

Adapting a palliative care intervention across seven European countries: The Pal-Cycles intervention

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Research Article

Keywords: Healthcare, palliative care, healthcare systems, end of life, advanced cancer, cultural sensitivity, patients, family members, cross-cultural, stakeholder engagement

Posted Date: June 10th, 2025

DOI: <https://doi.org/10.21203/rs.3.rs-6556722/v1>

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Additional Declarations: No competing interests reported.

Abstract

Background

International adaptation of healthcare interventions requires sensitivity to local contexts, especially in palliative care, where healthcare systems and cultural expectations about end of life differ widely. Pal-Cycles is an intervention that aims to improve transitions in care for patients with advanced cancer. This intervention was adapted for implementation across seven European countries. This paper aims to illustrate the process of adapting a palliative care intervention (Pal-Cycles) to meet the needs of those using healthcare settings across seven European countries.

Methods

Adapted nominal group techniques were used, which involved the use of both in country and cross-country adaptation meetings focussed on the five key components of the original intervention design, to ensure cultural sensitivity and best fit. Each country convened a group of clinicians and five countries also convened a secondary group of patient and family members. The adaptation process occurred in a series of meetings, which were mostly held online to accommodate participants' schedules.

Results

A total of 36 clinicians, 14 patients or family members, and 16 facilitators participated in the adaptation process over a four-month period. Structured guidance and iterative consultation meetings ensured that the final intervention was both standardised and adaptable to each country's healthcare setting.

Conclusions

This paper provides a model for future cross-cultural adaptation of palliative care interventions, illustrating the value of detailed methodological planning, structured guidance, and multi-stakeholder engagement in the adaptation process.

Trial registration:

ClinicalTrials.gov NCT06259136, registered on 6 February 2024.

Introduction

Conducting international research in palliative care is inherently complex due to differences in healthcare systems, levels of palliative care integration and development, and funding mechanisms across

countries. These factors necessitate careful consideration when adapting interventions to ensure cultural, clinical, and systemic relevance (1). In order to be effective, interventions developed in a specific context need to be adapted to the contexts where they will be implemented. This needs to be done efficiently and with sufficient expertise, requiring a structured approach.

Interventions developed for one population may not be effective when directly applied to other cultures or populations, while developing a new intervention for each population would be costly and time consuming (2). Cross cultural adaptation is one approach to address this, which involves considering language, culture, and context in a way that it is compatible with the area's cultural contexts, meanings, and values (3). However, this approach has many challenges, including what has been described as the "Fidelity-Adaptation Dilemma" (4), which describes the tension between delivery of evidence-based interventions as developed to ensure effectiveness, and the need to address the needs of the local population by making changes to the intervention. Cultural adaptation considers where there is an area of intervention-population gap and makes changes to increase the relevance and fit (5). However, this presents a risk that the intervention may be adapted in a way that decreases its effectiveness (2). It has been suggested that fidelity can be maintained by strategic cultural adaptation that retains an intervention's core theoretical components while making changes to ensure cultural relevance for the new population (4).

It has been identified that there is requirement for high-quality evidence-based interventions for people with cancer, and their family caregivers related to palliative care (6). The Pal-Cycles intervention was originally created in the Netherlands to facilitate transitions in primary care settings, which may be precipitated by changes in settings of care, management of care, or goals of care (7). The intervention includes five key components, previously described in a scoping review (8): identification of palliative care needs, compassionate communication, collaborative treatment planning, regular review and evaluation, and recognition of the end-of-life phase. See Fig. 1 below.

This intervention, based on the five components, was adapted for the Pal-Cycles clinical trial (9), specifically for patients with advanced cancer in both secondary and tertiary care. The clinical trial involves a palliative care transition programme between hospital and the community for patients with advanced cancer, through facilitating patient-centred communication and continuity of care. The trial aims to reduce unplanned hospital admissions and improve quality of life at the end of life.

The intervention, with its core components, was developed and adapted considering context-based integration in a) the local health system, b) interorganisational collaborations (hospital-homecare), for implementation in c) local care practices for advanced cancer patients.

The aim of the paper is to illustrate the process of adapting a palliative care intervention (Pal-Cycles) to meet the requirements of healthcare settings across seven European countries.

Methodology

In order to adapt the Pal-Cycles intervention to each country's local context, an adapted nominal group technique (NGT) was used to facilitate balanced participation across a series of consultation meetings, to encourage diverse viewpoints, and support consensus-building, ensuring that the intervention would be relevant and feasible across different clinical and cultural contexts (10). The NGT provides a structured method to obtain information and ideas related to the area of interest, through encouraging inclusive balanced decision making (11), without the need to achieve consensus across the group (12). Typically, NGT are performed face to face and start with individual generation of ideas, which are ranked and prioritised through voting during the groups' discussions although conducting online is known to be feasible (12). As the current context involved adapting an intervention across several countries, an adapted NGT method was used.

The adaptation process used is described below. This adapted NGT method involved structured group meetings with multiple rounds of feedback and discussions. This iterative consultation process included both cross-country and country-specific meetings (10). To guide the adaptation process, the ADAPT guidance (13) was used to ensure a systematic, evidence-based approach to tailoring the Pal-Cycles intervention across diverse healthcare contexts. The ADAPT framework emphasises key steps such as identifying core intervention components, assessing the need for adaptations, and systematically documenting changes to maintain fidelity while allowing for contextual flexibility. By following this guidance, the adaptation process ensured that the intervention's core components, described above, remained consistent across countries. Simultaneously, the framework supported the integration of culturally and contextually relevant changes, such as modifying terminology or adjusting tools to align with local healthcare systems. This structured approach facilitated transparency, consistency, and rigor throughout the adaptation process, ensuring the intervention's relevance and feasibility across all participating countries.

Study Design and Setting

The adaptation process for the Pal-Cycles intervention spanned seven European countries: Germany, Hungary, the Netherlands, Poland, Portugal, Romania, and the United Kingdom. Each country convened a group of clinicians, who were recruited purposefully through the professional networks of the research teams, to discuss the intervention's components. As cultural adaptation involves an iterative, and collaborative process, this should, where possible, include participation of those from the target population, for whom the adaptation is being developed (5). Although this is still an emerging concept in some countries, five of the countries were able to convene a group of patients and/ or family members to engage in the adaptation process. These Patient and Public Involvement (PPI) groups were invited to provide feedback on specific intervention components such as compassionate communication and the collaborative development of treatment plans.

To maintain consistency, the Lancaster University team (RH, SP, NP) developed standardised guidance, including a set of slides and instructions, to guide discussions. They also set up an initial cross-country meeting with the adaptation facilitators from each country and leading clinicians. This allowed

generation of initial themes, to be later discussed in the first round of adaptation meetings in each country. This meeting also served as a workshop to demonstrate how to conduct the adaptation meetings effectively, to allow all participants to have equitable input on the discussion using the principles of NGT.

Informed Consent

Prior to participation, all individuals involved in the study; healthcare clinicians, patients, and family members, were provided with detailed written information outlining the purpose of the consultation meetings, and their rights as participants. Informed consent was obtained in writing from each participant, with signed consent forms collected and securely stored. Participants were assured of their right to withdraw from the consultation process at any time without consequence. This process was conducted in accordance with Lancaster University's ethical guidelines and approval protocols.

Stepwise Adaptation Process

The adaptation process occurred in a series of meetings, which were mostly held online to accommodate participants' schedules and also to allow for sequential cross country adaptation meetings to facilitate feedback. Only one clinician meeting and two patient and family meetings were held in person. The Lancaster team organised the process into the following stages, detailed below:

- **Initial cross-country meeting (February 2023)**

This initial meeting involved facilitators from each country, who were part of the research team on the Pal-Cycles project. An NGT facilitation style was demonstrated by the Lancaster University team throughout the meeting as an example of how to effectively hold the adaptation meetings in each country. The meeting generated the key discussion points for the following adaptation meetings, which were structured around the five components identified in the original intervention design. Following this meeting the Lancaster University team wrote structured guidance in the form of PowerPoint slides, a guidance document and a feedback document, to ensure the key questions were asked in a similar manner and discussion points recorded consistently in each country.

- **First round of adaptation meetings (March 2023)**

The first adaptation round took place in March 2023. Clinician meetings were held in each participating country, while additional patient and family meetings occurred in Germany, the Netherlands, Poland, Romania, and the UK. The power point slides were translated as required. The guidance documents were used, with country teams summarising discussion points and submitting them to Lancaster for analysis (14).

- **Cross country meeting (April 2023)**

A second cross country meeting with facilitators and some clinicians from each country involved the Lancaster University team presenting analysis from the first round of adaptation meetings, including areas of consensus and disagreement. These were discussed and key areas to be followed up in the second round of adaptation meetings created. Following this, the Lancaster

University team created updated PowerPoint slides and guidance documents to be used in the second round.

- **Second Round of adaptation meetings (May 2023)**

The second round of adaptation meetings addressed the unresolved questions. This round again involved clinicians from each country and the separate patient and family meetings held in Germany, Poland, Romania, and the UK, focusing on any elements of the intervention that required further consensus or contextual refinement (15).

- **Final Cross-Country meeting (June 2023)**

The last cross-country meeting served to finalise the intervention, integrating feedback from both rounds and addressing outstanding issues. The Lancaster team then produced a draft intervention manual, which was shared with country team facilitators for final input and feedback. A final standardised version of the manual was the final result of the whole process.

Adaptation meetings took place in their local language. The feedback forms provided a summary of the discussion in English that were analysed by the Lancaster team, ensured content analysis of the adaptation meetings took place, and was more suitable for efficiency and ensured accurate summaries of key themes by the facilitators, in their native languages. See Figure 2 below showing the adaptation process.

Results

A total of 36 clinicians participated in the meetings, including 18 oncologists, five palliative care nurses, five general practitioners, four oncology nurses, three palliative care physicians and a surgeon. A further seven patients and seven family members also participated alongside 16 facilitators who ran the meetings over four months. The structured guidance materials provided by the Lancaster team enabled country partners to conduct consistent and culturally responsive meetings. Feedback indicated that flexibility was crucial in several areas, particularly in selecting culturally appropriate palliative care assessment tools (16).

As part of the adaptation process, structured consultation groups, including facilitators from the Pal-Cycles research teams and healthcare clinicians, were established in each of the seven participating countries (Germany, Hungary, the Netherlands, Poland, Portugal, Romania and the UK) to tailor the intervention to local healthcare practices. In each country, a group of healthcare clinicians (including general practitioners, oncologists, palliative care physicians, cancer nurse specialists, and palliative care nurse specialists) was formed. This diversity in clinical expertise was integral to understanding the varied perspectives within multidisciplinary cancer and palliative care teams. By involving professionals from both primary (GPs) and specialist care (oncology and palliative care), the adaptation process benefited from insights into each stage of patient care, including initial diagnosis, ongoing treatment, and palliative support.

In five countries, meetings with patients and family members ensured that end-user perspectives were central to the adaptation process. Feedback from the patients and family member meetings was incorporated when adapting the intervention across all countries, such as patients' request for more involvement in their own care plans, and the idea of a patient held form. The final intervention manual incorporated standardised elements but allowed flexibility for country-specific applications, such as defining "community teams" based on each healthcare context. The patient and family groups included current patients, relatives, bereaved relatives and patient representatives from self-help group associations.

All adaptation meetings, including the guidance documents were based on the key components of the original intervention design. However, within these key areas there needed to be flexibility in definitions and implementation across countries. Therefore, part of the adaptation process was related to which areas could be flexible across contexts and which elements of the intervention had to be defined and implemented the same in all countries to maintain the key components.

During the development of the intervention, key elements were established to ensure consistency across all countries. For instance, the Edmonton Symptom Assessment System Revised (ESAS-r) was chosen as the symptom assessment tool. While ESAS-r is commonly used in European countries, it is not typically used in the UK, however, maintaining a standardised tool across all countries was essential.

At the same time, certain aspects of the intervention design required flexibility to adapt to local contexts. For example, patient held forms and questionnaires used during the intervention remain the same across all countries, however the way in which they are administered may be different, with some countries using online versions and some using paper format. Additionally, as the current intervention is largely based on transitions which may include transitions from hospital into the community, there was flexibility in defining terms used in the intervention, such as "community teams," which varied based on the structure and context of each country's healthcare system.

As a result of the adaptation meetings, an intervention manual was developed, including the adapted intervention design. This was translated into local languages of the seven partner countries, where the intervention will be trialled. Furthermore, as a result of the adaptation meetings, it was important to consider the underpinning elements and mechanisms necessary for the intervention to have its desired impact. Therefore, a theory of change model was also created to help us understand how the Pal-Cycles intervention will affect the transition process and care trajectory of cancer patients. The theory of change model considered the following dimensions, and is shown below (figure 3):

- The goal of the intervention
- Long term outcomes
- The preconditions that need to exist for impact to be achieved
- The ceiling of accountability at which we would stop measuring if outcomes have been achieved
- Indicators that can measure progress achieved in relation to outcomes

- The intervention strategies
- Rationale
- Assumptions

Discussion

This paper demonstrates the feasibility and advantages of a structured, iterative process for international intervention adaptation. By involving stakeholders from multiple countries, the adaptation process ensured that diverse perspectives informed the intervention's design, leading to a final product that was both standardised and locally adaptable (17). Using adapted NGT allowed the clinicians to systematically discuss and prioritise adaptation needs, identify barriers to implementation, and suggest practical adjustments suited to their local health systems.

The adapted version of NGT used differs from traditional NGT to suit adaptation of an intervention for seven European countries. For example, NGT is usually done using face to face methods, however, to ensure feasibility for clinicians working busy schedules, and to allow countries to include international participants where necessary, our adaptation meetings were held online, with only two patient and family meetings held in person. Furthermore, typically NGT uses ranking of priorities through voting and result in both qualitative analysis (analysis of recordings) and quantitative analysis (numerical ranking of ideas) (12). In this case, as we developed the intervention between seven different countries, the aim was not to identify a single solution, but to assess how the key components of the intervention could be implemented across all contexts. Rather than using the traditional ranking method, the cross-country meetings enabled feedback from all countries to be considered, before confirming or re-generating ideas suitable for all.

The cross-country meetings considered cultural sensitivity and best fit, allowing ideas to be generated regarding how elements of the emerging intervention may be defined differently in each setting. Reliability of this cultural adaptation process was achieved through focussing on the five core theoretical components of the original intervention design throughout discussions which were maintained (4).

Across five of the seven participating countries (Germany, the Netherlands, Poland, Romania and the UK), a Patient and Public Involvement (PPI) group was also established. PPI groups are increasingly recognised as essential to the development and adaptation of healthcare interventions, ensuring that the patient perspective is integrated into research and practice (18). The PPI groups consisted of patients and family members, who provided insights based on their experiences, bridging the gap between research and patient-centred care (19). Engaging PPI groups is especially valuable when developing palliative care interventions, where understandings of patient needs and preferences are critical. Research has shown that PPI involvement can improve the relevance, quality, and feasibility of interventions by grounding them in the priorities of those directly impacted by healthcare services (20). For cross-country studies like the adaptation of the Pal-Cycles intervention, PPI groups also offer contextual insights that ensure the intervention aligns with cultural factors within each country. For

example, in the current study the PPI groups highlighted a need for improved and more compassionate communication, as well as suggesting the use a patient held form to improve communication regarding treatment and care plans. These elements were incorporated into the final intervention design.

PPI engagement is increasingly recognised as a cornerstone in designing healthcare interventions, as it bridges the gap between clinical objectives and patient priorities (19). While PPI engagement is still an emerging concept in some of the participant countries, the inclusion of patients and family members in five countries added valuable insights, highlighting the importance of user-centred approaches in intervention development. Their contributions helped refine the intervention, ensuring that it meets the needs of patients and families facing advanced cancer and palliative care across diverse healthcare settings. Furthermore, the structured guidance supported consistency across countries, emphasising the need for detailed, adaptable frameworks in international research collaborations (21).

Despite the usefulness of using NGT, it could allow inadvertent bias towards more dominant voices within groups or hinder deeper exploration of opposing perspectives (10). Therefore, ensuring balanced participation, especially in settings which could be perceived to be hierarchical, requires careful facilitation to avoid biased discussions (21). This was facilitated through frequent turn taking when discussing ideas throughout the meetings.

Furthermore, while it is important to involve PPI groups in this type of research, it is also important to ensure the representativeness of the PPI groups. As PPI groups were established in only five countries, there may have been some unique cultural insights that were missed from the other three countries. Given the cultural variability in perceptions of palliative care and death, broader PPI engagement could have further enhanced the intervention's contextualisation (22).

The flexibility incorporated into the Pal-Cycles intervention, such as tailoring assessment tools and defining "community teams," enhances the ability to implement the Pal-Cycles intervention across various European countries. However, it is important to ensure consistency in implementation, through maintaining core intervention components while allowing contextual modifications. This can be a challenge in healthcare interventions, as excessive flexibility could weaken results (16).

The model presented, involved using adapted NGT including multiple rounds of adaptation meetings, with multiple groups of key stakeholders and cross-country meetings with facilitators. The use of structured guidance was key to ensure consistency and ensuring that intervention elements remain consistent with key components of the original intervention across all countries increases the fidelity of the cultural adaptation of the intervention. This was a valuable method for international adaptation of a healthcare intervention. It emphasises the balance between standardisation and local adaptation. The iterative consultation process aligns with best practices in developing complex interventions, which advocate for systematic stakeholder engagement and phased development (17).

Conclusion

Adapting a palliative care intervention across multiple countries requires structured, systematic approaches to facilitate consensus while respecting cultural and systemic differences. The adapted nominal group technique, combined with structured guidance, enabled successful adaptation of the Pal-Cycles intervention across seven European countries. The process resulted in a standardised intervention manual, with flexibility for country-specific adaptations, underscoring the importance of adaptable, structured methods in the development of international healthcare interventions (23). This study provides a model for future cross-cultural adaptation of palliative care interventions, illustrating the value of detailed methodological planning, structured guidance, and multi-stakeholder engagement in the adaptation process.

Declarations

Ethics approval and consent to participate

This study was reviewed and approved by the Faculty of Health and Medicine Research Ethics Committee at Lancaster University. Ethics approval was granted under reference number FHM-2023-3277-RECR-2. All participants provided informed consent in accordance with the committee's guidelines and ethical standards. The study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki.

Consent for publication

No consent for publication was necessary, as no individual person's data is presented.

Availability of data and materials

No extra material supplied.

Competing interests

The authors declare that they have no competing interests.

Funding

The Pal-Cycles project is funded by the Horizon Europe programme of the European Union grant agreement number 101057243. Horizon Europe Guarantee UKRI Reference Number: 10038822.

Authors' contributions

JH, SP, NP designed the study. All authors were involved in the adaptation process described. RH, SP and NP contributed to writing the manuscript. JH is the funded project lead. All authors reviewed and approved the final manuscript.

Acknowledgements

The Pal-Cycles coordinating institution, Radboudumc (Stichting Radboud Universitair Medisch Centrum), Netherlands, as well as the other partners: Universitätsklinikum Bonn (UKB), Germany; Lancaster University (ULANC), UK; University of Pécs (Pecsi Tudományegyetem, UP), Hungary; University of Zielona Góra (Uniwersytet Zielonogorski, CM UZ), Poland; Hospice Casa Sperantei (HCS), Romania; European Association for Palliative Care (EAPC); Universidade Católica Portuguesa (UCP), Portugal; Universidad de Navarra (UNAV), Spain.

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Figures



Figure 1

Five Components

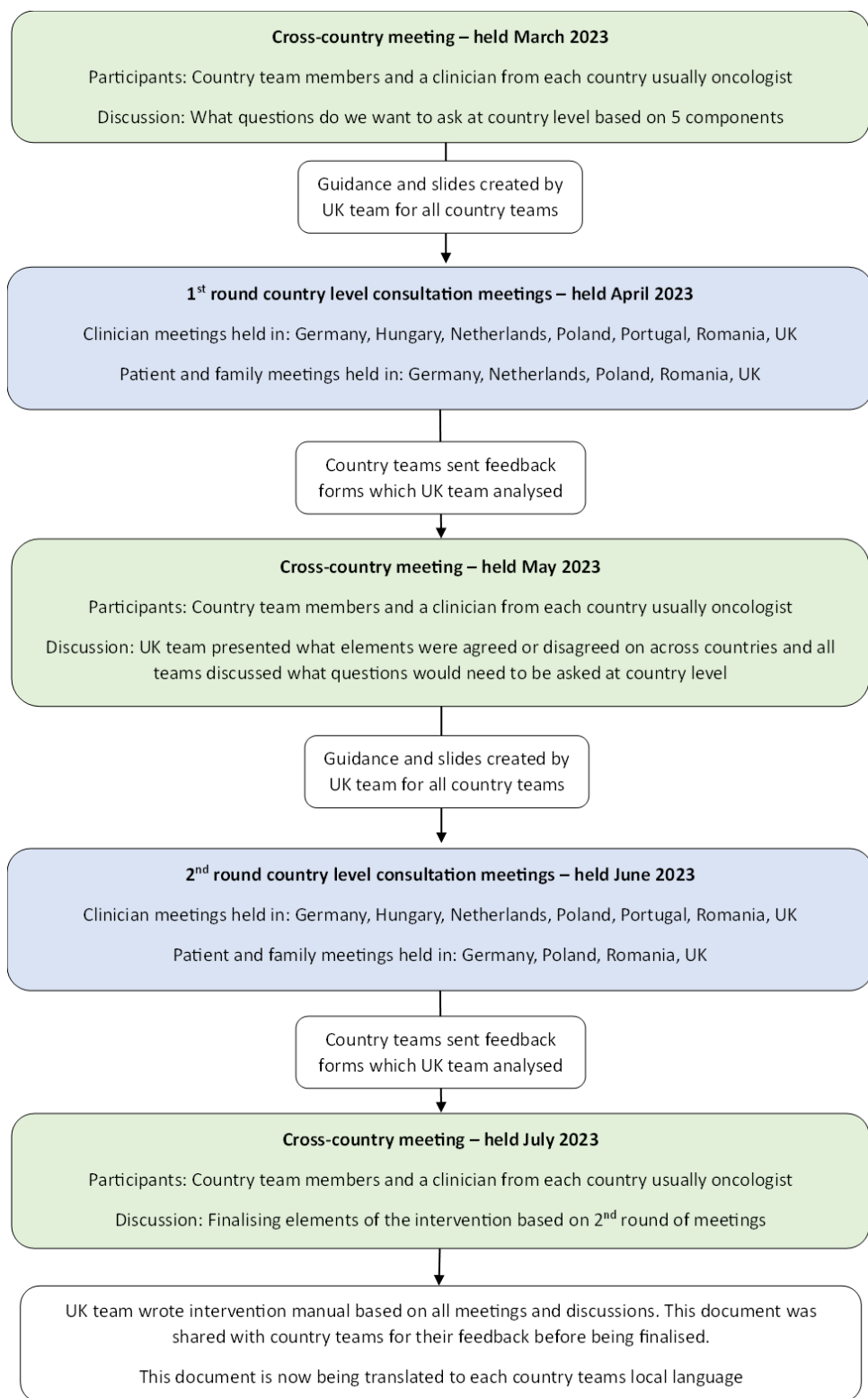


Figure 2

Process of adapting intervention

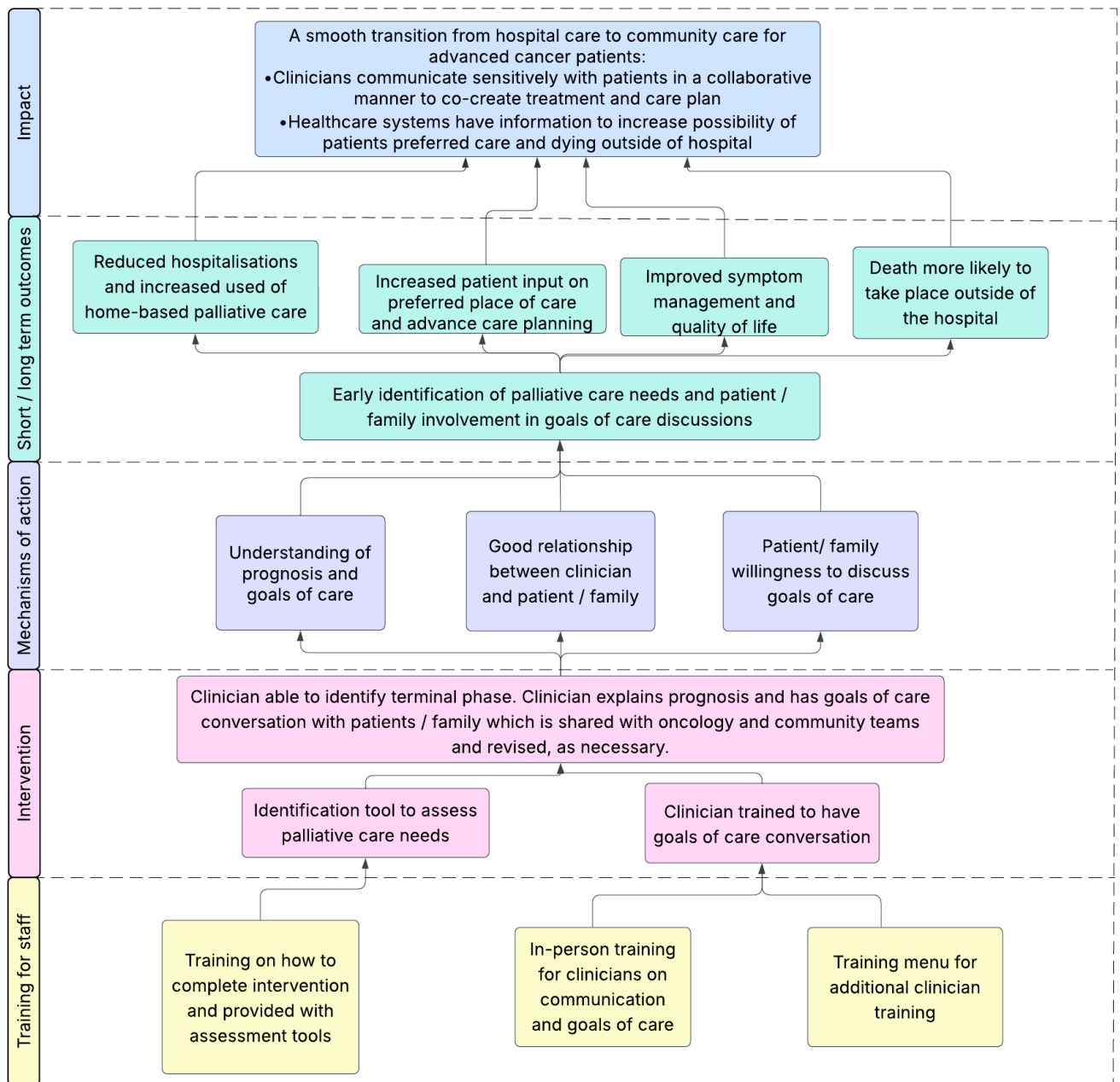


Figure 3

Theory of change model for the Pal-Cycles intervention