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Piloting Social Innovation in Long-Term Care: Application of Theory of Change and Lessons Learnt

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Introduction

The evaluation and monitoring activities of the InCARE project have been developed via the "Theory of Change (ToC)" approach (Breuer et al. 2022; Coryn et al. 2011). In this way, the project and its pilot intervention's evaluation design were not aimed at a *post hoc* evaluation of activities and outputs but instead had been co-developed with the implementation partners of the pilot cases and relevant stakeholders (such as care users, policymakers, and care providers) through a flexible participatory method of ongoing feedback loops. This approach has also allowed the project to assess the defined impact goals and the subsequent activities in a traceable, adaptable, and measurable way. This policy brief builds on the findings from the InCARE project 's evaluation and monitoring activities and the assessments of the pilot and project theory of change maps and indicators (Kayran et.al. 2023). The ultimate goals of the InCARE project, as a result of the ToC deliberations were decided to be: "older people and their families live well and with dignity at *home*" and "older people with care needs and their informal caregivers have access to adequate and affordable care".

As evidenced by the <u>European Care Strategy</u> and the subsequent Recommendation by the Council of the European Union (Council of the European Union 2023), today, it is necessary to improve long-term care (LTC) systems to ensure access to affordable high-quality long-term care. The latter is also described in the <u>European Pillar of Social Rights</u> (Principle 18) (European Commission 2023), which highlights the need for affordable long-term care services of good quality in home care and community-based services. Notably, promotion of the rights of the elderly is also linked to the Charter of Fundamental Rights of the European Union (European Parliament 2000). Despite this strong backdrop of the call for action, many of the ways in which long-term care provision needs to be further developed to ensure these rights are still being developed. Making the matter more urgent is the fact that it is widely accepted that the demand for long-term care in Europe will continue to rise increasingly in the (near) future (OECD 2020). The Recommendations based on the European Care Strategy provide a picture in which the development of long-term care systems should ensure the right to affordable and good quality long-term care aim to also cover the following principles in finding new solutions for the long-term care challenges in Europe:

- improving home care and community-based care,
- use of innovative technology and digital solutions,
- support for informal carers,
- improved training of long-term care professionals and
- involvement of diverse stakeholders.

As of now, difficulties in accessing long-term care by the elderly are often identified as the lack of availability and/or affordability. One potential pathway of addressing such issues of availability and affordability are community-based care provision and home care which are often not sufficiently developed and carry their own challenges surrounding both care users and providers as well as a host of actors who need to collaborate and adapt. Thus, to develop and inform the LTC policy design and debates in Europe, InCARE concentrated on providing comparable and generalizable findings, stakeholder driven insights, feasible, and scalable evidence, and policy suggestions on such care provision. While InCARE was developed before the European Care Strategy was published in 2022, the project ´s overarching goals and the specific goals and activities of the pilots exemplify different ways of addressing these elements described in the Recommendation.



The InCARE pilot projects focused on home care and community-based care, and the ways in which these forms of long-term care delivery can be developed to satisfy the current and future demand of care in Europe in a sustainable and fair manner. All pilot projects also addressed the needs of informal carers and involved diverse stakeholders in their design, and all pilots also trained professionals. What has been crucial for the evaluation and the future of InCARE activities was to make sense of the findings for a broader context in the EU and find ways in which the social innovations could be sustained beyond the project life cycle.

The InCARE ToC, therefore, began with multi-stakeholder inputs which lead to a comprehensive understanding of the *theory* which is assumed to be leading to the targeted *changes* and social innovations that are sought by the interventions. This multitude of inputs and flexibility enriched the interventions themselves. It also allowed researchers and the implementing organizations to explicitly trace which aspects have been more (or less) successful based on the framework. Furthermore, the social innovation pilot projects of InCARE covered a wide range of critical issues facing long-term care in Europe, implemented in the three pilot countries Austria, Spain, and North Macedonia. These concentrate on networking and information provision, training and psychological support for caregivers, and adoption of new digital technologies in a new context, respectively. Through the ToC framework, each of these intervention domains has been carefully mapped on clearly defined long-term and short-term outcomes to achieve their target impact goals via specific activities which were undertaken during the project implementation. The national pilot teams worked in a participatory manner to develop their theory of aimed change, and the mechanisms of such planned actions were designed and monitored in a comparable manner to be able to have some overarching conclusions.

In this policy brief, we explain and provide examples from the project and pilot activities as to how the implementation of the ToC allowed us to bring forward better evidence and practice in the field from three different angles. In the following sections, we describe these three points which are the generalizability and scalability of our social innovations, participatory development of actions, and co-production as a method of policy development.

Generalisability and scalability of InCARE pilots

One of the key advantages that the project has benefited from applying the ToC framework was the ability to assess and explicitly demonstrate the comparability of the results of the pilot activities in different contexts in Europe. Importantly, it is difficult to uncover the often-invisible processes that lead to the observable outcomes in social innovation pilots. Our approach of national ToCs that trace and link pilot activities to specific outcome indicators, which are comparable across cases made it possible for future research and practitioners to draw conclusions. The explicit and transparent learnings from the assessments of the pilots also allows us to be able draw lessons for the scalability of the pilots by the identification of "what has worked" as well as some of the limitations and hurdles encountered in the field.

Based on the situational analyses and SWOT analyses conducted, and as in many other countries in Europe, we saw that long-term care is characterized by multi-level governance and fragmentation in all three countries. Available services vary depending on the location of a care receiver in all three countries. Differences between the three countries can also be observed, for example in terms of the availability of services or the type of financial support for care receivers and informal carers. Therefore, additional measures have been taken by the project teams when evaluating the pilots with significantly different designs in such diverse contexts. Moreover, given this, scalability of the pilot projects depends on the level of political interest in upscaling and the alignment of the



pilot with existing policy agendas and the possibilities to select different parts of the pilot project and to scale these up wherever relevant.

With respect to the application of ToC in InCARE, we have taken several measures which facilitated the comparability of the pilot findings to establish a basis of upscaling. Pilot interventions were evaluated in two ways; first, each pilot was evaluated within the national ToC with distinct measurable indicators specific to the pilots and, second, within a broad project-wide indicators that were applied to all pilots. This embedded approach of the InCARE ToC ensured generalizable findings from the implementation of the pilot, taking them to a higher level of aggregation when it comes to assessments. All ToC frameworks have also followed the same principles which considered participation of stakeholders at the center, continuous monitoring of key target audience satisfaction and input, and building connections between different actors - including especially local and national policy makers. For instance, the Austrian intervention, which focused on integrated care and improved networking of LTC providers from a community based LTC perspective used participatory methods extensively to ensure the upscaling of the actions. As a result, the pilot project became highly visible due to the active collaboration with network partners, promoting mobile care in the regional context in Austria. Likewise, the project findings were disseminated directly with the decision-makers, especially with those at the regional level. The project team was also invited to comment on the new policy reforms in the field (Ondas 2023).

Scalability in InCARE is understood as the generation of evidence through the pilot studies which can be then used in other external contexts which could be different from the pilot context in terms of location, groups, or scope. Thus, scalability of the pilots is one of the targeted outcomes of the project where, each pilot project's evaluation plan ensures that activities and measures are foreseen in this regard. In addition to having an overarching frame of reference when it comes to evaluation and making sense of the results of the project actions, upscaling activities were embedded as targeted outcomes within the project activities and the ToC.

The pilot activities had been adapted to the local contexts and discussions were had with the target stakeholders. Extensive local knowledge gathered for each social innovation, where context specific adaptation is needed formed an important basis for future geographical upscaling. This is illustrated by the actions in the North Macedonian pilot where an "Emergency Button Service" for older people living in the community, which was used in other contexts, was designed, and implemented in the local context (Grbevska Mitalkovska 2023). In doing so, the project implementation team followed the ToC approach in documenting and processing the actions that were taken as well as establishing relationships with the local cooperation networks and home-care services. The team also was in continuous communication with the national level ministries and municipal decisionmakers with discussions and ideas over co-financing models for the upscaling and sustainability of the innovations, following the participatory steps defined in the national ToC model.

Participatory social innovation for European LTC

Participatory workshops, trainings, and events which were held with care users and care givers increased the value of InCARE's social innovation activities from start to finish. As improving home and community-based care is recommended within the European Care Strategy, developments on such fronts are also understood to be taken forward with the support and the consideration of formal and informal care givers, care users, and the various other stakeholders. Specifically, the Recommendations based on the European Care Strategy aim to draw more attention to the needs



of informal carers. The strategy calls for the involvement of various stakeholders and concretely defining these groups as the following:

"...those in need of long-term care, their family members and organizations representing them, relevant authorities at national, regional, and local levels, social partners, civil society organizations, long-term care providers, and bodies responsible for promoting and social inclusion and integration and for the protection of fundamental human rights, including national equality bodies."

Participatory social innovation applied through the InCARE ToC methodology beget wide information sharing and dissemination as well as the ensuring of the quality of the social innovation designs as these actors are already part of the process. At the core of InCARE monitoring and evaluation strategies were the design and deliberation of the ToCs for the social innovations with the LTC stakeholders from each local and national context (see Kayran et.al. 2023, pp 13-18 for further details). More specifically, InCARE provides an example of "low-level participation" - which is different from the application of the full scope of participatory research (Vaughn and Jacques 2020), but still successfully tested a method for involving stakeholders from local, regional, and national level.

For instance, in the Spanish case, the pilot team (Matia) and the national policy partner (IMSERSO) have continuously worked together, via monthly meetings, in involving and having feedback loops with decisionmakers. All pilot teams had informal and formal care givers in the pilot ToC workshop development as stakeholders. Related to care providers, several pilot countries had the advantage of having their target intervention directly involved in the engagement with carers. For instance, a key pilot activity of the Spanish team was trainings and support for informal care givers which involved the participation of 76 care givers in the intervention group.

In the Austrian case, there were also multiple activities undertaken to ensure the participatory dimension with the stakeholders. To illustrate, in addition to their participation in the ToC workshops, care professionals and informal carers were also actively present in the project national events such as the 3 stakeholder workshops, where a total of 14 care professionals and a total of 6 future care users and informal carers were present. Particularly of a high level of engagement in the Austrian pilot was with care professionals due to the target group of the pilot. In this respect, the Austrian team also had 4 trainings on various topics (resilience and self-care and caring communities) with the participation of about 20 individuals. The North Macedonian pilot team also had a component of care-giver trainings to about 60 participants. Such intervention topics were also developed and discussed accordingly in the relevant ToC workshop with the participation of the stakeholders.

Finally, beyond the number of participants and engagement of the stakeholders, we also collected data, wherever feasible, on the extent to which knowledge transfer and awareness have been achieved between the project teams and stakeholders. For each country pilot ToC workshop, the national pilot evaluation teams and the evaluation team monitored the feedback surveys and all three countries reported above average satisfaction with their role and opportunities for contribution and discussion (Kayran et. al. 2023).



Re-orientation of policymaking in LTC

With respect to the objectives of InCARE, to be achieved in the long-term and beyond the project lifetime, one important goal was making a positive impact on the level of policymaking where the pilot activities and results could contribute to the evidence base. The application of participatory methods and embedding upscaling within all actions of the project, as discussed above, were two measures designed within the ToC to achieve this. In this final section, we discuss one other way InCARE activities were designed through the ToC workshops with relevant stakeholders to make use of and build on existing resources and projects, which were already implemented and identified as priorities by the decision-makers and care organizations.

All three InCARE pilot projects have aligned themselves mostly in existing public projects and/or have used resources from previous and existing resources. For instance, the pilot project from Spain built its intervention within the existing public project SENDIAN (Decreto Foral 29/2008, De 29 De Abril, Por El Que Se Aprueba El Programa «SENDIAN» De Apoyo A Familias Con Personas Mayores Dependientes A Su Cargo). The SENDIAN programme pre-existed InCARE and provides psychological support groups, individual therapy, and other resources to help informal carers cope with caring for a loved one. It is open to caregivers of people with dementia in Gipuzkoa, the region in which the Spanish pilot was implemented. Thus, the Spanish pilot 's innovation of trainings and activities were embedded in the existing programme which has also facilitated the recruitment of participants. While it is difficult to achieve reform in, often rigid and path-dependent, institutional settings and in administration of services within the short span of the project, arguably, such links with a program with pre-existing funding and resources provided the Spanish pilot with better likelihood of achieving its goal of the improvement of the existing public services in the long run.

Likewise, in the North Macedonian pilot, the implementation team, through the national ToC, designed and made use of an existing method of LTC at home, i.e., the emergency button service, and learnt from the experiences of other contexts in which the method was applied. It also built on a feasibility study conducted before the InCARE project started. To facilitate and better use the resources in the project and to showcase to the relevant decision makers, the team made study visits to other locations where the services had already been used (such as to Red Cross Styria in Graz). During the visit, the North Macedonian team had the opportunity to visit the largest call center responsible for the Emergency Button service in Austria and the surrounding region. Even though the continuation of the provision of this service hinges upon the take-up from decision makers. The pilot team brought in sufficient evidence and know-how from other contexts to make a strong case for the design of this service in their local context.

Concluding remarks

Overall, the InCARE project aimed to improve the knowledge base and pilot test how to develop long-term care systems, concentrating on community based and home-based LTC delivery. InCARE contributes to both the development of innovative and community-based long-term care services and to the support for the development of long-term care systems at the policy level. In terms of the development of services, the vision was that InCARE contributes to empowering these communities, including people with care needs and their informal carers. Regarding the policy level, the aim was to support the development of the respective system by generating new evidence. Having both aims within the same project also provided extra opportunities for ensuring the sustainability of pilot projects.



As discussed here, the InCARE project provides an example of testing a method for involving diverse stakeholders in the development and local adaptation of social innovations. At the same time, it aimed to integrate the pilots through the InCARE project in the development of national LTC systems by involving policy makers on various levels. InCARE demonstrated how the ToC method can be successfully applied to tailor a social innovation in LTC to the local context. Implementation of the InCARE approach in three different countries also allowed us to see how this approach develops under different circumstances. The pilots differed in terms of whether they introduced a new service, improved an existing one or developed various impulses to improve integrated care. They also differed in the local policy context, in terms of which services already exist and which national reforms are ongoing. Through the evaluation of the InCARE pilot projects, we were able to trace the impact of using the InCARE methodology in these different contexts.



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InCARE (Supporting Inclusive development of community-based longterm 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.

More information on the project's website: <u>https://incare.euro.centre.org/</u>









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