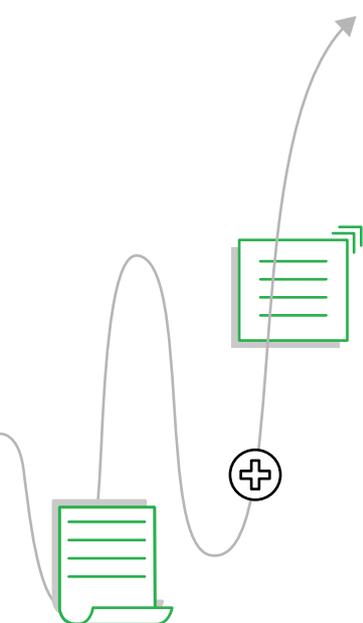


## 6. From theory to practice: a blueprint for inclusion of people who are patients at all stages of human-centred design

In light of the experts' views on the value of engaging people who are patients in eHealth development, in contrast with its current state of maturity (or the lack of), we propose an end-to-end practical blueprint that can guide the relevant stakeholders to successfully engage people who are patients as equal partners and cocreators in all phases of the HCD rather than mere testers of preplanned prototypes.

We chose the Human-centric design as the conceptual framework for the proposed blueprint because it places the people we are trying to serve at the centre and offers them the space to become partners in eHealth

innovation. It is an iterative approach in which the focus is on understanding the dynamics between stakeholders across the ecosystem and cocreating with them. The framework allows for a systematic investigation of the gaps and possible engagement opportunities for each step of the design process, rather than only the testing phase, as is commonly the case. Figure 4 below shows the proposed blueprint, summarising the state of maturity at each phase of the design process, and presenting suggestions for patient sample considerations and recommendations for the most suitable engagement approaches and strategies for each phase.



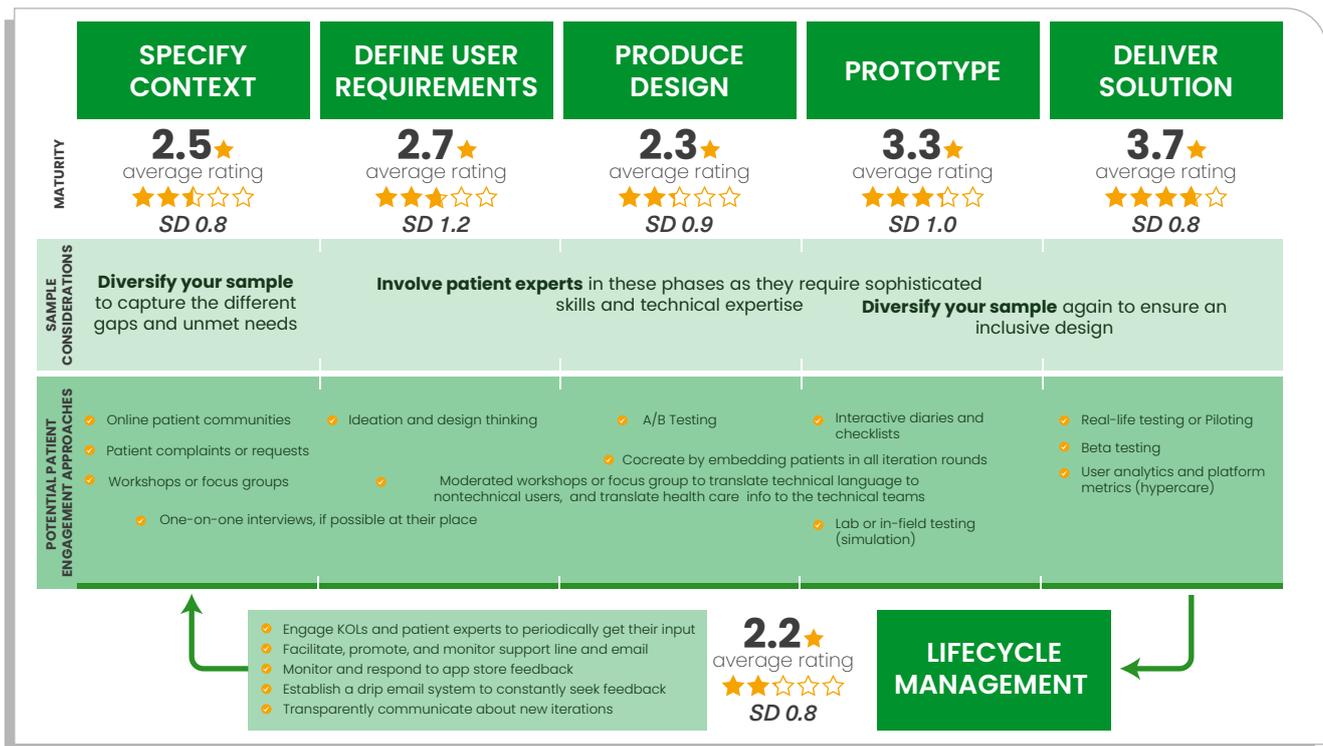


Figure 4: The proposed blueprint for engaging people who are patients as cocreators of eHealth technologies (adapted from [www.doi.org/10.2196/41481](http://www.doi.org/10.2196/41481))

### 6.1 The current state of maturity

While patients are mostly involved at the very end of the development process to test pre-planned prototypes - which is the development phase with the highest maturity score according to our participants - the middle phases of the design process seem to be the least mature, partly due to the technical nature of the discussions during these phases. Lifecycle management - or the continuous development and improvement of eHealth tools after they hit the market - is the least mature of all, according to our experts' practical experience. Developers don't seem to systematically collect patient input after the launch of their tools, missing a clear opportunity to keep their tools relevant and competitive in the long term.

### 6.2 Sample considerations

Sample diversification and tapping into the insights of patient experts that are equipped with the disease experience paired with the necessary professional know-how to engage in meaningful technical discussions may help overcome the lack of patient involvement in the design phases that require relevant professional skills such as the understanding of technology development.

However, it is crucial to ensure the diversity of patients engaged, especially in the first and last phases of the design, to ensure the creation of an inclusive design that is still usable even for the least capable users, enabling more healthcare equity and access.



*“If you can basically involve patients with different types of levels of understanding earlier on in the process, you’re more likely to get a product that actually is tailored to everybody’s familiarity.”*

-Patient Expert

### **6.3 Potential engagement strategies and approaches**

the blueprint also proposes different engagement approaches for each of the development phases.

For instance:



When specifying the context in the early phases of the design process, it’s helpful to monitor discussions in web-based patient communities and to look into patient complaints to their care teams. Conducting patient workshops or focus groups, as well as one-to-one interviews, may also provide in-depth insights, primarily when conducted in the patient’s natural environment, to best reflect the entire patient journey and unaddressed needs.



When collecting user requirements, the discussion becomes more technical; hence, engaging professional moderation services can enhance the chances of a mutual understanding between stakeholders with varying technical skills. Ideation sessions using a design-thinking approach and benchmarking existing apps are crucial strategies at this stage.



When producing the design and prototyping, additional approaches such as A/B testing can help assess user acceptance of things like language and design elements before moving to prototype to ensure that the basic design resonates with the potential users. Simulations and laboratory and in-field testing are very relevant at this stage. They help developers better understand actual user behaviour rather than solely relying on self-reported feedback through surveys or checklists.

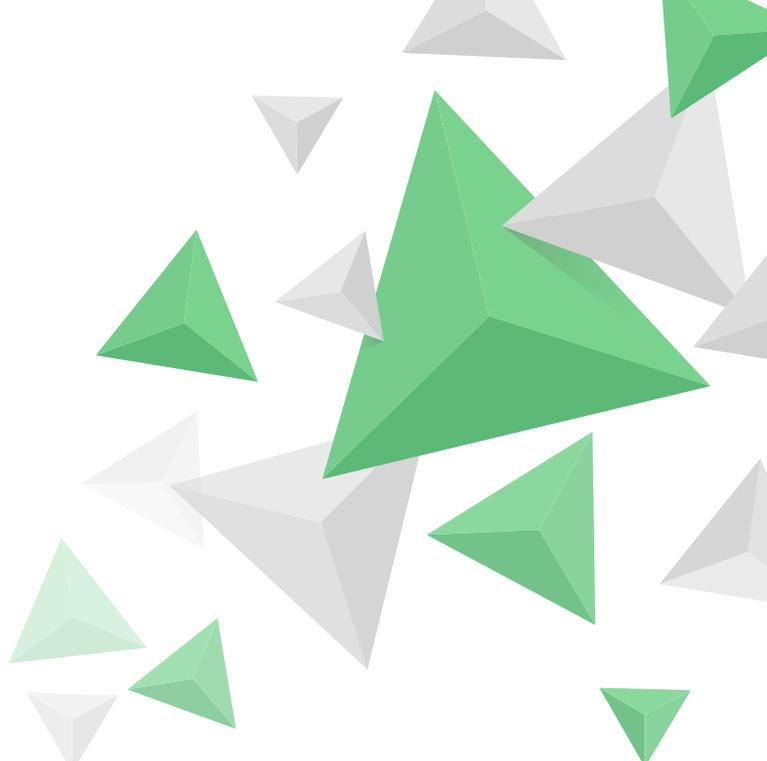


When delivering the solution, real-life setting testing becomes crucial to ensure that the tool fits well into the daily routines and treatment plans of people who are patients. Strategies such as beta-testing or piloting can be valuable in allowing eHealth providers to test their tool in a real-life setting on a smaller scale before rolling it out. It is also advised to have a hypercare period immediately after the launch of any eHealth tool, where developers closely monitor user analytics and platform metrics to act swiftly in case of any issues, providing a smoother integration in a real-world setting.



After the tool's launch, lifecycle management is vital to keeping the tool relevant and the business sustainable and competitive over the long term. Periodically engaging patient key opinion leaders to obtain their input and drip email systems to seek users' feedback constantly are examples of useful strategies at this stage. Transparent communications about new iterations to inform users how their feedback was taken into account in the constant development of the tool may also foster trust and enhance long-term engagement.



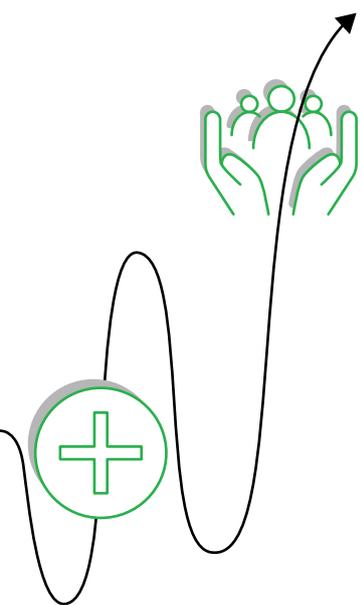


## 7. How can PersonalPulse help?

*PersonalPulse* is driven by Empowering People Who Are Patients. By proactively partnering across the entire healthcare system, PersonalPulse can give and gain value to all stakeholders. Are you inspired to create lasting change for people who are patients? Take the next step above patient-centricity and create a sustainable future where citizens hold the empowering position of partner. Personal Pulse will work with you to make that a reality. At the core, PersonalPulse believes in science-based research to bring lasting change to health system solution delivery. Our goal is that co-creation with people who are patients is the norm, not the exception.

### 7.1 The Organisation

With numerous successful projects and years of professional and personal expertise paired with a vast network of experts in all relevant healthcare stakeholder groups, PersonalPulse focuses on addressing the actual pain points in engaging people who are patients, targeting the tremendous value they can bring to close the current gaps, using systematic and strategic approaches. We partner with the experts who make up the PersonalPulse Gilde, a community of artisans practised in delivering meaningful outcomes that drive success and empower people who are patients. To understand the who, the what, and the why of PersonalPulse, [click](#) here to find more.

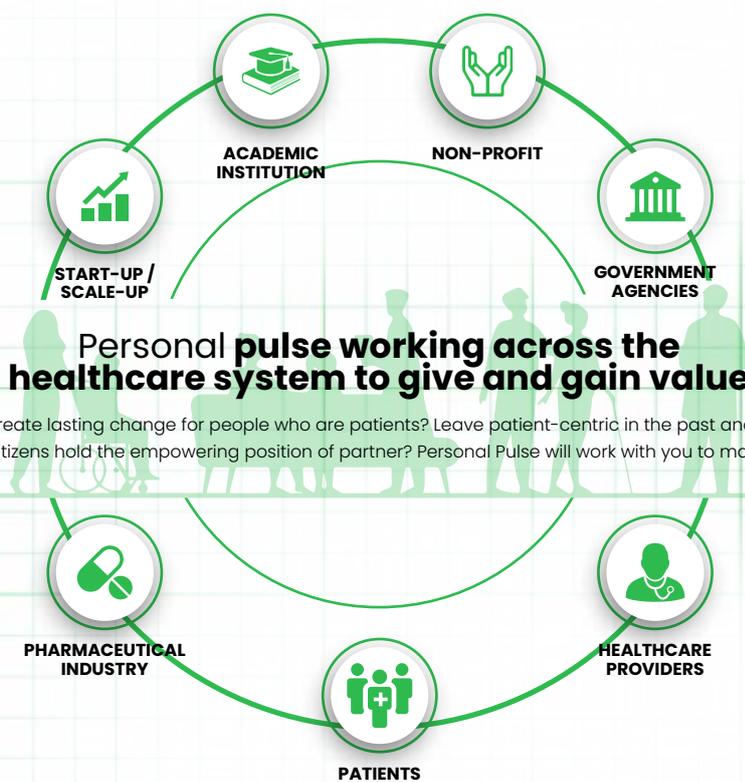


## 7.2 The offering

PersonalPulse has crafted and developed a set of tools to facilitate impactful value-based solutions that will bring the voice of patients into eHealth projects—creating a culture change where patients are part of the team at all product life cycle development stages. PersonalPulse is expertly positioned to facilitate and develop the strategy required to develop and complete eHealth projects driven by a mutual value for each stakeholder. It is a key step in the inclusion of people who are patients at all stages of human-centred eHealth development.

There are numerous gaps where organisations can look to improve their partnership with people who are patients, and PersonalPulse will

work with you to fill the gaps. Our offerings can assist in identification and access through matchmaking, help navigate compliance and access best practices resources for contracting and incentivising patients, moderation and facilitation to ensure technical teams and patients understand each other and manage expectations etc. PersonalPulse will take your organisation through the planning and implantation of the blueprint. This, in turn, can ensure a solid development and testing process involving the right type of patient at the right time in your eHealth or digital health development, leading to more adherence, acceptance, and approval by the community of patients who will use your solution in the real world.



# Notes

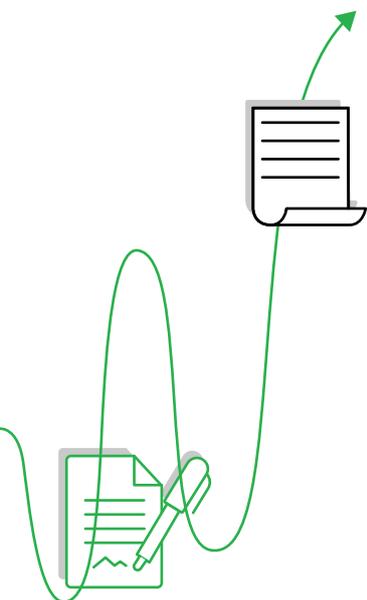
## A. Use of language and terminology

There was a considered language change by the authors from the peer-review manuscript and the white paper. Facilitating a mindset shift requires a considered and collaborative approach. To facilitate clarity in the message for the academic audience, specific “standard terms” were used throughout the manuscript. We recognise that these can be a challenge for people who are patients. An example is the use of the phrase “Patient engagement”. The phrase is in the lexicon of many partners and has become widespread in use. People who are patients were not included in the discussion of this and many terms. In discussion with our expert panel, we received a wide range of understanding and “what good looks like” when referring to patient engagement.

Similar discussions arise using the term “patient” in health. Both the

perception and definition of an “individual awaiting or under medical care and treatment” create a situation that dehumanises the individual and can impact the mindset change required to develop partnerships of mutual co-creation proactively.

We acknowledge that depending on the context and the stakeholders involved in the discussion, the use of accepted language may drastically change. Many of the well-established terminology around “patient engagement” did not include people who are patients when naming them. Therefore, we use terminology that takes this into account and sensibly respects people who are patients and the discussion around the use of specific language. To develop mutually beneficial solutions for stakeholders, we encourage actively creating the opportunity to discuss the language most accepted by the communities it serves.



## B. Funding for the original research

Funding for the peer-review was secured from Innosuisse Swiss Innovation Agency under the InnoCheque program, [grant number: 60330.1 INNO-ICT](#).

## C. Ethical considerations

The Ethics Committee of Northwest and Central Switzerland (EKNZ) determined that ethical approval was not needed for original peer-review research according to the Federal Act on Research involving Human Beings, article 2, paragraph 1 (reference number Req-2022-00119). All participants were briefed about the research background, signed a consent form, and agreed to participate.

## D. Research Methodology

This research used purposive sampling. Potential participants were recruited based on their ability to provide rich and in-depth information about the research topic; they had to be individuals who have personal experience with the topic being studied so that they could articulate their real-life experiences. The main selection criteria were that participants must belong to one of the key relevant stakeholder groups (ie, patient experts, patient organisations, eHealth providers and developers, clinicians, pharmaceutical experts, payers, and health tech researchers) and must have eHealth knowledge and experience to ensure a comprehensive view that takes the different perspectives into

account when identifying the existing gaps and challenges and how to overcome the existing gaps and challenges with strategic patient engagement points and their realisation to extend the benefit for all involved parties. After shortlisting the participants of interest, as per the criteria explained earlier, the researchers contacted the key informants. To minimise potential selection bias, the researchers worked with the key informants to identify suitable participants in their network, a sampling technique called snowballing, where the researcher builds the sample through the network of other participants, in this case, the key informants. Figure 5 below gives an overview of the research methodology and sample characteristics.

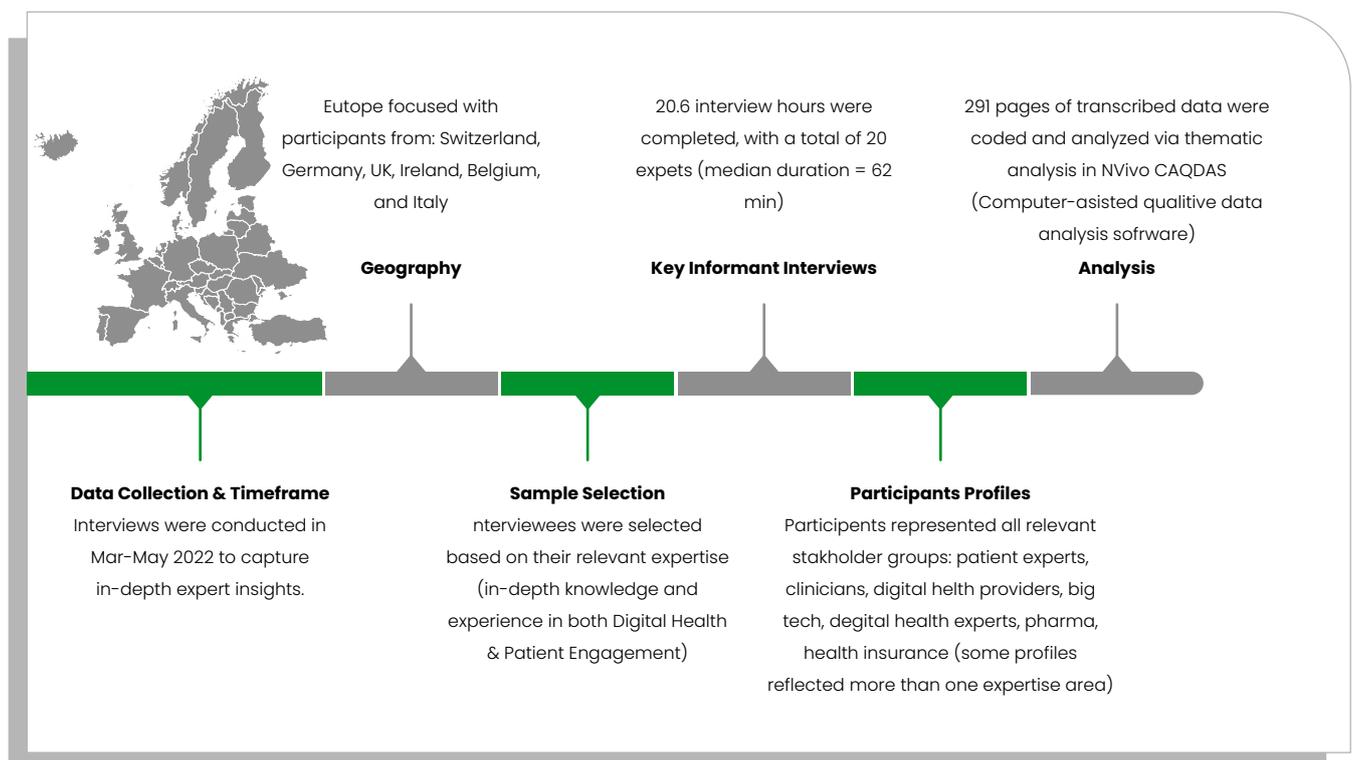


Figure 5: Overview of the research methodology and sample characteristics

## E. Data and anonymity

The twenty interviews generated over 290 pages of transcripts. Data was only accessible to the research team. Each expert was provided with the opportunity to be identified in the white paper as recognition for their commitment to facilitating the paradigm shift for people who are patients to move from testers to co-creators. Experts who agreed to be named provided a written waiver of anonymity for the whitepaper. The peer-reviewed paper data was and remains anonymised, as well as the quotes used in this white paper to protect the individual participants' privacy.

## F. Glossary

**eHealth:** electronic health

**[JMIR Hum Factors:](#)** The Journal of Medical Internet Research Human Factors

**HCD:** Human-centred design

**[PFMD:](#)** Patient Focused Medicines Development

**[EUPATI:](#)** The European Patients' Academy on Therapeutic Innovation

**[EKNZ:](#)** The Ethics Committee of Northwest and Central Switzerland

**[Innosuisse:](#)** Swiss Agency for Innovation Promotion

**[FHNW:](#)** University of Applied Sciences and Arts Northwestern Switzerland

**[WECAN:](#)** Workgroup of the European Cancer Patient Advocacy Networks