Human-centered integrated care pathways for co-creating a digital, user-centric health information solution

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Abstract

Purpose – A broader challenge of co-creating digital solutions with patients addresses the question how to apply an open-access digital platform with trusted digital health information as a measure to transform the way patients access and understand health information. It further addresses use this for adherence to treatment,

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risk minimization and quality of life throughout the integrated patient journey. The aim of this paper is to demonstrate the early steps in towards progress to co-creating the digital solution.

Design/methodology/approach – To coordinate the co-creation process, the authors established a multiphased plan to deep-dive into user needs and behaviors across patient journeys, to identify nuances and highlight important patterns in stakeholder and end-user segment at various stages in the patient's journey.

Findings – A set of tools was designed to serve as a human-centered compass throughout the lifecycle of the project. Those tools include shared objects; personas, user journeys, a set of performance indicators with related requirements – all those tools being consistently refined in ongoing co-creation workshops with members of the cross-functional stakeholder groups.

Originality/value – In this study, a multidisciplinary, public-private partnership looked at integrated digital tool to improve access, understanding and adherence to treatment for diverse groups of patients across all stages of their health journeys in a number of countries including European Union (EU) and United States of America (USA). As a result of this work, the authors attempt to increase the possibility that the improved availability and understanding of health information from trusted sources translates to higher levels of adherence to treatment, safer use of medication (pharmacovigilance), better health outcomes and quality of life integrated in the patient's journey.

Keywords Co-creation, End-users, Digital health, Human-centered design

Paper type Research paper

Purpose

The future of the healthcare systems relies on the capacity to provide integrated patient-centered services through multisectoral collaborations (Kaehne and Nies, 2021). These collaborations in health delivery and research include healthcare providers, medical developments and technologies, private and public institutions, universities, research centers, the pharmaceutical and other industries, patient organizations, and medicines regulators. Creating integrated care solutions requires each part to complete and complement the system as a whole; as too often the component parts are being seen and delivered in fragmented pieces that make up a stack.

To be effective, digital healthcare transformation must address not only the adoption of integrated care models but also broader, regional and global challenges along the way, such as health equity, health and digital literacy, health behaviors, adherence and access to and integration of and healthcare. Digital technologies can play an important role in this transformation, as they are key enablers for the provision of integrated care solutions and essential tools for empowering both patients and healthcare professionals (Chauvin and Rispel, 2016; Bird *et al.*, 2021).

Among the main challenges, adherence to treatment is recognized as a worldwide public health problem (Costa *et al.*, 2015). World health organization (WHO) reports that more than 50% of all medicines are prescribed, dispensed or sold inappropriately worldwide (World Health Organization, 2002), and Organisation for Economic Co-operation and Development (OECD) estimates that around 200,000 premature deaths annually in Europe relate to poor medication adherence (Organisation for Economic Co-operation and Development, 2018). Currently, medicinal product information in the patient information leaflets (PILs), attached to each packaging of medicines are the mandated, primary source of information for every patient (Poplas-Susič *et al.*, 2014; Raynor, 2018). This paper-based source comes with many shortcomings. Production and dissemination of new or revised information is both time-consuming and costly, and that information may not be up to date by the time the patient receives their medicine. Furthermore, information may not be understandable or relevant to the needs of many patients (Poplas-Susič *et al.*, 2014). This problem is only aggravated by aging, multimorbidity, and chronic diseases. Several studies have shown that the paper PILs often do not meet the needs of all patients since they are difficult to consult and comprehend due to an excessively lengthy and undersized text, coupled with the presence of many incomprehensible medical terms (Colledge *et al.*, 2008). Digital technologies offer new opportunities to personalize medicinal product information (Minutolo *et al.*, 2022). The COVID-19 pandemic has accelerated the uptake of digital health technologies and further illuminated the need for accessible health information, transforming the integrated digital healthcare delivery from being viewed as a potential opportunity to becoming an immediate necessity. Digital tools can also enhance access, understanding and adherence, enabling better patient engagement and integration of care (Minutolo *et al.*, 2022; Car *et al.*, 2017; Talmor *et al.*, 2018).

To address some of the above challenges and the need for trusted digital health information across the life-course, Innovative Medicines Initiative (IMI) funded the project gravitate-health [1]. This coordinated public-private partnership is a cross-functional effort setting out to demonstrate how the use of an integrated, digital, user-centric health information solution could create measurable improvements in availability and understanding of health information from a set of trusted sources, starting with the medicinal product information, electronic health records (EHR) and medicinal compendiums. Through the public-private model committed to accelerating the adoption of connected health solutions at scale and direct patient engagement, the gravitate-health project aims to empower and equip Europeans with digital health information for active and improved personal health management and increase treatment adherence as part of the holistic and integrated global digital effort.

Co-creating a digital, user-centric health information solution with patients has been a central inspiration in addressing our main challenge described in this paper: how to apply an open-access digital platform and user-relevant services with trusted digital health information to transform the way patients access and understand health information, and how to use this to improve adherence to treatment, risk minimization and quality of life throughout the integrated patient journey. The specific aim of this paper is to demonstrate the early steps as progress in co-creating the digital solution, by developing a set of personas that illustrate important segments and time-points in a patient journey.

Methods

To deliver the co-creation process, we established a multi-phased plan to deep-dive into user needs and behaviors across patient journeys, to highlight important patterns and stakeholder and end-user segment nuances, and identify the stages in the patient's journey highlighting the addressable health needs.

Human-centered design

The term "human centered design" has evolved over time and originated in the fields of ergonomics, computer science and artificial intelligence and is described in the International standard ISO 9241–210 as "approach to systems design and development that aims to make interactive systems more useable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques" (International Organization for Standardization, 2010).

Design thinking

The opportunity to focus on a Patient as a co-creator of digital health design solutions is well supported by methodologies such as design thinking that utilizes a human-centered approach. «As an approach, design thinking taps into capacities we all have but that are overlooked by more conventional problem-solving practices. Not only does it focus on creating products and services that are human centered, but the process itself is also deeply human. Design thinking relies on our ability to be intuitive, to recognize patterns, to construct ides that have emotional meaning as well as being functional and to express ourselves in media other than words or symbols. Nobody wants to run an organization on feeling, intuition and inspiration, but an over-reliance on the rational and the analytical can be just as risky. Design thinking, the integrated approach at the core of the design process, provides a third way. The design thinking process is best thought of as a system of overlapping spaces rather than a sequence of orderly steps. There are three spaces to keep in mind: inspiration, ideation and implementation.» (Brown and Wyatt, 2010).

Our approach was using the human centered design (International Organization for Standardization, 2010; Hargraves, 2018; Melles *et al.*, 2021) and design thinking (Stickdorn *et al.*, 2011; Brown and Wyatt, 2010) methodology, which are described in the text box below. We applied a mix of methodologies and approaches including qualitative and quantitative research, gathering needs with testing scenarios, engaging user advisory group (UAG) to guide the outcomes, facilitating feedback gathering sessions and co-creation workshops. We collected data through desk research, semi-structured interviews and Delphi study. These were gathered between January and April 2021, based on that we organized a design thinking workshop and involved stakeholders for feedback. The process was divided into 3 phases, which are shown in Figure 1.

Phase 1 - establishing user advisory group (UAG)

As a response to the "Call for interest" placed the UAG at the heart of the project guiding activities from a user perspective and enabling mechanisms for meaningful patient and public involvement and input throughout the project. A group of 20 individuals (10 Patients/Patient Representatives, 5 Citizens/Consumers, 5 Healthcare Professionals) got together to play a major role in identifying and understanding the key user needs of the digital solutions to be developed during the project and will contribute to validating the tools.

Phase 2 - interviews with patients to gather requirements and Delphi survey prioritization

From the very beginning, the project was designed to allow multisector stakeholders to work directly with patients to empathize and deeply understand their needs, goals and expectations. Those insights established the foundation of the further survey designed to refine and confirm the user need categories. Primary end-users (including both patients/caregivers and healthcare professionals) were identified from UAG established in Phase 1 and via the consortium networks for qualitative interviews, to gain insights that would enable the design of the survey. This served as a basis for a two-round Delphi survey, which was conducted to prioritize needs and to achieve consensus on the most important opportunity areas in the six categories of key performance indicators (KPIs): access and use, understanding, user experience, patient compliance/adherence, two-way communication, and risk minimization. Patients volunteered to participate following a "call for Patients" done in Phase 1. In total, 30 primary end users (patients/caregivers) responded to the call, with 23

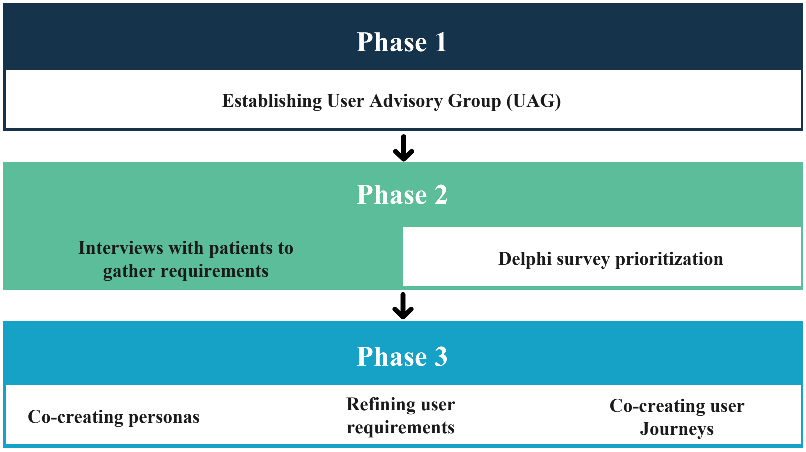


Figure 1.
Phases of the process

finally completing the survey. The interviews were framed and guided by statements co-created and validated by cross-functional project teams. They consisted of questions related to the patients' needs for focused, relevant, trusted information about medicine throughout the patient journey and their experiences interacting with healthcare, product information, available technology. Furthermore, it included questions about critical gaps in the ability to give or receive care that could potentially be addressed by the digital solution.

In addition to end-users, interviews were conducted with testing scenario owners, healthcare professionals and other stakeholder groups represented in the consortium. These stakeholder groups included pharma partners, SMEs, regulatory bodies, research institutes and universities, health policy advisors, and open-source communities with digital experience.

Phase 3 - Co-creating personas, refining user requirements and co-creating user journeys

The insights gathered from the interviews with the testing scenarios and the Delphi study were used to create a set of 6 primary user personas (see under Findings).

To aid our understanding of the patient's perspectives, we created diverse "testing scenarios" to allow us to zoom in on important "episodes" in a patient's life journeys, including self-care, periods of active treatment, and self-management. We also reviewed personas from different previous projects we had access to, such as CAPABLE [2] and EIP-AHA [3] addressing similar needs (varying demographics, health statuses, emotions, lifestyle, personality traits, education levels, life stage, home environment, health and digital literacy levels and behaviors) as additional input for persona development (Janson *et al.*, 2020; Vogt, 2021).

After initial version of personas was developed, a co-creation workshop was organized, where patients, cross-functional stakeholder groups, and designers came together to ideate and explore needs and requirements connected to the personas. We used these sessios to understand, define and map key factors in patient experiences, to discuss and ideate on how we could create a digital health information tool that would be meaningful and engaging for patients, enabling us to utilize their input and advice in order to develop human-centered user requirements. Then, further synthesis of the gathered material were shared in an in-depth reflection during the next session, ideas were conceptualized and visualized and brought back to the co-creation session for feedback. This cross-functional design thinking workshop allowed us to start connecting the touchpoints in the patient journeys and create an integration between the patient experience and the services that connect them with the people and activities that deliver them. This resulted in a holistic view of the key touchpoints that matter for patients using the digital tool. Patients' goals around access, understanding of information, and adherence were reflected in a guiding challenge statement for the workshop activity as part of developing the patient journey. This referred to co-creating a digital tool to transform the way patients access and understand health information, and apply this in their personal health for improved adherence to treatment, better health outcomes, and quality of life throughout the integrated patient journey.

Findings

A set of tools was designed to serve as a human-centered compass throughout the lifecycle of the project. Those tools include shared objects – 6 Personas, 6 user journeys, a set of KPIs with related requirements – all those tools being consistently iterated with members of the cross-functional stakeholder groups. These represent the different end-user activities for self-care, during active treatment and self-management and testing scenarios in the Gravitate-Health project.

All 6 personas are available at www.gravitatehealth.eu [4] and follow the same structure, namely: *Column 1:* About the Person, personality and interests and demographic data, *Column 2:* Health, including health conditions, medications and therapies, interaction with healthcare providers and sharing of information, *Column 3:* Behavior, including health routines, pain points/problems and patient engagement level and finally *Column 4:* Environment, including illustration of autonomy, health and digital literacy level, support network and using of a personal health navigation tool (Figure 2).

The personas provided shared representations illustrating early functional requirements, consisting of recurring themes that required further consideration. The requirements expressed by the patients and the stakeholders also provided valuable insight into the potential challenges our digital solution may face during the project, i.e. interoperability, access to EHR, and the requirement to provide context-relevant information to go beyond what is already available to patients and health care professionals (HCP).

For the purpose of visualizing a persona, in this article, we present the persona (Maria) in Figure 3.

The personas allowed for meaningful deep dives into unique patient cases, based on real world examples in “self-care” “active treatment” and “self-management” activities. The wish-list of the features of the digital tool in the patients’ health journey and behavioral preferences across the key outcomes: access, understanding of information and adherence to treatment.

We then began to consolidate the data from the personas [4] to draft a representation of “patient journey” as the starting point allowing us to further evaluate and iterate on and test our assumptions with other stakeholders across Gravitate-Health to get feedback and seek further input.

Drawing upon the patient research and taking the real-live end-user personas as a guide, scenario-based patient journey maps were developed [4] detailing the key phases in a patient journey including self-care, active treatment and self-management. A patient journey map served as a blueprint of important touch-points a patient goes through in their care journey and created a way to visualize and get an overview of the patient experience as the patients’ progress along their health journey. Figure 4 shows the patient journey for the Maria persona.

Being based on real patient experiences, the wishlist of the digital tool features can be traced back to specific pain points along with the patient personas, their health journeys and behavioral preferences across the key outcomes: access, understanding of information and adherence to treatment.

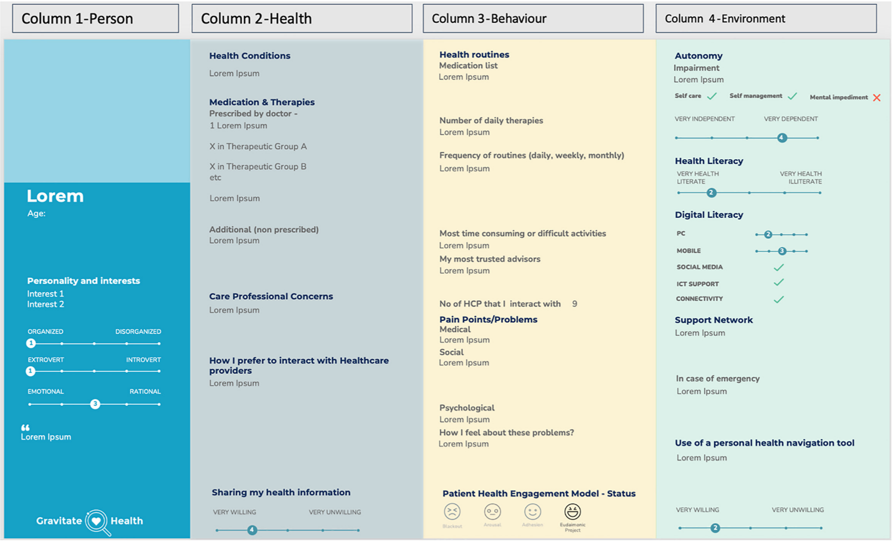
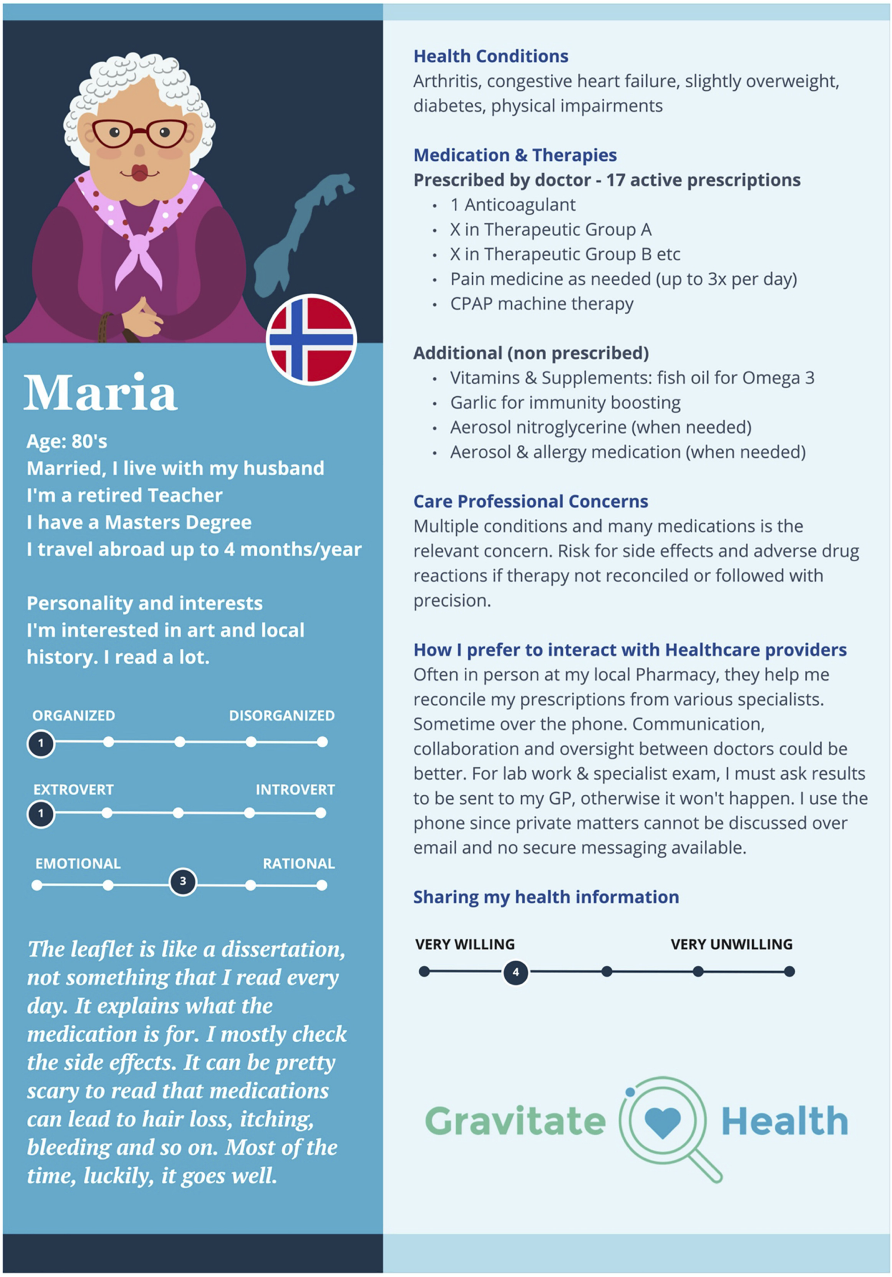


Figure 2.
Persona template



Maria

Age: 80's
Married, I live with my husband
I'm a retired Teacher
I have a Masters Degree
I travel abroad up to 4 months/year

Personality and interests
I'm interested in art and local history. I read a lot.

ORGANIZED ● 1 ○ ○ ○ ○ DISORGANIZED

EXTROVERT ● 1 ○ ○ ○ ○ INTROVERT

EMOTIONAL ○ ○ ● 3 ○ ○ RATIONAL

The leaflet is like a dissertation, not something that I read every day. It explains what the medication is for. I mostly check the side effects. It can be pretty scary to read that medications can lead to hair loss, itching, bleeding and so on. Most of the time, luckily, it goes well.

Health Conditions
Arthritis, congestive heart failure, slightly overweight, diabetes, physical impairments

Medication & Therapies
Prescribed by doctor - 17 active prescriptions
- 1 Anticoagulant
- X in Therapeutic Group A
- X in Therapeutic Group B etc
- Pain medicine as needed (up to 3x per day)
- CPAP machine therapy

Additional (non prescribed)
- Vitamins & Supplements: fish oil for Omega 3
- Garlic for immunity boosting
- Aerosol nitroglycerine (when needed)
- Aerosol & allergy medication (when needed)

Care Professional Concerns
Multiple conditions and many medications is the relevant concern. Risk for side effects and adverse drug reactions if therapy not reconciled or followed with precision.

How I prefer to interact with Healthcare providers
Often in person at my local Pharmacy, they help me reconcile my prescriptions from various specialists. Sometime over the phone. Communication, collaboration and oversight between doctors could be better. For lab work & specialist exam, I must ask results to be sent to my GP, otherwise it won't happen. I use the phone since private matters cannot be discussed over email and no secure messaging available.

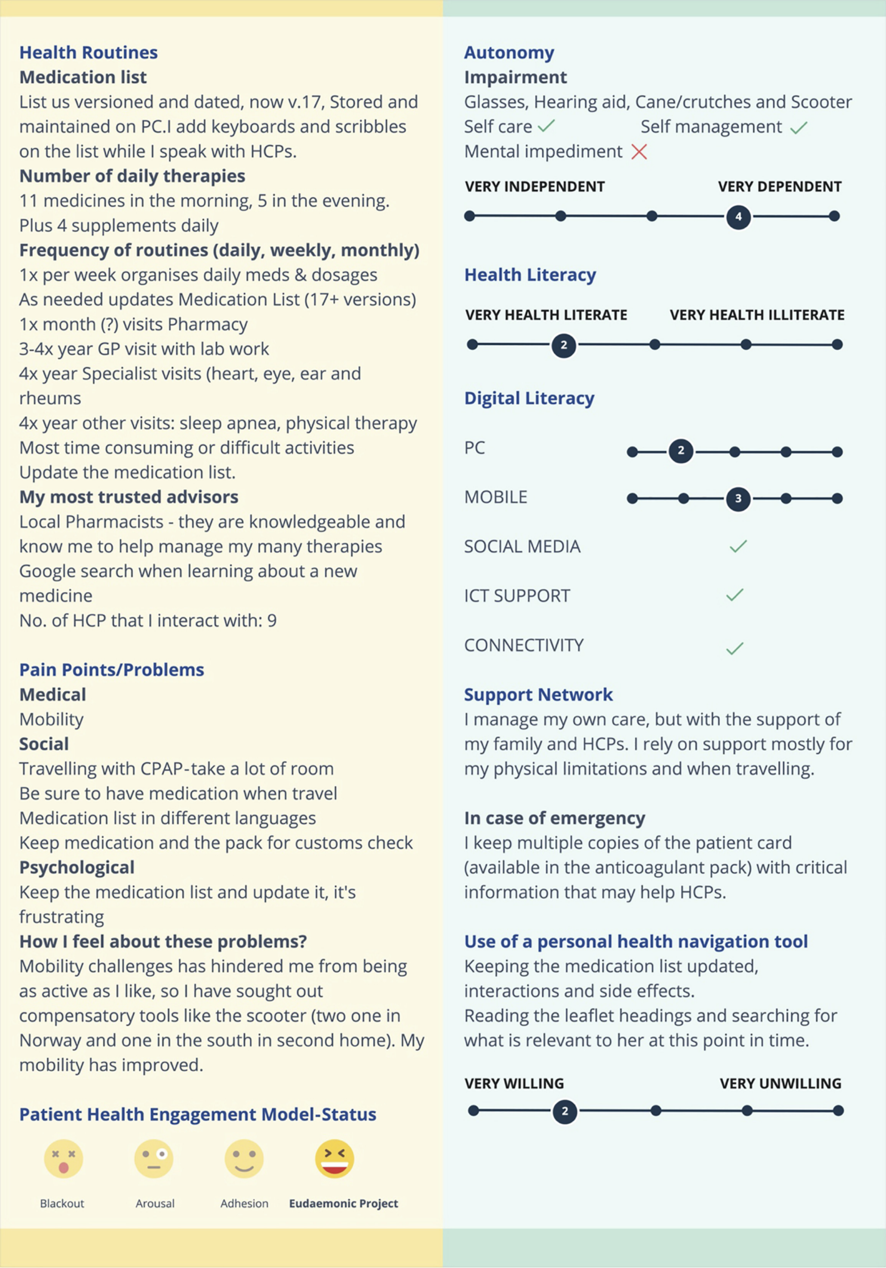
Sharing my health information

VERY WILLING ○ ● 4 ○ ○ ○ VERY UNWILLING

Gravitate Health

Figure 3.
Maria Persona

(*continued*)



Health Routines

Medication list

List us versioned and dated, now v.17, Stored and maintained on PC.I add keyboards and scribbles on the list while I speak with HCPs.

Number of daily therapies

11 medicines in the morning, 5 in the evening.
Plus 4 supplements daily

Frequency of routines (daily, weekly, monthly)

1x per week organises daily meds & dosages
As needed updates Medication List (17+ versions)
1x month (?) visits Pharmacy
3-4x year GP visit with lab work
4x year Specialist visits (heart, eye, ear and rheums
4x year other visits: sleep apnea, physical therapy
Most time consuming or difficult activities
Update the medication list.

My most trusted advisors

Local Pharmacists - they are knowledgeable and know me to help manage my many therapies
Google search when learning about a new medicine
No. of HCP that I interact with: 9

Pain Points/Problems

Medical

Mobility

Social

Travelling with CPAP-take a lot of room
Be sure to have medication when travel
Medication list in different languages
Keep medication and the pack for customs check

Psychological

Keep the medication list and update it, it's frustrating

How I feel about these problems?

Mobility challenges has hindered me from being as active as I like, so I have sought out compensatory tools like the scooter (two one in Norway and one in the south in second home). My mobility has improved.

Patient Health Engagement Model-Status

Blackout
Arousal
Adhesion
Eudaemonic Project

Autonomy

Impairment

Glasses, Hearing aid, Cane/crutches and Scooter
Self care ✓ Self management ✓
Mental impediment ✗

VERY INDEPENDENT **VERY DEPENDENT**

● ● ● 4 ●

Health Literacy

VERY HEALTH LITERATE **VERY HEALTH ILLITERATE**

● 2 ● ● ●

Digital Literacy

PC ● 2 ● ● ●
MOBILE ● ● 3 ● ●
SOCIAL MEDIA ✓
ICT SUPPORT ✓
CONNECTIVITY ✓

Support Network

I manage my own care, but with the support of my family and HCPs. I rely on support mostly for my physical limitations and when travelling.

In case of emergency

I keep multiple copies of the patient card (available in the anticoagulant pack) with critical information that may help HCPs.

Use of a personal health navigation tool

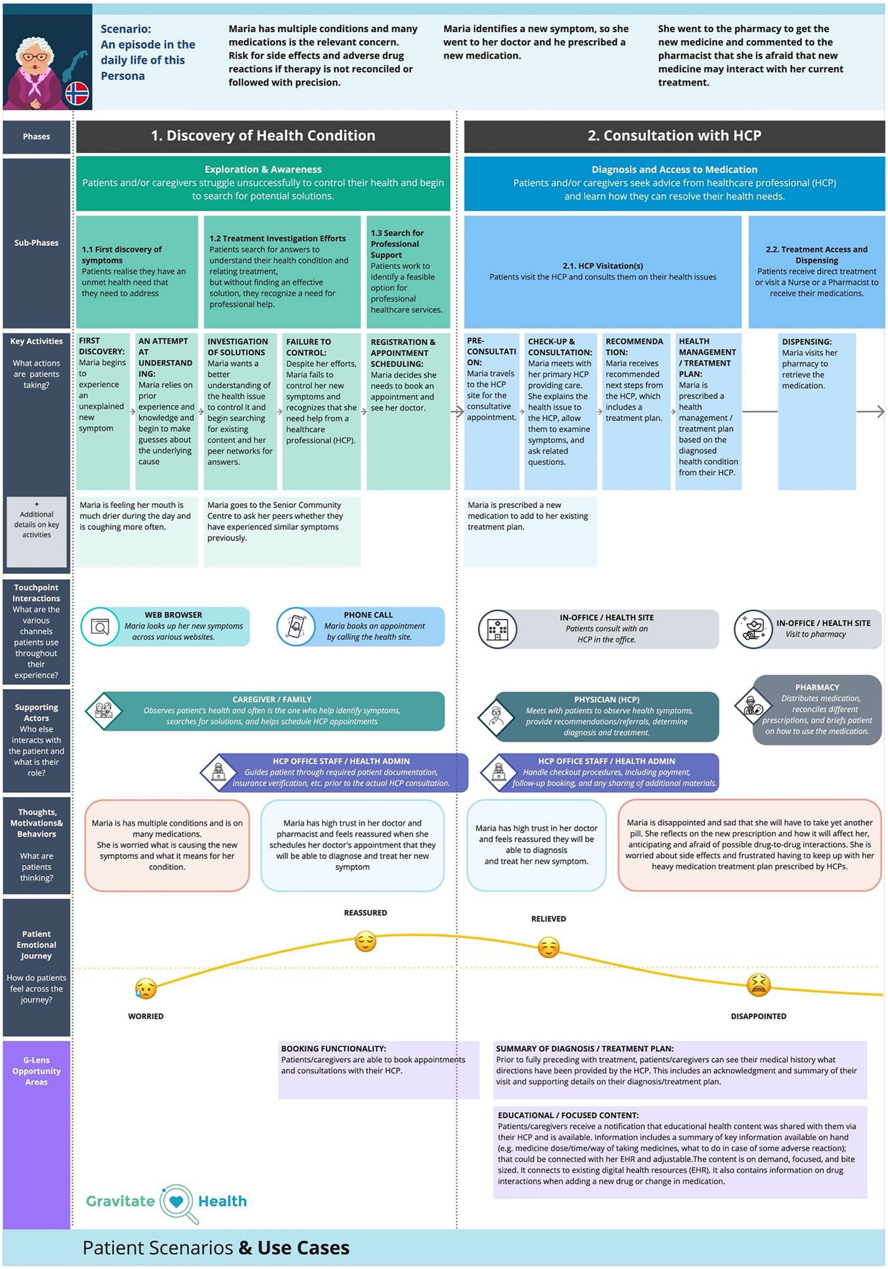
Keeping the medication list updated, interactions and side effects.
Reading the leaflet headings and searching for what is relevant to her at this point in time.

VERY WILLING **VERY UNWILLING**

● 2 ● ● ●

Figure 3.

Stakeholders and patients' involvement in the 3 phases provided valuable insights into all areas of the solution at the early stages and paved the way to create a practical and complete response to the challenge.



Scenario: An episode in the daily life of this Persona

Maria has multiple conditions and many medications is the relevant concern. Risk for side effects and adverse drug reactions if therapy is not reconciled or followed with precision.

Maria identifies a new symptom, so she went to her doctor and he prescribed a new medication.

She went to the pharmacy to get the new medicine and commented to the pharmacist that she is afraid that new medicine may interact with her current treatment.

Phases

1. Discovery of Health Condition

2. Consultation with HCP

Sub-Phases

Exploration & Awareness
Patients and/or caregivers struggle unsuccessfully to control their health and begin to search for potential solutions.

Diagnosis and Access to Medication
Patients and/or caregivers seek advice from healthcare professional (HCP) and learn how they can resolve their health needs.

1.1 First discovery of symptoms
Patients realise they have an unmet health need that they need to address

1.2 Treatment Investigation Efforts
Patients search for answers to understand their health condition and relating treatment, but without finding an effective solution, they recognize a need for professional help.

1.3 Search for Professional Support
Patients work to identify a feasible option for professional healthcare services.

2.1. HCP Visitation(s)
Patients visit the HCP and consults them on their health issues

2.2. Treatment Access and Dispensing
Patients receive direct treatment or visit a Nurse or a Pharmacist to receive their medications.

Key Activities
What actions are patients taking?

FIRST DISCOVERY: Maria begins to experience an unexplained new symptom

AN ATTEMPT AT UNDERSTANDING: Maria relies on prior experience and knowledge and begin to make guesses about the underlying cause

INVESTIGATION OF SOLUTIONS Maria wants a better understanding of the health issue to control it and begin searching for existing content and her peer networks for answers.

FAILURE TO CONTROL: Despite her efforts, Maria fails to control her new symptoms and recognizes that she need help from a healthcare professional (HCP).

REGISTRATION & APPOINTMENT SCHEDULING: Maria decides she needs to book an appointment and see her doctor.

PRE-CONSULTATION: Maria travels to the HCP site for the consultative appointment.

CHECK-UP & CONSULTATION: Maria meets with her primary HCP providing care. She explains the health issue to the HCP, allow them to examine symptoms, and ask related questions.

RECOMMENDATION: Maria receives recommended next steps from the HCP, which includes a treatment plan.

HEALTH MANAGEMENT / TREATMENT PLAN: Maria is prescribed a health management / treatment plan based on the diagnosed health condition from their HCP.

DISPENSING: Maria visits her pharmacy to retrieve the medication.

+ Additional details on key activities

Maria is feeling her mouth is much drier during the day and is coughing more often.

Maria goes to the Senior Community Centre to ask her peers whether they have experienced similar symptoms previously.

Maria is prescribed a new medication to add to her existing treatment plan.

Touchpoint Interactions
What are the various channels patients use throughout their experience?

WEB BROWSER
Maria looks up her new symptoms across various websites.

PHONE CALL
Maria books an appointment by calling the health site.

IN-OFFICE / HEALTH SITE
Patients consult with an HCP in the office.

IN-OFFICE / HEALTH SITE
Visit to pharmacy

Supporting Actors
Who else interacts with the patient and what is their role?

CAREGIVER / FAMILY
Observes patient's health and often is the one who help identify symptoms, searches for solutions, and helps schedule HCP appointments

HCP OFFICE STAFF / HEALTH ADMIN
Guides patient through required patient documentation, insurance verification, etc. prior to the actual HCP consultation.

PHYSICIAN (HCP)
Meets with patients to observe health symptoms, provide recommendations/referrals, determine diagnosis and treatment.

HCP OFFICE STAFF / HEALTH ADMIN
Handle checkout procedures, including payment, follow-up booking, and any sharing of additional materials.

PHARMACY
Distributes medication, reconciles different prescriptions, and briefs patient on how to use the medication.

Thoughts, Motivations& Behaviors
What are patients thinking?

Maria is has multiple conditions and is on many medications. She is worried what is causing the new symptoms and what it means for her condition.

Maria has high trust in her doctor and pharmacist and feels reassured when she schedules her doctor's appointment that they will be able to diagnose and treat her new symptom

Maria has high trust in her doctor and feels reassured they will be able to diagnosis and treat her new symptom.

Maria is disappointed and sad that she will have to take yet another pill. She reflects on the new prescription and how it will affect her, anticipating and afraid of possible drug-to-drug interactions. She is worried about side effects and frustrated having to keep up with her heavy medication treatment plan prescribed by HCPs.

Patient Emotional Journey
How do patients feel across the journey?

G-Lens Opportunity Areas

BOOKING FUNCTIONALITY:
Patients/caregivers are able to book appointments and consultations with their HCP.

SUMMARY OF DIAGNOSIS / TREATMENT PLAN:
Prior to fully preceding with treatment, patients/caregivers can see their medical history what directions have been provided by the HCP. This includes an acknowledgment and summary of their visit and supporting details on their diagnosis/treatment plan.

EDUCATIONAL / FOCUSED CONTENT:
Patients/caregivers receive a notification that educational health content was shared with them via their HCP and is available. Information includes a summary of key information available on hand (e.g. medicine dose/time/way of taking medicines, what to do in case of some adverse reaction); that could be connected with her EHR and adjustable.The content is on demand, focused, and bite sized. It connects to existing digital health resources (EHR). It also contains information on drug interactions when adding a new drug or change in medication.

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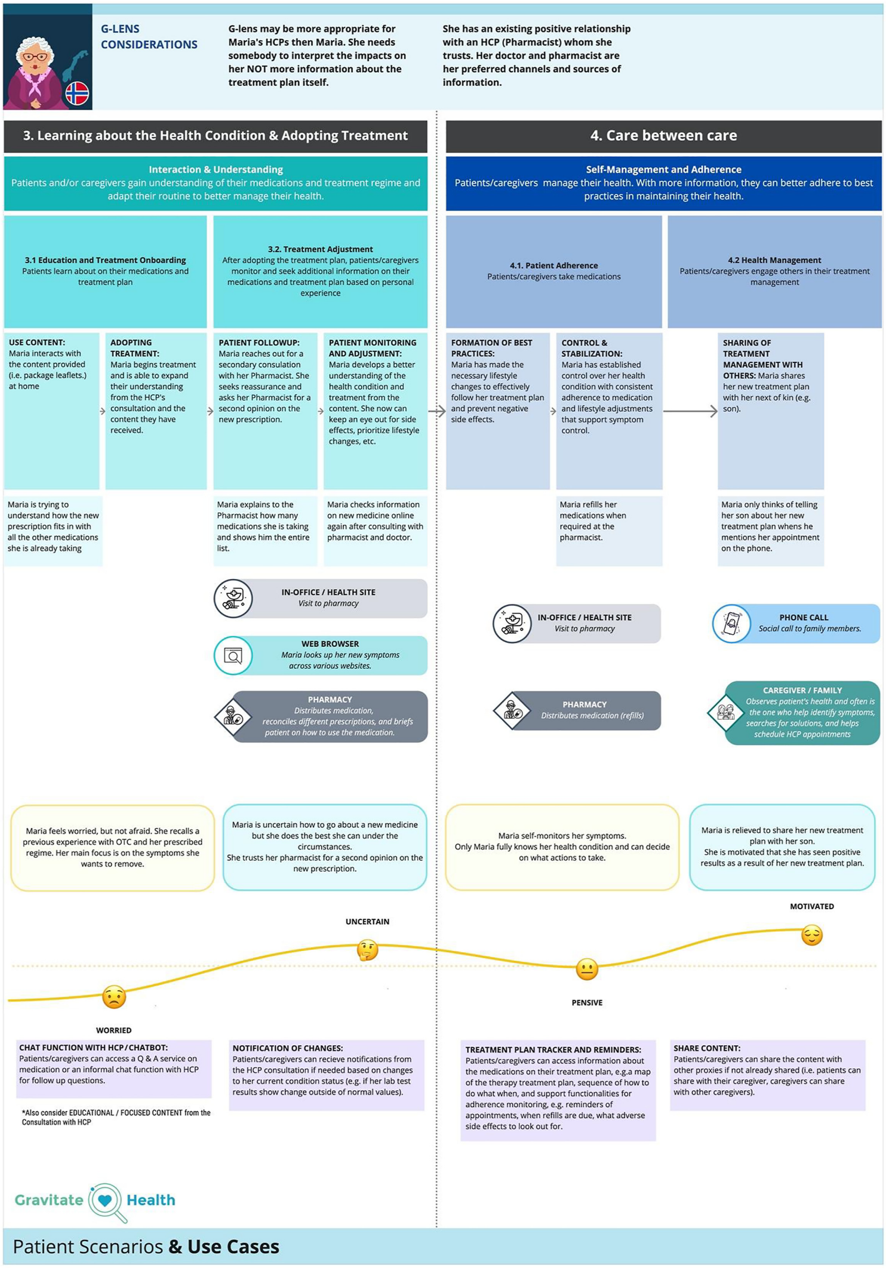
Patient Scenarios **& Use Cases**

Figure 4.
Maria's patient journey

(*continued*)



G-LENS CONSIDERATIONS

G-lens may be more appropriate for Maria's HCPs then Maria. She needs somebody to interpret the impacts on her NOT more information about the treatment plan itself.

She has an existing positive relationship with an HCP (Pharmacist) whom she trusts. Her doctor and pharmacist are her preferred channels and sources of information.

3. Learning about the Health Condition & Adopting Treatment

Interaction & Understanding
Patients and/or caregivers gain understanding of their medications and treatment regime and adapt their routine to better manage their health.

3.1 Education and Treatment Onboarding
Patients learn about on their medications and treatment plan

USE CONTENT: Maria interacts with the content provided (i.e. package leaflets.) at home

ADOPTING TREATMENT: Maria begins treatment and is able to expand their understanding from the HCP's consultation and the content they have received.

Maria is trying to understand how the new prescription fits in with all the other medications she is already taking

Maria feels worried, but not afraid. She recalls a previous experience with OTC and her prescribed regime. Her main focus is on the symptoms she wants to remove.

WORRIED

CHAT FUNCTION WITH HCP/CHATBOT:
Patients/caregivers can access a Q & A service on medication or an informal chat function with HCP for follow up questions.

*Also consider EDUCATIONAL / FOCUSED CONTENT from the Consultation with HCP

3.2. Treatment Adjustment
After adopting the treatment plan, patients/caregivers monitor and seek additional information on their medications and treatment plan based on personal experience

PATIENT FOLLOWUP: Maria reaches out for a secondary consulation with her Pharmacist. She seeks reassurance and asks her Pharmacist for a second opinion on the new prescription.

PATIENT MONITORING AND ADJUSTMENT: Maria develops a better understanding of the health condition and treatment from the content. She now can keep an eye out for side effects, prioritize lifestyle changes, etc.

Maria explains to the Pharmacist how many medications she is taking and shows him the entire list.

Maria checks information on new medicine online again after consulting with pharmacist and doctor.

IN-OFFICE / HEALTH SITE
Visit to pharmacy

WEB BROWSER
Maria looks up her new symptoms across various websites.

PHARMACY
Distributes medication, reconciles different prescriptions, and briefs patient on how to use the medication.

Maria is uncertain how to go about a new medicine but she does the best she can under the circumstances.
She trusts her pharmacist for a second opinion on the new prescription.

UNCERTAIN

NOTIFICATION OF CHANGES:
Patients/caregivers can recieve notifications from the HCP consultation if needed based on changes to her current condition status (e.g. if her lab test results show change outside of normal values).

4. Care between care

Self-Management and Adherence
Patients/caregivers manage their health. With more information, they can better adhere to best practices in maintaining their health.

4.1. Patient Adherence
Patients/caregivers take medications

FORMATION OF BEST PRACTICES: Maria has made the necessary lifestyle changes to effectively follow her treatment plan and prevent negative side effects.

CONTROL & STABILIZATION: Maria has established control over her health condition with consistent adherence to medication and lifestyle adjustments that support symptom control.

Maria refills her medications when required at the pharmacist.

IN-OFFICE / HEALTH SITE
Visit to pharmacy

PHARMACY
Distributes medication (refills)

Maria self-monitors her symptoms.
Only Maria fully knows her health condition and can decide on what actions to take.

PENSIVE

TREATMENT PLAN TRACKER AND REMINDERS:
Patients/caregivers can access information about the medications on their treatment plan, e.g.a map of the therapy treatment plan, sequence of how to do what when, and support functionalities for adherence monitoring, e.g. reminders of appointments, when refills are due, what adverse side effects to look out for.

4.2 Health Management
Patients/caregivers engage others in their treatment management

SHARING OF TREATMENT MANAGEMENT WITH OTHERS: Maria shares her new treatment plan with her next of kin (e.g. son).

Maria only thinks of telling her son about her new treatment plan whens he mentions her appointment on the phone.

PHONE CALL
Social call to family members.

CAREGIVER / FAMILY
Observes patient's health and often is the one who help identify symptoms, searches for solutions, and helps schedule HCP appointments

Maria is relieved to share her new treatment plan with her son.
She is motivated that she has seen positive results as a result of her new treatment plan.

MOTIVATED

SHARE CONTENT:
Patients/caregivers can share the content with other proxies if not already shared (i.e. patients can share with their caregiver, caregivers can share with other caregivers).

Patient Scenarios **& Use Cases**

Figure 4.

Discussion

In this study, a multidisciplinary, public-private partnership attempted use a co-creation process and the first steps towards developing an integrated digital tool to improve access, understanding and adherence to treatment for diverse groups of patients across all stages of their health journeys in a number of countries including EU and USA.

Numerous studies show the integral role that co-creation has in innovation work, with some citing creativity and co-design as the most central component of the process of innovation (Munt and Hargreaves, 2009; Fetrati and Nielsen, 2018; Bird *et al.*, 2021; Simonse *et al.*, 2019). The co-design strategies for healthcare innovation include lived experiences of end-users in research, generate ideas for patient-centered service improvements, empower and engage the included groups and tailor interventions to end-users' needs and requirements thus increasing the likelihood of their adoption and integration (Frow *et al.*, 2015; Fox *et al.*, 2018; Thabrew *et al.*, 2018; Graffigna and Barello, 2018). Co-creating the digital tool has involved a mix of methodologies and approaches including qualitative and quantitative research, gathering needs with testing scenarios, engaging UAG to guide the outcomes, facilitating feedback gathering sessions and co-creation workshops. Working closer with patients – whether that's as co-creators in a workshop or an advisory panel – allowed us to look out from the inside, rather than outside in, taking advantage of the accumulative life-long learnt experience, self-reflection and self-knowledge that goes above and beyond the assumed repeated behaviors and predictable outcomes. For the work reported here, harnessing the power of co-creation and delivering solutions that resonate and encourage feedback from actual users' changes the paradigm to foster human-centered health innovation and played a vital role in helping us build tangible recommendations based on astute and actionable insights.

Stakeholders, and in particular the UAG, who have been involved with co-creating the digital solution since inception, are critical team members in ensuring the success of the Gravitate-Health project. In being fully immersed in the development of the digital solution from the beginning, the user's expertise enables to support the overall goals of the project. The process featured distinctive ways of interacting and engaging in decisional negotiations between the patient and the healthcare system that depend closely on the phase of the process through which the patient is passing through.

Taking this work a step further, the personas and service designs will be used as we build a prototype, where co-creation workshops will be mainly on the design and content, and the emotional and behavioral impact the prototype created. We will deep dive into the use of language, tone of voice, feature design and imagery to gauge their effects when used in various combinations. By using the co-creation process in the Gravitate-Health project, we aim to increase the possibility that the improved availability and understanding of health information from trusted sources translates to higher levels of adherence to treatment, safer use of medication (pharmacovigilance), better health outcomes and quality of life throughout the integrated patient journey. The co-creation process described in this paper develops new and deeper insights into how the use of available health information can be optimized to act as effective risk minimization measure. This provides valuable testing grounds for new services and an evaluation framework to test the efficiency, efficacy and safety of integrated digital health services.

Healthcare delivery relies on a variety of interlocking ecosystems, where many of the problems are multifaceted and inherently human (World Health Organization, 2015). Leading in this disruptive era requires a range of new attitudes and traits: empathy, purpose, acting on behalf of all healthcare stakeholders, the ability to seek a range of inputs yet being decisive, being outcome-focused, providing strong vision-setting and balancing risks. Going beyond the digital and operational fabric, integrated health requires getting closer to the people at the center of care delivery. What we need above all is a new way to shape how we engage, connect and make healthcare transformation happen on a fundamental human level.

The personas and patient journey results will serve as inputs for development of a holistic service design blueprint and a unified journey across the stages of the patient journey. Moreover, these results will surface and uncover patient requirements for the prototype development. By putting a structured human-centered process in place to effectively capture insights and working directly with patients to identify initiatives that will bring benefits to their lives created a trusted environment. Here patients' voices were not only heard but their creative contributions were directly implemented throughout the design process, contributing to the integration throughout their patient journey.

Strengths and limitations

Humanizing the design process in the initial stages of the project allows for meaningful deep dives into the development of the unique features based on the personas and their interactions with the solution, underpinned by the diversity of the patient journeys based on real-world examples in self-care, active treatment and self-management phases. Taking the human-centered design approach and following the flow of the design thinking methodology helped identify key themes that informed our requirements and the emerging needs and tasks the patients want to perform, setting out our vision that can be traced back to specific patient needs and pain points along the journeys patients embark on in interaction with their healthcare. All the factors we can translate into relevant opportunities and a true path forward.

As the design method and the co-creation techniques are closely related to qualitative research methods, sample size is one of the possible limitations. Moreover, participation of key end-users to shape the digital solution may result in an overreliance on the perspectives of the UAG, a few end-users, who may not be representative of the larger population of interest. However, the work presented here is a starting point, and the risk of overreliance as limitation will be or adjusted for in our adopted step-wise, agile approach.

Conclusion

Any end-user interaction is an opportunity to build up our knowledge and understanding of patients. In order to maximize the effectiveness of any engagement, the interactions should be focused on retaining the insights and making them accessible to future project teams. Methods to measure health literacy and ways to integrate new parameters into healthcare protocols that support patient needs are needed for development of digital tools for integrated care pathways.

Creating useful tools such as personas, and user journeys for a digital, user-centric health information solution, is the first installment allowing teams to continuously use patient insight as a guide for patient-centered decision making across the entire product or a service design life-cycle, and thus enable the integration of the solution throughout the whole patient journey.

Notes

1. The Gravitate-Health is a public – private partnership with 40 members from Europe and the US, co-led by University of Oslo (coordinator) and Pfizer (industry lead), funded by the Innovative Medicines Initiative (IMI) under contract no 945334– a joint undertaking of the European Commission, the European Federation of Pharmaceutical Industries and Associations (EFPIA), IMI2 Associated Partners. www.gravitatehealth.eu
2. https://www.med.uio.no/helsam/english/research/projects/capable/
3. https://futurium.ec.europa.eu/en/active-and-healthy-living-digital-world/library/eip-aha-blueprint-personas
4. https://www.gravitatehealth.eu/wp-content/uploads/2021/11/Gravitate-Health_D1.2-Personas_V2.0_final.pdf

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