Gravitate-Health

WP1 – User needs, Scenarios, KPI

D1.2 Methodology Report

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LIST OF ABBREVIATIONS AND GLOSSARY

Table 1: LIST OF ABBREVIATIONS

Acronym / term	Full name / definition
EHR	Electronic Health Record
ePl	electronic product information
Human-Centered Design	Human-centered design is a creative problem-solving process that begins with understanding human needs and closes with innovative products or solutions that can be quickly prototyped and tested to address the identified needs.
Persona	A Persona is a fictional yet realistic description of a typical or target user of the product. A Persona is an archetype instead of an actual living human, but Personas should be described as real people.
Patient Journey Map	A patient journey map is a blueprint of all the touchpoints a patient goes through in her/his care journey and is a way to visualize and get an overview of the patient experience during their entire care journey. Patient journey mapping gives insights into the patient experiences during their care journey.
Service Design Blueprint	A service blueprint is a diagram that visualizes the relationships between different service components — people, props (physical or digital evidence), and processes directly tied to touchpoints in a specific customer journey.
End-User	In product development, an end-user is a person who ultimately uses or is intended to use a product ultimately. • Primary end-users (patients, citizens, caregivers) • Secondary end-users (HCPs) • Tertiary stakeholders
MVP	A Minimum Viable Product is a version of a product with just enough features to be usable by early customers who can then provide feedback for future product development.
Omnichannel	Connection if multiple channel touchpoints together so that, whatever journey the customer/patient/citizen chooses to take, online or offline, the experience is consistent and unified.
Customer/ Patient/ Citizen Experience (CX)	The holistic feeling and perception that a customer has regarding the sum of all interactions it has with a product or service; CX is where all decisions, activities, actions and solutions are derived from a complete understanding of the customers journey, addressing their emotional and behavioral needs, as well as clinical ones – if applicable.
User Experience/User Interface (UX/UI)	User experience (UX) design is the process design teams use to create products that provide meaningful and relevant experiences to users. This involves the design of the entire process of acquiring

and integrating the product, including aspects of branding, design, usability and function.

User interface (UI) design is the process designers use to build interfaces in software or computerized devices, focusing on looks or style. Designers aim to create interfaces which users find easy to use and pleasurable. UI design refers to graphical user interfaces and other forms—e.g., voice-controlled interfaces.

Touchpoint (touch point, contact point, point of contact)

Any encounter where customers engage to exchange information, provide service, or handle transactions; they are critical interactions within the customer journey that help define key moments in the process which can build or erode trust.

EXECUTIVE SUMMARY

In the Gravitate-Health Grant Agreement, Deliverable 1.2 is described as 'Delivery of a methodology report on the user Personas for information personalization and functionality for the organization of workshops.' This report delivers results from activities performed in Task 1.2, which had the goals of defining G-Lens design methodology, producing a set of Personas based on real-world data and tailored to primary end-users of the G-Lens. The deliverable contains the work from M3 to M8, meaning the time period from January 2021 until June 2021 (6 months).

The ultimate goal is to consolidate a wish-list of G-Lens functionality or features that will serve these end-users as more active participants in their health journey. The sum of these goals has led us to also present a Service Design Blueprint, in this case, more of an initial hypothesis of what the Service Design Blueprint model might need to include, which is the final result of Task 1.2.

Additionally, this Task began exploring how to integrate the Patient Health Engagement Model (PHE) into the G-Lens as a possible benchmark for measuring patient engagement at the point of entry and monitoring for changes in patient's engagement level during their interactions with G-Lens tools. These Π .2 activities were led by the authors of this document - a core team of Π .2 colleagues - and included numerous work sessions by the team.

We have shared the progress of our work in many ways: general assembly meetings for feedback, presentations to the broader Consortium in the Gravitate-Health Monthly Forums and Steering Committee, and a cross-WP Design Thinking workshop where more than 60 members of the Consortium were invited into the design process using breakout groups, Personas and Journey Mapping. The Deliverable is a report on what was done, synthesizing our activities' most valuable and relevant results. In the future, it can be a reference tool, a design handbook to use during the remaining 4.5 years of the project.

Introduction

Task 1.2 is a research and design task at its core. We want to set the stage with two quotes that illustrate the nature of our work and the current context we are living in. Perhaps, such context gets more complex if we layer in the stress and anxiety and the many other emotions that occur naturally in disease and disease management.

"There are three great design themes: making something beautiful, making something easier, and making something possible. Design is the art of the possible. Design isn't just about problem-solving; it's about creating a more humane future."

- Dan Saffer, Author and Interaction Design Thought Leader (<u>link</u>)

"What information consumes is rather obvious; it consumes the attention of its recipients ... a wealth of information creates a poverty of attention."

- Herbert A. Simon, Computer scientist and Nobel Prize laureate



Photo credit: Line Linstad, NSE, Norway.

Figure 1: Patient holding a medication list containing the treatment information

Figure 1 exemplifies information that matters to a patient engaged in self-management. Sometimes the best way to handle complexity (of treatment) is simplicity. Less is more?

One of the timeless rules of design says that "To design a great experience, you need to understand the user's perspective." As intuitive or reasonable as it may sound, that's not always the understanding of all stakeholders that sit around a table intending to bring a successful product to market. To design commercially successful products, it is fundamental to shift from a technology-centered design (where the focus is on the features the product will provide) to a human-centered design (where the focus is on the needs and wants of primary end-users).

Task 1.2 focused the conversation and creative efforts on the primary end-users, i.e., the people who will interact and use the G-Lens. The work was guided by principles of

human-centered design (HCD) and materialized by applying well-established user experience (UX) methodologies and tools.

The main method to obtain valuable primary end-user data is to conduct user research, namely via interviews with a sample of users who are representative of segment or population of potential users of the technology or solution.

Primary end-user data came from interviews with the Scenario Leads from Norway, Italy, Portugal, Spain and Ireland (as per Table 1; overview of Gravitate-Health proof-of-concept scenarios, G-lens intervention and evaluation measures, DoA, Annex1, Part B, p. 29). They functioned as indirect sources of primary end-user information in self-care situations, periods of active treatment and self-management, which are targeted segments of the end user journeys. In total, there are eight different scenarios, based in various European countries, and one US scenario in the project. These will act as a testbed for the use of G-Lens (as part of WP6). The work of Task 1.2 can be summarized in 3 Phases:

Phase 1: Co-leads and contributors performed an analysis of data sources existing from previous healthcare programs (see <u>Data Sources</u>) in order to gain insights about patients' needs and experience. Definition of end-user groups was proposed based on legal rights to health records and highest level of interest regarding the successful patient experience.

Phase 2: Scenario leads from Ireland, Portugal, Norway, Spain, and Italy who had a closer relationship and knowledge of the patients represented on their scenarios, were invited to provide information in a structured way, in order to characterize the Personas. The exercise consisted in filling the template of the Persona and identifying real-life situations of the Persona related to health management. The goal was to have the most accurate description of real patients and their contexts.

Phase 3: Crowd-sourcing of knowledge to validate the Personas and to characterize the journey maps and identify the G-Lens priority requirements ("must-haves"). This was achieved through the execution of a design-thinking workshop where members of the wider consortium were invited. Overall, the workshop counted with the participation more than 60 contributors and generated insights that helped to identify the patients' needs, map the patients' journeys, identify the G-Lens priority requirements, and create the service blueprint. The service blueprint (see Annex 2) is a very relevant part of this deliverable because it brings together the patient perspective and the technology requirements, acknowledging the roles and contributions of healthcare professionals (doctors, nurses and pharmacists) and support networks, throughout the patient journey.

Deliverable 1.2 is, by no means, a locked-up document; the user research tools provided such as Personas, Journeys and Service Blueprint are a living toolkit that will evolve as more data will become available. The process is continuous and highly iterative in nature. Needs will be prioritized and reprioritized as the work progresses and as primary end-user data becomes available. This is a first instalment that together with deliverables of other tasks will enable the creation of prototypes, to be tested by end-users. It's a highly interconnected work done in an agile and iterative way. The learnings that will come from testing will allow for adjustments and increase the accuracy of the work.

End-user Groups

"The role of the designer is ultimately about creating order and removing ambiguity. The role of the artist is often the opposite." - Dan Saffer, Interaction Designer and Author

As primarily a design task and also as written in the original task description, the first aim of Tl.2 was to bring clarity, order and focus to end-user groups relative to the G-Lens. This was needed because the results of Tl.2/Dl.2 should provide the design framework that will inform end-user prototypes both in Dl.3 and D4.1. And since the goals of the G-Lens - access, understanding and adherence – are centered around information needs of the patient, even if the end-user is a formal or informal caregiver, the focus of all interactions with the G-Lens will be on achieving those goals for the patient (i.e. not for the other actors involved).

To make this even less ambiguous, we took it a step further. The core of the G-Lens concept is focused around trusted health information and the electronic health record (EHR) of a patient, their health data and their medication list. We decided, therefore, that the EHR itself was the most accurate, precise and logical factor in which to organize and define the end-user groups. And therefore, as of January 14, 2021, the core members of Tl.2, as representative of the contributors to this deliverable document, defined three levels of Gravitate-Health end-user groups based around the defining principle of an **electronic health record**, which for the purposes of this report can be defined as:

An electronic health record (EHR) is the systematized collection of patient and population electronically stored health information in a digital format. These records can be shared across different health care settings. Records are shared through network-connected, enterprise-wide information systems or other information networks and exchanges. EHRs may include a range of data, including demographics, medical history, medication and allergies, immunization status, laboratory test results, radiology images, vital signs, personal statistics like age and weight, and billing information.

While we considered focusing solely on the medication list element of the EHR, we opted not to eliminate the other elements of the EHR for the primary reason being that if the G-Lens is meant to tailor and focus medicine information to a specific person (i.e. personalization of display of information), the most logical first step would be to eliminate any non-relevant information based on the complete patient data available in the EHR. For example, the EHR would contain gender, pregnancy status and allergies, which therefore could be used to filter out any warnings or information regarding conditions NOT present in that persons EHR (i.e. if patient is male, no information regarding pregnancy or nursing would be displayed to the patient).

The G-Lens end-user groups as proposed by TI.2 are as follows:

Primary End-User: the patient to which an Electronic Health Record (EHR) refers to, most often acting on their own behalf, OR the caregiver acting on behalf of the patient, with legal and consented rights to manage the patient's care (for example if patient's autonomy is impaired in any way, then the designated caregiver can act on behalf of the primary record holder).

Examples = citizens, patients, informal caregivers and formal caregivers in the community directly working for the patient. These are represented in self-care, active treatment and self-management phase.

Secondary End-Users: actors in a direct relationship with the patient to which the Electronic Health Record refers but are not the patient to which the EHR refers, nor acting

on behalf of the patient. Often these actors are primary sources of data on the patient's EHR, they curate the EHR, modify and manage the data/files, and will use the Gravitate-Health system to do so, always having a direct relationship with Primary end-users and direct access to their EHR.

Examples = Health Care Providers (HCPs) in clinic, hospital, surgery in primary and secondary care, pharmacists, HCP Admin staff

Tertiary End-Users: actors with no direct relationship / interaction with Primary End-Users or access to their non-anonymized EHR or health data. In regards to the G-Lens, they are interested in observing how active end-users are, how they use the system, are they reporting symptoms, adherence reports, observing the questions and interactions that primary and secondary end-users have with the G-Lens, Real World Data and Evidence, Reuse of data that is aggregated and anonymized for analysis and insights (via the G-Lens Real World Data RWD dashboard).

Examples = Pharma companies, regulators, researchers, SMEs, and other stakeholders.

While these groupings are both logical and extremely helpful for the design task at hand, it is important to keep in mind a few considerations. They are as follows:

- What matters most for use of digital health information in their health journey for all end-users of the G-Lens is to track the data flow and any changes in data so that any data-related events can be traced back to when, what, who and why. This is relevant to issues of trust (medicine and health information coming from trusted sources), safety (tracking modifications in data will help reduce risk, errors and danger related to inaccuracy of data for various reasons) and liability (implications of errors, responsibility and how to resolve problems at the care level and legal level).
- These groupings are also meaningful to the GDPR and data rights of people. It's only the patient or his / her legal representative that can grant access for the G-Lens to access his / her EHR, and it's the primary end-users that have rights to their health data. That said, all groups play some part in responsibility for the patient's health information which requires it be hosted, maintained, secure, accessible and follow the agreed upon principles for integrity. Take this into a cross-border setting where the patient is mobile, yet local and national HCPs and healthcare systems are not, and the stakes are raised for all in terms of making this feasible for the patient when they are not in their home healthcare setting.

An excerpt from the European Commission digital strategy related to General Data Protection Regulation (GDPR), EHRs and the importance of cross border access to health data, emphasizes that while it is the patient who is mobile, i.e. moving across borders, healthcare stakeholders (HCPs and national healthcare system) need to enable data sharing since they are most often the actors who host, maintain, curate and manage the patient's health data. As follows:

Enabling citizens to securely access and share their health data across borders is one of the priorities of the Communication on enabling the digital transformation of health and care. Moreover, the General Data Protection Regulation (GDPR) underlines that citizen have the right to access their personal data and provides the legal framework for the protection of personal data. GDPR sets out directly applicable rules for the processing of

the personal data of individuals, including health data. Rules for facilitating the access to safe and high-quality cross-border healthcare are provided for by the Directive on patients' rights in cross-border healthcare.¹

Other considerations that were raised at the time of presenting these groups to the Tl.2 partners include the following:

Numerous countries, especially Nordic countries, have implemented a significant legal separation between types of data in the EHR and International Product Summary (IPS). They are divided between sensitive medical and clinical information in support of the patient's health needs and administrative information for the purpose of record keeping, protecting professionals and for collecting payments / reimbursements. While there are various levels of readiness for the EHR to better support patient's health, such as being integrated into patient facing services like the G-Lens, the limiting factor today is often the organizations (hospital, clinic, lab) ability to maintain this information for the patient in a way that is effective, accessible, interoperable and secure over time.

Considering that G-Lens will provide for two-way communication between patient and HCP, it is also important to note that once data is released from the EHR, it can no longer be modified. Also, the patient is unable to modify their own EHR, even in cases where patient reports an error or wants to add a data point that is missing (an over-the-counter medicine or supplement that their doctor did not prescribe, for example, but that they take daily). These considerations were raised during Tl.2 partner meetings, however, will not be explored in depth in this report. Instead, they are meant to be reminders and flags for further investigation and decisions that will be made downstream.

Relevance in other Gravitate-Health WPs and Tasks:

These groupings are relevant for us considering the output of our Task which will feed directly into WP3 and WP4. While the G-Lens Platform will serve all 3 end-user groups, the G-Lens end-user services (user interface, mobile and web apps) will be piloted and evaluated in WP6 with Primary end-users. HCPs in each scenario have their own existing systems, software, workflows and practices, to which the G-Lens needs to connect, and we are complimenting that workflow by integrating new tools. Therefore, the G-Lens Service Design Blueprint will include all end-users, primarily focusing on Primary and Secondary end-users as we anticipate that the deliverables of the Gravitate-Health project will be distinctly:

- "Mobile apps" and "web apps" will be made for primary end-users (for demonstration and pilot purposes they will be new, stand-alone Apps, however with APIs for integration into existing Apps beyond the project)
- "Build Guides" (User Experience (UX), but not per se Interface (UI)) with requirements and EHR IT for secondary end-users
- "Real World Data" (RWD) dashboard for tertiary end-users

For this reason, as explained later, we decided to develop 5 Personas for Primary Endusers and 1 Persona for a Secondary End-User since Personas will support the design and development of the App user interfaces downstream in WP4 for piloting in the Gravitate-Health testing scenarios.

¹ https://digital-strategy.ec.europa.eu/en/policies/electronic-health-records

Rooting Personas' Design In Psychology: The Patient Health Engagement Model

1. What is Patient Engagement and why does it matter?

In the last decades, Patient Centered Medicine (PCM) has challenged the previously dominant biomedical paradigm and refocused healthcare organizations and procedures from giving a central, leading role to healthcare professionals, to a better consideration of "patients' voices" in the process (Coulter et al., 2013).

This shift re-oriented care criteria and objectives toward a better consideration of the entire burden of illness, and not only of the patient's disease. In other words, PCM advocated for a more holistic understanding of care recipients, not only as carriers of organic dis-functionality, but as persons deeply involved in a sociocultural context with complex backgrounds of life histories, experiences, and expectations of health and care. This epochal turning point laid the groundwork for the renovation of healthcare systems by casting light on the complex, subjective mechanisms that are involved in each process of care planning and delivering. This new representation of healthcare organizations has indubitably contributed to an improvement in the clinical effectiveness and psychological sustainability of care practices. In line with this, healthcare organizations and systems claim to have revised the implicit relational geometries that traditionally have ruled the delivery of services in favor of increased centrality to patients (Coulter, 2012; Graffigna et al., 2014).

In this perspective, patient engagement in health care is gaining increasing attention not only in the scientific literature, but also as a requirement for the everyday practices of health care organizations (Barello et al., 2012). In a situation of resource paucity, despite the greater demand for health services provision, healthcare systems are required to "do more with less": thus, the idea of patient engagement has been advanced as a potential solution to make the healthcare systems more effective and efficient. Patients not only need to be "put at the center" of medical action -in terms of consideration of their needs and expectations of care but should be seen also as one of the actors who contribute to the successful accomplishment of the healthcare organizations' missions and actions.

The proposal of establishing a true partnership between patients, healthcare organizations, and their professionals in the health care journey is magnified by the concept of patient engagement, which defines the individual not only as a passive recipient of care interventions but also as an actor who should orient service design in a co-creative and participative approach.

However, there is the risk to over-simplify the concept of patient engagement, considering engagement only as a behavioral dimension (e.g. adherence to treatment). From the perspective of health psychology, instead, patient engagement is a more complex construct.

Only considering the whole complexity of the patients' emotions, motivations and values that underlie their availability and willingness to engage in their own health management, it is possible to design services and interventions that really take into consideration their points of view. Thus, we felt the necessity for a psychological framework that can describe and profile patients according to their psychological readiness to play an active role in health management, and to provide useful insights in

how to tailor a service according to their specific needs: the Patient Health Engagement (PHE) model.

2. The Patient Health Engagement (PHE) model

The "Patient Health Engagement" (PHE) model was developed by embracing the notions and paradigms of consumer health psychology. It is an experience-based psychological framework, developed from the systematic and in-depth study of patients' illness experiences by means of narrative qualitative research (Barello & Graffigna 2015; Graffigna & Barello. 2018).

The model describes patient engagement as a process involving patients' capacity to plan realistic life projects (i.e., meaningful life aims that the patient might generate unless living with the disease condition) and to be goal oriented – even if living with a disease. The process of patient engagement as described by the PHE model involves four developmental phases, namely, blackout, arousal, adhesion, and eudaimonic project (see Fig.2).

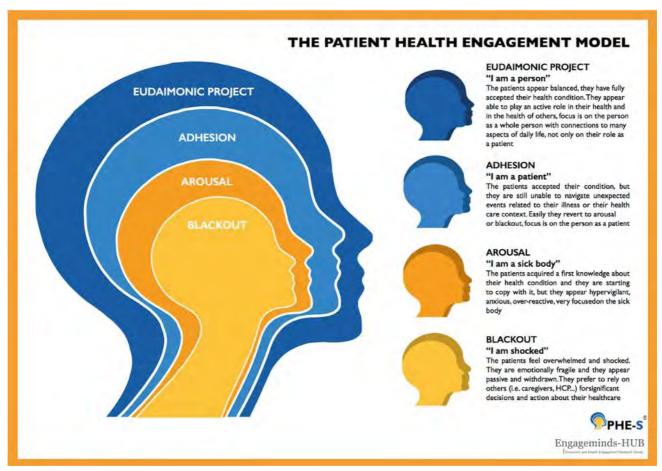


Figure 2: Patient Health Engagement model describes four different levels of health engagement

The model entails the role of the emotional component of engagement as the main driver of patients' ability to adjust and adapt to the changes of self-role identity requested during their journey. Thus, the concept of engagement implies patients' personal choices and intention to change their attitude toward the healthcare system, from a passive actor to a partner and co-pilot with the healthcare provider during the journey. This change in

the personal role identity is a function of patients' evolving adjustment and resilience to their health condition.

The PHE model suggests that a fully engaged patient results from a continuous emotional and motivational reframing of his/her health status and his/her role identity. According to the PHE model, becoming engaged in health and care management means being more resilient at the emotional level and effectively adjusting to the health condition and its medical requirements. The PHE model theorizes possible trajectories of engagement which are not necessarily linear (a patient may move backward and forward according to critical events in his/her life and disease course). This process also features 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.

2.1 The four phases of Patient Health Engagement

As already mentioned, the Patient Health Engagement model features four different positions with increasing levels of health engagement. These phases are:

Blackout: this phase of the PHE model mainly occurs when patients experience feelings of psychological vulnerability connected to a critical event, such as diagnosis, new symptoms, relapses, and the need to adopt a new lifestyle to manage the health condition. In this phase, patients seem psychologically frozen and feel paralyzed. In this stage of the PHE model, patients perceive the diagnosis and the requirements for managing the disease as distressing and conflicting with their life habits; for this reason, patients in "blackout" frequently experience feelings of deep sadness and anger. Consequently, these patients tend to be passive toward their healthcare providers. Patients in this phase need emotional and psychological support in order to adjust to their new health condition and develop a new sense of agency and control, as well as a sense of effectiveness concerning their health management.

Arousal: patients in "arousal" have acquired an initial awareness of their health condition, but still have superficial knowledge about how to manage it in an effective way. This uncertainty and lack of formal knowledge causes difficulty to adapt to their condition and to consider their new health status as part of their daily lives. Moreover, these patients often report that they are hypervigilant over their body and body signals: every unexpected change in their body status causes emotional alarm and overwhelming emotional responses. In this position, patients need to feel supported by healthcare professionals in managing their illnesses and coping with the disease, thus preventing care dropouts (that are particularly frequent in this phase).

Adhesion: these patients have at least partially succeeded in the process of regulating their emotional response to their condition and are starting to cope in a functional way with it. They have developed a good acceptance of their disease and have overcome the major psychological distress related to the disease onset. Moreover, they report being increasingly aware of their health status and of its impact on their lives and life habits. In this phase, moreover, patients are increasingly knowledgeable about how to effectively manage their disease and treatment. However, patients undergoing the "adhesion" phase are not yet fully autonomous in their disease management in terms of medical prescription (both life habits and therapeutic regimens), and they frequently experience trouble when something in their life context changes (i.e., going on a holiday, working life changes, and so on). This happens because patients in this phase are not totally aware of the reasons behind the medical prescriptions; they appear to be formally compliant with their health providers' requirements, but risk failing when some variables in their life

change. As a consequence, patients in this phase need to be assisted by an expert figure who can help them maintain correct health behaviors even in stressful or atypical situations.

Eudaimonic project: these patients have become almost totally aware of their disease and its implications in terms of requested lifestyle adjustments and behavioral change, they are able to become active agents in reaching a positive and satisfying quality of life, even though they have to live with a disease condition. They have elaborated and accepted their new "patient identity" as one of the many features in their own life. In the "eudaimonic project" phase, patients are able to integrate – in a more synergic manner – their health and disease management into their life goals. Patients experiencing this phase of the PHE model are generally also more effective in health information-seeking processes and understanding the reasons behind medical prescriptions. Finally, in this phase, patients are able to "activate" the health care professionals when needed, in order fully to respond to their needs and well-being expectations. Health care practitioners are thus considered as reliable allies, and patients see themselves as active members of the care team. Finally, patients in the eudaimonic project phase are also able to become advocates of patients' rights and to play the role of peer experts in patient associations and advocacy groups, or in co-producing services at a policy level.

3. Measuring Patient Health Engagement: the PHE-scale

During their journey patients go through the four positions, each one entailing different emotional, cognitive, and behavioral stances (see Fig. 3). Due to the complexities of patient engagement, it is necessary to use dedicated and specific assessment tools that can grasp the multifaceted nature of patients.

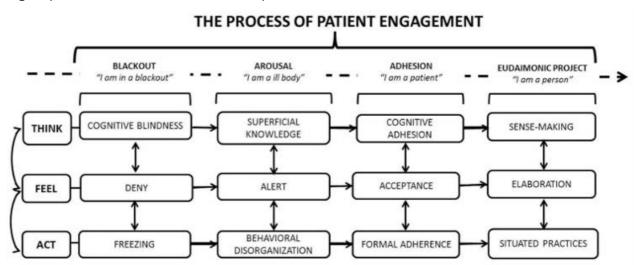


Figure 3: The process of patient engagement as described by the PHE model, picture retrieved from Graffigna et al. 2015

The Patient Health Engagement scale (PHE-s®) is a validated measure developed by Graffigna et al. (2015) which features 5 ordinal items. Each item consists of a row of 4 "points" labeled with different statements which reveal the underlying psychological state of the patient (see Fig. 4). Each patient is prompted to choose, from each line, the statement that best represents how he feels when thinking about his/her disease, or a point in the middle. The scale was developed with the theoretical model in mind, but starting from qualitative interviews and reported patients' experiences; this bottom-up

developmental process has been necessary to make sure that the PHE-s could grasp the complex psychological experience of the patient engagement journey.

Thinkin	g about my health st	atus	·					
1	I feel pyschologically frozen and blocked	l feel alert		I am aware			I feel positive	
	0	0	0	0	0	0	0	
2	I feel dazed		I feel worried		I am conscious		I feel peaceful	
	0	0	0	0	0	0	0	
3	When I think about my illness, I feel overwhelmed by emotions		I feel anxious every time a new symptom arises		I am used to my illness		I find my life meaningful despite my illness	
	0	0	0	0	0	0	0	
4	I feel very discouraged due to my illness		I feel anxious when I try to manage my illness		I have adjusted to my illness		I feel optimistic about my future	
	0	0	0	0	0	0	0	
5	I feel totally oppressed by my illness		I feel upset when a new symptom arises		I have accepted my illness		I have a sense of purpose despite my illness	
	0	0	0	0	0	0	0	

Figure 4: PHE-s®, picture retrieved from Graffigna & Barello, 2018

Thanks to its shortness and psychometric robustness, the PHE-s can be easily used not only in clinical settings and encounters, but also in digital implementations.

Personas

After anchoring the theoretical framework, we started with the development of Personas, and this chapter describes in detail the steps taken to arrive to 6 Gravitate-Health Personas: Maria, Filippo, Amalia, Pedro, Peter and Antonio.

4. What Are Personas

Personas are among the many tools available in the designers' toolbox when designing a service or experience.

The Nielsen Norman Group definition adopted in the Gravitate-Health project is:

A persona is a fictional, yet realistic, description of a typical or target user of the product. A persona is an archetype instead of an actual living human, but personas should be described as if they were real people.

While Personas are fictional, they are based on research performed on the end-users of a service or product. Ideally, field studies, like surveys or interviews, should be conducted before the design phase starts. Through raw data it is possible to define key characteristics of typical end-users. After data collection, analyzing the data is useful in order to recognize and cluster recurring attributes.

In this process it is reasonable to merge similar clusters, while eliminating the ones that are irrelevant for the product or service on design. Therefore, instead of creating a Persona for each individual end-user of a product or service, real world end-users are grouped together in segments that represent the largest number of people and include the entire range of diversity represented in the original research and raw data. In the consumer industry, these are often referred to as customer segments and used to deliver the most meaningful value to the largest number of people.

5. Benefits for Using Personas

Personas are archetypes that teams, not only designers, build to establish a common ground and connection with the target end-user. They can be used to assess the design, so you may answer questions related to the Persona's unmet needs or how she would act in a certain situation.

Using Personas helps the team to be on the same page. When speaking of a specific Persona each team member will be clear on the expectations, characteristics and behaviors that are related to it. In the opposite case, when thinking of generic users each member will have their own picture of the user. It is unsurprising that in the latter case discussion can be confrontational between members, rather than focusing on the team work to serve target's needs.

Personas are useful to prioritize and address the features that the team will implement. Once the Persona is the reference for everyone involved in a digital product or service, it will be much easier to decide what the team has to develop.

Personas are vital to the success of a service or product because they drive design decisions by taking common user needs and bringing them to the forefront of planning before the design actually starts. They also provide the team with a shared understanding of the end-users in terms of goals, capabilities, and context.

In Gravitate-Health Personas are a key instrument that would help the project members to have a common understanding of the end-users of the G-Lens. Having this model of the end-user was essential to achieve the project goals, being the Consortium a large and multidisciplinary team with very diverse mental models and points of view. The definition of Personas within Gravitate-Health has been also a valuable instrument to gather the user needs, to derive the requirements and specifications for the G-Lens design, and to prioritize the different developments according to the end-user priorities.

Although the definition of Personas has been performed and delivered in T1.2, the activity had a strong connection with the rest of the activities included in WP1. In this sense, task

Π.1, was the main source of information for identifying needs, motivation and context of the end-users. On the other hand, the Personas developed in Task Π.2 were mainly used by task Π.3 and Π.4 as an input for defining the data model and the KPIs to be used in the validation stage. Thus, if needed, Personas can be revisited and further elaborated in WP6 (in particular T6.2). As we go in depth on the priorities in the testing scenarios and learn from the iterative design cycles, we can further refine the Personas to match the priorities we do in the testing scenarios. In any case, and following the co-creation and user centered design principles, the interaction between these four tasks has been continuous during the whole process and has also followed several iteration cycles.

6. (Creative) Approach to Personas in Gravitate-Health

Usually, for a digital web or mobile-based service, one primary end-user Persona is enough. In some cases, a secondary Persona, less detailed may be added. As G-Lens will interest a broad range of actors, use cases and important episodes in the healthcare landscape distributed all over Europe the first idea was to develop 6 Personas in the primary end-user group (as described in Part 1 of this Deliverable).

Regarding the number 6, this decision was based on standard best practices in the field. Since TI.2 is a design task, meaning that Personas are being developed as design tools, to support in 1) the Service Design and 2) eventually the design of UX/UI of Apps.

As a core team, from our collective past experiences working with Personas (and 'customer segmentation'), 6 is standard for the maximum number recommended Personas to capture diversity but not lose meaning in a project. In design disciplines (industrial, product and digital design), the commonly accepted theory is that if you can design a product that serves 6 unique and diverse people (i.e. it helps serve their needs, it's easy to use and they love it so much they adopt it) then you have a product that will be widely adopted by large populations. This is supported by our direct experience in projects at Roche, Pfizer, Datawizard, Pearson, IDEO, Wolters Kluwer and other large organizations.

The decision of the Task 1.2 team to proceed on developing a Persona methodology with Maria as the first example, was the best solution to adapt the approach to deliver the best possible Personas in the absence of raw data/end-user research.

Maria is a real person used as a testimonial in the project. There is a video of her that explains her relationship with health. We had also indirectly accessed her in different iterations and collect her opinion through an interview as described in chapter Iterations on real data. We have used all this information to test our template and build up our first Persona as well.

Core members of Tl.2 also supported Tl.1 in the interview question preparation and actively participated in the Task 1.1 interviews to have early access raw data to gain insights.

From there, the Gravitate-Health Personas has been built

6.1 Collecting resources

The first step has been to collect similar patient-centric projects. Being in such a big consortium has given us the chance to have access or receive suggestions on many

different Personas to analyze. Personas from different projects with varying demographics, health statuses, and emotions and behaviors has been collected. Our sources have included:

- Blueprint from the WE4AHA Project https://ec.europa.eu/eip/ageing/blueprint_en.html
- Project Capable Personas led by UiO empower citizens to active use of their health information https://www.med.uio.no/helsam/english/research/projects/capable/
- eHealth Ireland EHR Personas https://www.ehealthireland.ie/strategic-programmes/electronic-health-record-ehr-/final-persona-scenario-files/list-of-final-personas-scenarios-.html
- Gravitate-Health WP1 Tasks and Testing Scenarios

This phase has been helpful to understand how to address the task. In general, our focus has been on the primary end-user group (citizens, patients, and caregivers), specifically the self-care and self-management phases. More work will be necessary related to the phase during active treatment, something that testing scenarios in WP6, T6.2 may point out later in the project. As we were determined to develop a tool that would be helpful to other partners throughout the project, easy to consult on paper and on-screen. Our aim was that anyone could have a touch on the lives of the patients with an eye's glimpse.

Therefore, we decided that Gravitate-Health's Personas would be based on a landscape ratio that fits in screens and easy to read. As you will soon see, we have iterated many times until we have reached consistency and self-explanation in the structure. It has been quite natural to have all the information on one page with short sentence text, avoiding a wall of text where readers can't take pieces of information.

The next chapter shows how we have squeezed issues like autonomy or research on patient engagement in one piece of information in the Personas.

6.2 Foundation

When you build, strong foundations are necessary. It does not matter if it is not explicit in the final work or just a detail, but you need it. This is the case of preliminary work executed on autonomy and engagement.

6.2.1 Daily activities

On autonomy, two instruments were useful to understand what are the difficulties that persons with comorbid conditions have to deal with:

- Basic Activities of Daily Living (BADL)
- Instrumental Activities of Daily Living (IADL).



Figure 5: Basic and Instrumental Activities for Daily Living - Source Kindly Care

Basic and instrumental activities are widely used by HCPs to quickly screen the patient's autonomy. Understanding the complexities behind independence has been crucial in our work. At the same time, while we have decided to synthesize it in self-management and self-care in the Personas, we were aware of how critical these aspects are in people's lives.

6.2.2 Patient Health Engagement Model

Regarding engagement, we take advantage of the previously described PHE model developed by the team from Università Cattolica del Sacro Cuore, a Gravitate-Health partner. Their Patient Health Engagement model helps to systemize the different emotional stages that a patient may live while copes with changes in his health status.

Profiling patients through the application of the PHE model not only allows for an assessment of patients' psychological state but is also useful for the development and implementation of diverse communication and educational strategies: indeed, patients in different positions generally also have different needs or expectations, and thus require different approaches to communication (Menichetti & Graffigna, 2016). In particular, each engagement position described by the PHE model suggests specific needs of psychological support and counselling to help the patient improve along his/her journey:

 Patients in the "blackout" phase need to acknowledge their own condition and have to learn to cope with the requests that their diagnosis imposes. Thus, communication with these patients should be aimed at promoting acceptance and awareness, while also providing basic skills for the organization of health-

- related information and the acknowledgment of the correct health-related behaviors;
- Communication aimed at patients in "arousal" should help them assume a more
 positive mindset: this can be accomplished by helping them become more aware
 of how to organize their daily lives and of their self-efficacy. Promoting their selfawareness, health literacy, and ability to interact with their healthcare providers is
 the key to help them improve in their journey.
- Patients in "adhesion" have already started to cope with their condition on an emotional level, but need support to sustain their acquired self-efficacy and guidance to correctly implement their knowledge and skills to, ultimately, become more autonomous in health management.
- Finally, patients in "eudaimonic project" need to be sustained in their autonomy and helped in maintaining their life project. Communication tailored for eudaimonic patients should then be aimed at further developing their personal set of self-management skills, and making them more aware of other available, external sources of information and support (e.g. peers or patients' associations).

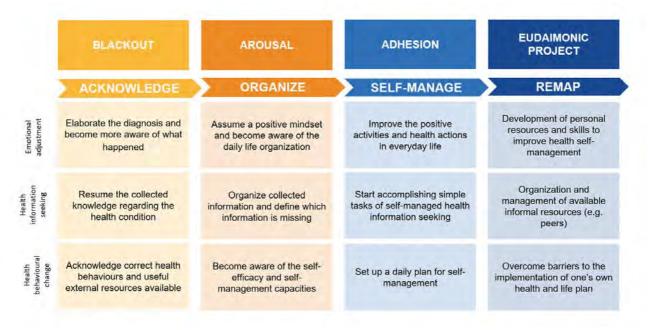


Figure 6: Objectives for each Patient Health Engagement position

Generally speaking, the PHE model is of interest for clinicians and policy-makers, as it can work as a "compass" capable of orienting and guiding personalized clinical actions and policy making initiatives based on the patient or population level of patient engagement (and, on the contrary, risks of disengagement). The PHE model has the strength of offering a processual explanation of the psychosocial dynamics occurring when a patient becomes engaged in his/her own health care and recognizes that being fully engaged strongly depends on individuals' choices and disposition to play an active role in the care team. For these reasons, the model – according to the current literature – does not necessarily imply that higher levels of engagement are better. On the contrary, effective patient engagement occurs when the health care system recognizes and addresses the patients' unique needs that are specific to each patient engagement phase.

This perspective makes this framework particularly suitable for implementation in patients' Personas and in the G-Lens: profiling patients according to Personas which entail the dimension of health engagement will allow the deployment of the most

suitable communication strategies (which will be developed in Task 4.2), thus increasing the effectiveness of the message and its potential to answer each patients' specific preferences and needs.

6.3 Iterations on Miro

The online collaborative whiteboard platform, <u>Miro</u>, has also been our choice to have a place where, as a distributed team, we could contribute and work on the Personas template.

All the images related to Personas are in <u>Annex #3</u> if needed.

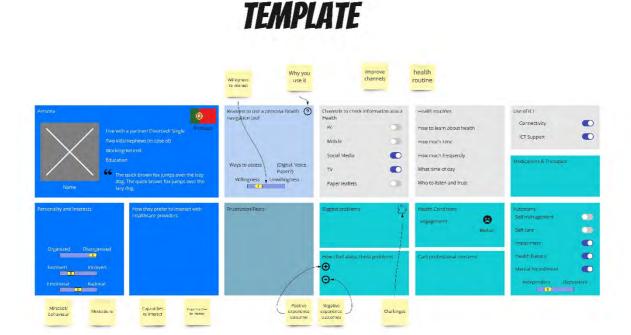


Figure 7: Persona's Template - First draft

We later tested with anonymized data of a real patient to ensure that we were in the right direction.

EXAMPLE

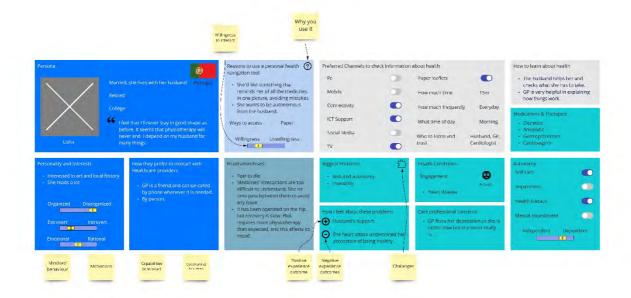


Figure 8: Persona's Template - First draft with anonymized data

6.4 From Template to Spreadsheet to Visual

The intention of the TI.2 was to have an easy way to share the template with everyone in the Gravitate-Health Project.

The next step in the process was to level up the template and test its contents with actual and accessible data immediately available within the project.

Firstly, we have decided to put the contents in a spreadsheet to have something easier to navigate and accessible to everyone.

Then the first draft has been transformed into a more appealing visual. We've also added an illustration of the Persona to establish a visual contact: a fundamental aspect to build empathy.



Figure 9: Persona's Template - Second draft

6.5 Iteration on real data

While working on the template, it has come naturally to work on data closer to reality. So we have focused on Maria, the patient presented in the Norwegian scenario, taking advantage of every bit of source data available.

Thanks to the collaboration with the University of Oslo, we had the opportunity to collect information and assessing the template with the only real data accessible to us:

- first <u>interviewing Anne Moen</u>, the coordinator of the Gravitate-Health project, and gaining insight from her scenario's knowledge;
- then reviewing our work conclusions thanks to the interview with the patient that Anne Moen has conducted for us.

6.6 Cleaning and Organizing

Iterating on the template was beneficial to improve the template's content and discuss the structure itself.

So we have decided to reorganize the template into four sections: Person, Patient, Behavior, and Environment to have a more solid and self-explained structure.

The Persona's structure must be as transparent as possible, to avoid any guess. In the end, its purpose is to sustain and organize content.

And if people don't wonder at all about it, it means that it works well, focusing on what matters most: content.

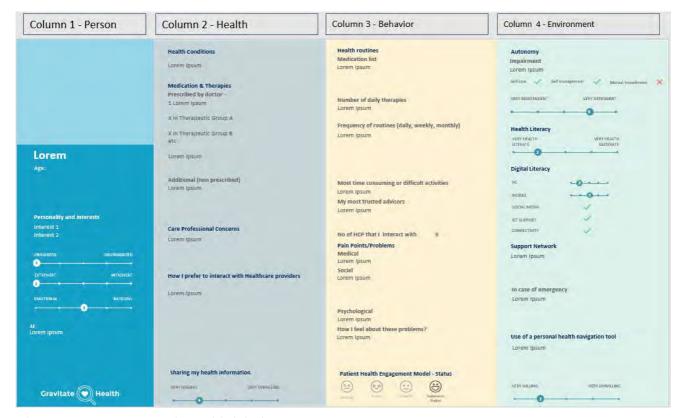


Figure 10: Persona's Template -Third draft

6.7 Feedbacks from the Forum

Through the Gravitate-Health Forum, we've received feedback that gave us the chance to sharpen the template.

So we've been able to:

- Check the consistency in Maria's Persona and improve it where necessary.
- Add more questions to Tl.1 interviews with patients that could be useful to verify our work on Personas.



Figure 11: Persona's Template -Third draft with notes to impact on Π.1 interviews

6.8 Caregiver Personas

We understand the need of caregiver Persona potentially arising when testing the G-Lens minimum viable product (MVP). Therefore, we have included an informal caregiver Persona in Annex #3, as an example for the future. Nevertheless, as the primary end users are patients, we focused on those for the following reasons:

- The patient Personas are solid, focused, and serve their goals in the project to build empathy, help personalize information, and identify the most critical features of the G-lens. Therefore, shifting efforts to doing multiple caregiver Personas would have detracted from this focus.
- 2. We don't have comprehensive data on caregivers, and the risk of not doing as thorough of a process as the patients will lead to weak caregiver Personas.
- 3. The only real gap in the patient Personas is around Autonomy. If a patient is not autonomous (in any regard) and a caregiver is acting on the patient's behalf, the focus of the G-Lens is still on the patient, their data, and their goals. Therefore, it should not impact the G-Lens if the patient is using it or the caregiver acting when a patient is unable.
- 4. Adding any more variables into the Persona templates to capture caregivers would bring the Task 1.2 team over the tipping point of preserving intended meaning. The risk is to lose the focus on the patient and create complexity which is not helpful in the project.

In conclusion, and for the reasons listed above, we did not proceed with developing other caregiver Personas in Ti.2. Nor did we develop Personas for healthcare professionals, since they belong to the Secondary End-User group. As described in 'End-User Groups' chapter in this Deliverable, Ti.2 is a design activity bringing focus to the patient, their health information and their therapy/goals. The G-lens needs to be first designed to support the Primary End Users in their everyday life, and then adapted to other end-users who will support the patients in their needs. In the case of HCP's the G-Lens will need to be

adapted to integrate into their existing hospital and medical software systems, therefore it will be done after the G-Lens is validated with the Primary End Users. That said, Partners in the Gravitate-Health project can follow the methodology in this report at any time to develop Personas for other end-users whenever needed and at any point in the future.

7. Personas delivered

In this chapter, we have collected the Personas developed in the Π .2. The Personas are also available in Annex #3, together with a template, if the need to create new Personas arises.

For each Persona, we have added a brief description plus the testing scenario reference.

7.1 Persona 1: Maria

Maria is a well-educated, autonomous and organized person. She represents a chronic case.

Testing scenario: self-care situations and self-management.

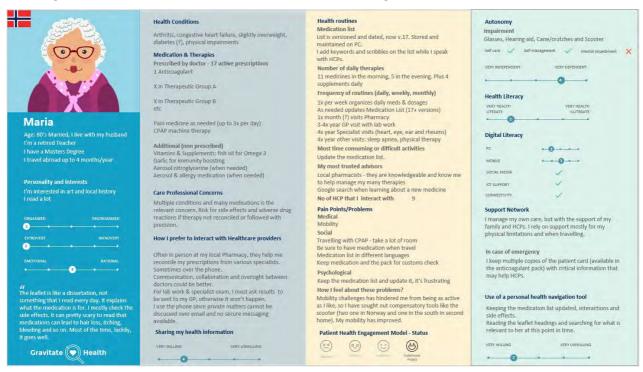


Figure 12: First Persona developed – Maria

7.2 Persona 2: Filippo

Filippo is a tennis player and a very active person. Out of the blue, he has been diagnosed with cancer. After 50 days in the hospital, he is back at home with a fatal diagnosis. He represents a palliative care case.

Testing scenario: self-care situations and periods of active treatment.



Figure 13: Second Persona developed - Filippo

7.3 Persona 3: Amalia

Amalia is a family-oriented person with a special bond with her daughter. She manages a chronic condition (diabetes) and does not always understand why things go out of control. Her eyesight and hearing issues are making it more difficult to enjoy her hobbies and to connect socially.

Testing scenario: self-care situations.

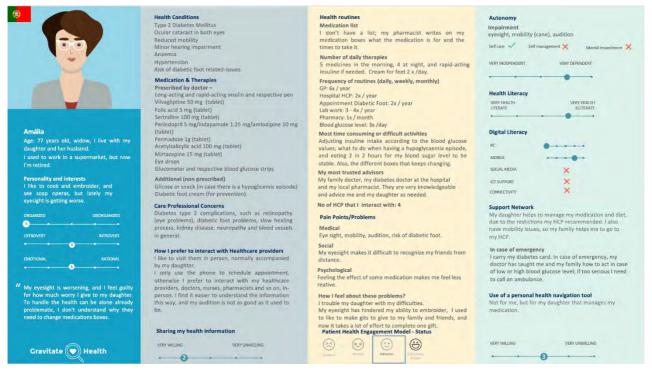


Figure 14: Third Persona developed - Amalia

7.4 Persona 4: Pedro

Pedro is a chronic patient with multimorbidity (HIV, depression, IBS) with a complex polymedication regime. He needs to regularly (monthly) visit the hospital to pick up his medication and have consultation with his doctors. He is worried about potential side effects and interactions between his prescribed treatment and non-prescribed medication he is also having (e.g. vitamin and protein supplements). He would like to have a trusted source of information for managing his condition and taking preventive actions against the spread of his disease.

Testing scenario: Periods of active treatment and self-management.



Figure 15: Fourth Persona developed - Pedro

7.5 Persona 5: Peter

Peter is a child with very complex care needs due to a spinal cord injury in his youth. To breath, eat and do other daily basic activities, Peter is dependent on caregivers and medical devices. His mobility is limited, and his medical devices must move with him. He takes many medications and his parents are his primary caregivers due to his lack of autonomy. They are all dependent on many healthcare professionals with regular interactions.

Testing scenario: Periods of active treatment and self-management.



Figure 16: Fifth Persona developed - Peter

7.6 Persona 6: Antonio (Caregiver)

Antonio has a sister, Elena, with Down syndrome. He is her legal caregiver and has to take care of her for every aspect during the day. Antonio represents a caregiver case.



Figure 17: Sixth Persona developed - Antonio

8. Use of Persona Template in Gravitate-Health

8.1 Impact on the project

At the time of completion of we have finished this document (May 2021), Personas have already been helpful in the project. Specifically:

- As you will read further in the next chapter, Personas have been the basis of the design workshop and later development of the service design blueprint.
- Task 1.3, which focuses on the information model, has analyzed dimensions defined in the Personas to make an abstract model and personalize the ePI.

8.2 Future use

Task 1.2 team has been careful to have an approach open to further improvements.

The main reasons are:

- Personas are alive and should evolve in time. So in the future, it has to be possible to work on them.
- Based on the Personas developed and using the template available in Annex #3, we want to be sure that everyone can add more Personas if needed.

The template is an editable file available as Annex #3. Some suggestions are:

- Coherence and consistency are essential to have a credible and impactful person.
- Choose wisely details to include. The Persona should consist of everything useful to have a complete picture, but too many details or overly long descriptions discourage people from reading.
- Aim to build empathy. Images that illustrate personas and writing in the first Persona go in this direction.
- As a direct consequence of the previous point, personas contain speech-language, so they should be easy to understand.

Service Design Blueprint Model and Journey mapping

While designing the intended experience for Gravitate-Health (G-Lens) we aim to develop an end-to-end process for how G-lens experience would be delivered to patients. To bolster our understanding of the patient perspective across this experience, we have drawn upon new and existing patient research to develop a scenario-based patient journey maps of the G-Lens solution. The patient journey mapping described in this section was related to the testing scenarios and phases of self-care, active treatment and self-management, as our personas were developed together with testing scenario leads. Although we took the starting point of all the phases, the current mapping applies for some aspects, but not all segments and testing scenarios, This work is meant to provide the starting point for creating and implementing G-Lens service that deliver a truly differentiated experience for the citizens.

Service blueprints are process diagrams for services that connect the customer experience with the people and activities that deliver it. They are used to deeply understand an existing service and identify challenges and opportunities for improvement to. We used design thinking to understand people's needs, look holistically at patient interactions, and iterated our way forward.

9. Data sources

As described in the previous chapter on Personas, we surfaced a collection of diverse Personas with varying demographics, health statuses, and emotions and behaviors.

Specifically for the G-Lens Service Design Blueprint, we identified common patterns across the Personas to infer interactions with the G-Lens solution. We examined:

- Patient daily life and activities
- Existing touchpoints and interactions with HCPs and health resources
- Unmet needs, pain points, and key moments in their care journey

We began to consolidate the data from the Persona sources to draft a 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. In future iterations of this journey, we recommend gathering input from User Advisory Group (UAG).

10. Initial investigations

10.1 Patient Journey Mapping

A patient journey map is a blueprint of important touchpoints a patient goes through in her/his care journey and is a way to visualize and get an overview of patient experience during their entire care journey. Patient journey mapping gives insights into the patient experiences during their care journey. Our approach was based on a unique health episode in a day of the life journey for each Persona. The knowledge gained from a patient journey will help WP4 to design the G-lens that will optimize the experience and generate value for both the user and the organization providing the service.

Figure 18 shows the Persona snapshot from our initial investigations and evaluation of journey from previous work (see <u>6.1 Collecting resources</u>), which has been used as a model for Design Thinking workshop described below. We used this model for structuring the initial draft of the Service Design Blueprint. On it, we evaluated each Gravitate-Health patient Persona and examined how their pain points and behavioral preferences would surface across key outcomes: access, understanding of information and adherence to treatment.



Figure 18: Persona Snapshot and Evaluation of Journey

After analyzing and evaluating the initial model, we identified that the key touchpoints that matter for patients using the G-lens converge around access, understanding of information and adherence. This led us to construct a guiding challenge statement for our workshop activity:

How might we create a trusted and highly valuable digital tool to transform the way citizens access and understand health information, and apply this in their personal health for improved adherence to treatment, better health outcomes and quality of life?

As part of the Journey Mapping task, the core members of Tl.2 organized a design thinking workshop where all partners were invited to join.

The workshop was carried out on April 22nd, 2021 on an Interactive Miro Board https://miro.com/app/board/09J_IICTOss=/

FOCUS AREAS:

In the workshop we wanted to:

- Become more acquainted with G-Lens end-users in order to empathize with their experience of access/understanding of information from trusted sources, and adherence in their healthcare journey today, focusing on the gaps and difficulties they face to understand their values and needs.
- Explore how the G-Lens can respond to their pain points/needs and add value, using Personas and mapping their journey in specific real-life scenarios.

Desired outcomes:

- Identify key pain points that the G-Lens can address
- Describing a wish-list of G-Lens functionalities and identifying the 'must-haves' that would relieve critical pain points or close critical gaps in the patient journey, and/or greatly improve their experience.

In the section below, we present some snippets of the patient journey map and the thought process driving to the features wish-list for each of the Personas addressed in the workshop. Each Persona was given a specific real-life scenario, where the workshop participants first empathized with the Persona, identified pain points and feelings, which lead to the identification of requirements for the digital solution in supporting self-care, active treatment or the self-management (depending on the Persona). The detailed description of the journey mapping workshop and the results for every single Persona can be found in Annexes 1a and 1b.



Maria's Map and Wish-list

In the scenario/episode we followed in the workshop, Maria got prescribed a new medication.

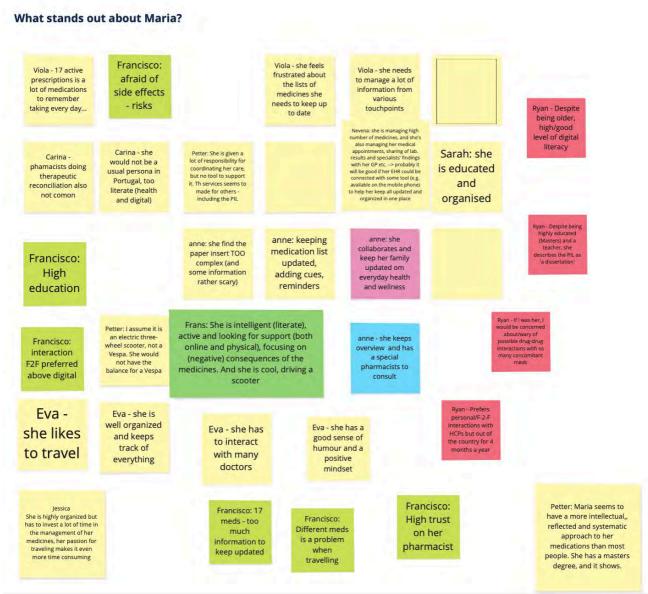


Figure 19: Empathizing phase Maria

Feelings: She feels sad that she will have to take yet another pill, she trusts her doctor and pharmacist, Frustrated (keeping up with medication and doctors) and worried about side effects of the new medication and the impact of the new medication, she is uncertain how to go about new medicine.

In the scenario/episode we followed in the workshop, Maria got prescribed a new medication, so the following G-Lens features could be useful:

- Access to information about new medication and its understandability
- Focused content (human readable- in a language that one can understand, in a way that is adapted to the understanding and knowledge of the Persona)
- Manage my health functional things (In case of new symptom, G-lens could suggest if the symptom might be due to a medication; Connecting the medicine with the specialists, List of meds and when the refill is due; alert function
- Sharing my patient journey (Sharing information with family members, caregivers and support circle, Connect to 'patient like me' - a network of patients with similar diagnosis as a support network)

• Travel health wallet (International Patient Summary, and subset of focused information; Standards, regulated sources, risk minimization, list of her mediation, evidence of prescriptions)

What will G-Lens bring for Maria? Feature 'wish list' based on access and understanding of information, adherence to treatment.

- Access to the information about the medication.
- Helping her navigate: focus on elements important for everyday management, like if the medicine is new or if it is a new brand name same substance, if it is obvious combinations in her set up.
- Have 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 or send some notifications that HCP consultation is needed based on her current condition status (e.g. if her lab test results show change outside of normal values)
- If medication has been changed, make sure that Maria demonstrates she understands why and how

Immersive and interactive options, videos, podcasts, audio learning and education materials

The one 'must-have' feature that would be incredibly valuable for Maria would be to get the product content information in a language she understands when she is travelling.



Filippo's Map and Wish-list

In the scenario/episode we followed in the workshop, Filippo's health status has suddenly changed without any significant warning.

For a sporty and very active person, the change in his health status has been very tough to deal with. Filippo's willingness to control what happens to him (battleship game).

He doesn't want to speak about his health condition (phone turned off).

What stands out about Filippo?

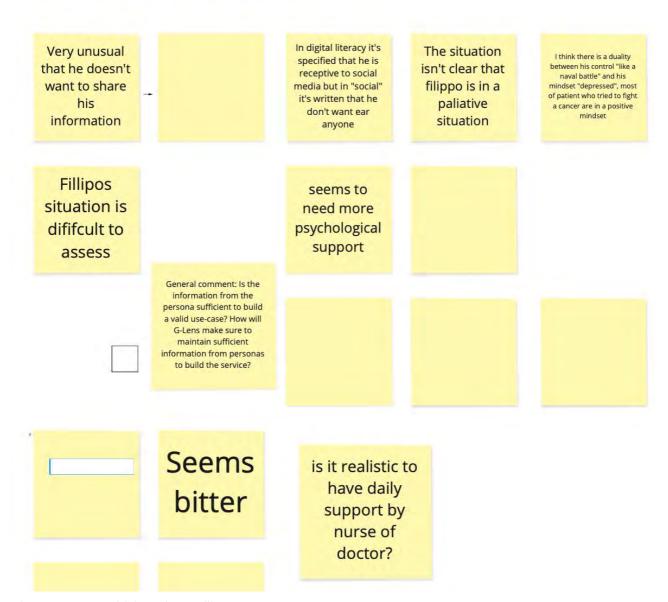


Figure 20: Empathizing phase Filippo

Feelings: Despite everything he does, he doubts his condition and feels powerless, tired, and depressed as he realizes reality. He is grateful to his family for the support that he receives.

Because of the characteristics of the disease, following G-Lens features discussed at the workshop could be useful. However, some of the features listed below might NOT be applicable to G-Lens as they may classify as medical devices and would need to comply with the MDR legislation.

- Personalize dosage plan and keeping things under control.
- Understand the impact of treatment to his social life and manage side effects.
- Increase the feeling to have the control on what's happening.

- Making room for decision making about his medication in collaboration with health team.
- Empowerment to decide about his therapy.
- Pain medication interactions with treatment.
- Allow to search for additional information and support options.
- How to organize his death and family support after.
- Reduce communication barrier through a communication tool.
- Get real time feedback and feel connected with care givers.

The values that we've identified in the workshop session are control, relief, impact, and autonomy. We think that empowerment may sufficiently synthesis everything in one word.

What will G-Lens bring for Filippo? Feature 'wish list' based on access and understanding of information, adherence to treatment.

While at home, some doubts arise about how to do a specific medication, give a therapy, react to a symptom, what Filippo and his family can do alone, and when it is better to ask for help from healthcare providers.

Currently, they have a phone number to call to ask for support 24/7. They need generic information as well as personalized to Filippo's case through data accessible in EHR.

The one 'must-have' feature for Filippo and his family: content (audio, video, or text) or a solution like a chatbot to clarify their doubts.



Amalia's Map and Wish-list

In the scenario/episode we followed in the workshop, it was a typically occurring episode in the life of a chronic patient that regularly needs to check a biomarker or metric in the outpatient setting (in this case, at home) in order to assess if disease is under control. This Persona also represents groups of patients that rely on a family caregiver to

maximize the successful management of the condition.



Figure 21: Empathizing phase Amalia

Because of the characteristics of the disease and the context where monitoring occurs, following G-Lens features could be useful:

- Accessibility needs that allow her to have access to information adapted to her limitations and level of digital health literacy (eyesight issues; dependency on caregiver, this would allow her to be empowered to better manage her chronic disease – she takes a lot of medications, need to adjust medication to blood glucose levels, diet restriction)
- Help to understand and manage her blood glucose levels and possible needs for action -> this was the issue that was analyze: what to do in case of high-level blood glucose?
- She is dependent on her caregiver, which manages her needs. The app would need to allow the caregiver to access her health data.
- Caregiver needs: access to Amalia's information; alerts could also be useful in case blood glucose levels were too high or low that could endanger Amalia.

It is important to note that some of her most pressing needs may not be directly related to better information on how to use medication nor the characteristics of the literatures made available as package inserts. This finding highlights the challenges of designing a patient centered solution where the needs of patients are of a nature that may be out of the scope of the initial remit of this project.

The one 'must-have' feature for Amalia: Having a user-adapted list of medication and reminders of when to take each medication.

A digital solution may open possibilities to a new way of managing her condition, allowing her to choose an audio option or a visual representation with good contrasts to access the information.



Pedro's Map and Wish-list

Pedro is at the stage of the patient journey where treatment is applied but therapy and/or medication doses changes on maybe in every visit. His treatment is restricted, and highly costly for the healthcare system. Although his medication is only dispensed at the hospital pharmacy, he needs to manage it at home and, thus needs to be empowered.

He goes for monthly visit and asks for explanations on the medicines, drug interactions, adverse effects. He feels that is very difficult to prioritize between personal needs and medical needs on the short time framework of visit.

Although Pedro is the main Persona for the scenario, he has a strong link with another stakeholder: his doctor or pharmacists (healthcare professional). These interact with him regularly (typically on a monthly basis either in medical consultations or when Pedro goes to the hospital to pick up his medication.

What stands out about Pedro? Craig Paper medication list and 6 therapies means complex dosing regimen to track. Higher risk o how HCP do able and no help quite a number He has to willing to have coordinate to of HCPs to manage on his follow up with digital contacts many and different and receive Pedro? do nutrition medications information they? making a mistake He has doubts wish for are the apps Where does self-sufficient says he would about his (health information and relying he look for medication navigation on family and info? Dr. on like to have but its not friends Google? clear why prevention reliable/ safe? more support on prevention He wants to Christine - Very literate both digitally Needs to be able of his disease to manage range taking know what he (assume since his a of helath medicines for pc sales person can do to be in conditions in worsening control of his the rest of his context of busy oppecite tough) and health condition and not only lifestyle cure Increasing complexity, recent diagnosis (depression?) added to other condictions emembering doses of medications as they change, and fear to adverse ffects or alergies Ouite proactive Going to the about his health hospital in taking working hours supplemets, might mean communication trying to stop smoking issues/barriers issues at work recent diagnosis, difficult to remember all the medication intake

Figure 22: Empathizing phase Pedro

Feelings: Before the consultation, Pedro is rushed, insecure, stressed, worried and unsure, he feels that is very difficult to prioritize between personal needs and medical needs on the short time framework of visits and he is uncertain/doubtful of correct actions. While at the doctor, he is embarrassed about asking too much, and feels a lot of uncertainty, insufficiency, and lack of knowledge, is looking for cooperation and dialogue about the side effects, interaction of new medication.

Because of the characteristics of the disease, our divergent ideation in the workshop led us to identify the following G-Lens features, however they will need to pass the viability, feasibility, and compliance criteria for the G-Lens as a final solution.

- Relevant information accessible at appointment.
- Time restraints for f2f meeting so a follow up service i.e., chat function.
- Possibility for 'digital' agenda/notebook included
- Accessibility not just to data source but to information tailored to suit the individual.

- Consolidate information on his 6 medications in one user friendly view.
- ePI available single source
- Auto registers of doubts/questions.
- One data source to access.
- Visibility of full medication list, opportunity to record details of questions to discuss with HCP, also reminders (or similar) could help him manage his various appointments and medicines.

The one' must-have' feature for Pedro: Focused (personalized) and trusted information on his medication and potential interactions (also with non-prescribed medication), risks, side effects, etc. for managing his condition.



Peter's Map and Wish-list

Peter (age 9) feels fear discomfort and anxiety, but the primary actors in this scenario are his parents as his full-time caregivers.

Feelings: His parents feel distress, urgency, sleep deprivation, adrenaline, dedication to resolving the issue.

What stands out about Peter? legal issues with a lot to Peter could benefit challenging going to school, consider and from interactions with parents as parents rather than homeschooling is & manage on a possible but daily basis that his primary complicated depends on caregivers could change health The extremely where is manually organised therapy response form the leaflet buildong sharable hope? knowledge The very difficult online Joy/wins - mini Peter probably matching of steps like a calm community just wants to day, full nights needs vs burdensome exhaustion be normal and - bonding service. Drugs sleep, shared healthy actions fun games family moment High risk of adverse events Does Peter have any social interactions reporting, enormous errors with televisits favorite activities / must be linical trials. gathering of hobbies / games? collaboration challenging - lots that many change in skills required of attention on with nurses socialize with involved medication to keep afloat health condition friends? Difficult organize constantly planning medication, lack of product changing information medication daily dosages due for pediatric to Peters schedule journal changing age patients

Figure 23: Empathizing phase Peter

age

a lot of HCP

interactions

In the scenario/episode we followed in the workshop, it was an emergency, so the following G-Lens features could be useful, however they will need to pass the desirability, viability, feasibility and compliance criteria for the G-Lens as a final solution.:

Medication is

actually the

smallest

component of

his care

- Crisis management support
- Decision aids related to medicine dosage and frequency

polymedicated

patients hinder

full knowledge

of treatment

• Reference to checklists to double check all possible problems (mechanical, drug-related, medical, psychological, etc) ß

The one 'must-have' feature for Peter that would be incredibly valuable to his caregivers: An interactive, easy to navigate, extremely personalized / customizable and dynamic GUIDE to administering Peter's medicines. This guide would be a template in the G-lens connected to his medication list (official EHR) but then flexible enough to

program precisely to Peter's unique case. It should include medicine preparation, sequencing, schedule (not only daily but weekly/monthly), and links for 'how-to' guides on administration, as well as general trusted related health information. The design should be so good that a care giver can navigate this tool on a mobile device, zooming in and out (clicking in or out) for the exact view they need in terms of detail at any moment.

11. Patient Considerations

Across all Personas, we uncovered key themes and considerations to inform the design of the G-Lens experience. These considerations provide valuable context to understand how patients perceive their care experience.

11.1 Discovery of Health Conditions at Different Times

Patients recognize a health issue and learn about their diagnosis at different points in time and are prescribed a new medication. Seemingly healthy patients, for instance, may discover an underlying concern once they visit a doctor, while patients with more complex issues might not get a diagnosis until after several tests and referral visits.

KEY CONSIDERATIONS: How might G-Lens provide patients with access to information about their medicines at varying stages of diagnosis that is easy to understand?

11.2 Significant Reliance on Caregivers and Patient Proxies

Patients who are children, seniors, or who have chronic and/or complex conditions are most likely to have a caregiver or a proxy who helps manage their health. These individuals often handle communications with HCPs, help manage treatment adherence, and observe the patient's overall health.

KEY CONSIDERATIONS: How might G-Lens provide content that is also suitable to caregivers and patient proxies? How might G-Lens focused content be easily accessible and understandable for patients and their caregivers?

11.3 Fragmented Care Experiences and Sources of Information

In some cases, patients rely on multiple HCPs and stakeholders to manage their care. Navigating between different HCP sites and occasionally different systems to visit the right specialists, patients communicate with different doctors who may not always be coordinating care amongst one another.

KEY CONSIDERATIONS: How might G-lens bridge information between the patient's multiple HCPs and help them reconcile the various info they are receiving?

11.4 Varying Circumstances Inhibit Accessibility to Health Resources

Many patients already face challenges accessing existing health resources due to a variety of issues such as health literacy, cost, proximity, etc. However, patients with chronic and complex conditions fair worse due to vision, auditory, mobility, and cognitive impairments that make access and engagement with health resources more difficult.

KEY CONSIDERATIONS: What existing capabilities or types of content (e.g., video, audio, infographic, accessibility options) can G-Lens leverage to help bring equitable access and engagement with health information to patients?

Occasionally, patients are reluctant to accept and consume health information. For some, additional health content may feel daunting because of the length or current complexity for existing literature. For others, a poor experience in the past may lead a patient to lose trust in HCPs and/or biopharma.

KEY CONSIDERATIONS: How might we create focusing mechanisms via G-Lens to improve patient confidence and receptivity to educational health information?

Varying Life Contexts Complicate Health Needs

Because many patients manage their health outside of the HCP setting, there are many life circumstances and behaviors that HCPs never have visibility into. In this case, HCPs are unable to advise on lifestyle adjustments or screen for underlying risks (e.g., financial struggles, mental health issues, poor hygiene, etc.)

KEY CONSIDERATIONS: How might G-Lens eventually provide life circumstance relevant information and content to patients to help them adhere to treatment?

12. Patient Journey Blueprint

Based on our analysis of end user Personas, we developed a future-state patient journey highlighting patient touchpoints with G-Lens, aligned to the desired outcomes around access to trusted sources, understanding of information, and adherence to treatment.

We started with mapping individual journeys for each of the Personas. We then analyzed the journeys (with exception of Peter) and have proven that all the journeys are unique, however some patterns in behaviors and interactions are in common. We have identified key requirements for each Persona journey, and afterwards consolidated the journeys and requirements.

In the section below, we demonstrate the feel of the development of the patient journeys. The detailed, high resolution pdf formatted patient journeys can be found in the <u>Annex 2</u>. Figures 24-27 show the individual patient journey for Maria, Amelia, Filippo, and Pedro. The patient journey of Peter is not demonstrated, as throughout the process, we realized that he is very dependable, and the discussions let to caregiver's needs rather than his own.

Each of the patient journeys' key elements are organized into horizontal swim lanes with vertical lines that separate the patient journey phases,

- 1. Discovery of Health Condition.
- 2. Consultation with HCP.
- 3. Learning about the Health Condition & Adopting Treatment,
- 4. Care between care.

The swim lines include the following:

Phases of the patient journey

- Subphases of the patient journey
- Key Activities (What actions are the patients taking? And more additional details on key activities)
- Touchpoint Interactions (What are the various channels patients use throughout their experience?),
- Supporting Actors (Who else interacts with the patient and what is their role?),
- Thoughts, Motivations, & Behaviors (What are patients thinking?),
- Patient Emotional Journey (How do patients feel across the journey?)
- G-Lens Opportunity Areas

These swim lines are described in Figures 29- 33 under the subtitle *Stages of the journey, substages and actions* and can be found for a zoom in view in Annex 2 (note: open in pdf).

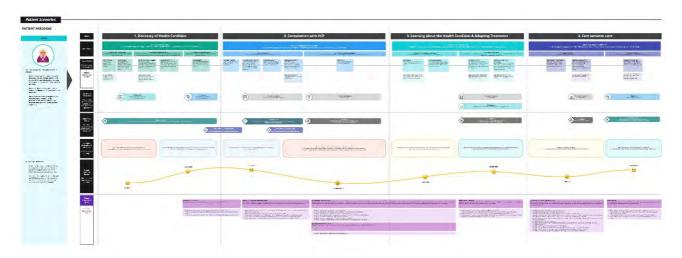


Figure 24: Consolidated journey Maria



Figure 25: Consolidated journey Amalia

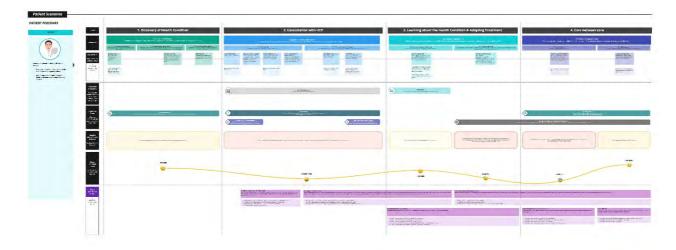


Figure 26: Consolidated journey Filippo

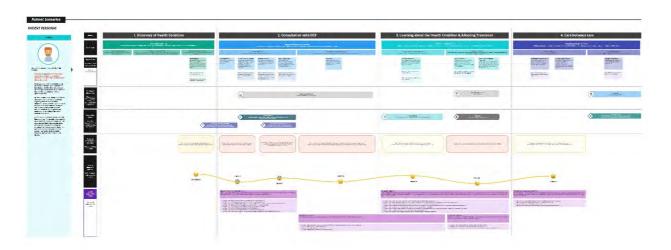


Figure 27: Consolidated journey Pedro

In the Task 1.2, we focused on building a more detailed frontend patient agnostic journey (Figure 28). Based on the front-end data points we identified the backend requirements that will inform the features for the G-Lens. The remaining backend requirements will be iterated as we obtain more information from other work packages. The technical aspects will be tackled in WP4.

As Service Blueprints can take different visual forms, we have opted for a framework that derived from our scenarios, the Persona data and the patient-journey map. For a more indepth view, all of the blueprint journeys are accessible in high resolution pdf format in Annex 2.

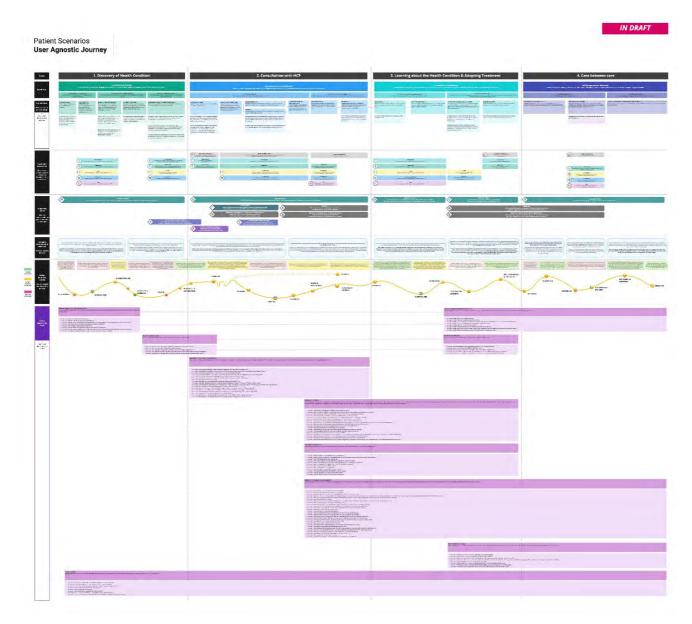


Figure 28: User Agnostic Journey

12.1 Stages of the journey, substages and actions

Our proposed blueprint includes the front-end steps, activities, and interactions that patients perform and the examples of interactions with a G-Lens service to reach a particular goal, which is improved access to information, understanding of the information and relation to adherence to treatment.

Frontstage actions

Actions that occur directly in view of the patient. These actions can be human-to-human or human-to-service actions carried out when the patient interacts with a service.

Backstage actions

Steps and activities that occur behind the scenes to support onstage events. These actions could be performed for example by a backstage functionality not visible to the patient.

Blueprint horizontal swim lanes- stages in the patient journey and relevant touchpoints

Internal processes, features, and interactions that support the G-Lens in delivering the service to the patient. This element includes anything that should occur for all of the G-Lens service to take place and offer an exceptional customer experience.

We have organized the key elements into horizontal swim lanes with vertical lines that separate the patient journey stages. There are three primary lines:

• The line of action depicts the stages in the patient journey



Figure 29: Line of action

• The line of interaction describes the various channels and digital ecosystems that Patients interact with and we must consider when we think of the holistic omnichannel experience



Figure 30: Line of interaction

• The line of support lists who else interacts with the patient at a given moment in the journey



Figure 31: Line of support

• The line of empathy informs about Patients' motivations, thoughts and behaviors



Figure 32: Line of empathy

• The line of emotion draws a curve of an emotional journey



Figure 33: Line of emotion

The line of visibility separates all service activities that are visible to the patient from those that are not visible. Everything frontstage (visible) appears above this line, while everything backstage (not visible) appears below this line. For this section we focused on showcasing the G-Lens functional and user requirements.

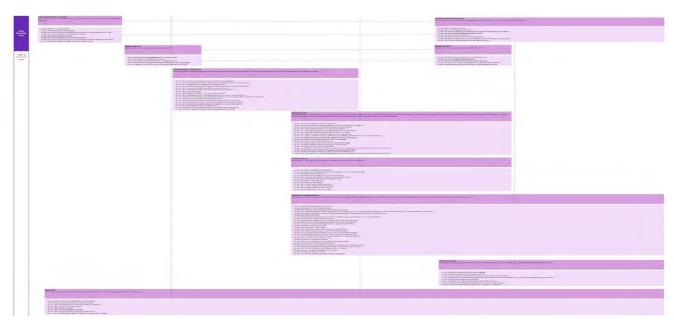


Figure 34: Line of visibility

When consolidating insights and data we examined individual journeys we have identified there is not always a parallel frontstage for every patient and the G-Lens interaction points (moments of truth) must support the core principles and heuristics of access, understanding and adherence.

Conclusions

The G-Lens end-user groups have been well defined at the start of the Task, with a focus to provide the design framework that informs prototypes both in D1.3 and D4.1 while remaining predominantly centered on the G-Lens design efforts downstream where it really counts – the patients, their needs and those who are assisting them when their autonomy is impaired. In addition, we have specifically tailored the end-user categories based on the electronic health record of a patient, because we believe this will truly enable the G-Lens to fully tailor and personalize the information on the medicines, by using the complete patient data available in the EHR. To avoid distracting the focus on the most critical feature around patient data, their goals relevant to their information, we have also refrained from providing multiple caregiver Personas. In this way Task 1.2 has preserved a truly patient-centric approach which is one of the primary ambitions of this project, and at the same time, not exclude other actors on the patient's care journey.

The G-Lens design methodology involved collaborating with the Gravitate-Health testing scenarios leads from Norway, Italy, Portugal, Spain and Ireland to develop the 5 patient Personas – Maria, Filippo, Amalia, Pedro and Peter – and 1 caregiver Persona – Antonio additional information on the scenarios are captured in Task 1.1. We used the mixed-approach which incorporates the G-Lens Service Design Blueprint, to map the patient journeys of the Personas in a co-creation workshop with members of the Gravitate-Health consortium; this resulted in the identification of unique features for each Persona as well

as common patterns across the Personas to infer interactions with the G-Lens solution. The converged blueprint of these 5 patient Personas and the caregiver Persona are not 100% comprehensive for all the possible end-users of the G-Lens and the testing scenarios in subsequent tasks, however they are underpinned by the diversity of their patient journeys, and they were extremely helpful in humanizing the design process in the initial stages of the project. They allowed for meaningful deep dives into 5 unique patient cases, based on real world examples in self-care, active treatment and self-management phases, and therefore the wish-list of G-Lens features that resulted can be traced back to specific pain points along one of these Personas in their health journey and behavioral preferences across the key outcomes: access, understanding of information, and adherence to treatment. The Patient Health Engagement Model (PHE), as previously described in chapter 3, was developed by the Gravitate-Health partner's team from Università Cattolica del Sacro Cuore to systemize the different emotional stages that a patient may live while copes with changes in his health status and is the framework on which we suggest evaluating the impact of the G-Lens in terms of supporting patients to move up the scale for better understanding, adherence, health outcomes and overall well-being / quality of life. The PHE model further suggests that a fully engaged patient results from a continuous emotional and motivational reframing of his/her health status and his/her role identity. According to the PHE model, becoming engaged in health and care management means being more resilient at the emotional level and effectively adjusting to the health condition and its medical requirements. The PHE model theorizes possible trajectories of engagement which are not necessarily linear (a patient may move backward and forward according to critical events in his/her life and disease course).

This process also features 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. The Personas reflect this continuous journey patients embark on in interaction with their healthcare and they are valuable input for the G-Lens Data Model in tasks Tl.3 and Tl.4 for defining the data model and the KPIs to be use in the validation stage and where they will be useful to analyze against the Delphi results coming out of Tl.1. The Service Design Blueprint Model as presented in this document, will be the suggested starting point for task 4.1 for G-Lens end-user mock-ups.

Limitations

While our methodology is robust and inclusive, there are some limitations which we wish to highlight:

- We focused our work on the target group of primary end-users of the G-Lens, while broader target population or segment that this technology (G-Lens) will serve, has not been addressed. The main reason being that if target population is poorly characterized, too broad, or too undifferentiated it may be difficult to focus enduser research efforts which may bring challenges to developers later.
- Limited primary end-user data on time for the creation of D1.2. Primary end-user data is important for the creation of robust and reliable Personas and journey maps. Utilizing indirect end-user data may unintentionally introduce personal

- understanding, beliefs, preconceptions and stereotypes into the Personas. Further validation with primary end-user data ("real" end-users) are important for further development, update and validation of D1.2. content.
- Usability and reading experience could have been optimized. Although the graphs and maps presented on this deliverable have high quality and high resolution, it may be challenging to have an integrated and comfortable digital experience. These materials work best when printed on AO canvasses that allow end-to-end visualization. We provide recommendations are provided next to each map on how to improve the readability and usability of the Personas, journeys, and blueprint, on electronic devices.

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Annex #1 - Design Workshop,

Annex #2 - Service design blueprints

Annex #3 - Persona Template + Example



We are delighted you could join us!

Gravitate (Health

Before we start...

Rules of the road...



It's okay not to connect your camera if you are having connectivity issues

We would love to see everyone's faces, but unfortunately **Zoom can cause delays**. If you are experiencing a lag, please feel free to turn off your camera.



2 This session will be recorded

The audio and video will be recorded. **By** participating in this meeting you consent to your voice and video being recorded. This recording will be used by the workshop team for post session evaluation of outputs and content.



3 Questions are welcome

We want to hear from you. **Your questions are super-valuable**.



4 Zoom may lag a bit

Please be patient. If you experience some lagging, **use the comments box** to let the facilitators know if you have missed anything.

Digital etiquette

Some little dos and don'ts to make sure that we have the best experience and everyone gets a chance to participate.



If you have background noise, please set computers and phones to **mute until you are ready to speak**



1 person speaks at a time. If your facilitator asks a question and no one is talking at the moment, go ahead!



Raise your hand if you'd like to speak when someone else is already talking.

Let's test this functionality now.



Use the chat function if you have questions or need support, please **send us a message in the comment box**. We will be monitoring the conversation and will respond to your questions. *Let's test this functionality now.*

Rules of the road

Let's get the necessary out of the way....



Be honest and candid

Relax, you are in a safe space

We are here to learn from you! Please share your true opinions and feelings so that we can learn from you. There are no wrong answers to our questions.



Be fully here

Today is about sharing all of our thoughts "on the board" and actively collaborating

Share with us anything that comes to your mind. There are no silly or impossible ideas – any idea can help us move the conversation forward.



Yes, and...

Be positive minded

Build on each other's ideas, don't refute them. Don't judge yourself and don't judge others. Look for innovative ideas. Don't feel constrained and think big!

Challenge (HMW) statement

Why are we here?



How might we create a trusted and highly valuable digital tool to transform the way citizens access and understand health information, and apply this in their personal health for improved adherence to treatment, better health outcomes and quality of life?

FOCUS AREAS

Today we want to:

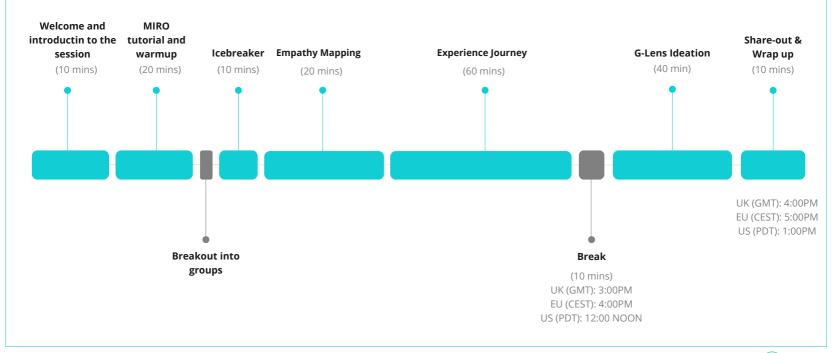
- Become more acquainted with G-Lens end users in order to empathise with their experience of access/understanding/ adherence in their healthcare journey today, focusing on the gaps and difficulties they face to understand their values and needs.
- Explore how the G-Lens can respond to their pain points/needs and add value, using Personas and mapping their journey in specific real-life scenarios.

Desired outcomes:

- Identify key painpoints that the G-Lens can address
- Describing a wish-list of G-Lens functionalities and identifying the 'must-haves' that would relieve critical pain points or close critical gaps in the patient journey, and/or greatly improve their experience.



Agenda





Opportunity Areas: User scenarioes

We are validating this opportunity through the value it presents to our personas.

We are looking at our opportunity through the following lenses:



Maria Norway Scenario



Filippo Italy Scenario



Amalia Portugal Scenario



Pedro Spain Scenario



Peter Ireland Scenario

We ask you to think holistically and not on what can be done today, but **imagine what** the future might look like, and to think from the perspective of those we serve, our patients.



Let's all log into Miro now!





(Please log in with Chrome)

Join us on Miro:

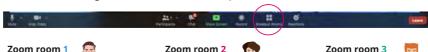
https://miro.com/app/board/o9J_IWGODsw=/





Let's break out into teams

- 1. Find your group
- 2. Click on the Breakout Room icon and select your Room
- 3. Hover over the number on the right next to the Room and click **Join** to enter!







Plenary

Maria **Norway Scenario**

Eva Turk Viola Wontor

Eleni Germanopoulou Nevena Milisavlievic Anne Moen Charles Flint Frans Folkvord Sarah Frise Kevin Airev Elena Arredondo Lillo Francisco Hernandez Carina Dantes lessica Paul

Anne Gerd Granås

Casper Winsnes

Zoom room 1



Zoom room 2 Group 2

Amalia

Portugal Scenario

Natercia Rodrigues

Isabella Sanderfelt

Vanessa Mendes

Kirsty Johnston

Shimon Yoshida

lanos Karovits

Janine Clulow

Amy Cramer

Dennis Gentges

Iulian De Gabriele

Linn C. Svenningsen

Samuel Jacinto





Group 3

Pedro **Spain Scenario**

Cecilia Vera

Craig Anderson Macarena Torrego Bentz lürgen Carolyn Sperl Xenia Beltran Giovanna Maria Ferrari Christine E. Hallgreen Devric Dodds Dipak Kalra Elena Balestra Marianne Groeneveld Daniel Tortora Ulrike Michaux

UiO-Eva Turk

Room 3



Group 4

Zoom room 4

Peter **Ireland Scenario**

Lucia Comnes Maria Brenner

Ioris Vugt Koen Nauwelaerts Georg Lang Line Løw Núria Febrer Camprubi Michele Calabro E.S. Hofmans Jurgen Hauck Tanja Jäntges Joakim Fagerli Fanny Mavroeidi

lens Kristian Villadsen

Allan Kirui

Group 1 **Filippo**

Italy Scenario

Roberto Sorrentino Matladi Ndlovu

Arielle Weir

Arif Govani

Maria Carolina Saavedra

Kine Toure

Ronnie Mundair

Nva Feldthus

Peter Elleby

Yuri Quintana

Martin Ingvar

Catherine Mc Cabe

Fline Aerts

Godbold, Karen Laurent Coste

Margo Raja Maximiliane Rauch

Mini-superpower Endurance Everyone describes a mini-Choose a coloured sticky note and double-click to write your minisuperpower they wish they had. This superpower has to illustrate a minisuperpower and your name improvement in their everyday life. Petter: The ability to Carina choose my own password Am a I have Shimon/UK Alan: I independent of any endless anne/uio Mum:) Super-hero site restrictions (will Patience wish I levels of energy never happen) energy Elinaz and could flv. patience persistance Ryan: Slow - Nevena down time to get a bit more Evalanine / done befor the enjoying day ends:) Uk Viola the imagining nning innovative moment and thinking & viisualising project Linn Francisco: leader - Ana n: Making Camilla/Norway/o r without rganised invisible moving Ulrike: Frans: know the Lift future lessica Keeping stones tea/coffee hot

Take a moment to read and reflect. What stands out to you about Maria?



Material process probability of a sproof

The section of the latest section of the lat



Personality and Interests

.

Gravitate (Health



Health Consistents

Your medicine as resided for to be one day?

Additional form presented Agreed trotaging prior lather needed!

Care Professional Concerns

How I prefer to interact with Healthcare providers

Ofton in person at my soul Photology, they fire mo Communication, collaboration and oversight because

Sharing my health information

-



Health routines

Madicalline list

Nicombine of daily thoroughly.

Ly moreth (75 vives Progressoy

My most trusted advisors

Pain Points/Problems

Medical

Psychological

List it versioned and dated, now v.17, Stored and

I delif be payords next sandables on the last soldle I speak

Cliniediones in the molning. 5 in the avening. Pluria.

Frequency of routines blaily, weekly, morthly)

As needed updates Medications by (17e version)

4x year other state steep series, physical therapy

Most time consuming or difficult activities

No of HCF that I interact with 's

Traveling with CPAP take a lot of room Be sore to have medication when travel

Medication by in different languages

Hose I feel about these problems?

In personal regarders dolly much & thought





Mobility challenges has hindered me from being as active

as I like, so I have smaply out compensativy took the tre-

acoster item one to Norsky and one in the worth in second.





total of becomes of becomes &

Autonomy

Volumes Printers



60 min

Maria's scenario Take a moment to read and reflect. What stands out to you about Maria?

10 min

Identify key activities, emotions along the journey and the key pain points / gaps / decision making points. Work individually with post-its, then collectively to agree on the key milestones.

Maria's Journey

The second and personal

- New to complete the Empathy May
- Basil drough an opinite in the daily life of this Persons

 Identify the lasy pain points J gaps, I disables making points along the
 journey likely individually with peak in, then individually agree on the
 lasy relievance.

 Wide on which of the relaxiones, is most patched, and our relevance in give

MARIA



Petter: Dry mouth may be a sideeffect, and the action should probably be to consider reducing the current medication rather than a new pill. Coughing might be an effect of chronic obstructive lung disease, and increase of current medication would be a probable action.

Scenario: An episode in the daily life of this Persona

- Maria 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.

Resources

Scenario

Petter: With 17 active prescriptions, noone knows about interactions - neither the doctor not the pharmacist. The doctor should tell her to observe effects and side-effects. A particular problem is that "a doctor" isn't a doctor - none is omnipotent. The prescribing doctor most likely do not have the knowledge of all the other specialists. A major problem is that Marias is given the task to coordinate the various doctors, not the health care system

What does Maria DO?

RELEVANT ACTIVITIES RELATING TO MARIA'S JOURNEY

11. She needs

reassurance from the Pharmacist

and asks for an

opinion on the

 Maria is feeling her mouth much dryer during the day and coughs more

10 Petter: She

does the hest

she can under

the

circumstanses.

ng 2. Becomes
th aware she needs
to see a doctor
and books an
appointment.

 Maria seeks council from health care practitioners an is open for discussion

12. She explains

to the Pharmacist

how many

medications she is

taking and shows

3A Maria is aware that there are other specialists who may be able to provide some answers He decided to prescribe a new antihistamine

thinks of this

when telling her

son (?) about the

 After leaving the doctor she reflects on the new prescription and how it will

eaving 6.Knowing she got or she a new medicine on the she anticipated possible drugit will drug interactions

knows her entire

and needs to decide what

actions to take

7. Maria is proactive

understand how does the new prescription fit with all the other medications she is already taking She does not rely on the package leaflets to try to understand how this new medication is going to affect her 30 min

What does Maria FEEL?

What motivates Maria during these activities?

Afraid for drug-drug interactions

Frustrated

(keeping up

medication

and doctors)

Trusting (pharmacist)

recall a previous

OTC and her

prescribed

regime

anne: she trust in her doctor and pharmacist

worried about impact of new medication

again after consulting with pharmacist and doctor

> she feels sad that she will have to take yet another pill

> > uncertain

how to go

about new

medicine

e side effects

noone has mentioned the product leaflet

worried

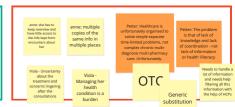
about the

Petter: She feels worried, but not afraid, Luckly, she is not aware of the limitations in the doctor and pharmacists knowledge this should indeed frighten her. Her main focus is on the symptoms she wants to remove not the interactions

What are the **BRIGHT SPOTS** for Maria?

Petter: She they should she has a trusted and get back to survived understand the pharmacist / doctor / NP when the first 80 / appreciate with pharmacist what I do already vears or so. Interacting with Healthcare Professionals face to face

What are the **PAIN POINTS** for Maria?



As a group vote on the key painpoints you would most important for Maria that G-Lens can solve?



Break time

Refuel and refresh



We are having a short break! See you in 10 mins

(please keep Teams open)

See you back at (10 mins) UK (GMT): 3:10PM EU (CEST): 4:10PM US (PDT): 12:10PM

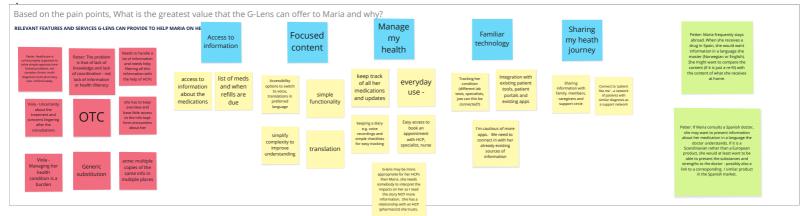


Maria's journey with G-Lens

20 min

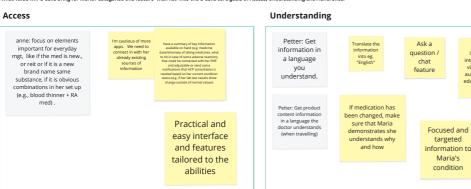
20 min

How might G-Lens help Maria on her journey? Brainstorming key features of the G-lens tool that could best improve patient experience and outcomes. What might they look like?



Maria's target outcomes

What value will G-Lens bring for Maria? Categorise this feature 'wish list' into the G-Lens core goals of Access, Understanding and Adherence.



Adherence

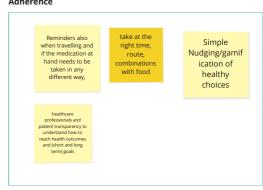
Immersive and

interactive options.

videos, podcasts.

audio learning and

education materials



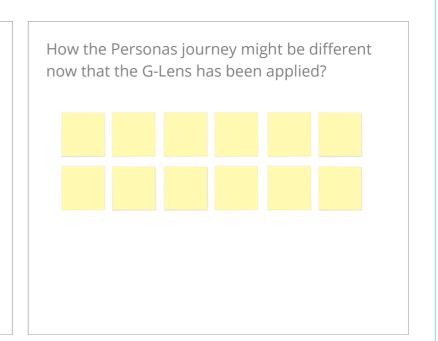


Let's wait a moment for the other groups to return to this session



Reflecting and looking forward

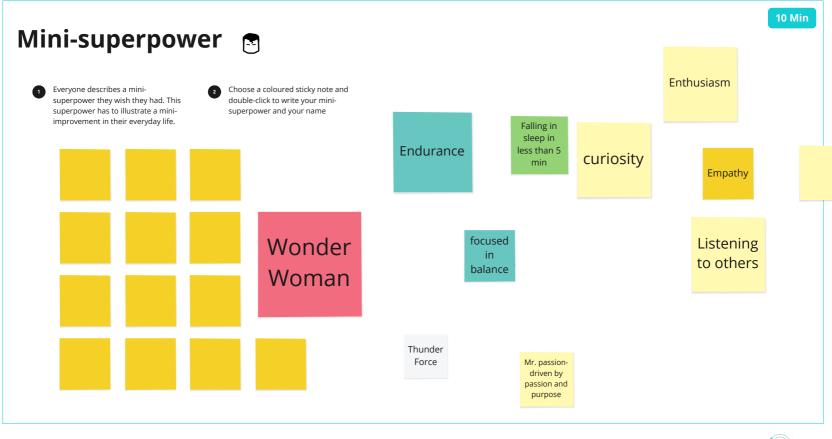
What have you discovered? What surprised you? how can we make content how can Miro is understandable technology great! :-) help? think of all the complexities behind the lack of individual journey empowerment





Thank you!

Stay safe. Stay well.



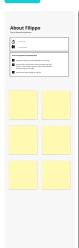


Take a moment to read and reflect. What stands out to you about Filippo?

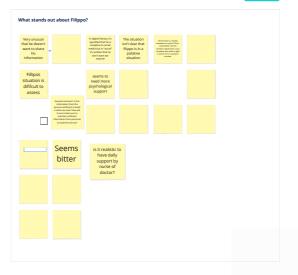
0 min

Your reflections and observations

10 min







40 min

Filippo's Journey

Filippo's scenario 10 min

30 min

Take a moment to read and reflect. What stands out to you about Filippo?

Filippo has played tennis thoughout his life. Then he has

After 50 days in the hospital, Filippo is finally back home.

Scenario

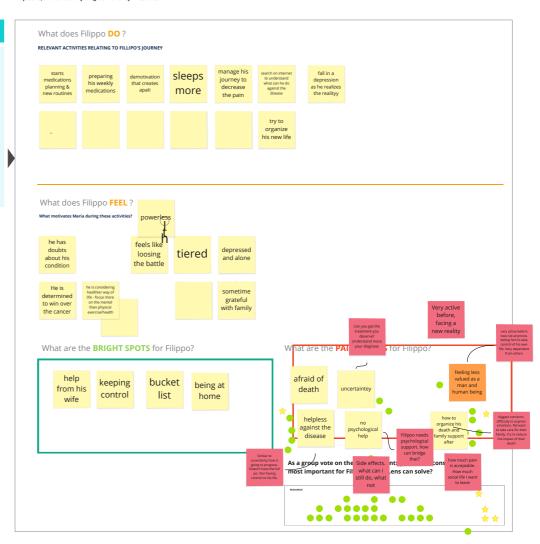


been diagnosed cancer

It was a much-awaited moment.

Resources

Identify key activities, emotions along the journey and the key pain points / gaps / decision making points. Work individually with post-its, then collectively to agree on the key milestones.



Break time

Refuel and refresh



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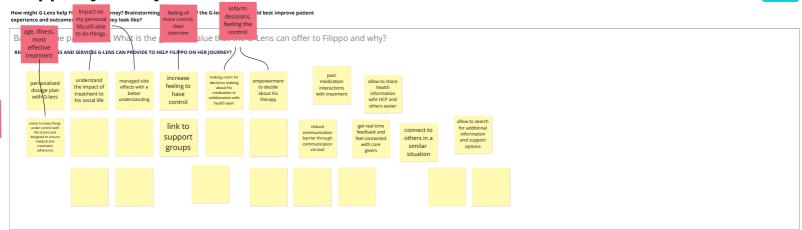






Filippo's journey with G-Lens

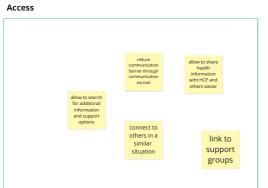


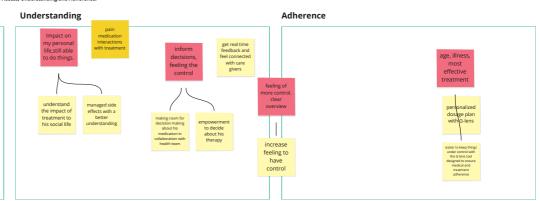


Filippo's target outcomes

20 min

What value will G-Lens bring for Filippo? Categorise this feature 'wish list' into the G-Lens core goals of Access, Understanding and Adherence.





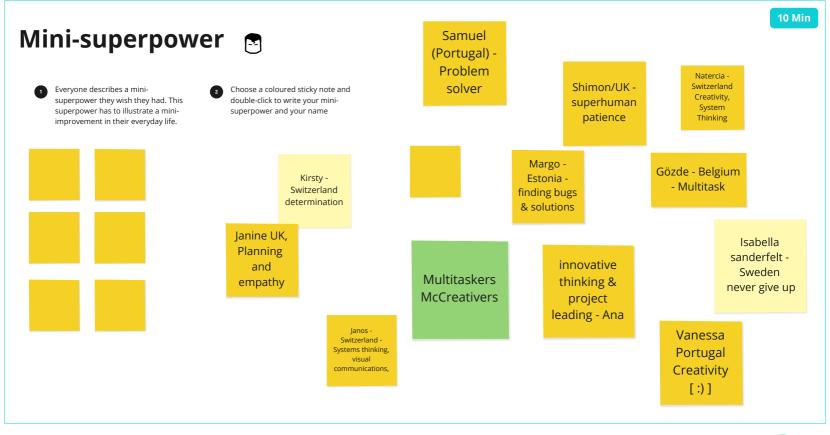


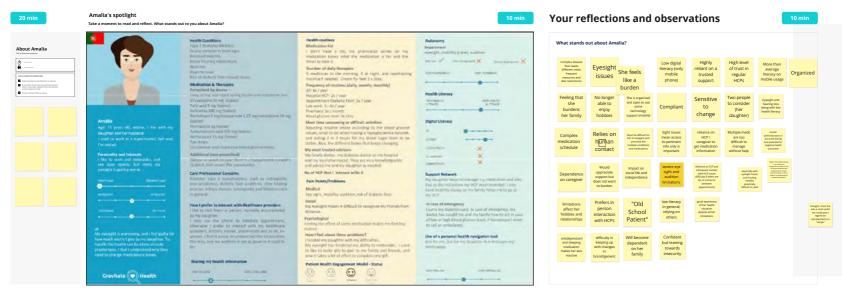
Great work!Let'd return to our main session

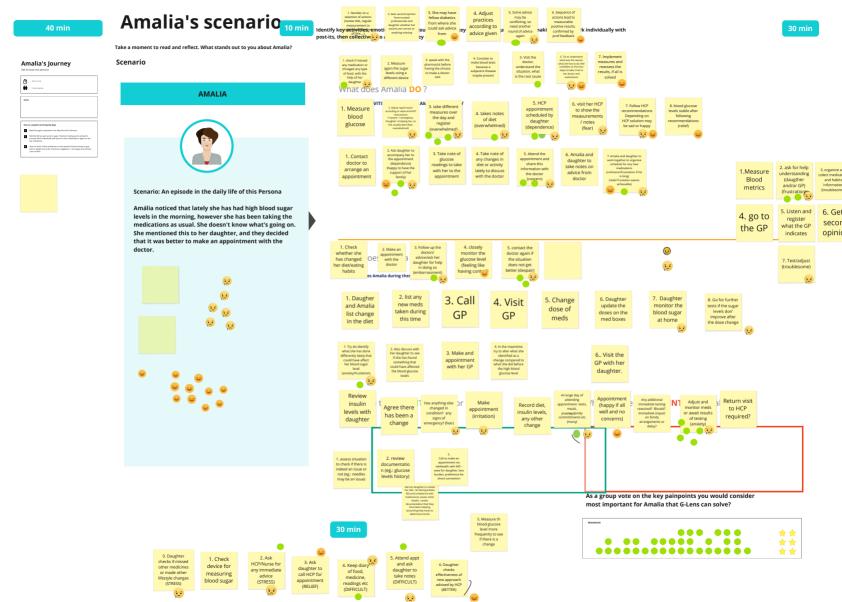
We look forward to hearing from everyone!

UK (GMT): 3:50PM EU (CEST): 4:50PM US (PDT): 12:50PM









Break time

Refuel and refresh



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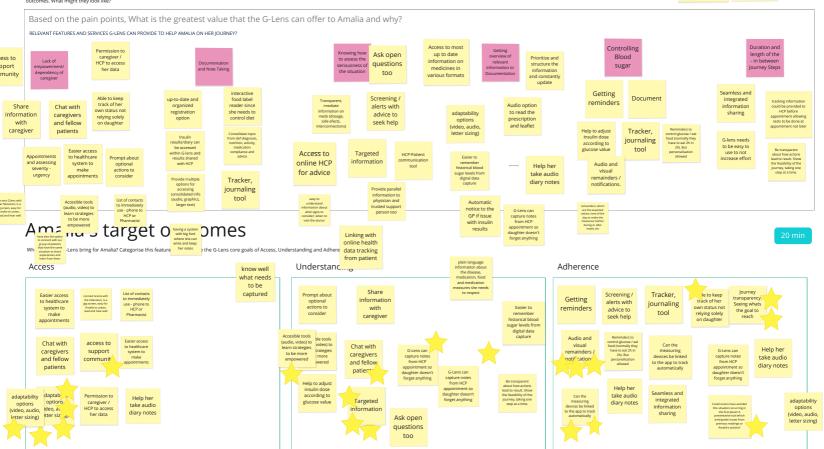


Amalia's journey with G-Lens

How might G-Lens help Amalia on her journey? Brainstorming key features of the G-lens tool that could best improve patient experience and outcomes. What might they look like?

Interesting that there is nothing here concerning the label itself to this case the late is not so relevant.

Maybe because of the lack of accessibility she learn to live without this info?







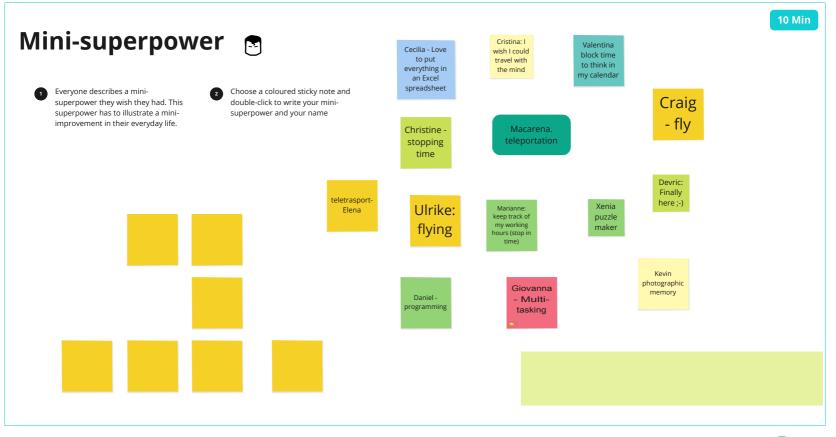
Great work!Let'd return to our main session

We look forward to hearing from everyone!



UK (GMT): 3:50PM EU (CEST): 4:50PM US (PDT): 12:50PM





Pedro's Journey

Pedro's scenario

30 min

Lack of

Take a moment to read and reflect. What stands out to you about Pedro?

Scenario

PEDRO

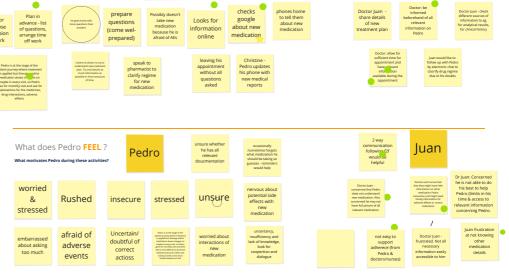


Scenario: An episode in the daily life of this Persona

- · Pedro has an appointment at the hospital today. He has to pick up his monthly medication and has a consultation with his doctor afterwards.
- He prepares some of the questions to ask his doctor in advance. But his medication has changed, and he is in a hurry because he has to go back to works; so, he leaves the hospital without asking some of the questions he had.
- · At consultations, he is usually embarrassed about asking some of the doubts he has regarding interactions with other medication, so he just does not do it most of the time. He is also afraid of suffering an adverse event and worried about the documentation he needs regarding his medication for travelling or in case of mobility restrictions.
- · On the other side, Pedro's doctor, Juan, left him wondering if he actually understood his new treatment, because they had very little time. Juan has limited information about Pedro in terms of other medication he consumes. He is also concerned about not having his microbiology and analytical results integrated with the Hospital Pharmacy software and/or the clinical history.

Identify key activities, emotions along the journey and the key pain points / gaps / decision making points. Work individually with post-its, then collectively to agree on the key milestones.

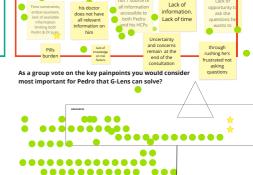




What are the BRIGHT SPOTS for Pedro?



What are the PAIN POINTS for Pedro?



Break time

Refuel and refresh

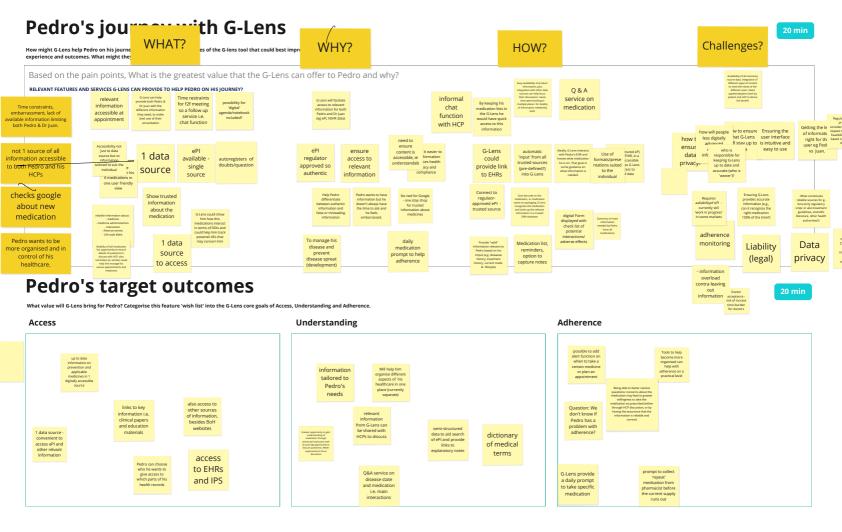


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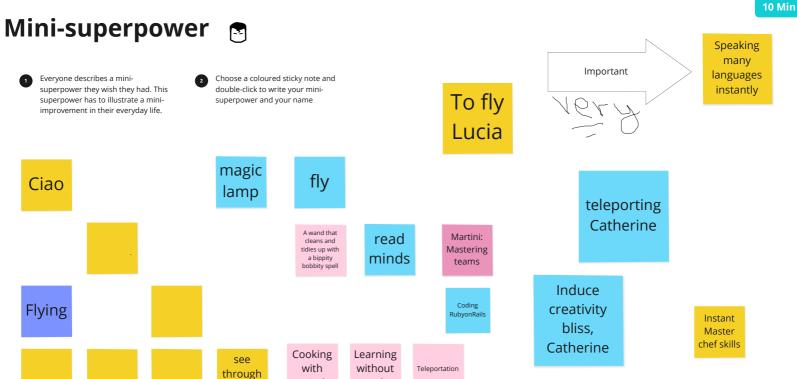
Great work!Let'd return to our main session

We look forward to hearing from everyone!

UK (GMT): 3:50PM EU (CEST): 4:50PM US (PDT): 12:50PM







study

mind

walls

Peter

Take a moment to read and reflect. What stands out to you about Peter?

About Peter

Material process probability of a sproof The section of the latest section of the lat

Gravitate | Health

Medication & Therapies Prescribed by doctor - 14 active

prescriptions including medications to support respiratory, cardiac. gastric and neurological functioning. and pain medications. Care Professional Concerns

As Peter's parents are his primary carers it is relevant up-to-date information. They require access to information on side effects and notential drug interactions. Peter's parents live over 200kms from their nearest. ternary care centred and there is very lette.

access to respite care in their are. How they prefer to interact with

Healthcare providers Their main point of contact in the community is the complex care service. witek. She is concerned about the level of care that Peter's parents have to manage have any questions on any aspect of Peter's care on a day to day basis, in between neview by the nucrology, renairasing and

all utual home care to evoid infection and are very teached of the risk of injection to

Sharing Peter's health

information

Medication list

There is a list of Peter's medications in the kitchen and in his bedroom and in the car. Peter's parents keep a list of any queries or concerns and will ring the complex care Service manager with any questions.

Peter usually has 8 medicines in the morning. 6 at lunchtime. 6 in the evening and 5 at: nighttime. Peter's medication routine will often depen on his respiratory atatus an dother clinicia parameters. Idepending on Peter's respiratory status).

Frequent care: home nursing team.

occupational therapy neurology team pain team respiratory team

No of HCP that Peter's parents interact with: 18

Pain Points/Problems

Supporting siblings

Access to respite care.

Medical care and changes as Peter arows Polypharmacy Transport Access to therapies

Dependency

Peter's parents are very dependent on support from the home nursing team and all allied health professionals

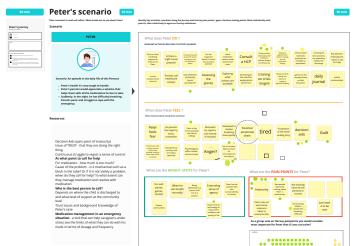
Health Literacy PERFORMANCE.

- 17 Digital Literacy

Support Network

Peter's parents relay on the horse care team and HCPS. They have no femily fiving close to them, though they have very supportive friends nearby. They have a (si) of emergency contacts which includes some of the name care nurses and the complex care service manager and local GP.





Further observations at close of breakout sessi

Scope of this activity is valuable

illustrates the general complexity for delivering care from multiple providers Glens has to be sleek and offer value to be useful, rather than adding to cognitive load reduce, realign, make simple, make predictable, it becomes painfully clear how important this is

shock on the emotional level

original idea was information provider on drugs this scenario - something I didn't imagine the glens would do this requires more knowledge beyond drug info, i.e. crisis management

who would give this training in the G-lens

medication on its own is an isolated part of a dynamic situation

Alan - 2 groups - pain medication and respiratory medications, if issue with those, you find out about it right away. The other things are very ional support, that medication could be or too low and months before any meaningful feedback

Could be med risked, but more labely were in a table communities.

The property of the propert

Does Peter have a medication list? Maria can provide one for further design/testing activities if helpful

Special case for therapy ePI, how can this be linked to crisis management and actions? Very contextual information where you could link training materials

Medical crisis comes from 1 of 2 things - something happens suddenly, or because it has been building up for weeks/months and reaches a tipping point We don't know which of those 2 circumstances we are in - a chronic issue has turned to a breathing crisis or someone forgot his resp med this relationship. This is where remote assistance can be helpful.

mmunicate with an HCP in a crisis management mo

underlying problem

Where does G-lens come in? Is it a resource that someone would look at for the next hour case? Or next day? Or longer term

rce/tool or not? This needs to be decided.

A journal fo the medications - check for counter indications and drug-drug intera

Or used in chronic care condition

Therapy ePi - does it change in the morning or evening?

If at the end it is not clear what the product is for or not intended for, then Risk and liability issues in emergency situations will be very hard to addre

Break time

Refuel and refresh



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Peter's journey with G-Lens

20 min

20 min

How might G-Lens help Peter on her journey?

Based on the pain points, What is the greatest value that the G-Lens can offer to Peter and why?

RELEVANT FEATURES AND SERVICES G-LENS CAN PROVIDE TO HELP PETER ON HIS JOURNEY?



Observations:

Is G-lens a General health seeking tool or an info tool on drug / correct use of meds (drug focused)

But in this scenario, the drug focus is limited

understand how to provide general empowerment tools with chronic care diagnosis

Need to delineate what the g lens can contribute

Wouldn't it be great if his parents record what he's taken, his energy levels, moods, etc and also get push alerts that might be relevant for them, so setting their preferences based on Peter

example medicine X, rash has been added, they can look out for it

A more focused conversation with practitioner when there is an interaction

monitor pro actively how the patient is doing before parents contact, example - 6 days that he hasn't slept

Quality of life aspect - how to improve quality

Close to patient services - from an information point of view

clear line from drug co to regulatory endorsement of information, this is the core G-lens services, and this can be used for 'close to patient services' that can be translated to advice, support,

integrated with all sources, closed information circle

Hook up Glens to that as an information giver, and also force questions about USE of glens in the patient information circle

people not reading medicine leaflet so -Value to bring forward information that is new and from a safety aspect to be aware of but to do this. we need centralised repository, or a common mapped

Peter's target outcomes

What value will G-Lens bring for Peter?

Access



Understanding



Adherence





Great work!Let'd return to our main session

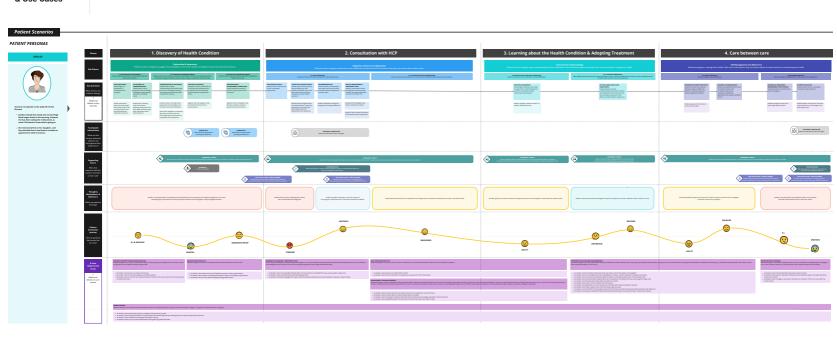
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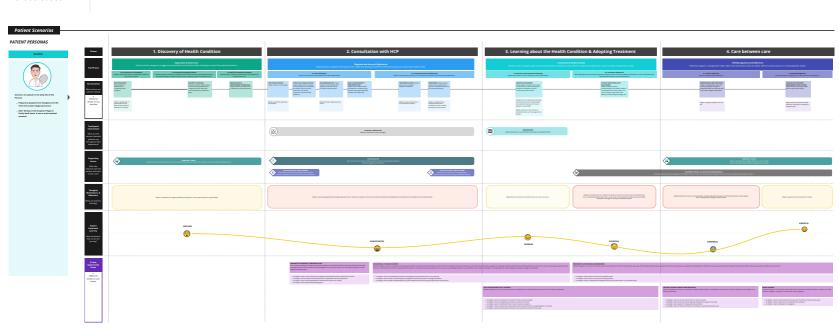




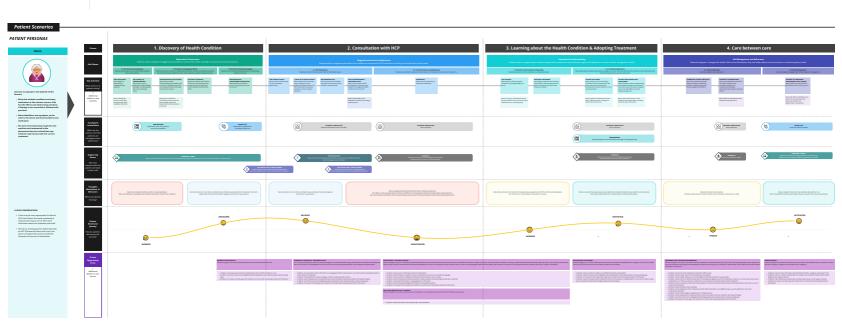
Patient Scenarios & Use Cases

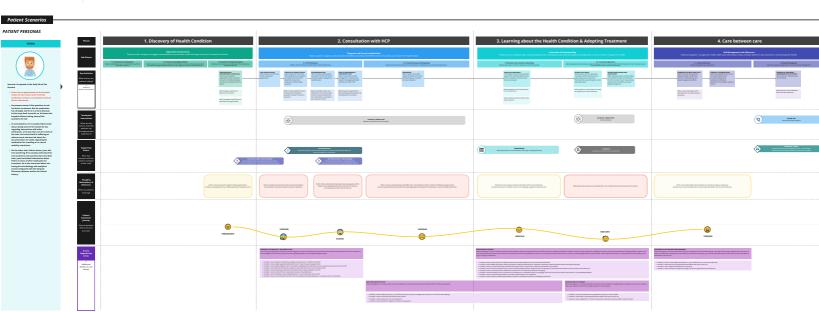


Patient Scenarios & Use Cases

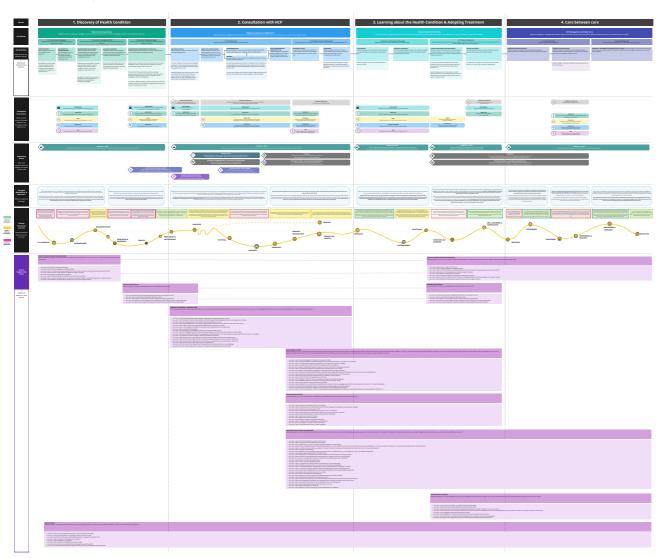


Patient Scenarios & Use Cases





Patient Scenarios
User Agnostic Journey



Medication & Therapies Prescribed by doctor -1 Lorem Ipsum X in Therapeutic Group A X in Therapeutic Group B etc Lorem Lorem Ipsum Age: Additional (non prescribed) Lorem Ipsum Personality and interests Interest 1 **Care Professional Concerns** Interest 2 Lorem Ipsum **How I prefer to interact with Healthcare providers** Lorem Ipsum **EMOTIONAL** Lorem Ipsum Sharing my health information

VERY WILLING

Health Conditions

Lorem Ipsum

Health routines Medication list Lorem Ipsum Number of daily therapies Lorem Ipsum Frequency of routines (daily, weekly, monthly) Lorem Ipsum Most time consuming or difficult activities Lorem Ipsum My most trusted advisors Lorem Ipsum No of HCP that I interact with 9 Pain Points/Problems Medical Lorem Ipsum Social Lorem Ipsum **Psychological** Lorem Ipsum How I feel about these problems? Lorem Ipsum

Health Literacy VERY HEALTH LITERATE **Digital Literacy** PC MOBILE SOCIAL MEDIA **ICT SUPPORT** CONNECTIVITY **Support Network** Lorem Ipsum In case of emergency Lorem Ipsum Use of a personal health navigation tool Lorem Ipsum VERY WILLING

Autonomy

Impairment

Lorem Ipsum

VERY INDEPENDENT

Self management

✓ Mental impediment X

VERY DEPENDENT

VERY HEALTH

VERY UNWILLING

ILLITERATE





VERY UNWILLING





Project



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



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 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. Sometimes 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

VERY UNWILLING

Health routines

Medication list

List is versioned and dated, now v.17. Stored and maintained on PC.

I add keywords 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 organizes 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

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









Autonomy

Impairment

Glasses, Hearing aid, Cane/crutches and Scooter



Health Literacy



Digital Literacy



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.





Filippo

I'm married and live with my wife. I was an excellent tennis player, and now I'm a coach. Sport has meant something throughout my life.

Personality and interests

I've a healthy lifestyle I like playing music.



11

I am confident that I'll be fine, but my body is giving me signs that things are not right.



Health Conditions

Apparently in good health but profound tiredness for 3 weeks

Medication & Therapies

Prescribed by doctor -

Pain relievers Diuretics Cortisone Anxiolytics

Care Professional Concerns

The situation is worrying, and the prognosis may be fatal. The patient want to fight this battle.

How I prefer to interact with Healthcare providers

I've been admitted urgently to the hospital.

Doctors have diagnosed me with cancer. I've been 50 days in hospital after which I've returned home.

They have assigned many therapies with precise schedules. I've to follow precisely the prescriptions.

I've developed my scheme as if it like play a naval battle.

Sharing my health information

VERY WILLING

VERY UNWILLING

Health routines Medication list

I've orgnized the list like a naval battle.

Number of daily therapies

15 therapies

Frequency of routines (daily, weekly, monthly)

Daily therapies Every 2 days the doctor and nurse 1 time a week physiotherapist

Most time consuming or difficult activities Naval battle setup My most trusted advisors

Wife and daughter

No of HCP that I interact with

Pain Points/Problems

Medical

Tiredness and inappetite.

Social

I have turned off my phone, I don't want ear anyone

Psychological

I feel depressed and aptic. I hope to stay better soon.

Patient Health Engagement Model -Status





Arousal





Autonomy

Self care √

Impairment wheelchair



Self management X

Mental impediment X

Health Literacy



Digital Literacy



Support Network

I feel more and more tired and need help from my family.

Use of a personal health navigation tool

I would appreciate a tool that let me have more control on my health.

VERY WILLING VERY UNWILLING





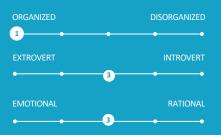
Amália

Age: 77 years old, widow, I live with my daughter and her husband.

I used to work in a supermarket, but now I'm retired.

Personality and interests

I like to cook and embroider, and see soap operas, but lately my eyesight is getting worse.



My eyesight is worsening, and I feel guilty for how much worry I give to my daughter. To handle the health can be alone already problematic, I don't understand why they need to change medications boxes.

Gravitate Health

Health Conditions

Type 2 Diabetes Mellitus

Ocular cataract in both eyes

Reduced mobility

Minor hearing impairment

Anaemia

Hypertension

Risk of diabetic foot related-issues.

Medication & Therapies

Prescribed by doctor -

Long-acting and rapid-acting insulin and respective pen

Vilvagliptine 50 mg (tablet)

Folic acid 5 mg (tablet)

Sertraline 100 mg (tablet)

Perindopril 5 mg/indapamide 1.25 mg/amlodipine 10 mg (tablet)

Permadoze 1g (tablet)

Acetylsalicylic acid 100 mg (tablet)

Mirtazapine 15 mg (tablet)

Eye drops

Glucometer and respective blood glucose strips

Additional (non prescribed)

Glicose or snack (in case there is a hypoglicemic episode) Diabetic foot cream (for prevention).

Care Professional Concerns

Diabetes type 2 complications, such as retinopathy (eye problems), diabetic foot problems, slow healing process, kidney disease, neuropathy and blood vessels in general.

How I prefer to interact with Healthcare providers

I like to visit them in person, normally accompanied by my daughter.

I only use the phone to schedule appointment, otherwise I prefer to interact with my healthcare providers, doctors, nurses, pharmacists and so on, inperson. I find it easier to understand the information this way, and my audition is not as good as it used to be.

Sharing my health information

VERY WILLING

VERY UNWILLING

Health routines

Medication list

I don't have a list; my pharmacist writes on my medication boxes what the medication is for and the times to take it.

Number of daily therapies

5 medicines in the morning, 4 at night, and rapid-acting insuline if needed. Cream for feet 2 x /day.

Frequency of routines (daily, weekly, monthly)

GP: 6x / year

Hospital HCP: 2x / year

Appointment Diabetic Foot: 2x / year

Lab work: 3 - 4x / year Pharmacy: 1x / month Blood glucose level: 3x /day

Most time consuming or difficult activities

Adjusting insuline intake according to the blood glucose values; what to do when having a hypoglycaemia episode, and eating 2 in 2 hours for my blood sugar level to be stable. Also, the different boxes that keeps changing.

My most trusted advisors

My family doctor, my diabetes doctor at the hospital and my local pharmacist. They are very knowledgeable and advice me and my daughter as needed.

No of HCP that I interact with: 4

Pain Points/Problems

Medical

Eye sight, mobility, audition, risk of diabetic foot.

Social

My eyesight makes it difficult to recognize my friends from distance.

Psychological

Feeling the effect of some medication makes me feel less reative.

How I feel about these problems?

I trouble my daughter with my difficulties.

My eyesight has hindered my ability to embroider, I used to like to make gits to give to my family and friends, and now it takes a lot of effort to complete one gift.

Patient Health Engagement Model - Status









Autonomy

Impairment

eyesight, mobility (cane), audition



VERY HEALTH

ILLITERATE

Digital Literacy

VERY HEALTH

LITERATE



Support Network

My daughter helps to manage my medication and diet, due to the restictions my HCP recommended. I also have mobility issues, so my family helps me to go to my HCP.

In case of emergency

I carry my diabetes card. In case of emergency, my doctor has taught me and my family how to act in case of low or high blood glucose level; if too serious I need to call an ambulance.

Use of a personal health navigation tool

Not for me, but for my daughter that manages my medication.



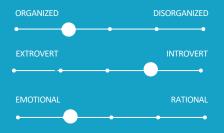


Pedro

Age: 42 years, I live alone, single. Electronics store salesperson Smoker since the age of 20

Interests:

cultural events and concerts. I enjoy mountain activities, skiing in winter and hiking the rest of the year.



information for preventive actions against the spread of my disease.

Health Conditions

HIV (diagnosed with 38 years) Depression Irritable bowel syndrome (IBS)

Medication & Therapies Prescribed by doctor

- Dolutegravir/Lamivudina
- · Mirtazapine 15 mg
- Calcium
- Cinitapride 1mg

Additional (non prescribed)

- -Collagen and magnesium supplements
- -Vitamin c supplements
- Protein supplements

Diet (IBS)

Physical exercise (gym)

Care Professional Concerns

- Chronic disease, with potential complications
- I try to practice a moderate level of physical activity, because it has positive effects on my physical health but also emotional mood. Subscribed to gym
- In the smoking cessation attempt phase

How I prefer to interact with Healthcare providers

- I have to pick up my HIV medication monthly at the Hospital Pharmacy. On some visits I have a follow up consultation with a pharmacist, to whom I pass on my doubts.
- Monographic internal medical consultancy: I would like to be able to have online consultations so that I can combine them with my work schedule.
- Primary Care doctor follow-up: once a year, to update the electronic prescription
- Psychiatric consultation:

Sharing my health information

VERY WILLING **VERY UNWILLING**

Health routines

Medication list

I have the list in paper and in a file which I access through my mobile phone

Number of daily therapies: 6

2 at morning, 1 at night, 3 during the day (before main meals)

Frequency of routines (daily, weekly, monthly)

- Medication: daily
- Exercise: weekly
- Hospital pharmacy: monthly
- Psychology: monthly
- 2 times a year: Internal Medicine specialist + analytic
- 1 time a year: Psychiatric consultation, Primary care consultation:

Most time consuming or difficult activities

My most trusted advisors

Hospital Pharmacist

Internal medicine doctor

No of HCP that I interact with 5

Pain Points/Problems

Medical

Risk of potential interactions or complications when infection.

Social

Travel frequently

Be sure to have medication when travel

Psychological

«Recent» diagnosis, assuming chronic condition with chronic treatment

I go to a psychologist (private practice)

Patient Health Engagement Model - Status



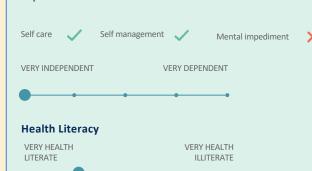




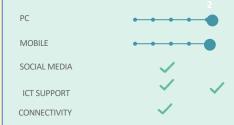


Autonomy

Impairment



Digital Literacy



Support Network

I manage my own care I rely on emotional support with friends, family.

In case of emergency

I save digitalized the medical reports in my phone

Use of a personal health navigation tool

Reliable information of potential interactions of **HIV** medication Lifestyle (dietetic) recommendations for IBS

VERY WILLING VERY UNWILLING



Peter

Age: 9 years old

He has a spinal cord injury. He has a tracheostomy and he has been on home ventilation for the last year. He is fed through a gastrostomy tube. He is confined to a wheelchair and he lives with his parents, who are his primary carers, and his 2 older sisters.



I'm very dependent on my parents and caregivers, without them I would not survive. I wish that they have tools to help avoid unnecessary risks and avoid additional problems so I can just be myself and enjoy my parents company as parents and not nurses. It is rare when we can all forget about my complex conditions and needs.



Medication & Therapies

Prescribed by doctor - 14 active prescriptions including medications to support respiratory, cardiac, gastric and neurological functioning, and pain medications.

Care Professional Concerns

As Peter's parents are his primary carers it is essential that they have constant access to relevant up-to-date information. They require access to infomation on side effects and potential drug interactions. Peter's parents live over 200kms from their nearest tertiary care centre and there is very little access to respite care in their area.

How they prefer to interact with Healthcare providers

Their main point of contact in the community is the complex care service manager who leads a team of nurses who come in to care for Peter for 20 hours every week. She is concerned about the level of care that Peter's parents have to manage. They usually speak to her when they have any questions on any aspect of Peter's care on a day-to-day basis, in between visits to specialists. They also connect regularly with thier local pharmacist who assists them with accessing Peter's medications. They have 6 monthly visits to the tertiary care centre where Peter has a full review by the neurology, respiratory and orthopaedic teams.

During COVID-19 Peter's parents stopped all usual home care to avoid infection and are very fearful of the risk of infection to him.

Sharing Peter's health information

VERY WILLING

VERY UNWILLING

Medication list

There is a list of Peter's medications in the kitchen and in his bedroom and in the car. Peter's parents keep a list of any queries or concerns and will ring the complex care service manager with any questions.

Peter usually has 8 medicines in the morning, 6 at lunchtime, 6 in the evening and 5 at nighttime. Peter's medication routine will often depend on his respiratory status and other clinical parameters (depending on Peter's respiratory status).

His parents say that they rarely refer to medication leaflets as they do not find them useful. This is because Peter's medication management can change as he grows and with any fluctuations with his clinical condition.

Frequent care:

home nursing team
physiotherapy
occupational therapy
neurology team
orthopaedic team
pain team
respiratory team
physical therapy,
psychology and social care.

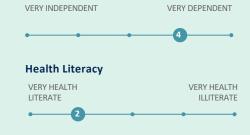
No of HCP that Peter's parents interact with: 18

Pain Points/Problems

Medical care and changes as Peter grows Polypharmacy Transport Access to therapies Supporting siblings Access to respite care

Dependency

Peter's parents are very dependent on support from the home nursing team and all allied health professionals



Digital Literacy

Peter's parents have good digital literacy and frequently use social media.

Support Network

Peter's parents rely on the home care team and HCPS. They have no family living close to them, though they have very supportive friends nearby. They have a list of emergency contacts which includes some of the home care nurses and the complex care service manager and local GP.



Antonio

Age: 80

At home I'm the caregiver of my syster Elena. She has 70 years old and has Down syndrome. She depends completeley on me. I'm her tutor.

Personality and interests

I've a healthy lifestyle like playing music.



After our parents' death, everything related to Elena's health has been up to me. She's my sister, and it was natural to deal with her condition.

As we get older, I demand myself what happens if I can't take care of her anymore.



Health Conditions

Elena has frequent aspiration pneumonia. Hypothyroidism

Medication & Therapies

Prescribed by doctor -

Gastroprotector Therapy for hypothyroidism Psychotropic drugs

Additional (non prescribed)

Leg dressings for pressure sores. Urinary catheter.

Care Professional Concerns

Doctors are concerned about the increasingly frequent inhalation of food and how to get her to eat.

How I prefer to interact with Healthcare providers

I have known the GP for 40 years, and I trust him completely.

He helps me manage Elena at home; usually, I hear him by phone.

Sharing my health information

VERY WILLING

VERY UNWILLING



Health routines Medication list

It's very easy, medications are unchanged from a long time.

Number of daily therapies

4 therapies. I have to mince the tablets.

Frequency of routines (daily, weekly, monthly)

Daily therapies
Each month GP visits her.

Most time consuming or difficult activities Leg dressing and eating without drowning.

My most trusted advisors

GP, nurses, and physiotherapist.

No of HCP that I interact with 4

Pain Points/Problems

Medical

She's not able to walk.

Social

Since her birth, Elena has depended on a family member, first our parents, then me.

Psychological

Elena is a fragile person.

Autonomy

Self care X

Impairment Elena is on a wheelchair

Self management X

Mental impediment &

VERY INDEPENDENT VERY DEPENDENT

Health Literacy (Antonio)

VERY HEALTH VERY HEALTH LITERATE ILLITERATE

Digital Literacy (Antonio)

PC

MOBILE

SOCIAL MEDIA

ICT SUPPORT

CONNECTIVITY

Support Network (Antonio)

My family: my wife and my sons help me a lot.

In case of emergency

In case of need, I have to use the vacuum to prevent Elena from drowning.

Use of a personal health navigation tool

I would appreciate a tool that lets others help Elena in case I'm not able anymore.

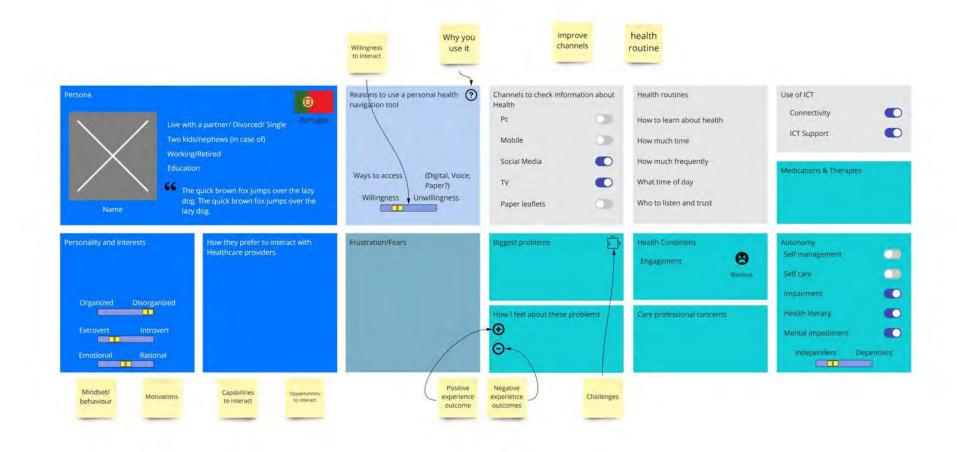
VERY WILLING VERY UNWILLING



Structuring personas

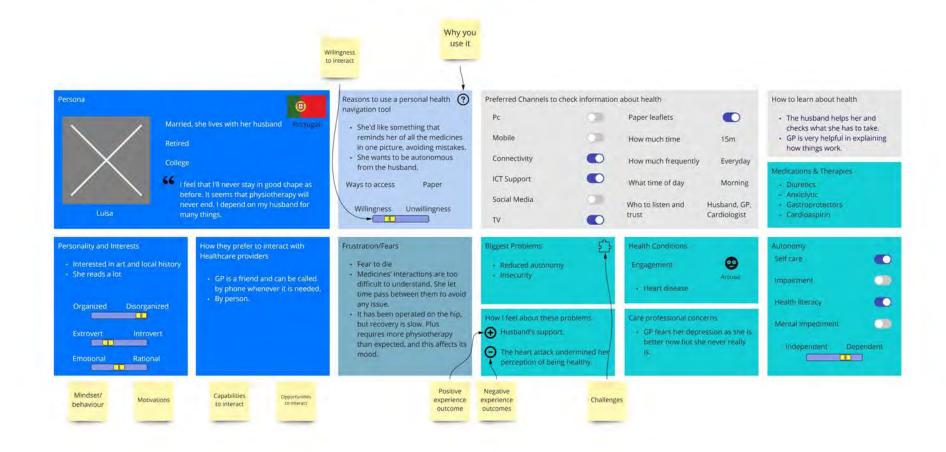
Persona's template – First draft

TEMPLATE



Template tested with real data

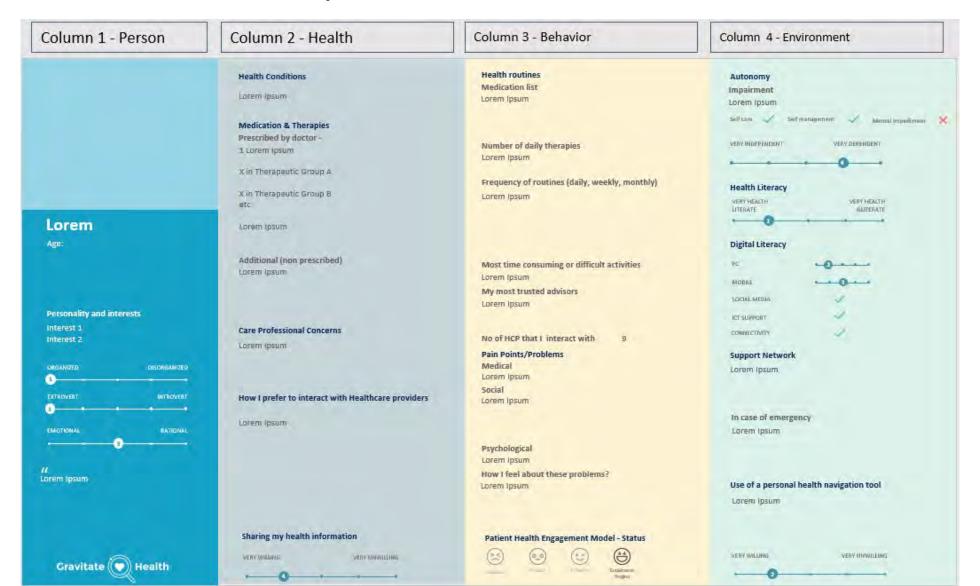
EXAMPLE



Persona's template – Second draft



Persona's template – Third draft



Persona's Template -Third draft with notes related to T1.1 interviews

