

innovAge

SOCIAL INNOVATIONS PROMOTING ACTIVE
AND HEALTHY AGEING

Guidelines on involving older people in social innovation development

Age Platform Europe
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www.innovage.group.shef.ac.uk

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Executive Summary

INNOVAGE is an ambitious project dedicated to developing and testing, as well as surveying and cataloguing, social innovations with a solid impact on improving the quality of life and well-being of older people. Co-funded by the European Commission's 7th Framework Programme, the project aims to make a major contribution to the European goal of extending healthy life years, as promoted by the European Innovation Partnership on Active and Healthy Ageing¹.

Knowledge exchange and transfer is one of INNOVAGE's four central objectives. It is given such a high priority because of the strong commitment to knowledge exchange and transfer held by the project consortium and because it is the essential route to the widespread implementation of the Social Innovations (SIs) generated by INNOVAGE and, therefore, their impact on older people's well-being.

The mission of INNOVAGE is to concentrate the highest possible quality of scientific expertise, together with stakeholders from all relevant fields (policy, practice, product development) and the active participation of older people, to produce and identify major innovative approaches to better quality of life and well-being as people age. The project prioritises strategic knowledge exchange and transfer activities with stakeholders in a position to influence its work and implement its outputs. In such a frame, the involvement of stakeholders is essential, and in the light of the INNOVAGE project, the engagement of the older part of the population is key.

This deliverable has therefore been conceived having older people in mind and aims at presenting some common practices and suggestions for allowing the genuine participation of seniors in social innovation process. The document highlights the complexity of dealing with users and of engaging with them, while suggesting useful methodologies for user involvement, taking into account the inter-disciplinary approach needed when discussing and implementing social innovation.

¹ http://ec.europa.eu/research/innovation-union/index_en.cfm?section=active-healthy-ageing

1. Introduction

Why and how did we prepare these guidelines?

The INNOVAGE Consortium welcomes the higher importance that the European Union is assigning to innovative approaches to better quality of life and well-being as people age. We believe that this will help optimise opportunities for physical, social and mental health to enable older people to take an active part in society without discrimination and to enjoy independence and good quality of life.

Involving older users in the planning and development of innovative approaches is essential when developing new goods and/or services. Transforming users into partners ensures relevance and adequacy of new approaches and will help them to be implemented and adapted to different contexts.

Therefore, these guidelines aim to present a strong recommendation for involvement of older people in the planning, development and implementation of social innovations, new ideas meeting social needs and creating new relationships or collaboration. They also provide social innovators with practical tips to incorporate users' perspectives in the social innovation processes.

The guidelines are based on literature findings and also on AGE Platform Europe's experience of working with older people in the framework of INNOVAGE and other European research projects. Since its foundation in 2001, AGE Platform Europe has participated in many European funded research projects aiming to promote a society of all ages, to foster active and healthy ageing and to protect the wellbeing and dignity of older persons.

Who should use the guidelines?

These guidelines intend to serve **project managers**, **researchers** and **social innovators** by supporting them in engaging users in the social innovation processes. They provide basic concepts, principles and tools to plan user involvement as well as practical step-by-step procedure to engage users in the social innovation process.

How can the guidelines be consulted?

The guidelines describe tools and methods to involve users, learning from the experience gathered through various European research projects, including INNOVAGE. At the end of the document, readers will find a check list for innovators.

2. Background information

What does social innovation mean?

Social innovation is not an easy concept but has been widely encouraged as a means to improve, expand and diversify innovation for the benefit of society. It is not an easy concept to define, but is broadly understood to mean new ideas meeting social needs and creating new relationships or collaboration.

The social innovation process

The Young Foundation identified six stages that take innovative ideas from inception to impact². These stages provide a framework for thinking about the different kinds of support that innovators need in the social innovation process.



Source: Young Foundation 2010

Please find below an abstract of the Young Foundation's Open Book of Social Innovation:

Prompts In this stage we include all the factors which highlight the need for innovation – such as crisis, public spending cuts, poor performance, strategy – as well as the inspirations which spark it, from creative imagination to new evidence. This stage involves diagnosing the problem and framing the question in such a way that the root causes of the problem, not just its symptoms, will be tackled. Framing the right question is halfway to finding the right solution. This means going beyond symptoms to identifying the causes of a particular problem.

² <http://youngfoundation.org/wp-content/uploads/2012/10/The-Open-Book-of-Social-Innovationg.pdf>

Proposals and ideas. This is the stage of idea generation. This can involve formal methods – such as design or creativity methods to widen the menu of options available. Many of the methods help to draw in insights and experiences from a wide range of sources.

Prototyping and pilots. This is where ideas get tested in practice. This can be done through simply trying things out, or through more formal pilots, prototypes and randomised controlled trials. The process of refining and testing ideas is particularly important in the social economy because it's through iteration, and trial and error, that coalitions gather strength (for example, linking users to professionals) and conflicts are resolved (including battles with entrenched interests). It's also through these processes that measures of success come to be agreed upon.

Sustaining. This is when the idea becomes everyday practice. It involves sharpening ideas (and often streamlining them), and identifying income streams to ensure the long term financial sustainability of the firm, social enterprise or charity, that will carry the innovation forward. In the public sector this means identifying budgets, teams and other resources such as legislation.

Scaling and diffusion. At this stage there are a range of strategies for growing and spreading an innovation – from organisational growth, through licensing and franchising to federations and looser diffusion. Emulation and inspiration also play a critical role in spreading an idea or practice. Demand matters as much as supply: how market demand, or demand from commissioners and policymakers is mobilised to spread a successful new model. This process is often referred to as 'scaling', and in some cases the word is appropriate, as the innovation is generalised within an organisation or the organisation itself expands. But scaling is a concept from the mass production age, and innovations take hold in the social economy in many other ways, whether through inspiration and emulation, or through the provision of support and know-how from one to another in a more organic and adaptive kind of growth.

Systemic change. This is the ultimate goal of social innovation. Systemic change usually involves the interaction of many elements: social movements, business models, laws and regulations, data and infrastructures, and entirely new ways of thinking and doing. Systemic change generally involves new frameworks or architectures made up of many smaller innovations. Social innovations commonly come up against the barriers and hostility of an old order. Pioneers may sidestep these barriers, but the extent to which they can grow will often depend on the creation of new conditions to make the innovations economically viable. These conditions include new technologies, supply chains, institutional forms, skills, and regulatory and fiscal frameworks. Systemic innovation commonly involves changes in the public sector, private sector, grant economy and household sector, usually over long periods of time. In this part of the book we explore each of these stages in depth, with a section listing some of the main methods used for each one.

Older people as users

In a very broad context, “users” or “end users” are a group of persons who benefit from a developed service, product, technology or policy. However, the definition can change according to the disciplines and the fields of application³.

Users as they age encounter a number of personal and external challenges. Older people can suffer from physical and psychological constraints, such as loss of sensory abilities (hearing, eyesight, taste, etc.), physical impairments (speech, dexterity, mobility, strength, endurance, etc.), and cognitive and intellectual problems (memory loss, information processing, etc.). Besides, the environment can become an enemy of the ageing process: most of the problems older people face today arise because the environment is too slow to adapt to the needs of an ageing society.

However, people as they age do not represent a homogeneous category. Besides, the evolution of ageing, its socio-demographic and geographic declinations – among others- is worth being explored when dealing with “users”.

In order to help with this complexity, the definition of end-users suggested by the Ambient Assisted Living (AAL) Joint Program⁴ can serve as a good starting point:

- <u>Primary end user</u> is the person who is actually using an AAL product or service, a single individual (i.e. older people and people with chronic diseases)
- <u>Secondary end users</u> are persons or organizations getting directly in touch with a primary end user, such as formal and informal care persons, family members, friends, neighbours, care organizations and their representatives.
- <u>Tertiary end users</u> are such institutions and private or public organizations that are not directly in contact with AAL products and services, but who somehow contribute in organizing, paying or enabling them.

Talking about the users in the field of social innovation requires to pay heed of all these issues and their interdependence. This deliverable wants to contribute to understand older users and their implication in processes, researches and practices that concern them, with the ultimate goal to allow older people to play a role and be an active part of their society.

What does user involvement mean?

User involvement means involving users in the research work that concerns them. In particular, users can be involved in the definition of the social needs and the identification of

³ This is the case experienced by the 7FP projects OASIS (<http://www.oasis-project.eu/>) and VERITAS (<http://veritas-project.eu/>) that created advanced ICT solutions for older people's independent living and accessible design. European projects focusing on ICT often consider designers and developers of technologies as “users” because the outcomes of the projects are used, adapted and exploited by them in the future. In these projects, citizens and customers are designated as “beneficiaries” to make a distinction with “end users”.

⁴ <http://www.aal-europe.eu/>

possible solutions. They can also participate in pilot tests and help innovators disseminate the outcomes of the social innovation processes through their networks. User participation can improve the outcome of the innovation process and lead to more effective and relevant innovations.

As users, older people have a right to be consulted about social innovations that affect their lives. Therefore, user engagement represents another way to challenge age discrimination or social exclusion.

As you can see in the table below, there are different levels of user participation:

Type	Description	Examples
Full control:	Service users control decision making	<ul style="list-style-type: none"> • Community-run committees, groups or organisations • Specific projects that are fully service user led, but within the stability and structures of a hosting organisation
Sharing Power:	Shared decisions and responsibility, including governance level. Service users can influence and determine outcomes.	<ul style="list-style-type: none"> • Staff recruitment • Supported volunteering • Governance level
Participation:	Encouraging people to take part in shaping services, policies or perceptions. Service users can make suggestions and influence outcomes.	<ul style="list-style-type: none"> • Focus groups • Participatory Appraisal • Stakeholder events • Peer research & Peer education
Consultation:	Asking people what they think of a service or policy. Service users have limited influence.	<ul style="list-style-type: none"> • Questionnaires • Exit interviews • Focus Groups • Suggestion Boxes
Information:	Telling people about a service or policy. Service users have no influence.	<ul style="list-style-type: none"> • Newsletters • Leaflets • Notice boards • Digital Information

Source: FEANTSA's Participation Toolkit⁵

You can also foresee different level of engagement in the different phases of the social innovation process. In our guidelines, we will focus in any case on the second (sharing power), third (participation) and fourth (consultation) types of involvement.

⁵ <http://www.feantsa.org/spip.php?article122&lang=en>

Why should we involve older people in the social innovation processes?

We believe that user involvement can bring an added value both to research and practice. Users have experiences, skills and abilities that complement the knowledge and expertise of researchers and policymakers. They also consider topics from a different perspective.

When older people are involved from the outset, their needs and preferences can be better understood and taken into account, thus better and directly informing the outcomes of the research itself. Market deployment of the products and services is facilitated and improved as real needs and problems are addressed. This obviously translates into better ownership and sustainability of the social innovations, leading thus to cost benefits for the society as a whole. Finally, user involvement can also help innovations to be adapted to the needs of different communities and to be transferred and scaled up.

Based on AGE Platform Europe's experience, user involvement helps:

- bridge gaps between research and practice;
- highlight ethical concerns;
- pinpoint issues of acceptability (e.g.: privacy, safety)
- raise questions of affordability and costs;
- address issues of interoperability, technical reliability, and support;
- cross-evaluate from a user's point of view the social innovations and bring the experience of users in the social innovation process;
- qualify the outcomes of the social innovation process;
- identify issues that need to be further studied;
- draw attention from media and political stakeholders;
- strengthen the dissemination strategy;
- better adapt the social innovation to the needs of different communities by listening to users from different contexts.

However, user involvement also presents challenges. INVOLVE⁶, a UK advisory group which supports greater public involvement in the National Health Service (NHS), public health and social care research identified the following ones.

⁶ www.involve.org.uk

Consultation Definition: users only express their opinion; there is no sharing of power over decision-making	Collaboration Definition: research is an on-going partnership where users are informed about the whole process and there is a share of responsibility between users and researchers	User Control Definition: users are in charge of research, they initiate, design, undertake and disseminate results of a research project.
Users opinion might not be heard Users are not informed about the whole research process and unable to follow it Maintains power of professionals	Issues of time and cost Additional supports required to sustain commitment Problems with power 'sharing'	Lack of experience and expertise Higher research costs Lack of evidence about what constitutes good support Claims that the research cannot be scientific and independent

Source: INVOLVE, Paul Ramcharan's presentation "The language of involvement, diversity and inclusion"⁷ in an event organised by NHS R&D Forum (2006)

In the guidelines, we will provide you with tips on how to overcome the challenges identified by INVOLVE in case of consultations or collaborations.

Further reading: AAL Guidelines on user integration⁸

⁷ www.rdforum.nhs.uk/confrep/public06/uc_programme.htm

⁸ http://www.aal-europe.eu/wp-content/uploads/2014/01/AALA_Guideline_YOUSE_online.pdf

3. Some methods to involve users in the social innovation processes

Hereby, we propose an overview of the tools we have used so far to involve users in our project. For each of them, we highlight our direct experience in order to add practical insights and suggestions to the guidelines.

The tools are:

- Questionnaires and surveys
- Focus groups
- Workshops
- User or stakeholder fora
- Advisory board
- Pilot tests

Questionnaires and surveys

Definition Questionnaires and surveys enable the collection of information from users by setting a list of questions with a choice of answers. They can be used not only as a remote type of involvement, but also in the framework of other tools that we will mention below.

Advantages:

- They are easy to collect;
- They are easy to evaluate.

Disadvantages/ challenges:

- Users may not fully understand the questions and possible responses;
- Users may not be concentrating while replying;
- Users can lack motivation to participate.

Tips:

- Foresee an introduction where you explain the aims of the questionnaire for the sake of clarity; this will also make user feel motivated to reply;
- Use plain language that is clear and easy to understand;
- If necessary, provide support to the users and help them understand the questions;
- Be sure to include the contact details of the person who will be in charge of the questionnaire (phone number, mail and e-mail);
- Combine questionnaires with other techniques that involve a greater level of interaction.

ASAPS⁹ – A Sharing Approach to Promoting Science

ASAPS is the name of a 7th Framework Programme project which intends to communicate the benefits of European health research to increase the visibility and impact of health research. The core of the ASAPS concept is the promotion of science and health through sharing. Therefore, it aimed to detect what matters and interests Europeans as a first step.

With this regard, ASAPS developed an anonymised questionnaire, translated into different languages for a broader outreach and disseminated online¹⁰ and in paper version. ASAPS relied on an early involvement of external stakeholders and was successful in gathering information about the need and the demand for health science information, with Europeans specifically interested in new medical discoveries, research results, causes and treatment rather than research processes, or ethical issues. Moreover, ASAPS benefited from the direct involvement of the general public. Through a public campaign, the project engaged scientists and lay-persons ambassadors for spreading relevant health-related information to the European citizens.

⁹ <http://www.asaps-sharingage.eu/>

¹⁰ The on-line dissemination used the official project website <http://www.asaps-sharingage.eu/> and the partners' webpage on ASAPS.

Focus groups

Definition: Focus groups and research circles are research methods in which a specifically selected group of people can be asked about their opinion on a particular topic. In particular, research circles include practitioners, researchers and users in the discussion. Questions and specific discussion points are raised in an interactive group setting and members of the group are encouraged to talk freely. Normally these methods work better with small groups (6-8 people maximum) and should last no longer than 2 hours.

Advantages

- They provide a bottom-up approach;
- Working in a group facilitates generation of reaction and input from individuals;
- The direct communication between the users and the innovators makes the purposes of the activities and the methodologies clearer;

Challenges:

- It requires much effort in terms of planning and effective time keeping;
- Some participants might have difficulties to understand their role and the scope of the focus groups;
- Some participants might be reluctant to contribute or find it difficult to share their point of view.

Tips

- Use plain language;
- Set up and formulate questions that are easy to understand;
- Keep the agenda of the meeting simple;
- Overcome any linguistic barriers and ensure a common understanding of the terminology in use;
- Take care of practical issues about engaging older people as accessibility, hearing and vision impairments;
- Appoint a skilled moderator to coordinate the discussion, encourage equal participation and differentiate between individual and group opinions;
- Foresee the groups with a reasonable size to ensure manageable discussion and comparable reactions between different groups;
- Provide opportunities and time for effective discussions.

On the framework of the INNOVAGE project, the University of Lund involved 41 people in the four research circles on user-driven housing. The composition of participants was 26 end-users with a range of functional capacity and 15 professionals with a variety of backgrounds. An additional 20 experts were invited by participants as guests. The research circles led to a cross-national synthesis of user requirement specifications for the development of an ICT-based tool to assess housing accessibility.

Workshops

Definition: Workshops are small groups that meet to explore a subject, provide input or feedback, brainstorm or carry out a project based on interaction and exchange of experiences and information. While focus groups are pretty structured and directed by the researchers, a workshop involves a more interactive and iterative process. The discussed topics are normally broader and more complex than in the focus groups.

Advantages:

- They collect the views of participants with varying background and expertise on a specific topic or methodology;
- The outcomes include different perspectives, competences and experiences.

Challenges:

- It may be challenging moderating the discussion and to summarise the results to reach general conclusions;
- The language used can be a barrier for the participation of users;
- Equal participation of all relevant stakeholders is difficult to ensure;
- Discussions can take more time than expected. This can become an issue when many participants are involved.

Tips:

- Involve users in the planning of the event from the beginning in order to take into account their needs and point of view;
- Make sure that you are reaching an equal number of all relevant groups, eventually with the support of networks that can reach them;
- Foresee discussion groups, questionnaires or other tools that can help participants express their points of view during the meeting;
- Foresee an evaluation form to receive a feedback from participants on the organisation of the event and the ways participants were involved.

FUTURAGE¹¹ - A Road Map for Ageing Research

As a result of an extensive consultation in Europe on ageing research, the FUTURAGE project created the Road Map for Ageing Research in Europe. In order to include the point of view of users in the roadmap, AGE Platform Europe and AGE UK organised two workshops on users involvement, with the goal of gathering insights from a wide variety of stakeholders, including older people themselves. During these two workshops, user engagement was discussed with reference to real research priorities in order to feed into the Road Map process and contribute to the development of a methodology of user participation for future research.

¹¹ <http://futurage.group.shef.ac.uk/>

User or Stakeholder Fora

Definition: User or Stakeholder Fora provide a space for dialogue with users or between stakeholders about a specific topic. Participants should of course share an interest in the activities and issues around which the forum is conceived, but they are not necessarily expected to be experts in the covered subjects.

Advantages:

- They represent a concrete way to test ideas, technologies and services;
- They normally gather together representatives of user organisations and/or users themselves with the aim to make their voice better heard.

Challenges

- Discussions may be quite wide in their content and keeping to the planned schedule might become difficult;
- The participation of stakeholders from very diverse backgrounds can hinder the process and the elaboration of the results.
- As the pool of expertise can be broad, it is important to ensure that attendees have a common understanding of the terminology in use;

Tips:

- Plan in detail the forum, paying attention to logistics, the definition of the agenda and the follow-up of the event;
- Proper moderation can mitigate possible difficulties arising in fora and ensure the use of plain language;
- Scenarios, which are brief descriptions of an event or a situation, can facilitate the understanding of users and clarify the purpose of the fora. They elucidate problems and explore possible solutions.
- Narratives and concrete examples can facilitate the discussions with the users;
- Fora can be combined with other methods, like individual interviews.
- Provide definitions of key terms; attendees from diverse backgrounds may understand the same terms differently and early clarification can help to reduce confusion and miscommunication.

INNOVAGE and ENGAGED Fora

INNOVAGE foresees a forum per year to provide inputs to the project activities from the perspective of older people as final beneficiaries of the project. Representatives of older people with different experiences, interests and concerns were invited to the first Stakeholder Forum which took place in Lund, Sweden in September 2013. Alongside representatives of AGE Platform Europe, individuals were also invited to attend and actively participate in the Forum. Individuals were selected using a number of criteria to arrange for a wide representativity, covering diverse geographic, cultural and social backgrounds.

Advisory Board

Definition: A group of individuals, normally subject-related experts, who have been selected to provide advice on a particular topic or project.

Advantages:

- They tend to have a more permanent composition that allows for larger visibility of their actions;
- They provide specific expertise;
- They normally enable a long-lasting contribution because they are generally consultative bodies that assist a project throughout the life-span;
- Their members are generally selected from organisations of users that make sure that the most relevant person sits in the advisory group.

Challenges:

- It may not include the most excluded users;
- As the pool of expertise can be broad, it is important to ensure that the advisory board uses has a common understanding of the terminology in use;
- Accurate planning is needed, especially ex ante, to allow the board's members to dig into the issues to be discussed and get prepared prior to the meeting.

Tips:

- Provide participants with sufficient background material well in advance;
- Disseminate the invitations through various channels in order to reach the most excluded users.
- Provide definitions of key terms; board members from diverse backgrounds may understand the same terms differently and early clarification can help to reduce confusion and miscommunication.

DREAMING¹² and HOME SWEET HOME¹³ Advisory Boards

Dreaming and Home Sweet Home, two projects which trialled home solutions for older people's independent living in different European countries, have established advisory boards with the purpose to provide consultation from the user viewpoint throughout the whole project. The members of the board were asked to contribute in various ways: attending meetings with relevant stakeholders and project partners, meeting with individual users of the tested services, providing feedback on project deliverables, helping with the dissemination of the project outcomes both through their networks and through reviewing communication material.

¹² <http://www.dreaming-project.org/>

¹³ <http://www.homesweethome-project.be>

Pilot test

Definition: A pilot test is a smaller version of a larger test, which is conducted to get ready for more substantial testing. It can involve pre-testing a research tool, such as new data collection method, and it can also be used to test a design or hypothesis.

Advantages:

- It helps researchers assess whether the social innovation is well accepted by users or whether the prototype needs to be adapted;
- The role of users in a pilot is clear;
- It allows users to see the practical implication of a social innovation.

Challenges:

- Pilot tests normally require a considerable budget;
- If the feedback of the users is negative, it can be very costly to change the prototype;
- It can be difficult to recruit a sufficient number of users.

Tips:

- The point of view of users need to be taken into account from the very beginning in order to avoid a too negative feedback during the pilot;
- Rely on networks that can help you reach enough users for the pilots.

INNOVAGE pilot test for informal carer online support

On the framework of the INNOVAGE project, INRCA is in charge of pilot tests in Italy, Germany and Sweden to collect first evidence of the usability and effectiveness of the web-based services being developed for informal carers. In each country a different mix of services is tested by 180 users, including 60 informal carers, for a period of 4 months. The results will be used to refine and amend the web-based service,

4. User involvement in practice

Meaningful involvement in social innovation requires planning and adequate resources. Preparation for user participation should include identifying legal, ethical and practical risks, defining roles and responsibilities for all parties, deciding on methodologies as well as timing and budgets. As it has been demonstrated by INNOVAGE, FUTURAGE and other European research projects, early user involvement is the best option. When user participation comes at a later stage, there is a higher risk that the feedback from the users will not be implemented and users will experience their involvement as tokenistic.

This section will present to social innovators our recommendations to involve users in the social innovation processes.

Before starting

- *Define your objectives*

The user's capacity and motivation to engage varies as a result of their knowledge of the objectives of the project and the scope of their engagement.

You need to clarify the objectives of the involvement in order to select the right users and the appropriate methods with which to engage them. When you recruit them, you need to give them an answer to the following questions:

▶	What are the objectives and criteria of the work?
▶	Why is this work done now?
▶	Who will benefit from the social innovation?
▶	Who is funding the work? What resources are available?
▶	What happens after?
▶	Where will the work lead?

If you opt for a user-controlled social innovation, users will also be able to provide answers to these questions.

- *Define the target group*

The target group has to be clearly defined and this process depends on the subject and objectives of the study undertaken. This means to decide on the “**who**” (seniors, their relatives, paid or informal care workers and others) to be called to express his/her view.

The target group is defined not only in terms of “who”, but also in terms of “**how many**”. Ensuring that a representative range of individuals are involved is important. Representativeness may depend on some of the following factors:

- Age
- Gender
- Socio-cultural and ethnic backgrounds (profession, ethnicity, nationality, community, sexuality etc)

- Physical and cognitive ability
- Sensory ability (hearing and vision)
- Personal circumstances (living arrangements, income, etc)

An important issue linked with representativeness, but also with the practicalities of how to reach older people is whether participation should be **organisation-based or not**. Users selected through organisations have the mandate to represent their peers within their organisation. As they may consult with others within the body they belong to, indirectly the view of a largest group is represented in the user involvement process. More importantly, the outcomes will effectively reach a wider audience as dissemination can be facilitated through the organization's channels and networks. In general, it is also relatively easier for researchers and policymakers to work with organisations who can help them choose the most relevant people but also to support the participants. However, people engaged in organisations are more likely to have the opportunity to have their voices heard, compared with individual users. As a result, this approach may result in failing to reach groups which are seldom heard. When excluding non-mainstream users, one has to acknowledge that the findings may not embody the perfect solution.

- *Assess your resources: time and budget*

Time schedules

A genuine user involvement requires time. Project timelines should include enough time for users' recruitment, for the actual participation in the process and the evaluation of the outcomes and the follow-up with the users.

It is important to dedicate time to listen. You should give users the time they need to express themselves and actively participate in the planning and development of the social innovation. Moreover, you should allocate adequate time to enable users to build up trust and familiarity with the social innovation process.

Older people and people with intellectual and/or physical limitations will have specific requirements which should be reflected in the planned timetable, for example include frequent pauses/breaks and "wrap-up" sessions, ensure they have a reasonable amount of information about questions they are requested to answer. It is important to underline this issue, as it can significantly alter the time planning.

Budget Constraints

Sufficient resources to involve users have to be foreseen. Travel and hotel costs constitute an important barrier for user participation, especially in European projects, where users are often asked to travel abroad to participate in the social innovation process. All these costs should constitute an integral part of the budget planning. The time to be devoted to prepare the participation in the project also needs to be taken into account.

While remuneration might be envisaged, especially for long-term user engagement, users are often motivated to participate on a volunteer basis, as long as their basic expenses are covered. However, users should not be asked to pay any extra fees for participation in the

project. In case participants are compensated for their contribution, *Memoranda of Understanding* should define the compensation policies and be signed by both parties. Memoranda should also encompass the duties of all parties and the timeframe of the action. Innovators should take care to check whether and how payment, even to reimburse travel costs, might affect any benefits/pension rights of older participants.

In case users are not remunerated, the budget should envisage small gifts, certificates of acknowledgement or a social event as means to show appreciation of the commitment of the users. Of course the opportunity to learn or practice some skills can also be an important reward.

- **Choose the right method**

According to the objectives of the involvement, as well as the time and budget available, you can select different tools to engage users (see previous session). You can also foresee different or multiple methods for the different phases of the innovations' development.

- **Foresee the possible risks**

1. **The risk of drop-out**

When selecting users, the risk of a high percentage of drop-outs should be taken into account. It is quite common that some people are either forced to leave the process, for instance due to worsening health condition or even death, or they lose their motivation to participate in the study.

How to proceed? From the very beginning, it is crucial to foresee an adequate pool of users in order to mitigate risks.

2. **The exit strategies**

How the knowledge produced will be used, whether users will benefit from it and what will happen to users after the end of the process need to be considered. This is particularly relevant for those experiences such as pilots that run for a long time which have an impact on everyday routines of older people. For instance people participating in pilot testing who have been using technological assistance in their home environment would need to adapt to the lack of technology at the end of the social innovation process if the technology will be withdrawn from them.

How to proceed? The innovators need to foresee exit strategies when designing the project, encompassing plans for maintaining solutions and ensuring their take-up. Measures should be taken so that users fully understand that the testing applications will be withdrawn after the end of the project (if this is the case) and that a deterioration of the status (health, psychological, social) of the user will not occur as a result of the end of the innovation project.

- ***Take into account the ethical issues***

Ethics are brought strongly at the fore especially when dealing with the world of new technologies when applied to the quality of life (and work) and the well-being of people. Ethical issues must be duly considered in the healthcare and social care sectors, in the implementation of technologies, in the relationship among workers, users, clients, and of course with regard to social innovation. Ethics are furthermore important at the policy and governance level, helping to define how to allocate resources, how to justify political, economical, social choices, how to appropriately regulate research and practice. Finally ethics are at stake for ensuring the acceptability of products, services and organisational models, both at individual level (e.g. the older worker) and at the ground of the general public and its perceptions.

Ethics are a world of dilemmas and doubt par excellence. Moreover all actors involved in a social innovation process (e.g. social innovators, researchers, older users, carers, families, industrial stakeholders, decision-makers) may have different and conflicting interests, ideas and positions. Universal ethical principles may be even shared and agreed, but their interpretation and implementation is not straightforward. To this extent, codifications and guidelines are important tools, but the adoption of transparent and consistent approach to the domain of ethics is even more relevant for building the necessary awareness around ethical issues and choices, regardless to the field of application.

When planning user involvement, all relevant legislation, regulation and ethical codes should be taken into account.

How to proceed? An ethical committee should monitor the risks that may arise throughout the process, taking into account the existing soft and hard law instruments enshrining rights and ethical duties. Moreover, it is recommended to appoint a person responsible for ethics, charged with the mission to report on ethical implications and to be the contact point for users in this field. Indeed, not only an ex-ante ethical evaluation is needed, but also an “in-itinere” one.

- ***Complying with the legal requirements***

Besides ethics, a set of legislation and regulations enter into the practice.

How to proceed? It is important to appoint a person in charge of assessing the legal requirements and monitoring the compliance throughout the process. They should define in detail how these provisions will be met in terms of processes, timing and responsibilities. For example, a project involving users in the trial of technologies, needs a legal framework defining who is responsible in case of failure (e.g.: in case an alert system does not work in an emergency or a device causes damage/injury due to a technical problem). These questions have to be raised during the planning phase, otherwise if the problem arises, it will be hard to remedy and it may even have legal and economic consequences.

Besides, users must be informed in advance both regarding the legal framework and its consequences, as well as the liability of the parties involved. It is an issue of utmost

importance and light must be shed on the grey area delimiting the user's responsibility in the use and mis-use of technical equipment, and the service provider's responsibility. The legal liability and the ethical implications of choices need to be thoroughly elaborated during the planning phase.

Recruitment

Recruitment will impact the quality of the outcomes and the sustainability of the social innovation. In this phase, you should:

- Pay attention to the representativeness of the users involved;
- Be aware of the high possibility of withdrawals and adopt a strategy to ensure sufficient participation of users during the whole process;
- Inform users in a comprehensive language on the basic questions of the project;
- Make users understand how they can benefit from their engagement;
- Make users feel that their participation is valued.

- *How to approach users*

The stakeholders must be willing to cooperate and be open to the **dialogue**: respect must indeed be at the basis of any process. This includes being flexible on the project development, as topics which were not initiated by researchers may arise.

Using appropriate language and modes of **communication** are important factors. Users have often little idea of the problems faced by social innovators whereas researchers and developers may not be aware of the interests and problems of older people. Communication tools are essential: narratives, examples, scenarios or dramatisation can help stimulate discussions. In addition, a simplified and shared terminology should be used when engaging with different users, paying attention to the employed acronyms, terms, concepts and expressions. Finally, cultural diversity has to be taken into consideration. Respecting local customs and routines and avoiding stereotypes is of primary importance.

The methodology for contacting the users should be carefully decided. Personal contacts, meetings in local communities and telephone discussions are good alternatives to emails which in most cases can reach only a small part of the senior population. Bear in mind that different methods may work in different settings. For instance, while a meeting in a local community centre may attract those who are socially interested, the more isolated part of the population will not be reached.

In order to **motivate** users, it is essential to make them understand that their opinion is valued and how it will be used in the planning, development and implementation of the social innovation. Knowing that they can make a change will persuade people to get engaged even if user involvement requests a lot of time and commitment. Finally, users should also have the possibility to opt-out. This is not necessarily a failure; on the contrary, it should be valued and analysed, as the opt-out can say more than an unfruitful involvement.

Tips:

- Foresee small groups for the discussions;
- An informal atmosphere makes participants feel comfortable and relaxed;
- Good **moderation** can enhance the motivation and dynamic of the group, avoiding conflicts and ensuring focused discussions;
- Older people often need encouragement and guidance to say what they want;
- Try to avoid tensions and conflicts and foresee procedures for the resolution of conflicts;
- Pay attention to your non-verbal behaviour, such as gestures, body posture, attitude (for example being ironic) and actions, like giving a small gift;
- Eye contact is important as it may supplement poor hearing;
- Use open-ended but simple questions;
- Repeat when necessary;
- Give time for questions;
- Use **easy language**;
- Avoid jargon and acronyms;
- Adapt the language according to your audience;
- Avoid using English terms when the users are not English speaking;
- If possible, use the same language or dialect of the users;
- Using locals as interpreters but also as contact persons with seniors can facilitate engagement and build trust among the participants;
- Provide accessible **information material**: large and clear characters in printed material or presentations;
- Flipcharts, cameras and other simple tools can facilitate the discussion.

Please find below a list of questions that can help you well inform users when you engage them:

General information	▶ When will the experience start and finish?
	▶ Is there a contact person?
	▶ Who will be involved in the process?
	▶ What written 'ground rules' are there?
	▶ Are there any risks involved?
	▶ What are the methods?
	▶ What if I have any further questions or concerns?
Meetings procedure	▶ Which meetings am I expected to attend?
	▶ Who will pay for my expenses?
	▶ Will I get information or papers in good time to read before a meeting?
	▶ Will my views be noted and recorded?
	▶ Will specialized or technical language be explained to me clearly?
	▶ What is expected of me?
	▶ What will happen during the meetings?
Dissemination of results	▶ Will the reports be written in a way that can be understood by those who might benefit?

	▶ Will the results of the work be fed back to the people who participated in it?
	▶ How will the research be disseminated? Where? Through which channels?

Further reading: Some principles and practices for supporting older people from culturally and linguistically diverse backgrounds can be found in the *Research to Practice Briefing* prepared by The Benevolent Society in Australia¹⁴.

Supporting users throughout the process

Some participants may lack confidence or familiarity with the methodologies used or the topic studied. Without support only the most confident, well-resourced, and experienced individuals and groups are likely to get involved.

Supporting and empowering the users includes:

- Supporting their personal development by increasing people’s confidence, assertiveness and expectations, as well as encouraging them to fully participate in the discussions;
- Providing them with trainings and practical support (e.g. information, reimbursement of the expenses);
- Ensuring equal opportunities to participate, regardless of age, gender, sexuality, disability and communication differences;
- Supporting project team work.

You can facilitate user participation by various means:

- Making **arrangements** so that older people feel comfortable and are able to participate effectively in the process. Hearing (e.g. proximity to speaker), access (e.g. lack of stairs, disabled access, proximity of toilets), vision impairment (choice of colours and contrast in written materials) need to be considered;
- Preparing a **welcome or introduction pack** explaining clearly what the expectations and the objectives are. It helps older participants understand their role and value in the process;
- Distributing material in an accessible language and format that they can easily understand;
- Providing people with the necessary support and/or training;
- Engaging qualified researchers, trainers and/or facilitators who can encourage them, help them understand and observe them in real-life conditions in order to appreciate older people’s needs. The staff members who will interact with the users should have high social abilities and empathy for older people.

- **Meeting venue**

When searching for an appropriate place to meet users, make sure that the venue is fully accessible and easy to reach, especially by public transport. Providing a place with sufficient

¹⁴ https://www.sprc.unsw.edu.au/media/SPRCFile/10_Report_BenSoc_ResearchtoPractice4.pdf

air and light, as well as clean and accessible entrance and toilets, is also particularly important for older users.

The **OASIS Project**¹⁵ used to organise five-minute chats amongst the users before the moderator intervenes in the focus groups. Older people make small talk more easily amongst themselves and support each other.

On the framework of the **AENEAS Project**¹⁶, the City of Krakow decided to use the church to make users meet. This choice made some older people feel more at ease. On the other hand, perhaps not everyone would have felt comfortable in a religious venue.

- **Catering**

When organising meals and coffee breaks for participants, make sure that you are taking into account the dietary needs of the participants. In addition, the food should be culturally appropriate. Although catering may not seem to be the principal concern for efficient user involvement, taking care of this issue means respecting everyone's diversity and facilitating their participation. Catering breaks also help stimulate informal engagement outside the formal programme.

- **Personal Assistance**

Users could have physical or mental impairments. Make sure that users with special needs are adequately supported. When drafting the budget, it is important to foresee some funding for at least some of these expenses.

The needs of people with hearing problems should also be catered for, by providing written material and simultaneous interpretation in sign language. Other issues, such as visual impairments, should also be addressed in the planning.

- **The agenda of the meetings**

When building an agenda it should be noted that older people, including pensioners, have other commitments such as caring for their grandchildren or taking up an activity. To ensure their availability, they should be consulted in advance.

Assessing user involvement

Assessing user involvement can help innovators:

- Identify what works in a specific context and what does not ;
- Assess the different impact that a social innovation can have in different target groups and people living in different contexts ;
- Improve the planning of future social innovation and share the lessons learned with relevant actors.

¹⁵ <https://www.oasis-project.eu>

¹⁶ <http://www.aeneas-project.eu/?page=home>

Assessing user involvement helps innovators see the influence of different cultures, attitudes and opinions in the successful implementation and scaling of the social innovation.

Disseminating the results to users

At the end of the process, it is important to ensure that the results of the work reach all relevant stakeholders and users, in particular those who have been involved in the social innovation process. The dissemination can happen through different channels: presentations during events, newsletter, social media, articles in magazines and newspapers, websites. The language that is used to communicate the results should be adapted to the different target groups.

6. Further reading

These guidelines mainly highlight the methods that we have used in the INNOVAGE project. We invite the reader to also take a look at other methods that can be used to involve older people as generators of new innovation.

This overview has been compiled thanks to the contribution of the consortium's partners.

- **The User-centred Healthcare Design (UCHD) Project** (www.uchd.org.uk)

This website provides material on creative participatory methods . The UCHD is a way of developing and promoting healthcare technologies and services that can give patients the control and choice as well as service that they need..

- **Better service by design website** (<http://www.bsbd.org.uk/using-bsbd-methods/>)

This website includes a database of methods that can be used within social and health care design projects (some are widely used, others represent emerging practice).

- **The participation toolkit of the Scottish Health Council** (http://www.scottishhealthcouncil.org/patient_public_participation/participation_toolkit/the_participation_toolkit.aspx)

The Participation Toolkit supports the delivery of UserFocus and Public Involvement. It offers a number of tried and tested tools along with some more recently developed approaches.

- **Experience-based co-design toolkit** (<http://www.kingsfund.org.uk/projects/ebcd>)

This toolkit outlines a proven way of improving patients' experience of services. A 2013 global survey discovered that EBCD projects had either been implemented, or were being planned in more than 60 health care organisations.

7. Conclusion

We conclude these guidelines with a checklist that can be used by social innovators to check whether they are taking into account the aspects of user involvement while designing, planning and implementing social innovations.

Planning

- User involvement and its evaluation is part of the project design
- Enough resources are allocated for recruitment and planning for effective user involvement
- The target audiences for dissemination are identified
- The level, methods and phases of involvement are identified from the beginning
- Ethical, privacy, security and legal risks have been and will continue to be carefully measured and ethical/data protection authorities' opinions taken into account
- The time schedules take into account the need for users to have sufficient time to understand the process and provide fruitful contributions
- The informed consent of the users will be ensured
- There will be plans for the support of the users
- Incentives for participation and/or rewards for contribution are considered
- Practicalities like communication tools, transport and food are part of the planning, notably the special requirements (i.e. accessibility, dietary needs, personal assistance...)
- Staff are trained to support users and ensure their involvement throughout the project

Recruitment

- The target group is clearly identified
- The involved users represent those affected by the findings of the study
- Diversity of the potential user group is taken into account by applying suitable recruitment criteria
- A satisfactory number of users will be selected in case of drop-outs
- Users clearly understand the purpose and the process of the study
- Users are informed in straightforward language about the research and the expectations from their participation
- The benefits for users arising from their involvement and also the entire study are clearly explained to them
- All potential risks are explained to the users
- Users' opinions are valued and users feel respected
- Users are aware that they can opt-out at any stage of the process without disadvantages

Practice

- Users will be trained on methodologies, procedures and/or tools
- Users can influence the study design and the decisions made
- Users' views will be taken into account in the implementation phase
- Users will be involved from the beginning till the end of the process
- Users will have the possibility to identify and/or prioritise the topics studied
- Users will be supported with appropriate assistance and means throughout the process
- Contribution of user involvement to outcomes will be acknowledged and evaluated
- Users are and will be seen as credible partners throughout the process
- Easily understandable language will be used
- Evaluation of the user involvement will be undertaken both by users and researchers
- Effective communication and appropriate working methods will be deployed
- Withdrawals will be evaluated and analysed
- Accessible and comfortable venues will be provided:
 - Before arriving;
 - Practical information (place, time, access, agenda) will be given beforehand
 - The location is accessible
 - Meeting location
 - The lighting (preferably natural lighting) is adequate
 - The seating is adequately arranged
 - The environment is quiet
 - The catering has been planned
 - The sanitary facilities are adequate
 - During the meetings
 - The schedules are appropriate and breaks are foreseen
 - Emotional and informational support is provided
 - The atmosphere is friendly
 - Group interaction is available and facilitated
 - The purpose and share of responsibilities are clear
 - Feedback is welcome