SHAPES

Smart and **H**ealthy **A**geing
through **P**eople **E**ngaging in supporting **S**ystems

D10.6 – SHAPES Dialogue Workshops – V1 – V1.0

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Revision History

Table 1 Revision History

Revision #	Date	Editor	Comments
0.1	15/05/2020	Luisa Buzelli (AGE)	Main author establishing ToC
0.2	15/11/2020	Ilenia Gheno (AGE)	Continue editing and inserting contributions
0.3	22/06/2021	Ilenia Gheno, Borja Arrue Astrain (AGE)	Continue editing and inserting contributions
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0.5	09/11/2021	Barbara Guerra (EDGE)	Internal review
0.6	11/11/2021	Lucia D'Arino (WFBD)	Internal review
0.7	19/11/2021	Ilenia Gheno (AGE)	Review based on comments
0.8	25/11/2021	Ilenia Gheno (AGE)	Review based on comments
0.9	26/11/2021	Ilenia Gheno (AGE)	Review based on comments
1.0	29/11/2021	Ilenia Gheno (AGE)	Finalisation

Table of Contributors

Table 2 Deliverable Contributors

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List of figures	Ilenia Gheno (AGE)
List of tables	Ilenia Gheno (AGE)
Executive summary	Ilenia Gheno (AGE)
Introduction	Luisa Buzelli, Ilenia Gheno (AGE)
T10.5 Shapes Dialogue Workshops	Luisa Buzelli, Ilenia Gheno (AGE), Niamh Redmond (NUIM)
1st Dialogue Workshop on concept validation	Luisa Buzelli, Ilenia Gheno (AGE), Markéta Pešoutová (UP)
2nd Dialogue Workshop on integrated care models	Ilenia Gheno, Borja Arrue (AGE), Philip Franke (CCS), Richard Lombard Vance (NUIM)
3rd Dialogue Workshop on technological platforms	Borja Arrue, Ilenia Gheno (AGE)
4th Dialogue Workshop on lifeworld of the individuals	Ilenia Gheno (AGE)
Conclusions	Ilenia Gheno (AGE)
Ethical check list	Ilenia Gheno (AGE)
Reference	Ilenia Gheno (AGE)
Annexes	Ilenia Gheno (AGE)

Table of Acronyms and Abbreviations

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Table 3 Deliverable Contributors

Acronym	Full Term
AHA	Active and Healthy Ageing
AELTD	Access Earth Limited
AGE	AGE Platform Europe
AI	Artificial Intelligence
CCS	Carus Consilium Sachsen Gmbh
CRPD	United Nations Convention on the Rights of Persons with Disabilities
D	Deliverable
DoA	Description of Action
DW	Dialogue Workshop(s)
EU	European Union
EUD	European Union of the Deaf
FhG	Fraunhofer Gesellschaft für Angewandte Forschung
GA	Grant Agreement
H&C	Health and Care
IA	Innovation Action
KPI	Key Performance Indicator
LAUREA	Laurea University of Applied Sciences
NUIM	National University of Ireland Maynooth
SHAPES	Smart and Healthy Ageing through People Engaging in Supportive Systems
T	Task
UAVR	University of Aveiro
UCLM	Universidad de Castilla-La Mancha
UP	Palacký University Olomouc
WFDB	The World Federation of the Deafblind
WHO	World Health Organization
WP	Work Package

Keywords

Engagement, dialogue, innovative solutions, participation, synergies, accessibility, older people, active and healthy ageing.

Disclaimer

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Executive Summary

This deliverable reports on the Dialogue Workshops organised by the SHAPES project to target the project's key stakeholders and promote the adoption of the SHAPES Platform and Digital Solutions across Europe.

The document summarises the preparation, organisation, the various contents, feedback, and results of the four Dialogue Workshops implemented from the beginning of the project (November 2019) until October 2021. Overall, these events gathered over 400 participants from across the globe to discuss relevant challenges in the health and active ageing domain.

Through this work, the reader can understand the synergies exploited to set up four virtual interactive events addressed to different stakeholders, and the main outcomes of each event, linking them with the SHAPES constellation of tasks and objectives.

This deliverable is structured in different sections.

The first section provides the overview of the main task (T10.5) and underlines the roles, aims, scopes and target groups of the performed Dialogue Workshops.

Secondly, the document details each implemented Dialogue Workshops, describing the preparation and organisational phases, diving into the content overview and outlining the main results registered by the workshops' organisers.

The final conclusions hand over the baton to the organisers of the next editions of the dialogue workshop, for leveraging on the current experience.

The present deliverable can be coupled with deliverable D10.4 – Awareness Raising Campaigns, which reports on four social media campaigns sustaining the topics of the various Dialogue Workshops and the involvement of stakeholders ahead of each event.

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1 Introduction

With the aim of setting up a dialogue with the various stakeholders[1] of the project, SHAPES has implemented a total of eight Dialogue Workshops, four of which took place from the project start until October 2021, and therefore are covered by the present document.

The Dialogue Workshops aim at effectively reaching out to the SHAPES target groups to:

- Reinforce connections between stakeholders;
- Facilitate networking among the diverse audience;
- Promote the project's objectives and results;
- Develop new synergies and cross-fertilisation among similar projects, fruitful for knowledge sharing;
- Demonstrate and validate the Platform developed withing the SHAPES Consortium;
- Enable its adoption across Europe.

1.1 Rationale and purpose of the deliverable

The Dialogue Workshops were conceived as important moments for SHAPES to share the project's results and to engage new stakeholders and enlarge the SHAPES' network.

This deliverable explains in detail the objectives, the structures and the results of the Dialogue Workshops performed from November 2020 until October 2021.

The deliverable covers the following topics:

- main organisational details (including workshops' logistics, invitations and structure);
- main contributions from speakers and attendees;
- overview of the invited external stakeholders;
- the workshop's results and impact.

1.2 Key inputs and outputs

This deliverable provides further details on the Dialogue Workshops, which were firstly introduced and explained in deliverable D10.1. Moreover, this deliverable relates to deliverable D10.4 – Awareness Campaigns for Citizens Engagement; and incorporates some of the results presented in it.

[1] For the stakeholders' list, check chapter 1.2 "1.2 Dialogue Workshops' target groups"

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SHAPES Awareness Campaigns and Dialogue Workshops have been implemented back-to-back, and the strong linkages and synergies between these two tasks have been highlighted in their respective deliverables.

1.3 Structure of the document

The D10.6 – SHAPES Dialogue Workshops – Report 1 presents in detail the organization, the event and the results for each one of the Dialogue Workshops implemented from the beginning of the project until today.

After giving a general overview of the SHAPES Dialogue Workshops' preparation and organisation, the document gives detailed information on each of the Dialogue Workshops, reporting on the main discussions and feedback, including details on the main stakeholders involved, and results achieved.

This deliverable reports on the four workshops organised between M1 and M24.

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2 Task 10.5 - SHAPES Dialogue Workshops

T10.5 is dedicated to the preparation, organisation, conduct and assessment of the SHAPES Dialogue Workshops.

The SHAPES Consortium hosts 8 Dialogue Workshops gathering players and stakeholders of the SHAPES Ecosystem to present projects' achievements and findings and collect valuable feedback. Each workshop covers different themes, as shown in section 2.1.

2.1 The role of SHAPES Dialogue Workshops

SHAPES has developed a Communication and Dissemination Strategy to approach different stakeholders, targeting specific audience communities. Within this strategy, Dialogue Workshops have been considered as the means to bring together partners within the SHAPES consortium and their visions, as well as external stakeholders.

Dialogue Workshops are meant to foster the gathering of large audiences and to enable the participation of relevant stakeholders in the SHAPES development and validation activities. By fostering dialogue between different stakeholders, the purpose of the SHAPES Dialogue Workshops is to support and raise awareness on active and healthy ageing and independent living, to discuss the best approaches for integrated care, to promote the audience's understanding and adoption of the SHAPES Platform and ecosystem, and to support the digital transformation of the health and care delivery in Europe.

To maximise their impact and respect and value the diversity across Europe, the Dialogue Workshops are hosted by partners based in different countries and are scheduled according to the project's progress and achievements with the intention to disseminate the latest-to-date project results.

Table 4 List of the SHAPES DW across the project lifespan

Workshop	Name	Partner	Dates	Tasks
1	SHAPES Concept Validation Workshop	UP, Czech Republic	M6	Use cases V1 (D2.5)
2	SHAPES Integrated Care Models Workshop	CCS, Germany	M12	Ecological organisation models (D3.1)

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3	SHAPES Technological Platform Workshop	UCLM, Spain	M18	User requirement (D3.9) and Architecture (D4.1)
4	The Lifeworld of Smart Healthy Ageing Individuals Workshop	AGE, EU/Belgium	M24	Lifeworld of Individuals (T2.1) and empowerment (T2.4)
5	SHAPES Scaling up Integrated Care in Europe	AIAS, Italy	M30	Improved care delivery (D3.3)
6	SHAPES Digital Solutions Empowering Older Individuals	UAVR, Portugal	M36	Empowerment (T2.4) and Digital Solutions (D5.4)
7	SHAPES Across Europe - Results of a Large-Scale Pilot Campaign	DYPE, Greece	M42	Pilot Campaign (D6.8 and D6.9)
8	SHAPES Final Workshop	NUIM, Ireland	M48	Project completion

Seven Awareness Campaigns[2] towards targeted audiences are implemented ahead of each Dialogue Workshops. These campaigns are meant to involve the community and civil society organisations within SHAPES and to sustain the debates at stake at the Dialogue Workshops.

2.2 The SHAPES Dialogue Workshops' target groups

In line with the stakeholders identified in the SHAPES Communication and the Dissemination Plan (Deliverable D10.1 delivered in M4), the Dialogue Workshops reached out to the following groups:

- **Political**
  Decision-makers, regulatory bodies and policymakers at local, regional, national and European levels, including Members of the European Parliament, EU Commission and other EU institutions.

[2] More information on the Awareness Campaign in the deliverable D10. 4 (under submission)

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- **Practitioners**
  Caregivers, H&C professionals and public and private H&C service providers.

- **Academia**
  Health research community from universities and research laboratories involved in innovative research within healthcare, students enrolled in the social and health care sector, AHA processes, eHealth and assistive technologies, H&C and policy scientific domains.

- **Industry**
  Large industry and SMEs working in Health care, eHealth.

- **Services**
  Insurance companies, travel agents, fitness centres.

- **Societal**
  European, national and regional users' community; civil society organizations including organisations of persons with disabilities (deaf and deafblind organisations); general public; media.

The above-mentioned stakeholders comprise different audiences to whom SHAPES developments and results are relevant. Some crucial target audiences which have been taken part to SHAPES Dialogue Workshops consist of:

- **The End-users community** – a target audience comprising public and private health and social care service providers, non-profit associations and citizens that have the required knowledge and skills to support SHAPES's development and endorse its early adoption: Therefore, it is a target audience that is crucial to SHAPES's ambitions.

- **The SHAPES Consortium** – an internal target audience that must always be kept fully informed about communication procedures, planned activities and existing resources, to ensure consistent, accessible and effective communication of the SHAPES information and results.

- **The European stakeholder community** – a target audience that is relevant in order to communicate the Action's evolution and raise awareness of SHAPES' research, objectives and innovative results, as well as to trigger collaboration that enables SHAPES to exploit synergies with similar or complementary European initiatives.

- **The Scientific community** – a target audience that is important to echo SHAPES's scientific results and achievements, contributing to their transferability to other knowledge and application areas (e.g., knowledge translation).

- **The Industrial community** – a target audience that comprises the large corporations and small businesses that operate in the healthcare services sector and associated

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value chain and would be instrumental in fostering the early adoption of SHAPES's results;

- **The Decision-makers community** – a target audience that is in the privileged governmental/authority position to support SHAPES's predicted results and drive its early adoption;

- **The Policy-makers community** – a target audience that is relevant to involve throughout the Action both from the regulatory and standardisation perspectives, considering all synergies SHAPES rises within this community, building recommendations for new health and care service delivery standards;

- **The Key Opinion Leaders** – a target audience that is vital for SHAPES's success and early adoption, as it is formed by personalities who are seen as experts in their field of expertise (health and care service delivery, active and healthy ageing) and therefore, influence the behaviour or decision-making of peers in these fields. The approval of Key Opinion Leaders is seen to have more influence than the media, due to its trustworthiness.

- **The Media community** – a target audience that facilitates global awareness on the SHAPES IA and would be instrumental to SHAPES stakeholders' involvement activity, providing a more public dimension and a broader reach to the communication effort of SHAPES's results.

- **Citizens** – a target audience that contributes to steering the SHAPES Action as part of the end-users' community and facilitates the development of global public awareness on the SHAPES Action, being addressed by printed and online channels and by the SHAPES partners' communication activities with local/national media.

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3 1st SHAPES Dialogue Workshop on Concept Validation

In line with the GA, the first SHAPES Dialogue Workshop "Concept Validation Workshop" focused on the Action, the vision and concept of the Platform and Ecosystem and the SHAPES personas and use cases.

3.1 Workshop's preparation

Palacký University (UP) in Olomouc, is the partner of the SHAPES Consortium leading WP2 (Understanding the Lifeworld of ageing individuals and Improving Smart and Healthy living), and responsible for the organization of the workshop with the support of AGE, leader of WP10 (SHAPES Outreach and Awareness Generation), in M6.

The workshop took place virtually on the 12th of May 2020.

AGE and UP started to collaborate in early February to organize the workshop, which was supposed to take place in the Czech Republic for two days (12 and 13 May). However, the health emergency related to COVID-19 pandemic made it impossible to physically gather the workshop's participants in the host country. Therefore, the SHAPES Consortium decided to organise the event on-line.

To involve as many stakeholders as possible despite the circumstances, an **Awareness Campaign** run from mid-April until May 15th (see deliverable D10.4).

Each week of the awareness campaign, which relied on social media and the SHAPES website, focused on each one of the topics which would be addressed during the dialogue workshop, namely:

- The SHAPES project and its key messages;
- The ethics requirements for the technological platform and digital solutions;
- The co-creation of a think-tank for European Integrated Care;
- The conduct of a Foresight exercise, thinking about future technologies for the users of the future;
- The SHAPES work involving the Human dimension: the SHAPES use cases, personas and scenarios.

For each topic, videos, key messages, news, reading materials and presentations were shared on the SHAPES website and social media channels.

After having opted for the EU Survey registration form to comply with the EC suggestions, and having established an invitation letter, the whole SHAPES consortium was encouraged to disseminate the letter and reach out to stakeholders with the invitation since mid-March 2020.

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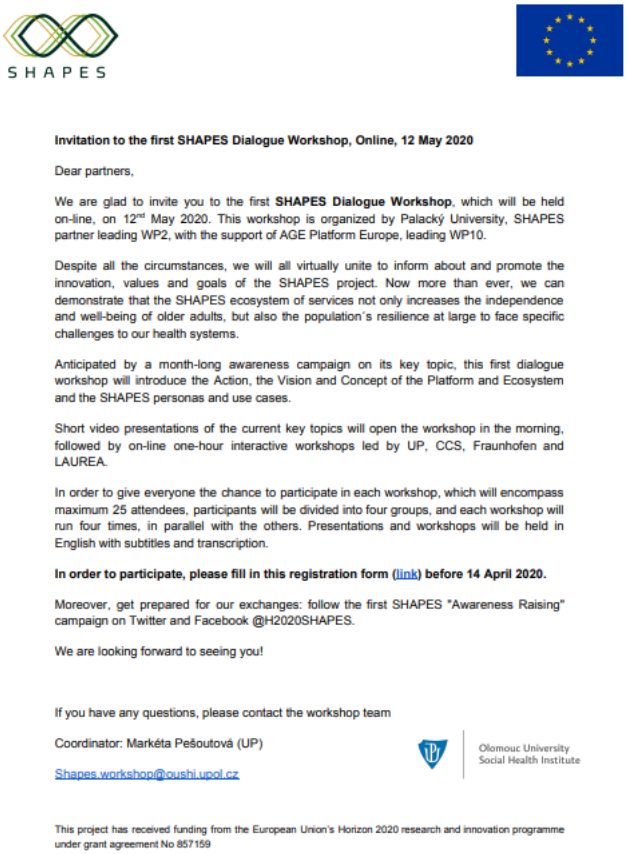

Invitation to the first SHAPES Dialogue Workshop, Online, 12 May 2020

Dear partners,

We are glad to invite you to the first **SHAPES Dialogue Workshop**, which will be held on-line, on 12nd May 2020. This workshop is organized by Palacký University, SHAPES partner leading WP2, with the support of AGE Platform Europe, leading WP10.

Despite all the circumstances, we will all virtually unite to inform about and promote the innovation, values and goals of the SHAPES project. Now more than ever, we can demonstrate that the SHAPES ecosystem of services not only increases the independence and well-being of older adults, but also the population´s resilience at large to face specific challenges to our health systems.

Anticipated by a month-long awareness campaign on its key topic, this first dialogue workshop will introduce the Action, the Vision and Concept of the Platform and Ecosystem and the SHAPES personas and use cases.

Short video presentations of the current key topics will open the workshop in the morning, followed by on-line one-hour interactive workshops led by UP, CCS, Fraunhofen and LAUREA.

In order to give everyone the chance to participate in each workshop, which will encompass maximum 25 attendees, participants will be divided into four groups, and each workshop will run four times, in parallel with the others. Presentations and workshops will be held in English with subtitles and transcription.

In order to participate, please fill in this registration form (link) before 14 April 2020.

Moreover, get prepared for our exchanges: follow the first SHAPES "Awareness Raising" campaign on Twitter and Facebook @H2020SHAPES.

We are looking forward to seeing you!

If you have any questions, please contact the workshop team

Coordinator: Markéta Pešoutová (UP)

Shapes.workshop@oushi.upol.cz

Olomouc University Social Health Institute

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Figure 1: Printed and e-mailed invitation to DW no. 1

3.2 Accessibility

Participants were asked about their accessibility requirements ahead of the workshop to be able to fully participate. Therefore, two groups with specific accessibility requirements were created. One group was provided with simultaneous transcription to the Czech language. The second group was supported with International Sign interpretation during the plenary talks. Unfortunately, only live captioning was available during the group discussions, allowing sign language users to participate only via the chat box.

A post assessment of the workshop's accessibility was voluntarily and jointly performed by the SHAPES partners WFDB and EUD, providing useful feedback, resources and guidelines to improve the accessibility of future workshops and ensure the participation of all. That feedback is enclosed in the "SHAPES Accessibility Report" provided by WFDB and EUD after the event.

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3.3 Workshop's structure

Aware of the effort required to host and to participate in a workshop fully conducted online, the event was conceived to last one day only (from 9AM to 6PM). A link to an online registration form was made available both on SHAPES's social media channels and website.

While the Workshop's morning was dedicated to present the already referred topics, through previously recorded YouTube videos (available here), aimed at limiting connectivity problems, the Workshop's afternoon allowed space for ample discussion.

Participants were assigned to 4 smaller groups of around 25 participants each, ensuring a certain degree of diversity among the target stakeholders in each break-out room. The four sessions, run by LAUREA, CCS, Fraunhofer and UP, ran parallelly on the Zoom platform, four times each. At 5.30 PM all participants reconvened in the virtual plenary sessions to discuss the results achieved and formally close the Dialogue Workshop.

The programme for the SHAPES Concept Validation Workshop is presented here:

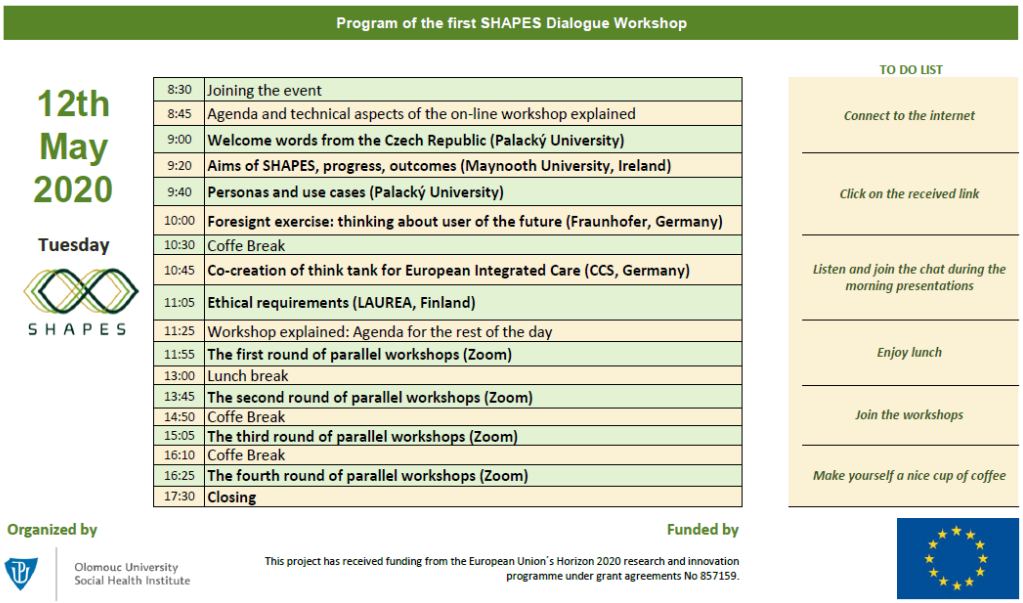

Figure 2: Programme of the Workshop

3.4 Workshop's participants

Overall, 123 participants signed to attend the workshop. Around 100 people watched the YouTube streaming. Eventually, around 80 people attended the afternoon sessions.

Participants included SHAPES partners, academics, students, NGO representatives from all over

Europe. About 14% of attendees belonged to civil societies or were private persons, representatives from the health and care sector gathered 13% of the overall audience, while 11% of participants came from the industrial sectors. The vast majority of the audience came from the research world of academia.

3.5 Overview of contents

The SHAPES Concept Validation Workshop helped to build awareness concerning the SHAPES vision and to validate the starting blocks of the SHAPES work, focusing on the human and ethical dimensions of the project and contributing to build the SHAPES ecosystem and forward-thinking.

To support the outreach efforts, each speaker uploaded invitation videos on YouTube, explaining the topics at stake for SHAPES and for the society at large.

3.5.1 Validation session from LAUREA

LAUREA leads WP8 “SHAPES Legal, Ethics, Privacy and Fundamental Rights Protection”. During the SHAPES Concept Validation Workshop, representatives Sari Sarlio-Siintola and Nina Alapuranen presented SHAPES’s insights on the Legal, Ethics, Privacy and Fundamental Rights Protection aspects.

LAUREA focused on the explanation of the ethical requirements considered in building the SHAPES vision and Platform, concerning Fundamental Rights and Human Capabilities, Privacy and Data Protection, as well as the ethics of Artificial Intelligence in the SHAPES context. In fact, all these requirements have an impact on SHAPES technology, user processes, business and governance models and the entire SHAPES ecosystem.

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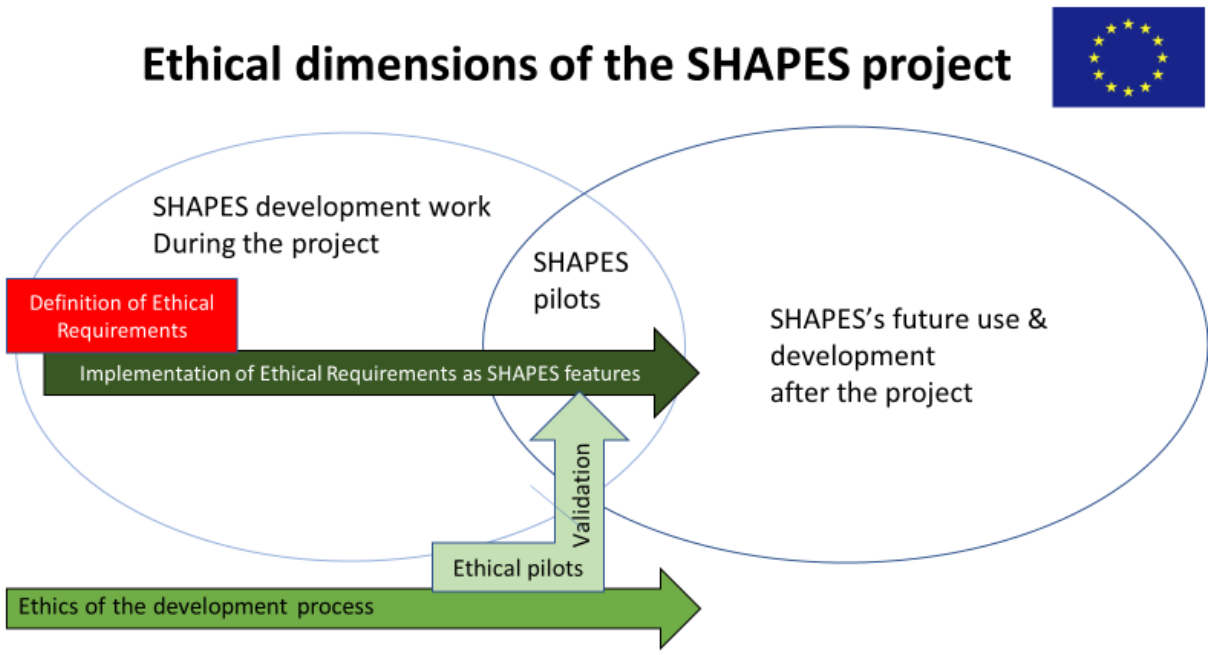

Figure 3: Ethical Dimensions of the SHAPES Project

During the Dialogue Workshop, LAUREA collected valuable feedback from stakeholders on the ethical challenges and opportunities for the SHAPES digital solutions and services ecosystem. These outputs were used both in setting the ethical requirements for the SHAPES technologies and in assessing the ethical risks of the SHAPES Platform. In addition, participants were asked about the importance of ethical requirements. Ethical requirements were seen as necessary alongside end-user requirements to enable SHAPES to create a sustainable solution. Ethics was seen less as a risk management issue, but more as an opportunity to create innovation, which becomes a positive result for end-users and society.

An example of a small working group's output during the workshop is presented next.

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Ethical Challenge	> Ethical requirement needed
Facial Recognition	Security. Safety Issues. Monitoring of all facial feelings/movements. Consent with regard to which facial emotions are monitored?
Remote In home Wellbeing	Consent. Ensure loneliness is not increased. Visitors in the home. What type of data is being transferred and to whom. Role of the caregiver – increased workload?
Using Robots	Consent. Increase loneliness. Limit the interaction with actual humans. Transparency in how the decision making is processed/how the device works. What do the sensors sense?? Autonomy of the individual. Role of the caregiver – increased workload? Caregiver might rely solely on data from tech as oppose to listening to participant.
Retaining Autonomy of the individual.	
How information is provided to participants. Is it accessible and easy to understand. Safety/Privacy should be easily understood.	
Health Data. How is it shared and with whom? Is it anonymized? Are medical records going to be shared – if so, with technology companies?	GDPR. This should all be explained within consenting participants to the research.

Figure 4: LAUREA - Small working group's output

3.5.2 Validation session from CCS

CCS leads WP9 “SHAPES Ecosystem Building”, which focuses on the SHAPES Ecosystem.

This workshop explored the worth, benefits and shortcomings of building an ecosystem by using the co-creation of SHAPES Pilot Theme 1 example, dedicated to smart living environments for healthy ageing at home. The discussion involved experts from the digital healthcare ecosystem, representing health authorities and government, academia, industry and civil society organizations.

In this joint discussion, Olaf Mueller, the managing director of the Carus Consilium Saxony, looked for insights into the needs of older people in order to highlight a set of solutions that could enable and support a sustainable and independent life for them.

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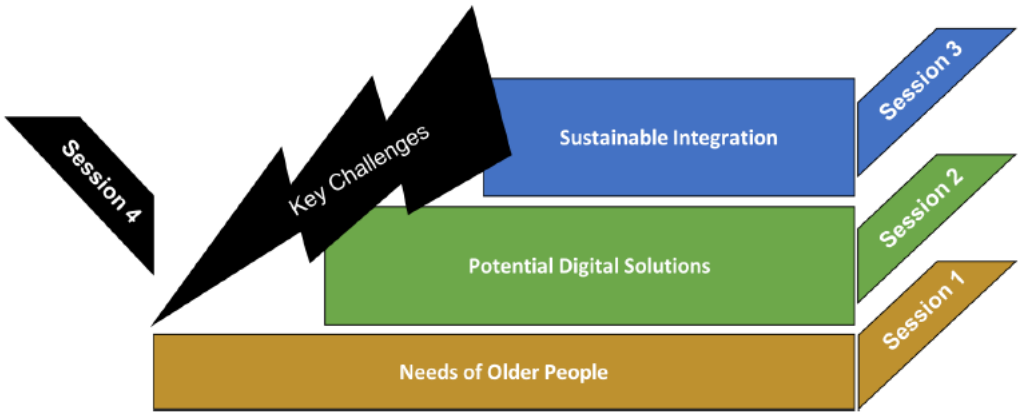

Figure 5: Main topics for discussion during the session hosted by CCS

During this session of the first SHAPES Dialogue Workshop, CCS performed four separate virtual meetings that built on one another and dealt with the following topics: (1) the needs of older people in rural areas, (2) the potential of digital solutions, (3) how to sustainably integrate digital solutions, and (4) the key challenges for a successful implementation of the SHAPES future platform.

During the workshop, CCS collected several feedback and ideas useful for going ahead with the work in WP9 and worked it further into the identification of older people's needs:

Figure 6: Needs of older people identified during the session hosted by CCS

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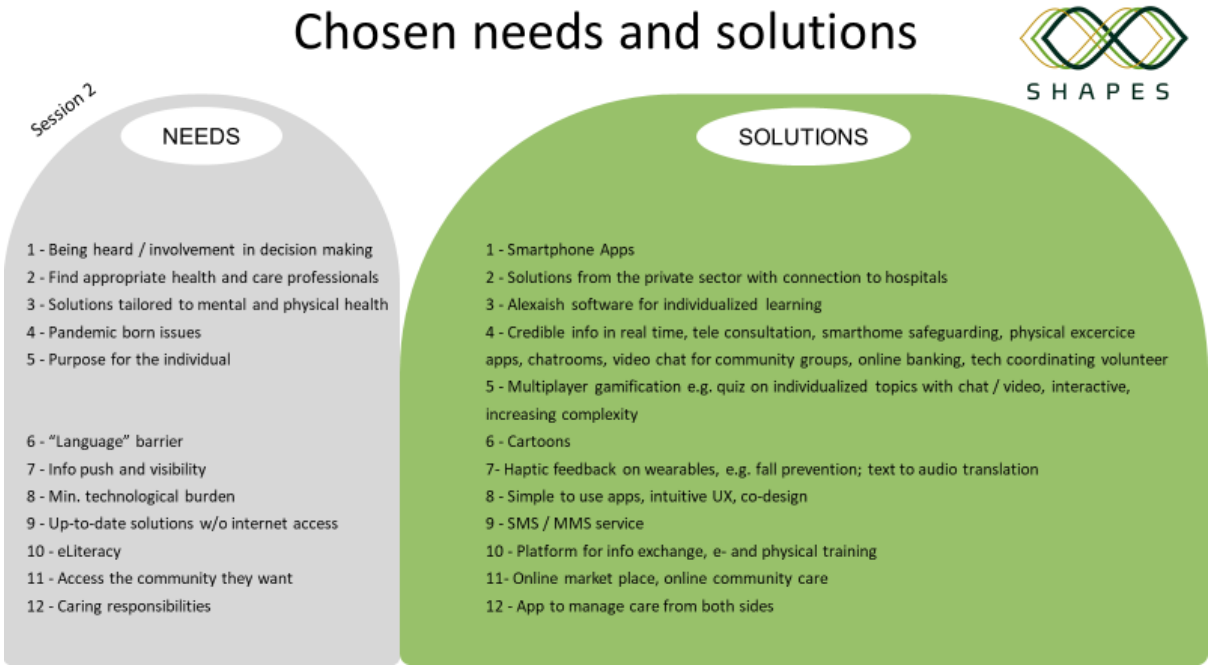

Figure 7: Chosen needs and solutions identified during the session hosted by CCS

Figure 8: Barriers for integration of digital solutions identified during the session hosted by CCS

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3.5.3 Validation session from Fraunhofer

The SHAPES partner Fraunhofer, leading WP6 “SHAPES Pan-European Pilot Campaign”, hosted a session that performed a foresight exercise. Explained by representatives Diana Freudendahl and Simone Schmitz, the discussion aimed at keeping a future perspective in mind while identifying technology gaps and being able to plan for the future of health and care delivery.

A time horizon of around ten years was selected for this foresight approach. Hence, the foresight exercise addressed viable technological solutions and important influencing factors in the context of SHAPES up to the year 2030.

During the first SHAPES Dialogue Workshop, the following seven SHAPES pilots’ topics and corresponding personas were used as sorting criteria for the foresight exercise:

- Smart Living Environment for Healthy Ageing at Home;
- Improving In-Home and Community-based Care;
- Medicine Control and Optimization;
- Psycho-social and Cognitive Stimulation Promoting Wellbeing;
- Caring for Older Individuals with Neurodegenerative Diseases;
- Physical Rehabilitation at Home;
- Cross-border Health Data Exchange Supporting Mobility and Accessibility for Older Individuals.

The gathered feedback received from participants was then organised as cards on influencing factors and technologies to consider in the future of health and care systems in Europe. These cards serve to provide information and inspiration to other work packages in SHAPES. Additionally, these cards are used as information source for relevant stakeholders, including individuals and organisations that are not directly involved in SHAPES, but are interested in future technologies concerning smart and healthy ageing:

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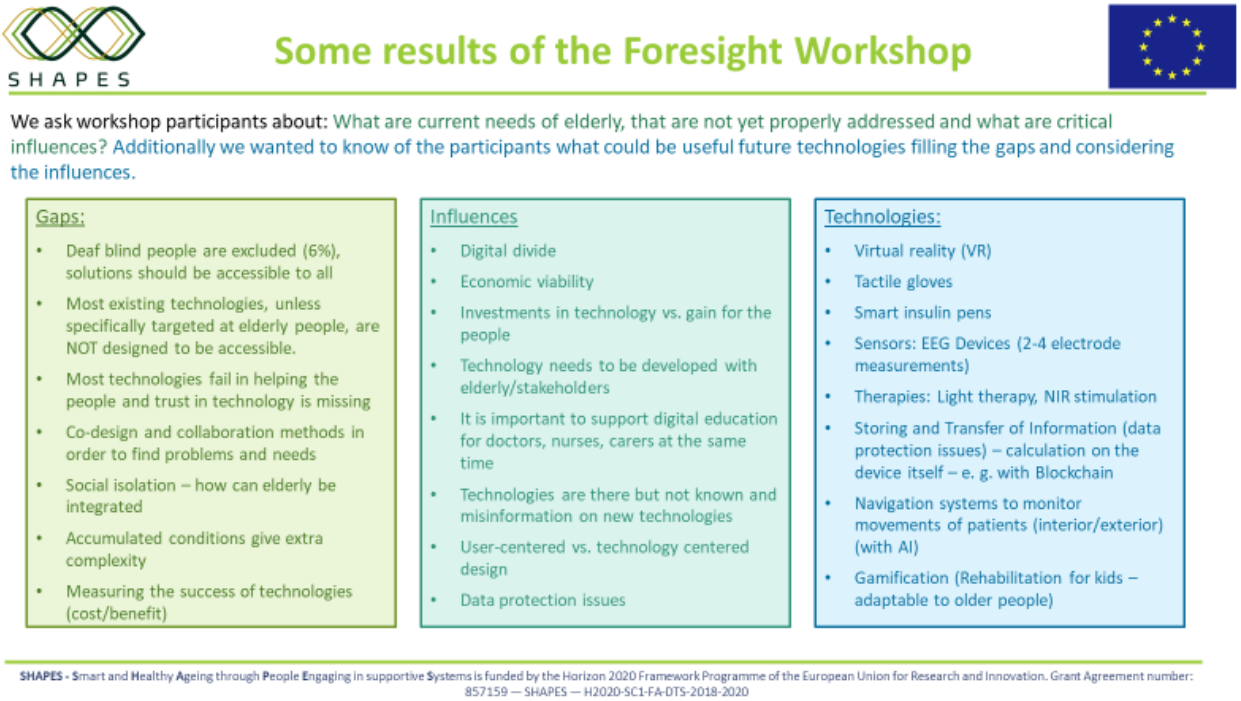

Figure 9: Results from the session hosted by Fraunhofer

3.5.4 Validation session from UP

As the leader of WP2, the University Palacký in Olomouc (UP) presented its work in an interactive session.

During the first six months of the project, the UP team led the SHAPES team in the development of key personas, depicting older adults and informal caregivers and covering the stories of their lives, daily challenges and their needs that might be addressed through technology. Persona, known also as "user persona", is a detailed description of a fictional person (often a composite of real individuals) used to communicate the key motivations, concerns, and interests of a user group. Personas include fictitious characters described in narrative form to help solve design questions. Personas enable designers to better focus on primary users, especially on their behavioural patterns and user needs. They provide a basic prototype of persons/users for the interaction of a person with a product/digital solution. Data for the SHAPES personas were gathered from different sources.

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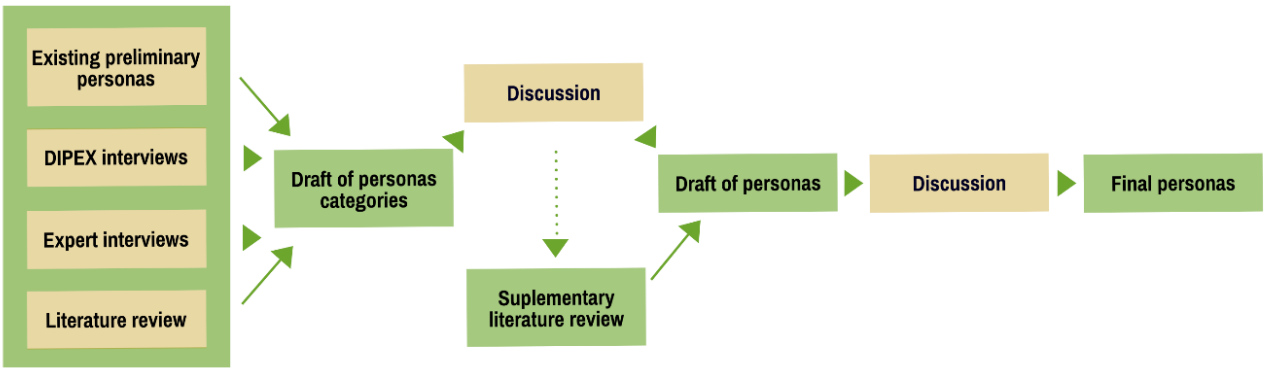

Figure 10: Gathered data for defining personas

During the SHAPES Dialogue Workshop, representatives Eva Dubovská presented several SHAPES personas and their different stories. Participants shared their ideas and insights on how to support the needs associated with the presented personas (available in a dedicated section of SHAPES website).

The goal of the session was to get to know the SHAPES personas to brainstorm and create ideas of:

- What does the persona need in their life?
- What are their everyday challenges?
- What technologies could be beneficial for them?

After being introduced to the SHAPES personas and the personas methodology applied in SHAPES, participants worked in small groups to brainstorm on individual persona‘s needs and possible solutions. Ideas from each working group were then presented and discussed in plenary.

Through an open discussion, UP collected the following possible solutions when dealing with cases represented by the SHAPES personas developed:

1. Support peer groups and networks for older adults with multiple chronic conditions;
2. Create networks for matching volunteers with isolated older adults based on interests, favourite activities and places;
3. Help older adults with musculoskeletal disorders to get easily accessible online physiotherapy and training;
4. Support peer groups for informal caregivers and also create a new persona solely describing informal caregivers;
5. Consider additional technical solutions that could, to some extent, replace interpreter-guides for deafblind older adults.

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3.6 Results

The feedback gathered during this first edition of the SHAPES DW addressed both the workshop's organisation, its implementation and impact.

The effort placed to convert a two-day face-to-face workshop into a one-day virtual event was portrait in a detailed guideline, developed by UP for the whole SHAPES consortium. Such booklet (see Annex I) is a precious legacy of this first DW and helped the preparation and logistics of the following SHAPES DW editions.

An evaluation form was also distributed by UP after the event, gathering interesting feedback and especially the great appreciation of the audience for the quality of the interventions and the smooth running of the overall workshop.

In terms of impact, each organiser of the parallel sub-sessions was greatly pleased with the feedback received by external participants. Those inputs, collected by each partner, informed their respective deliverables and their current work, i.e. by consolidating the ethical work of the project, by reinforcing and validating the current use cases and personas.

Equally successful was the outreach performance: thanks to the effort of involving a broad variety of stakeholders in the event, the first SHAPES DW managed to attract new voices for the SHAPES ecosystem, while its dynamic formulation allowed those voices to be captured and directly impact on the SHAPES project's work. Among the positive spill-out effects of the Workshop, the visibility of SHAPES among partners in Czech Republic should be noted, thus contributing to make the project (and its European funds) more attractive to Eastern European stakeholders.

Workshop talks remain available in YouTube, in SHAPES's channel. All materials can be accessed via the SHAPES website, in which a web article as a follow-up of the event can also be found.

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4 2nd SHAPES Dialogue Workshop on Integrated Care Models

In line with the GA, the second SHAPES Dialogue Workshop, entitled SHAPES Integrated Care Models Workshop, discussed integrated care models, considering the SHAPES architecture and user requirements for a Platform supporting healthy ageing and independent living at home.

4.1 Workshop's preparation

Being already scheduled in the DoA the SHAPES DWs are planned by each responsible partner, with the support of AGE as leader of T10.5.

To efficiently organise the next meeting, AGE and CCS (in charge of the second SHAPES DW) set up bilateral preparatory calls, including also UP to take stock of its experience. Considering the epidemiological situation across Europe and at international level, the second DW was also set up as a virtual event.

AGE and CCS worked jointly through the agenda preparation and invitation efforts. CCS and UP coordinated inputs on logistics and accessibility.

From the dissemination perspective, an online awareness raising campaign anticipated the DW. Like the first DW, specific content was produced and distributed across the SHAPES social media channels for five weeks ahead of the event (more details on the structure and impact of the awareness raising campaigns are included in D10.4).

A five-week long campaign on social media focused on the four selected topics of the event (cf. below), including a series of set-the-scene posts and tailored invitations to stakeholders.

4.1.1 Accessibility

Based on the feedback and support of SHAPES partners WFDB and EUD to deliver accessible events and contents, the organizers sought to ensure full accessibility to the workshop.

Through the registration form, attendees were asked about their accessibility needs ahead of the workshop, allowing CCS to organise International Sign Language interpretation and speech-to-text.

After the event, direct feedback on accessibility was shared by WFDB and EUD to continue improving the next editions of the SHAPES Dialogue Workshops.

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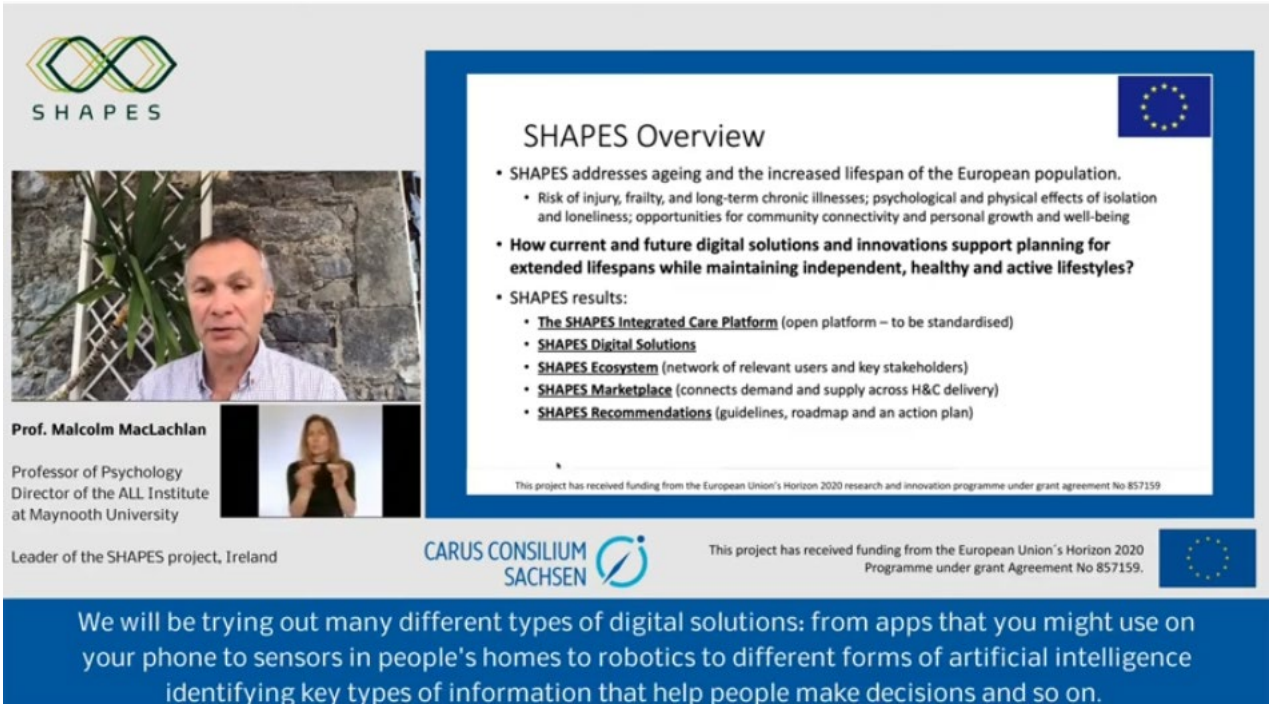
4.2 Workshop's structure

On October 29, Carus Consilium Sachsen GmbH hosted the 2nd Shapes Dialogue Workshop, which focused on integrated care and user perspectives. The workshop consisted of two parts: the morning talks, broadcasted on YouTube, and four parallel interactive sessions on Zoom in the afternoon. These latter sessions covered the following topics:

- Topic 1: Good Practice Examples of Integrated Care, Lessons Learned and Future Concepts.
  Moderated by Dr. Olaf Müller, CCS.
- Topic 2: User Perspectives on Integrated Care.
  Moderated by Borja Arrue, AGE.
- Topic 3: Scaling up solutions for integrated care.
  Moderated by Evert-JanHoogerwerf, AIAS.
- Topic 4: Disrupting Disintegration: Constructing a new mindset for caring.
  Moderated by Prof. Mac MacLachlan, NUIM.



Detailed agenda, composed of 2 pages, is available as Annex II

4.3 Workshop's participants

In total, 124 participants registered for the workshop. Of those 124 registered participants, 55 were part of the SHAPES consortium and 69 were external participants. The final list of registered participants comprised representatives from civil societies/private persons (18,15%), industry (28,23%), health & care / government (30,24%) and academia

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(47,38%).

On the day of the workshop, there were 60 attendees resulting in an attendance rate of 48 % from 124 registered participants. The sum of attendees comprised 36 participants from inside (60%) and 24 participants (40%) from outside the SHAPES consortium.

4.4 Overview of contents

The SHAPES Integrated Care Models Workshop aimed to share the SHAPES work performed on integrated care, and therefore included the most involved partners on the topic.

Thanks to the simultaneous run of parallel sessions, attendees were able to assist to additional sub-sessions and were asked to contribute with their knowledge across the four topics.

To support the outreach efforts, speakers' introductory videos were uploaded and used as invitation videos on YouTube, explaining the topics at stake for SHAPES and for the society at large that would be addressed in the SHAPES Dialogue Workshop.

4.4.1 Topic 1 - Good Practice Examples of Integrated Care, Lessons Learned and Future Concepts

The goal of the session on topic was to find good practice examples of integrated care, to identify success factors and to discuss potential future concepts. To achieve this goal, the workshop was divided into four sessions, each building on the results of the previous ones.

Session 1 and 2 were identical. These sessions were introduced with "Gesundes Kinzigtal" in Germany as a good practice example of integrated care. After that, the workshop participants were asked two questions:

- Do you have additional examples for best practice and why?
- What do you think are the success / key factors for integrated care?

In session 3, the participants were asked to evaluate and complement the results previously found. To weight the success factors identified, each participant assigned a total of 3 points to the listed success factors. For this interaction, the stamp function in Zoom was used.

Session 4 focused on the summary of the sessions 1 – 3, followed by questions and discussion about potential future concepts of integrated care.

The following examples for good practice in integrated care were identified in sessions 1 – 3:

- Continual care network, Portugal

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This is a care network aiming for patients to age with dignity and have access to all health services. Especially during the COVID-19 pandemic, the network provides necessary support for old people.

- Medical centre with focus on deaf people, Finland

  Deaf people have significant challenges in the communication with healthcare providers. To improve the access to healthcare, the medical centre uses powerful and visually accessible communication via the use of sign language. Furthermore, the medical centre provides important communication technologies and cultural awareness training for health professionals. The medical centre empowers deaf people to realize their right to enjoy the highest attainable standard of health.

- Integrated care prototype, Northern Ireland

  This example shows a new way to provide care services. The involved healthcare providers share the care pathway and have individual contracts. However, the prototype is not integrated in hospitals, yet.

- Short patient medical file to be shared between general practitioners (GP) and hospitals, Greece

  Because of a new legislation basis, it is possible to share short patient medical files between general practitioners (GP) and hospitals. That makes medical work much easier and more efficient. Necessary information or medical results are exchangeable and do not have to be collected again.

- TOMY – paediatric / social workers / nurses / health, Greece

  The units – known as “TOMYs” (*Topikes Monades Ygias* in Greek) – are key elements of the newly designed primary healthcare system. They are staffed with multidisciplinary teams of general practitioners, internists, paediatricians, nurses, health visitors and social workers to provide primary healthcare services at the community level. Currently, more than 100 TOMYs are operatingall over Greece and new units are expected to be launched.

- Janecare, Czech Republic

  Janecare is a high-level innovation action initiated by the EU Commission’s DG SANTE. It addresses accessibility of digital services in health and care in general and aims to integrate persona-view, technology centrism and patient empowerment into healthcare by 2030.

Additionally, in session 1 and 2, a set of success factors was identified, which was later evaluated by the participants in session 3 using the "stamp method" in Zoom. The workshop

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participants identified and weighted the following success / key factors for integrated care.

- Patient empowerment (3 evaluation points);
- Standardisation (3 evaluation points);
- Supportability / accessibility (2 evaluation points);
- Pricing and costing (2 evaluation points);
- ICT centred;
- Access to health data;
- Stratification;
- Legislation base;
- Quality measuring;
- Financial resources;
- Governance;
- Capacity building;
- Soft skills / communication;
- Data security / data protection;
- Service availability;
- Personal resources.

Participants in session 4 mentioned the following future concepts for integrated care:

Participants from Health & Government:

- Integrated budget, focusing on needs;
- Global standardization in medical care / treatment and technology with personalized focus;
- Partnership instead of procurements.

Health and Government stakeholders highlighted the urgency to focus on the right needs or requirements to get an integrated budget. It will be a great challenge to further develop and promote global standardisation in healthcare, while giving treatments a personalised focus. The focus will shift to partnerships instead of procurements.

Participants from Academia:

- Role of data issue;
- Integrated care;
- Value based care;
- Case manager based by artificial intelligence (AI);
- Artificial Intelligence as a new player;
- Integration private sector.

Participating academia representatives underlined the important role of data issues in comparison to value-based topics. In addition to integrated care, it will become increasingly important to offer value-oriented care. However, this leads to the following questions:

- How can this be mapped, documented and evaluated?
- What role will artificial intelligence play in healthcare in the future? How can this be reconciled with value-oriented care?

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Artificial intelligence will generally play an increasingly important role in healthcare systems, for example, case managers may be replaced by artificial intelligence in the future. However, the necessary prerequisites for this approach must be illuminated.

Next to artificial intelligence, academia representatives mentioned to consider the private sector. Specifically, the private sector must be involved into the topic of integrated care, which has so far only beendone marginally.

Participants from Industry:

- Global standardization in protocols in medical care.

Industry representatives mentioned the importance of focusing on global standardization of protocols and data exchange in medical environments to increase efficiency and to reduce possible sources of mistakes.

Participants from Civil Society:

- Connection to community and society.

Representatives from civil societies referred to the importance of soft skills. In their opinion, the connection between patient and community / society is one aspect, which requires more and more attention in the future.

4.4.2 Topic 2: User Perspective on Integrated Care

This topic is part of SHAPES's Task 3.4 *Governance Model and Guidelines*, within Work Package 3, *Organisational, Structural and Sociotechnical factors for the SHAPES Ecosystem*, the goal of which is "to identify the optimal form of governance with older individuals' participation in mind. Then different levels at which the [SHAPES] Platform's ownership is distributed will be examined and appropriate models identified and analysed for suitability in a collaborative manner"[3].

Task 3.4 understood governance as a set of structures, processes, and activities, that permit effective management. SHAPES partners in T3.4 intended to explore existing governance-related practices and processes, to understand where the SHAPES Platform could fit within the range of governance processes to enable person-centred care (particularly in SHAPES partner countries). With reference to the governance structure and process, the aim was to identify who makes decisions, who receives care, which type of care is delivered, when, and how and to understand the information processes surrounding care delivery. This informed the development of the SHAPES governance model and guidelines (deliverables D3.5 and D3.6).

A comprehensive overview of this work is presented in deliverable D3.5 – Initial SHAPES Collaborative Governance Model (relevant excerpts are made available in this deliverable

[3] SHAPES Grant Agreement.

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as Annex III). This section summarises key findings. Dialogue workshop participants numbered approximately 55 – 60, and included physicians, engineers, healthcare recipients, and academics. The following overview of the various inputs and exchanges is presented according to seven broad themes.

The seven broad themes were:

1. Actors and Inclusion in the Care Process and Decision-Making;
2. Dis/Connection and Non/Communication Between Health and Social Care Systemsand Components;
3. Funding Mechanisms and Equity of Access;
4. Non-Integration Engendering Worse Outcomes and Institutionalisation;
5. Informal Caregivers as Care Coordinators, Mediators, and Persons with Needs Divergent from Recipients;
6. Agents of Change: The Pandemic and Technology;
7. Risks and Ethical and Legal Implications.

1. *Actors and Inclusion in the Care Process and Decision-Making*

Participants emphasised a need to listen to care recipients, to genuinely involve them in the decision-making process, and understand all care alternatives. There was unanimity about considering the care recipient as the primary decision-maker. Decision-making processes were described as asymmetric, with the care recipient feeling on a different level of power to physicians and administrators (due to differences in, for example, knowledge, status, reputation, control over processes, etc.). Informed decision-making was addressed. As care recipients may not have an extensive medical knowledge or training, they may not always be able to make informed decisions. Insufficient communication and lack of comprehensive explanations to recipients were also noted. Attendees underlined the need to communicate in a plain and simple language for accessibility. The discussion also highlighted that care recipients should not be made accountable or legally responsible for decisions when they could not be duly and fully informed.

2. *Dis/Connection and Non/Communication between Health and Social Care Systems and Components*

Health and social care were reported to be operating as separate systems; a barrier to integrated care. Miscommunication or lack of communication between the systems was a common experience for service providers and care recipients. Different degrees of integration across countries and regions were reported, with funding schemes and service provision varying greatly across Europe. Participants stressed the slow process of innovation and how that presented a problem for providing adequate, innovative solutions to health and care, and integrating care.

3. *Funding Mechanisms and Equity of Access*

Differences across countries and regions were reported in relation to the funding sources of health and care and equity of access. In Spain, for example, homecare is the norm for less wealthy people, while in Nordic countries, and in Finland more specifically, universal access to homecare is provided, although wealthier people may opt for private services.

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4. *Non-Integration Engendering Worse Outcomes and Institutionalisation*

The lack of integration of care has many consequences. One consequence of lack of integration is the continued existence of obstacles to the sustainability of independent living. Another consequence is persistent institutionalization, "which is directly in contravention of the UN *Convention on the Rights of Persons with Disabilities"* [4].

5. *Informal Caregivers as Care Coordinators, Mediators, and Persons with Needs Divergent from Recipients*

Debate was focused on the role of informal care providers, who were seen as essential to connect, mediate, and organise care, including formal care, at grassroot level. A number of potential influences on quality of care were noted: contrasts or conflicts of views or priorities between informal providers and receivers, lack of informal care provider availability, difficult relationships between provider and recipients, and lack of support for informal care providers. Particular attention was paid to the gender bias in informal caregiving, with women providing a disproportionate amount of informal care; much more than men.

6. *Agents of Change: The Pandemic and Technology*

The COVID-19 pandemic shed light on various disconnections and gaps in care provision, including. Examples given included: silos in the care process, a lack of monitoring of health, and the disappearance of care pathways during the lockdown periods. These were discussed as problems that lead to increased morbidity and mortality. Attendees believed that integrated care would improve the resilience and the performance of the health and care systems.

Technology was perceived as helpful in care provision. However, it was emphasised that technology should not replace human interaction or substitute informal care. Workshop attendees felt that technology was valuable for supporting connection to family and services, and that it should be designed to remain accessible and useful when the user experiences distress, impairment, or emergencies.

7. *Risks and Ethical and Legal Implications*

Among the main risks identified, changes in responsibilities or in the distribution of such responsibilities among care recipients were highlighted. Ethical issues related to the data sharing between providers were also highlighted.

Summary of inputs for topic 2

To facilitate active and healthy ageing, and person-centred, integrated care, governance systems and processes should recognize the full scope of health and quality of life and protect healthcare recipients from institutionalisation. The role of communication is particularly important; systems with better communication and integration are more likely to promote better outcomes.

[4] Zurkuhlen, A., Cooke, M., (2021), D3.5 – Initial SHAPES Collaborative Governance Model, page 105.

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Person-centredness and the role of care recipients were prominent concerns among participants. Care recipients' needs should remain the centre of the health and care system. Particular attention must be paid to the consequences of shifting the burden of too much responsibility for health and care onto the recipient, as such a shift represents a risk.

The role of informal caregivers was also given consideration. Informal caregivers are perceived to function as mediators or translators within the care process, but discrepancies in the way recipients' needs are understood or conveyed by informal caregivers may impact care. The role of caregivers in communicating between recipients and providers is particularly noteworthy from a governance perspective. The gendering of informal caregiving warrants careful consideration in SHAPES.

Communication, and ease of communication, was deemed essential, and it clearly has central importance in everyday care and in response to acute public health concerns, such as the COVID-19 pandemic. The pace of innovation in service providers and systems is problematically slow. The introduction of new technologies, systems, or practices, and the overall implementation of innovations was described as very challenging.

Overall, the findings in relation to different aspects of individuals' perspectives on governance evidence the concepts of integrated care and person-centredness, and promote their use as foundation stones for the process of understanding and developing governance structures and processes in Task 3.4 and beyond.

4.4.3 Topic 3: Scaling-up solutions for integrated care

Many person-centred digital solutions addressing challenges in the health and social care sector increasingly facilitate or even enable an integrated approach to care provision. Nevertheless, it seems that the adoption of those solutions in the care sector remains difficult for various reasons. Even more difficult is the deployment of solutions in a determined care context that were developed elsewhere and thus must be adapted and localized. The SHAPES platform and its aggregated digital solutions will have to address the same challenges if the aim is to boost the technology uptake to support integrated care pathways inthe care sector across Europe.

The questions that the SHAPES Integrated Care Models Workshop has tried to address are the following:

- What are the key factors to consider when adopting a digital solution in a specific care context?
- Can these key concerns be adapted to specific phases of the technology adoption process? *(The following phases were distinguished: Needs identification – Definitions of functions – Choice of technology – Procurement -Implementation – Evaluation and outcome measurement)*
- How can these factors be "translated" in requirements for technology developers and providers that seek to respond to market demand?

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Following an introduction by the workshop chair Evert-Jan Hoogerwerf from the WeCareMore Centre for Research and Innovation of AIAS Bologna, the group was divided in several subgroups of participants, each session lasting 15 to 20 minutes. The task of the groups was to reflect on the questions above and to report back to the entire group of participants of this SHAPES Dialogue Workshop. In the final phase of the Workshop, participants were invited to comment on the outcomes. Last, the Workshop chair made some wrap-up comments and drew some conclusions.

The following factors and requirements were identified and discussed by the participants:

Table 5 Key factors and requirements to consider when adopting a digital solution in a specific care context.

	Key factors to consider	Requirements
Needs Identification	The importance of a good understanding of the care contexts, the values expressed in that carecontext (e.g., multi-disciplinarity) and the needs expressed by the different stakeholders (identify them and ask!) and how these are interrelated in order to reach overall higher outcomes. Assessment of the technology adoption and readiness of the context.	Adaptability to a variety of needs of different stakeholders. Reflect a holistic approach to care.
Definition offunctions	Clear need of the objectives and goals. Correct definition of requested functions and functionalities of the solution considering the complexity of the needs and their evolution over time. Definition in functions based on nature of the organisation (e.g., public statutory or private for profit or non-for profit). Need of data and data analytics and the response time of the system to data needs. Clear awareness of how the way of working will change, definition of responsibilities.	Scalability and Modularity of functions allowing for incremental development anddeployment. Interconnection of functions. Different levels of data output and analysis aswell as response time are foreseen.
Choice of technology	The importance of choosing technologies that are interoperable among themselves, scalable,mature, robust, stable and supported over time by local providers. Connectivity issues are considered.	Interoperability of technologies included in thesolution. Solution can cope with different levels of connectivity (e.g., alternative solutions are available).
Procurement	The need to have tailor suited solutions. Legislative compliancy, including privacy anddate	Compliancy with industrial and commercial standards and legislation.

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	protection. Compliancy with local regulations and practices in terms of data storage and data exchange protocols. Appropriate language version available. Reliability of the company. Costs of procurement and support/maintenance over time. Trial out period or pilots should be foreseen. Clear responsibilities.	Compliancy with data protection legislation. Different language versions are available.
Implementation	The solution should be understood and trusted by end-users, accessible (tech-wise, cost-wise), adaptable to different cases, fed by updates in new format/products and services as context evolves (laws, needs of the users etc.). Learnability for the correct use of the functions provided by the solution. The need for training of staff and end users. The easiness of use.	*Universal design* principles are respected. Manuals and tutorials are available. Training and support are provided on a need basis and in the local language.
Evaluation and outcome assessment	Assessment of the impact the technology can make on the outcomes of care. The definition of appropriate assessment and evaluation protocols and tools: Standard outcome measurement parameters and tools/scales can be used or specific ones need to be defined. Monitoring should be possible, as well as intervention adjustment. Awareness that results might only come in the medium long term. Evaluation should not only include usability but impact on the lives of the people and the quality of care.	Solutions provide data allowing for monitoring, outcome measurement and evaluation.

As a conclusion, the participants managed in a relatively short time to put together a comprehensive and shared view on key factors to consider and corresponding requirements. Summing up the requirements, apparently only highly adaptable modular and complex systems available in different languages and well supported in time and locally can respond to these expectations. For this reason, the little transfer of existing holistic solutions is not surprising. One solution may be to transfer single interoperable components through

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standardized protocols. Recognizing that interoperability is much broader than technological interoperability, it might be worth to investigate the existence of holistic ontologies describing different aspects of the technology uptake process in integrated care programmes, starting from the needs, the functions, the ecosystems, the technology itself, the actual deployment and the outcomes assessment.

At a higher systems level, the question was discussed about who should lead the changes atinstitutional level: national level, regional or local administrators. There was not a clear answer,but it is important to identify the appropriate policy level to seek a dialogue aiming at fosteringthe technology uptake in the sector.

Also, market immaturity in terms of sales and support networks across Europe should be addressed.

4.4.4 Topic 4: Disrupting Disintegration - Constructing a new mindset for caring

Disintegration is the process through which something becomes weakened, divided or destroyed. *Disruption* is about making a change to the usual way of doing things. If we value something and we can prevent its disintegration, then that should be a good thing. The idea of integrated care for older people is valued in terms of the recipients' experience, the providers' motivation for quality service and economic efficiency. The SHAPES Integrated Care Models Workshop was based on the idea that a lack of integration in our health and social care services for older people is not only a consequence of poorly thought-through inter-linkages and systems. Sometimes a lack of integration is designed into the systems. That is, some systems are *designed to disintegrate*. One of the ways in which this may happen is where groups of people working together are placed in hierarchical relationships that result in some form of domination or privilege, which may undermine effective integration. If one is able to identify and disrupt such relationships, one may be able to deliver more integrated care.

Through a series of four interactive workshop sessions with a broad range of stakeholders, including service users and service providers for older people, a range of different themes were identified as being related to dominance within the service provision landscape.

1. *Financial Factors*

In Germany, insurance companies have a strong role in determining which sorts of conditions and what sorts of treatments should be eligible for financial support. Even though these insurance companies are socially funded, and operate through government-mediated mechanisms, they still enjoy a degree of autonomy, which means that it may be difficult for other stakeholders to challenge their decisions. In some countries, private healthcare may enjoy a dominant position over public healthcare and be associated with socio-economic disparities in access to timely and appropriate treatment. This may also be associated with different attitudes towards and assumptions about individuals working in these different sectors. Clearly, the cost of services may differ for the service users, as so may the salaries for those working in each sector. Pharmaceutical companies may seek to influence the sorts of medications local pharmacies provide, thus influencing access to the full range of

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medicines,including the provision of less expensive generic forms of drugs. Other forms of dominance may result in inequities in the distribution of finances from centralised to more local and peripheral services.

2. *Governance*

Within many countries, a centralised system determines the key protocols adopted in service provision for older people. Thus, more local and peripheral service providers may feel they have little latitude to influence intervention decisions. In federated systems, there may be a greater delegation of these responsibilities at the sub-state level. The role of politics within healthcare can also be a dominating interest. Local and constituency concerns can override concerns for effective services. For example, evidence may indicate that specialised centres of excellence are more effective than local hospitals that do not have the opportunity to develop the same level of familiarity with disorders, yet politicians may champion smaller local facilities if this is what their electorate prefer.

3. *Clinical Professions*

The status of different professions may be associated with differing degrees of privilege and dominance. This may affect the efficient working of multidisciplinary teams, where some perspectives are given more credence than others, with the result that interventions reflect dominant views rather than necessarily the best practices. It was suggested that one example of this is the use of medication to treat mental health problems. Professions may also wish toprotect their scope of practice and prevent others – including service users – from infringing on it. The example of occupational therapists seeking to restrict the prescription of, and therefore access to, assistive technologies, was discussed. For many professions, the narrowing of expertise is seen as being related to status (higher status = more specialisation), thus encouraging compartmentalisation of work and making integration more complex.

4. *Gender relations*

Within many health and care systems, resources may be patterned by gender differences. For instance, jobs or roles (often unpaid) characterised as caring relationships often are performed by more women than men, while technical jobs often are performed by more men than women. There continues to be a gendered difference in caring *fo*r and caring *about* older people in the community: in many domestic situations, the burden of care often falls disproportionately on women. Part of the integration agenda may therefore require addressing gender disparities, including recognising that gendered role differences are associated with gendered pay differences. However, if gender is simply considered as a binary – male or female - then we arealso reinforcing a form of dominance which does not recognise, for example, intersexed or gender fluid individuals, as being equally legitimate.

5. *Representation*

One way in which dominance may influence healthcare integration is through some types of experience or knowledge being valued above other types. This could be in relation to either service user or service provider experience being disproportionately valued. In both situations,there may also be difficulty in questioning the authenticity or authority of another person's experience. Networks (e.g., "knowing each other") also may perpetuate dominance in certain sectors. Patient/service user advocates may not always be able to contribute

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effectively to discussions and may require support, time and resources to make the contribution they are capable of.

4.5 Results

The second SHAPES DW focused on possible future approaches of integrated care. The exchanges highlighted the need for post-integrated care service structures but exhorted SHAPES to contribute to the design of better and more sustainable services.

Topic 1

In practical terms, the Workshop findings helped CCS to sharpen the pilot's alignment to the actual needs of the quadruple helix stakeholders. Especially the weighted success factors will serve CCS to reinforce the pilots' sustainability within SHAPES.

Topic 2

Results from the SHAPES Dialogue Workshop have been coupled with findings from the literature and insights to data sources across SHAPES work packages (e.g., work package 2, *Understanding the Lifeworld of Ageing Individuals and Improving Smart and Healthy Living*). This helped to identify the appropriate stakeholders for further investigation of governance, thus informing the development of a quantitative questionnaire to understand the health and social care recipients' perspectives on the range of existing governance systems and processes.

Ultimately, the outcomes of the Workshop informed the development of the SHAPES governance model and guidelines (deliverables D3.5 - Initial SHAPES Collaborative Governance Model) and will inform deliverable D3.6 - Final SHAPES Collaborative Governance Model due in M42. Specifically, the long-term objectives are to ascertain the optimal form of governance with older individuals' participation in mind, examine the different levels at which the SHAPES Platform's ownership is distributed, identify appropriate governance models, and collaboratively analyse their ethos and outcomes. This will help to illuminate the role that SHAPES and its governance may play in facilitating person-centred, integrated care for active and health ageing within health and social care systems.

Topic 3

Feedback of the third session has been included in Deliverable D3.2, and feed into the recommendations for developers and pilot sites that will work with the SHAPES solutions.

At project level, SHAPES partners will continue to dialogue with international networks working on the same issues such as EIP on AHA – the European Innovation Partnership on Active and Healthy Ageing, ECHAlliance, EASPD – the European Association of Service Providers for Persons with Disabilities, and others. It might be interesting to promote projects and events that further explore non-technological interoperability and industry collaboration across Europe between SMEs and Start-up companies.

The European Union should be stimulated to continue harmonizing legal frameworks and to

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develop new regulations where these do not exist. Standardization efforts must be supported.

Topic 4

The idea of dominance through finance, governance, professions, gender and representation should be considered in recommendations for promoting integrated health and social care for older people living in their communities. The potential value of an assessment tool exploring these, and other domains related to dominance and integration in SHAPES, will be explored by WP2.

4.6 Participants' Feedback

After the workshop, CCS send out a feedback form to all participants. As a result, 17 attendees provided feedback for the workshop and evaluated the workshop based on 9 criteria with a Likert scale from 1 (= "bad", "non", "low", "relevance not given") to 5 stars (= "good", "very much", "high", "highly relevant").

Table 6 Workshop rating criteria and evaluation based on a 1 - 5 star Likert scale.

ID	Evaluation Criterion	Average Score (1 – 5 stars; n = 17)
C1	Fun that the workshop brought the participants.	3.9
C2	Structure of the workshop (talks on YouTube + interactive sessions on Zoom).	4.5
C3	Satisfaction with the morning session talks.	4.1
C4	Relevance of the interactive workshop topics for integrated care.	4.6
C5	Satisfaction with the interactive workshops on Zoom.	4.6
C6	Organization of the workshop.	4.7
C7	Accessibility to workshop content.	4.4
C8	Overall workshop quality.	4.6
C9	Overall satisfaction with the workshop.	4.5

Table 6 and Figure 12 show the 9 evaluation criteria for the workshop that the attendees were asked to rate. The ratings range from 3.9 (Fun during the workshop) to 4.7 (Organization of the workshop) and show very positive feedback from the attendees that also rated the overall satisfaction with the workshop with 4.5 out of 5 stars (Table 6, C9).

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Figure 12 : Visual representation of the workshop rating based on a 1 - 5 star Likert scale. Criterion IDs (C) from table 6

Furthermore, in the feedback form, SHAPES asked the attendees four open questions. The questions and the given answers comprised the following:

What is your key take home message from the workshop?

- "Collaboration is the best practice."
- "We should cultivate smart integration in aging Europe".
- "A lot still to be achieved before widespread integrated care becomes a reality".
- "Each one of the participants is a decision maker of the future health choices."
- "Inclusion."
- "The issues of security and accessibility/platforms has to be discussed in more detail because it is a success factor for applications to be provided."
- "The interoperability issue in the integrated electronic care systems".
- "A dialogue between EU countries is fundamental".
- "The high variation of health systems in Europe".
- "Integrated care, in most of the EU countries, is still an ongoing and blur process."

What did you especially like about the workshop?

- "The organization".
- "The moderation of the breakout groups."
- "That there was a facilitator in each breakout session".
- "Interaction between stakeholders, end users".
- "Interactivity".
- "The different views the different people involved bring".
- "I enjoyed the whole day. I really liked the flow, the topics were interesting."
- "The interview was a brilliant idea".
- "Format".
- "The focus of the organizers".
- "Interactive session".
- "Different views on a specific subject/topic".
- "The way that we could tell our opinion on relevant matters".
- "Accessibility."
- "The interactive sessions, allowing the participant´s confrontation with several point ofviews of the same topic."

What did you not like about the workshop?

- "There isn't something that I didn't like".

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- “Nothing” (x2).
- “I would have preferred 2 half day sessions than one full day online”.
- “Few participants”.
- “Most of the questions were related to how the integrated care is managed in my country. If we come from a company, we could not really provide useful feedback, as our area of expertise is more focused in the technology.”
- “I had to take a break after the second interactive workshop, it is quite demanding, on the other hand I do not know how to improve the program, maybe having just three butlonger interactive workshops? Following on that topic, I would go for 1,5 h instead of 50 min as the time was not sufficient for longer discussions - however, maybe that is something speakers can evaluate better than participants as the workshop´s outcomesare most relevant for them.”
- “Facilitation in one or two could have been improved”.
- “Some of the participants did not have a good connection, thus some dialogs were notthat clear to me.””
- “(too) prepared presentation in the morning but it is a detail”.
- “There were some parallel sessions that I could not participate”.
- “The morning session would be more engaging if live talks were considered. It wasquite extent.”

What should we do better in the coming Dialogue Workshops? Where can we improve?

- “More interactive sub-groups in the workshops”.
- “Possibility to re-watch pre-recorded session”.
- “More case studies”.
- “It can be very difficult to maintain engagement for online workshops that run over an entire day. I believe there is research showing the optimum length being approximately3 hours. Perhaps if the workshop could be run over 2 days or have the pre-recorded sessions available to view in the run up to the event it might achieve even better engagement.”
- “More action.”
- “Questions/discussion points for a broader target (e.g., ICT companies).”
- “Face to face”.
- “Maybe more visual features during presentation?”
- “Stay as is”.
- “Shorten the period of the non-synchronous part of the workshop and focus on the asynchronous part”.
- “Involve external participants. From what I could understand, the workshop participantswere mainly SHAPES partners.”

It is important to note that the 17 attendees that filled the feedback form resemble 28 % (17 out of 60) of the workshop attendees. Thus, the opinion of the majority or roughly three quarters of attendees is not included in the received feedback.

Nevertheless, the received feedback was useful to improve the planning, organization and execution of the next dialogue workshop.

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5 3rd SHAPES Dialogue Workshop on Technological Platform

In line with the GA, the third SHAPES Dialogue Workshop, titled SHAPES Technological Platform Workshop, focused on the challenges of the SHAPES Technological Platform and the added-value solutions brought by SHAPES.

5.1 Workshop's preparation

Once again, the third SHAPES DW was scheduled to happen virtually. Based on the feedback gathered through the first two editions of the DWs, AGE proposed to shorten the format and reduce the workshop to a full morning event, thus avoiding a certain virtual fatigue from attendees, speakers and moderators along the day.

As per the previous editions of the DW, AGE liaised with the workshop's organiser, the University of Castilla- La Mancha. Bilateral talks and exchange helped setting the scene and planning the logistics and agenda. Jointly, AGE and UCLM took care of the event's dissemination, both in English and in Spanish.

UCLM aimed to attract a composite Spanish audience, thus offering simultaneous interpretation in Spanish.

5.1.1 Accessibility

With respect to accessibility issues, the organizers counted on the guidelines and feedback provided to the consortium by the SHAPES partners WFDB and EUD on the SHAPES Accessibility Report.

In the registration form, participants were asked about their accessibility needs ahead of the workshop, allowing UCLM to organise International Sign interpretation, simultaneous language interpretation and speech-to-text in both Spanish and English. The whole Workshop was web-streamed through an English and a Spanish channel.

After the event, WFDB and EUD released a detailed report on accessibility of the third SHAPES Dialogue Workshop (see references), a precious legacy for the organisers of the following editions of the SHAPES DWs.

5.2 Workshop's organisation

On 27 of April 2021, the 3rd SHAPES Dialogue Workshop took place virtually gathering more than 200 registered participants. This one-day event was entitled "Technological platforms and healthy ageing: challenges and opportunities", in which representatives from industry,

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academia, health and care organisations, and civil society focused on finding out what are the challenges and opportunities faced by agents involved in healthy ageing and how technological platforms could help improve the quality of life.

The workshop agenda was organized into individual speeches and two-panel discussions addressing the following objectives:

- Identify the challenges that arise throughout the different phases in the creation of a technological platform, from hardware and software designers to end-users;
- Envision the potential of a common European platform that facilitates long-term active and healthy ageing;
- Discuss the strengths and weaknesses of technological platforms for integrated care and healthy and active ageing, with a sight on the ethical implications and the acceptance among potential users;
- Understanding the different concerns, points of view, and needs of the stakeholders involved in health and care delivery.

As per the past editions of the DW, the recoding of the event remains accessible in YouTube, both in an English version and Spanish version.

5.3 Overview of content

On behalf of UCLM and as regional coordinator of the SHAPES project, Prof. Juan Carlos Lopez welcomed the attendees and introduced the objectives of the workshop. Besides Prof. Malcolm MacLachlan, who introduced the project as coordinator of the SHAPES, Teresa Riesgo Alcaide, Secretary General for Innovation at the Ministry of Science and Innovation in Spain explained the Spanish perspective about innovation, technology, and health system, and welcomed the project and its inputs towards a fair and innovative recovery from the COVID-19 pandemic. Prof. Antonio Mas, Vice-rector of Scientific Policy at the University of Castilla-La Mancha in Spain, closed the opening session by highlighting the academic role in the new technological era.

The first panel discussion, titled *eHealth technological platforms: Challenges and Opportunities* focused on aspects such as the strengths and weaknesses of technological platforms for integrated care and healthy and active ageing, the interoperability of information and technology and privacy, and security.

The second panel, titled *A multidisciplinary reflection for synergy identification around healthy and independent living of older individuals* focused on the different concerns, points of view, and needs of the involved stakeholders with respect to health and care delivery. The panel also highlighted the desires of the potential consumers represented by the actual older adults and the seniors-to-be.

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Figure 13: Screenshot of an intervention

The workshop closed with Prof. Ricardo Cuevas, Director General for Universities, Research and Innovation at the Regional Government of Castilla-La Mancha, who highlighted that the regional government would pay particular attention to SHAPES outcomes. The event closed on the agreement, by regional representatives, on the relevance of technology to promote a healthy and active life for European citizens. Also, the workshop highlighted the role of public organizations in promoting technological and innovative advances.

During each panel discussion, an open discussion with questions and live polling with the audience were organised. A total of 55 participants expressed their ideas and reflections through the questions launched during the two panels discussion. Their participation contributed with 91 inputs. The main topics covered are depicted below:

5.3.1 Digitizing the home

The smart home is one of the main assets of future technological platforms designed to support active ageing. This context, due to its particularities, poses different challenges such as access to broadband telecommunications networks (especially in rural areas), the challenges of retrofitting a home in terms of technological infrastructure and its acceptance/rejection by users, or the need to safeguard the privacy of the individual living at home.

The following question was asked: What is the greatest challenge to make the smart home concept a reality?

The replies greatly stress the issues of usability, interoperability, security, privacy and costs, among many others. The word cloud below shows the various replies, with the most popular ones in bigger font.

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Figure 14 : Replies to question no. 1

5.3.2 Interoperability of information and technology

On this issue, conversation was guided by the open question “how key is interoperability in the development of a technological platform?” and resulted in the following highlights (no word cloud was installed for this question.

Interoperability is essential to ensure the success of multidisciplinary platforms that can provide personalized and comprehensive care (covering all spheres of an individual's life). For this, it would be necessary to integrate information from different sources such as medical information, information related to lifestyle habits, social and environmental factors surrounding an individual's life. However, the heterogeneity of these sources of information makes a comprehensive treatment very difficult.

5.3.3 Privacy

A platform for healthy ageing will have different user profiles (the user, the caregiver, the family member, the physician, the nurse, the hospital administrator) with different privileges when it comes to accessing the information handled by the platform. Data management requires more advanced mechanisms than those based solely on the level of privileges associated with user profiles.

The following question was raised: What actions are most important to ensure privacy and to build trustworthy systems for older individuals?

Participants underlined the issues of transparency, certification, training on digital skills, clarity and avoid intrusive technologies, among the many other aspects that emerged during the discussion. An overview of the complexity of the replies is provided through the figure below.

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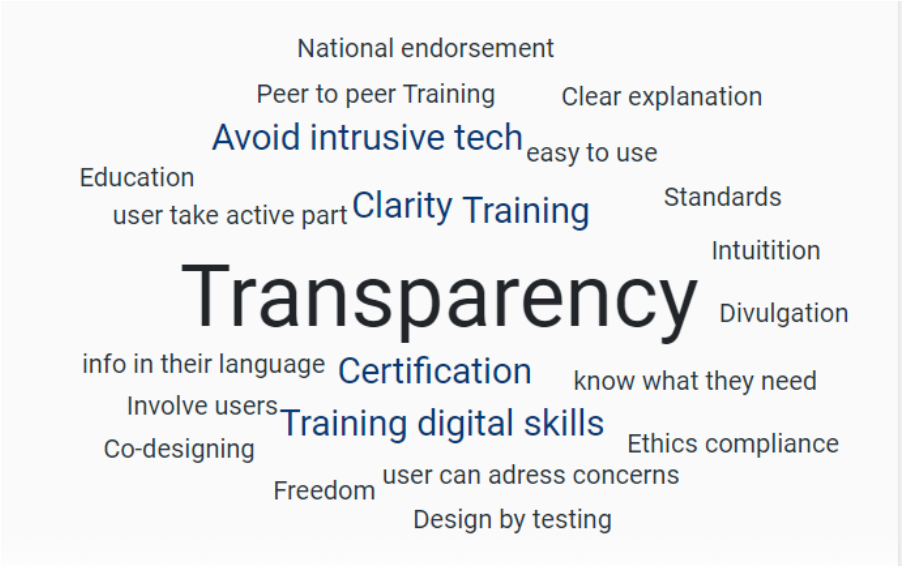

Figure 15: Replies to question no. 3

5.3.4 Digital literacy

The use of technological platforms that will assist older people as they age entails a series of decisions and actions that impact areas such as privacy, data ownership, trust in technology, self-determination, the digital footprint, or the impact that the use of certain artificial intelligence systems may have on mental health.

The following question was addressed: What types of devices would be considered less intrusive and would be better accepted in the home environment and facilitate better integration into the lives of older people?

Most participants opted for wearables, internet of things and invisible tools for registering activities, pointing towards sensors rather than cameras. The figure below summarises the various replies and shows the most popular replies in bigger font.

Figure 16 : Replies to question no. 4

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5.3.5 What agent should take the lead in healthy ageing?

Who should lead the effort towards digitization of health and support for independent living at home for older people? Social issues are primarily driven by government initiatives, but is it the same for healthy ageing? The silver economy (economic activities generated by and for older people) seems to be a good incentive for other agents, companies from different sectors, to be promoters of initiatives in this field. At the same time, it seems clear that healthy ageing demands a life course approach, so that people go through the different stages of their lives and reach older age in good health.

The following question was asked: what actions can ensure that healthy ageing is a reality throughout the life cycle? The answers comprised: health promotion, education, accompany, respect for one's knowledge, life achievements and legacies, share good experiences, awareness, public health actions and interventions, ownership on one's own lifestyle, good facilities, feedback, access to healthcare, introducing habits, knowledge.

5.3.6 Health and healthy ageing

Medical devices, for being labelled as "medical", must undergo a certification process that guarantees, among other things, the devices' accuracy. These devices are therefore more expensive than others that are not considered medical and they are also more rigid when it comes to implementing technological advances (each improvement must go through the certification process again). There are parameters for which, perhaps, it could be considered sacrificing precision in favour of having cheaper and easily upgradable platforms, based on general consumer technology such as activity wristbands (Xiaomi, FitBit, Apple).

The open question addressed was: what do you think about this issue? Answers stressed the relevance of health, and the impact that certain decision might have on the users' health and wellbeing. When growing older, chronic diseases may more often appear: cardiovascular, musculoskeletal, diabetes or depression, are among the most common diseases in older people. Technology can play many roles in this area, not only providing a monitoring capability for health parameters (glucose, blood pressure, heart rate, etc.) but also offering the capacity to have a direct impact on behavioural change and re-education in healthy habits, for which precision or measurement of health parameters are not so important.

Mentimeter was introduced to produce word cloud on the next question: how to reconcile new technologies and face-to-face contacts in care? The replies underlined how technologies can help but not replace the human support, as shown below.

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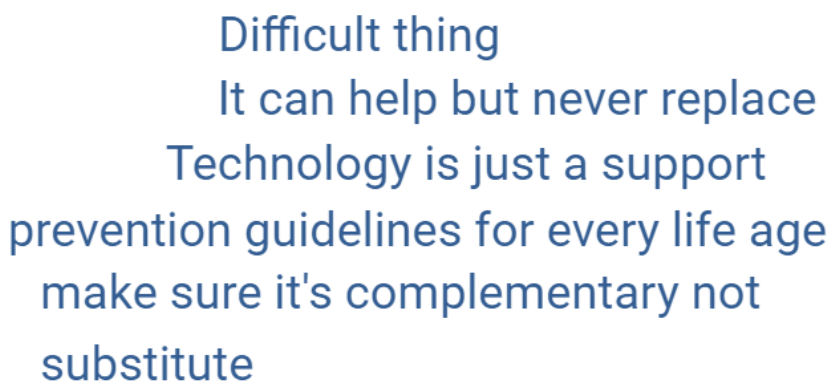

Figure 17: Replies to question no. 6

5.4 Results

Technology has a huge potential for healthy ageing – and poses some challenges: the SHAPES Technological Platform Workshop highlighted some main items on both sides.
As emerged from the question and answer in chat-box and in the live discussion, the Workshop successfully reflected on important challenges and potential of technologies for healthy ageing.

This work underpinned the consolidation of two deliverables, namely deliverable D4.1 SHAPES TP Requirements and Architecture and deliverable D3.9 Final Draft User Requirements for the SHAPES Platform.

Moreover, the Dialogue Workshop allowed SHAPES to become more visible for a good number of stakeholders based in Spain or Spanish-speaking, thus widening the base of interested stakeholders for the project.

In terms of registrations, a total of 205 persons completed the registration form. But because the event was broadcast in streaming, it was finally decided to make it open to anyone who wanted to participate, without the need to have registered in the form in advance. Data gathered shows a total of 506 plays in the English language streaming with 143 unique viewers, for its part, the Spanish Language streaming obtained a total of 426 plays with 126 unique viewers.

One of the Workshop's goals was to gather representatives from industry, academia, health and care organisations, civil society as well as older people. Looking at the results obtained from the following question, asked in the registration form, it confirms that the objective was achieved.

To generate heterogeneous workshop groups, please let us know who you are going to represent?

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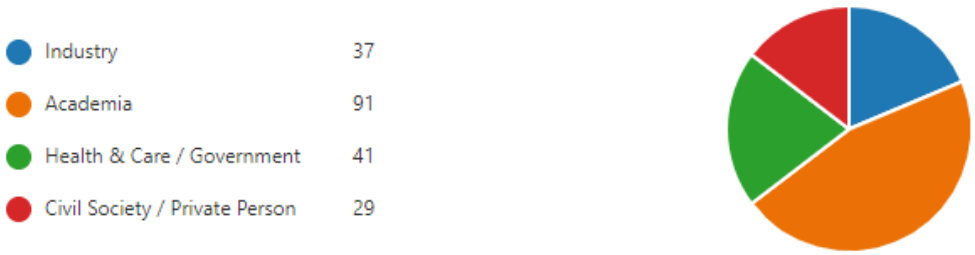

Figure 18: Attendees' main affiliation DW number 3

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6 4th SHAPES Dialogue Workshop on Lifeworld of Individuals

In line with the GA, the fourth SHAPES Dialogue Workshop, originally titled "The Lifeworld of Smart Healthy Ageing Individuals Workshop", intended to address the real world on how people live in old age to understand the experiences and expectations for older people across Europe.

6.1 Workshop's preparation

AGE started the organisation of the fourth SHAPES DW in June 2021, brainstorming with WFDB and EUD about the focus of such a broad topic. At that time, there was still uncertainty about the possible format (face-to-face, online, hybrid) of the event. During the summer 2021, AGE decided to for the online format, in line with the epidemiological projections related to the COVID-19 pandemic.

Taking stock of the experiences of the past DWs, the fourth SHAPES Workshop was conceived to last a maximum of 3 hours, thus mainly accommodating the needs of older people and people with disabilities to avoid virtual fatigue. The main goal for the Workshop was to set up a dialogue among those stakeholders, considered as the potential final beneficiaries of the SHAPES project's results, their representative organisations, the public and the research partners, to focus on the lived realities for better understanding older age.

Equally to the other SHAPES DWs, the organisation and logistic was very demanding. However, differently from the past editions, AGE could not partner with a counterpart on the consortium, as the fourth workshop was entirely appointed to AGE.

For the preparation of the Workshop, AGE had the valuable support of SHAPES partners involved in T2.1. Particularly precious was the ongoing involvement of WFDB, which provided useful feedback since the earliest stage, e.g., contributing to the agenda's definition, and the dissemination efforts, e.g., reaching out to WFDB members and other network of persons with deaf blindness. NUIM greatly coordinated the contributions of T2.1, conceiving time-efficient and well-structured take-home messages from six selected #SHAPESstories.

Building on the third SHAPES DW's impact on Spanish participants, the fourth SHAPES DW (run in English) opted to offer simultaneous interpretations in German, Spanish and Italian, as together they represent the main spoken languages in the SHAPES consortium (by 11 partners) and in the European Union. The choice of the Spanish language was also an attempt to attract some of the attendees of the previous workshop and to make the SHAPES content accessible outside the European borders (in Latin America, especially).

6.1.1 Accessibility

AGE relied on WFDB's guidance also in terms of accessibility considerations.

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Under WDBF's supervision, AGE developed an accessible registration form, available in the four selected languages in which the workshop was available. The event's agenda, firstly available only in English, was then translated into German, Spanish and Italian.

The event took place as a Zoom Webinar, with International Sign interpretation and speech-to-text in English, German, Spanish and Italian.

Highly supportive were also the various documents and resources provided by WFDB and EUD to ensure the event was accessible. Excerpts of those guidelines were shared with the event's speakers and moderators. Speakers' presentations were collected before the event and shared with interpreters and registered participants who requested supporting materials beforehand.

After the event, closed captions (in English only) were also shared upon request.

6.2 Workshop's organisation

The fourth SHAPES Dialogue Workshop took place online on 26 October 2021, from 10.00 to 13.00 CET. Entitled "Diversity and Empowerment: understanding the realities of older people", the event's title was changed from the original "Lifeworld of Individuals" to clarify the concept also outside the SHAPES consortium. The workshop intended to expose the lived realities of older people and people with disabilities and sought to challenge prejudices about ageing. Through a series of panel discussions, the event exhorted participants to get closer to people's realities and experiences. The workshop highlighted some selected ways in which SHAPES tries to respond to users' needs, as illustrated by the #SHAPESstories.

The workshop's agenda (cf. Annex III) foresaw an introduction to the project via one of its principal investigators, Prof. Mac MacLachlan (NUIM, Project Coordinator), followed by a session meant to highlight challenges and real-life stories about ageing and ageing with disabilities through the voices of self-advocates – Joke de Ruiter-Zwannikken, Sanja Tarczay and Marc Wheatley, respectively representing AGE, WDFB and EUD. The session was moderated by another WFDB representative.

A second panel introduced the project's ethnographic research from T2.1 - Understanding Older People: Lives, Communities and Contexts- thanks to the involvement of various partners, selecting six #SHAPESstories and delivering poignant experiences and take-home messages.

A third panel provided a broader picture, explaining the European work around active and healthy ageing through the intervention of EUREGHA (currently coordinating the IN4AHA project, pursuing the work of the EIP AHA – European Innovation Partnership on Active and Healthy Ageing) and the TRANS-SENIOR research on empowerment of older people in care decision-making process, greatly connected to T2.4 - Empowerment of Older Individuals in Health and Care Decision-making.

As per the past editions of the SHAPES DWs, the recording of the event will made available in the project YouTube channel. At the moment of drafting this deliverable, the video was not officially disclosable, and some editing was needed (the part related to the TRANS-

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SENIOR research being under embargo, pending the acceptance of a publication). It will be however uploaded onto the channel once the editing work is completed.

6.3 Overview of content

The introduction to the project focused on the role of the European innovation in SHAPES to support people to age in place and in their communities, with the help of digital solutions. As much as technology is an enabler, SHAPES seeks to put technology at the service of the people, especially older people and people with disabilities.

This SHAPES DW aimed to engage with self-advocates from the ageing and disability movements, who took the floor and shared excerpts of their life experiences, useful in framing ageing and disabilities, raising awareness to their everyday challenges and strengths. The first panel discussion was therefore focused on the free speeches of representatives from AGE, WFDB and EUD. The session reminded that older people and people with disabilities have equal rights in our societies, they contribute to more inclusive communities and are an integral part of them. All barriers to their effective participation to life and societies are unacceptable and must be removed.

The second panel focused on the project's ethnographic study, showcasing six selected #SHAPESstories from European pilots in SHAPES:

- Czech Republic "**And now I am scared**": Delay and Avoidance in Uncertain Times" (Corona, Family, Fear, Ambiguity);
- Northern Ireland "**Trains, Planes and Mobility Scooters**" (Mobility, Frailty, Independence);
- Greece "**Weighty Matters – Changing Habits in Later Life**" (Health, Motivation, Digital Tools, Habits);
- WFDB Spain "**The Red and White Cane: Obstacles and Barriers**" (Independence, Technologies, Awareness, Discrimination);
- Italy "**A Captured Glance, a Lifetime of Memories**" (Being, Memories, Digital tools, Legacies);
- Germany/Dresden "'**Ageing is Not for Cowards': Older Adults as Caregivers**" (Caring for self and others, Generations, Time, Gender).

The research underlined the obstacles older people face to fully participate in all areas of society, including strong stigma and prejudices. But those stories also show the resilience, as well as older people's willingness to enjoy life as anyone else, despite the many challenges.

During this session, some eloquent quotes were gathered, also via the various feedback in the chat and Question & Answer functions: "*older age is a period full of opportunities and freedom", "technology is key for independence and inclusion", "ageing is complex, but it is not a medical condition", "the care system is in need of technology as much as individuals and carers", "technology should not just address deficits, but build more directly on*

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strengths", "esteem is boosted when we hear that there are enablers to live a life of inclusion and dignity" and "getting older is one thing, feeling no longer useful is the worst".

The third session focused on the connections SHAPES can make with other European projects. The floor was given to EUREGHA, representing European regional and local health authorities, and coordinating the follow-up initiative of the EIP AHA, currently called IN4AHA. EUREGHA could provide the team building efforts the project puts to leverage good and best practices serving the European research on active and healthy ageing. Such intervention was useful to set the (European) scene for the several SHAPES pilots and to highlight possible connections and opportunities. Also in the panel, a representative of the TRANS-SENIOR project gave a presentation of the project's research, focusing on the transitions in care and investigating older people's decision-making process in care. This topic is particularly relevant for T2.4 - Empowerment of Older Individuals in Health and Care Decision-making- and allowed participants to exchange views and feedback on the research methodology and expected outcomes.

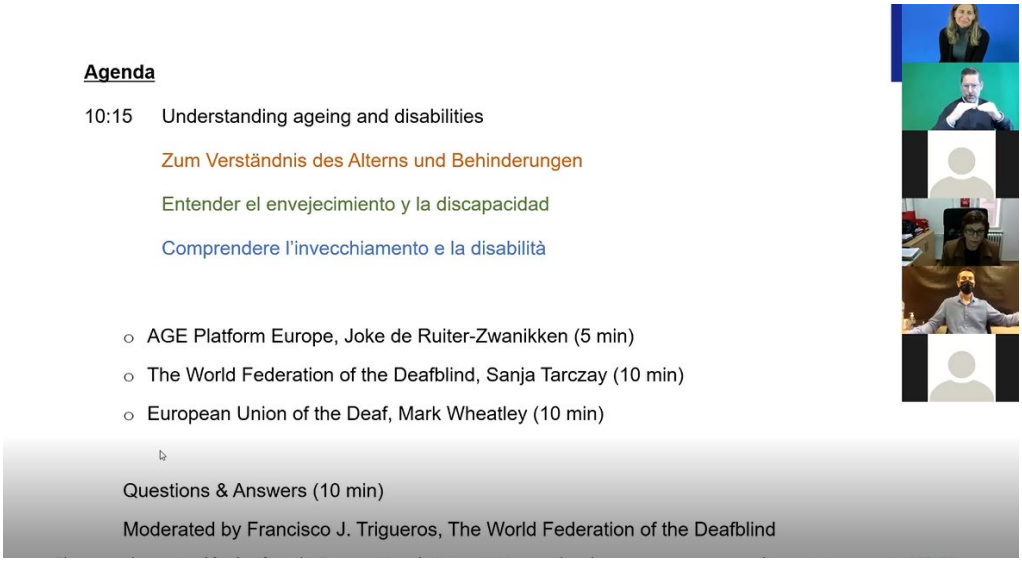

Figure 19: the first session of the fourth DW

Last, the Secretary General of AGE, Maciej Kucharczyk condensed and conveyed the main take-home messages, stressing the work on SHAPES and AGE for inclusion and accessibility for all, free from ageism, discrimination and based on mutual respect.

6.4 Results

A feedback survey was sent to all participants right after the event. From the direct feedback received during and when closing the event, the fourth DW was very much appreciated by the participants, who enjoyed the rich and interesting discussions that emerged in each session.

The goal of inviting self-advocates to take the floor and engage with a composite audience interested in ageing and disability meant that interesting issues were discussed, alongside with increasing the visibility to the SHAPES studies on the lifeworld of older people.

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The SHAPES project succeeded to convey the message that a better society for all must exist and that innovation helps to pave this way when grounded on the inclusion and engagement of the beneficiaries to that endeavour. Selected interesting quotes and positive feedback gathered after the event will be part of a visual work on the SHAPES website and social media. The main messages collected, alongside with the contacts made for the preparation and during the implementation of the Dialogue Workshop will serve to build the next edition of the SHAPES DW (in April 2022) and to advance on T2.4 - Empowerment of Older Individuals in Health and Care Decision-making, whose deliverable is due in October 2022.

The various speakers were clear, stating punctual, meaningful, and concise messages. Participants seemed to appreciate the short format (3 hours, with a pause of 15 minutes) and the provision of speech-to-text in English. Feedback on the use of other languages was not obtained, neither during the session nor from the interpreters.

6.5 Participants' overview

Like the other editions of the SHAPES DWs, also the fourth one gathered mostly representatives from academics and research (49% of registered participants), older people, people with disabilities, representatives of associations and civil society (24%), health and care professionals (16%) and representatives of industrial partners and service providers (10%), for a total of 176 registered participants.

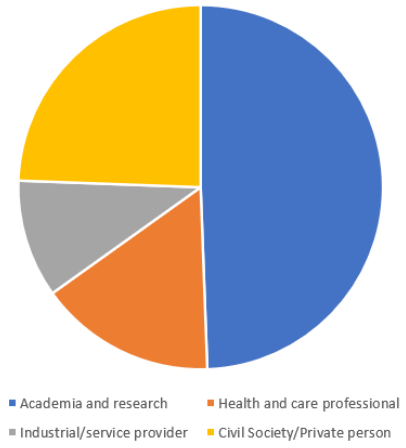

Figure 20: Participant's categories

Differently from the past editions, though, the fourth SHAPES Dialogue Workshop managed to attract attendees outside Europe. Among the Europeans, German, Spanish and Greek participants held most seats, while the following division was observed among international attendees, for a share of 32% of the total registered people attending from beyond the borders of the European Union:

Table 7 International registered participants

International registrations (total: 56)	
Africa	3

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Australia	2
Brazil	1
Canada	3
Caribbean	1
India	8
Philippines	10
United Kingdom	24
United States of America	4

This is most likely due to the invitation AGE shared with the informal GATE community, a mailing list of stakeholders across the globe working or interested in assistive technologies for all. The community was set up and is moderated by WHO.

From the Zoom Webinar usage report, it is possible to detail that the fourth SHAPES Dialogue Workshop had a maximum of 75 attendees, and a total of 195 logins.

Webinar ID	Unique Viewers	Total Users	Max Concurrent Views
843 6073 2986	110	195	75

Figure 21: Total users and maximum concurrent views

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7 Conclusion

This deliverable summarises the first four Dialogue Workshops organised by the SHAPES partners since November 2019 until November 2021.

Through the document, the reader takes experience of the various SHAPES events organised to showcase the progress and results of the project and to engage with the audience, with the attempt to raise awareness on the SHAPES's topics and innovation, as well as to facilitate connections among the large spectrum of invited stakeholders.

Held in a virtual format due to the Coronavirus pandemic, each SHAPES Dialogue Workshop built on the experiences of the past ones, both in terms of preparation and organisation, as in terms of implementation and feedback gathering.

Overall, the four Dialogue Workshops allowed SHAPES to be known and experienced by over 400 participants from all over Europe and beyond, involved in commenting, suggesting, and even validating some salient parts of the project's innovation. Special attention has been placed to accessibility, a main feature of the SHAPES events, products, and outreach, with the goal to extend the project's network of interested stakeholders.

The Workshops' results served the SHAPES partners and project, namely the tasks directly involved in the events themselves, spanning from the validation of the personas and use cases, to the work on integrated care models and the SHAPES Technological Platform, to the sharing of experiences on the lifeworld of older individuals.

The feedback and experience gained so far will undoubtedly serve the next editions of the Dialogue Workshops, until their apex, with the final event of the SHAPES Project.

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8 Ethical Requirements Check

The focus of this compliance check is on the ethical requirements defined in D8.4 and having impact on the SHAPES solution (technology and related digital services, user processes and support, governance-, business- and ecosystem models). In the left column there are ethical issues identified and discussed in D8.4.(corresponding D8.4 subsection in parenthesis). For each deliverable, report on how these requirements have been taken into account. If the requirement is not relevant for the deliverable, enter N / A in the right-hand column.

Ethical issue (corresponding number of D8.4 subsection in parenthesis)	How we have taken this into account in this deliverable (if relevant)
Fundamental Rights (3.1)	N/A
Biomedical Ethics and Ethics of Care (3.2)	N/A
CRPD and supported decision-making (3.3)	N/A
Capabilities approach (3.4)	N/A
Sustainable Development and CSR (4.1)	N/A
Customer logic approach (4.2)	N/A
Artificial intelligence (4.3)	N/A
Digital transformation (4.4)	N/A
Privacy and data protection (5)	Personal information (name, surname and position/affiliation) of external participants was provided upon agreement with the interested person.
Cyber security and resilience (6)	N/A
Digital inclusion (7.1)	N/A
The moral division of labour (7.2)	N/A
Care givers and welfare technology (7.3)	N/A
Movement of caregivers across Europe (7.4)	N/A

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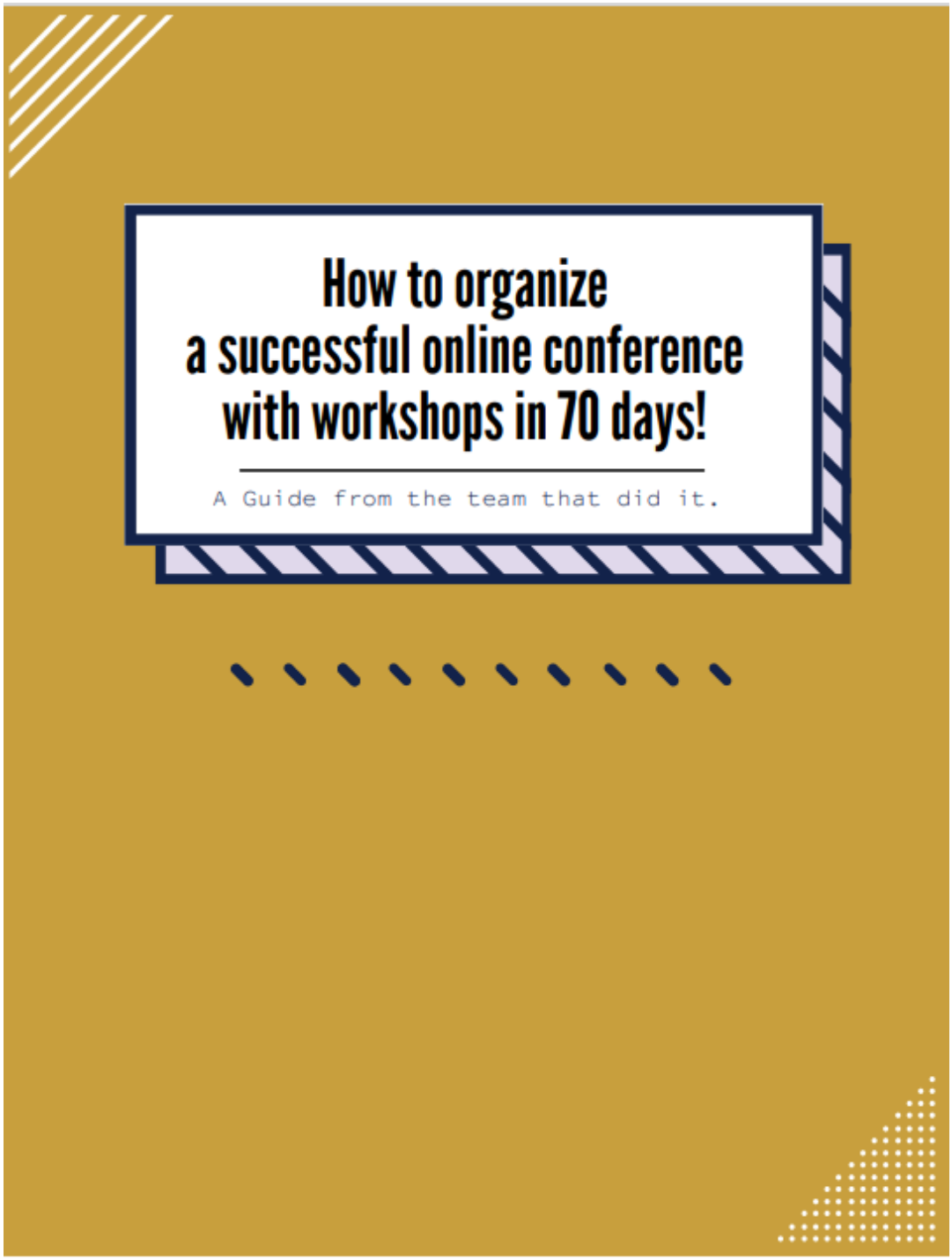
Annex I


How to organize
a successful online conference
with workshops in 70 days!
A Guide from the team that did it.
This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 857159
SHAPES

INTRODUCTION TO THE GUIDE

This Guide will help you organize your online conference through sharing good practice.

WHAT IS IMPORTANT FOR THE SUCCESS OF THE EVENT

- Event management itself (deadlines, clear division of responsibilities, internal communication etc.)
- Content of the event (assuring quality, unity, diversity and engaging content)
- Technical part (pre-recorded videos, presentations, animation, visual identity)
- PR of the event (social media, internal communication among SHAPES partners)
- Team management (taking care of the organizing team)
- Communication (clearly defined platforms, content, etc.)

USEFUL TIPS FOR THE MAIN ORGANIZERS BEFORE WE START

- Create a timeline the way it fits you (e.g. mind map, Excel sheet etc.)
- Take the week before the event as an off week from other responsibilities to have full capacity to focus on the event itself & management
- Delegate – when there is a task, always ask yourself if it is possible to be delegated; management of the event is already a full time workload; don't forget to ask for help when needed
- Do not underestimate preparation for each small task during the preparation.
- Stay healthy :) – take care of yourself too – relax & have fun!
- Keep in touch with all stakeholders

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WORKSHOP GUIDE

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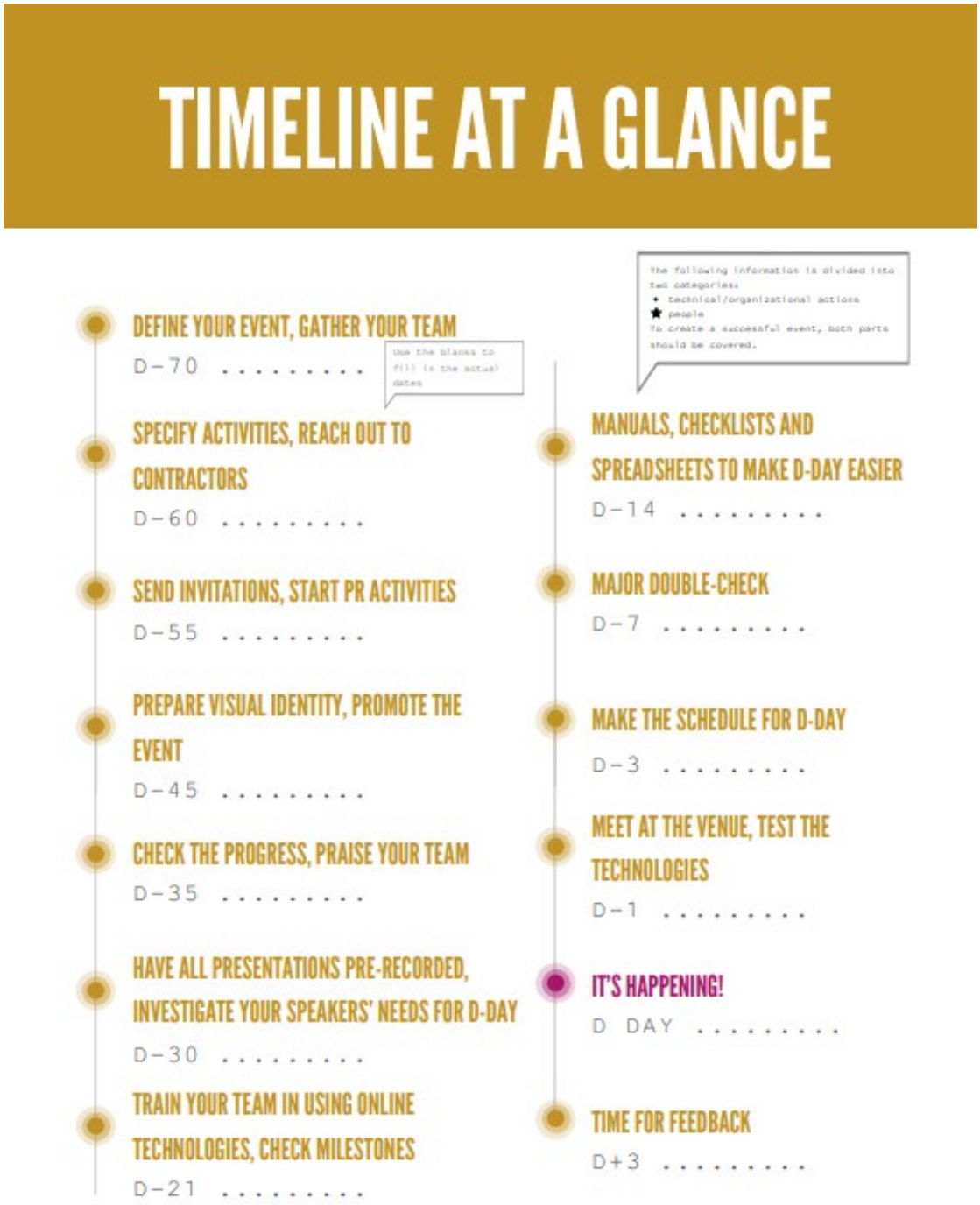

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D-70a / DEFINE YOUR EVENT, GATHER YOUR TEAM

TECHNICAL / ORGANISATIONAL ACTIONS

- Define what kind of event you are going to host. How many people will be involved in the preparation, how many guests are expected to join. Calculate how many people you need in the organizing team.
- Clarify the expectations and goals of the event
  - It is important to agree on the flow of the event, speakers and content. Keep in mind that it is a validation workshop.
  - Also, remember that the organizer is responsible for creating the final summary of the event.
- Set the budget.
  - Create a list of the costs and estimate the price.
- Set the time budget. Clarify the capacity of each organizer. Plan the most important and demanding tasks.
- Make a timed plan. Agree on the plan with the key stakeholders.
  - The best way is to divide tasks according to months, create SMART goals for each part, time them and assign a responsible person.
- Collaborate with WP10 – make sure you are on the same page and communicating fluently.
  - WP10 is also responsible for the official webpage and communication towards various stakeholders. Make sure to have time for the tasks given by WP10. Tip: create your local webpage in your own language in order to reach out to a broader audience. Especially in countries where English is not the official language.

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D-70b / DEFINE YOUR EVENT, GATHER YOUR TEAM

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70 .....
SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60 .....
SEND INVITATIONS, START PR ACTIVITIES
D-55
PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45
CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35
HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30
TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21
MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14
MAJOR DOUBLE-CHECK
D-7
MAKE THE SCHEDULE FOR D-DAY
D-3
MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1
IT'S HAPPENING!
D DAY
TIME FOR FEEDBACK
D+3

PEOPLE

- Establish the organizing team.
  - 2 main coordinators
  - 1-2 support organizers
  - 4 (or more) "assistants" for the day of the event. The number depends on the planned number of workshop groups. They can be called in approximately two weeks before the event. It is not necessary to have them on board the whole time.
- Clearly define the responsibilities within the team.
  - In our case one person was:
    - coordinating the whole process
    - taking care of deadlines
    - communicating with SHAPES partners involved in the dissemination activities (as they are responsible for promotion and you will need to create the content for the posts)
    - communicating with the speakers (setting deadlines, clarifying goals of the event, exchanging information)
    - communicating with the participants (creating forms, sending out invitations; this task can be delegated)
    - managing the team
    - overseeing the budget
  - Second person was:
    - taking care of the technical part (negotiating with the technical partners)
    - arranging translations (provide full support for the deaf and blind community throughout the event; communicate with the DBC representatives)
    - taking care of logistics
    - supporting the first person with anything that was needed (be prepared to complete ad-hoc tasks)
  - Third person was:
    - promoting the event on social media (locally; as dissemination is part of the agenda of WP10)
    - inviting local guests (e.g., NGOs, university lecturers and students) Tip: Create the guest list in a team and contact rather more people than less.
    - creating promotional materials (bags, pens, sticky notes with SHAPES logos) -> later responsible for sending them out
  - In our case the process was supervised by the UP team/WP2 leader. It was highly valuable to have this support as we were able to reach out to many interesting speakers, possibilities and support. We suggest having senior researchers/project managers on board.
- Agree on regular team meetings (live or online) until D-day.
  - Create minutes from each meeting. This will save you a lot of time.
- Create one place where all the materials will be collected (e.g., google drive, if not everyone has access to SHAPES Teams).

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D-60 / SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7

MAKE THE SCHEDULE FOR D-DAY
D-3

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY

TIME FOR FEEDBACK
D+3

TECHNICAL / ORGANISATIONAL ACTIONS

- Prepare a rough time schedule for the day – this will be needed for potential contractors to prepare quotations.
- Specify what activities/services will be needed (such as recording presentations, subtitling, transcription, translation, sign language, graphic design, etc.)
- Review the capacities in terms of technology you (your organization) have available and decide whether it (and what) is to be done in-house/outsourced.
- Select the streaming channel (e.g., YouTube).
- For the outsourced services – contact potential contractors, check their availability, technical capacity, references, request quotations.
- For the interactive workshops – select the online platform to be used (recommended: Zoom) and obtain sufficient number of licences corresponding with the number of groups for workshops (each session must have its own dedicated host).

PEOPLE

★ Prepare a list of candidate participants – names, organizations, email addresses.
★ Define what information is to be collected from the participants in order to plan the event to satisfy any of their communication or other needs (keep GDPR regulations in mind).
★ Design an invitation and registration form. Do not forget to set a deadline for closing the participant list. Tip: D-30 is recommended as the requirements by the participants trigger some other services to be arranged for.
★ Define a list of speakers and the topics to be covered. Tip: Have a moderator to open up the conference with general information, technical information, to link the individual presentations together in one coherent whole.
★ Contact the speakers to make sure they are on board.

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D-55 / SEND INVITATIONS, START PR ACTIVITIES

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55 .....

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45 .....

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7

MAKE THE SCHEDULE FOR D-DAY
D-3

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY

TIME FOR FEEDBACK
D+3

TECHNICAL / ORGANISATIONAL ACTIONS

- Select your contractors.
- Send out purchase orders to your contractors, clearly defining their responsibilities and deadlines/milestones until D-day and cancellation policy (including cancellation fees or late delivery penalties). Request written (email) acceptance of POs. Alternatively sign written agreements with your contractors.
- Respond to the unsuccessful candidates for contractors saying thank you and kindly asking them whether you can keep their contacts, if needed. This is the basis for an emergency plan.
- Prepare a minute-by-minute script of the event. Share it with your contractors and the team.
- Book your D-day rooms. Investigate the type of Internet connection. Broadband (optic fibre) is a must. One workshop group = one room. All close to each other in one building.

PEOPLE

★ Start sending out invitations and registration forms. Tip: Create one common e-mail address that can be accessed by all team members. Use only this address from this day on.
★ Kick-off of PR activities – create content for website/social media.
★ Decide whether you want to support your online event with actual gifts to be sent to your participants (pens, printed promotional materials, etc.) – if so, investigate the options, lead times, prices.
★ Connect your speakers and your presentation recording contractor in order to start pre-recording the presentations. The contractor is to provide them with technical guidelines and details of how to record their presentations.
★ Set realistic deadline for the recording and START RECORDING (more ambitious is better as this gives all stakeholders involved maneuvering room for any errors in the process) and share this deadline with both your speakers and your
★ contractor. Tip: D-30 would be ideal (as it may easily end up as D-21 deliveries).
★ Ensure flow of information to all stakeholders involved – your team, your speakers, your contractors.
★ Inform "down the stream" contractors (subtitlers, transcribers, sign language interpreters, etc.) that as of D-30 they should be ready to start working on their part of the project.

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D-45 / PREPARE VISUAL IDENTITY, PROMOTE THE EVENT

TECHNICAL / ORGANISATIONAL ACTIONS

- Prepare (or ask the contractor) to prepare a visual identity of the event (using your project logo, your organization logo, EU funding information, etc.) including Presentation template.
- Review your budget.
- Promote the event. Send out reminders for registration.

PEOPLE

- ★ Team meeting to check progress, milestones, discuss and address any challenges, share any other information.
- ★ Talk to your people about what they are worried about, address their concerns, define actions to address these concerns.
- ★ Praise your team for their effort!
- ★ Regularly update the list of registered participants, checking their needs – and act accordingly, if needed.

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D-35 / CHECK THE PROGRESS, PRAISE YOUR TEAM

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7

MAKE THE SCHEDULE FOR D-DAY
D-3

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY

TIME FOR FEEDBACK
D+3

TECHNICAL / ORGANISATIONAL ACTIONS

- Prepare some (audio)visual content for the "coffee breaks" (if any). Tip: great opportunity to introduce your organization, your city/country better - since this is an online event.
- Check the progress of the tasks - check deadlines, needs of the speaker and the external providers.

PEOPLE

- ★ Team meeting to check progress, milestones, discuss and address any challenges, share any other information.
- ★ Praise your team for their effort!
- ★ Regularly update the list of registered participants, checking their needs - and act accordingly, if needed.

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D-30 / HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7

MAKE THE SCHEDULE FOR D-DAY
D-3

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY

TIME FOR FEEDBACK
D+3

TECHNICAL / ORGANISATIONAL ACTIONS

- Together with the contractor check whether all pre-recorded presentations have been delivered. If not, contact the speakers with a friendly deadline reminder. Ask them if there is anything you can help them with to deliver their pre-recorded presentation as soon as possible.
- Organize (or check that the contractor organized) the transfer of the pre-recorded and pre-processed presentations to providers of other services – transcription, subtitling, sign language.
- Set clear deadline for the "downstream" services. Tip: D-10 as it allows you to address any challenges on the way.

PEOPLE

★ Close the registration. Review all registrations for any additional services required. Act accordingly.
★ If live interpreting from English to any other language is
★ required, contract simultaneous interpreting services. Tip: Zoom offers simultaneous interpreting feature OR Google doc uses voice dictation for voice to text interpreting. 2 interpreters are needed! Update the budget.
★ Based on the number of registered participants order promotional materials to be sent out as gifts.
★ Start preparing groups of participants for the interactive workshops depending on their characteristics/needs/requirements (names and email addresses in one Excel spreadsheet).
★ Ask speakers about their needs for D-day. Make sure your plan/D-day checklist covers them.

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D-21 / TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES

TECHNICAL / ORGANISATIONAL ACTIONS

- Select plan B platform. If Zoom fails on D-day, you need to have another online platform. Tip: We used Big Blue Button.
- Make sure all the team members and assistants are familiar with all the technologies. Try things out, enjoy the process of learning.

PEOPLE

- ★ Team meeting to check progress, milestones, discuss and address any challenges, share any other information.
- ★ Praise your team for their effort!
- ★ Start training your assistants in using the workshop online platforms (Zoom, BBB). Apply the hands-on approach – they all have to try the necessary features. Zoom offers a multitude of webinars and training materials. The two coordinators need to familiarize themselves with the application to be able to share their skills with the assistants.

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D-14 / MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER

TECHNICAL / ORGANISATIONAL ACTIONS

- Prepare a short manual for participants how to Zoom (e.g., launch Zoom meeting, mute/unmute…). Do not assume they are experienced Zoom users.
- Organize an e-meeting with the contractors to check their progress, any milestones, any concerns. "Face-to-face" communication is better than many e-mails.

PEOPLE

- ★ Prepare an email with information to be sent to the participants – INCLUDING LINKS FOR WORKSHOPS + DETAILED SCHEDULE OF THE DAY.
- ★ Prepare a checklist for the assistants for D-day workshop sessions, specifying what is to be said and done at the beginning of each session, during and at the end. Tip: check out our checklist in the Appendix. Provide the assistants with a detailed schedule of the event.
- ★ Prepare a spreadsheet with contact information – organizers, speakers, assistants. This will ensure smooth exchange of information.
- ★ Organize a Zoom meeting between your speakers and assistants. Introduce the assistants to the speakers and explain their roles. Ask the speakers what Zoom features they would like to use (e.g., polls, breakout rooms). Discuss plan B.
- ★ Second round of training for the assistants, both platforms.

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D-7 / MAJOR DOUBLE-CHECK

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7 .....

MAKE THE SCHEDULE FOR D-DAY
D-3 .....

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY

TIME FOR FEEDBACK
D+3

Check that all the above have been completed! By now all presentations should be recorded, subtitled, sign language (if required) translation recorded, interpreters contracted and confirmed. All individual elements should be put together.

TECHNICAL / ORGANISATIONAL ACTIONS

- Contact your local IT support to be ready in case something goes wrong. Make sure you have people on board ready to help.
- Ideally a week before the event you should have a rehearsal of the event. See the pre-recorded video compilation and discuss the content and form of each interactive workshops. Tip: find out the most suitable day through doodle application and make sure all the stakeholders are available (external providers, speakers, assistants, translators, organizers, etc.)

PEOPLE

- ★ Organize a Zoom meeting with your interpreters and your transcribers. Plan how they are going to work in detail. Use this information for the session opening speech to explain your participants how to use these services, if required.
- ★ Inform the speakers before the event what is expected from them after the event (e.g., a one-page summary to the newsletter).
- ★ Organize an online team meeting to review the plan step-by-step to make sure everything is ready to prevent any potential disasters!

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D-3 / MAKE THE SCHEDULE FOR D-DAY

- **DEFINE YOUR EVENT, GATHER YOUR TEAM**
  D-70
- **SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS**
  D-60
- **SEND INVITATIONS, START PR ACTIVITIES**
  D-55
- **PREPARE VISUAL IDENTITY, PROMOTE THE EVENT**
  D-45
- **CHECK THE PROGRESS, PRAISE YOUR TEAM**
  D-35
- **HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY**
  D-30
- **TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES**
  D-21
- **MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER**
  D-14
- **MAJOR DOUBLE-CHECK**
  D-7
- **MAKE THE SCHEDULE FOR D-DAY**
  D-3 .....
- **MEET AT THE VENUE, TEST THE TECHNOLOGIES**
  D-1 .....
- **IT'S HAPPENING!**
  D DAY
- **TIME FOR FEEDBACK**
  D+3

PEOPLE

- ★ Prepare a draft of the opening session speech. It prevents important information from being left out at the beginning, during and at the end of every session.
- ★ Divide participants into groups (if relevant) and send out all the invitations (e.g., zoom links).
- ★ Create a schedule for the organizing team. Be there to support.

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D-1 / MEET AT THE VENUE, TEST THE TECHNOLOGIES
DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70
SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60
SEND INVITATIONS, START PR ACTIVITIES
D-55
PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45
CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35
HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30
TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21
MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14
MAJOR DOUBLE-CHECK
D-7
MAKE THE SCHEDULE FOR D-DAY
D-3
MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1
IT'S HAPPENING!
D DAY
TIME FOR FEEDBACK
D+3
TECHNICAL / ORGANISATIONAL ACTIONS
• Organize a meeting of your team at the venue. Final technical rehearsal for Zoom sessions. Any concerns, problems to be addressed. All technical equipment such as chargers, adapters for Internet connections, headsets, extension cords to be prepared and kept at the venue.
PEOPLE
★ Decide who is going to follow the morning streaming to answer questions posted in the chat.
★ Motivate your team before the event. :-)
★ Buy snacks, drinks, energy boosters for D-day.
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D-DAY / IT'S HAPPENING!

DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70

SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60

SEND INVITATIONS, START PR ACTIVITIES
D-55

PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45

CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35

HAVE ALL PRESENTATIONS PRE-RECORDED, INVESTIGATE YOUR SPEAKERS' NEEDS FOR D-DAY
D-30

TRAIN YOUR TEAM IN USING ONLINE TECHNOLOGIES, CHECK MILESTONES
D-21

MANUALS, CHECKLISTS AND SPREADSHEETS TO MAKE D-DAY EASIER
D-14

MAJOR DOUBLE-CHECK
D-7

MAKE THE SCHEDULE FOR D-DAY
D-3

MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1

IT'S HAPPENING!
D DAY .....

TIME FOR FEEDBACK
D+3 .....

TECHNICAL / ORGANISATIONAL ACTIONS

- Arrive early to your booked venue.
- Test that power and internet connections work.
- Have all the necessary equipment ready.
- Be ready for the streaming and follow and answer the questions in the chat.
- When the time comes, open the Zoom session rooms early. Connect with the speakers.
- Follow D-day checklist (see Appendix).

PEOPLE

- Prepare your refreshments.
- Cheer your team up!
- Pre-order lunch!
- Have one person (coordinator) available to address any problems/issues the individual session assistants may have.
- Send out feedback forms.
- Celebrate :) !

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D+3 / TIME FOR FEEDBACK
DEFINE YOUR EVENT, GATHER YOUR TEAM
D-70
SPECIFY ACTIVITIES, REACH OUT TO CONTRACTORS
D-60
SEND INVITATIONS, START PR ACTIVITIES
D-55
PREPARE VISUAL IDENTITY, PROMOTE THE EVENT
D-45
CHECK THE PROGRESS, PRAISE YOUR TEAM
D-35
D-30
D-21
D-14
MAJOR DOUBLE-CHECK
D-7
MAKE THE SCHEDULE FOR D-DAY
D-3
MEET AT THE VENUE, TEST THE TECHNOLOGIES
D-1
IT'S HAPPENING!
D DAY
TIME FOR FEEDBACK
D+3 .....
PEOPLE
★ Collect summaries from the speakers.
★ Collect feedback form.
★ Prepare a report based on the summaries!
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LESSONS LEARNED

- The biggest challenge was to collect the videos from all the speakers for the first part of the day. It is important to set rather short deadlines and rely on reminders after the deadline, rather than expecting the speakers to send the videos before the deadline.
- Also, it is important to take time to find the best solution for external providers. Do not settle with the first possibility - check for price and reputation. In a contract/PO clarify consequences if not delivered on time.
  - Moreover, discuss "worse case scenarios" or "risk management" of the collaboration and create back-up plans together.
  - Prevent the situation where you are constantly reviewing the outcomes of the external provider's work. It is extremely demanding and frustrating to check the outcomes in the end, if the provider is not responding to your questions.
- From the workshop coordinator position it is key to delegate as many tasks as possible. As your role should really be "only" coordinating.
- Keep the team spirit and the flow of information among the team members. Stay open to suggestions and tips how to make things better.
- Keep boundaries and reflect on ongoing process. It is important to discuss frustrations and problems rather than hiding from them. Almost everything can be solved and this should be the common mindset among team members.
- Suggestion for the future: discuss the length of the online event. It was suggested by some of the participants to have the morning pre-recorded part followed by only two interactive workshops and keep the other two for the next day.
  - This approach has its downside in terms of losing the flow of the event. On the other hand, participants could possibly be more engaged. It is definitely a topic to be discussed.
  - Moreover, do not make the workshops longer than 1 hour and keep the breaks. Online presence is highly demanding.
- As the final summary report is highly important for SHAPES, it is better to partially delegate this task. Those who are moderating the sessions could also take notes. These notes would be greatly appreciated for the final summary.
- Assistants (and speakers) could also be trained in facilitating the discussions. It is useful to share some tips on how to make a presentation engaging, specifics of online communication, etc.
- The sooner you start establishing the technical parts, the better. E.g., Enabling YouTube streaming should be done in the early stage of the whole process.
- Ask! Make sure you understand how things are done by the external provider. Ask your team & speakers open ended questions.

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D-DAY CHECKLIST

Have a special checklist for every Zoom session

WHAT TO DO BEFORE START

TECHNOLOGY	READY
Computer connected to the charger	
Use cable for internet connection	
Headset connected	
Telephone connected to the charger	
Open FB/Messenger for team communication	
PHYSICAL AND MENTAL WELLBEING	**READY**
Water!!! Keep hydrating.	
Snack? Cookie? Fruit?	
Do powder your nose when you need to!	
Stretch between workshops	

BEGINNING OF THE WORKSHOP

FOR ALL	READY
Say "we are going to wait a few more minutes"	
Welcome - opening speech	
Inform about recording	
START RECORDING	
FOR TRANSCRIPTION / INTERPRETING	**READY**
Inform participants how to take advantage of transcription/interpreting services	
Copy links for shared Google docs into the chat	
FOR THE TEAM	**READY**
Drop a line to your team at FB:	
• OK, rolling!	
• NOK, problem - help!	

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D-DAY CHECKLIST

Have special checklist for every Zoom session

END OF THE WORKSHOP

5 MIN PRIOR TO THE END	READY
Remind that the time is up - a private chat message may be sent to the speaker	
END	**READY**
Thank you for joining us! Sorry the time is up! Great ideas! Enjoy the upcoming workshop!	
STOP RECORDING	
FOR THE TEAM	**READY**
Drop a line to your team at FB: • Almost done, finishing up - finished!	

END OF THE LAST WORKSHOP

	READY
Save videos! (it takes some time)	
Closeout session!	

//07

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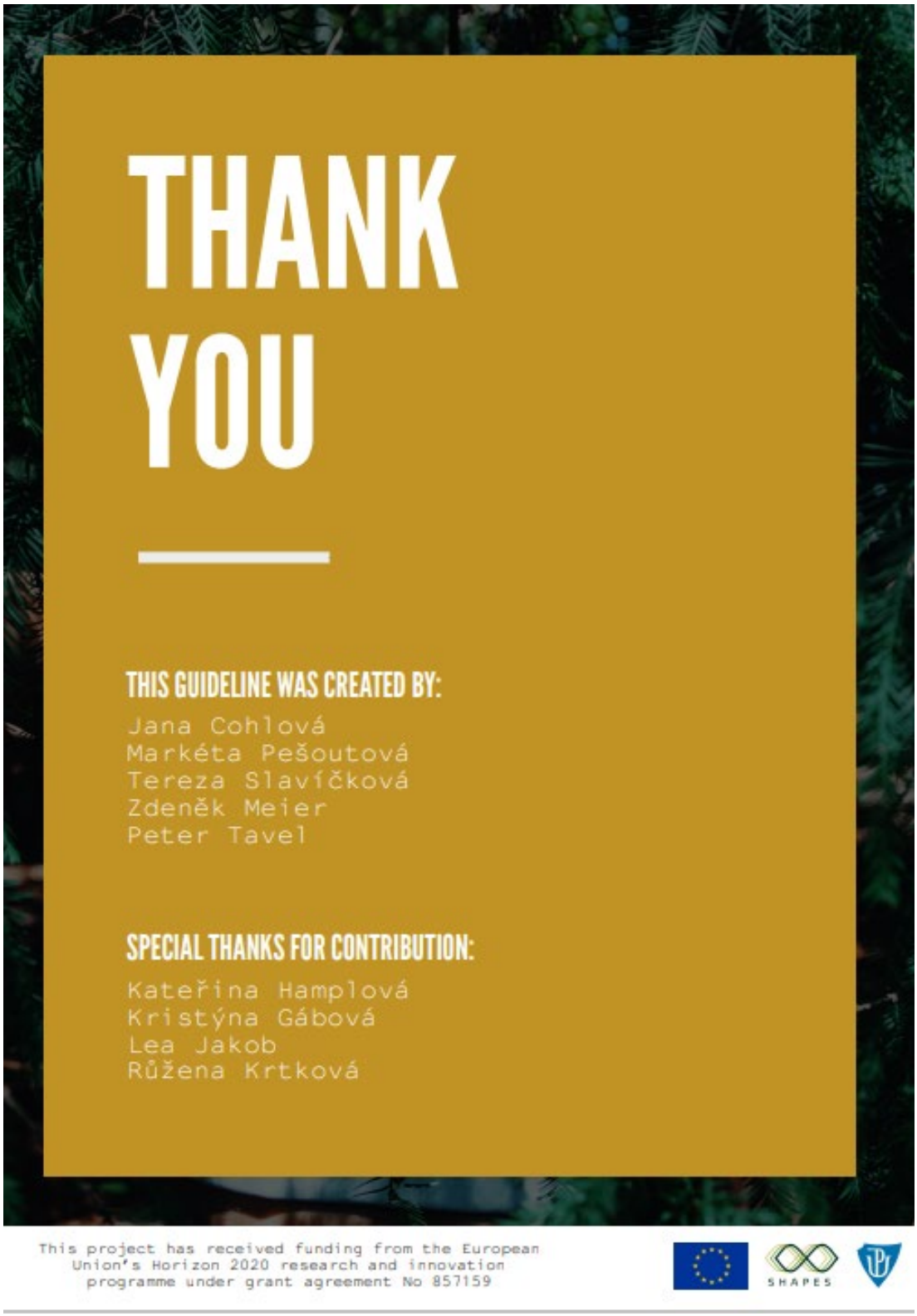
THANK
YOU
THIS GUIDELINE WAS CREATED BY:
Jana Cohlová
Markéta Pešoutová
Tereza Slavíčková
Zdeněk Meier
Peter Tavel
SPECIAL THANKS FOR CONTRIBUTION:
Kateřina Hamplová
Kristýna Gábová
Lea Jakob
Růžena Krtková
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Annex II

SHAPES - 2nd Dialogue Workshop

SHAPES Integrated Care Workshop

29 October 2020 (9:00 – 16:40)

Fully accessible morning session talks on Youtube and virtual interactive sessions on Zoom
(links will be provided to registered participants).

Agenda (Time Zone: CET)

9:00 - 9:15	Welcome and Introduction - Philip Franke, CCS (15 min)
9:15 – 9:35	Introduction to SHAPES - Prof. Mac MacLachlan, NUIM (20min)
9:35 – 9:45	**Governance of Health Systems in Selected European Countries** - Dr. Melanie Labor, NUIM (10 min)
9:45 – 10:20	**Interview: Integrated Care in European Context and Comparison**: Prof. Michael Scott, NHSCT, Dr. Rania Pinaka, 5th DYPE and Dr. Pedro Rocha, UPORTO (35 min)
10:20 – 10:30	**The Future of EU Health Policies - Lessons to be learnt from the COVID-19 pandemic** - Prof. Delia Ferri, NUIM 10 min)
10:30 – 10:40	**SHAPES High Level Architecture and Information Exchange Challenges** - Dr. Alexander Berler, GNO (10 min)
10:40 – 10:50	*Coffee break (10 min)*
10:50 – 11:00	Introduction to 4 parallel interactive sessions: each participant will be assigned to one of four groups and will be able to contribute to all four sessions (10min)
11:00 – 11:10	*Attendees join their Zoom groups and sessions (10 min)*
11:10 – 12:00	Interactive session #1 (all topics in parallel - 50 min)
12:00 – 13:20	*Lunch break (80 min)*
13:20 – 14:10	Interactive session #2 (all topics in parallel - 50 min)
14:10 – 14:25	*Break (15 min)*
14:25 – 15:15	Interactive session #3 (all topics in parallel - 50 min)
15:15 – 15:30	*Break (15 min)*
15:30 – 16:20	Interactive session #4 (all topics in parallel - 50 min)
16:20 – 16:30	*Break (10 min)*
16:30 – 16:40	Closing remarks (10 min)

Topics per session:

Topic 1: **Good Practice Examples of Integrated Care, Lessons Learned and Future Concepts** by Dr. Olaf Müller, CCS Carolus Consilium Sachsen

Topic 2: **User Perspectives on Integrated Care** by Borja Arrue Astrain, AGE Platform Europe

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Topic 3: **First Ideas about Scaling up SHAPES Integrated Care** by Evert-Jan Hoogerwerf, AIAS Associazione Italiana Assistenza Spastici

Topic 4: **Required Mindset of all Stakeholders to Make Integrated Care Work and Strategy to Establish this Mindset** by Prof. Malcolm MacLachlan, NUIM Maynooth University

Participant groups by topics:

	Participant Group	1	2	3	4
11:10 - 12:00	Session #1	Topic 1	Topic 2	Topic 3	Topic 4
13:20 - 14:10	Session #2	Topic 2	Topic 3	Topic 4	Topic 1
14:25 - 15:15	Session #3	Topic 3	Topic 4	Topic 1	Topic 2
15:30 - 16:20	Session #4	Topic 4	Topic 1	Topic 2	Topic 3

Overview

Integrated care focuses on the needs of the recipient of care, on the coordination between diagnosis and treatment, on the links between primary and secondary care, and it connects different therapeutic areas and specialties. Benefits of integrated care models comprise improved outcomes, established chains of prevention, diagnosis and treatment.

However, the complexity of health and care systems poses great challenges. SHAPES aims to provide guidelines, a roadmap and an action plan, including a set of priorities dedicated to standardisation, to support key EU stakeholders to foster the large-scale deployment and adoption of digital solutions and new integrated care services in Europe.

This 2nd dialogue workshop intends to gather representatives from industry, academics, health and care, civil societies as well as older people.

The Workshop will unveil the project's preliminary findings and in particular will:

- Highlight a Co-creation of think tank where to discuss European Integrated Care.
- Present an overview of EU systems and governance for health and care delivery.
- Present legal aspects of integrated care facing COVID-19
- Present first concepts of the SHAPES architecture and user requirements
- Discuss the user perspective and the stakeholder mindset on integrated care
- Discuss first ideas about scaling up SHAPES integrated care

The morning part will be dedicated to talks and interviews focusing on the above mentioned topics (YouTube video). The afternoon will give space for discussion in virtual sub-workshops, allowing greater interaction with and contribution from all participants: each attendee will be associated to each sub-workshop, thus able to attend all 4 sessions in the afternoon (the 4 sub-workshops will run parallel on the Zoom platform).

Links to presentations (YouTube) and workshops (Zoom) will be provided to the registered participants. Language and subtitles: English and German. Interpreting: International Sign.

Register to participate before 26th October 2020:
https://ec.europa.eu/eusurvey/runner/2_SHAPES_Dialogue_Workshop_October2020_eng

The workshop is organised by Carus Consilium Sachsen GmbH, with the support of AGE Platform Europe. For information, please contact **philip.franke@carusconsilium.de**

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Annex III

4 Governance participation: Consultation, empirical investigation and matrix development

4.1 Aims of the consultation

To enable the development of the SHAPES collaborative governance model, we effected broad consultation, using empirical methods. Consultation took three forms: a dialogue workshop with parallel workshops that functioned as a focus group discussion; drawing on data from interviews with integrated care service providers who had implemented person- centred technology, and a governance participation consultation survey. Each of these formsof consultation is reported on in turn in the following sections.

4.2 Dialogue workshops

4.2.1 Discussion

From the individual perspective, a key concern was the role of recipients in integrated care. There remains work to be undertaken to best understand how to facilitate person centredness and incorporating the needs of recipients in the governance of care systems. Particular attention must be paid to the consequences of shifting responsibilities, which could result in responsibilisation. Responsibilisation, or the transfer of all responsibility for decisions and their consequences into the hands of care recipients, presents as a risk. It is a risk which could present as a requirement for care recipients to assume a managerial role and accountability for their own *outcomes*. We obtained relatively little data in relation to the ethical and legal consequences of changes in practices or governance, or indeed of existing systems and processes.

Governance systems and processes, in facilitating person-centred integrated care and activeand healthy ageing, ought to be cognizant of the full spectrum of health-related outcomes andquality of life, and ought to protect healthcare recipients from institutionalisation. The role of communication in the system is a particularly important consideration for governance, as is understanding how systems are interconnected, if at all. Systems with better communication and integration are likely

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to promote better outcomes, better overall quality.

The role of informal caregivers in integrated care was raised numerous times, and the integralrole of informal caregivers in present HSC systems needs due consideration in any model. Ofparticular note was the perception that informal caregivers often assume the role of a mediatoror translator within the care process, although a range of concerns emerged about potential –or likely – mismatch between the needs and priorities of recipients and informal caregivers, including whether informal caregivers accurately represent the needs and views of recipients. Perhaps of particular interest from a governance perspective was how frequently caregivers assume a role in the process of communication between recipients and providers, linking thehealth and social care systems, and making care arrangements. The highly prevalent gendering of informal caregiving is an important finding, particularly in light of the consideration that SHAPES will give to the gendered nature of "smart and healthy ageing at home" (SHAPESGrant Agreement).

A point made in relation to modes of communication is also particularly relevant to how services are structured in response to the SARS-Cov-2 pandemic and how technological innovations are implemented or may drive changes in practice. The pace of innovation in service providers and systems is problematically slow, and it was described as very difficult tointroduce new systems or practices or technology or to implement innovations more generally.

There are some limitations to consider when interpreting the findings. While the 2nd SHAPES Dialogue Workshop sessions did facilitate the collection of individual perspectives on health and social care governance, a full appreciation of all the moving parts in the governance structures and processes in health and social care was not elicited. This is partly reflective ofthe care system related roles of the session participants. There were few, if any, participants who had a role in care system governance, particularly at the macro level. The sessions werealso limited by the amount of time available for discussion; 20 minutes of discussion time in parallel, plus a further 20 minutes for collective discussion.

In uncovering some elements of the individual perspective on governance, these findings imprint the perspective of integrated care and person-centredness on the process of understanding governance structures and processes.

4.2.2 Aim of the workshops

We aimed to gain insight into existing governance structures and processes from the standpoint of individual actors, specifically care recipients, their families, and their informal caregivers. Our principal objective was to generate a descriptive understanding of existing systems and

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experiences across Europe. Systems change and evolve, and so any care platform or ecosystem, such as SHAPES, must be responsive to change in both design and implementation. Designing health and social care systems in line with the principles of integrated care is desirable to improve quality, efficiency, and stakeholder experiences. Suchredesign is also a present reality and increasingly likely in the future (Hughes et al., 2020). Therefore, we also wished to scope the injunctive, or how participation in decision making and governance might occur or might be facilitated in care systems that are integrated.

4.2.3 Workshop method

The 2nd SHAPES Dialogue Workshop was held online on October 29th, 2020. At the workshop,we facilitated group discussions with the aim of understanding existing governance structuresand processes from the standpoint of the individual.

We facilitated a total of nine individual group discussion sessions in total across the day acrossthe four interactive sessions scheduled on the day. The first four of these occurred in parallel,followed by the next two in parallel, the next two again in parallel, and one final group discussion. After each of the first three sets of parallel sessions, all of the parallel sessions convened for a summary discussion.

Participants were prompted to discuss various open questions about HSC governance acrossthree broad categories: agency and responsibility, risks and implications, and sustainability.

- Agency and responsibility: Who are the decision makers? To what extent is decision making participatory? What are the channels of communication? How are decisions made? To what extent is informed consent sought and at what point in the health andcare process?
- Risks and implications: What are the potential risks/implications if more responsibility is shifted to the individual? What does it mean for accountability? What are the ethicaland legal implications?
- Sustainability: How can sustainability of the individual situation be ensured beyond the crisis?

Additionally, participants were provided with the following vignette to prompt discussion and ground the discussion in the consideration of the individual perspective:

> *Mary is an older adult healthcare recipient. Following a fall, she is admitted to hospital. The hospital has deemed Mary to be medically ready to leave acute care*

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and the hospital 'needs the bed'. Mary would really like to go home. However, Mary faces health-related challenges. She has difficulty taking blood sugar readings, needs to manage chronic illness, and experiences forgetfulness. As well as specialised clinical assessment, Mary may need tertiary or rehabilitative care and adaptations in the home environment. Mary lives alone, but has two adult children, one of whom lives near her home.

The responses of workshop participants were recorded by facilitators, with notetakers assigned to each parallel session. Responses were then subjected to a qualitative, thematic analysis; coded and categorised thematically.

4.2.4 Workshop findings

There were approximately 55 to 60 participants across the 9 separate sessions. Participants included physicians, engineers, healthcare recipients, and academics (including social scientists and economists). One parallel session included participants with hearing impairments and these sessions were facilitated with live signing and transcription.

The discussion topics were distilled into seven broad themes, which are:

- Actors and Inclusion in the Care Process and Decision Making
- Dis/Connection and Non/Communication Between Health and Social Care Systemsand Components
- Funding Mechanisms and Equity of Access
- Non-Integration Engendering Worse Outcomes and Institutionalisation
- Informal Caregivers as Care Coordinators, Mediators, and Persons with Needs Divergent from Recipients
- Agents of Change: The Pandemic and Technology
- Risks and Ethical and Legal Implications

4.2.4.1 Actors and Inclusion in the Care Process and Decision Making

Discussion participants highlighted that involving health and social care recipients in the care process is main aim of integrated care and is a precondition for ensuring quality of care. The need to ensure the voice of the recipient. Participants spoke of the need to hear the person inneed of care, to fully explain all alternatives in terms of care options, to involve recipients in care decision making, and to offer alternatives to the care recipient. Participants variously described care

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recipients, informal providers or family, formal providers (e.g., physicians, occupational therapists, physiotherapists, psychologists), administrators and managers, and engineers as decision makers. Although, some participants cited professionals (e.g., physicians and engineers) as the appropriate decision makers as a function of their (professional) expertise participants generally agreed that the recipient should be the primary decision maker. Decision-making processes were described as asymmetric with participants, directly or indirectly, telling of thepower imbalance between recipients and other actors within health and social care systems. Physicians and administrators in particular were held to possess much more power and influence in decision making than care recipients. In reference to this hierarchy, it was said that while the care recipient may be in a position to decide on care, they may feel too shy, or be reluctant to express opinions that differ from those of physicians.

Participants reported that currently recipients may not always be enabled or empowered to make informed decisions. For example, this partly related to recipients not having the requisiteformal medical knowledge and training to fully evaluate alternative options and their consequences. Participants also cited insufficient communication and a lack of presentation and full explanation of alternatives to recipients. The need to communicate and explain to participants in ways that meet each recipient's accessibility needs was also highlighted. This also related to the point that recipients ought not be made accountable or legally responsiblefor decisions. This was especially so when recipients may not be in a position to make fully informed decisions.

4.2.4.2 Dis/Connection and Non/Communication Between Health and Social Care Systems and Components

Issues of connection and communication between systems were often linked. Participants generally reported disconnection between the health or 'medical' care and social caresystems, with these systems being conceived as separate systems, and operating as such inmost of the referenced countries and regions. Additionally, numerous participants reported a lack of communication between whole systems, between service providers, and between thesystem and the care recipient. This was also reported to be the case across several countriesor regions. This separation of care systems, and the absence or insufficiency of communication was cited as a major barrier to integrated care. Participants identified the slowprocess of innovation in service providers and systems as problematic and that it was very difficult to update provision with new systems or technology or implement innovations.

One participant described discharge from hospital as a "done deal". Taking the example of discharge from acute care, there was general disconnection although there were some differences in the degree of integration across countries and regions. In Greece, there was reportedly no structure to coordinate the health and social care systems; arrangement was

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dependent upon family. In Germany also, the system was dependent upon the availability of informal care. One participant mentioned that in Germany, many with the means to do so seek private home care provision, with these services often being provided by caregivers from Eastern Europe (implicitly: less wealthy countries). In Portugal, it was outlined that the only contact from the hospital was to arrange for collection from the hospital on discharge. In Spain,healthcare is the responsibility of regional authorities with variation in progress towardintegration. In one region, there is reportedly a complete divide between health and social care, with no communications or sharing of information. In Ireland a community nurse was reported in one case to have made contact prior to discharge, although the extent of this contact was not reported. Recent and/or ongoing system developments in Northern Ireland involved development of a prototype system where health and social care systems "talk to each other" and stepdown care packages. These were aimed at improving integration and continuity of care, facilitated by improved interparty communication. Relating to Northern Ireland, there was a full evaluation by the social worker. This often meant that recipients had longer acute stays while this was completed. Participants were unsure to whom those evaluations were sent. Funding mechanisms, structures, and systems relate to this issue of dis/connection. The need to have a care package in place prior to discharge was highlighted.

4.2.4.3 Funding Mechanisms and Equity of Access

Participants discussed the funding sources of health and social care systems in partner countries. Relatedly, participants discussed access and equity of access to social care. Whilea wealth of specific detail on care funding mechanisms did not emerge, there were some points of note. Participants identified differences in whether certain elements of social care were publicly funded across different countries. In Spain, homecare is typically not means tested. For Nordic countries, and Finland specifically, it was reported that there is universal access to home care, but wealthier people might choose private services. Structures in Finland and Sweden were described as partially decentralised. Private, formal caregiving and informal caregiving may be filling a gap of care provision needs left by public services.

4.2.4.4 Non-Integration Engendering Worse Outcomes and Institutionalisation

Participants reported that non-integration of care leads to worse health and social care outcomes. It creates barriers to the sustainability of independent living and to HSC recipients'ability to remain in their own home if that is their preference. This non-integration of systems engenders institutionalization, which is directly in contravention of the UN *Convention on the Rights of Persons with Disabilities*. The need to recognise people with disabilities not as patients but as people with rights and freedoms was expressed.

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4.2.4.5 Informal caregivers as care coordinators, mediators, and persons with needs divergent from recipients

Participants highlighted the integral role of informal caregivers (e.g., care recipients' family members) in existing health and social care systems, and the systems' reliance on informal caregivers. The importance of informal caregivers as care coordinators was highlighted. Informal care providers were reported to play a major role in connecting health and social careservice providers, linking recipients to different parts of existing systems, and often arrangingor organizing care or assisting recipients in doing so. In many cases informal care providers act ostensibly as mediators between the care recipients and formal care providers.

It was noted however, that informal providers may not accurately or fairly represent the wishesof care recipient with complete reliability; informal caregivers may have conflicting views, priorities, or objectives. It was also noted that informal caregivers were not always available to assist recipients. This could be due to the recipient not having family, or having difficult relationships, or with informal caregivers having limitations on what they can provide themselves. Indeed, informal caregivers' have their own needs (which, as noted above, may not match those of recipients), and may lack relevant supports.

The gender bias in informal caregiving was made clear, with women providing a disproportionately much higher share of informal care. In addition, psychosocial sequelae of informal care provision were outlined. This included psychological wellbeing and feelings of guilt in relation to providing, inability to provide, feeling obliged to provide, and being relied upon by formal systems to provide health and social care.

The family have been said to play a more central role in some parts of Europe – Spain and Portugal for example – than in other parts, such as Finland, where formal homecare meets the needs of care recipients.

4.2.4.6 Agents of Change: The Pandemic and Technology

In addition to the push of prevailing socioeconomic conditions and demographic changes, the ongoing coronavirus pandemic has reiterated and reinforced the need for integrated care to ensure continuity of care. It has highlighted problems of lack of coordination and gaps in care provision; COVID was exposing silos. It was also reported that pathways of care haddisappeared during lockdown, and that mortality had increased because of lack of monitoring.

Participants felt that the pandemic may catalyse the development of integrated care by way of necessity. However, participants also noted that the pandemic and associated public health lockdown measures may obscure a portion of true care needs. One contributor to this might be

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the different or additional capacities of informal caregivers to provide assistance or care under lockdown conditions that they otherwise might.

Technology was described as helpful, though not a substitute for informal care. Another participant described technology as very important to facilitate recipients' connectivity to family, support services, and emergency services. Technologies should be designed in such a way that even in situations where the recipient is experiencing panic or impairment, that theycan use the device.

4.2.4.7 Risks and Ethical and Legal Implications

Participants identified risks in the event of changes in responsibilities or the allocation and distribution of responsibility. Participants identified ethical issues around the sharing of data between providers. They raised the question as to whether recipients would have the ability to (reliably) make the correct self-assessments of health status alone at home.

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Annex IV

Diversity and empowerment: understanding the realities of older people

On-line dialogue workshop
26 October 2021, 10:00 – 13:00 CET

Where: Zoom Webinar https://us06web.zoom.us/j/84360732986

The workshop will be in English, and simultaneous interpretation will be available in *Italian, Spanish and German.* English sign language interpretation available, and speech-to-text across the four languages.

Registrations:
https://ec.europa.eu/eusurvey/runner/SHAPESDialogueWorkshop_26102021

Rationale

Our ever-changing world makes us face numerous challenges, many of which affect our quality of life, personal health and care systems. Replying to those challenges requires a comprehensive and yet detailed understanding of each individual and the real-life contexts in which people live.

Do you feel you master your well-being? Are you at the driving seat regarding the way you are catered for?

Understanding ageing in its complexity is the ethos of the Horizon2020-funded SHAPES project, developing a whole organizational, structural, social, and technological ecosystem for ageing well.

This workshop will be a dialogue between older people, people with disabilities, academics, researchers and the general public. By exposing the lived realities of older people and people with disabilities, the workshop will seek to challenge prejudices around ageing. It will exhort participants to get closer to people's realities and experiences. The workshop will show the ways in which SHAPES is working hard to respond to users' needs, as illustrated by the #SHAPESstories.

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Agenda

10:00 Welcome and introduction to the workshop by AGE Platform Europe

10:05 The various shapes of SHAPES: Mac MacLachlan, National University of Ireland Maynooth

10:15 Understanding ageing and disabilities:

- AGE Platform Europe, Joke de Ruiter-Zwanikken (5 min)
- World Federation of the Deaf-Blind, Sanja Tarczay (10 min)
- European Union of the Deaf, Mark Wheatley (10 min)

Q&A (10 min)

10:50 Real-life stories shaping lives, individuals and societies: the SHAPES ethnographic study

- Czech Republic "**And now I am scared**": Delay and Avoidance in Uncertain Times" (Corona, Family, Fear, Ambiguity)
- Northern Ireland "**Trains, Planes and Mobility Scooters**" (Mobility, Frailty, Independence)
- Greece "**Weighty Matters – Changing Habits in Later Life**" (Health, Motivation, Digital Tools, Habits)
- WFDB Spain "**The Red and White Cane: Obstacles and Barriers**" (Independence, Technologies, Awareness, Discrimination)
- Italy "**A Captured Glance, a Lifetime of Memories**" (Being, Memories, Digital tools, Legacies)
- Germany/Dresden "'**Ageing is Not for Cowards': Older Adults as Caregivers**" (Caring for self and others, Generations, Time, Gender)
- **Analysis of key insights**

Q&A (20 min)

12:00 15-min break

12:15 Understanding people's lives, communities, and contexts

- Active ageing in Europe - Insights from local and regional authorities, Valentina Polylas, EUREGHA (10 min)
- Older people's decision-making in health and care, Lotan Kraun, TRANS-SENIOR project - Wit-Gele Kruis van Vlaanderen vzw (10 min)

Q&A (15 min)

12:50 Wrap-up and conclusions by Maciej Kucharzyck, AGE Platform Europe

13.00 End of meeting

Contact details

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