



Policy Brief No.3

Co-developing and contextualising long-term care innovations in Europe using Theory of Change: lessons from InCARE


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Ensuring affordable and high-quality care to all those who need it, a goal enshrined in the European Pillar of Social Rights¹, remains a considerable challenge for all EU Member States² and other European countries. In the aftermath of the devastating effects of the COVID-19 pandemic on long-term care systems, considerable reforms are being implemented or planned across the region – including the first European Care Strategy, with sustainability and appropriateness of care recognized as paramount concerns. At the same time, there is growing recognition of the need to deliver care in the community and to reimagine traditional care models through socially innovative approaches, grounded in local community strengths and reflecting their needs and preferences. As momentum for re-imagining long-term care systems continues to build, strategies to empower stakeholders and co-develop contextually relevant and scalable solutions are important to ensure sustainability, relevance and fit of long-term care innovations³. Theory of Change, a planning and evaluation approach which is increasingly used in planning health and long-term care provides a systematic and robust way to approach this.

We have successfully applied Theory of Change in InCARE (<https://incare.euro.centre.org>), a multi-country project which aims to develop and design co-ordinated approaches to local and regional care services and national level policy for long term care. Our experience offers a proof of concept for the applicability and usefulness of this approach in long-term care service and policy development. In this policy brief, we describe the Theory of Change process in InCARE and focus on formulating transferable lessons and recommendations for expanding Theory of Change approaches in this field.

What is Theory of Change?

Theory of Change is an approach which can be used with stakeholders to understand the strategic direction of a project, program or policy; develop relevant interventions and monitor and evaluate programs. It has been increasingly used in international development⁴, health⁵ and long-term care⁶. Often developed in a series of participatory workshops, Theory of Change asks stakeholders to identify the intended **impact** of the project, program or policy, the **outcomes** which need to be achieved on the path to impact, the **activities** required to achieve the outcomes, the **assumptions** about what needs to be in place for the program to achieve its impact and the **ceiling of accountability** which indicates which part of the Theory of Change is the responsibility of the program or policy. Stakeholders are guided through this process during workshops and develop a Theory of Change map which can then be used to guide the development, implementation and evaluation of the program⁷, including the development of **indicators**.

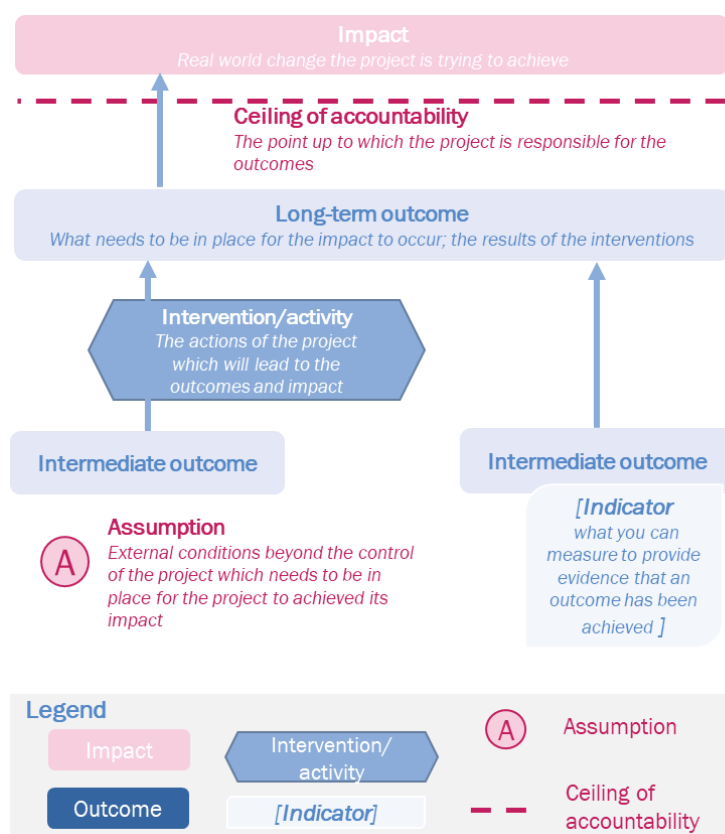


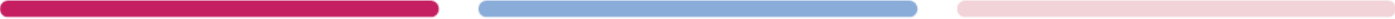
FIGURE 1 A VISUAL EXAMPLE OF THE KEY COMPONENTS IN A THEORY OF CHANGE WITH DEFINITIONS ADAPTED FROM DE SILVA ET AL. 2014 ⁷

Figure 1 illustrates the key components of a Theory of Change map and their definitions.

How did we use Theory of Change in the InCARE project?

We conducted four Theory of Change workshops: one across and one within each of the implementation countries. These four workshops brought together approximately 100 stakeholders including care users, care partners, service providers, InCARE team members and policy makers to develop a common vision for long term care in the InCARE project both across and within countries and a collective understanding for how to achieve these.

We used the STRiDE Theory of Change guidance to guide the format of our workshops, adapted where necessary to an online format⁸. Preparation for the workshops included meetings with the facilitation team, InCARE partners with experience in Theory of Change or other experts, for example, in Austria we met with a trainer specialised in online tutoring and we examined different options for apps we could use in the Theory of Change workshops. During these meetings we decided on the purpose and scope of the Theory of Change, the meeting agenda, discussed the evaluation of the workshops and refined the list of participants. Substantial work was required to invite stakeholders including individual pre-workshop meetings to introduce stakeholders to the project, multiple contacts and preparation of invitation, flyers and summary documents for the registered participants. Personal contact with stakeholders and multiple follow ups were important to ensure participation.



We initially conducted an online Theory of Change workshop within the project team over two 3-hour sessions. The twenty-one participants included policy and implementing partners from Austria, North Macedonia and Spain, and technical partners. As a team, after identifying some challenges we decided on the impact of the project, “*Older people and their families live well and with dignity at home*” with outcomes developed into a Theory of Change in four levels: ‘policies and processes’, ‘organizational’, ‘project’ and ‘care users and their families’.

We mapped on the work-packages from the grant proposal onto the Theory of Change to understand how they would lead to the outcomes, identified assumptions and then used this to develop a monitoring and evaluation strategy for the project (see Figure 2). We also used this workshop (together with additional sessions) as a capacity building opportunity to help implementing partners gain the skills to organize a Theory of Change workshop themselves.

Country Theory of Change Workshops

The project level Theory of Change workshop was followed by a workshop in each of the InCARE implementing countries: Austria, North Macedonia and Spain. The workshops are described below and outlined in the table on the next page.

Austria

The Austrian team conducted a two part online Theory of Change workshops with local and national stakeholders involved in long term care in Styria. The facilitators co-developed a Theory of Change map with stakeholders by using multiple online tools and moderated group discussions to explore what the innovation was aiming to achieve and its potential impact.

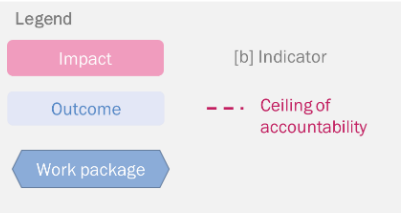
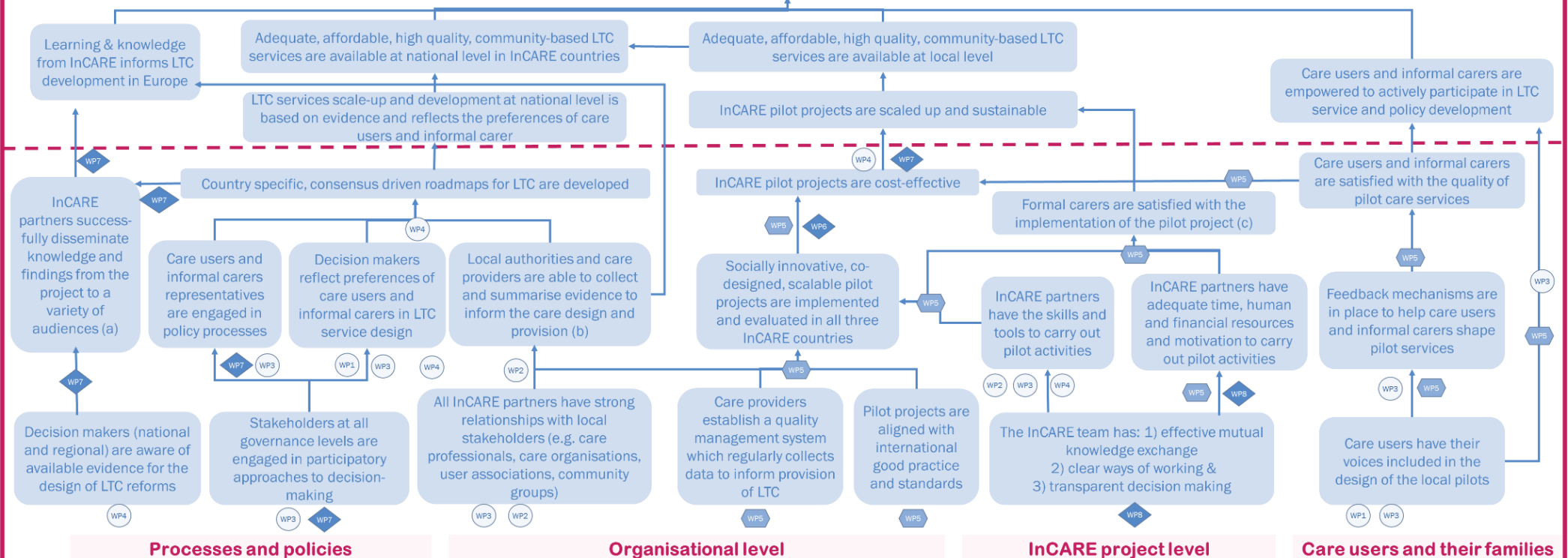
Prior to the workshop, the Austrian InCARE team was planning to adapt an integrated provider network based on the Buurtzorg model from the Netherlands to the Styrian context and to establish a local care management platform to link local authorities with care providers. However, during the workshop it became clear that some of these functions already existed in the community and the innovation changed to better linking together these existing service providers rather than creating a duplicate system. The workshop also helped identify key issues which will be addressed by the pilot: lack of capacity building opportunities for care providers, limited co-ordination between actors and agencies involved in long-term care and the importance of increasing empowerment and control of care users throughout the care process.

North Macedonia

The InCARE team in North Macedonia conducted a two-session workshop with one face-to-face and one online session to develop a Theory of Change. They aimed to set common impacts for long term care in North Macedonia and as well for the pilot of the integration of an emergency button intervention in a home care package and its provision as licensed service in the social protection framework. Stakeholders included representatives of the Ministry of Labour and Social Policy, Ministry of Health, local decision makers, NGO representatives, providers and users of long-term care. Stakeholders agreed on the impact (“Older persons with care needs and their family members lead quality, safe and decent life”) and mapped on the outcomes and the activities needed to achieve the impacts and the risks, barriers and opportunities related to the pilot project. Following the first day workshop, the InCARE team developed the draft version of the ToC Map which was validated during the second online ToC workshop.

Older people and their families live well with dignity at home (d)

Older people with care needs and their informal caregivers have access to adequate and affordable care



**Project level
Theory of Change**
December 2020

Work-packages

- WP1 - Evidence base
- WP2 - Situational analyses
- WP3 - Theory of Change
- WP4 - Policy toolkit
- WP5 - Pilot implementation
- WP6 - Evaluation
- WP7 - Dissemination
- WP8 - Coordination

Example indicators

- (a) Number of participants attending InCARE events
- (b) Existence of a quality management system
- (c) Level of satisfaction of formal carers with implementing pilots
- (d) Level of quality of life of care users/informal care givers

Assumptions

A. Policy and processes at system level

1. Community-based LTC remains high on the EU and national policy agendas (despite competing objectives)
2. Activities across governance levels and sectors are coordinated
3. LTC workforce is stable, qualified, and motivated
4. Funding mechanisms for LTC service development are available and stable at national and EU level
5. Stakeholders agree on the concepts of adequate and high-quality care

B. Organizational resilience

1. The Covid-19 pandemic does not severely affect care provision and workforce availability and motivation
2. National and local stakeholders are able to react to changes in context and policy landscape (including Covid-19 related)
3. National and local stakeholders have a long-term vision for LTC development, that spans beyond reacting to the Covid-19 crisis
4. Funding and support is provided at local level to ensure pilot sustainability (despite competing objectives)

C. InCARE Project level

1. Delays related to Covid-19 are managed to ensure InCARE implementation and evaluation is completed on time
2. InCARE has effective virtual communication processes, which can build trust with collaborators while preventing virtual overload
3. InCARE project and implementation teams maintain motivation and focus throughout the project despite Covid-19 related demands
4. InCARE evaluation is able to detect changes in outcomes and impact during the project life

D. Care users, informal carers and community

1. Covid-19 does not substantially reduce the ability of care users and their families to participate in the design of care services
2. Care users and informal carers are able to participate effectively in the decision-making process without formally organized representation
3. Older people with care needs and their informal carers are willing to use piloted care services
4. InCARE project teams are able to develop trust with care users and informal carers

FIGURE 2 INCARE PROJECT LEVEL THEORY OF CHANGE

The Theory of Change took a broad view of the long-term care system and some of the outcomes, particularly around policy processes, are longer term policy changes which need to be addressed in the longer term. These include changes in legislation on the employment and working conditions of caregivers, financing, quality assurance and monitoring of long term care services and increasing availability of employment measures for stimulation of the care economy. The changes are relevant for transforming the innovation (emergency button) into a regular social care service and its financing in the frame of the social protection system. Cooperation with health-care, especially emergency care was considered as well. Lastly, both long term social and healthcare providers emphasised the importance of setting clear information for and ensuring early involvement of the users, family members and caregivers.

Spain

The Spanish InCARE team conducted a Theory of Change workshop on long term care in Spain, with two days of face-to-face sessions followed by an online consolidation session. This workshop involved policy makers, long-term care providers and long-term care users and their informal caregivers. The workshop defined the underlying short-, medium and long-term outcomes, activities and strategies that could enable change in national long term care policy over the next decade to achieve the following impact agreed with stakeholders: "All people in need of long-term care can develop their life project in community and improve their quality of life, with quality care and quality jobs. Family and professional carers can continue to develop their life project". Based on themes and expertise, participants were divided into two groups: 1) long-term care in Spain; and 2) InCARE pilot project to develop parts of the Theory of Change.

After these sub-group sessions, the results short-, medium and long-term outcomes were shared which included the existence of funding, coherent regulations, social and health care coordination, sufficient and quality resources and services, dignity within the care sector, ensuring quality of care and autonomy and that old age is socially perceived as another stage of life. After the face-to-face sessions, the organising team synthesized the inputs from the workshop in an iterative way to develop the Theory of Change map. This map was subsequently presented in the online consolidation and feedback session and validated by the participants.

In order to ensure the engagement of local stakeholders and operationalize the pilot study further, an additional two session ToC workshop with sixteen stakeholders (representatives of provincial government, care organizations, family caregivers and health services) in the implementation area, San Sebastian was carried out. This was valuable to understand the local context and ensure an implementable and sustainable social innovation.

TABLE 1 OUTLINE OF THE INCARE COUNTRY WORKSHOPS

		Austria		North Macedonia		Spain		
Social innovation		Integrated provider network for delivery of community-based long-term care in Styria		Integration of an Emergency Button Service within a home-care service package		Support for family caregivers of people with dementia within an integrated service approach		
Workshop sessions		1	2	1	2	1	2	3
Date held		10 th June 2021	17 th June 2021	14 th December 2021	24 th December 2021	1 st December 2021	2 nd December 2021	27 th January 2022
Length(hours)		4	4	5	4.5	7	3.25	1.5
Format		Online	Online	In person	Online	In person	In person	Online
Software		Zoom Padlet Yopad Mural	Zoom Padlet Yopad Mural	n/a	Zoom Mural	n/a		Zoom PowerPoint

Language	German		Macedonian		Spanish		
Stakeholders (total)	22	18	24	15	32		22
Policy makers	6	5	7	3	10		7
Care users	1	1	2	1	2		1
Non-professional carers	2	1	-	-	2		-
Healthcare professionals or providers of counselling/advice	3	1	2	2	2		2
LTC service providers	3	4	8	4	10		6
Other	2	1	-	-	6		6
Facilitators/project team	5	5	5	5	7		

Following the country Theory of Change workshops, a monitoring and evaluation plan for each implementation country was developed.

All face-to-face workshops were held with COVID-precautions in place (e.g. masks).

Evaluation of the country Theory of Change workshops

The Theory of Change workshops were well received by the stakeholders across all three countries. Overall, results of our evaluation showed that the participants were satisfied with the workshops and rated the technical organization and facilitation highly. The majority reported that the prior expectations were met and that they welcomed the opportunity to contribute as well as to receive valuable inputs from peers. The majority found the exchange with other participants very useful, which inspired them to make a change because of the workshop. Qualitative feedback following the Austrian workshop showed that stakeholders appreciated the engagement with the multi-disciplinary group as a learning experience. In Spain, stakeholders indicated they were keen to use this approach in their work in the future and appreciated the Theory of Change approach as a driver for change. In North Macedonia, the stakeholders appreciated that they got a chance through the workshop to broaden their network, as well as the whole TOC where they can exchange their opinion and knowledge with colleagues from other organisations and sectors (social versus healthcare), as these kinds of workshops and meetings are rarer due to the pandemic.

“The most valuable part was thinking together about the improvement of long-term care, the inclusion of all relevant stakeholders. Especially positive was that interest groups of care givers were present.”

Participant, Austrian ToC workshop

Lessons

Structured engagement with stakeholders

Theory of Change workshops provided a structured opportunity for the developing team to interact with policy makers and other stakeholders and get feedback on the pilot project and the wider policy changes required which is a key to working together in a project, program or policy that requires substantial collaboration. For example, the InCARE Theory of Change workshops, particularly those in North Macedonia and Spain highlighted the need for structural reform, for example, in relation to co-ordination between the health and long-term care system and quality monitoring, to ensure improved outcomes for people in need of long-term care. In Spain, the direct involvement of a key senior policy maker in the workshop made it possible for them to identify activities, strategies and barriers. The co-creation of the ToC with these key stakeholders provides a common framework and shared objectives.

Theory of Change as an established participatory approach gave legitimacy to the process amongst stakeholders and increased participation, especially in Austria. However, engagement of policy makers remained challenging due to the length of time required for the ToC workshops.

Diversity of stakeholders

Bringing together diverse stakeholders in the process ensures multiple perspectives are considered. In the InCARE Theory of Change workshops, stakeholders included long term care users, their care partners and care providers in addition to policy makers. This breadth of stakeholder representation ensured that discussion was enriched by multiple perspectives resulting in more nuanced Theories of Change and plans for pilot implementation. For example, decision makers in North Macedonia shared their different perspectives on how the services can cooperate with the emergency and social care and highlighted the different roles of organizations providing services. Caregiver participation in Spain ensured the inclusion of outcomes related to care-giving including self-care, considering the caregiver and the time and resources required to care. Care-user participation in Austria highlighted the importance of addressing the risk of violence in private care arrangements.

Existing hierarchies may need to be explicitly managed during the workshop to ensure that all participants are able to contribute. The program of the online Austrian Theory of Change workshop was explicitly designed to reduce the existing hierarchies, for example, by not using formal titles and including special welcomes for and by key stakeholders. Different contexts may require different approaches to this.

Sustaining stakeholder engagement

Theory of Change is only a first step in what should be a continuous engagement process using other formats and approaches to ensure long term and sustained engagement. Although the Theory of Change approach helps to introduce key stakeholders to the project, program or policy and use their expertise to shape and refine the initiative in the initial stages, it does not guarantee their sustained engagement. In addition, when planning the workshops teams should recognise that different stakeholders may have worked together previously and in the context of fragmented services, lack of resources and previously established barriers which may require further work to repair relationships and build collaboration.

Additional strategies for engagement could include ongoing meetings, invitations to update meetings, disseminating key outputs, including the evaluation of the pilot projects. For example, in Austria, the InCARE team is planning four regional stakeholder workshops during the project to sustain engagement relationships.

Contextualization

Theory of Change workshops help teams to adapt the project, program or policy to the local context. For example, in Austria, the pilot implementation project changed its approach after the Theory of Change

workshop to take into account and to integrate with existing local services. In North Macedonia, the Theory of Change workshop resulted in changing how the emergency button could fit into the existing social protection framework afterwards and helped to generate solutions which would work in the highly regulated health and emergency environment. This ensures that the innovations are not just best practice but best-fit for purpose and more likely to be sustainable. In Spain, an additional set of Theory of Change workshops in the implementation area helped to refine the pilot prior to implementation.

Flexibility of the Theory of Change Approach

Theory of Change can be an adaptive and flexible process so the facilitating team should identify the purposes of the Theory of Change process for the project, program or policy in advance and plan accordingly to ensure that the key purposes of the workshop are fulfilled. The flexibility of the Theory of Change approach means that it is suitable to use both for high level conceptualization of system changes (for example, related to legislation and financing) as well as a detailed and step by step exploration of how these changes could be achieved (for example, detailed activities related to the implementation of the pilot project). The detailed Theories of Change can be used directly to formulate indicators for monitoring and evaluation. Although both the high-level Theories of Change and detailed implementation level Theories of Change can be developed, it is not always easy to switch between the two. Expert moderation and careful planning of the expected scope of the Theory of Change is required. This is particularly important to ensure a realistic and achievable Theory of Change. For example, in the workshop in North Macedonia, changes to legislation and financing were suggested which are beyond the scope of the project and we had to ensure that these changes were carefully described in the Theory of Change to ensure that they were not included in the remit of the project.

To develop the detailed Theories of Change and related monitoring and evaluation strategies additional meetings may be required with implementers and service providers. For example, in InCARE in Austria and Spain, additional sessions were held with a sub-group of participants and the project team.

Conducting Theory of Change workshops before funding is allocated or finalised would increase the contribution stakeholders can make to the choice of interventions. For example, in InCARE, although the Theory of Change workshops were valuable in refining and operationalizing the pilot projects, the Theory of Change still focused on a broadly defined, pre-specified intervention. To mitigate this, seed funding could be provided for Theory of Change workshops with stakeholders to ensure genuine engagement with the needs of stakeholders and local contexts or have funding models which allow flexibility for the project to be refined and changed following a Theory of Change process.

Format

Online Theory of Change workshops can replace or supplement face-to-face workshops as long as there is adequate time for discussion. The bringing together of multiple stakeholders in the same room has always been a key strength of Theory of Change workshops. However, in the initial stages of COVID-19 pandemic face-to-face meetings were not possible due to restrictions and safety concerns. As a result, the InCARE project level workshop and the Austrian workshop were held online despite initially having been planned face-to-face. Although it was challenging to move online, the Theory of Change approach is flexible enough to be adapted to a wide set of restrictions and particular conditions. In fact, in the Spanish Theory of Change process and in subsequent Theory of Change development processes we have been involved in, we often use a mix of initial face-to-face workshops with a follow up workshop held online. This approach works well because it helps to further develop networks and relationships with stakeholders.

Online Theory of Change workshops may be challenging for people not used to engaging online and may hinder the full participation of older people. Additional strategies may be useful to ensure adequate participation including pre-workshop meetings and training, assigning a buddy either within the workshop or in the persons' home, allowing multiple ways to engage (small group meeting, chat, online platform) and a post-workshop debriefing session.

Time constraints

The Theory of Change approach is a useful but resource intensive process with a steep engagement curve. This was particularly apparent in the online workshops where we opted for shorter workshops to prevent Zoom fatigue and maximise stakeholder input, but this resulted in less time for detailed discussions. We recommend allowing for sufficient time for discussions but balancing this against the availability of stakeholders and their time constraints. Careful planning of workshops is necessary. This includes skilled moderation of the workshop which is necessary to ensure all aspects of the ToC are covered and to ensure participation from all stakeholders in the allocated time. Where possible, additional online sessions or longer workshops may increase the time for discussion.

Recommendations

Our InCARE experience shows that Theory of Change can be a useful approach to develop complex change processes including projects, program and policies. This is because:

- 1) Theory of Change is an inclusive participatory approach which brings diverse stakeholders together, including users of long-term care, to understand and shape projects, programs and policies
- 2) A Theory of Change for a project, program or policy can be developed in a structured way to incorporate the strengths, resources and to overcome the challenges of the local context. This ensures a most relevant program which is more likely to be implemented well and sustained because it has been co-developed with a range of stakeholders
- 3) Theory of Change provides a structured and systematic way to monitor and evaluate the project, program or policy based on the key outcomes the initiative is trying to achieve
- 4) Theory of change is a useful tool for the early stages of public policy development which can provide a process to engage all stakeholders involved in the change and take into account their views and needs.

As is increasingly the case in international development and health, we recommend that Theory of Change or a similar methodology is required by funders and commissioners for projects, programs and policies in the care sector at European Union, national and regional level to ensure they include the voices of all stakeholders, including care users and care-givers.

At the time when the EU is drafting an ambitious Care Strategy expected to address the blatant gaps in accessibility, affordability and quality of long-term care services, the Theory of Change approach seems particularly useful to prepare for its implementation. Specifically, to overcome the existing difficulties such as the fragmentation of actors, the multiplicity of policy areas involved, and the need to combine a regulatory framework ensuring the right to long-term care with the specificities of each context. Importantly, participative methodologies such as Theory of Change are needed if we want to capture people's evolving situations and aspirations ⁹, in order to rethink and re-organise care around their needs, and advance urgently needed reforms capable of meeting acute and complex challenges in care.



InCARE (Supporting **In**clusive development of community-based long-term **CARE** services through multi-stakeholder participatory approaches) aims contribute to the design of a coordinated approach to the development of national long-term care policy and care services at local and regional level, by establishing socially innovative and participatory decision-making processes. We work with care users, care providers and policymakers in Spain, Austria and North Macedonia to design, implement and scale-up innovative care services.

For updates on our progress and publications please subscribe to our newsletter [here](#) or send an email to cc@eurocarers.org.

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References

1. European Commission. European pillar of social rights. European Commission Brussels; 2017.
2. European Commission D-GfE, Social Affairs and Inclusion, . Long-term care report : trends, challenges and opportunities in an ageing society. Volume I: Publications Office; 2021.
3. Ilinca S, Simmons C, Zonneveld N, Benning K, Comas-Herrera A, Champeix C, et al. Social Innovation in LTC in Europe: Towards a common narrative for change InCARE Short Report no 1. 2021.
4. Vogel I. Review of the use of 'Theory of Change' in international development. UK: Department for International Development (DFID); 2012.
5. Breuer E, Lee L, De Silva M, Lund C. Using theory of change to design and evaluate public health interventions: a systematic review. Implementation Science. 2016;11(1):63.
6. Breuer E, Comas-Herrera A, Freeman E, Albanese E, Alladi S, Amour R, et al. Beyond the project: Building a strategic theory of change to address dementia care, treatment and support gaps across seven middle-income countries. Dementia. 2021;14713012211029105.
7. De Silva MJ, Breuer E, Lee L, Asher L, Chowdhary N, Lund C, et al. Theory of Change: a theory-driven approach to enhance the Medical Research Council's framework for complex interventions. Trials. 2014;15(1):267.
8. Breuer E, Comas-Herrera A, Docrat S, Freeman E, Schneider M. STRiDE Theory of Change Workshops: Guidance and Resources. STRiDE Research Tool No.1 (version 2). London: Care Policy and Evaluation Centre, London School of Economics; 2019. Available from: <https://www.stride-dementia.org/publications>.
9. Ilinca S, Simmons CP. The time to talk about care: responding to changing attitudes, expectations and preferences on long-term care in Europe. 2022.

