



Progressive Standards Around ICT for Active and Healthy Ageing

Deliverable 9.1

Guidelines for user co-production in standards



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Reviewers	Alexandra Engelt, Ophelie Durant, Malcolm Fisk, Caroline Holland, Estelle Huchet, Frederic Lievens, Fernando Machicado, Roberto Scano, Stephan Schug, Verina Waights, Diane Whitehouse, Thamar Zijlstra and external reviewers
Editor	DMU
Abstract	<p>This guide aims to guide standardisation work to introduce, develop, and validate a framework for user co-production practices in standardisation at national level.</p> <p>While recognizing the important role of ANNEX III organisations at EU level to represent civil society stakeholders, national standardisation committees are encouraged to reach out to underrepresented user groups and solicit their opinion on relevant questions.</p> <p>This guide provides guidance on when and how to do so. The guide highlights the need for standardisation committees to embrace a co-production strategy and provides practical methodologies for the participatory approach.</p> <p>In standardisation, inclusiveness – that is, the participation of a wide range of stakeholders – is important to improve the quality of standards and legitimise the outcome of the standardisation process.</p>
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	07.12.2017	NEN	Thamar	Suggestions to make the doc more practical
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	21.08.2018	NEN	EHTEL, AGE, OU, DMU	Comments resolved and approved by WP 9 partners
	10.12.2018	NEN		Including /alt text to the images to make them more accessible to visually impaired readers

List of abbreviations

AHA	Active and Healthy Ageing
ANEC	European consumer voice in standardisation
CEN	European Committee for Standardisation
CENELEC	European Committee for Electrotechnical Standardisation
EC	European Commission
ECOS	European Environmental Citizens' Organisation in Standardisation
EFTA	European Free Trade Association
EHTEL	European Health Telematics Association
ESS	European Standardisation System
ETUC	European Trade Union Confederation
EU	European Union
ICT	Information and Communication Technology
ISO	International Standardisation Organisation
IWA	International Workshop Agreement (international pre-standard)
JIS	Joint Initiative for European Standardisation
NEN	Netherlands Standardisation Organisation, partner in the PROGRESSIVE project
OU	Open University, partner in the PROGRESSIVE project
TC	Technical Committee
WHO	World Health Organisation
WP	Work Package. Way of dividing the PROGRESSIVE project into different categories of work

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Executive summary

In standardisation, inclusiveness – that is, the participation of a wide range of stakeholders – is important to improve the quality of standards and legitimise the outcome of the standardisation process.

According to the ISO principles national standardisation bodies are committed to informing and seeking input from a broad range of relevant national stakeholders on any new standardisation project when they are proposed. The standardisation committee, its leaders and members are committed to achieve the best possible representation and that all stakeholder interests are appropriately considered in determining consensus (ISO, 2010).

While appropriate representation of all stakeholders in standardisation activities is a desirable goal, it is difficult to achieve. Despite all good faith efforts to achieve balance, not all parties may have the resources or priorities to become involved. Several publications from outside and from within the European standardisation system, such as the European Commission publication Joint Initiative on Standardisation and the CEN publication Civil Society, acknowledge the need to improve the inclusiveness of standardisation work.

This guide aims to guide standardisation work to introduce, develop, and validate a framework for user co-production practices in standardisation at national level. While recognizing the important role of ANNEX III organisations at EU level to represent civil society stakeholders, national standardisation committees are encouraged to reach out to underrepresented user groups and solicit their opinion on relevant questions. This guide includes participatory methodologies and provides guidance on when and how to use them.

User co-production provides several benefits to standardisation. For example, it:

- brings fresh thinking and new value to the standardisation committee;
- better understands future market needs and possibilities;
- helps identify and mitigate risks;
- motivates member involvement in the committee and fosters teamwork and collaboration;
- improves the legitimacy of the standard.

There is no standard user co-production process for standardisation. Each committee may define a strategy and activities based on its needs and resources.

Foreword

Research within the H2020 PROGRESSIVE project (<http://platform.progressivestandards.org/>) has identified good practices in user co-production strategies and methodologies. Early findings from research in the PROGRESSIVE project were shared with relevant stakeholders outside the consortium for consultation and review. The outcomes of that initial investigation highlighted the need to focus on the objectives, processes, and methods used in user and older people co-production. This guide, in the format of a CEN guide, adapts these insights and makes them relevant specifically for standardisation in ICT for active and healthy ageing.

This guide was approved by representatives of the PROGRESSIVE project on 22 February 2018. The consortium has requested comments from interested stakeholders in an enquiry that ran from 1 March to 30 April 2018. The PROGRESSIVE guide was approved on 5 June 2018. Annex A elaborates on the methodology used to develop the guide.

The following consortium organisations and representatives have been involved in the development of the guide on user co-production in standardisation, in which NEN had the secretariat:

Organisation	Representative
AGE Platform Europe	Estelle Huchet Ophélie Durand
Asociacion Espanola de Normalizacion y Certificacion, UNE	Fernando Machicado
Associazione di Normazione Informatica, UNINFO	Roberto Scano
De Montfort University	Malcolm Fisk
Deutsches Institut für Normung, DIN	Alexandra Engelt
European Health Telematics Association	Diane Whitehouse Stephan Schug
Open University	Caroline Holland Verina Waights
Polish Society of Gerontology, Warsaw School of Economics	Andrzej Klimczuk
Telehealth Quality Group	Frederic Lievens
Stichting Nederlands Normalisatie Instituut, NEN	Marlou Bijlsma Thamar Zijlstra

NOTE This list does not include the organisations that were involved in early discussions, consultations and reviews on the co-production strategy as presented in guide.

1. Scope

This guide provides guidance on user co-production in standardisation for ICT in active and healthy ageing:

- understanding the user context of the standardisation effort;
- establishing leadership and commitment for user co-production;
- planning for and implementing user co-production;
- choosing and using user co-production methodologies.

This guide applies to national standardisation committees encouraging them to expand their competencies for user co-production and outreach to underrepresented user categories. This will eventually generate more value for the work of standardisation, for the users of standards and result in better products and services for society.

This guide does not reiterate the normal procedures for stakeholder engagement in standardisation. This guide has been developed to focus on user co-production for standardisation in ICT for active and healthy ageing, although it could also be of interest in other standardisation fields.

2. Terms and definitions

For the purposes of this document, the following terms and definitions apply.

2.1

co-production

working in partnership with users in the generation of ideas, decision making and development of a standard for a product or service

Note 1 to entry: Co-production is about more than good participation and/or engagement. It is a value-led approach which is characterised by inclusive processes and a range of participatory activities that bring together different voices and perspectives on a common issue or problem – a shared agenda – to achieve positive change at different levels.

[Source: NDTi. 2013. Co-production involving and led by older people, an evidence and practice review]

2.2

guide

document published by CEN/CENELEC giving rules, orientation, advice or recommendations relating to European standardisation

[Source: CEN-CENELEC Internal regulations part 2. Common rules for standardisation work. 2017]

2.3

new work item proposal (NP)

proposal for a new standard, a new part of an existing standard or other normative document

[Source: adapted from ISO/IEC Directive 1 Procedures specific to ISO. 2018]

2.4

review

activity of checking a normative document to determine whether it is to be reaffirmed, changed or withdrawn

[Source: ISO/IEC guide 2:2004 Standardisation and related activities – General vocabulary]

3. User context of the standardisation work

3.1. General

According to the ISO principles, national standardisation bodies are committed to informing and seeking input from a broad range of relevant national stakeholders on any new standardisation project when they are proposed. The standardisation committee, its leaders and members are committed to achieve the best possible representation and that all stakeholder interests are appropriately considered in determining consensus (ISO, 2010).

National standardisation bodies have the responsibility of ensuring that their technical standpoint is established taking account of all interests concerned at national level (ISO/IEC Directives Part 1). In case some user groups are underrepresented, national standardisation committees may need to reach out to these user groups and solicit their opinion on relevant questions.

NOTE 1 Guidance for ISO national standards bodies - Engaging stakeholders and building consensus (ISO, 2010) provides principles and guidance on stakeholder engagement.

NOTE 2 The 'committee' in this guide is the national standardisation committee. Standards committee, mirror committee, project committee, technical committee are other alternative terms for the 'committee' in this guide.

NOTE 3 The Annex III organisations are ANEC, the European consumer voice in standardisation; ECOS, the European Environmental Citizens' Organisation in Standardisation; ETUC, the European Trade Union Confederation and SBS, Small Business Standards. ANEC, ECOS, ETUC and SBS ensure that the voices of civil society are heard at European level and complement the 'national delegation principle' in CEN and CENELEC.

3.2. Identify the users in the standardisation context

The committee should determine the different categories of users that are relevant to its purpose.

NOTE 'Standards for products and services' in this guide refer to all subjects that can be the scope of the standards. Standards for products and services may also include standards for systems, processes, compatibility, evaluation or analysis when applicable.

A range of different users/user categories can be identified for ICT in active and healthy ageing products and services. They include¹:

- **Primary users** are individuals who use a product or service. This group could benefit directly from the product or service, for instance through maintaining or improving autonomy, timeliness, efficiency or quality of life;
- **Secondary users** are people or organisations in direct contact with primary users, such as formal and informal carers, family members, friends, neighbours, and care organisations and their representatives. This user group benefits directly from the product or services, and indirectly when primary users are assisted with their health- and social care needs;

¹Adapted from AAL 2016. Active and assisted living programme ICT for living well – Why user's involvement is important to us. <http://www.aal-europe.eu/get-involved/i-am-a-user-2/>

- **Tertiary users** are institutions and private or public organisations that do not use directly active and healthy ageing products and services, but that organise, pay for, or enable them, such as public-sector service organisers, social security systems, procurers, commissioners and insurance companies. They benefit from the increased efficiency and effectiveness of the products and services.

3.3. Understanding the needs and expectations of the users

The standardisation committee should identify the needs, expectations and requirements of the different user categories. The committee should identify user issues when applicable. User issues at the different standard development stages typically include:

NOTE ISO guide 76 may provide additional suggestions.

- **proposal stage** (to confirm that a new standard is needed; new work item proposal (NP) or that an existing standard needs to be updated; (systematic) review)

Identify:

- providers and users of product or service being standardised;
- user perspective on purpose; scope and field of application of standard;
- current user satisfaction with product or service and key user priorities;
- current accessibility of the product or service by a broad range of users;
- interactions between users, products and service providers;
- sources: user groups, user surveys, customer satisfaction and complaints data, checklists, guides and policies such as ISO/IEC guides 51, 71 and 76; WHO Global strategy on ageing and health.

- **committee building stage**

Ensure:

- user representatives of the identified user categories are informed and invited on the committee;
- training is provided for members who are unfamiliar with the process of standards development;
- guidance is provided for user representatives to address user issues such as 'design for all'/universal design, inclusiveness, accessibility, usability and user experience, for instance as proposed in the relevant CEN/ISO guides;

- gaps in user representation are acknowledged and this guide is used to develop co-production strategies to ensure that user interests are identified and addressed.
- **standard drafting stage** (drafting and consensus building)
 - Determine:
 - particular needs and concerns of potential users;
 - ways of removing hazards (safety, security and financial) through new requirements;
 - ways of maximizing usability and accessibility of product or service to a broad range of users;
 - ways of ensuring good customer-service provider relationships;
 - appropriate methods for evaluating the product or service against user needs;
 - language and terminology of standards is acceptable to the targeted users of the product or service.
- **standard enquiry stage** (public enquiry on draft standard)
 - Ensure:
 - draft is pro-actively circulated to a wide range of concerned user groups, including the identified stakeholders who do not actively participate in the committee;
 - users are supported to develop text proposals that address their comments, for instance in the comments table, to meet the requirements of the review process.
- **standard publication stage**
 - Ensure:
 - standard can be reproduced in alternative formats, if applicable;
 - there is a plan for the application, implementation and promotion of the standard.

4. Leadership for co-production with users

4.1. User co-production strategy

When users are an underrepresented stakeholder group in the committee, the committee should reach out to these users and solicit their opinions. The committee should establish a user co-production strategy that:

- is appropriate to the purpose of the standardisation work;
- sets targets for user co-production;
- includes a commitment to satisfy applicable requirements.

The strategy and commitment include arguments how user co-production enhances the proposed standard and its intended outcomes. The arguments typically consider aspects such as:

- market aspects (developing the standards for products or services that meet the real needs of the users);
- technical aspects (design in partnership with users adds relevant knowledge, thereby improving the quality of the standards);
- political aspects; user engagement in standardisation improves on the legitimacy of the proposed standard;
- economic aspects, such as macro-economic situation, business models and funding opportunities;
- social aspects such as demographics, diversity, trends, impact of sustainability.

4.2. User co-production commitment

In the committee, the chair should demonstrate commitment to user co-production by:

- ensuring the integration of user co-production strategy into the committee's business plan;
- communicating the importance of user co-production in standardisation.

NOTE The chair represents the leadership in the committee. The chair works in coordination with the standardisation secretariat on standardisation issues, including user co-production.

4.3. Roles and responsibilities

Based on its user co-production strategy, the committee should assign the responsibility and authority for relevant roles in user co-production:

- ensuring the user co-production achieves its intended outcomes;
- directing and supporting persons to contribute to user co-production;

- reporting on the performance of the user co-production.

4.4. Fostering a user co-production culture

The committee should foster a culture that supports user co-production. A culture that supports user co-production can be promoted through²:

- Idea support: Allow time for and incentivise the development of user co-production. Create a constructive and positive work environment that encourages user co-production. Recognise promising ideas;
- Communication: Support open and frank exchange of user co-production ideas and recommendations;
- Openness and collaboration encouragement: Cooperation across different internal and external stakeholders is essential for user co-production. A user co-production friendly committee encourages collaboration, builds mutual respect and provides means for communication;
- Awareness of potential conflict: Some level of conflict fosters debate and creativity and is essential to the user co-production process. It should be actively managed as a potential source of user co-production;
- Tolerance of failure: The committee should accept that user co-production comes with some uncertainty and thereby also some risks. A user co-production friendly committee focuses on the learning aspect of failure.

² Adapted from CEN/TS 16555-1:2013 Innovation management system.

5. User co-production planning and operation

5.1. User co-production process

The committee should plan, implement and control the processes needed for the user co-production activities. The co-production process typically includes the following steps:

- set targets and create understanding;
- specify target user group(s);
- select an appropriate methodology.

NOTE Clause 6 of this guide provides suggestions.

- recruit and incentivise the users³;
 - connect the process to a concrete agenda or decision;
 - be clear about the process and purpose;
 - give feedback to the participants;
 - define the added value for the participants and the standardisation work;
 - mobilise online and offline: a combination works best;
 - repeat and correct: follow an iterative process;
- consider the ethics relating to user engagement;
 - ethical concerns include: consent of the end-user, objectives of participation, beneficence to the user, safety, respecting decisions, dignity and integrity of user, gender balance, diversity, equality, privacy and data protection;
- report back to the users.

5.2. Competence

The committee may:

- ensure the persons involved in user co-production are competent for the selected activities;

³Adapted from Rathenau in Online meebeslissen, 2018, on recommendations for involving citizens to improve the democratic process.

- where applicable, take actions to acquire the necessary competence. Applicable actions may include, for example, providing training or hiring of competent persons.

5.3. Resources

The committee may determine and provide the resources needed for the user co-production activities, such as human resources, equipment, facilities and budget.

5.4. Communication

The committee should determine what to communicate, when, to whom and by whom, the provision of communication channels and the intended feedback.

The committee should provide feedback to the users who participated in the development of the standard. Feedback should include gratitude for their contribution and explanation of how their contribution has influenced the outcome of the standardisation work.

5.5. Documented information

The committee may document the user co-production activities and the evidence of its performance. The documentation may be created, updated, stored, protected and shared where appropriate.⁴

⁴ The CEN STAIR platform on Active and Healthy Ageing would enable or facilitate the sharing of experiences and good practices of user co-production in standardisation.

6. User co-production methodologies

6.1. General

Co-production is based on a mixture of participatory methodologies. The combination of methodologies, rather than a single procedure, requires teamwork and flexibility. The common aim to all these methods is the meaningful participation of people in the process of identifying their needs, learning about opportunities and deciding on the actions required to address those needs.

Participatory methodologies do not rely on the representative sampling of participants, but on the deliberate selection of a range of viewpoints. Marginalized groups are purposely included, since their views could not be heard otherwise. It is therefore important to be transparent about who is represented and how.

The outcomes of participatory methodologies are by nature unpredictable, since the focus is on people’s views and analysis of key issues in their lives. Participatory methodologies are neither a quick fix nor a tick-box exercise. The findings are context specific: they reflect the view of a group of people in a particular situation and cannot be viewed as quantitative research methodology. At the same time, the detailed information revealed can be extremely helpful in shaping development, implementation and delivery of products and services.

Any selection of participatory methodologies should ideally combine different methodologies to decrease the chance of missing important aspects. The following methodologies are examples of methodologies that could be used at different stages of standards development. The list is not exhaustive.

The choice of methodology depends on the questions you want to ask and the stage of standardisation process. Table 1 provides suggestions.

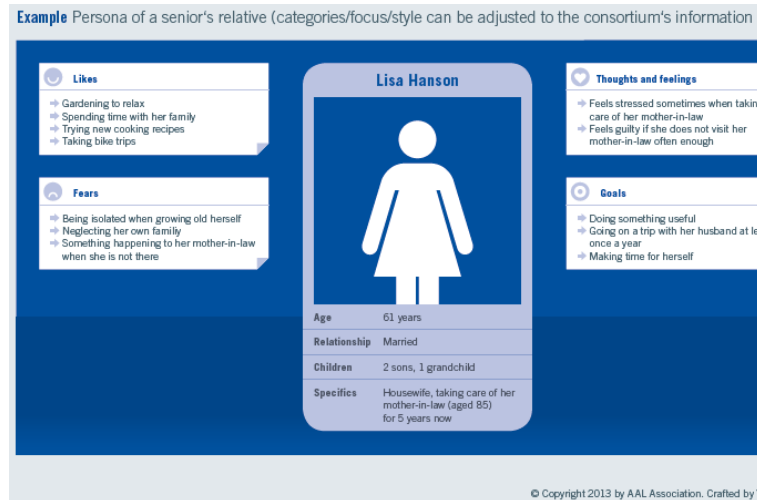
Table 1: Suggestions for methodologies for the different stages of standardisation

Stage of standard development Methodology	Define or review standards project	Drafting standard	Enquiry on draft standard	Publication
Persona	X	X	X	
Focus group discussion	X	X		
Problem tree analysis	X	X		
Photoscan	X	X		
Customer journey	X	X	X	
Storyboard		X	X	
Gamestorming workshop	X	X		
Gaming		X	X	X
Users/citizen panel	X	X	X	
Delphi survey	X	X	X	

6.2. Persona

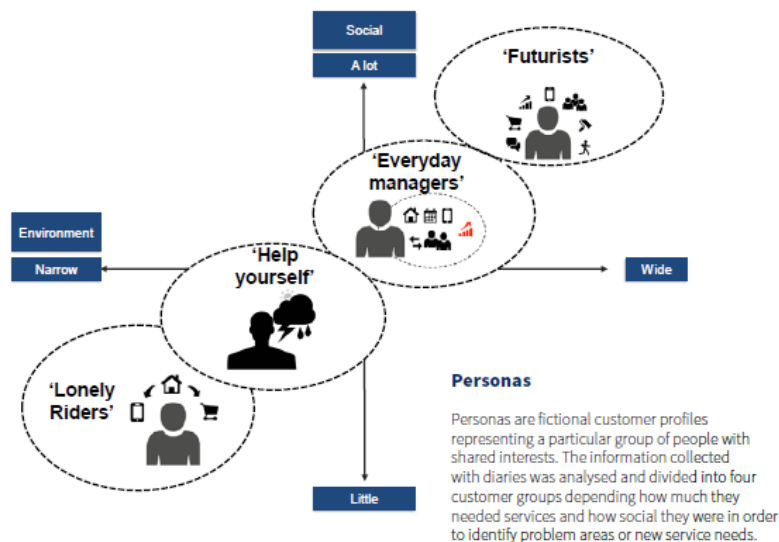
What is it?	A persona provides a description of an archetypical user, specifying their characteristics or demographics, for example, providing details about their lifestyle, budget and affinity with technology.
Why use it?	<ul style="list-style-type: none"> • To view the product or service from your most important target users' perspective; • To keep users' wishes, desires and fears in mind throughout the standardisation phases.
When to use it?	To create understanding of the users.
How to use it?	<ol style="list-style-type: none"> 1. Identification of the most important users of product or service in the standardisation context; 2. Information about each user is collected; detailed character (with whom you can empathize), contextualised settings, goals, causality and obstacles; <p style="margin-left: 40px;">Note: Individual archetypes are more interesting than 'the average user' (who does not exist).</p> <ol style="list-style-type: none"> 3. A persona card is created for each user, describing their typical characteristics and demographics; 4. The persona cards help standardisers keep track of the users' needs throughout the standard development.
Special hints	<ul style="list-style-type: none"> • Do thorough research on the persona. Who is he/she, age, background, living situation, work/activities, goals/ambition, problems/frustrations, network, what happens on a good day? • Do not overgeneralise; create an actual persona. • Find suitable, memorable names for the persona to which the committee may refer. • The exercise of building a persona/story elicits participation and collaboration with users. • Do not oversimplify or make stereotypes.

Example



Example 1: Persona of a older person's relative.

(Source: AAL, 2013)



Example 2: Personas were used to elaborate user profiles

(Source: May I help you)

Further reading

- AAL, 2013, Guideline: The art and joy of user integration in AAL projects. http://www.aal-europe.eu/wp-content/uploads/2015/02/AALA_Guideline_YOUSE_online.pdf
- Powertoolkit. 2018. <http://www.powertoolkit.nl/wat-is-co-design/co-design-methodes/persona/>
- DIY toolkit. Personas. <http://diytoolkit.org/tools/personas/>

- DesignResearchTechniques. Empathy tool.
<http://designresearchtechniques.com/casestudies/empathy-tools/>
- Persona. <https://www.usability.gov/what-and-why/user-research.html>
- Jäppinen Tuula and Janika Kulju (eds.). 2017. May I help You? Citizen-driven development as a systematic tool in renewing social and healthcare services in Finland.
- Movisie. 2013. Praat met mij. Persona methodiek.
<https://www.movisie.nl/praat-met-mij/pdf/persona-s-praat-met-mij-spreads.pdf>

6.3. Focus group discussion

What is it?	A focus group discussion is a survey method in which a specifically selected group of people, usually a diverse group of one user category, talk about their opinions on a particular topic.
Why use it?	<ul style="list-style-type: none"> • Participants talk about their experiences; • They provide a bottom-up approach; • Working in a group facilitates people to comment on other people's input.
When to use it?	<ul style="list-style-type: none"> • To understand the perspectives of the users; • To understand challenges of the use of the product or service; • To review products or services; • To solicit input for a proposed change/innovation.
How to use it?	<ol style="list-style-type: none"> 1. Questions and specific discussion points are raised in an interactive group setting; 2. Members of the group are encouraged to talk freely; 3. Small groups (6-8 people maximum); 4. Discussion should last no longer than 2 hours; 5. A skilled moderator asks the questions and coordinates the discussion; 6. A rapporteur meticulously notes the different answers, comments and discussions; 7. Participants are prompted to be specific in clarifying their preferences and motivations; 8. Focus group discussions are repeated with different groups until no new opinions are presented; usually 4-6 are sufficient.

Special hints

- requires effort in terms of planning and time keeping;
- some participants might have difficulties to understand their role and the scope of the focus group;
- use plain language;
- take care of practical issues engaging users such as accessibility, functional impairments;
- the moderator encourages equal participation;
- differentiate between individual and group opinions;
- not relevant to interview representatives of users.

Additional methodologies such as a persona, storyboard or problem tree analysis can be used in a focus group discussion.

Example

On-line focus groups have been used for hard-to-reach groups, such as cancer or mental health patients.

Further reading

- AGE Platform Europe. 2014. AGE Platform Europe Guidelines on involving older people in social innovation development.

- CBO. 2009. Patiënten betrekken bij de zorg in het ziekenhuis. De instrumenten.

- US Department of Health and Human services. 2018. User research basics. Focus groups. <https://www.usability.gov/how-to-and-tools/methods/focus-groups.html>

- Komorowska, Zofia, and Maria Perchuć, eds. 2013. *Jak usłyszeć głos seniora? Praktyczny przewodnik po partycypacji obywatelskiej osób starszych [How Do You Hear the Voice of a Senior? A Practical Guide to Civic Participation of Older People]*. Warszawa: Fundacja Pracownia Badań i Innowacji Społecznych "Stocznia". http://partycypacjaobywatelska.pl/wp-content/uploads/2015/06/jak_uslyszec_glos_seniora_2014.pdf

6.4. Problem tree analysis

What is it?

Problem tree analysis (also called Situational analysis or Problem analysis) helps to find solutions by mapping out the anatomy of cause and effect around an issue. Problem tree analysis is similar to a mind map, but with more structure.

Why use it?

- Clarify priorities by breaking down a problem into chunks. This enables the prioritization of factors and a focus on objectives;
- Create understanding of the problem and its often interconnected and even contradictory causes;

- Identify issues and arguments, and establish who and what the actors and processes are at each stage;
- Establish whether further information, evidence or resources are needed.

When to use it?

Exploration and consultation; to get better understanding of any problem, its causes and effects. The process of analysis often helps build a shared sense of understanding, purpose and action.

How to use it?

1. To discuss and agree the problem or issue to be analysed. The problem or issue is written in the centre of the flip chart and becomes the 'trunk' of the tree;
2. The group identify the causes of the focal problem - these become the roots;
3. Then identify the consequences, which become the branches.

Problem tree analysis is best carried out in a small focus group of about six to eight people using flip chart paper and or post-its. It is important that factors can be added as the conversation progresses.

Special hints

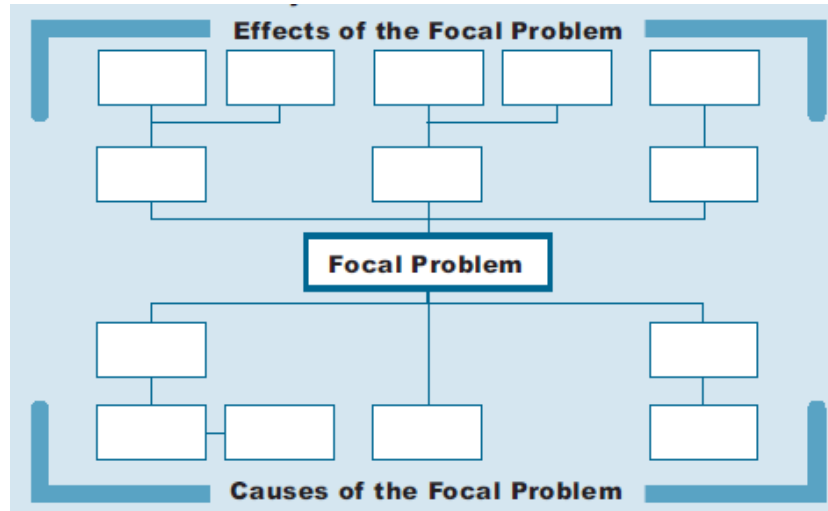
Do not worry about the exact wording or if it seems like a broad topic; the problem tree will help break it down and clarify matters.

The heart of the exercise is the discussion, debate and dialogue that is generated as factors are arranged and re-arranged, often forming sub-dividing roots and branches (like a mind map). Take time to allow people to explain their feelings and reasoning, and record related ideas and points that come up on separate piece of flip chart paper under titles such as solutions, concerns and decisions.

Questions could be:

- Which causes and consequences are getting better, which are getting worse and which are staying the same?
- What are the most serious consequences? Which are of most concern? What criteria are important to us in thinking about a way forward?
- Which causes are easiest /most difficult to address? What possible solutions or options might there be?

Example



Example: Problem tree analysis format (Source ODI 2009)

Further reading

- ODI. 2009. Planning tools: problem tree analysis. Toolkit.
<https://www.odi.org/publications/5258-problem-tree-analysis>
- DFID 2003. Tools for development. Problem tree analysis.
<http://webarchive.nationalarchives.gov.uk/http://www.dfid.gov.uk/Documents/publications/toolsfordevelopment.pdf>
- DIY toolkit. Causes diagram: <http://diytoolkit.org/tools/causes-diagram/>

6.5. Customer journey

What is it?

An analysis and description of the different steps/tasks and their sequence in the use of a product or service from the perspective of the customer or user.

Why use it?

- To view the product or service from the perspective of the user, rather than from the producer/provider/organisation viewpoint.
- To untangle complexities.

When to use it?

Especially relevant when different service providers work together in a chain.

How to use it?

1. Share individual personal stories or use cases;
2. Re-tell stories publicly modified by others' input;
3. Recast stories based on previous steps and other information such as a literature review;

- Synthesize a customer journey in which participants can see their own story. This could be done by pairing people together to come up with one story from both of their personal stories and then continuing to pair groups until one customer journey is formed.

Special hints

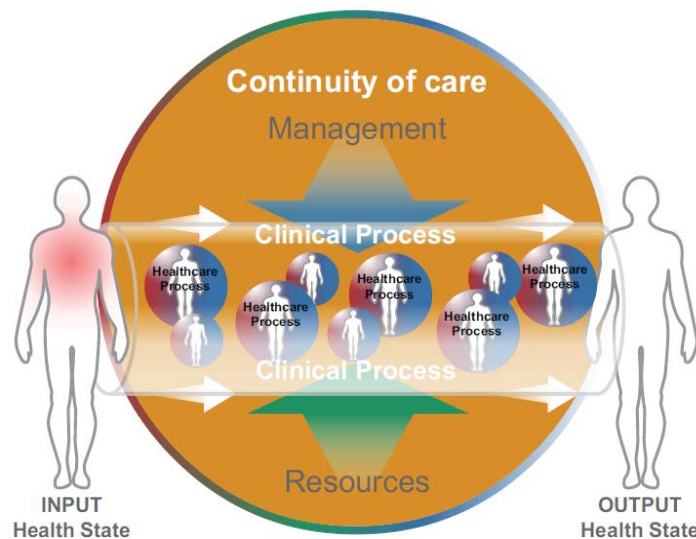
Different use cases could be compared to develop the customer journey.

Example

CEN/TC 431 'Service model social care alarms' is using the customer journey to design a service standard around the needs of the customer in order to organise the different service partners in the chain to work together and align service provision.

NEN 8028 'Quality criteria telemedicine' has included two use cases to illustrate the standards' methodology on risk analysis and taking of appropriate measurements.

EN 15224 'Quality management for healthcare' differentiates between the clinical process and the healthcare process. The clinical process is the care process from the perspective of the subject of care, in line with ISO 13940.



Example: The clinical process and the healthcare process
(Source: EN 15224)

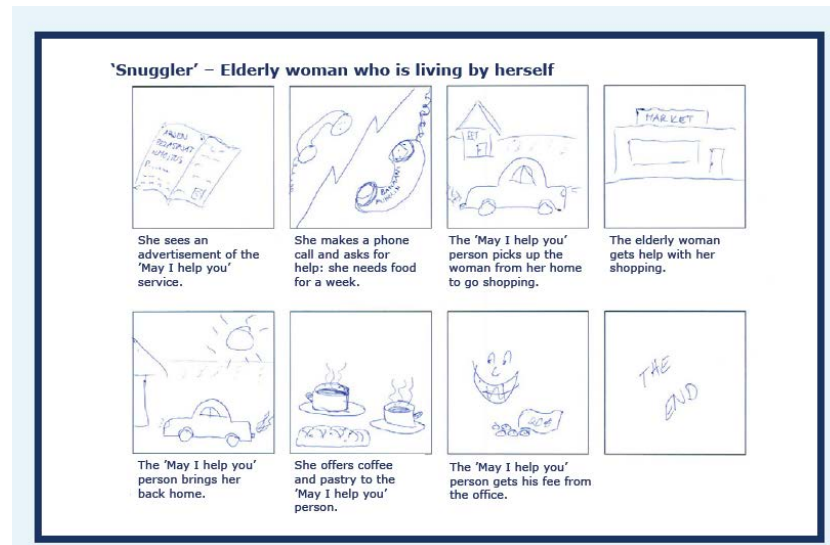
Further reading

AGE Platform Europe. Home sweet home. ICT for ageing well: Listen to what older persons think! Case studies. http://age-platform.eu/images/stories/Publications/HSH_publication_webversion.pdf

6.6. Storyboard

What is it?	A storyboard is a series of images (drawings, illustrations or photographs), displayed in sequence. In storytelling, the story is a narrative.
Why use it?	<ul style="list-style-type: none"> • To analyse key events a sequence of events and interactions are illustrated in a storyboard format. • To visualise a process or service. In the elaboration of a concept it is very useful to test a sequence of users' interactions with a new product or service. • In the formulation phase, storytelling can be a useful tool for collaborative design, making it possible to engage users in exploring possible innovations, generating feedback and refining the product or service.
When to use it?	Storyboard (and storytelling) is a tool for sharing new concepts, situating the new product or service. Presenting a project in an emotional context enables people to follow closely the details of the new proposal.
How to use it?	<p>When making a story choose:</p> <ul style="list-style-type: none"> • detailed characters with whom the audience can empathize; • rich, contextualized settings; • goals (what to accomplish and why); • causality; • obstacles (what problems to overcome to accomplish the goal).
Special hints	<p>Stories are illustrative, symbolic and easily memorable in order to create a strong emotional bond with the audience. The storyboard tool is frequently combined with storytelling to communicate visually the story about the use of the new product or service, and to discuss obstacles and the new experience:</p> <ul style="list-style-type: none"> • tell the story of a successful innovation; • tell the story of an unsuccessful innovation.

Example



Example: Storyboard (Source: May I help you?)

Further reading

- DesignResearchTechniques. Storytelling. <http://designresearchtechniques.com/casestudies/storytelling/>
- DIY toolkit. Storyworld. <http://diytoolkit.org/tools/storyworld/>
- Tschimmel, K. (2012). Design Thinking as an effective Toolkit for Innovation. In: Proceedings of the XXIII ISPIM Conference: Action for Innovation: Innovating from Experience. Barcelona.
- ODI. 2005. Effective communication. A Toolkit for Researchers and Civil Society Organisations.

6.7. Photocan

- What is it?** Users of a service or product make photos about their experiences and challenges with the service or product.
- Why use it?** To allow users to explain their practices in the use of a product or service.
- When to use it?** Exploration: understanding the use of a product of service;
Consultation: review of product or service.
- How to use it?**
 1. Based on identified questions users make photos about their experiences;
 2. Interview the users who made the pictures to explain the photos;

3. Use the photos for group discussions; first, with the users who made pictures and, second, with other users. Present the photos and explanations and ask participants whether they recognise the situation/experience and can provide additional information.

Special hints	Relevant for the review of a product or service. Input is used to improve the service.
Example	Local governments make use of mapping, storytelling and photo surveys for public consultation: for instance, for changes in the built environment. https://en.wikipedia.org/wiki/Participatory_design
Further reading	- CBO. 2009. Patiënten betrekken bij de zorg in het ziekenhuis. De instrumenten.

6.8. Gamestorming workshop

What is it?	A gamestorming workshop is a combination of brainstorming and prioritizing on the different options.
Why use it?	A gamestorming workshop is used in situations when the solutions are not yet clear.
When to use it?	The workshop can be part of a meeting or conference where users or stakeholders meet to solicit their opinions.
How to use it?	<p>The workshop has three stages: opening, exploring and closing:</p> <ol style="list-style-type: none"> 1. Opening: Create a list of key issues through brainstorming; Individual participants write their ideas silently on separate post-its: The participants are encouraged to: <ul style="list-style-type: none"> • go for quantity; • seek wild ideas; • not worry about making any judgements. 2. Exploring. After generating a large number of issues, groups of around five participants map the issues into a matrix based on their relative importance on two competing aspects; for instance, for the customer and for the service organisation: <ul style="list-style-type: none"> • combine and build; • group and sort, giving every option a fair chance; • improve on the ideas by combining several aspects; • appreciate novel, original ideas; • reverse and reframe.

The groups present their ideas and compare them with the outcomes of the other groups.

3. Closing. Mostly too many ideas are generated. Stage 3 assesses the ideas and draws conclusions;
 - Voting is a way to prioritize and rank the ideas. Every participant has 5 stickers and attaches these to their vote;
 - Tally the votes and rank them.

The prioritised list becomes the subject of discussion and decision making.

Special hints

Criteria are purposefully applied as the people involved screen, select, evaluate, and refine the options, all the while knowing that raw ideas still need development.

Example

CEN/TC 431 wants to start a new standard. The existing standard describes the situation of current (analog) alarm systems. The use of digital alarms opens “a Pandora’s box” of additional applications for the alarm systems. The gamestorming workshop is used to identify key developments that the new standard will elaborate on and subsequent challenges that need to be addressed.

Further reading

- Creative Education Foundation.
<http://www.creativeeducationfoundation.org/creative-problem-solving/brainstorming/>
- Gray D., S Brown and J Macnufo. Game storming, a playbook for innovators, rulebreakers and changemakers. 2010.

6.9. Gaming

What is it?

Games are devised to mirror real life scenarios or to teach specific skills. They deal with human issues and are mostly played in groups, usually helped by a facilitator.

Why use it?

Gaming provides practical insight into social structures and impacts on human behaviour, like actions, reactions, goals and considerations of stakeholders. The experiences can be used to improve the product or service.

When to use it?

- Chance to pre-test behavioural assumptions in decision models prior to implementation;
- Games aid decisions, planning, and policy implementation, by getting a clearer idea of possible reactions.

How to use it?	<ol style="list-style-type: none"> 1. Decide on type or structure: Regarding objectives, constraints and critical factors determine the ideal type of participants and structure of the game. 2. Write or find appropriate scenarios: Write scenarios that fit into type or structure and test behavioural impacts of participants. 3. Run session: Play the game with the participants. 4. Debrief participants and observers: Question participants and observers on their behaviour and findings in the game and possibly the resemblance to reality. Findings can be used to improve the game/service.
Special hints	Reiterative gaming exercises can be used to solicit bottom-up input from users and gradually improve a product or service.
Example	Gaming is used to design web-based healthcare services, such as for mental health.
Further reading	<p>- http://www.foresight-platform.eu/community/forlearn/how-to-do-foresight/methods/creative-methods/gaming/</p> <p>- DIY toolkit. Prototype testing plan. http://diytoolkit.org/tools/prototype-testing-plan/</p>

6.10. Users panel

What is it?	A users panel is a consultative body of users.
Why use it?	Users or citizens' panels are typically used by organisations, societies and (local) authorities, to identify (local) priorities and to consult members or service users and non-users on specific issues.
When to use it?	<ul style="list-style-type: none"> • Allows the targeting of specific groups, if the panel is large enough; • Allows surveys or other forms of research to be done at short notice; • Allows the assessing of product or service needs and identifying priorities; • Can determine appropriateness of developments; • Can track sentiments over time. <p>Standardisers could make use of existing user panels for review of existing products/services, consultation on priorities and getting feedback on proposed solutions.</p>

How to use it? Once users/citizens agree to participate in a user panel, they will be invited to a rolling programme of research and consultation. This typically involves regular surveys and, where appropriate, the use of further in-depth research tools, such as focus groups and workshops. Not all members will be invited to take part in all panel activities. It is important to be clear, at the recruitment stage, about what is expected of each panel member, and what their membership is likely to entail in terms of type of contact and frequency of involvement.

An online platform could be the format of the panel.

- Special hints**
- Identify a good reason/incentive for citizens/users to participate in the panel;
 - Planning a sensible programme of research and consultation for the panel is important to ensure that a variety of topics and research methods are employed, and that activities are spaced out throughout the time-period during which they take place;
 - It may not be feasible to set up a panel for a standardisation committee. Options could include a users panel for a national standards body for all standardisation committees.
 - Alternatively, a standardisation committee could approach the moderators of an established panel and request them to submit a questionnaire to their members;
 - May exclude non-native speakers or non-“digitally savvy” users, if the panel is done through online platforms.

Example In 2017 the Dutch mirror group of ISO/TC 173/SC2 in the review of ISO 10535 on 'patient hoists' is working together with the Dutch Patient Federation. The Dutch mirror group consulted the patient panel; patients, carers and health professionals with experiences with patient hoists were consulted on identification of customer satisfaction and challenges that need to be addressed when reviewing the standard.

Further reading

- AGE Platform Europe. 2014. Guidelines on involving older people in social innovation development, <http://participationcompass.org/article/show/131>
- Design Research Techniques. <http://designresearchtechniques.com/casestudies/citizen-juries-an-action-research-method/>
- Rady seniorów w działaniu! [Senior Citizens' Council in Action!]. 2016. Warszawa: Towarzystwo Inicjatyw Twórczych “e”. <http://e.org.pl/wp-content/uploads/2016/11/rady-seniorow-w-dzialaniu.pdf>

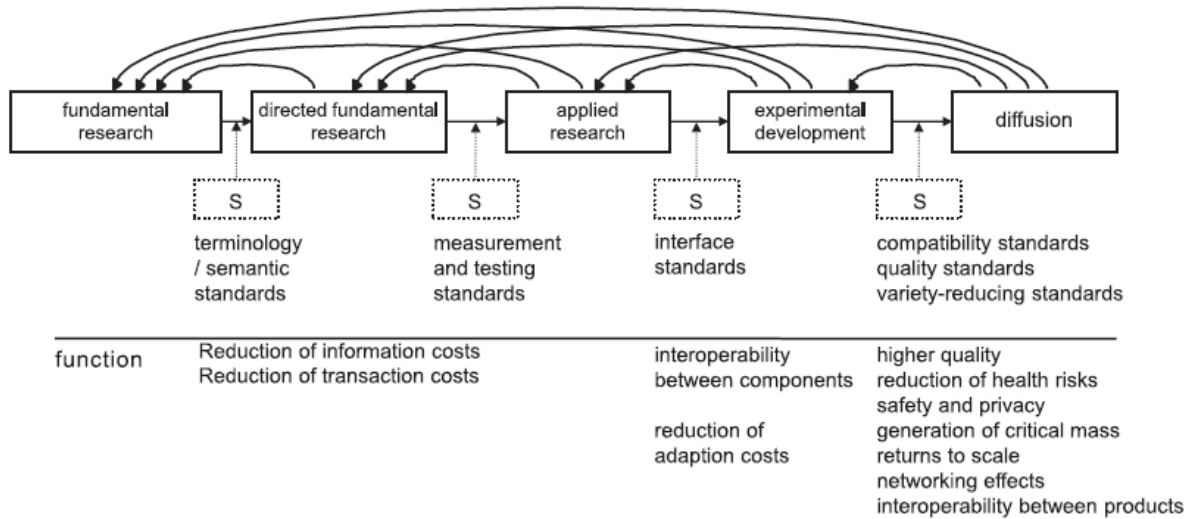
6.11. Delphi survey

What is it?	<p>The Delphi survey technique involves multiple rounds of interviews with the same individuals, usually a specific user/stakeholder group, using questionnaires and feeding back anonymised responses from earlier rounds.</p> <p>The participants are encouraged to revise their earlier answers in light of the replies of other members.</p>
Why use it?	<p>To generate new ideas and scenarios. The underpinning concept is that this feedback loop will allow for better judgements to be made without there being undue influence from forceful or high-status advocates.</p> <p>Delphi interviews do not result in statistically significant outcomes; they provide the opinion from a stakeholder group.</p>
When to use it?	<ul style="list-style-type: none"> • To frame a complex problem; • To generate new ideas and scenarios; • To identify objectives from the stakeholder(s) perspective; • To choose between, prioritise potential or validate solutions; • To make judgments in the face of uncertainty.
How to use it?	<ol style="list-style-type: none"> 1. The standardisers select a topic and ask the questions; 2. Selection of a group of stakeholders; 3. Stakeholders answer questionnaires in two or more rounds; 4. After each round, a facilitator provides an anonymised summary of the different stakeholder responses from the previous round as well as the reasons for their judgements; 5. Amend/reorient the questions; 6. Stakeholders revise their earlier answers. It is believed that during this process the range of the answers will decrease, and the group will converge towards consensus; 7. The process is stopped after a predefined criterion (e.g. number of rounds or achievement of consensus).
Special hints	<p>Users or citizens often have a more holistic view on a challenge and possible innovations compared to experts or politicians.</p>
Examples	<p>Delphi interviews have been used by local authorities to select/prioritise for instance for sustainable innovation or services for older adults.</p>

Delphi interviews have been used for family carers to identify future care scenarios (CBO. 2009. Patiënten betrekken bij de zorg in het ziekenhuis. De instrumenten).

Further reading

- European Foresight Platform <http://www.foresight-platform.eu/community/forlearn/how-to-do-foresight/methods/classical-delphi/>
- Design Research Techniques. <http://designresearchtechniques.com/casestudies/delphi/>
- Identification of future fields of standardisation: An explorative application of the Delphi methodology. In Technological Forecasting & Social Change 78 (2011)



Example: Delphi method to identify standardisation needs in research and innovation

[Source: Goluchowicz and Blind, 2011]

7. Annex A Methodology

This annex describes on the methodology to develop this 'guide on user co-production in standardisation' within the work of the PROGRESSIVE project (<http://platform.progressivestandards.org/>). The different activities in the project are divided in Work Packages (WPs). WP9 identified mechanisms by which co-production approaches can be harnessed to maximise the engagement and inclusion of a wide range of stakeholders (including especially older people) in the standardisation process. The work in WP9 includes an orientation stage, a consultation stage and a consolidation stage. As much as possible the work on co-production in standardisation used co-production methodologies to develop the guide. The guide in this Deliverable 9.1 is the result of the work in WP9.

Orientation (task 9.1)

Research within the H2020 PROGRESSIVE project identified good practices in user co-production strategies and methodologies, as presented in the internal report "Researching approaches to co-production and application in standards context (9.1)".

This report addresses the **why** of working in partnership with users in standardisation for ICT solutions in active and healthy ageing. It draws on experiences with co-production. It compares these experiences with existing standardisation efforts and procedures. This report was a preparation for guidelines on the **how** of working in partnership with users in standardisation.

Consultation (task 9.2)

AGE and NEN consulted relevant stakeholders on their ideas on the why and how of user participation in standardisation, identifying ways of engagement, inclusion and co-production. Suggestions were compared with the early findings and ideas from the orientation stage. Suggestions from earlier interviews and workshops/meetings were shared with later interviewees and meetings to refine the outcomes of the task.

A combination of methodologies was used:

- Interviews with selected stakeholders: ANEC (consumers), EDF (disability movement), ETUC (trade unions), SBS (small businesses), EASPD (service providers), AFNOR (consumer group of the French national standardisation body), Standards Norway (Norwegian standardisation body – more specifically: for their role in SAGA, the CEN-CENELEC Strategic Advisory Group on Accessibility), ISO (more specifically: the Committee on Consumer Policy), ITU-WISE (Women in Standardization Expert Group); and SF-SSCC (CEN-CENELEC-ETSI Sector Forum on Smart and Sustainable Cities and Communities);
- Presentations and discussions with: Multi-stakeholder platform on ICT standardisation (MSP-ICT); Sector Forum on Smart and Sustainable Cities and Communities (SF-SSCC); Strategic Advisory Group on Accessibility (SAGA); AGE Task Force on age-friendly environments, new technologies, and standardisation; PROGRESSIVE Forum meeting on October 19, 2017; and CEN/TC 251 Health informatics meeting;

- Consultation of the PROGRESSIVE Advisory Board members, members of the PROGRESSIVE Task Force of older persons as well as external stakeholders (from 19 October 2017 event or online survey) willing to contribute more.

This task was crucial in helping to understand what is both possible and practical in the area of co-production, to collect insights and ideas regarding the options for effective co-production and to help respond to the concerns about shortcoming in standardisation. The outcomes of the consultations highlighted the need for a guide for standardisers at national level that focuses on the objectives, processes, and methods used in user- and older people co-production in standardisation in ICT for active and healthy ageing.

Consolidation (task 9.3)

Based on the suggestions collected during the consultation phase NEN developed a (first) draft which was commented on by the PROGRESSIVE WP9 partners AGE and EHTEL. The national standardisation bodies in the project, NEN DIN, UNE and UNINFO, selected the format of a CEN guide. CEN Guides⁵ are reference documents published by CEN-CENELEC to give orientation, advice or recommendations on standardisation principles and policies and guidance to standards writers. PROGRESSIVE decided that a proposal for a guide on user co-production in standardisation would be a relevant addition that perfectly fitted within the objective of PROGRESSIVE.

In February 2018, the other PROGRESSIVE partners reviewed the (second) draft of the guide. Especially the other national standards bodies in the PROGRESSIVE project, DIN, UNE and UNINFO, commented on it. NEN used the CEN comments tables, as used in regular CEN standardisation work, to solicit comments and discuss and approve text proposals. Text proposals to resolve the comments were approved by the PROGRESSIVE project on 22 February 2018.

From 1 March to 30 April 2018, NEN organised an enquiry. NEN invited PROGRESSIVE stakeholders and experts from the standardisation activities in CEN/TC 251 Health informatics, ISO/TC 314 Ageing society and CEN/TC 450 Person centred care to comment on the (third) draft of the guide. The PROGRESSIVE national standardisation bodies distributed the enquiry in their respective networks. PROGRESSIVE partners extended the invitation to the interviewees from earlier activities in the project. NEN used the CEN comments tables, again, to solicit comments and to discuss and approve text proposals. The PROGRESSIVE partners approved the guide on 5 June 2018.

Comments tables on the different drafts are available on demand from NEN.

⁵ (<https://www.cencenelec.eu/standards/Guides/Pages/default.aspx>)

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- (3) AGE Platform Europe. 2014. Guidelines on involving older people in social innovation development.
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