

D2.2

Report on first Users Consultation

Group meeting

VASILIS PAPANIKOLAOU, ATC SA (VERSION 1.0, 30/06/2020)



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	Mathilde De Bonis (APRE)
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Abstract

The Users Consultation Group (UCG) is meant to advise the experts selected by IDIH to work in the Digital Health Transformation Forum, a long lasting and umbrella mechanism set by the project to foster collaboration between the European Union and five Strategic Partner Countries (USA, Canada, China, Japan and South Korea) in the field of Digital Health for AHA. Composed of the most relevant representatives of "end users" of the digital transformation of health and care in the EU and in the Strategic Partner Countries, the UCG will guide the experts of the IDIH Forum to adopt a user-centred perspective by providing inputs and feedbacks to their work: a *roadmap* addressing policy makers to enhance international cooperation in priority areas, that will also point to suitable potential funding schemes.

This document reports the work of the 1st meeting of the UCG within IDIH that has been held virtually between May and June 2020.

Keywords

Digital Health, Active and Healthy Ageing, User Consultation Group

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Abbreviations and Acronyms

Abbreviation, Acronym	Description
APRE	Agenzia per la Promozione della Ricerca Europea (project partner)
ATC	Athens Technology Center S.A. (project partner)
CIHR	Canadian Institutes of Health Research (project partner)
EC	European Commission
EG	Expert Group
GSBC	Global SMEs Business Council (project partner)
Health 2.0 LLC	Health 2.0 LLC (project partner)
inno	inno TSD (project partner)
MedPeer Inc.	MedPeer Inc. (project partner)
PLC	Programme Level Cooperation
S2i	Steinbeis 2i GmbH (project partner)
SPS	School of Pharmaceutical Science Tsinghua University (project partner)
UCG	User Consultation Group
WP	Work Package





Executive Summary

This document reports the works of the 1st meeting of the Users Consultation Group (UCG) that has been held between May and June 2020 within IDIH - International Digital Health Cooperation for Preventive, Integrated, Independent and Inclusive Living - a project funded under the European Union Horizon 2020 Research and Innovation Programme.

The UCG aims and activities, its current composition, and the selection process of its members, are presented as *background information* in the first part of this Report.

The works of the 1st UCG meeting are described in detail in the second part of the Report, whose structure follows the 6 sessions that have been held between May and June 2020:

- 5 online plenary sessions, held on May 26, 2020 between 14.00 and 16.00 CEST:
 - <u>Session 1</u>: aimed on providing a clear overview of IDIH's identity, objectives, goals and methodology. It also presented in a thorough and detailed manner, the role of UCG, and the expected inputs and outcomes of the group, as part of the Digital Health Transformation Forum.
 - <u>Session 2</u>: dedicated to the actual UCG members, who had the opportunity to give a brief, but comprehensive presentation of their organisation/associations.
 - <u>Session 3</u>: dedicated to a group discussion and Q&A coming from the members, and answers provided by the consortium or other UCG members.
 - <u>Session 4</u>: dedicated on collecting live feedbacks from the participants (through Mentimeter¹) to deepen knowledge on UCG members and foster mutual exchange.
 - <u>Session 5</u>: devoted to presenting the contents and methodology for the follow up phase
- **1 follow up session**, held in June 2020, allowing UCG members to work remotely of the basis of the findings worked out together in the last sessions.

The Report ends with a reflection on the meeting results, outlining the next steps to be undertaken by the UCG members in the framework of IDIH.

¹ <u>https://www.mentimeter.com/</u>





1 Background Information

1.1 Rationale of the User Consultation Group

The purpose of the IDIH project is to promote and increase international cooperation to advance digital health in the EU and five Strategic Partner Countries (USA, Canada, China, Japan, South Korea) to support active and healthy aging through innovation. To this purpose, IDIH will identify shared priorities and set up a **Digital Health Transformation Forum** as a long-lasting and expert-driven catalyst to foster collaboration between the EU and the Strategic Partner Countries.

In order to ensure the involvement of research, technology, innovation, policy stakeholders, and the user associations, the Digital Health Transformation Forum operation is **based on an expert-driven approach** that has foreseen the establishment of 4 Experts Groups (EGs) and a User Consultation Group (UCG).

IDIH Expert Groups will work on four strategic topics (Preventive care, Integrated care, Independent and connected living, Inclusive living) in order to investigate collaboration pathways in digital health between countries and regions. <u>The User Consultation Group (UCG) will guide the EGs to adopt a</u> <u>user's-centered perspective</u> in the development of the "Report Towards an international collaboration in digital health" (D3.6/D3.7) that will address policy makers in Europe, USA, China, South Korea, Canada, and Japan. To be meant as a roadmap to enhance international cooperation in priority areas, the Report will also point to suitable potential funding schemes, between the EU and the five Strategic Countries, providing clear suggestions per topic of interest.

As representatives of the needs and expectations of users and patients in the field of Digital Health for AHA, **UCG members will benefit** from the participation in the Digital Health Transformation Forum, then, **by contributing to better align the policy orientations set at country/regional level in the field of Digital Health for AHA to the users' needs and to the related RTI landscape and trends.**

Positive impact is expected for society, above all the patients, but it can clearly be expected that research and development (R&D) collaboration and market opportunities for industry players will arise from an open policy dialogue in the field taking into account the needs and expert view of the respective stakeholders along the value chain.

1.2 Selection Process of UCG members

APRE - *Agenzia per la Promozione della Ricerca Europea* is the partner responsible for the engagement of users' associations in IDIH, as part of the WP2 activities.

Starting from a **desk research** and its experience in the field as a hosting organization of H2020 "Health" NCPs, APRE - in collaboration with the other IDIH partners, who carried out research at regional/country level - has **selected 23 organizations** from the EU and the 5 Strategic Partner Countries (USA, Canada, China, Japan, South Korea), considering the following selection criteria:

- "REPRESENTATIVENESS" CRITERIA (at least 1 fulfilled):
 - \circ $\;$ Representation of the elderly (and their families)
 - \circ $\;$ Representation of patients (and their families)





- o Special attention to diseases related to Ageing
- Special attention to cross-cutting aspects (e.g. gender)
- o Representation of care providers/care givers/professionals
- Representation of Public Health institutions
- "ADVOCACY/GEOGRAPHICAL COVERAGE" CRITERIA (at least 1 fulfilled):
 - Being umbrella organizations (II level associations)
 - o Demonstrated advocacy power
 - Listed in the List of NGOs Accredited to the OEWG on Ageing (Open-ended Working Group on Ageing for the purpose of strengthening the protection of the human rights of older persons).

A phase of contacts development has followed, by reaching possibly the managerial levels of these organizations and those potentially interested by the field of operation of IDIH. In particular, APRE has contacted:

- 9 organizations from the EU
- 5 organizations from the USA
- 3 organizations from Canada
- 3 organizations from China
- 2 organizations from Japan
- 1 organization from South Korea

By foreseeing 2 levels of engagement in IDIH:

- **1° level**: Direct participation in the Forum as members of the Users Consultation Group (UCG)
- 2° level: Remote Support to the Users Consultation Group (UCG)

APRE and the IDIH Consortium have opted to engage the organizations that provided a positive feedback in the planned timeframe (May 14th, 2020) as <u>UCG members with a 1° level of engagement</u>. These are:

Table 1 UCG members to May 14th, 2020

Organization	Website	Region
Smart Health Care and Home Care Branch of China	http://www.cagg.or	China
Association of Gerontology and Geriatrics (S2HC-	g.cn/portal/page/in	
CAGG)	dex/id/5.html	
European Public Health Association (EUPHA)	www.eupha.org	EU
AGE Platform Europe	https://age-	EU
	platform.eu/	
European Institute of Women's Health (EIWH)	https://eurohealth.i	EU
	<u>e/</u>	
Aging 2.0	https://www.aging2	USA/Japan/Canada
	<u>.com/</u>	







Figure 1 Information Sheet on Users engagement in IDIH

The Terms of Reference for the engagement of these organizations have been outlined in the **Information Sheet on IDIH Users engagement** that has been shared with the contacted entities and included the following sections:

- 1. Invitation
- 2. What is IDIH all about?
- 3. Why have I been invited to take part in IDIH?
- 4. What will my participation involve?
- 5. Are there any risks involved?
- 6. How will I benefit from taking part in the study?
- 7. Is my participation voluntary?
- 8. How will you handle my data?
- 9. Will I receive feedback?
- 10. Who can I contact in case of questions, problems or concerns?

The **5 Informed Consent Forms** included in the Information Sheet – signed by a representative of the organizations – have been collected before the date of the Meeting (May 26th) and stored, according with the provisions of the IDIH privacy policy.

Moreover, the following **information material** has been shared via email to the identified reference persons, in order to give a preliminary and brief overview of the project, and to highlight the role of Users Associations within the Digital Health Transformation Forum and, in particular, in the UCG.



Figure 2 IDIH/UCG Flyer (page 1)







Figure 3 IDIH/UCG Flyer (page 2)

1.3 Activities for the UCG

A continuous dialogue and the engagement with Users associations in all target countries and in Europe, throughout the whole project duration (36 months) is crucial in the context of IDIH. Therefore, a close exchange will take place with the most relevant representatives of "end users" of the digital transformation of health and care – gathered in the UCG - on a regular basis and in occasion of key project progresses in order to ensure that "patients" will be at the heart of IDIH investigations and outcomes.

In particular, all Users associations engaged in the project will stay informed and become aware of the work implemented by the EGs, on a regular basis. EGs meetings minutes and draft versions of all publications related to their work, will be shared for commenting and feedback. APRE will facilitate the communication between the Expert Groups and the Users associations.

The effort requested to the UCG members within IDIH includes the following activities:

- 1. Take part in 2 User Consultation Group (UCG) meetings back-to-back with 1st (May, 2020) and 3rd (March 2022) EGs meetings. In these occasions, Users Associations from the EU and the Strategic Countries will:
 - a. give feedback and inputs for the development of the successive iterations (D3.6/D3.7) of the report *Towards an international collaboration in digital health*.
 - b. **give general inputs on IDIH activities**, taking into account that a widespread awareness raising and outreach campaign will be organized by IDIH in order to ensure





involvement of researchers, technology experts, innovation facilitators, representatives from industry, other user associations, advocacy groups, and policy makers.

2. Participate in a virtual meeting with the EGs Chairs and the IDIH Consortium, after the 2nd EG meeting (June 2021). The provisional agenda for this meeting includes to date: (i) the presentations of EG chairs/facilitators of the works in the 2nd EGs meeting; (ii) the collection of instant feedbacks from Users Associations (e.g. through Slido/Mentimeter). Then, feedbacks will be analyzed and processed in a Report to be returned to Users Associations for a final validation.

Networking between the UCG members, with the experts and other IDIH stakeholders will be encouraged during the whole project duration. A particular attention will be paid to the recent publications and initiatives by the UCG organizations that – if considered as relevant in the framework of IDIH - will be brought to the attention of the experts in the EGs and to the RTI stakeholders in the EU and in Strategic Partner Countries through IDIH public channels (e.g. website, social media, public events).





2 1st User Consultation Group Meeting

2.1 Meeting Objectives

The 1st User Consultation Group Meeting took place online - due to the limitations that stem from the Expert Group Meetings, held online as well – on May 26, 2020, with the following concrete objectives:

- Infuse a common understanding of IDIH's scope and objectives between all UCG members
- Present the UCG members and encourage mutual exchange among them, also introducing the concept of co-creation in UCG's activities
- Define the role of the UCG Group
- Gathering inputs from UCG members for the experts, even by discussing, validating and refining the findings of D2.4: *Briefing Note on (priority) Topics for the Expert Groups*
- Discuss and agree on next steps and ways of working

The meeting has been completed with a follow up phase that has been held in June 2020, allowing UCG members to work remotely and independently to finalize their contribution to the group and activate indeed synergies with the EGs.

2.2 Meeting Agenda

The 1st UCG online meeting took place in the afternoon of May 26th 2020 (14.00 – 16.00 CEST), using the web conferencing platform Adobe Connect., covering 5 plenary sessions. The 6th session has been held in June 2020, as a follow up phase that has allowed the UCG members to work in parallel and remotely. The agenda of the meeting as a whole is given in the following table:

ONLINE MEETING (MAY 26, 2020)			
Timeslot (CEST)	Session No	Session Description	
14:00 - 14:15	1	Presentation of IDIH Project/ The Digital Health Transformation	
		Forum and the role of the UCG – Users Consultation Group	
14:15 - 14:45	2	Presentation of Users Associations	
14:45 - 15:00	3	Q&A	
15:00 - 15:30	4	Gathering instant feedbacks: deepening knowledge on UCG members	
15:00 - 16:00	5	Next steps: contents and methodology for the follow up phase	
	REMOTE WORK (JUNE 12-19, 2020)		
Timeslot (CEST)	Session No	Session Description	
n.a.	6	Follow up phase: Proving further inputs to the Consortium and the	
		EGs, by working remotely and independently on a Google Form	

Table 2: 1st UCG Meeting Agenda

2.3 Meeting Participants

The meeting was attended by **five** UCG members, coming from three different regions: EU, USA and China. Considering the <u>Chapters</u> of Aging2.0, however, the UCG has demonstrated the ability to provide also a linkage with the Japanese and Canadian area.





Figure 4: UCG Members

The following table (Table 3) lists the reference persons appointed by the organizations to act within the UCG of IDIH, who attended the meeting.

Name	Organization	Region
Dr. Jie Wang Vice President	Smart Health Care and Home Care Branch of China Association of Gerontology and Geriatrics (S2HC-CAGG)	China
Anna Odone Digital Health Section President	European Public Health Association (EUPHA)	EU
Ilenia Gheno Research Project Manager	AGE Platform Europe	EU
Peggy MaguireEuropean Institute of Women's HealthDirector General(EIWH)		EU
Stephen Johnston Co-Founder	Aging 2.0	USA/EU

In addition to the above mentioned key UCG members, **3 other** participants (including the host) attended the online meeting, representing the IDIH project and the Expert Groups as well.

Table 4: 1st UCG Meeting Participants-IDIH Members

Name	Organization	Region
Mathilde De Bonis Project Manager	APRE IDIH Project Partner and Preventive Care EG Facilitator, Leader of IDIH WP2 – <i>Policy engagement</i> –	EU



	validation of priority collaboration fields through interaction with Funding Agencies	
Martina De Sole Head of International Cooperation	APRE IDIH Project Partner and Preventive Care EG Facilitator, Leader of IDIH WP2 – Policy engagement – validation of priority collaboration fields through interaction with Funding Agencies	EU
Vasileios Papanikolaou Senior Innovation Manager	ATC SA IDIH Project Partner and Inclusive Living EG Facilitator, Leader of IDIH WP3 – Set up of a sustainable Digital Health Transformation Forum driven by international Experts Group	EU

2.4 Sessions Overview

According with the Meeting Agenda, the contents and the implementation methodology of the 1st UCG meeting is here reported by referring to six consequential sessions.

2.4.1 Session 1: Presentation of IDIH Project/The Digital Health Transformation Forum and the role of the UCG

This first session was held by APRE and aimed on providing a clear overview of IDIH's identity, objectives, goals and methodology. It also presented in a thorough and detailed manner, the role of UCG, and the expected inputs and outcomes of the group, as part of the Digital Health Transformation Forum (see: part 1.1 *Rationale of the User Consultation Group*).

In particular, the following aspects – even if already brought to the attention of the organizations during the contacts development phase, as part of the Information Sheet signed by the participants before attending the meeting - have been highlighted (see for details: part 1.3 *Activities for the UCG*):

- How will Users associations will benefit from taking part in IDIH
- How and when UCG members will be involved in IDIH
- What is expected from UCG members in IDIH

No comments or additional discussion was made on this session.

2.4.2 Session 2: Presentation of Users Associations

The second session was dedicated to the actual Users associations, who had the opportunity to give a brief, but comprehensive presentation about their organisation/associations.

The contents of the presentations were the following:

1. European Public Health Association (EUPHA), by Anna Odone:

EUPHA is an umbrella association that brings together all the national associations in EU and the European region. It has different thematic sections and I'm the President of the Digital Health section. This section was funded last year with the aim of bringing together members





interested in research, practice and policies in digital health, by sharing experiences and conducting pooling of research conducted at European level on digital public health.

2. European Institute of Women's Health (EIWH), by Peggy Maguire

I'm representing the European Institute of Women's Health that was founded in 1996. It is a non-governmental organisation set up to promote gender equity in public health, research and social policies across the Europe. We promote gender-specific biomedical and socio-economic research, to ensure quality and equity in health policy, research, treatment and care for women and their families throughout their lifespan. We used an evidence-based approach, and we do this in our position papers and policy briefs where we are taking to the European Commission or the European Parliament, or other NGOs. We work very close with the European Commission and we have been engaged in the Aging and Disability Expert Group, as well as in the H2020 Societal Challenge on Health, demographic change and wellbeing, as expert advisor on gender. In 2016, we contributed as experts to the WHO strategy on Gender Women's' Health in Europe. We also provide advice to the European Medicine Agency and we are part of the Advisory Group of the European Centre for Disease Control and Prevention, also dealing with Health Technology.

3. AGE Platform Europe, by Ilenia Gheno

I'm representing AGE Platform Europe that is an intergovernmental not-for-profit organization "of and for" citizens aged 50+, currently including 110 members around the EU. We mainly focus on policies in different areas, from discrimination to unemployment, social protection and all what is related to patients' reform and welfare; we deal of course with issues related to health, elder abuse, social inclusion, and research and technologies.

Even if our main focus is on policies, we do not neglect our involvement in projects, since this is a very practical way to have older person contributing directly to the research. We are involved in several research project, indeed, dealing with technology aspects and digital health, so that they can raise awareness about their own needs and preferences. We do this especially through our experts gathered in the advisory boards and tasks forces of these projects. We would be glad to forward to our experts the IDIH products and what you are going to share.

4. Aging 2.0, by Stephen Johnston

Aging 2.0 is a global network for innovation in aging. We operate a bit different perhaps from the other organizations. We currently have 120 cities around the world where our Chapters operate, all run by volunteers, bringing together technology companies, industry providers, research and users' groups, all engaged in connecting tech with aging.

5. We have <u>Grand challenges</u> which we are looking to solve, also supported by our <u>network</u> <u>sponsors</u>. We are now building out the world's first collective intelligence platform for innovation in aging, <u>The Collective</u>, that will connect thousands of innovators with providers. The digital tool is being developed by Shapeable.ai, drawing on their experience building technology solutions for the World Economic Forum, among other global organizations. Smart Health Care and Home Care Branch of China Association of Gerontology and Geriatrics (S2HC-CAGG), by Dr. Jie Wang

I'm representing a newly established organization that is part of the China association of Gerontology and Geriatrics. It is a branch of this association called "Smart Health Care and Home Care" that was established in 2018, whose members are mainly research institutions, but also professionals and industry providers in the frontline of senior care. We actually realize a meeting at academic level once a year addressing "smart health care and smart senior care".





The China Association of Gerontology and Geriatrics of which we are part is the oldest association in China in the field of aging, established on 1986; almost all the other organizations in this filed are under its umbrella. As you may know, in China the government is the major primary forces behind aging and health care, so we normally work very closely with central and local government. We really hope that we can make some meaningful contribution to this project.

No comments or additional discussion was made on this session

2.4.3 Session 3: Q&A

The third session was dedicated to some short questions coming from the members, and answers provided by the consortium or other UCG members.

In particular, the participants were asked:

- You listened to the presentations of the organizations currently participating in the UCG:
 - Any comments?
 - Did you know them all already?
 - Have you ever collaborated with one or more of them?
- Any need of clarification about IDIH and your engagement in IDIH?

The most critical questions and answers were the following:

<u>Question 1</u>: What are our obligations as UCG members? Do we are supposed to generate some kind of report, or anything specific? by Dr. Jie Wang

Reply by APRE (Mathilde De Bonis): The main and critical obligations of UCG are to go through the documents provided by the Expert Groups and provide valuable feedback and comments in order to reflect the views and positions of the users, which then will be communicated to policy makers. Moreover, UCG members are required to attend UCG meetings and discussions with Expert Group Chairs and facilitators when requested.

<u>Question 2:</u> What are the success metrics for the UCG? How are you measuring success of users engagement in the next couple of years? by Stephen Johnston

Reply by APRE (Mathilde De Bonis): The success of the UCG cannot be measured in a quantitative way. However, we can say that our main measure of success is the adoption of the priorities that will stem from the EGs and UCG views, and that we are going to propose to the policy makers; this would be our ultimate performance indicator. WP2 is mainly dedicated to engage policy makers. We'll start and manage the process of priority setting in synergy with the policy makers during the project. This will allow us to better align our priorities to the agenda that is currently set at policy level. In this way we'll have much more chances to see our priorities or approaches adopted at policy level. For us it is really important to integrate the works of the experts that will inspire policy makers, with the point of view of the final users, keeping in mind that co-creation is at the core of Horizon Europe and EU policies, and demonstrating this approach is a key for our success.

Question 3: What is IDIH Forum? How is it conceived? Is it working in silos? by llenia Gheno





Reply by APRE (Mathilde De Bonis): The Digital Health Transformation Forum of IDIH consists of 4 Expert Groups (EGs), each one dedicated to a specific topic (Preventive Care, Integrated Care, Independent and Connected Living, Inclusive Living). The project foresees 3 EGs meetings, with parallel sessions - in which experts will work within their own group – and plenary sessions – to allow the exchange between the EGs. In this first stage, all Expert Groups are working independently, however after the 1st Expert Group Meeting, Expert Groups will join forces and will start working on parallel streams towards a common target and agenda. Back-to-back with the EGs meetings, the Forum will be enriched by the insights coming from the policy makers, gathered in PLC – Programme Level Cooperation meetings, and by the inputs and feedback of the UCG. As a final outcome of the Forum, the "Report Towards an international collaboration in digital health" (D3.6/D3.7) will be produced, outlining a roadmap to policy makers (from the EU and the five Strategic Partner Countries) to enhance international cooperation in the 4 priority areas, also through potential funding schemes.

2.4.4 Session 4: Gathering instant feedbacks: deepening knowledge on UCG members

Section 4 was dedicated on collecting live feedbacks from the participants, by using **Mentimeter**², an interactive presentation tool that allows to engage audiences in real time. The main outcomes of the sessions are summarized below for each of the following questions made through this tool:

1. Which are the categories your organization represents the most?

<u>Results</u>: As from the answers, the most represented categories in the UCG are the *Elderly*, the *Public Health Institutions* and *Care Providers/Professionals*, as showed in Figure 5. [Reference scale: from "0 = no representativeness" to "5 = maximum representativeness"]

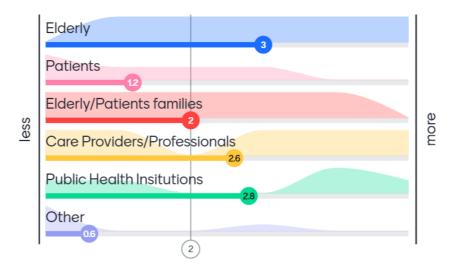


Figure 5 Categories represented by UCG members

2. Is your organization an umbrella organization? <u>Results</u>: All UCG members are umbrella organizations

²https://www.mentimeter.com/





3. How many members does your organization represent?

<u>Results</u>: Each of the participant UCG members brings together more than 50 member organizations.

4. What about the geographical coverage of your organization?

[Reference scale: from "0 = no coverage" to "5 = maximum coverage"] <u>Results</u>: Currently, thanks to their network members, UCG organizations are mostly present in Europe. However, a significant coverage is provided in USA and China, as showed in Figure 6.

This information contributes to outline the potential impact of IDIH action.

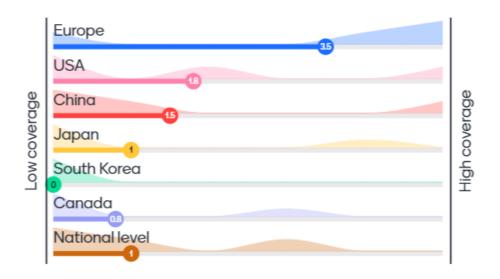


Figure 6 UCG members' geographical coverage

5. Does your organization carry out advocacy activity?

<u>Results</u>: 4 out of 5 UCG members carry out advocacy activity.

6. If yes, which are the policy makers and/or funding agencies with which your organization is in contact with?

<u>Results</u>: UCG members are in contact with the following policy makers/funding agencies:

- Corporate funding Multinational
- Local government agencies in China
- European Commission
- EU Parliament
- WHO
- 7. Would you suggest relevant publications by your organizations that may be taken into account from the EGs in the interlocution with policy maker?

<u>Results</u>: UCG members suggested the following publications and initiatives:

- The work of Thecollective.aging2.com.plus
- <u>https://www.aging2.com/covid-19/</u> initiative
- <u>CoverAGE Newsletter</u>
- Aging 2.0 Report 2018-2019: For nearly seven years, Aging 2.0 has worked to support innovators taking on the biggest challenges and opportunities in aging. This unprecedented confluence of demographic, technological and policy trends is creating massive need and



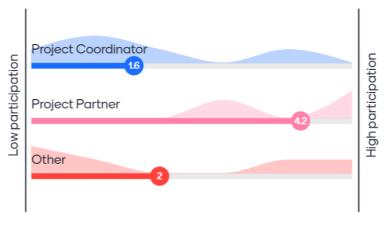


opportunity. We know that there is enormous economic potential and we believe that a person-centric, collaborative and tech-enabled approach will benefit all stakeholders, most importantly older adults themselves. The Aging2.0 Grand Challenges framework provides structure and context to the broad topic of aging. We've spent the last year collecting the best ideas from our global community across all 8 Grand Challenge topics, with a particular focus on Caregiving and Brain Health. This report was updated at the end of 2018 to reflect the latest information and resources.

- EIWH EU Manifesto for Women's Health 2018
- <u>EIWH Position Paper on Women and Dementia</u>: Addressing the disproportionate burden of dementia on women
- <u>EIWH POSITION PAPER CORONAVIRUS (COVID-19).</u> Prepared by the EUROPEAN INSTITUTE OF WOMEN'S HEALTH – April 2020. Authors: Peggy Maguire and Kristin Semancik, European Institute of Women's Health
- Odone et al. (2019). Public Health Digitalization in Europe. Published by Oxford University Press on behalf of the European Public Health Association (see at: https://pubmed.ncbi.nlm.nih.gov/31738441/)
- <u>COVID-19 and the human rights of older persons</u>, by AGE Platform Europe (latest update: 18th May 2020).
- ICT for ageing well: Listen to what older persons think! (Feb. 2014), by AGE Platform Europe, and more recent publications available at <u>https://www.ageplatform.eu/publication-type/age-publications</u>
- Other: Accelerator & Startup pitch events and search

8. The experience of your organization in R&I projects | Role

<u>Results</u>: UCG members have experience in R&I projects mostly as Project Partners (see Figure 7). This aspect may depend on the type of expertise of the organizations (if they conduct also research activities, or not) and may be connected with the "ancillary" role requested for users' associations by R&I funding schemes.





9. The experience of your organization in R&I projects | Collaborative experience





<u>Results</u>: UCG members have experience in R&I projects mostly at European level (see Figure 8), and are less familiar with International Cooperation projects. In this perspective, IDIH may contribute to develop the networking of UCG organizations at international level, and to enhance the exchange and mutual learning between the EU and the Strategic Partner Countries.

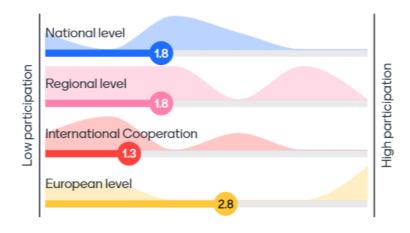


Figure 8 UCG members' collaborative experience in R&I projects

10. The experience of your organization in R&I projects | Digital Health and AHA

<u>Results</u>: UCG members has a medium-high experience in R&I projects in the field of Digital Health and AHA, as showed in Figure 9.

[Reference scale: from "0 = no experience" to "5 = maximum experience"]

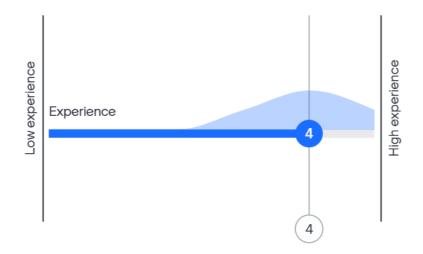


Figure 9 UCG members' experience in projects dealing with R&I in the field of Digital Health and AHA

11. Is your organization currently part of a relevant project to activate synergies with IDIH? <u>Results</u>: the projects suggested by the UCG members are here listed and will be brought also to the attention of the EGs, in order to consider relevant initiatives, outcomes and publications.





The boxes include project summaries, highlighting the most interesting aspects to be taken into consideration.

Operating Grant [EUPHA] [811123] - Operating Grant

Start date: 1 January 2018 End date: 31 December 2018

The European Public Health Association (EUPHA) is a major player in the European public health area. Since our establishment in 1992, EUPHA has been growing and has an increasing influence on the public health dialogue in Europe.

EUPHA will continue her activities in 2018, fully in line with the 3rd Health Programme of the European Commission. In order to be a leading actor in the public health arena in Europe, we will be introducing a number of new initiatives made possible through the additional funding of the 2018 operating grant. EUPHA identifies the following operational targets for 2018:

1. Strengthening national public health associations;

2. Advocating for public health on the European agenda;

3. Representing the European voice at global level and supporting public health at global level;

4. Providing actively and accurately the evidence to make informed practice and policy decisions in the field of public health;

5. Nurturing the expertise and knowledge on specific public health topics;

6. Preparing the future generation of public health professionals for their leadership role in public health.

EUPHA's strong organisation, with 25 years of experience, is a solid basis to contribute to the objectives of the Third Health Programme and to play a key role in the European public health area.

EUPHA's working methods in 2018 are:

European Journal of Public Health (EJPH)

The European Public Health Conference (EPH Conference)

EUPHA seminar in Brussels on vaccine confidence

Source: https://webgate.ec.europa.eu/chafea_pdb/health/projects/811123/summary

DigitalHealthEurope

Full title: Support to a Digital Health and Care Innovation initiative in the context of Digital Single Market strategy

Start date: 1 January 2019 End date: 30 June 2021

DigitalHealthEurope will provide comprehensive, centralised support to the digital transformation of health and care (DTHC) priorities of the Digital Single Market. The partners bring a broad range of collective knowledge and expertise, originating from the longstanding leadership and engagement in the whole spectrum of activities, from interoperability and standards to health service innovation and from the technical to the policy level. The project will support large-scale deployment of digital solutions for person-centred integrated care by identifying, analysing, and facilitating the replication of highly impactful best practices, utilising the consortium's exceptional expertise on knowledge management and impact assessment (EIP on AHA repository of innovative practices, MAFEIP),





twinning schemes, and mobilisation of stakeholders. A marketplace will enable organisations to find suitable partnerships. At least 46 twinnings ranging from adaptation of impactful best practices to full adoption will be carried out. A funding advice service and capacity building framework will be provided to further stimulate deployment and scale up. Building on the unique composition of the consortium, the project will establish and manage 3 collaboration platforms to align all efforts of ongoing and future initiatives supporting the 3 DTHC priorities. The partners will utilise their vast network of more than 1,100 members representing national, regional, and EU-wide stakeholders. The collaborative work will lead to common strategic agendas and commitments for action that will boost innovation and progress in the respective topics. <u>A Board of Associated Experts with proven high-level competence on all key fields will support the delivery of an actionable strategic vision and recommendations for EU policy beyond 2020.</u>

Source: https://cordis.europa.eu/project/id/826353; https://digitalhealtheurope.eu/

WE4AHA

Full Title: Widening the support for large scale uptake of Digital Innovation for Active and Healthy Ageing

Start date: 1 September 2017 End date: 31 December 2020

WE4AHA will advance the effective, large-scale uptake and impact of Digital Innovation for Active and Healthy Ageing (AHA), building on a comprehensive set of support and promotion services. Through WE4AHA's centralised administration, coordination and external communication, the relevant stakeholders will be mobilised to help develop and implement three EU guided activities: Innovation to Market (I2M), Blueprint Digital Transformation of Health and Care for the Ageing Society, and EIP on AHA.

WE4AHA will support the definition and execution of an I2M plan, further development of the Blueprint to drive the policy vision on digital innovation, and the consolidation of EIP on AHA Action Groups and Reference Sites. It will connect demand- and supply-side stakeholders through matchmaking, twinning, assessing innovative interventions using MAFEIP, and fostering engagement and many other support activities. It will leverage additional private and public investments by mobilising a growing number of stakeholders in Europe's digital health and care and silver economy sectors - industry, public authorities, end users, financial institutions, investors, insurers, and research communities committed to innovate on a large-scale.

WE4AHA will draw on its numerous, strong synergies and links to relevant H2020 R&I actions and other EU and international programmes. The highly interdisciplinary consortium will ensure the proper execution of the work plan by leveraging the partners' access to expertise and evidence. The consortium composition is an unparalleled matching of partners with strategic competences in health and active ageing and leading experts in policy analysis, research and innovation oriented to business, ICT enabling technologies, stakeholder engagement, communication, dissemination and the multiplier effect. Additional support is provided through a pool of experts and an Advisory Board of key stakeholder organisations with high-level competences in relevant fields.

Source: https://cordis.europa.eu/project/id/769705



SHAPES

Full Title: Smart and Healthy Ageing through People Engaging in Supportive SystemsStart date: 1 November 2019End date: 31 October 2023

SHAPES aims to create the first European Open Ecosystem enabling the large-scale deployment of a broad range of digital solutions for supporting and extending healthy and independent living for older individuals who are facing permanently or temporarily reduced functionality and capabilities. SHAPES builds an interoperable Platform integrating smart digital solutions to collect and analyse older individuals' health, environmental and lifestyle information, identify their needs and provide personalised solutions that uphold the individuals' data protection and trust. Standardisation, interoperability and scalability of SHAPES Platform sustain increased efficiency gains in health and care delivery across Europe, bringing improved quality of life to older individuals, their families, caregivers and care service providers. SHAPES Large-scale Piloting campaign engages +2k older individuals in 15 pilot sites in 10 EU Member States, including 6 EIP on AHA Reference Sites, and involves hundreds of key stakeholders to bring forth solutions to improve the health, wellbeing, independence and autonomy of older individuals, while enhancing the long-term sustainability of health and care systems in Europe. SHAPES's multidisciplinary approach to large-scale piloting is reflected across 7 themes that, together, provide a clear understanding of the reality of European health and care systems and enable the validation of cost-efficient, interoperable and reliable innovations capable of effectively supporting healthy and independent living of older individuals within and outside the home. Building an ecosystem attractive to European industry and policy-makers, SHAPES develops valuebased business models to open and scale-up the market for AHA-focused digital solutions and provides key recommendations for the far-reaching deployment of innovative digital health and care solutions and services supporting and extending healthy and independent living of older population in Europe. Source: https://cordis.europa.eu/project/id/857159

Pharaon

Full title: Pilots for Healthy and Active AgeingStart date: 1 November 2019End date: 31 October 2023

Pharaon's overall objective is to make a reality smart and active living for Europe's ageing population by creating a set of integrated and highly customizable interoperable open platforms with advanced services, devices, and tools including IoT, artificial intelligence, robotics, cloud computing, smart wearables, big data, and intelligent analytics. Platform interoperability will be implemented within Pharaon ecosystems and platforms, as well as other standardised platforms within health and other domains (energy, transport and smart cities). Pharaon will consider relevant standards and will contribute to them with the help of the two standardisation bodies of the consortium. Data privacy, cybersecurity, interoperability and openness will be key design principles to pursue through the requirements generated by Pharaon experts.

Pharaon will be built upon mature existing state-of-the-art open platforms and technologies/tools provided by the partners, which will be customised and will implement cloud technologies, AI techniques and traditional algorithms for big data intelligent analytics. A user-centric approach will be





followed. Pharaon will evolve based on the user feedback and the results from a MAFEIP framework that will be implemented for impact assessment. Both inputs will be used to find innovative solutions through two "open calls": (1) single solutions, and (2) solutions to be demonstrated in small-scale pilots.

Pharaon's integrated platforms will be validated in two stages: pre-validation and large-scale pilots (LSPs), in six different pilot sites: Murcia and Andalusia (Spain), Portugal, The Netherlands, Slovenia and Italy. A team of partners in each pilot will ensure its right development.

A set of development tools will be created and made publicly available to simplify the customisation and integration. These tools and the results of dissemination will spread the generated knowledge to promote the development of new solutions similar to Pharaon.

Source: https://cordis.europa.eu/project/id/857188

Global Innovation Search

The Global Innovation Search provides an opportunity for innovators around the world to showcase their product or service and compete for international exposure. Aging2.0 & The Louisville Healthcare CEO Council (LHCC) are searching for innovations that help keep older adults connected to their communities, families, healthcare providers and vital information. The global COVID-19 pandemic is hitting the older adult population the hardest, not only from a risk and mortality perspective, but also in the way it is exacerbating isolation and loneliness due to social distancing. At this stage of the competition, Chapter Ambassadors from around the world are processing their nominations. Selected innovators will then proceed to the semi-final round, where their company profiles will be featured and the general public will have an opportunity to vote on their favourite solutions. The ten innovators with the most public votes will then move on to the final round of competition: a virtual pitch competition judged by a panel of leaders from LHCC and Aging2.0.

Finalists (based on online public voting) will:

- Receive Bronze Aging2.0 Network Sponsorship (\$5K value)
- Receive Aging2.0 mentorship and pitch training
- Compete in a virtual pitch event (P4P) judged by a panel of leaders from LHCC and Aging2.0. The overall event winner will continue on to pitch at the LHCC CareTech2.0 Pitch event in September

Program Goals:

- Identify and learn about new innovations focused on mitigating social isolation and loneliness among older adults
- Educate the community about Aging2.0 and innovations related to aging
- Expand and deepen the global community

Source: www.aging2.com/gis

Choose 3 words to describe your organization

<u>Results</u>: The UCG members' expertise may be summarized by the keywords included in the Word Cloud in Figure 10.







Figure 10 UCG member's expertise

2.4.5 Session 5: Next steps: contents and methodology for the follow up phase

The current section included 4 sub-sessions. In the first 2 sub-sessions, the background documents provided to the UCG members prior to the meeting have been presented and analysed in brief:

- 1. Briefing note on (priority) topics for the Experts Group (IDIH deliverable D2.4)
- 2. Annex 1 of the "Orientation towards the first Strategic Plan implementing the research and Innovation framework programme Horizon Europe" (EC document).

A 3rd sub session has been dedicated to the presentation of the work method of the 1st EGs meeting, in order to align the inputs of the UCG members to the issues currently at stake within the 4 Experts Groups.

Finally, the UCG methodology to give inputs in the follow up phase starting from these documents, has been described (4th sub-session).

2.4.5.1 1st Sub Session: Briefing Note on (priority) Topics for the Expert Groups (D2.4)

APRE provided a brief presentation of the relevant material included in D2.4, related to the three main regions/countries represented by the attending UCG members, namely EU, China and USA.

The overviews of funding agencies and programmes supporting Digital Health and AHA in the three regions/countries, as well as some policy directions on in the field (part 3. of D2.4), as identified by the IDIH Consortium in D2.4, have been showed and discussed.

The main questions presented to the Users for further reflection on the contents proposed were the following:

- Is there something missing?
- Are there opportunities for International Cooperation?
- Is there something missing in the users-centered perspective?





- Would you add or integrate priority areas for future policies?
- Would you add relevant policy documents?

Despite the fact that UCG members weren't asked to provide their constructive feedback and inputs through online means - but remotely in the follow up phase - some preliminary and valuable comments have been collected throughout the meeting, as follows:

About the "China" overview on Funding Agencies and Programmes – feedback by Dr. Jie Wand

MoST - Ministry of Science and Technology is mainly dedicated to basic research and not specific to health. The most important ministries and agencies that provide funding and policies related to health and IDIH's topics of interest are:

- Ministry of Industry and IT³
- Ministry of Civil Affairs⁴
- National Health Commission⁵

About the "USA" overview on Funding Agencies and Programmes – feedback by Stephen Johnston

Even though AARP⁶ is a key association related to IDIH's topics of interest, it is also quite big, there are numerous associations and foundations that are more focused on specific diseases and issues (i.e. Dementia, Parkinson, isolation reduction, connectivity, etc.), that also provide significant funding for research and innovation on health.

2.4.5.2 2nd Sub Session: Annex 1 of the "Orientations towards the Implementation Strategy of the research and innovation framework programme Horizon Europe web open consultation"

This sub session was dedicated not only on presenting the key-parts of Annex 1 on Key Strategic Orientations in the Cluster 1 HEALTH⁷, related to IDIH's topics of interest, but also to highlight the value of the co-creation process towards strategic decisions and important policies for the European Commission.

In particular, during the presentation emphasis was given to the following aspects:

1. International cooperation conception in Horizon Europe:

Similar health challenges and needs for health promotion and disease prevention are faced by other regions and countries. International cooperation should be sought and promoted in order to benefit from new knowledge and solutions as widely as possible.

- 2. Key EU Partnership:
 - Large scale innovation and transformation of health systems in a digital and ageing society
- 3. Key Challenges under the "Health" Cluster of Horizon Europe

⁷ <u>https://ec.europa.eu/research/pdf/horizon-europe/annex-1.pdf</u>





³ <u>http://www.miit.gov.cn/</u>

⁴ <u>http://www.mca.gov.cn</u>

⁵<u>http://en.nhc.gov.cn/</u>

⁶<u>https://www.aarp.org/</u>



- Challenge 1. Staying healthy in a rapidly changing society
- Challenge 3. Tackling diseases and reducing disease burden
- Challenge 5. Unlocking the full potential of new tools, technologies and digital solutions for a healthy society
- 4. Relationships between Areas of Intervention & Challenges under the "Health" Cluster of Horizon Europe (see Figure 11).



Figure 11: Key-challenges and their interrelations with Areas of Intervention under the "Health" Cluster of Horizon Europe

Co creation is key to process! **UCG should highlights aspects that can guide the experts** of the Digital Transformation Forum of IDIH **to adopt a user's-centered perspective** even in this preliminary phase

2.4.5.3 Experts' work at the 1° EG meeting

In this sub-session, the UCG members have been invited to take into consideration the following topics of discussions within the 4 EGs, in order to provide better aligned inputs and feedback to their work:

- Can we improve Strategic Topic definition?
- Strategic topic priorities: identifying up to 5 main priorities for future development
- International cooperation: identifying up to 5 main topics/priorities suitable for international cooperation and, if possible, the suitable countries for cooperation
- Requirements: identifying potential bottlenecks or barriers to the R&I in the field
- Covid-19 and its relation to the Strategic Topics



2.4.5.4 The Follow up phase: methodology for gathering feedbacks remotely

The meeting has closed by informing UCG members about the implementation methodology of the follow up phase that would have started after the end of the meeting, allowing them to provide a more focused contribution to the work of the experts.

In particular, participants have been informed that starting from June 2020 they would have been further contacted and asked to fill in a Google Form with their inputs and comments, based on the background documents already shared and presented in the UCG.

2.4.6 Session 6: Follow up phase (UCG remote work)

As anticipated during the online session 5 of the UCG meeting on May 26, 2020, participants have been contacted later - on June 12, 2020 - to provide further inputs to the Consortium and the EGs, by working remotely on a Google Form: <u>https://forms.gle/MvQpgYzkqQxuneeG9</u>.



IDIH | 1st UCG meeting - Follow up Form

Figure 12 "Follow up" Google Form available at https://forms.gle/MvQpgYzkqQxuneeG9

This form was meant, thus, to complement the collection of inputs and feedback from the Users Consultation Group carried out during the online meeting on May 26, 2020, asking the UCG members to guide the experts of the Digital Transformation Forum of IDIH to adopt a user's-centred perspective in the development of the "Report Towards an international collaboration in digital health" that will address policy makers in Europe, USA, China, South Korea, Canada, and Japan.

The form was composed of 3 parts:

- 1. UCG members networking
- 2. Briefing note on (priority) topics for the Experts Group
- 3. Reflection on "Horizon Europe", the next EU Framework Program for Research and Innovation (2021-2027)

2.4.6.1 PART 1: UCG members networking

The aim of this part of the Form was to investigate if the participation in IDIH may represent, for the organizations involved in the UCG, an occasion to enhance their networking.

The results of the brief survey conducted in this part of the Form are presented below - starting from the **question 1**. *Did you know already all the organizations above before the UCG meeting of May*





26, 2020? (Figure 13) – and showed that <u>the majority of UCG members didn't know all the organizations attending the meeting.</u>

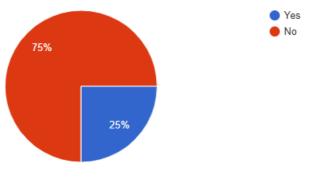


Figure 13 UCG members' networking | Question 1 - Results

Based on answers provided to **question 2**. *If you selected "No", please specify which organization you didn't know before?:*

<u>4 new contact relationships</u> can be reported as opportunities created by the UCG meeting for its members.

Moreover, answers provided to **question 3.** *Have you ever collaborated with one or more of the organizations above?* have showed that <u>the majority of UCG members have never collaborate before</u> with the organizations attending the meeting (Figure 14). The results highlight also previous collaborations between UCG members, that will be further explored by the IDIH Consortium to be eventually improved in the framework of the project, and have been identified by the following to **question 4.** *If you selected "Yes", please specify with which of the above organizations you have already collaborated and in which occasion (e.g. national/EU/international projects or initiatives, awareness raising campaigns, for research and innovation purposes, etc.).*

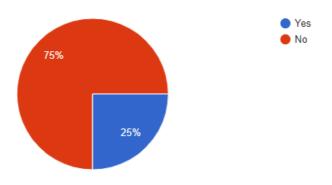


Figure 14 UCG members' networking | Question 3 - results

Finally, the UCG members were also asked to indicate if they ever had **experiences of collaboration with Users' association outside their country/region** (from EU, USA, China, South Korea, Japan, and Canada), other than the members of the UCG (question 5). This allowed the consortium to identify potential new stakeholders to be engaged within IDIH, as it is the case of:





CAHBI - **Centre for Aging + Brain Health Innovation (Canada):** The Centre for Aging + Brain Health Innovation (CABHI) is a solution accelerator focused on driving innovation in the aging and brain health sector. Established in 2015 through funding of \$124 million (CAD), it is the result of the largest investment in brain health and aging in Canadian history, and one of the largest investments of its kind in the world. Through its funding programs, CABHI helps global innovators gain access to key user groups in order to test, develop, validate and accelerate their solutions in the field of aging and brain health.

2.4.6.2 PART 2: Briefing note on (priority) topics for the Experts Group

This section of the form was based on the **IDIH deliverable D2.4 "Briefing note on (priority) topics for the Expert Groups"** available online at <u>https://idih-global.eu/wp-</u> <u>content/uploads/2020/06/D2.4_Briefing-note final.pdf</u> and already presented during the online meeting on May 26, 2020.

The questions that were part of this section of the form were designed around the countries/regions that are relevant in the framework of IDIH (EU, USA, South Korea, China, Japan, Canada). If one or more of these countries/regions wasn't relevant for the UCG members, they were asked to reply "N.A./not applicable".

For all the relevant regions/countries, UCG members were asked to consider their experience with the Funding Agencies and Programmes presented by the IDIH deliverable D2.4 (Part 3. Digital Health and AHA. Policy priorities and topics in the EU and in Strategic Partner Countries) and to:

1. Eventually highlight if there is something missing, by specifying which other Funding Programme/Agency should be considered in the overview presented by D2.4;

On this regard, some interesting insights have been collected on:

Country/Region: China

• There are other ministry level funding agencies in China providing more funding than the Ministry of Science and Technology, such as Ministry of Civil Affairs, Ministry of Industry and Information Technology, National Health Commission.

Country/Region: Canada

- CAHBI Centre for Aging + Brain Health Innovation (Canada
- 2. Reflect on the opportunities for international cooperation offered by those Programmes;

On this regard, some interesting insights have been collected on:





Country/Region: USA

• Opportunities seem poor. We are building a platform for international collaboration given none seemed to exist!

Country/Region: China

- All the ministries have a branch for international cooperation and there are funding opportunities, though some regions are more emphasized than others.
- 3. **Reflect on the engagement of users** (e.g. elderly patients and their families, caregivers, care providers/professionals) in those Programmes: if it is properly foreseen or if there's something that should be improved to ensure a user's-centred approach in Funding Programs and Calls for proposals in those countries/regions;

On this regard, some interesting insights have been collected on:

Country/Region: EU

- Users should be involved from the design of the project stage until the completion of the project.
- A gender perspective should be ensured.
- Users engagement is foreseen, but not properly implemented.

Country/Region: USA

- No, I don't think they engage users very much
- A criteria for funding should be that users are involved from the project concept stage to ensure their needs are properly met.

Country/Region: China

- In 2018, the three ministries mentioned above jointly launched a program to identify a number of successful cases of technologies applied to health aging. So far, a few hundred such cases have been identified and published. One of the key criteria is "Users-Centric".
- Recently Shanghai government published a list of users-centered scenarios of digital application in AHA, which has received a lot of positive reactions. I believe that using these kinds of users-centered application scenarios to guide the development of the technologies will become more and more common in China.

Country/Region: South Korea

• Meaningful involvement of end users as criteria for funding is needed

Country/Region: Japan

• Meaningful involvement of end users as criteria for funding is needed





4. Identify the areas that should be considered as key-priorities for addressing the needs of the users in future policies of those countries/regions in the field of Digital Health for AHA.

On this regard, some interesting insights have been collected on:

Country/Region: EU

- Developing a data model/assessment to account for social determinants of health
- Inform patients and carers on privacy and data ownership
- Gender perspective in R&I in the field
- All priorities are already covered by the various funding schemes. There is just the climate priority that is not duly covered, e.g. with respect to the production and disposal of all technological devices, among others.

Country/Region: USA

- Developing standards of social determinants of health care assessment
- Users well informed on: impact of digital health, the advantages for their health and wellbeing, data protection and ownership.
- Carers should be involved right from the start.
- A gender perspective should be included

Country/Region: South Korea

- Users well informed on: impact of digital health, the advantages for their health and wellbeing, data protection and ownership.
- Carers should be involved right from the start.
- A gender perspective should be included

Country/Region: Japan

- Users well informed on: impact of digital health, the advantages for their health and wellbeing, data protection and ownership.
- Carers should be involved right from the start.
- A gender perspective should be included

Country/Region: China

- Users well informed on: impact of digital health, the advantages for their health and wellbeing, data protection and ownership.
- Carers should be involved right from the start.
- A gender perspective should be included
- Technology usability for elderly is an area getting more and more attentions and is believed to be the foundation for Digital Health for AHA.

Country/Region: Canada

- Users well informed on: impact of digital health, the advantages for their health and wellbeing, data protection and ownership.
- Carers should be involved right from the start.
- A gender perspective should be included





2.4.6.3 PART 3: Reflection on "Horizon Europe"

"Horizon Europe" is the next EU Framework Program for Research and Innovation (2021-2027). This section of the form was based on the publication of the EC "Orientation towards the first Strategic Plan implementing the research and Innovation framework programme Horizon Europe" and, in particular, on its Annex 1 on Key Strategic Orientations in the Cluster 1 HEALTH available here: https://ec.europa.eu/research/pdf/horizon-europe/annex-1.pdf

UCG members were informed that, according to this policy document, R&I interventions in the field of Health under the next 2021-2027 period will be oriented towards the following six health-related challenges.

- 1. Staying healthy in a rapidly changing society
- 2. Living and working in a health-promoting environment
- 3. Tackling diseases and reducing disease burden
- 4. Ensuring access to sustainable and high-quality health care in the EU
- 5. Unlocking the full potential of new tools, technologies and digital solutions for a healthy society
- 6. Maintaining a sustainable and globally competitive health-related industry.

The form asked the UCG members to consider only the challenges 1.) 3.) 5.), considered as the most relevant in the framework of IDIH.

Looking at these Challenges, UCG members were asked to indicate how do they consider the related Key R&I orientations (here below) in terms of less/more relevance with respect to their aims and current priorities, taking into account the needs of the users that they represent.

CHALLENGE 1. Staying healthy in a rapidly changing society:

1.1 Better understanding of human health at various developmental stages and their impact on ageing, including individual factors affecting health and individual resilience to diseases.

1.2 Better understanding of specific health and care needs and better solutions for addressing those needs, including specific needs of people in vulnerable stages of life, people with physical or mental impairments, or of population groups in socioeconomic situations with structural disadvantages.

1.3 Personalised solutions for health promotion and disease prevention of individuals or stratified solutions tailored to groups, including for improved prediction and prevention of diseases before/at birth.

1.4 Development of digital tools applications and other solutions, including social innovation, fostering health literacy and empowering citizens to better manage their own health and wellbeing throughout their life course and to protect them from health threats, including for countering health-related misinformation, manipulation and fraudulent sales of substandard, falsified or inappropriate medicines and illicit drugs.

CHALLENGE 3. Tackling diseases and reducing disease burden





3.1 Better understanding of diseases and their drivers, including the causative links between environmental and behavioural factors and diseases, and better evidence-base for policy-making.

3.2 Better methodologies and diagnostics that allow timely and accurate diagnosis, identification of personalised treatment options and assessment of health outcomes, including for patients with a rare disease.

3.3 Development and validation of effective intervention for better surveillance, prevention, detection, treatment and crisis management of infectious disease threats.

3.4 Innovative health technologies developed and tested in clinical practice, including personalised medicine approaches and use of digital tools to optimise clinical workflows.

3.5 New and advanced therapies for non-communicable diseases, including rare diseases developed in particular for those without approved options, supported by strategies to make them affordable for the public payer.

3.6 Scientific evidence for improved/tailored policies and legal frameworks and to inform major policy initiatives at global level (e.g. WHO Framework Convention on Tobacco Control; UNEA Pollution Implementation Plan).

CHALLENGE 5. Unlocking the full potential of new tools, technologies and digital solutions for a healthy society

5.1 New tools and technologies for biomedical research, prevention, diagnosis and therapy of diseases and tools for monitoring diseases as well as treatment progression are designed, developed, tested or validated for the benefit of patients and the health and care systems, including nanomedicines, advanced therapies, medical devices, digital solutions, Artificial Intelligence applications robotics, -omics and other data-driven interventions and procedures.

5.2 Health data accessibility and interoperability across the EU, including the free flow and secure exchange of health data, leaning on existing research infrastructures as well as the creation of a European health cloud(s) for research purposes.

5.3 Improved risk-benefit ratio of the developed innovative tools, technologies and approaches owing to powerful digital solutions using and processing big data for better detection, diagnosis and monitoring of disease, including real-world data, for efficient value assessment.

5.4 Efficient up-scaling and production systems, including advanced manufacturing techniques, enabling targeted and personalized health interventions.

5.5 Improved health technologies and interventions based on digital solutions, which support timely health information and secure use of health data.

5.6 New data-driven approaches, computer models and -simulations and other digital solutions are developed, translated and optimised for the prevention, health care and person-centred care, including smart data infrastructures and AI-based data analytics.

Based on a reference scale where the value "0" represented "no relevance" and "5" represented "maximum relevance" for the organizations involved, <u>the participants have showed the positioning</u>





represented in Figure 15 with respect to the above mentioned Challenges and the related Key R&I orientations proposed by the EC document.

All the above Key R&I Orientations seemed to be all very relevant for the missions of the UCG organizations, presenting all values greater than 4. However, the Key R&I Orientation reported as the most relevant – with the maximum value assigned - has been:

5.5 Improved health technologies and interventions based on digital solutions, which support timely health information and secure use of health data

The following have reported, in any case, very high values (4.75), suggesting the experts to pay particular attention to these aspects:

1.2 Better understanding of specific health and care needs and better solutions for addressing those needs, including specific needs of people in vulnerable stages of life, people with physical or mental impairments, or of population groups in socioeconomic situations with structural disadvantages.

3.1 Better understanding of diseases and their drivers, including the causative links between environmental and behavioural factors and diseases, and better evidence-base for policy-making.

3.3 Development and validation of effective intervention for better surveillance, prevention, detection, treatment and crisis management of infectious disease threats.

3.4 Innovative health technologies developed and tested in clinical practice, including personalised medicine approaches and use of digital tools to optimise clinical workflows.

3.6 Scientific evidence for improved/tailored policies and legal frameworks and to inform major policy initiatives at global level (e.g. WHO Framework Convention on Tobacco Control; UNEA Pollution Implementation Plan).

5.1 New tools and technologies for biomedical research, prevention, diagnosis and therapy of diseases and tools for monitoring diseases as well as treatment progression are designed, developed, tested or validated for the benefit of patients and the health and care systems, including nanomedicines, advanced therapies, medical devices, digital solutions, Artificial Intelligence applications robotics, omics and other data-driven interventions and procedures.

5.6 New data-driven approaches, computer models and -simulations and other digital solutions are developed, translated and optimised for the prevention, health care and person-centred care, including smart data infrastructures and AI-based data analytics.





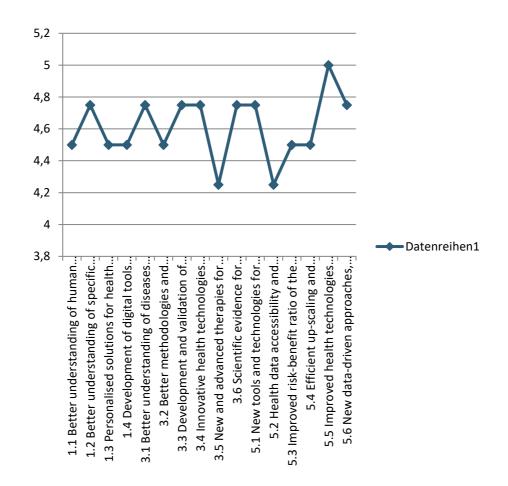


Figure 15 UCG positioning with respect to the Key R&I Orientations (from the Annex 1 - Cluster "Health")

3 Conclusions & Next Steps

During the works of the 1st UCG meeting, **UCG members** – umbrella organizations operating at regional/country level in the EU and some Strategic Partner Countries (namely USA, China, Japan, Canada), representing the users of R&I solutions dealing with Digital Health for AHA (mainly the Elderly, Public Health Institutions and Care Providers/Professionals) - **have provided valuable starting inputs to the work of the experts within the Forum, allowing them to address the 4 key Strategic Topics** (Preventive care, Integrated care, Independent and connected living, Inclusive living) **in the light of a user-centred approach.**

In particular, UCG members have contributed to improve the comprehensiveness and the understanding of the overview of funding agencies and programmes dealing with Digital health for AHA in the EU and in Strategic Partner Countries, that has been presented as part of the D2.4 *Briefing note on (priority) topics for the Expert Groups.*

Several other aspects - that are also relevant for the work of the EGs – have been highlighted by the UCG members and concern, for instance, the engagement of users (e.g. elderly patients and their families, caregivers, care providers/professionals) as it is conceived in those funding programme and/or it is addressed by projects at implementation level. On this regard, **UCG members have pointed out how users are often not enough involved from the design phase of the project, and should be**





properly engaged during the whole project life cycle; or how a gender perspective is often missing in R&I projects, from the scientific point of view and in needs analysis, testing and validation.

On this regard, as a concern of UCG members, the Development of a data model/assessment to account for social determinants of health, has been identified as key priority for addressing the needs of the users in future policies of different countries/regions.

On the other hand, looking at the UCG positioning with respect to the of the EC proposal for the next multiannual framework program for research and innovation, Improved *health technologies and interventions based on digital solutions, which support timely health information and secure use of health data* has resulted as the most relevant topic for the UCG members, among those proposed as relevant "Key R&I orientations" by the EC document.

Finally, very interesting and valuable publications, project and initiatives have been indicated as relevant by the UCG members and will be brought to the attention of the EGs for their work within the Digital Health Transformation Forum. On this regard, the IDIH consortium will look for potential synergies to be activated with such projects and initiatives.

The 1st UCG meeting has been the occasion for the 5 organizations involved to get more familiar with the IDIH project and to better focus on the UCG role within the Digital Health Transformation Forum. Moreover, the UCG members had the opportunities to present themselves and, in most cases, start developing contacts for the first time with certain organizations, by sharing experiences, projects and initiatives and activating a mutual learning process that will also contribute to enhance their networking potential or represent interesting occasions for further future collaborations.

On this regard, UCG members have showed to have experience in R&I projects mostly at European level and to be less familiar with International Cooperation projects. In this perspective, IDIH may contribute to develop the networking of UCG organizations at international level and, in particular, between the EU and the Strategic Partner Countries.

The 1st UCG meeting was supposed to be held in Helsinki, back-to-back with the first EG meeting. This would had allowed a real exchange with the experts and, thus, a more synergic work between UCG and the 4 EGs. Due to the limitations imposed by COVID-19 pandemic containment and management measures, 1st EGs meeting has been rescheduled as virtual and split in 4 different online meetings, including also remote and independent work session by the experts, in order to manage the dense agenda previously planned for the meeting.

Therefore, the 1st UCG meeting has been re-designed as well as virtual, including an *online-plenary* meeting and a follow up phase allowing the UCG members to finalize their contribution independently and remotely. **Despite these new conditions, the meeting has enabled the IDIH consortium to collect fundamental insights from the participants, that will be helpful to improve the project capacity to reach significant results.**

As next steps concerning UCG, its members will be kept up to date on the works of the EGs: the documents resulted from the 1st EGs meeting will be shared with UCG members who will be eventually asked to provide feedbacks.





General inputs on IDIH activities may also be requested, especially to ensure involvement of all relevant stakeholders (researchers, technology experts, innovation facilitators, representatives from industry, other user associations, advocacy groups, and policy makers).

The next meeting of the group will be held virtually after the 2nd EG meeting (June 2021); in this occasion, a more structured contribution may be asked to UCG members to guide the experts in the development of the successive iterations (D3.6/D3.7) of the report *Towards an international collaboration in digital health*.



