

## Gravitate-Health

### WP2 – Capacity building and multistakeholder engagement

# D2.1 Recruitment, trainers toolkit for peer-peer support

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## ABBREVIATIONS

Acronym/term	Full name/definition
Continua	Continua Design Guidelines
DICOM	Digital Imaging and Communications in Medicine
EC	European Commission
ECHAlliance	European Connected Health Alliance
EFPIA	European Federation of Pharmaceutical Industries and Associations
EMA	European Medicines Agency
ePI	Electronic Product Information
EPF	European Patients' Forum
EU	European Union
FOSPS	Federated open-source digital platform, developed in Gravitate-Health
G-lens	Gravitate Lens, the Gravitate-Health focusing mechanism
HCPs	Healthcare professionals
HIMSS	Healthcare Information and Management Systems Society
HIEs	Health Information Exchanges
HL7 FHIR	HL7 Fast Healthcare Interoperability Resources
IEEE	Institute of Electrical and Electronics Engineers
IHE Profile	Integrating the Healthcare Enterprise Profile
IMI	Innovative Medicines Initiative
PIL	Patient Information Leaflet
SME	Small Medium Enterprises
UAG	User Advisory Group
WP	Work Package

*Table 1. List of Abbreviations, acronyms and definitions*

## EXECUTIVE SUMMARY

The various engagements to share, discuss and ultimately co-create the development and final version of the Gravitate Lens (G-lens) within Gravitate-Health will be of critical importance to the success of the project. These engagements will be necessary across a spectrum of multi-stakeholders that will be important during and post completion of the project.

Therefore, having guidance on how to and when to engage with various multi-stakeholders and understanding the value of this interaction will support consortium partners to recognize, plan for and conduct these engagements. This Toolkit provides that guidance and shares completed and planned engagements namely related to the User Advisory Group (UAG), Ecosystems, Connectathons, Hackathons and Interoperability showcases. Additionally, case studies and recommendations have been included so that consortium members can learn from direct multi-stakeholder feedback.

Note to the reader: Throughout the document the term internal stakeholder(s) refers to consortium members of Gravitate-Health that are engaging in research and development activities (such as WP3, WP4, WP5, WP6). The term external stakeholder(s) refers to outreach activities and engagement with key groups such as the UAG and Ecosystems. Finally, the term Multi-stakeholder(s) refers to both of these types of groups and is an umbrella term.

## 1 Introduction

The “Recruitment, trainers toolkit for peer-peer support” is an early output of the Gravitate-Health project acknowledging the importance of engagement and co-creation in the development of digital health initiatives. It shares pertinent engagement information and experience with consortium partners to guide and optimise their ongoing and future planned engagements.

This toolkit will enable strong and consistent relationships with all relevant external stakeholders and their constituencies and further iteration will be completed during the later stages of the project.

### 1.1. Background

Gravitate-Health is a public-private partnership initiated to deliver digital health improvements in the European Union (EU). Our partnership is funded by the Innovative Medicines Initiative (IMI) – a joint undertaking of the European Commission (EC), the European Federation of Pharmaceutical Industries and Associations (EFPIA) and IMI2 Associated Partner Datapharm Limited.

Gravitate-Health aims to equip and empower citizens with digital information tools that make them confident, active, and responsive in their patient journey, specifically by encouraging the informed and safe use of medicines, reducing risks, and for better health outcomes and improved quality of life.

Gravitate-Health will develop an open digital health information tool called the Gravitate Lens (G-lens) that will focus and share approved information on medicines (like package leaflets) and other health information (e.g., data from health records) from trusted sources in an understandable format that can be accessed in multiple languages.

The G-lens will use the information from these trusted sources to guide patients to understandable, trustworthy, and up-to-date information that meets their needs and fits with their health context and literacy levels.

The project will also develop a white paper with recommendations on realistic strategies for the future use of digital services like electronic product information (ePI) that can be used to further minimise the risks associated with incorrect understanding and adherence to advice on medicines.

A key consideration for the success of the project is effective engagement and input from representatives of the eventual end-users of the G-lens tool throughout the duration of the project.

### 1.2. The Toolkit

#### 1.2.1. Purpose

The purpose of the toolkit is to assist all members of the Gravitate-Health consortium to effectively engage with individuals and groups not part of the direct partnership of the consortium and representing the potential users of the G-lens tool.

The toolkit will provide and accumulate experience gained from initial engagements and feedback with the aim that consortium members may build on the lessons already learned from the ongoing and completed engagement activities during the initial phase, which can be utilized in the further execution of the project.



### 1.2.2. Content

The toolkit has been organised into several sections, which are summarised as follows:

- **Section 1 (Introduction)** – This section of the toolkit covers the background of the Gravitate-Health project, and the purpose and content of the toolkit.
- **Section 2 (Initiated & Planned Engagement)** – This section of the toolkit covers some key general principles for successful engagements in multi-stakeholder projects. This section also describes the current and planned Gravitate-Health engagement activities with individuals and groups not part of the direct membership of the consortium and representing the potential end-users of the Gravitate Lens (G-lens) tool.
- **Section 3 (Case Studies & User Experience)** – This section of the toolkit covers case studies of engagement between User Advisory Group (UAG) and consortium members in relation to various aspects of the design and intended functionality of the G-lens tool. The case studies illustrate the potential value of engagement with end-users during early stages of development of digital tools such as the G-lens. To further understand the perspectives of potential end-users of the G-lens tool this section of the toolkit also includes two examples where members of the Gravitate-Health UAG have provided their direct experiences in relation to: a) providing input on digital health initiatives, and b) daily use of digital health applications.
- **Section 4 (Feedback & Recommendations)** – This section of the toolkit provides direct feedback from UAG members, Ecosystem partners and members of the Gravitate-Health consortium on their experiences in working with Gravitate-Health and other digital health initiatives. This section also includes a summary of key recommendations based on the feedback received.
- **Section 5 (Resources)** – This section of the toolkit provides listing of the various Gravitate-Health related resources that could be provided to patients and citizens who may be consulted on various aspects of Gravitate-Health project. In addition, some other useful resources that are not specific to Gravitate-Health are also provided.

## 2. Initiated & Planned Engagements

Section 2 of the toolkit provides a summary of some general principles for successful engagements in multi-stakeholder projects that Gravitate-Health consortium members should consider in any ongoing or planned engagements.

This section also provides a summary of the current and planned engagement activities with individuals and groups not part of the direct membership of the consortium and representing the potential end-users of the G-lens tool.

### 2.1. General principles

As a general principle, for multi-stakeholder engagements to be successful they should contain five key inter-related factors of success.

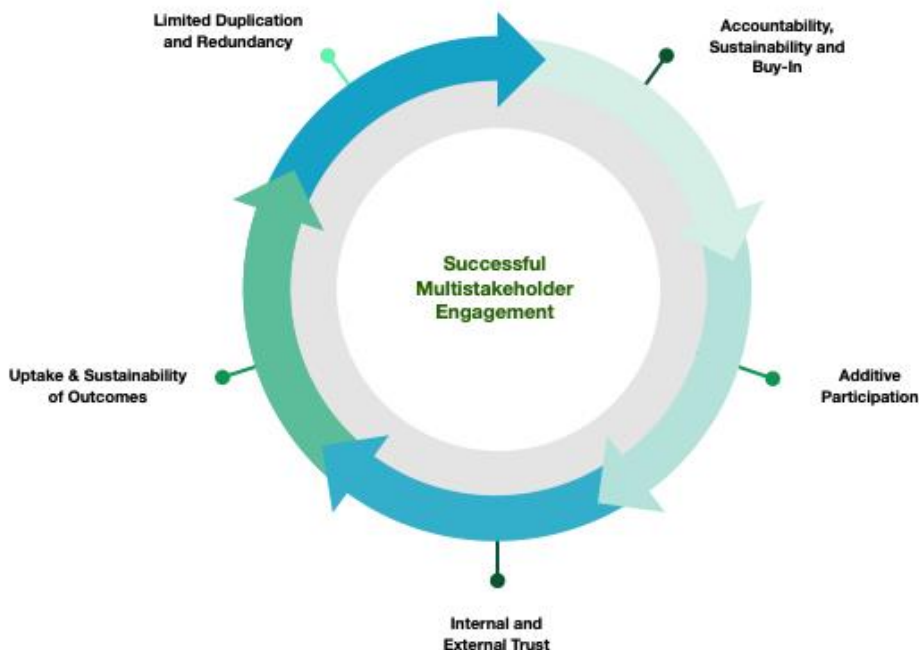


Figure 1. Inter-relationship of five key principles of multi-stakeholder engagements

**1) Limited Duplication and Redundancy:** As multi-stakeholder projects evolve there is a potential risk of duplication of effort. Engagement strategies should focus on ways to identify and reduce duplication and redundancy for projects with similar outline and goals, to obtain resource efficiency gains. However, some duplications and redundancies, where controlled, can be useful and allow improvement and reinforcement in the purpose of the engagement.

**2) Accountability, Sustainability and Buy-In:** As partners start working together in a multi-stakeholder environment, it is critical to ensure a shared level of understanding and accountability among partners for a sustainable collaborative engagement.

**3) Additive Participation:** In multi-stakeholder projects, the efforts of each individual partner need to build on and support other partners efforts, and the partners and their

consortium members should recognise the “others” contribution as additive to their own. Efforts should be made to clearly identify and showcase how all efforts are additive to the broader project.

**4) Internal and External Trust:** A foundation of trust needs to exist between Internal and External partners.

**5) Meaningful Uptake and Sustainability of Outcomes:** Many multi-stakeholder partnerships can be successful in delivering on short term goals but still fail in terms of their intended long-term impacts because they focus more on positive collaboration rather than effective outcomes. Multi-stakeholder collaborations need to find the balance between driving effective interactions and driving meaningful outcomes.

### **Evaluating engagements:**

Regular feedback from consortium members on their experiences with engagements and collaborations within the project will be done via a “**Temperature check**” survey. The survey will be completed each quarter based on experience with ongoing and completed engagements in order to identify longitudinal trends and progress on the principles.

An initial “Temperature check” survey was done at the Gravitate-Health Forum on 30 January 2022 to establish a baseline for how the consortium members were performing against the general principles described above. The specific questions asked and the results, based on 30 participants, from this initial “Temperature check” are detailed below. Individual working groups are also encouraged to evaluate their success of implementing these principles in their ongoing engagements.

### **Questions asked:**

1. How much **Duplication or Redundancy** do you feel exists in the collaboration today?
2. How much **Accountability, Sustainability and Buy-In** do you feel exists in the collaboration today
3. Do you feel that **collaboration with your peers** is leading to **additive value** with new and more complete insights?
4. How much **internal and external trust** do you believe exists between multi-stakeholders?
5. Currently, do you feel the Project will have **meaningful** uptake and **potential for sustainability**?

Figure 2 below provides the results of the initial “Temperature check” survey that was done at the Gravitate-Health Forum on 30 January 2022.

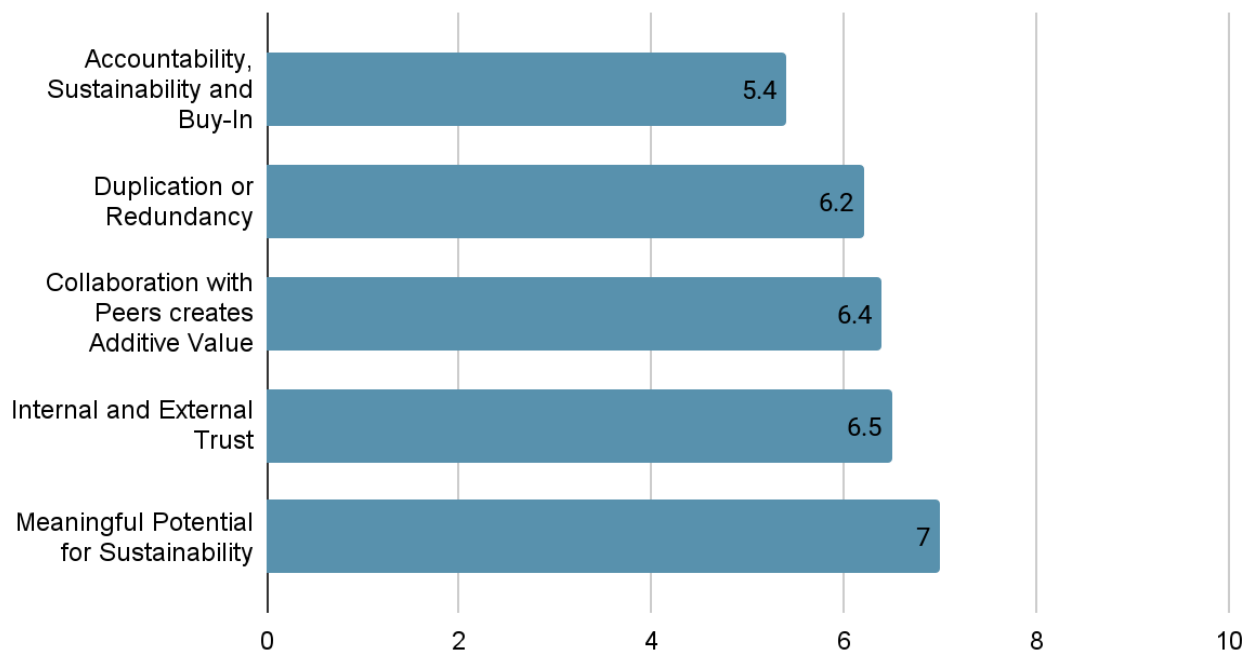


Figure 2. Results of the initial Gravitate-Health “Temperature check” survey

## 2.2. Initiated & planned engagements

To further assist Gravitate-Health consortium members in planning for future engagements, a summary of the initiated and planned engagements from the initial phases of the project is provided. This covers the initial engagements with Gravitate-Health UAG and Ecosystems, as well as planned engagements via Connectathons, Hackathons and Interoperability showcases. These illustrate the various ways that engagements have been used in the project so far, and how they could be used in further stages of the project.

The above-mentioned examples represent key engagements from the perspective of the Gravitate-Health Communication - Dissemination - Sustainability Triangle (see Figure 3 below). This is a framework that has been elaborated within Gravitate-Health to illustrate the interlinked nature of activities within these three domains to ensure the better uptake and impact of the project results among the multi-stakeholders.

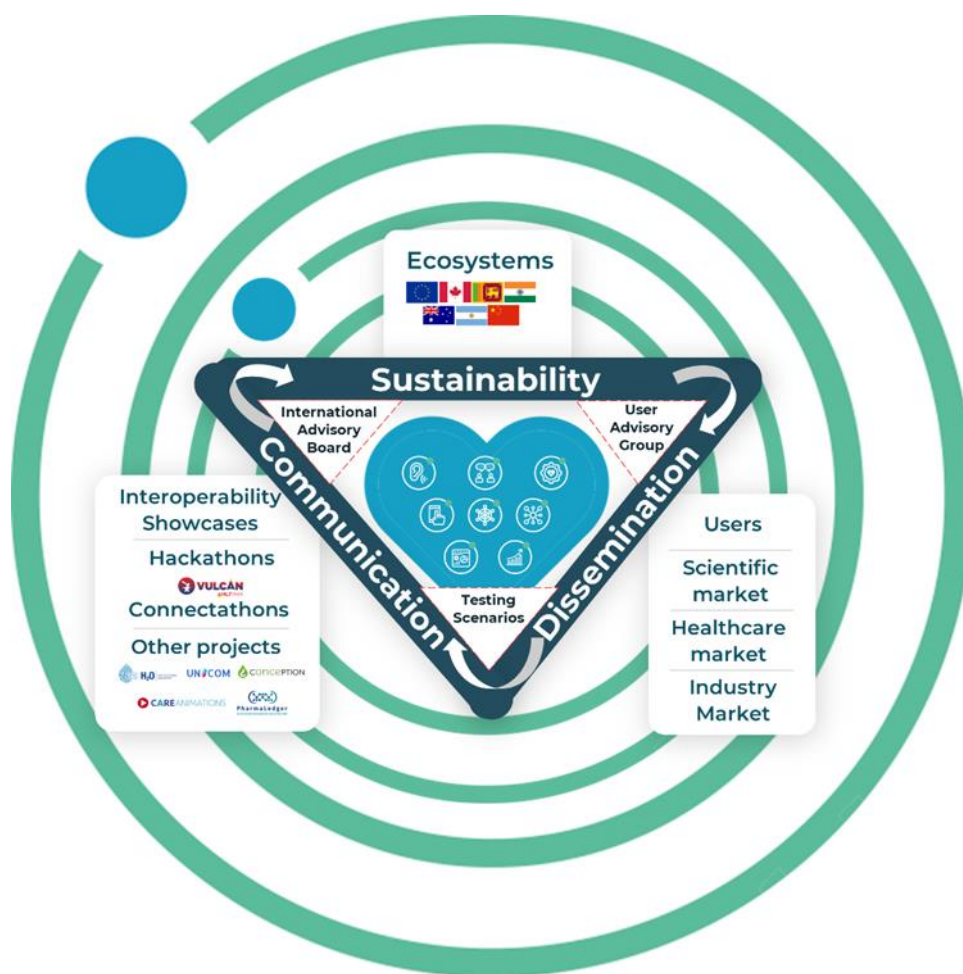


Figure 3. Gravitate-Health Communication - Dissemination - Sustainability Triangle

The purpose is also to illustrate the various ways that these engagements have been used in the project so far, and how they are planned to be used in further stages of the project for awareness by consortium members.

Each of the initiated or planned engagements are presented according to the following structure:

- Purpose of engagement
- Selection of participants/recruitment approach
- Format and maintenance
- In progress/completed engagement activities

### 2.2.1. User Advisory Group

#### *Purpose of engagement*

The UAG<sup>1</sup> is a group composed of patients, patient representatives, healthcare professionals (HCPs) and citizens/consumers that is consulting and advising on the work of the Gravitate-Health project from their field of expertise and/or past/current experience.

<sup>1</sup> <https://www.gravitatehealth.eu/our-experts/>

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UAG members participate in key project meetings and ensure that the group's voice is represented throughout the project. They are often deeply involved in co-designing and delivering patient engagement activities.

The UAG plays an important role in shaping the work of the project and ensures that patients are not only at the centre of the project's mission but that they are also active partners.

The UAG reviews and advises on the Gravitate-Health activities from a user perspective and identifies mechanisms for meaningful patient and public involvement and input throughout the project. They are of particular importance to the project, as they are also aimed at advising on the development, functionality, and usability of the G-lens.

The group plays an important role in identifying and understanding the key user needs of the G-lens platform that is being developed during the project and will contribute to the validation and testing of the tools.

### *Selection of participants/recruitment approach*

The UAG was recruited via an open call by the European Patient Forum (EPF) as one of the consortium partners of Gravitate-Health. EPF ran two rounds of 'call for interests' within the first phase of the project. The applicants filled in an online form and uploaded their CVs via the same online form. The aim was to recruit Patient, Citizen/Consumer and HCP representatives from a diverse range of age groups, genders and geographical origins and specifically for Patients and HCPs, a variety of disease/therapeutic areas.

All applicants needed to be 18 years of age and older, and although applicants did not need to be proficient in the topic area they did need to indicate a strong interest in digital health.

The initial selection process was led by two EPF staff based on the questions asked in the application form. The application form included a privacy notice providing details about the use of their personal data under the General Data Protection Regulation (GDPR). The criteria shared above (such as age diversity, etc.) allowed for an allocation of percentages that were totaled to form a shortlist. This shortlist was shared with the other Task 2.1 partners to select the final shortlist. In the first round of 'call for interest in early 2021, 17 representatives from diverse nationalities and backgrounds were recruited. The second round of the 'call for interests' was initiated almost a year later to bring the group up to an originally targeted total of 20 representatives (consisting of 10 Patients/Patient Representatives, 5 Citizens/Consumers, and 5 HCPs). Both 'calls for interests' were kept open for four weeks.

All the applicants were contacted after the selection process was completed. The selected applicants were then invited to an induction call to introduce themselves to the rest of the group and learn more about the concept of the UAG and the purpose and means of engagement planned for the group (see section 5.1). After the induction calls, each UAG member signed a Memorandum of Understanding (MoU) with EPF to complete the recruitment process. Participants received compensation during the time of their commitment, and this is clearly indicated in the mutually signed MoU. The agreement starts from the day of the induction call until the end of the Gravitate-Health project.

### *Format and maintenance*

The group initially received an 'info pack' that included the code of conduct, a summary of the project, a summary of the role of the UAG and a plan for interactions. Prior to the regular meetings set up for the group, EPF created a platform where both UAG members

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and other partners of the work packages were invited to suggest resources to be uploaded in this space.

To evaluate the groups' understanding of the general digital health related topics, EPF ran a survey which was built with the help of the other WP2 partners (see section 5 for link to the survey).

The outcome of the survey suggested that the group already had quite a high-level understanding of the general digital health concepts. Taking this into consideration, it was concluded that the group was ready to be introduced to more advanced digital health concepts and those focused around and related to the Gravitate-Health project.

Hence EPF initiated several engagement channels with the support of Pfizer co-leads of the task to engage the UAG with other Gravitate-Health work packages in order for them to understand the concepts and planned scope of activities and eventually, with increased confidence, contribute to the deliverables or activities in general that would span the project.

Overall, the members of the UAG were and will be invited to attend several meetings, such as the Gravitate-Health project's Annual General meetings (3 members per year), the induction meeting (online), online workshops (throughout the project) and other multi-stakeholder meetings (throughout the project).

Generally, EPF communicates with the UAG on a regular basis to keep them engaged in the project. The group meets once a month either to participate in a workshop held by another work package or cover other topics relevant to their participation in the project.

### *In progress/completed engagement activities*

The UAG is currently playing a vital role in identifying and understanding the key user needs of the G-lens services and will contribute to validating and user testing the tools.

To date, the key elements of engagement of the UAG besides their internal meetings within the Gravitate-Health have included:

- Participating in the Delphi Survey run by Task 1.1<sup>2</sup>
- Reviewing the testing scenarios and personas
- Participating in the workshops held by WP4<sup>3</sup> for G-lens mockups and patient summaries (My Health Data)
- Participating in an info session on the concept of Connectathons and the current activities held by WP5<sup>4</sup> partners and how UAG can get involved and contribute to the future activities

Further details on these engagements can be found under section 3 of this toolkit. They can also be accessed via a number of the published deliverables from the project.

## 2.2.2. Ecosystems

### *Purpose of the engagement*

Within Gravitate-Health Task 2.2 ("Wider Stakeholder Engagement Across National, Regional and Global Ecosystems"), selected worldwide ecosystems were subcontracted

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<sup>2</sup> Task 1.1. of WP1: Stakeholder requirements, gap analysis and synthesis of previous digital health efforts, prepare selection of user scenarios

<sup>3</sup> WP4: Digital Solution, end-user services, RWD, educational material

<sup>4</sup> WP5: Interoperability, accessibility and regulatory support



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by Gravitate-Health to actively engage their networks in the development, feedback collection, dissemination and exploitation of G-lens.

Together with the Gravitate-Health team, the aim is that the ecosystems create a roadmap handbook tailored to the regional or national context of each ecosystem. The Handbook will include narratives from the creation of the network to validation of the Gravitate-Health solution, therefore contributing to a set of actionable recommendations to integrate the Gravitate-Health outputs. The results of this work will feed into Task 7.1 (“Exploitation and sustainability planning”) for the development of multi-stakeholder business model(s) suitable for different healthcare systems globally.

The ecosystems will act as a bridge between the project activities, multi-stakeholders and the markets where G-lens can be introduced and exploited.

### *Selection of participants/recruitment approach*

To date, 11 ecosystems belonging to the global network of ECHAlliance ecosystems were selected and contracted<sup>5</sup>. The selection process was based on the following criteria: maturity of the ecosystem, thematic diversity, geographical diversity and capacity to conduct the tasks as foreseen in the project plan.

According to the ECHAlliance<sup>6</sup>, a digital health ecosystem is a permanent, mutually beneficial partnership amongst multi-stakeholders in a defined geographical area committed to accelerating adoption of connected health solutions at scale and on commercial terms.

The ecosystems benefit from:

- Exchange of knowledge and intelligence
- Connections and network
- Innovation implementation and scale up

The ecosystems from Europe and Rest of the world have been formally engaged for Gravitate-Health:

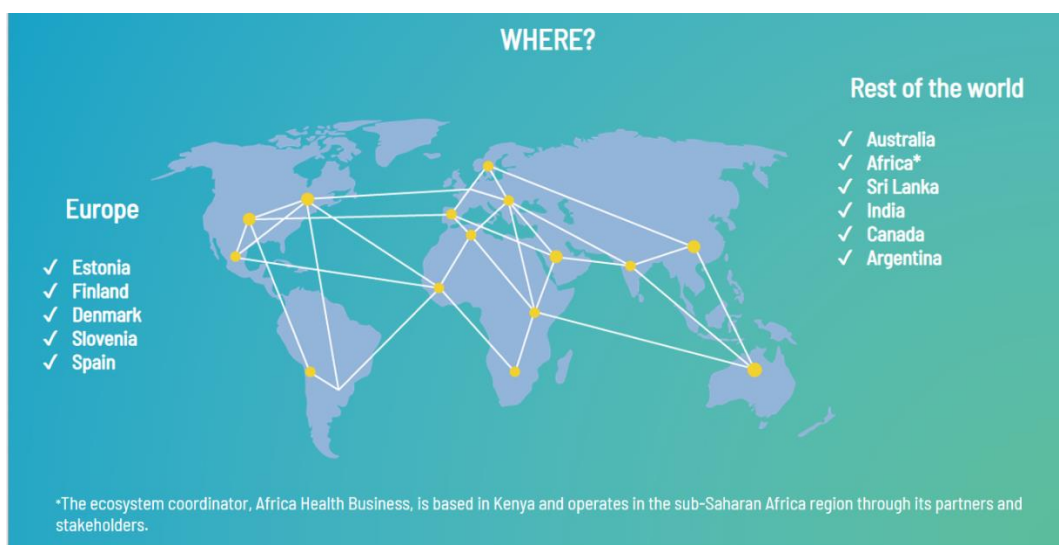


Figure 4. Map of the ecosystems sub-contracted within Gravitate-Health project.

<sup>5</sup> To the date of submission of this deliverable, the 12<sup>th</sup> ecosystem from China was engaged, but not subcontracted as it is the subject of the pending project amendment.

<sup>6</sup> [www.echalliance.com/ecosystems/](http://www.echalliance.com/ecosystems/)



### *Format/maintenance of engagement*

ECHAlliance communicates with the ecosystems regularly to keep them engaged in the project. The positive value is that the subcontracted ecosystems are part of the ECHAlliance's wider global network which guarantees that connections are maintained both within and outside the project activities.

The key elements of engagement within Gravitate-Health include:

- Contribution of the ecosystems to the Roadmap Handbook – through co-creating webinars, workshops, co-writing sessions, and regular information exchange.
- Presentation of Gravitate-Health during the regular ecosystems' gatherings and direct exchange between project partners and ecosystems to present and discuss relevant themes.
- Between 2022–2023, each ecosystem will host one webinar session aimed at their stakeholders (+50 direct participants) in their respective languages (with translated materials if necessary) to promote the “Design G-lens Contest”.

### *In progress/completed engagement activities*

The following activities have been completed:

- One representative organization in each of the selected sites was subcontracted by Gravitate-Health.
- Each participating ecosystem held a meeting with a slot dedicated to Gravitate-Health.

The following activities are ongoing:

- The Gravitate-Health T2.2 team are creating a roadmap handbook that registers the main recommendations received from the different ecosystems.
- Monthly, the ecosystem gathering includes a slot for Gravitate-Health during which the ECHAlliance involves one key Gravitate-Health partner to discuss a relevant theme with ecosystem members.

Future activities planned:

- As previously mentioned, between 2022–2023, each ecosystem will actively promote the Gravitate-Health project within their external stakeholders, including the “Design G-lens Contest”.

## *2.2.3. Connectathons*

### *Purpose of engagement*

In collaboration with HL7's Vulcan Accelerator, Gravitate-Health T5.1 and T5.2, use HL7 FHIR Connectathons as an essential part of the G-lens' development process.

HL7 FHIR Connectathons are events that offer external stakeholders the opportunity to test FHIR related specifications and use cases with input from a diverse range of multi-stakeholders. Connectathons are a safe place for everyone to fail forward. Meaning, Connectathon participants iteratively test content that is at various stage of development; resolve issues; gain experience; and receive feedback in an open setting. As a result, projects can deliver more robust outcomes at an accelerated pace because they are able to leverage an international community of experts.

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In collaboration with other organizations (e.g., HL7 Vulcan, EMA, UNICOM (H2020 project)), Gravitate-Health uses the HL7 FHIR Connectathons as a platform to test ePI and IPS prototypes within specific consumer-centred use cases. These Connectathon tests are instrumental in accelerating the pace of development; and have proven that Gravitate-Health's intended solution is on the right path. The testing also accelerated the maturity of the FHIR ePI use case. This benefits international regulators since they benefit from the early phase development work performed by Gravitate-Health and they will have earlier access to a well-tested FHIR ePI specification.

Gravitate-Health will continue participating in Connectathons throughout the project's lifetime to test and explore more complex real-world scenarios; adding more complexity from one Connectathon to the next and incorporating lessons learnt. Gradually, a community of diverse multi-stakeholders that work on ePI is built around the Connectathons. This community of expertise will eventually take part in Hackathons where even larger and more diverse community of end-users, start-ups SMEs and regulators is sought.

This methodology will lead to strong and consistent relationships with the relevant external stakeholder groups. These stakeholder relationships and community of experts is a critical success factor to ensure Gravitate-Health's Implementation Guides for ePI and IPS are implemented and used throughout the healthcare system.

### *Selection of participants/recruitment approach*

The Connectathons initially target external stakeholders who would work on ePI, such as app developers, electronic health record vendors, software engineers, and biopharma manufacturers who author ePI documents. The aim is to eventually engage end-users (such as the UAG), business developers, and pharmaceutical companies interested in developing use case ideas and solutions.

### *Format/maintenance of engagement*

The Connectathons are events hosted by HL7. HL7 has its own communications and engagement plan to target a growing community of external stakeholders (app developers, electronic health record vendors, business developers, software engineers and pharmaceutical companies) who are interested in specifications and use cases based on FHIR.

Gravitate-Health will work to gradually expand this community from one Connectathon to the next. This is done with the support of Gravitate-Health's communications team via various media platforms (e.g., Gravitate-Health website, Twitter, LinkedIn, HL7 Vulcan website).

This community will form the core of the target group that the Gravitate-Health project aims to engage with during the planned Hackathons later in the project.

### *In progress/completed engagement activities*

Three HL7 FHIR Connectathons are planned per year (January, May and September).

Gravitate-Health has already participated in the 28<sup>th</sup> HL7 FHIR Connectathon (September 2021)<sup>7</sup>, the HL7'S 29<sup>th</sup> FHIR Connectathon (January 2022)<sup>8</sup>, and is preparing for its 3rd participation in HL7'S 30<sup>th</sup> FHIR Connectathon (May 2022)<sup>9</sup>.

#### 2.2.4. Hackathons

##### *Purpose of engagement*

Gravitate-Health Task 2.3 (“Foster Private-Public Partnerships, SMEs and private industry engagement beyond the consortium”) will promote Hackathons, whose role will be essential to build strong and consistent relationships with specific external stakeholder constituencies (SME, start-ups, etc). This activity will be led by Mindview with support from within and outside the consortium.

A “Hackathon” is another useful tool (similar to Connectathons) to unlock innovation and is ideal, especially when many external stakeholders are involved. The process is enriching to all participants, allowing that through teamwork, they can better understand the different perspectives of multi-stakeholders on the same matter. In the context of Gravitate-Health, the vision is for the ‘patient or citizen to be the primary actor in all personal health matters’. The aspiration is to offer personalised health advice, to improve access, understanding and adherence to healthcare information and, ultimately, promote safe and compliant use of medicines.

Essentially, it is about innovative and novel G-lens services for the end-users and a spectrum of others invested in this vision, such as health care professionals, researchers, educators, industry, regulators, local or central government officials. The purpose is to include them all by promoting an inclusive and literate environment

Usually, over the course of two days, multi-stakeholders (such as researchers, coders, project managers, company executives, health professionals, NGOs, patients and active citizens, start-ups, SMEs and large companies) will form teams with varying levels of skills and knowledge to effectively work collaboratively to build functional digital solutions.

Diverse multi-stakeholders join the Hackathon. Some have an idea or a specific problem in mind and will try to form a team to work on a solution. Others have an application to test and some others just join to participate and gain from the experience. Teams are formed during the first part of the Hackathon where participants with “ideas”, in order to attract other participants of the Hackathon, will pitch their idea and form their working teams from the pool of the registered participants (developers, professionals, scientists, regulators and other external stakeholders). Often, small teams participate, e.g., a start-up or an SME, that do not have all the skills needed to complete their solution, participate in Hackathons to attract those missing external stakeholders.

In the Gravitate-Health context, project leaders will promote specific themes based on the project needs. The aim is to attract private businesses (SMEs) to participate and test their commercial solutions/applications on the Gravitate-Health platform for different disease/therapeutic areas. During the Hackathons, participants will use the FOSPS (federated open-source digital platform) to address the challenges set. Moreover, they will also use the FOSPS to ultimately develop new digital solutions based on their novel ideas and compete with one another. In this way, they are expected to add value to the open-source platform and G-lens services.

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<sup>7</sup> <https://confluence.hl7.org/pages/viewpage.action?pageId=120095544>

<sup>8</sup> <https://confluence.hl7.org/pages/viewpage.action?pageId=81004335>

<sup>9</sup> <https://confluence.hl7.org/pages/viewpage.action?pageId=90361476>

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The role of mentors in the Hackathon is pivotal for a successful outcome. Experienced mentors with different backgrounds will be essential to complement the teams' skills, as well as to lead them and contribute to their work. These mentors may be Gravitate-Health project managers or invited external experts. As mentioned above, the Hackathon is set up like a competition and will involve prizes, the G-lens design award. For the competition, a multidisciplinary jury will be set up, which may be unfamiliar to the Hackathon process but it will need to be aware of its challenges.

### *Selection of participants/recruitment approach*

Hackathons within the health space will require participants such as patients, physicians, nurses, engineers, researchers, scientists, coders, designers, entrepreneurs, managers, executives from insurance, pharmaceuticals, biomedical devices, health policy experts, and active citizens, all with diverse backgrounds and knowledge.

The Gravitate-Health community is a rich base to attract participants from. Attendees from the Gravitate-Health consortium could participate as either direct participants, mentors and/or judges.

In addition to this community, we would ideally like to attract external participants with similar interests in the development of digital tools such as the G-lens. The aim is to recruit and attract these participants via conferences and events where the project will be presented and discussed alongside the utilisation of the Gravitate-Health website, newsletters and social media promotion and advertising as well as publications.

We will endeavour to also attract participation from outside the consortium via other projects and by formally sending invitations to public health officials, key opinion leaders, regulators and policymakers and patient organisations. Finally, to foster cross-fertilisation of ideas, the aim is that applicants from other disciplines will also be invited.

Many of the participants will have the important incentive to join the Hackathons due to being able to have access to the FOSPS- open platform. The G-lens is a financial incentive to attract participants but the opportunity to work on the FOSP and test applications or create new services is an incentive in its own right, irrespective of any award.

### *Format/maintenance of engagement*

There will be a "G-lens Design Award" and proactive invitation of participants as outlined above. The Hackathon will be help to promote the use of Gravitate-Health's FOSPS as a Data Providing Platform for commercial companies, entrepreneurs, and service providers to create commercial solutions. The design award will be used to attract high profile coders.

### *In progress/completed engagement activities*

The UAG members will be pivotal in Hackathons, and therefore, as a starting point, they have received an introduction to Connectathons and Hackathons. The aim is that specific interested UAG members can take on a role of competent mentor at the events especially since they are not only end-users but also familiar with Gravitate-Health's goals and vision.

### 2.2.5. Interoperability showcases

#### *Purpose of engagement*

Gravitate-Health Task 2.3 also aims to promote external stakeholder engagement by organising Interoperability Showcase demonstrations at HIMSS's events by bringing together key players, for instance, solutions providers within and outside the consortium as participants of the showcase demonstrations, as well as addressing the wider audience to educate and inspire about what opportunities G-lens can hold for the future.

The role of these players will be to:

- Demonstrate the functionality and value of the FOSPS platform and highlight how additional services could be created or added,
- Challenge usability of the Gravitate-Health FOSPS platform and provide constructive feedback,
- Explain how technical interoperability needs to be supported by data and policy governance to achieve real societal value and impact across ecosystems globally,
- Stimulate public-private partnerships and multi-disciplinary collaborations to create market-specific applications which can reflect on needs of national or local ecosystems.

As further background, HIMSS Interoperability Showcase<sup>10</sup> demonstrations, or health stories, are collaborative projects between organisations using interoperability standards to exchange information to improve the quality, value and access to care. Together, organisations develop a person-driven storyline that contextualises the value of their technology.

In addition to showcasing how interoperability works at the technical level, the aim of the demonstration is to explain to a broad audience – wide range of external stakeholders with different backgrounds from different geographies – how technical interoperability needs to be supported by interoperability governance to achieve real societal value and impact across ecosystems.

#### *Selection of participants/recruitment approach*

It is foreseen that the Interoperability Showcase demonstrations of the FOSPS (and later the G-lens) will take place during the HIMSS European Health Conferences starting as early as 2023 – customarily the event happening annually in the Spring – and then, based on the development of the Gravitate-Health project components, in coordination with other WPs, more mature demonstrations can follow in 2024 and 2025. HIMSS will make sure that during the preparations of the Interoperability Showcases outputs and lessons learnt from Connectathons and Hackathons will be taken into account and feedback from the Interoperability Showcase demonstrations will be shared to facilitate continuous improvement for all related Gravitate-Health activities.

The demonstrations will be led by Gravitate-Health partners who played an active role in developing the FOSPS and will be supported by others that are active in WPs and that are closely linked to interoperability, data governance, exploitation and multi-stakeholder engagement.

External third parties – primarily but not exclusively solution providers – joining the connected demonstrations will be recruited through HIMSS channels supported by Gravitate-Health partners leading up to the annual European conference.

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<sup>10</sup> <https://www.himss.org/what-we-do-initiatives/himss-interoperability-showcase>

### *Format/maintenance of engagement*

Participants demonstrating interoperable technologies and solutions can include government agencies, market suppliers, non-profit organisations, payers, providers, academia, HIEs, standards development organizations and consulting firms. Using an interoperability standard to exchange information (such as HL7 FHIR, IHE Profile, DICOM, IEEE, Continua, etc.) is a minimum requirement for all contributing partners.

Showcasing Gravitate-Health can be a two-staged approach depending on the readiness of the project in consecutive years during the HIMSS European Health Conferences:

- Stage 1 (Project Demonstration): Gravitate-Health FOSPS demonstration based on a Persona(s) done by project partners only,
- Stage 2 (Connected Demonstration): A more mature version of a Stage 1 demonstration with the involvement of external third parties to showcase the added value, benefits as well as the technical know-how and potential of additional services that could contribute to the further development of G-lens.

Joining a connected Interoperability Showcase demonstration is a one-time activity for the duration of the HIMSS Europe Health Conference, however, interested parties will be engaged throughout the year for post-conference debrief sessions to capture feedback and planning activities capturing interest, ideas and inputs leading up to next year.

As for the audience engagement, which is vital to spark ideas, to stimulate partnerships across the public and private sectors, the HIMSS Conference attendees will be invited to guided tours to visit the demonstrations and follow up talks.

Also, the HIMSS TV crew will produce a promotional video of the Gravitate-Health Showcase onsite that can be used with information and dissemination purposes.

### *In progress/completed engagement activities*

This part of Task 2.3 will start in November 2022.



### 3. Case Studies & User Experience

Section 3 of the toolkit includes some selected case studies of engagements between consortium members and the Gravitate-Health UAG.

This section also provides user experiences in relation to providing input on digital health initiatives and regular use of digital health applications.

#### 3.1. Case Studies

Two case studies of engagements between UAG and consortium members in relation to various aspects of the design and intended functionality of the G-lens tool are shared below. The case studies illustrate the value of engagement with end-users during the early stages of the development of digital tools such as the G-lens, as well as detailed accounts of the engagements. The two engagement cases studies will share details of a) UAG contribution to the design of the Delphi survey initiated as part of Task 1.1, and b) UAG input on design of mock-ups for the G-lens user interface and functionality.

##### 3.1.1. UAG contribution to Delphi survey

The Delphi surveys (one for patients/caregivers and a parallel survey for HCPs) in Gravitate-Health Task 1.1 (T1.1) aimed to prioritise the end-user needs and requirements that would feed into the G-lens<sup>11</sup>.

In this method, several diverse statements were rated by patients/caregivers according to the level of importance. Although the language of the statements was reviewed by a professional writer, the T1.1 team decided to have a lay language and understandability check by the UAG to ensure that the statements were easy to read and understand by survey participants. For this reason, the statements were sent to participants of the UAG for feedback. This was coordinated with the support of EPF.

The outcome was that the T1.1 team received written feedback and comments from the UAG to integrate into the final survey. Suggestions included changing specific terms and wording to simplify the survey for the patient/caregiver respondents. The engagement with the UAG was very helpful to optimise the Delphi for better respondent rates and outcomes.

##### 3.1.2. UAG input on design of mock-ups for the G-lens user interface & functionality

#### Introduction to G-lens co-creation with the Gravitate-Health UAG

The Gravitate-Health Task 4.1 (T4.1) – Graphic, visual and UX/UI design mock-ups and wireframes of end-user app prototypes – team considered each testable idea as a hypothesis to be co-created with end-users. This was the stage where the impact of the Gravitate-Health UAG patient-focused approach was most critical. Working together with WP2, four user co-creation sessions were performed with the Gravitate-Health UAG. The co-creation process was designed to enable effective concept testing and sharing of

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<sup>11</sup> The main results of T1.1 are described on D1.1 “Identification of key stakeholder needs and preferences, information personalization and functionality”. Available at: [https://www.gravitatehealth.eu/wp-content/uploads/2021/11/Gravitate-Health\\_D1.1-User-requirements\\_V1.0\\_final.pdf](https://www.gravitatehealth.eu/wp-content/uploads/2021/11/Gravitate-Health_D1.1-User-requirements_V1.0_final.pdf)

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ideas, impressions, comments and feedback for further iterations. The Gravitate-Health UAG became an integral part of the design process and the iterative exploration and ideation.

Tangible design artefacts that emerged from co-creation, like visualisation and wireframing, provided crucial support for conversational evaluations and further co-design activities. The goal was to engage end-users in the creation of a portfolio of tangible solutions, iterating, getting feedback and further learning to understand the emotional and behavioural impact the G-lens designs create.

In this regard, for the Gravitate-Health UAG, a co-creation and co-design led qualitative approach was adopted, enabling the understanding and validation of patient goals and objectives. Question prompts were given to co-creators to spark conversation in relation to the key areas that would be focussed on. Each answer and perspective from a patient allowed for building further discussions between co-creators on areas of interest and focus. Such deep and meaningful conversations gave the T4.1 team a rich understanding of patient perspectives.

The methodology for collecting these valuable insights is explained below:

- **Step 1: Virtual ethnography through co-creation.** The focus was on capturing in the moment observational insights, e.g., What is on top of the patient's mind? What are their priorities? How comfortable are they with the concepts? What is their level of approval, understanding and buy-in/engagement? How would concepts be perceived and fit into their daily lives?
- **Step 2: Co-design of the G-lens solution.** To further understand and validate the most relevant activities, engagement points and features, the T4.1 team focused on designing and prototyping how a concept would appear in the G-lens.

### Co-creation sessions with Gravitate-Health UAG

The T4.1 team has had the chance to work with the Gravitate-Health UAG participants in four different sessions thus far. In the sessions, the number of UAG participants varied between 5 to 9, with a total of more than 20 participants over the four sessions. There were representatives from each category of the UAG participating in all four sessions. To promote an inclusive and interactive session, the participants were divided into groups based on the topics of each session and the total number of participants. According to the topics that the T4.1 team explored in each session, it was decided whether or not to divide the group into subgroups. Overall, it was important to create and ensure the right environment to allow for each participant to have adequate time to share their thoughts, ask questions and express their feedback.

Key successful outcomes from the four sessions were:

- The sessions provided a clear understanding for designers about patient needs.
- A small group (5-9 people) proved to be a very effective approach to receiving quick and focussed feedback.
- T4.1 team had shown iterations on wireframes and was able to demonstrate improvements following UAG feedback in subsequent sessions.
- T4.1 team had an insightful opportunity to ameliorate features like Medication List, evaluate doubts like information trust, and usefulness of specific information like active ingredients.



## Importance of G-lens co-creation with the UAG

Gathering patient insights from the multiple UAG sessions has been crucial in aiding the decision points regarding the G-lens functionality across the main four epics that the T4.1 team focused on as a deliverable<sup>12</sup>. The patients, patient representatives, citizens and HCPs members of the UAG worked together to uncover patient challenges, ideate on opportunities, and identify strengths and areas of improvement for the G-lens. The collection of insights gathered during the UAG sessions has significantly helped to understand what and how patients want to visualise information patients want to see, and the best methods of patient interaction within the application. By receiving regular feedback from patients throughout the creation of the mock-ups, the patients have always been at the forefront of design decisions to help create the best user-friendly experience possible. In the absence of insights and feedback from the UAG, the process of design development would have been based only on assumptions. However, by utilising patient insight sessions, the T4.1 team made sure to base key design decisions on real patients and end-user experiences and perspectives.

The co-creation process has provided a detailed direction for the design of the mock-up screens. Some summarised examples of key findings were:

- Patients would like a focused and easy way to understand Patient Information Leaflet (PIL) in a simplified and more visual format.
- Patients prefer simple solutions to avoid the need of managing their disease or condition every day to allow better quality of life.
- Patients prefer simplified, plain and personalised language over complex clinical terminology.
- Patients with impairments would prefer to have options regarding text, audio readouts and visual cues for PILs.

It is important to emphasise that as the T4.1 team worked on the design and development of these mock-ups; it became evident that there was a need to prioritise what problems to focus on.

The following important feedback was provided by a patient member of the UAG during one of the sessions:

*"We have to keep that balance between living with the disease and living our own lives."* (Gravitate-Health UAG patient participant).

This feedback showed that the team needs to continually consider the balance between managing the disease and the quality of life for patients. Therefore, the team's task has not only been to flag and address problem areas mentioned by co-creators but also to provide an easy, seamless useable experience that will be adopted for the long-term quality of life rather than the short-term disease management.

## Feedback from UAG on the co-creation sessions

After a cycle of four UAG co-creation sessions consisting of iterative gathering feedback and patient insights implementation, gradually, more and more positive celebratory feedback was received.

Some examples are shared below:

- *"It's clear and very visible on my phone."*

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<sup>12</sup> At the time of this deliverable submission, D4.2 "Annotated visual design mock-up documents of end-user app prototypes" are submitted, pending approval, and will available here: <https://www.gravitatehealth.eu/multi-media/>

- "A very logical structure and I like it very much as a whole."
- "I can't wait to download it when it's ready!"
- "Great work, and I think it's going to be a lot more user friendly for a lot of people so congratulations!"
- "I think this looks great. I'm really impressed with all the work that's gone into it since the last mock-up or trial version that we saw."
- "I was very, very happy to see more organised medication information and the ability to extend the relevant information I want to see. I loved the Audio and Video preferences. Absolutely fantastic. Lots of praise."
- "I think it's perfect from my point of view."

This positive feedback further emphasised the importance and success of using patient insights and feedback to create the most user-friendly experience possible.

In summary, the co-creation insights sessions have been vital to ensure the direction of the design and development of the G-lens mock-ups. The progress is visible when looking at the original low-fidelity mock-ups compared to the higher-fidelity deliverable, which emphasises the significance and effect that the UAG feedback has had on the creation.

### 3.2. User Experiences

To further understand and place the perspectives of potential end-users of the G-lens tool at the centre of the development, two examples are shared where members of the Gravitate-Health UAG have provided their direct experiences in relation to: a) providing input on digital health initiatives, and b) daily use of digital health applications.

#### 3.2.1. UAG member stories – Experiences with working on digital health initiatives

##### **Digital Patient Involvement: engaging with user groups in the digital health world**

*It would be easy to say, in times before the pandemic everything was much easier, especially when it comes to patient involvement in the digital health world. You sent an invitation, booked a room, arranged some bookings to enable patients to travel and then come together face to face. Things have changed. The pandemic stopped us to meet in person, now we meet online. There is still an invitation, but you sit in front of your computer and discuss from home.*

*This is, for some people more comfortable. No travel planning, no delays in flights or trains etc. But nevertheless, it is time and energy consuming for all. Sitting in front of the computer for a while can be exhausting right?*

*Especially when it comes to some issues like the use of new tools without explanation, not noticing that people living with diseases have some special needs, like unexperienced users struggle to meet online, or a very tight time frame for breaks, it is hard for a disabled person to go to the bathroom and grab a coffee within 5 minutes. Sometimes the technical tools don't work very well, the internet connection is lousy. In other case, participants want to talk so much and are not very patient with others and interrupt them to say their opinion.*

*There are some struggles for both, participants and organisation teams, and many things to notice.*

*As an expert working in between of two “worlds”, the world of consultants running meetings with teams and the world of participants or patient experts, I see many challenges and I have listed my best strategies or tips to make the digital engagement to a successful meeting.*

*For the organisation team:*

- 1) Know your panel. Are there specific needs for a longer break? Ask the people about it to make the meeting for all as comfortable as possible.*
- 2) Let them know in advance if any new digital tools will be used. If so, create a short introduction with screen shots with the most important functions and explain your idea.*
- 3) Structure the meeting and let people know the agenda in advance, also if people should review materials or prepare something, give them enough time to do this.*
- 4) Use an easy and understandable wording, not everyone is a very professional English-speaking person. Think about how you would feel if you attend a meeting in another language and you know not everything about the wording and phrases.*
- 5) Set-up some rules for the meeting, like to avoid so-called “jellyfish” moments or that everyone should have the chance to finish a sentence or thoughts.*
- 6) To involve patients must be your first priority, don't involve patients if you are not serious in working with them. Patients are not there for just being there and to enable others to say that there were patients involved.*
- 7) Be prepared too. Know what you are talking about. Patients are mostly very professional in the things they do so be professional too.*

*If a meeting is well structured and organized you can find a lot of advice, ideas or new perspectives to make a project more valuable. Patients are very creative and they know very well what their needs are. So, it would be sad to miss that power in a project because of some issues in the organisation of the meeting.*

*There is another factor to influence meetings: the participants, known very often as patients.*

*It's one thing to expect professionalism from the team, but be professional too. It is important also for participants to prepare, think about the project. Just for the case that something goes wrong, let the team know as soon as possible. This is the professional way to solve problems and find solutions.*

*It makes no sense to complain in the public about unknown tools or too short breaks or to let people in networks or that the moderator was not prepared and the timing was totally wrong. This is not very constructive. The organisation team has no good chance to reply and discuss or to ask for advice. Additionally, not every issue must be discussed publicly. This is a hurdle to come together in a constructive dialogue and this would be a missed opportunity and it leaves a negative impression.*

*So before making a scandal out of something what was not really a big thing, everyone, means the team, should have a chance to think and give feedback too. Otherwise, public complaints are not very helpful in general. Because it has a bad influence on the reputation, not just for the organizing team by the way, also for the person who started to complain in the public.*

*The best way to stay in a constructive mood is to go back to the team via email or a call to let them know what didn't work well and to find solutions. A conversation creates understanding on both sides and helps to make next meetings more valuable for all.*

*Additionally: Take a night to sleep before you give feedback. Digest the things happened and think if it was really a bad thing. Then start to talk. This is important and appreciated. It helps all and additionally it avoids negative emotions and feelings.*

*Last but not least, bring a team together with a coffee-chat.*

*Pre-pandemic we came together a while before the meeting started. We had a coffee and a funny conversation, before the meeting has started. This can be done online too. Be there, have fun and take some minutes just for fun to learn something about the people. This is a good start, brings people into the conversation, shy people can see the others for a moment and can also see that a bad English is not the end of the world. Because there is always somebody to help.*

*Have relaxed conversations and productive meetings.*

### 3.2.2. UAG member stories - Experience with use of digital health applications

Looking to design a health app? Companies are becoming increasingly aware of the importance of involving patients in the development process of new applications. Read on as a member of the - Gravitate-Health UAG shares experiences of using digital health tools, including thoughts on what aspects work well and not so well from a patient's perspective.



**Patient driven insights are the key to unlocking the future of m-health development**

*I regularly use the “My Health App” and “Arthritis Power App”. The My Health App (by my provider) is a form of electronic medical record, which can be accessed by patients and their doctors. Data found on this app consists of past medical history, including information related to past hospital admissions (case summaries), upcoming medical appointments, entitlement to free medication, laboratory results and medical imaging reports. As a patient, having access to such information is essential to keep track of progress or worsening of various medical conditions/diseases. But what I love the most, is that fact that I have ultimate control; I can choose with whom I share my personal data and I can actively engage in my health management around the clock, at the click of a button. Another bonus is that I am also equipped with medical records in case of emergency while travelling abroad.*

*Another great example of a digital health tool is the “Arthritis Power App”, which allows me to track symptoms related to my condition, including pain and fatigue and hours of restful sleep. It can also provide me with a record of the treatments that I have been prescribed. Because of this, I feel that my care is self-directed as I can use the in-app function to gauge how I am responding to new medications and treatments – which can identify subtle abnormalities/effects that I may not have ‘clocked’ otherwise. Another beneficial aspect is that the app includes educational tools to help me manage my condition.*

*With regards to the My Health app, one drawback is that laboratory results and medical imaging reports are not released until the specialist consultant reviews the results. In my experience, specialist consultants sometimes only review results at the following appointment, which can be months later. This can mean that a patient is left unaware of their test results, and precious time that could have been used to address any issues may have been lost. This may also cause anxiety for patients if they have to wait for an extended period of time for their results.*

*M-health apps and telemedicine are increasing in popularity and have become a useful tool to both patients and clinicians. Patients can keep track of their own health data in real time and inform healthcare providers of any abnormalities. In my opinion, patients should have access to test results as soon as possible to empower them to be proactive.*

*Although health apps are becoming more sophisticated, I think more could be done in terms of medication management. For example, push notifications could help to remind patients to take their medications and notify them when they are due to refill their prescription. By compliantly helping patients to self-manage their care, we can ensure less treatment interruptions, which ultimately improve outcomes and quality of life.*

*I think the language we use when talking about m-health and digital health more broadly can be off putting or isolating to some people. Having a glossary to explain terms such as artificial intelligence, big data, data protection, digital health, and digital literacy amongst others, could be extremely valuable.*

## 4. Feedback & Recommendations

Section 4 of the toolkit provides direct feedback from UAG members, Ecosystem partners and members of the Gravitate-Health consortium on their experiences in working with Gravitate-Health and other digital health initiatives.

This section also provides recommendations to Gravitate-Health consortium members to enhance their ongoing and planned engagements based on some of the key points highlighted in the feedback from UAG members, Ecosystem partners and members of the Gravitate-Health consortium.

### 4.1. Feedback

To understand how to optimise future engagements between Gravitate-Health consortium partners and external contacts representing the potential end-users of the G-lens tool, feedback was requested from colleagues within Gravitate-Health consortium as well as external colleagues that are currently participating in the Gravitate-Health project. These colleagues included members of the UAG, Ecosystem leads and consortium members of Gravitate-Health that have collaborated so far with the UAG. The colleagues were asked to reflect on both their current and past experiences where project partners of digital health initiatives (such as Gravitate-Health) wished to obtain input on their project development through impactful engagement with members of the public (i.e. representing citizens, patients, health care professionals, etc.).

The feedback was collected based on the key questions listed below.

- What aspects of the engagement worked best?
- What aspects of the engagement did not work well?
- What improvements would you recommend to the engagement?
- What tools could support better engagement?
- What background knowledge or resources could support better engagement?

The feedback is presented in terms of the different groups of colleagues it was requested from, namely a) UAG members, b) Ecosystem leads and c) Gravitate-Health consortium members.

Associated recommendations based on the feedback of each of these groups is included in section 4.2 below.

#### 4.1.1. UAG feedback

##### What aspects of the engagement worked best?

- “For online meetings, when organisers are really informed about the needs and aware of the patients and how to structure a meeting. Give enough and long enough breaks, let people talk and give their thoughts. Preparation was good and the materials were not too long and time consuming.”
- “I think that there is always someone from the user side/public, who has interest to provide feedback to the initiative/project. It is not enough to find a user representative, but a user representative that also shows dedication to the initiative/project. Moreover, the person/user must be taken seriously and the involvement of the user has to be holistic: for example, present the main objectives of the project to him, the project partners, include the users in some meetings... It helps to establish personal links with users – in the sense of live meetings etc. Let



the users present their stories if they want to. New ideas, new projects, may arise from it.”

- “A brief training that explains the workshop, tool, simulation from scratch and where users are able to experiment with the digital environment. A dosed “exposure” to the digital tool that increases in phases so new information has time to settle before more intricate or advanced functions are shown. A focus group method where a group is split in subgroups of 2 that discuss their opinions. These subgroups are then combined into groups of 4, 8, 16 up to the total of 32.”
- “I liked the Gravitate-Health WP4 meetings, and the format for displaying the product/tool development, I also like the icebreaker questions to start discussions, and the facilitators of the meetings did a great job.”

#### What aspects of the engagement did not work well?

- “I have had some experiences where organizers are not aware of patients’ needs. No or just short breaks, very long preparation materials but not enough time to read > a) the timeframe is too tight, the time for the meeting is too short and we all have a live too ;- ) b) they are not experienced in working with people living with diseases and expect too much some time c) they think patients are just in to be able to say we involve patients, but they don’t take this voice very serious d) not always agency people are prepared and you can see this.”
- “If the user was not taken seriously from the project partners and was not included in the project work, both sides were not much active and the result was not good.”
- “Asking for input directly after showing the tool.”
- “Assumptions about pre-existing digital abilities of the people that are to be involved.”
- “A tight schedule that does not offer time for flexibility if elements need to be adjusted or explained more so than planned initially.”

#### What improvements would you recommend to the engagement?

- “Well prepared teams, enough time to prepare, a contact person if there are questions, understanding that some people need more than 5 minutes to go to the bathroom and grab a coffee, materials easy to read and easy to prepare, teams must know and understand the need of patients when they work with them, calculate enough preparation time in the contracts, mostly this is too tight, especially for non-native English speakers.”
- “As the users are representing very different user groups (different diseases, different countries and different health systems, various demographic indicators (children vs. adult, developed and less developed countries ...) etc., some projects or project parts are going to be accessed and evaluated differently, which has to be made possible, as this is needed (Europe is very different across member states). There is not only one answer to a question, but many. All have to be recognised.”
- “I am a strong advocate for the focus group method when participants are split in subgroups of 2, and these subgroups are progressively combined into groups of 4, 8, 16 up to the total of 32. This method ensures that everybody is able to collect their thoughts and not only the vocal participants’ opinions and impressions are recorded.”
- “Perhaps shorter meetings - even if that means more frequently.”
- “Always assure that the community is formed of individuals fully committed and with genuine interest (make a mix of people with the best possible previous background record).”

What tools could support better engagement?

- “For online tools, stay in one tool. We have so many tools and to learn something new is not that easy for everyone. Use tools which are known. Ask before using tools if they are ok and if someone is not very experienced offer support or a short online education for the tool you want to use.”
- “Online communication (emails, collaboration platforms, video calls etc.). But not forget the live aspect – if possible, a live meeting is good, as the users and project members get to know each other better and find synergies.”
- “I am a big fan of online meetings, and Zoom is preferred to Microsoft Teams.”
- “From my point of view the best possible tool is a time to time more or less formal or informal face-to-face get-together (only good vibes and positive emotions help to produce superior outcomes).”

What background knowledge or resources could support better engagement?

- “Detailed, but easy understandable info in advance. I would say if you want to make sure, that engagement is supported, give a good info to people, and ask them if they need more explanation etc.”
- “Agendas and perhaps a statement on scope and purpose of the meetings.”
- “The EPF Congress 2021 dealt widely with all aspects of *digital health* however a relevant idea that comes to my mind is the EPIS Digital Engagement Toolkit which provides guidelines and tips for a successful toolkit. Advocating for simplified and standardised digital platforms, improving digital health literacy across the board even on pan-European level and common to all all-member states. It proposes four steps, namely Review, Plan, Act and Adjust. It outlines the basic guidelines about the following: Accountability, Communications, Informed consent and Patient Advocacy who work together to advocate for the required positive change within Europe.”
- “Try to get together people with various background knowledge, people that have been able to make as many as possible mistakes in any areas related to the managed project (get people with an experience).”

4.1.2. Ecosystems feedback

What aspects of the engagement worked best?

- “I think this type of engagement is very important, and you will get good insights and feedback from the interested parties/stakeholders, but asking the right questions to get specific feedback is important. Once engaged them, Surveys/questionnaires are probably the easiest tools to collect data from them.”
- “If you want more insightful feedback, focus groups/semi-structured interviews could gather more qualitative insights. But this study design is more complex and will take more time.”
- “Recruiting them to participate is always the key challenge so consider using incentives or using targeted recruitment strategies to increase engagement/response rate, have a project manager locally to drive the data collection and engagement.”
- “Having existing relationships or building initial relationships and connecting with target organizations will assist with the purposive recruitment/engagement. Once the relationship is built, it is easier to engage them in future research.”
- “Engaging the stakeholders as project team members or as members of an advisory committee; engage them early in the process.”



- “Discussions with other similar actors and exchange of experiences, e.g. on good practices, have been good.”
- “The understanding. Be assertive in the scope of the requirement, not limited to time but also to retribution. Transparency of compliance, stakeholders etc.in relation to the project the potential partner would be involved.”
- “The assets required and the compensation. The engagement ethically grounded requires proper step by step explanations. Only the informed perspective gets real engagement.”
- “The ratio between the goals and investing requirements.”
- “Access to outcomes as an ethical performance of security, efficiency etc.”

What aspects of the engagement did not work well?

- “Initiatives that have been done in a silo without collaboration with relevant health specialties and relevant medical associations/authorities.”
- “Implementations which were not suitable for ground situation.”
- “Low recruitment/engagement/participation rate is a challenge, particularly if there is no buy-in from them or no existing relationship.”
- “Not getting all the stakeholders’ views.”
- “Not gathering enough useful data if the research tools are not right.”
- “Proper communication and the lack of clear outcomes.”

What improvements would you recommend to the engagement?

1. “Connect with the stakeholders and focus on building the initial relationship.”
2. “Use expert help/insights when developing the survey or interview questions so that useful data can be collected. Pilot test the surveys or data collection tools to ensure the data collected is valid and useful.”
3. “Take advantage of the external stakeholders’ expertise and insights by involving and engaging them from early stages.”
4. “Any kind of exchange of information between like-minded actors is interesting.”
5. “Stakeholder identification. Planning interaction with stakeholders.”

What tools could support better engagement?

- “Meetings, common Teams platform, list of participants.”
- “Centralized and interactive tracking tools such as Slack, etc.”

What background knowledge or resources could support better engagement?

- “Need to firstly understand (and communicate) how this project will benefit them and why their engagement is needed.”
- “Understanding (e.g. some initial scoping research) who to target and why and how.”
- “Provide participant information for the stakeholders when recruiting or looking for EOI to sell to them why their engagement is needed and the positive impact their engagement/contribution could provide (e.g. information about what does participation involved, risk and benefits for participating etc.)”
- “Good to know participants and organizations. Main topics of Gravitate-Health project and aims could be good to go through?”
- “Be skilful in getting a variety of methodologies not limited to agile methods.”
- “Communication abilities and soft skills are important factors.”

### 4.1.3. Consortium partners feedback

<p>What aspects of the engagement worked best?</p> <ul style="list-style-type: none"> <li>• “A big challenge was compliance and ethics. In engaging with the patient community we needed to have this point validated, and we were dependent on some members of the consortium to advise us on how to proceed with recruitment, interviews, processing etc in a legal and ethical way. We lost quite a lot of time trying to sort out these points. Once we had something to work with, the recruitment and interviews went pretty smoothly. We are not sure if a clear process has been established in the meantime.”</li> <li>• “Different roles to facilitate engagement meetings, e.g. host/moderator, notetaker in the Miro board &amp; notetaker for the minutes.”</li> <li>• “Useful to record sessions.”</li> <li>• “Consider the size of the group relative to the purpose of the engagement meeting to be sure the right balance is achieved.”</li> <li>• “Demonstrate quick and efficient implementation of patient feedback.”</li> <li>• “Having a specific focus for each workshop helped create focused and enriched feedback (specific to each epic).”</li> <li>• “Take account of different nationalities, ages and other factors of the participants in the engagement sessions.”</li> <li>• “Speaking to the UAG helped us to think about aspects we were not thinking about.”</li> </ul>
<p>What aspects of the engagement did not work well?</p> <ul style="list-style-type: none"> <li>• “The patients and stakeholders we spoke to were well prepared and happy to talk to us. We are not sure if there was anything else we could have provided externally in advance.”</li> <li>• “Some do’s and don’ts for handling patient data may be helpful just in case some partners are not experienced with handling private data and are not aware of what we can and cannot ask.”</li> <li>• “Could improve the accessibility by inclusion of e.g. low literacy people, people with specific needs, older people, etc.”</li> <li>• “Not having enough continuity between UAG members attending the multiple iterative sessions.”</li> <li>• “Not being able to show a real prototype of G-lens on a mobile phone.”</li> </ul>
<p>What improvements would you recommend to the engagement?</p> <ul style="list-style-type: none"> <li>• “It would be helpful to know which consortium members have networks of specific types of stakeholders that can be used to reach a specific target audience (like EPF and patients).”</li> <li>• “People that interact directly on their phone with the prototype.”</li> <li>• “Time management. 1.5h was felt to be the optimal length for these meetings.”</li> </ul>
<p>What tools could support better engagement?</p> <ul style="list-style-type: none"> <li>• “It was felt that we missed an opportunity to “iterate” with the end users, for example to create mock-ups to further validate. However, this point may already be addressed via the UAG and WPs 3 and 4?”</li> <li>• “Video Call system (Zoom/Meet), Call Recording, Miro Board, Prototype, Figma, Notes.”</li> </ul>
<p>What background knowledge or resources could support better engagement?</p> <ul style="list-style-type: none"> <li>• “Share things in the board was key.”</li> <li>• “Skills of the moderator was important factor.”</li> </ul>

- “Careful planning and organization of the sessions was a key.”

## 4.2. Recommendations

A summary of some of the key recommendations based on the feedback collected from UAG, Ecosystems and Gravitate-Health consortium members is provided below. It is envisioned that these recommendations will be reviewed and considered by consortium members as part of their ongoing and planned multi-stakeholder engagements. In addition, these are valuable insights when collaborating with these groups directly.

### 4.2.1. Recommendations based on UAG feedback

- Create a flexible and relaxed structure for the engagements. Icebreakers work well and set off engagements on a positive note. Allow enough time for questions.
- Avoid long meetings with only a few breaks. Preference for shorter meetings even if it means more frequent meetings.
- Provide meeting agenda in advance as well as scope and purpose of each meeting (i.e., what is aim to be achieved). Keep this as brief and easy to understand as possible, as it will set any meetings off to a clear start.
- Don't assume existing knowledge or experience. Make sure that presentations start from basic concepts presented in an easy-to-understand way and build up knowledge/understanding in a step-wise approach. Allow time between sessions to digest chunks of information to avoid overload and keep partners on board.
- Keep in mind partners may not have English as their first language and therefore be conscious of speed and clarity of speaking, and try to keep the language as simple and as understandable as possible.
- Make sure everyone has a chance to provide input. Potentially split groups into sub-groups to ensure there is time for everyone to provide input.
- Be serious about listening to the input received and be ready to adapt the project approach and proposals to take feedback into account. Provide feedback back to partners on how their input has been incorporated as this will build trust and enhance motivation.
- Know the audience and why their input is needed, and what specific aspects of the project the input is needed for. Select the right partners to provide input and make sure that they are as representative as possible.
- Limit the number of new tools/technologies needed for the engagement, and make sure that any tools (e.g., meeting tools, etc.) are explained and demos provided.

### 4.2.2. Recommendations based on Ecosystem leads feedback

- Carefully plan the activities that will generate engagement. Ask the right questions and plan ahead how feedback will be collected and analysed.
- Surveys/questionnaires are a good way to collect feedback. Focus groups or semi-structured interviews are also effective in collecting feedback.
- Engage early!
- Make sure to involve the right external stakeholders. Engagement partners need to understand the benefit of the project to them and others, and why their engagement is required. Consider the incentives of the participants to ensure that you engage with the right partners.

#### 4.2.3. Recommendations based on Gravitate-Health Consortium member feedback

- Carefully organise and plan the session. Ensure a good support structure for engagement meetings (i.e., separate presenter and notetaker roles). Capture all the notes from meetings and the feedback received. Record the meetings in case anything is missed.
- Consider the right length for engagement meetings. 1.5 hours felt like a good balance allowing enough time for icebreakers, questions, a short break and not having to rush the meeting.
- Provide pre-meeting materials in advance of meetings and in different formats (where possible) that are suitable for users with impairments, such as visual or auditory.
- Keep a clear focus for each meeting. Lay out what are the goals that each engagement session is aiming to achieve.
- Be aware of all of the legal, compliance and ethics considerations of the engagements. Get the right advice on these aspects. Know the do's and do not's of handling patient/citizen data.
- Be receptive to feedback and demonstrate the ability to implement changes in response to feedback received, and relay back where and how the feedback was incorporated in the project.
- Take into account the differing needs of a potentially diverse audience that may include people with different fluencies in English, different ages, impairments, and varying levels of familiarity with digital health tools and other tools/technologies that may be utilised as part of the engagement meetings.

## 5. Resources

Section 5 of the toolkit provides a listing of the various Gravitate-Health-related resources that may be useful for enhancing engagement with external partners, and to build strong and consistent relationships with external stakeholder constituencies.

This section also provides a listing of other useful resources that are not specific to Gravitate-Health but provide foundational information on the key digital health concepts that may be required for optimised engagements with external partners.

These resources are useful for providing patients, health care professionals and citizens with foundational information on key digital health concepts thereby enhancing their ability to provide constructive and valuable input during development and testing of the G-lens.

These resources can also contribute to support the contribution of valued communities such as the Ecosystems, SME/Start-ups and Pharma including in preparation for planned Hackathons, Connectathons and Interoperability show cases. The toolkit should offer value and help to reach beyond “traditional” end-users.

### 5.1.Gravitate-Health related resources

The resources listed below are specifically related to Gravitate-Health. Some of these resources are available in the public domain. While others are only available to members of the consortium, they may be helpful to refer to in considering how best to educate patients, health care professionals and citizens on various aspects of the Gravitate-Health project, as the understanding of project concepts and objectives can be a key factor in the success of engagements with these parties.

#### 5.1.1. Gravitate-Health website repository

<https://www.gravitatehealth.eu/multi-media/>

Includes external facing materials that can support engagement, such as helping external stakeholders become more familiar with the work of Gravitate-Health, and its area of work. This includes slide decks, videos, press releases, publications, etc.

#### 5.1.2. Gravitate-Health Glossary

<https://glossary.ramit.be/public/home.cfm?pid=7>

The glossary is shared with a number of European digital health projects (including OpenMedicine, concePTION, UNICOM, Gravitate-Health), committed to collaborate to grow and maintain the glossary to be and become a useful resource for all. The project glossary editors can review each other's entries and bring them into their own project glossary if they wish.

The glossary has been developed and is hosted by the European Institute for Innovation through Health Data (i~HD), in partnership with RAMIT.

#### 5.1.3. Gravitate-Health UAG Information pack

Teams Location: WP2 - Task 2.1 / Files / Meetings / 2021-04-27 - UAG induction meeting ([Direct Teams Link](#))

The final selected UAG members attended an induction call to introduce themselves to the rest of the group and learn more about the concept of the UAG and the purpose

and means of engagement planned for the group. The agenda, information pack and presentation given at the induction call are included.

#### 5.1.4. Gravitate-Health UAG Assessment Questionnaire

<https://www.surveymonkey.com/r/7HSG8SP>

In order to evaluate the UAG's understanding of the general digital health related topics, this is the survey that was taken by the group and built with the help of the other WP2 partners.

#### 5.1.5. Gravitate-Health UAG Application Form

<https://eupatient.wufoo.com/forms/user-advisory-group-application-form/>

This is a copy of the form used by patients, patient representatives, healthcare professionals and citizens/consumers to apply for membership of the Gravitate-Health UAG.

#### 5.1.6. Gravitate-Health WP4 & UAG Workshop Minutes

Teams Location: WP2 - Task 2.1 / Files / UAG Admin / UAG – WP4 engagement ([Direct Teams Link](#))

Minutes from WP4-UAG sessions.

#### 5.1.7. Gravitate-Health on Patient Engagement Synapse

<https://patientengagement.synapseconnect.org/initiatives/gravitate-health>

Synapse is the global map and network around different societal issues. Patient engagement Synapse aims to map the patient engagement ecosystem, including experts, organisations, initiatives, resources and events, in order to facilitate collaboration and best practice sharing. By having a profile on Patient Engagement Synapse, Gravitate-Health collaborators have the opportunity to engage with a global network of actors interested in improving patient engagement and patient outcomes. It is also an opportunity to increase awareness of Gravitate-Health outputs.

Gravitate-Health is also visible on [Maternal Health Synapse](#), [Precision Medicine Synapse](#), and will soon be available on the newest platform Digital Health Synapse.

## 5.2. Other useful resources

The resources listed below are not specific to Gravitate-Health but can also prove useful in preparing patients, health care professionals and citizens with foundational information on the key digital health concepts, thereby enhancing their ability to provide constructive and valuable inputs during the development of G-lens.

#### 5.2.1. Data Saves Lives – Glossary

<https://datasaveslives.eu/glossary>

Data Saves Lives is a multi-stakeholder initiative led by the European Patients' Forum (EPF) and the European Institute for Innovation through Health Data (i~HD). The aim is to raise wider patient and public awareness about the importance of health data, improve understanding of responsible health data sharing, and establish a trusted environment for dialogue on this issue.

Data Saves Lives developed a range of resources to make this possible, including the Glossary linked above. Most of the terms listed in their glossary are sourced from a

glossary produced by the Connected Health Cities Programme in the UK. Some terms have been drawn from the IMI Code of Practice. Some terms have been defined in accordance with international (ISO) standards or European Commission publications. The terms have been reproduced or adapted in the Data Saves Lives glossary with permission.

### 5.2.2. Digital Health Europe – Glossary

<https://digitalhealtheurope.eu/glossary/>

Digital Health Europe provides comprehensive support to the Digital Health and Care Innovation initiative in the context of the Digital Single Market Strategy. The project's approach involves a number of actions that will boost innovation and advance the Digital Single Market priorities for the digital transformation of health and care (DTHC), as outlined in the European Commission's 2018 Communication on the topic.

The glossary aims to provide a listing of common terms and concepts used in discussions concerning digital health. It supports the Digital Health Europe's priorities to provide digital tools for citizen empowerment and person-centred care.

### 5.2.3. European Health Data Evidence Network (EHDEN) Academy

<https://academy.ehden.eu/>

Patient Organisations - Introduction to Real World Data & Real-World Research:  
<https://academy.ehden.eu/course/view.php?id=15>

The EHDEN Academy has been created as the online educational resource for anyone working in the domain of real-world data and real-world evidence. Originating in the European Health Data & Evidence Network (EHDEN) IMI2 project, its goal is to build upon the foundations of that project and its collaboration with the Observational Health Data Science and Informatics (OHDSI).

The course on "Patient Organizations - Introduction to Real World Data & Real-World Research" is intended for non-professional level and is therefore a useful resource for engagement partners less familiar with aspects of digital health.

### 5.2.4. Digital Health EPF Webinars

Episode 1 – Introduction

<https://www.youtube.com/watch?v=PnbrUS7bjBk&t=4s>

Episode 2 - The Role of Health Data in Medicines Regulation

<https://www.youtube.com/watch?v=nMACPmMogpM&t=1s>

Episode 3 – Health Data Sharing

[https://www.youtube.com/watch?v=958bLD\\_CKck](https://www.youtube.com/watch?v=958bLD_CKck)

Episode 4 – E-Health and Telemedicine

<https://www.youtube.com/watch?v=P1biBiF4HGo>

Series of webinars hosted in 2020 by EPF (European Patient Forum) to educate patients on digital health.

### 5.2.5. Patient Engagement Open Forum 2021

<https://patientengagementopenforum.org/event-highlights-2021/>



<https://patientengagement.synapseconnect.org/events/pe-open-forum-2021/resources>

The Patient Engagement Open Forum 2021 (PEOF2021) was a series of virtual sessions that took place in April, June, October, and December 2021. The aim was to use this patient-centred series of online events to shape and co-create stronger patient engagement across health systems

PEOF2021 was organized with sessions in each quarter of April, June, October, and December 2021.

#### *5.2.6. EUPATI Patient Engagement Toolbox resources*

[https://toolbox.eupati.eu/resources/?post\\_types=peresource](https://toolbox.eupati.eu/resources/?post_types=peresource)

The EUPATI Toolbox is an online library on the A-Z of medicines research and development and patient engagement. The information is not medicine-or disease-specific, but is applicable to the majority of diseases and/or medicines.

The Toolbox is organised in two main areas: Medicines R&D and Patient Engagement, and it is also possible to search via category or keyword. At the next stage you can also refine the search by "tags" (sub-categories). The link above provides the EUPATI Toolbox resources on Patient Engagement.



## 6. CONCLUSIONS

There are many types of varied engagements (both completed and planned) that have been included in this initial version of the 'Toolkit' - and those that have completed have shown to be of immense value to deliver high quality outputs from various Gravitate-Health work packages.

To support uptake of the Toolkit, it is envisioned that this toolkit will be communicated across the consortium so that it can support further engagement activities throughout the remaining duration of the project, and will be further refined as new engagement experiences, feedback and case studies become available.

The mechanism for gathering engagement feedback and refining the toolkit will be captured via a questionnaire template to be shared across the consortium.

Evaluation of engagements will also be captured via the "Temperature check" surveys, which indicate the progress in the application of general engagement principles within the project.

The next and final iteration of the Toolkit will be planned to be completed by the end of Year 4 (October 2024) and will be made available to both multi-stakeholders support continued engagements within Gravitate-Health and future Digital Health initiatives.