THE KERRY SPECIALIST PALLIATIVE CARE SERVICE
A CASE STUDY RESEARCH EVALUATION

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Abbreviations

ANP	Advanced Nurse Practitioner
CHO	Community Healthcare Organisations
CNM	Clinical Nurse Manager
EOLC	End-of-life Care
GP	General Practitioner
HR	Human Resources
HSE	Health Service Executive
HTA	Health Technology Assessment
IC	Integrated Care
IFIC	The International Foundation for Integrated Care
KHF	Kerry Hospice Foundation
KPI	Key Performance Indicators
KSPCS	Kerry Specialist Palliative Care Services
MDT	Multidisciplinary Team
NIHR	National Institutes of Health Research
OT	Occupational Therapy
PACE	Psychosocial Assessment and Communication Evaluation
PCOC	Palliative Care Outcomes Collaborative
PHN	Public Health Nurse
QOL	Quality of Life
RGN	Registered Nurse
SPC	Specialist Palliative Care
TC	Terminal Care
UCD	University College Dublin
UHK	University Hospital Kerry
WHO	World Health Organisation

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1 Executive summary

Background

Kerry Specialist Palliative Care Service provides a comprehensive palliative care service in County Kerry that is highly valued by those using the service, families, clinicians, and the entire community. The service provides care in four settings i.e., in a Specialist-Inpatient Unit; through a Specialist Palliative Care Community Team; at a Specialist Palliative Care Day Service and through an Acute Hospital Specialist Palliative Care Service. The service is delivered in partnership between the HSE and Kerry Hospice Foundation.

This evaluation was commissioned by the HSE/Cork Kerry Community Healthcare with the objective of reflecting on and learning from the integrated palliative care journey to date, investigating the emergence, evolution, success, and transferability/replicability of Kerry Specialist Palliative Care Services (KSPCS).

This report followed a case study research evaluation approach, allowing the authors to provide a unique and detailed insight into the KSPCS service. It is our hope that the learning of this work will also allow consideration of the key elements in KSPCS which may be replicated elsewhere.

Key Findings

During the case study research evaluation, a consistent message was that, coupled with HSE support of the local community, availability of and adherence to a national clinical blueprint by committed and connected local leaders were key to the development of the specialist palliative care service available in Kerry.

This national framework (the report of the National Advisory Committee on Palliative Care, 2001) allowed for the local implementation of a service which has a strong sense of local ownership, aligned with existing national policy. Service delivery and design has followed the principles of integrated palliative care. There has been clear and consistent leadership working to clear goals, and a shared belief in the ethos of palliative care. The relationship between all the leaders, working in an aligned way towards the same goal is one of the most robust components of the success of the service.

The case study research evaluation also demonstrated the high value which the entire community places on the service, and the level of recognition among the wider community of the impact of this combination of strong local leadership and consistent community support.

It is clear that this strong leadership and commitment in the various sectors involved in palliative care in Kerry created a shared vision and purpose. Engagement with stakeholders including the volunteer sector, specialised clinical team, community care, hospital services managers, and health service representatives created a strong local support network.

The role of Kerry Hospice Foundation in the development of the service is clear, and there is no doubt that the service would not be as far advanced as it is without the existence of Kerry Hospice Foundation.

The partnership with Kerry Hospice Foundation allowed for an innovative approach to funding the development of services. The collaboration and trust between the Foundation and the service, and the commitment to national standards led to a coherent development of a locally embedded service which was faithful to a national blueprint. The local fundraising support empowered local leaders to negotiate the development of this service with national authorities and means that this service is locally owned but integrated into the national system.

Main Recommendations

As outlined above and in greater detail in the body of the report, local commitment to the national guidelines was key to the coherent development of KSPCS. A lack of such guidance and commitment would be a challenge for local initiatives in developing an integrated palliative care service. Without such guidance and commitment, other similar services would be at high risk of working in disconnected silos.

The case study research evaluation allowed us to identify some opportunities for the continued development of an integrated palliative care service as KSPCS continues to grow and evolve.

- The community support and continuing backing for the service is evident. There are further opportunities to involve service users, families and community in the planning, commissioning, delivery, and evaluation of the service. Kerry Hospice foundation could play a key role in reaching to the community and facilitating this increased inclusion of the voices of the community and staff as the service continuously move towards co-design and co-production of the service.
- This engagement would also facilitate the emergence and identification of future leaders in the community.
- We also see a greater role for both the service and the Kerry Hospice Foundation in informing and advocating for palliative care services and advance care planning in the community.
- There are also opportunities to continue to integrate even further within community care, even acting as a reference point for specialised or complex care.

On a broader level, we also see the opportunities witnessed in Kerry Palliative Services as a template for development of services both regionally and nationally:

- Differences between care mean inequalities in palliative care provision, and to prevent this there is a need for a consistent national blueprint for local services to follow. In this regard, the next national integrated programme report (due for revision in 2024) will be key in the development of integrated services. This will require leadership regionally and nationally, and political commitment.
- We also believe that a Regional Development Group could facilitate the development of palliative care from a regional perspective (with HSE service delivery aligning to Regional Health Areas in the coming years).
- Fragmented national or regional structures can pose challenges in the development of integrated services and addressing this requires innovative solutions. We recommend a local oversight group with representation from all stakeholders to facilitate future growth of the service in an integrated and inclusive way, while still retaining the strong local leadership and community support.
- Digital infrastructure to allow for greater sharing of data and information is a key component in the provision of more integrated care, but development of a secure digital environment must be led nationally. In the meantime, we recommend consideration of greater access by service-users to their own data in the interests of supporting self-management.
- Finally, there are opportunities locally and nationally to develop a systemic research evaluation process, with the collection of standardised information which could guide future developments and support a culture of continuous improvement and learning.

2 Introduction

World Health Organisation (WHO) defines palliative care as "*an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness*" [1]. These problems include physical, psychological, social, legal and spiritual elements of people and their families [2].

Even though palliative and hospice care is internationally recommended as an essential part of healthcare systems [1], the provision of palliative care is a complex intervention. It has multiple dimensions and elements that are necessary to improve the quality of life of people and their families such as [2]

- prevention and relief of suffering, including pain and any other distress;
- early identification and comprehensive assessment;
- treatment and care throughout the persons course of life until their death;
- family-centred approach including support during bereavement;
- integration of all the wellbeing elements such as physical, psychological, social, legal or spiritual elements of people and their families;
- assistance and support with decision-making process respecting people's values;
- provision of a multidisciplinary, interdisciplinary and/or transdisciplinary approach;
- training and support of staff and workforce;
- engagement with the local community and community members;
- accessibility at all levels of the health care system including people's home;

Palliative care provision is not a unique model, and it is highly dependent on local culture, system, and resources. There are different models of care delivering integrated palliative care around the world with different governance and leadership models [3]. In general terms, even though the need for high integration between services or integrated palliative care is recognised, there is little guidance on how to operationalise or implement integrated palliative care [4].

Kerry Specialist Palliative Care Service (KSPCS) combines several of the components described above for the delivery of high-quality integrated palliative care service. The service has been recognised in the Irish media as "*one of the country's most highly regarded Palliative Care Services"*[5]. It was also selected as a study tour site as a good example of integrated care service as part of the accelerated learning programme on integrated care, organised by the IFIC Ireland in 2019 [6].

The creation and evolution of the KSPCS is a unique journey of service development of integrated palliative care in Ireland, that this case study research evaluation aims to capture. The key

learning of this research evaluation can inform future local plans and other areas in the country and worldwide.

2.1 Overview of Kerry and KSPCS

County Kerry is a rural county located in the southwest region of Ireland and covers an area of over 4,807km² and is the second largest county in the province of Munster, with the population of over 147,707 people (as per Census 2016; http://census.cso.ie). Kerry is part of the Community Healthcare Organisation (CHO)[4] area number 4 together with North Cork, North Lee, South Lee, and West Cork. University Hospital Kerry (UHK) is the third largest acute hospital of the southern areas providing care to the population of Kerry parts of North Cork and West Limerick. It is located in Tralee, which is considered the capital of Kerry. There are presently 300 inpatient beds [7].

Kerry Hospice Foundation was created in 1990 as an initiative to respond to local need for cancer care as there was no organisation covering this service in the area. This voluntary organisation has been the driver to develop the palliative care service in Kerry. Currently, Kerry Hospice Foundation in partnership with the HSE fund the specialist palliative care services in Kerry.

The Community Specialist Palliative Care Team was founded in 1991, with two nurses initially and has progressed to have two teams. The two teams are attributed to the large geographical spread. KSPCS is currently lead by two consultants, 24/7 on call service which has proven of immense value to the hospital and community in improving palliative care services. The service is currently provided in the following four settings:

1) **Specialist Palliative Care Inpatient Unit**

A 15-bed specialist inpatient palliative care unit in Kerry opened in December 2017 and like the Day Care Services facility is attached to UHK. The patients are admitted to the Specialist Palliative Inpatient Unit for complex symptom management, rehabilitation and end of life care that cannot be met in other care settings. Staffing of the unit includes a Clinical Nurse Manager (CNM) II, CNM I's, Registered Nurses (RGN), healthcare assistants, porters, clerical staff, Allied Health Professionals including occupational therapy, physiotherapy, pastoral care, speech and language therapy, medical social workers, dietitian, pharmacist, catering and domestic staff.

[4] Community Healthcare Services are the broad range of services that are provided outside of the acute hospital system and includes Primary Care, Social Care, Mental Health and Health & Wellbeing Services. These services are delivered through the HSE and its funded agencies to people in local communities, as close as possible to people's homes. (Source: https://www.hse.ie/eng/services/yourhealthservice/feedback/complaints/officers/pccc/chos.html, HSE, 2022).

2) Specialist Palliative Care Community Service

The KSPCS is delivered by two teams. The two teams are attributed to the large geographical spread of the county and its population. The North Kerry team is based in the Specialist Palliative Care Unit in UHK delivering a service to North Kerry and a second team is based in Killarney Community Hospital delivering a service to South Kerry.

It is a 7-day service caring for the patients in their place of residence; this may be the patients' home, community hospital, or private nursing home. In the community, the Specialist Palliative Care Team works closely with the GP, Public Health Nurse, Community Hospital Team, Primary Care Team, and Nursing Home Teams.

3) Specialist Palliative Care Day Service

The Specialist Palliative Day Service is located on the grounds of UHK and opened in 2007. The service provides a mixed medical/social/supportive model of care. Staffing of the unit includes a CNM II, CNM I, RGNs, healthcare assistants, porter, clerical staff, Allied Health Professionals including occupational therapy, physiotherapy, pastoral care and speech and language therapy, medical social workers and dietitian. Specialist Palliative Day Care offers complementary therapies two days a week and sessions with a psychotherapist. The service also provides volunteer services including hairdressing, beauty therapy and creative arts.

4) Acute Specialist Palliative Care Service

The Acute Specialist Palliative Care Service includes two Consultant in Palliative Medicine, Registrar, Senior House Officer, one Advanced Nurse Practitioner, Social Worker and access to administrative support.

KSPCS cares for the following profile of people:

- Patients with malignant and non-malignant disease (e.g., MND) – experience of outpatients, day service, inpatient unit, hospital, and community care.
- Patients referred to the service with malignant or non-malignant disease for end-of-life care (EOLC). Short involvement in the hospital and referred to the community (home). May have required night nursing services.

- Patients referred to the service with malignant or non-malignant disease for EOLC. Short involvement in the hospital and referred to the hospice for EOLC.
- Patients with a Haematological diagnosis with advanced disease best supportive care including bone marrow support.
- Patients with malignant or non-malignant disease transferred from the hospital or home to a community support bed.

3 Purpose and objectives

The case study research evaluation of the KSPCS was commissioned by the Cork Kerry Community Healthcare, Health Service Executive (HSE), with the objective of reflecting on and learning from their integrated palliative care journey. The development and evolution of the KSPCS was shaped and influenced by the national level policy, local culture, organisations, and people. This research evaluation provides an opportunity to revise KSPCS' journey in its development of a person-centred integrated palliative care service.

The learning of this work will contribute to the knowledge of palliative integrated care and will identify key elements that should be considered for its replicability or transferability in other areas in the country and worldwide.

The aim of this case study research evaluation is to understand the emergence and evolution of the KSPCS, determine the factors that explain its success and identify the potential for replicability and transferability to other geographical areas in Ireland.

The case was defined as the KSPCS including its inpatient, day service, hospital team and community services. This case definition was collaboratively agreed with the commissioners and the research team. The case study research evaluation was overseen by the Governance Group composed by meso and macro level stakeholders of the KSPCS, and an international palliative care Expert Panel revised the research evaluation protocol and the findings of the international literature.

3.1 Research evaluation questions and objectives

3.1.1 Research questions

Primary question:

> How has the KSPCS emerged and evolved, and which factors contribute to its success and potential replicability / transferability?

Specific questions:

1. **Emergence and evolution:**
    a. How was the service built?
    b. How have the structures and relationships emerged and changed to support the service?

2. **Success factors:**
    a. Why is the KSPCS perceived as a good example of integrated palliative care practice?
    b. What elements of the KSPCS can be considered as good practice?
    c. Which factors make the service successful, and widely accepted and valued in the community?
    d. How are they making the service successful?

3. **Replicability and transferability:**
    a. Which factors (or moderators) that contribute to KSPCS success could be replicated or transferred to other settings in Ireland?

3.1.2 Objectives

1. Identify the key elements of the KSPCS journey from its creation until now.
2. Identify the elements that enable integrated palliative care service provision.
3. Provide guidance as to which factors (or moderators) that contribute to KSPCS success can be replicated or transferred to broader settings for supporting integrated palliative care in Ireland (Figure 2).
4. Apply a broader international perspective to reflect on KSPCS and identify the learnings of their journey.

4 Methodology

This project followed the case study research evaluation approach. Case studies are recognised to benefit from having multiple sources of evidence to allow the researchers to address a broader range of historical and behavioural issues and a mix of qualitative and quantitative data allows for triangulation. Collecting data from multiple sources and methods improve the credibility of findings [8]. This provides a unique and detailed insight into the KSPCS service, its journey and evolution.

Case study research evaluation uses a variety of methods to explore complex phenomena within the context of the case or cases, and palliative care is a complex mix of provision between health and social services, voluntary and statutory agencies. It has been used internationally in healthcare studies [9] to explore systems of palliative care [10], diverse contexts for palliative care delivery [11], roles of professional groups such as pharmacy [12] the impact of services such as complementary therapy [13] and nursing [14]. Case study is not bound to any single research paradigm [22, 23], and therefore, may employ both qualitative and quantitative methods independently or together which is the approach planned in this research evaluation.

The study, in keeping with case study methodology, was co-designed with the service itself. The regional CHO Chief Officer gave his permission for the research team to access participants and the documentary and data material required. The research evaluation project was in line with recently amended Health Research Regulations (2021).

4.1 Data collection methods

This case study applied a mixed methods approach, and data was collected at different levels of macro (policy and strategy), meso (local context including service planning, funding and governance) and micro level (the experience of the service user, family and representatives of the multidisciplinary team).

We used several methods to collect data which were carefully aligned to the research questions and objectives (see Table 1 and Table 2):

Table 1. The alignment of research questions and methods

Research method	Research questions					
	Primary question					
	Which factors explain the emergence, evolution, success and potential scalability of KSPCS?					
	↓					
	Specific questions					
	Emergence	**Evolution**	**Success**			**Replicability**
	How was the service built?	How have the structures and relationships emerged and changed?	Why is the KSPCS perceived as a good example?	What elements of the KSPCS can be considered as a good practice?	Which factors make the service successful?	What factors contributing to KSPCS success should be replicated in Ireland?
Interviews	x	X	X	X	x	x
Journal entries			X	X	x	x
Observation			X	X	x	x
SCIROCCO		X		X	x	x
Literature review				X	x	x
Review of documents & physical artefacts	x	X	X	X	x	x

Table 2. The alignment of research objectives and methods

Research method	Research objectives				
	Identification of KSPCS key elements of evolution	Identification of KSPCS integrated care practices	Identify success factors and inhibitors	Replicability and transferability	International perspective
Interviews	X	x	X		
Journal entries	X	x	X		
Observation	X	x	X		
SCIROCCO				x	

Literature review				x	X
Review of documents & physical artefacts	X	X	X		

4.1.1 Primary data collection methods

4.1.1.1 Stakeholder mapping

The research team together with the Governance group performed a stakeholder mapping exercise to identify the relevant stakeholders in KSPCS from the micro, meso and macro levels inspired in the Rainbow Model of Integrated Care [15] (Figure 1).

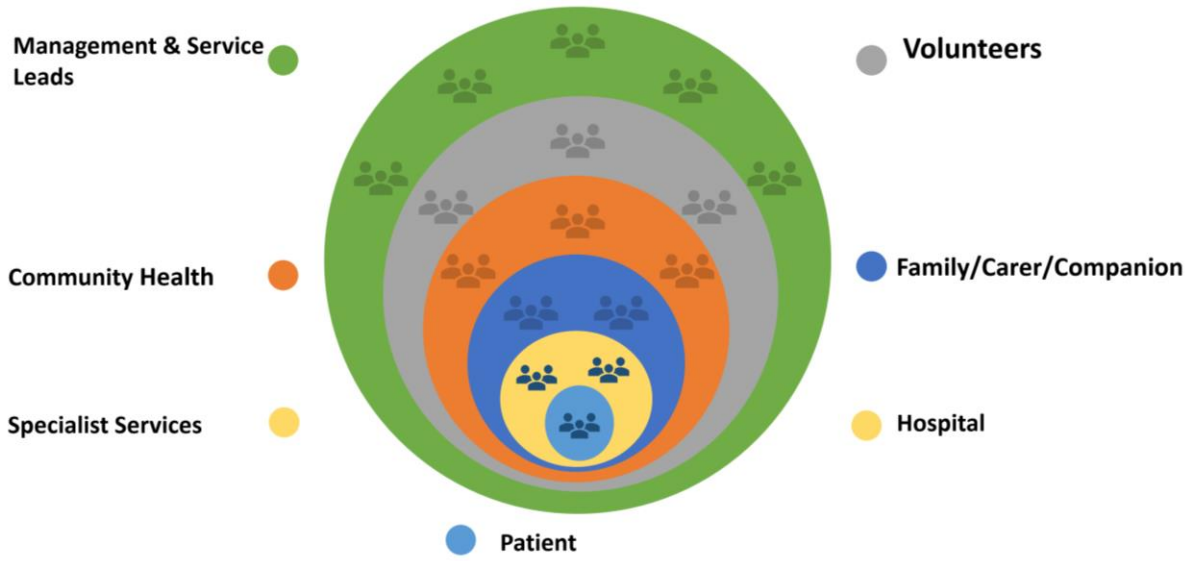

Figure 1. Stakeholder mapping

The research team assessed and proposed the best research methods to engage with each of the stakeholder groups considering the limitations due to the COVID pandemic and HSE ransomware attack that occurred during the project.

- Micro level:
    - Patient and family or care partner: one-on-one interviews

- Care service practitioners from hospital, community health and specialist services: one-on-one interviews, multidisciplinary team meeting observation (MDT), SCIROCCO participatory workshop.

- Meso level:
  - Management and service leads: one-on-one interview, SCIROCCO participatory workshop.
- Macro level:
  - Management and service leads: one-on-one interview, SCIROCCO participatory workshop.

4.1.1.2 Qualitative interviews (macro, meso and micro level)

Macro and meso level

Three 1h-long virtual interviews were conducted from the macro an meso level (two macro and one meso). The interviewees were proposed by the Governance Group and their profiles included people involved in the planification and implementation of the national palliative care policy, KSPCS development and Kerry Hospice Foundation fundraising activities. The objective of these interviews was to get an overview of the KSPCS. The interviews were adapted to the expertise and background of the interviewee.

Micro

15 interviewees who were selected by purposive sampling strategy and included 3 current family representatives, 3 past family representatives, 3 service users, 6 MDT members. The researcher recruited service user/family/MDT representative clusters to ensure all participants had experienced the KSPCS at the same time. 12 interviews were in person, 1 over the phone and 2 online. The selection criteria included service users and their families who attended KSPCS for at least 4 weeks, and considered the maximum variation of geographical spread, timing with coronavirus pandemic, referral source and service type to include elements that may impact in the experiences users have with the service. Due to the characteristics of the research population, prevent obligation to consent or avoid any perceived coercion, the researchers collecting the data were external to the KSPCS and they reiterated that the research evaluation project was separate to the services being provided for the person by KSPCS.

4.1.1.3 Non-participant observation of the MDT meetings

Three non-participatory observations of MDT meeting were conducted in KSPCS over a six-week period (September – October 2021). The observations lasted approximately 90 min each. The data collection template was piloted during the first observation and was subsequently modified to reflect the structure of the MDT meeting and allow for clearer recording of the data. No individual identifiable data were collected during the observations.

4.1.1.4 Reflective journal

The learning from the in-depth interviews and observations was complemented with the journal entries and fieldnotes completed by the researcher (interviewer). Reflective notes were recorded throughout the data collection process (recruitment, contacting participants, immediately post-interviews / observations). These notes complemented interview transcripts and observation recording during the data analysis stage. It was suggested to the participants to record own reflections / comments after interviews, but this was optional.

4.1.1.5 Quantitative data analysis

The analysis of the quantitative data included KPI and anonymised individual datasets. The KPI datasets were provided by the HSE National Palliative Care Integrated Operations team for the period between 2018 and 2020. The anonymised dataset was collated manually from a number of sources - activity records for the in-patient unit, day unit and community teams of KSPCS along with an extract from the University Hospital Kerry Patient Information Management System (iPIMS). The collection and collation of the data was conducted by a service administrator dedicated to the project for the purpose of data collection and data understanding. The anonymised dataset was provided to the data analysts for cleaning, interpretation, and reporting.

Individual level dataset was collected on demographics, diagnoses, and service use in the last year of life, and included the following variables:

a. Geographical area: County Kerry
b. Population: all patients on community services who died in 2019 and 2020
c. Observation period: from referral to outcome (usually death)
d. Indicators
    - Date of death
    - Place of death (Home, hospital, nursing home…)
    - Age in years
    - Gender

- Reason for referral
- Hospital admissions
- Diagnosis: cancer / non-cancer / non-cancer breakdown
- Date of first referral to EOLC (as starting point of palliative care)
- Any other relevant services
- Any experience measures collected

4.1.1.6 Participatory workshop

The SCIROCCO Exchange participatory self-assessment tool was used to meet three objectives of this research evaluation:

1) Facilitate the multi-stakeholder dialogue and progress towards the implementation and delivery of integrated care in the KSPCS.
2) Understand the strengths and challenges of the KSPCS for integrated care.
3) Inform the scalability and transferability of the KSPCS based on the maturity level of each dimension (see Figure 2).

Figure 2. SCIROCCO Exchange Maturity Model dimensions

The SCIROCCO Exchange Tool is a questionnaire developed in the SCIROCCO Exchange project, which aims to support health and social care authorities in the adoption and scaling up of integrated care [16]. The maturity model questionnaire of the SCIROCCO Exchange Tool assesses the maturity of the service or organisation in relation to 12 dimensions as shown in figure 2. The Population Approach was eliminated from the exercise in agreement with the participants because it was not deemed appropriate in the context of KSPCS evaluation. The Funding dimension was adapted to better reflect the context of analysis.

The use of the SCIROCCO Exchange Tool followed three steps:

1) The stakeholder mapping (see 4.1.1.1)
2) Completion of an online maturity assessment questionnaire individually
3) A 2h-long participatory workshop where results were discussed to achieve consensus on the level of maturity KSPCS has in the different dimensions

In total, eight people completed the self-assessment survey and nine people participated in the workshop. Participants profiles included: management and service leads (macro level n=2, meso n=2); voluntary sector (macro n=1, meso n=1); community (meso n=1); specialist services (micro n=1) and hospital (micro n=1).

4.1.2 Secondary data collection methods

4.1.2.1 Review of archives, documents and physical artefacts

Content analysis was used to identify and analyse the information from documents and physical artefacts [17] to understand the journey of the KSPCS and its value in the community. Data was collected from the following documents and physical artefacts:

- Peer-reviewed journals: articles published by the KSPCS
- National reports: where KSPCS is mentioned or included
- Other documents: published by commercial publishing organisations (e.g., newspapers)
- Grey literature: not controlled by commercial publishing organisations (e.g., internal reports, working papers, newsletters)
- Grey data: user-generated, web-based (social media)
- Grey information: published or unpublished (annual reports, strategy documents, service plans, meeting notes, emails, personal memories)

4.1.2.2 *Review of the international literature*

The search of international literature commenced in October 2021 and concluded in March 2022. A broad search on the topic of integrated palliative care was conducted across five academic databases and grey literature. Particular focus was placed on articles describing integrated palliative care service models. 2204 studies were screened and 64 were included in the full text review (all were published within the last five years). 18 studies provided data regarding the integrated palliative care models and pathways of service. The findings were presented to the International Expert Panel for discussion.

4.2 Ethics

Ethical approval was originally granted on the 17/02/2021 by the University College Dublin (UCD) Human Research Ethics Committee (reference: LS-21-13-McGovern) and subsequent modifications to the research protocol were reassessed and approved on 15/10/2021. A detailed system was developed to avoid coercion and minimise the burden of research for the participants. The recommendations of the Methods of Researching End-of-Life Care (MORECare) project [18] were considered in the development of the research evaluation project.

4.2.1 Consent process

Participants received oral and written information about the study and had the opportunity to ask questions. Written informed consent was obtained from every participant. The process of consent was renegotiated at different stages of the interaction between the researcher and the participant. The clinical team consulted the research team if any service user or family representative become too unwell (physically or emotionally) to participate. Confidentiality was assured, and participants were able to withdraw from the study at any time without any repercussions.

4.3 Data analysis

The process of data analysis began in November 2021 and concluded in February 2022. In line with the mixed methods design, both qualitative and quantitative data analyses were completed.

Qualitative analysis went through several cycles and was guided by the framework analysis [19]:

1. Familiarisation with the data: Each transcript was read a number of times until a sense of immersion in the data was achieved.

2. Preliminary inductive analysis via open coding (to allow for a discovery of unexpected aspects of the participants' experiences).
3. Refinement of themes (in line with research aims: emergence, evolution, success, replicability and transferability).
4. Deductive approach where the data was categorised based on pre-selected themes derived from the nine pillars of IC described by IFIC (see Figure 3). Data collection activities used two other frameworks of IC, the Rainbow Model of Integrated Care (stakeholder mapping and MDT observation categories) and SCIROCCO Exchange dimensions (participatory workshops), and the information obtained was re-organised following the nine-pillar framework. The finding section of this report will follow the nine pillars of IC structure.

Figure 3. The nine pillars of Integrated Care

The quantitative data analysis included KPI and anonymised individual datasets. The KPI data were separated for each service type (outpatients, acute, community, palliative care inpatient unit). In order to be able to view the development of the individual indicators per service, the total values per year were calculated. Where possible, percentages were calculated for

comparisons of the different characteristics of the indicators (e.g. cancer vs non-cancer). The individual data were analysed descriptively. Frequency distributions of the basic variables (e.g., sex, diagnosis, place of death) were taken and cross-tabulations were made. In addition, the days elapsed between referral and first visit and outcome were calculated. Finally, a calculation was made of how many services the patients received 365 days before the outcome (death).

Data triangulation and the development of converging lines of inquiry were the key analysis techniques to integrate all the data (see Figure 4), which involves developing the reliability of the findings through multiple data sources within each type.

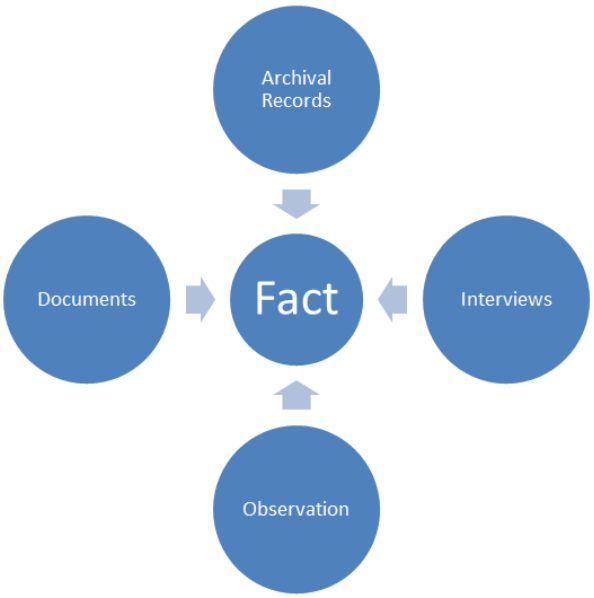

Figure 4. Convergence of multiple sources of evidence [10]

There were four types of triangulation:

1. Data triangulation (of the different data sources which helps address issues of construct validity. In additional, data collected remotely were triangulated with data collected in person)
2. Investigator triangulation (between the different members of the research team)
3. Theory triangulation (of perspectives to the same data set)
4. Methodological triangulation

4.4 Limitations of the research evaluation

This case study research evaluation had a number of limitations that are discussed below.

Case study was a valuable approach, and it was appropriate to conduct the above service evaluation. Case study allowed for iterative, flexible, and adaptable approach, which accommodated the challenges experienced during this service evaluation (such as adapting to the national restrictions related to COVID-19 or limitations due to the ransomware attach of the HSE). Having the KSPCS representatives involved in co-design of the study provided an opportunity to discuss key decisions and greatly contributed to collecting comprehensive data. Mixed methods design enabled in-depth investigation of KSPCS as a complex system. Multiple perspectives and data sources allowed for data triangulation and contributed to the validity of findings. Data were collected and analysed rigorously. Sensitivity to context was maintained throughout the process of data collection and full flexibility was offered to the participants regarding the mode, place, date and time of data collection activities.

Although the data collection process was comprehensive, limitations were recognised during the study:

- No economic evaluation was undertaken, and although this was not an objective of this project, it may have provided new evidence beneficial for the service planning and resource allocation.
- Community representation was limited to the management team of the Kerry Hospice Foundation. Lay people involved in the voluntary sector and members of the public were not recruited, and it is possible that some valuable insights from community perspective or regarding fundraising aspects of the service was missed.
- Data collection was impacted by restrictions associated with COVID-19. In addition, the ransomware attack to the HSE networks affected electronic communication channels. The above difficulties were resolved by close cooperation of the research team and all stakeholders. The methodology chosen (case study) allowed to overcome the above challenges and complete the service evaluation.
- The importance of the local culture and context poses a risk of the findings not being easily transferable to other locations.
- The quality of the quantitative data obtained for the study limited the capacity to interpret the results to respond to the research questions. More details will be described in the finding and conclusion sections.

5 Findings

In this section, we will present the summary of the main finding of the case study research evaluation, answering to the research questions and using as reference the dimensions of the nine pillars of integrated care. There the subsections will include findings about the emergence and evolution of the KSPCS, success factors and main challenges, and factors or moderators that can contribute to replicability and transferability.

5.1 Emergence and evolution

This section will describe the main factor that have influenced the emergence and evolution of the KSPCS.

The development of the KSPCS started with a local initiative to develop cancer care in County Kerry. Ted Moynihan, Comdt Owen O Sullivan & Mr Tom McCormack started a movement in 1990 that together with some local healthcare representatives led to the creation of the Cancer and Hospice Fund. The initial proposal of supporting cancer care evolved to palliative care support in Kerry and it was formalised in the voluntary organisation called Kerry Hospice Foundation.

Specific contextual and local elements enabled the integrated approach of the service development. The Board of the Kerry Hospice Foundation was composed of local clinical representatives, who had a clear vision to align the new palliative care service with the principles and recommendations presented in the Report of the National Advisory Committee on Palliative Care published in 2001. This report proposed an iterative implementation process of integrated palliative care and the old Southern Health Board took this on board in 2002 under chairmanship of Pat Healy of the HSE. Local leadership and resources determined the capacity in County Kerry to implement integrated palliative care services.

Some of the key elements that guided and influenced initial plans, structures and relationships are described below.

1) **Shared vision and values**

The shared vision and values in the different levels, from community leaders, health board representatives and the clinical team have produced a unique and exemplar journey of service development. Local and regional stakeholders shared the vision and values in their approach, not only in their understanding of what was needed in the community but also in setting the principles on how to develop the service. Strong local cohesion around the vision and values of how to develop an integrated palliative care service and the alignment with the national policy were key elements of the formula that resulted in the development of the KSPCS.

2) Local leadership

Apart from the shared vision and values discussed above, two other key elements that allowed Kerry to advance and promote the development and implementation of an integrated palliative care service, were local leadership and clear distribution of roles. Several people have been identified as a key person in the emergence and evolvement of the service. The strong local leadership, converged in and steered by the Kerry Hospice Foundation enabled leading and engaging with relevant stakeholders at the national, regional, and local level. Representatives of community, clinical leaders and health boards worked together with the same goal, with a distributed leadership and a clear role in their area of influence. Individual leadership was boosted by the collaboration between the leaders of different areas: they imprinted a local personality to bring the national policy to Kerry. Local leaders have been publicly recognised by the community and granted community awards like Kerry Person of the Year on several occasions (2017, 2020, 2022).

> *"And Kerry Person of the Year is: Hospice activist Ted Moynihan. Prestigious honour awarded for 'selfless and remarkable example of community spirit'.* (Source: grey literature. Irish Times, 2017, https://www.irishtimes.com/news/social-affairs/and-kerry-person-of-the-year-is-hospice-activist-ted-moynihan-1.2935006)
>
> *"Dr Patricia Sheahan, Blennerville, Tralee, is the 2020 Kerry Person of the Year by the Kerry Association in Dublin. Dr Sheahan is head of the Palliative Care Services at UHK and has been recognised for her outstanding dedication and commitment to cancer patients in Kerry and her tireless efforts in providing one of the country's most highly regarded Palliative Care Service Units (…)"* (source: grey literature. Independent, 2020. https://www.independent.ie/regionals/kerryman/news/patricia-is-kerry-person-of-the-year-38927238.html)
>
> *Dr Patricia Sheahan collects Kerry Person of the Year award (…) Alongside Kerry Hospice Foundation, she has helped develop a fully integrated palliative care service for the county.* (source: grey literature, 2022. https://www.radiokerry.ie/news/dr-patricia-sheahan-collects-kerry-person-of-the-year-award-296132*)*

3) Alignment with the national palliative care strategy

There was a change in the culture, vision and values at the national level that coincided with the initial interest in developing cancer care in Country Kerry. The Irish Government's growing interest in developing community services for palliative care was first reflected in the National Health Strategy in 1994. The Minister for Health & Children established a national advisory committee for Palliative Care in 1999 with a view to preparing a report on Palliative Care Service

in Ireland. The seminal moment that marked government commitment to growing and sustaining services at the national level arrived with the Report of the National Advisory Committee on Palliative Care published in 2001 which was signed off by the Government. This report defined how specialist palliative care services should be structured in three levels of specialisation and highlighted that comprehensive palliative care services should meet the needs of the patients and their families.

> *In assessing the need for palliative care services, patients and their carers are prime stakeholders, and as such, their opinions and preferences should be sought and incorporated into national and regional policies.* (Report of the National Advisory Committee on Palliative Care, 2001)

The Report of the National Advisory Committee on Palliative Care acknowledged and recognised the key role of the voluntary sector to identify and respond to the community needs and develop integrated palliative care services. Therefore, the national report provided a clear role to the Kerry Hospice Foundation to be involved and lead the development of the local palliative care service.

> Volunteers are an integral part of the specialist palliative care service, whether they are working directly with patients and their families, or giving other essential support, such as raising money. (Report of the National Advisory Committee on Palliative Care, 2001)

The Report of the National Advisory Committee on Palliative Care has been perceived as a strong policy guidance to develop comprehensive and integrated palliative care services in Ireland, and it is still accepted as the reference document. The Kerry Hospice Foundation, regional and local health boards, and the team of KSPCS were in consonance with the principles and proposals of the Report of the National Advisory Committee on Palliative Care, which they used as a reference in every step of the service development.

4) National and regional level collaboration

KSCPS has taken to its core to collaborate with national and regional bodies, and they have been represented in all national and regional forums and influence spaces. The Report of the National Advisory Committee on Palliative Care (2001) recommended the development of two regional committees for palliative care: the Regional Consultative Committee and the Regional Development Committee.

> *Each health board should establish two regional committees for palliative care. These are:*
> *1. A Regional Consultative Committee, which should provide a broadly based forum for the exchange of information and ideas on all matters pertaining to palliative care.*

2. A Regional Development Committee, which would advise the CEO on the implementation of the National Policy.
(Report of the National Advisory Committee on Palliative Care, 2001)

The Southern Health Board developed both committees, with representation from Cork and Kerry, voluntary organisations, primary care, and the relevant hospitals. These committees were very successful and provided the strategy for the regional development of Specialist Palliative Care Services across all sectors. The region became the Southern Area in 2008 with the amalgamation of the Community Healthcare Organisation (CHO) 4 and CHO5. This juncture saw the formation of the Southern area consultative committee, but before this could further enhances services the economic downturn of 2008 limited the possibility of future regional development.

Even though collaboration at the regional level has continued in the subsequent years, formal structures of collaboration such as regional consultive or developmental committees have not been re-stablished yet.

5) Collaboration between local services

The hospital specialist service and the community services collaborated to build the KSPCS. Before the creation of the KSPCS there were community teams that operated as two teams funded by the Kerry Hospice Foundation under the line management of the Director of Public Health Nursing. This nursing team provided specialist palliative care advise to the GPs, PHNs, district hospitals and the county hospital. Their offices were based in the district hospital Killarney and at the time, Tralee General Hospital. During the first steps to create the KSPCS everybody worked closely together to build the service, with the same vision and collaborative attitude, including the palliative care specialists, community nurses and primary care.

6) The role of the volunteer sector, fundraising capacity, community ownership

The Kerry Hospice Foundation resulted from a community initiative to create a cancer support and care in County Kerry. The movement that started with cancer support progressed to palliative and end-of-life care, and the community and volunteer sector initiative materialised in the creation of the Kerry Hospice Foundation.

In February 1990, a conference held in Ballymullen Army Barracks in Tralee announced that the 15th Battalion of the F.C.A. was to undertake a 150-mile sponsored walk, that included the Ring of Kerry, with the proceeds going to Baile Mhuire Tralee and the Kerry Cancer Support Group. This prompted Ted to establish a Hospice movement in Kerry, along with Dr. Tom McCormack F.R.C.S.I. at Tralee

General Hospital. (Source: Kerry Hospice Foundation website, https://www.kerryhospice.com/copy-of-home)

The Kerry Hospice Foundation's main role was to raise money to support the creation of a local palliative care service. The HSE and its previous iteration the Southern Health Board, had national, regional and local structures in place to enable the implementation of national palliative care policies locally. The fundraising role and capacity of the Foundation allowed the development and implementation of palliative care services far quicker that what the national and regional rollout would have allowed for. The fundraising capacity also allowed the Kerry Hospice Foundation to agree different arrangements with the HSE to plan the next steps of the service development. One of the examples is the inpatient unit, where the Kerry Hospice Foundation proposed and undertook the funding to build and resource the unit along with the pledge of funding some revenue cost for five years. The State committed to provide the land for the building in return KHF agreed to fund the revenue cost to open the building, as well as additional level of revenue to support the service for a further five years. The State committed to take over the full revenue costs after this period of time. This arrangement enabled the inpatient unit to be built and operational much earlier than if there was total reliance on State funding.

This model of collaboration between local volunteer sector and the state has been very attractive for the state and fruitful and beneficial for the local service development. The collaboration between the Kerry Hospice Foundation and the state has been highly productive and positive.

> *The attractiveness to the state of the offer to have a purpose built, new, modern facility, built and to the standards required by the state, along with a significant revenue component to meet at least some of the additional staffing costs, was so attractive that favoured the building of the inpatient unit in advance of other planned units around the country.* (Source: senior management team)

Both parties, the Kerry Hospice Foundation and the state, have fulfilled and lived up to the expectations and commitments allowing trusting relationships to develop and grow. This constructive relationship has empowered local leaders to design and plan future service delivery to provide the local community the services they need earlier than if they wait until the stated can fully fund the services. There is confidence that additional service development using this model of collaboration can be feasible as the KSCPS moves on to the next phases of service development.

On a final note, and at the community level, The Kerry Hospice Foundations has encouraged and stimulated community involvement in the fundraising activities since its foundation. As a result,

the community has the perception of ownership and pride with the local palliative care services, which is a relevant element of the KSPCS journey.

5.2 Success factors and challenges

This section will describe the main success factors and challenges of the KSPCS. The section will be structured following the nine pillars of integrated care (see Figure 3).

One of the activities conducted during data collections was a consensus building workshop using the SCIROCCO self-assessment tool. The objective of the exercise was to have an open discussion between meso and macro level representatives (see 4.1.1.2). and get a snapshot of how different dimension of integrated care were perceived in the KSPCS. The visual representation of the SCIROCO Maturity Model is shown below (see Figure 5).

Figure 5. Visual representation of the SCIROCCO Maturity Model consensus (NOTE: The red circles represent individual self-assessment responses and the black line and the numbers, the consensus scoring)

This image represents some of the areas that meso and macro representatives perceived as more successful than others. The main success factors identified were process coordination, removal of inhibitors, citizen empowerment and capacity building. On the other hand, less mature dimensions appeared to be of readiness to change, structure and governance, funding, evaluation methods, breadth of ambition and innovation management, with special emphasis in the need for digital infrastructure development.

This section will provide more detailed information on all these dimensions integrating after data from all the sources and data triangulation.

5.2.1 Shared vision and values

The values and principles of palliative care are aligned with the principles of person-centred care, and therefore, palliative care services can be a good example of how person-centred care would look like in practice. One of the core missions of palliative care is to relieve suffering and it has traditionally a more holistic and person-centred approach than other healthcare services. The value of person-centredness is well embedded in the KSPCS and have been perceived as person-centred by staff and users equally. Users mention that they feel supported and cared during their journey.

> *[It is] home away from home* (Source: interview)

The service design and delivery aspire to follow integrated care principles. The vision and culture of palliative care services nurture an environment of good will, multi- and interdisciplinary-team working, integration of allied professionals and alternative therapies as well as family-centred and community-orientated approaches. The care team show high individual level commitment with the users, but also with the team and the service itself. There is a collaborative approach to care and the local culture enables working together collaboratively towards a common goal where users' comfort is prioritised.

> *Having a culture that is ready for the kind of model that you want to put in place that is community based and recognises the importance of the patient at the centre and then having people who are willing to keep going, keep on at that, keep persisting with that vision.* (Source: interview)

One of the key vision and purpose of the KSPCS is providing the same standard of care in the community and at home as in the inpatient unit. There is a recognised effort to train and empower primary and community care staff to provide and support non-specialised palliative care. The relevance of providing community palliative care was one of the relevant elements highlighted in the Report of the National Advisory Committee on Palliative Care (2001). There has

been a recognised effort to work together and collaborate with primary care providers, with a very successful coordination with General Practices (GP) and Public Health Nurses (PHN). The needs of the users are prioritised every time a member of any team visits the patient in the community: instead of providing the care based on the division of the roles of the practitioner or the service, the practitioner focuses on the needs of the patient and provided the full service. This is recognised as one of the greatest achievements of the KSPCS.

Finally, even though national level policy is aligned and guides the vision for integrated palliative care in Ireland, national and regional level stakeholders are not always fully engaged. This transition from national level vision to local capacity is sometimes lost due to the changes at intermediate levels, where political priorities shift into different directions. Ensuring permanent communication and engagement with all different representatives, regional, and national level is identified as a priority for the optimal service delivery, sustainability, and future development.

5.2.2 Population health and local context

Population health involves an understanding of the determinants of health in the population of focus and a determination to reduce health inequalities by resourcing the services that address those inequalities. KSPCS does not have a direct influence in the factors creating inequalities in the population, but the service design and provision tries to provide coverage for all the people in need for palliative and end-of-life care in Kerry. The service started as a palliative care service for adults with cancer, and progressively has broaden its coverage to provide care to people of all ages including children, as well as people with malignant or non-malignant conditions. There is an aspiration to support aging population that may benefit from palliative care.

From the local context perspective, the small and disperse rural population pose specific challenges for the KSPCS. Geographical location has been identified as one of the limitations for an equity of service provision by the staff. Team members recognise the value of outreach clinics to fill some of the gaps related to this geographical area. This concern did not arise in the data collection with service users or carers. On the other hand, Kerry being a small hub, the lack of human resources may limit their capacity to implement changes in comparison to bigger hubs. There has not been staff recruitment or retainment problem for now, and this factor is seen only as a potential risk for the future.

One of the key elements that all stakeholder highly value is the location of the inpatient unit. The principles proposed in the Report of the National Advisory Committee on Palliative Care (2001) were applied to design and decide the location of the facility which has a significant impact from the operational perspective as well as in the experience of the users. Staff appreciate how the location and being attached to the general hospital enables greater accessibility to other services.

It allows to have a better integration with on-site specialist, mix of employees, seamless care and transitions between services, better coverage, access to junior doctors and access to hospital interventions. From the user and family perspective, they also value the design of the facility, with single bedrooms with an outdoor sitting area, which ensure privacy and comfort.

> *They're going to have to get something more than what they're getting in their community, that will improve their quality of life. And that location with the hospital enabled us to do that.* (Source: interviews)

5.2.3 People as partners in care

Successful integrated care is dependent on high quality person- and community- centred care. As described in a previous section (see 5.2.1) there is a commitment in the KSPCS with person-centred care focused on the needs of the service users and their families. As is in the core of palliative and end-of-life care, KSPCS also pursues to provide comprehensive approach to the persons needs and personalised care through shared decision-making. Users recognise the feeling of being cared by the team, where their desires, wishes and preferences are respected.

> *And they cared. You know, you weren't just a number to them. Like they really do like all the girls, they really cared, and it didn't matter what time of the day or night or anything. They answer the phone. (Source: interview)*

> *They'd never just make this decision for me (…). And if I felt uncomfortable about taking a medication, which sometimes I do, they listen to me as well. I find that doesn't happen in other places. (Source: interview)*

Even though much effort has been done in this area already, one of the identified improvement areas for KSPCS is to continue strengthening and enhancing family support, which is especially relevant in palliative and end-of-life care.

Collaboration between team members, including practitioners and support staff is essential to provide person-centred integrated care in a palliative care service. This collaboration is seen as a key element of the success of the KSPCS. KSPCS staff value being part of a team, working as a team and having a good collaboration with each other. The collaboration and coordination with GPs and PHNs have been a strength of the service to provide person-centred care. Even though the governance, funding and information sharing system do not have the same governance and development strategies, the vision, willingness, and effort of the KSPCS, GPs and PHNs to work together has enable to overcome some structural barriers.

> *And they had initially been funded by the Kerry Hospice Foundation, and they were under the line management of the Director of Public Health Nursing. They worked all this very closely with our public health nurses in the Community teams, and I think that's one of the huge strengths of the Kerry service. There were never, you know, silo. This beautiful specialist nurses, they actually were working in tandem with their public health nurses and the GPs the whole time*. (Source: interview)

The public and users perceive the KSPCS as a community achievement, and they put effort in its continuous expansion and progress. The community involvement in Kerry has been organised through the Kerry Hospice Foundation, where community materialised its effort on fundraising activities. Managers and staff appreciate the ownership and pride the community has in the development of the KSPCS.

> *We've had citizen engagement provide from the beginning. That's most because our Partnership Care unit has come from the grassroots of fundraising in the local community. It was that the people of Kerry who built this unit and put their money into it and they had a huge say in what the service was to become.* (Source: interviews)

There is an opportunity to enhance community involvement and engagement with the KSPCS. A more mature integrated care approach requires high levels of local population, person- and carer involvement and engagement in the development and delivery of integrated care. It is believed that people and public involvement and engagement will enable people to be supported to look after their own health and wellbeing, understand when they should seek help, and get the support they need from the care system when they need it. In this sense, public and service users' involvement and engagement with the KSPCS has been a more limited. The team makes an effort to build trust with users and their families, so they are comfortable providing informal feedback to any team member, as well as a more formal approach by offering a voluntary satisfaction survey that is available in the service. The team recognise they consider and acknowledge people's opinion and feedback, even though there is no formal structure about how to respond or act to the feedback. Community, public and user engagement in the co-design or co-production of the care model and the service has been mentioned but not put into practice yet and therefore, there is no meaningful engagement or embedment in decision-making around the service and how it is delivered. There is a recognised opportunity for future development around people, family and public involvement and engagement in Kerry, especially in the context of KSPCS.

> *And that to me is what real integration is about. As I said, it's one thing to be integrated within your own specialism. And, I mean, I know the Kerry does reach out and they are they are to some*

extent involved, but to me, until you get your local stakeholders around the table, because you have to hear what's going on for them, you know, at a real and a formal level. (Source: interview)

5.2.4 Resilient communities and new alliances

County Kerry is a small and homogeneous community, with a strong local culture that values being part of the community and supports local people and initiatives. Led and encouraged by the members of the Kerry Hospice Foundation, community effort has focused mainly on fundraising activities which has allowed to speed the pace of the service creation and development to respond to local needs. Even if the opportunity of greater community engagement in the service design and delivery has been recognised, this research evaluation has not identified any unsolved tensions or disparity of aspiration between volunteer sector representing the community and clinical team or leaders. The role and expectation of each stakeholder is clear and well defined.

Being part, being very much a part of the community has been really important. (Source: interview)

This study demonstrates how community care is central to the successful achievement of an integrated care system. The partners need to be inclusive and demonstrate relationships that are mature and based on trust and shared commitment. In Kerry, collaboration between local services in the community is nurtured and the staff and leaders of KSPCS teams recognise their effort and willingness to support community care and the integration between primary and secondary care. National and regional level governance and structures do not always facilitate the integration between different services, but local interest and disposition have enabled working together in the interest of person-centred_care. For example, KSPCS has taken the initiative to train community and primary care services to provide some interventions traditionally offered by specialist palliative care services, such as syringe drivers, to empower staff in the community to deliver palliative and end-of-life care.

Locally we have formation of task forces, alliances, and other informal ways of collaboration. (Source: interview)

We were lucky that we all wanted to work together and develop the service. (Source: interview)

There is, however, recognition of the opportunity for a greater and better structured integration with all the community services, programmes or organisations that can support people with

palliative or end-of-life care needs as any gap in the coordination can affect service users negatively.

> *We need to integrate with the wider system. (…) With the enhanced Community Care Programme, and with the new reform program for older persons, we have to start stepping outside.* (Source: interview)

5.2.5 Workforce capacity and capability

An integrated workforce is the key mechanism through which models of integrated care are delivered, and health and care practitioners need adequate skills and competencies to deliver integrated care.

One of the pivotal factors of the KSPCS success is the work culture and environment of KSPCS. The success and appreciation of the service cannot be understood without the beliefs, attitudes, and behaviour of the team. Members of the KSPCS team have a flexible approach to their role beyond what is written in their job description, to ensure that all teams work together to provide the best person-centred care in the community and hospital. There is a multidisciplinary working environment where all the disciplines work together to provide the best personalised care for the person. Even though the word interdisciplinary has not arisen from the data collection, the collaborative working environment described during the data collection shows some trend of interdisciplinary approach. There is also a good working relationship with other specialties in the acute and community settings and new collaborative developments are reported.

> *Palliative care is delivered across a number of settings: it is acute, it is IPU, it is community, it is day care. And the same patient can cross over those four settings up backwards and forwards in the course of their up the trajectory of their disease. And I think Kerry reflects that*. (Source: interview)

However, due to the nature and design of the service itself, the care pathway is mostly clinically led. National level governance and financing structures do not facilitate integration between different stakeholder and tend to prioritise healthcare and healthcare professionals in comparison to social care or allied professionals. As described before (see 5.2.4), greater and more structured integration with social care and other community organisations and programmes would provide an opportunity to enhance a more comprehensive approach to people's needs. The experience of KSPCS in opening and collaborating with different health care practitioners beyond the boundaries of national level structures (e.g., GP and PHN) may be used to have a greater collaboration with other organisations focused on social and community care at the local level in the future.

You need to face to make sure that people work through those organisational boundaries. (Source: interview)

I had a dental problem going back about a month ago, and they referred me to a dentist, and they had to wait to get all green from him because they had to stop one of the chemos because that was causing the problem with the teeth. And they just kept the contact with the dentist to see how things were. (Source: interview)

There is a continuous learning culture in the service where education and training are highly valued and provided to service users, families, and other professionals. The importance of transferring skills from the specialised team to community care has been recognised during the research evaluation, and KSPCS has made an effort to train and build capacity in community care. Community staff have the opportunity to rotate in the inpatient unit to acquire new skills and competencies. The COVID-19 pandemic has suspended some of the ongoing initiatives such as the education training, for staff and other health care professionals. The Pandemic has provided an opportunity to broaden capacity building to new settings areas, such as nursing homes. There is an expectation to maintain the previous and new training activities in the future. Even though this is beyond the reach of the KSPCS, it has been recognised that there is an opportunity to develop national level capacity building to share knowledge and experiences among different palliative care teams and improve national level skills and competencies.

You're always encouraging staff to develop professionally and to do courses and teach each other, and you know, within the unit. (Source: SCIROCCO)

One of the specific characteristics of the KSPCS, is the low staff turnover. There are more than one factors identified to explain it. On the one hand, the service is reported to be comfortable and a nice place to work, and therefore, staff is satisfied in their role and job.

People go into the service, and they stay for life. (Source: interview)

On the other hand, the County Kerry is a small, close, and rural community, where people turnover is not as high as in more urban areas. In consequence, skills are retained in the team professional experience is valued. In general terms, teams with very low turnover may be at risk of having less external influence on innovative approaches. This risk is compensated by ensuring exposure to other regional, national and international initiatives and services, and the KSPCS has

recognised their effort to be involved in all the discussion boards and forums at regional and national level.

> *Within our services and within palliative care nationally, we all work together. We're able to take on new projects and look at developing them and see how to go.* (Source: interview)

There are some gaps identified in the capacity of the service to provide continuous care in the community on twilights and weekends. Filling the gaps of workforce capacity and reinforcing community care is one of the priorities for future development of the service.

5.2.6 System wide governance and leadership

This section will refer to existing structures and processes which have the authority, legitimacy, and capacity to oversee system wide integrated care and make collective decisions. Local, regional, and national governance structures and leadership can have a great impact in the capacity to enable or hinder care integration at community level.

Strong and distributed local leadership has been identified as one of the foremost elements of the development and success of KSPCS. Significant leaders have been named in different areas including for example community representatives, clinical leaders, public health nursing and managers. All of them have been recognised as people who gained credibility through their constant and consistent presence, actions, and commitment with palliative care development for Kerry. Beyond individual leadership, the most important feature of local leadership has been a clear focus on relationship building and collaboration between all the leaders to work aligned and in the same direction towards the shared goal.

> *We had a XXXX, (…) who was inspirational making sure the patient stayed at the core of us. (…) She if you saw her going into battle at any the development meetings.* (Source: interview)

> *There was a lot of really good people who worked.* (Source: interview)

> *I think that's come across, really strongly as the importance of having those people.* (Source: interview)

> *XXXX never gave up*. (Source: interview)

> *So that continuity of leadership has been really important.* (Source: interviews)

In this sense, continuity of leadership has been paramount for KSPCS to develop. Future leadership with the incorporation of new generations of leaders will need to show if they can continue with the legacy of collaboration and commitment left to them by previous generations.

Local initiatives are dependent on the regional and national structures, and they are influenced by regional and national governance, leadership, and political context. The impact of regional and national context in the development and evolution of the KSPCS has been identified in two main areas. On the one hand, governance is established at the regional and national level. The fragmented governance structures at ~~the~~ national level and the local split of human resource agencies make integration between different services more difficult. There is division between acute and primary care, between hospital and community care, and between social and health care which are key elements that integration could provide a more comprehensive and person-centred care. Future opportunities for KSPCS development may be in finding innovative governance solutions to facilitate integration with single accountability and governance of different care services and settings involved in palliative and end-of-life care.

> *All the services need clear governance structures to ensure effective communication and integration of care across all sectors.* (Source: SCIROCCO)

One the other hand, there is a recognition that regional and national leadership and governance structures and changes affect local services, but they are not clear to the public or staff.

> *Leadership is not clear to the general public or the health care professionals currently. Leaders and champions are not emerging as even though policy / plan exists. Political and management intent is not there. There is no stakeholder engagement.* (Source: SCIROCCO)

National level innovation management and implementation do not have a clear and formalised structure, which are not perceived as enabling processes at the local level. There is a recognition of an innovation enabling culture in the system, but not a formalised innovation management process. Similarly, implementation of palliative care services is supported, but without a clear implementation plan at the national level which results in different levels of maturity around the country based on local capacity and resources.

> *There is a culture of innovation and supportive of the innovation rather than a formalised innovation management process.* (Source: SCIROCCO)
>
> *Innovation management is not being used as a key enabler.* (Source: SCIROCCO)

"(…) there had been acceptance of agency level, and the government level and the department level. What had happened until then was it just depended on the local area who was prepared to put my money into it and who wasn't. And because of that, I think services themselves have developed in slightly different ways." (Source: interview)

In this sense, local capacity, resources and innovation and collaboration culture have allowed County Kerry to be one of the early adopters of palliative care services in the country.

5.2.7 Digital solutions

The digital systems, architectures and applications can enable models of integrated care through digital delivery of care in different stages, as well as support data and information collection and analysis at individual and population level.

As shown in Figure 5, the lack of a mature digital infrastructure has been identified as a key challenge in KSPCS. There need of developing stronger digital infrastructure is recognised, but there is no strategy and/or plan on how to deploy and standardise digital infrastructure to support integrated care in place at the moment. There are many recognised limitations in the digital infrastructure affecting KSPCS. These include:

- There are no electronic health records or single referral system. The team has worked to overcome this limitation by collaboration closely with each other to ensure staff can access information at all hours. Any local initiative of data collection is at risk of creating a silo within the system, and therefore it is acknowledged that HSE level electronic data sharing is one of the key elements to enable integrated care.

- There is interest in developing telehealth and self-monitoring opportunities, but digital literacy and access to technology by staff and users is seen as a limitation still.

- Digital innovation requires development and funding in community care. Many health centres in the community and in the hospital do not have access to basic or standard technology, such as Wi-Fi and depend on hot spotting from their phones.

- Electronic health records would allow to a better data information collection and analysis.

All notes are handwritten, not transferred between hospital and community – depend on referral. (Source: SCIROCCO)

There is no seamless IT service. (Source: SCIROCCO)

There is a lot of communication that the services do not have access to. (Source: SCIROCCO)

We would like to see an infrastructure in place, but it isn't there as yet. I would hope that there are plans to be part of the single referral system, but it certainly wasn't in the first phase of it. (Source: SCIROCCO)

Digital development and data security is not mature at the national level and local services are dependent on national level development and have a limited margin to find local solutions. Two major emergencies occurred during this research evaluation project that affected the development of IT systems and digital infrastructure in Ireland:

- First, the adoption of digital technology, at KSPCS staff and user level, speeded up in response to COVID-19 pandemic between 2019 and 2021. There was a collective effort to improve digital literacy and access to technology to facilitate access to care to service users and their families as much as possible. However, despite this effort and progress, digital literacy of the staff has been identified as a key working area for the adoption of the technology, and to ensure sustainability of the changes introduced during the COVID pandemic.

- Second, the HSE of Ireland had a major ransomware cyberattack in May 2021. All information technology systems depending on the HSE shut down at the national level, which had a huge impact in the communication and data sharing. The HSE has been working on internal data sharing, cybersecurity capability and leadership, and preparedness since.

In summary, digital innovation requires development in the community and at the national level. Its development would facilitate care integration is many levels, from improving communication between services and people through data sharing, electronic health records and single referral system, as well as support self-management through telehealth and self-monitoring solutions.

Digital development is hard to develop locally as this needs HSE national approval and leadership. (Source: SCIROCCO)

5.2.8 Aligned payment systems

Financial flows can significantly support the whole system of integrated care by incentivising to collaborate and work towards a collective shared goal. The role of the Kerry Hospice Foundation

in providing financial resources and sustainability to develop the KSPCS is one of the most important and innovative elements of the KSPCS creation and evolution.

> *Hospice foundation itself, the plan is very clear of support for the palliative care service and funding.* (Source: interview)

The local capacity to raise money empowered local leaders negotiate with national representatives the development of local palliative services to build the KSPCS. It allowed the Kerry Hospice Foundation to negotiate and plan the next phases of the service development with the HSE (for more details, see section 5.1, point 6). This innovative model of collaboration between local volunteer sector and the HSE has been highly productive and positive for the local development and a very attractive model for the HSE to deploy palliative care services.

The possibility of collaboration between the volunteer sector and health boards was already recognised in the Report of the National Advisory Committee on Palliative Care (2001) in which the role of the volunteer sector was specially highlighted.

> *Health boards should work in partnership with the voluntary service providers in their areas.* (Report of the National Advisory Committee on Palliative Care, 2001)
>
> *Fundraising groups should identify key objectives and strategies in relation to their activities and should be fully accountable for all money raised. Any projects funded should be in accordance with the overall palliative care development plan for the region.* (Report of the National Advisory Committee on Palliative Care, 2001)

The Kerry Hospice Foundation is a very strong charity with high recognition of its fundraising capacity in the local community and within the HSE locally and nationally. The Foundation is a trusted partner in their negotiation with the health boards.

> *This collaboration and business model has been recognised as an innovative approach other hospices are using as a reference in the country.* (Source: interview)

There is a future opportunity for the Kerry Hospice Foundation to enable higher involvement and engagement with users, families and public in the service design and development, as well as in the community awareness of palliative beyond end-of-life care. Up to ~~k~~now, the role of the Kerry Hospice Foundation has been limited to fundraising and fund stewardship, but its value and recognition in the community could channel higher community engagement with the service.

5.2.9 Transparency of progress results and impact

The capacity to measure progress and impact is one of the most important mechanisms through which the whole system of integrated care can assess and quantify the progress it is making towards the shared vision and against the agreed population health outcomes. The meso and macro level participants agreed in the SCIROCCO self-assessment workshop that evaluation of progress and impact needed further development. There are two main sources to obtain data for local continuous learning: a) on the one hand, research projects, pilots and initiatives are conducted locally; b) on the other hand, the team is open to users' feedback and there is a possibility to complete a voluntary survey about satisfaction with the service. The results and feedback are used to improve local services.

> *Got loads of audits and evaluations and quality improvement plans, and we have a multidisciplinary operational meeting that happens where we discuss everything that's happening within the service, and we improve as we're going along.* (Source: SCIROCCO)

However, there is need for a systematic approach to evaluation both locally and at national level. Despite many KPIs and service data being collected, quantitative data was identified as one of the main limitations of this case study research evaluation. The analysis of the quantitative data, both KPIs and individual level service data, revealed considerable limitations to answer the research questions and to draw conclusions on the effectiveness of the palliative and end-of-life care provided by the KSPCS.

- From the KPI perspective, since the data are aggregated, it was not possible to track a person over the course of their journey or connect data with individual indicators. Moreover, KPIs do not allow the in-depth analysis of access to services or outcome quality.

- From the individual data, we sought to track the journey of single individuals between services. However, since this data is not systematically collected and was compiled especially for this project, coding errors occurred frequently. Several variables also showed high percentage of missing values. Moreover, the data was not complete for every service, and therefore, it was very difficult to draw a complete picture of the journey of the users. Therefore, individual data did not allow the answering of most of the planned research questions.

The Report of the National Advisory Committee on Palliative Care (2001) already recognised the importance of developing local and national level systems to measure the quality of the services as well as to standardise information at the national level.

> *Systems should be put in place in all specialists palliative care services to measure the quality of the services provided.* (Report of the National Advisory Committee on Palliative Care, 2001)

> *A Minimum Data Set should be developed in Ireland, in order to provide standardised information on all patients of the specialist palliative care services. Suitable performance indicators and outcome measures should be identified and utilised in specialist palliative care services in order to evaluate and maintain quality standards.* (Report of the National Advisory Committee on Palliative Care, 2001)

From a more mature and ambitious integrated care perspective, data collected should reflect the user journey and access to services, as well as the understanding of how the services are impacting public and population health outcomes. There is a future development opportunity locally and nationally to develop a systematic evaluation process and integration of data to support a continuous learning culture.

> *There is a need for a systematic approach to evaluations that contribute to a learning system*. (Source: SCIROCCO)

5.3 Replicability and transferability

Palliative care has been described as one of the areas where care integration is necessary. Requirement for palliative care is predicted to grow due to the ageing population, the increased burden of non-communicable diseases, and due to the efforts to reduce the unacceptable burden of suffering globally [20]. The need for early integrated palliative care has been established in the literature, and integrated palliative care is considered to improve quality of life (QOL) and survival for patients [21]. Integrated palliative care could optimise continuity of care and thus improve quality of palliative care in Europe [22], but most European countries are reported to be in the early stages of integrating palliative care into their respective health systems [23].

The integrated palliative care model proposed by Herrera-Molina *et al.* "*involves a set of professional health and social care services, which envelop the support and assistance of family and volunteers from an empowered community capable of caring for their families and neighbours*"[24]. Person-centred integrated care pathways were explored in the integrated palliative care in cancer and other chronic conditions (InSuP-C) project funded by the European Commission (2012-2016) (https://www.insup-c.eu/) [25]. The project acknowledged that even though the need for integrated palliative care is recognised, there is little guidance on how to

operationalise or implement integrated palliative care [4]. Moreover, it was also recognised that the contextual factors were very important to integrate the service in the local system. The InSuP-C project identified the requirements for good practices [26]:

- multidimensional and comprehensive approach to treatment
- development of integrated care pathways
- inclusion of palliative care into the care provision chain
- a contact point in the region to get palliative care knowledge and expertise
- accountability and visibility in the community
- resource sustainability
- offer palliative care to everybody that needs it beyond cancer.

Palliative care provision is not a unique model, and it is highly dependent on local culture, system, and resources. There are different models of care delivering integrated palliative care around the world with different governance and leadership models: some are part of the regional palliative care programmes, some others are built around hospices, and others are community-owned services [3].

A recent qualitative study assessed four integrated care domains (content of care, patient flow, information logistics and resources) in 19 integrated palliative care initiatives in Europe. The study concluded that even though there is a need for standardising palliative care, the most relevant elements to develop a good integrated palliative care service were to build a professional network and a core care team with shared vision and values, and support by external authorities [27]. More countries must have all the key policies in place for palliative care to be accepted and appropriately developed [20]. Professional bodies, insurers and policy makers should promote integrated palliative care for patients with various disease backgrounds [27]. At the regional level the importance of integrated information systems that promote continuity of information across settings of care is recognised. At the health system level, accountability and evaluation mechanisms should be essential to measure and assess the impact of service integration on quality of care, user satisfaction, and effective organisational relationships [28]. The literature describes various models of palliative care but there appears to be no consensus as to which model is most effective especially from the economic perspective [29].

The above summary of the recent international literature confirms that the challenges experienced by the KSPCS are not unique, and that the approach for integrated palliative care services employed by the KSPCS is in line with international recommendations. However, the learning from the KSPCS journey and some of the local initiatives described in this report may be

adopted, adapted or contextualised in other settings. There are some key elements of the KSPCS that other setting may consider in their development of palliative and end-of-life care:

1) The importance of national level guidance and policy

One of the main referenced key elements in the research evaluation was the Report of the National Advisory Committee on Palliative Care published in Ireland and signed by the Government in 2001. The progressive and comprehensive-report has been a clear guidance for over 20 years in the development of palliative care nationally. The existence of a national guideline with governmental support provided a framework to local initiatives to develop palliative services aligned with existing national policy. The lack of national guidance and commitment may become a true challenge for local initiatives to develop an integrated palliative care service and at high risk of becoming a silo within the country.

2) Strong leadership with shared values, vision and purpose

Another key aspect of the success of KSPCS development is the strong local leadership in the various sectors involved in palliative care. The buy-in of the shared vision and purpose among relevant sectors, from volunteer sector, specialised clinical team, hospital team, community care, managers, and health board representatives, empowered the community with a very strong local network. The relationship between all the leaders to work aligned towards the same goal is one of the most robust components of the success of the service.

3) Volunteer sector and fundraising capacity

The role of the non-statutory sector in the development of the KSPCS in unquestionable, as far as saying that local development would not be as advanced as it is at the moment without its existence. The initiative to start building palliative care in the area started with the initiative of one person in the community, that consequently evolved to create the Kerry Hospice Foundation. The main role of the foundation was to raise money. As simple as it seems, independent source of funds through fundraising activities empowered local leaders to negotiate the development of local palliative care services with national authorities. The innovative approach to funding the development of services consists of mutual collaboration and trust, in which the foundation would advance the money to start developing the service by the support of and integrated in the national system. Even if there is national commitment to develop palliative care services, local funds may help in adopting progress earlier or in adapting national initiative to local needs. Even though the local funds were channelled by the volunteer sector in Country Kerry, areas with less

culture or structured volunteer sector could find other ways of acquiring and using local funds, such as municipalities for example.

4) Collaborative culture

The success of the KSCPS cannot be separated from local collaborative culture. Collaboration and engagement with other services and sectors has been paramount in the service development. Strong collaborative culture facilitates an enabling environment for integrated care and its values. and working environment. Workforce belief, attitude and behaviour are not influenced so much by knowledge and skills, but by the values, motives and groups norms and roles. Creating an enabling ecosystem of collaboration to work in an interdisciplinary way of working is one of the key learning for successful integrated palliative care.

5) Community ownership

Finally, linked to the previous two points, strong local community involvement and local culture of collaboration in the community develop a feeling of ownership in the community. Due to the role of the Kerry Hospice Foundation and people's collaboration in fundraising activities, there is an ownership and pride in the community towards the KSPCS. The service is perceived as "theirs" and therefore, as part of the community-led service that meets the needs of the community. There is a non-written contract and responsibility with the public, where the public invest the money in the service, and therefore, managers and leaders make a bid to deliver what they promised. The development of the service was enabled by the buy-in on the part of the community and local leaders of the national clinical blueprint.

The learning of the KSPCS journey can be applied to other care settings and pathways beyond palliative care. There are values and initiatives around palliative and end-of-life care that can be transferred to other areas to provide a more integrated care, such as for example:

- Person-centred approach with a comprehensive assessment to their needs
- Person- and family-centred care
- Inclusion of different care settings respecting people's preference
- Collaboration between specialised care, primary and community care and allied professionals
- Initiatives around compassionate communities

Palliative care services, and as such KSPCS, could do more to transfer some skills to specialist care, primary and community care. However, there is still an acknowledgement of a limitation or barrier to influence other services from palliative care. On the one hand, palliative and end-of-life care does not always find its place in the existing health and care services. The more holistic approach, with different care settings from hospital to community, caring but not curing and family-centred approach make palliative and end-of-life services different from other services, and therefore, challenging to be incorporated in the mainstream healthcare services. On the other hand, even if some skills can be taught and transferred, attitudes, believes and sensitivity in the palliative and end-of-life care is part of the ethos and culture of this specific care and can be very difficult to teach or transfer.

From the integrated care perspective, the experiences from palliative care service development such as KSPCS are very useful to continue learning about different components that can affect and influence the capacity to provide integrated care.

6 Summary and Conclusions

This report summarises the emergence, evolution and the factors influencing the success of KSPCS. Data was collected from multiple sources and a case study approach was employed. A maximum variation technique was implemented during recruitment regarding the geographical spread of participants, referral source, service type (received or provided), diagnosis and progression of disease, and the impact of the COVID-19 pandemic (the experience of KSPCS prior and during the global pandemic). The findings were analysed in depth and triangulated at multiple levels. To evaluate the level of integrated care the findings were mapped in line with the nine pillars of integrated care and compared to the recent international literature. An independent and evidence-based framework (SCIROCCO) was used to assess the components of integrated care. A team approach was employed throughout the project, where the research team discussed the key points of the project with the Governance Group and the Expert Panel.

KSPCS is a dynamic, adaptive and progressive palliative care service which strives to provide integrated care. The KSPCS has assimilated and consolidated the ethos about person and family centredness in palliative care and the users, community and staff acknowledge the effort. The vision and the values around the concept of person and family centredness set the principles to create the service and have guided its evolution since. Users involved in this evaluation have recognised and felt supported and cared for during their experience with the KSPCS.

Strong local leadership has emerged as one of the key factors driving the success of the KSPCS. Leaders emerged from the community, hospital and voluntary sector, as well as from the clinical and management areas, and have worked together for the same goal. The alignment and role distribution between different leaders has permitted the individuals to work as one force to achieve relevant milestones and to overcome difficulties and barriers during the development of the KSPCS.

From the clinical perspective, we have observed the effort of all the local services to work as one team despite the fragmentation of the system. From the specialist palliative care perspective, staff have done their utmost to create a multidisciplinary team including aligned professionals, to integrate the team at the community and hospital locations and provide the same standard of care and to integrate primary care with KSPCS. Individual and team commitment to enhance and facilitate collaboration beyond their job description has emerged as one of the underpinning characteristics of the KSPCS.

Together with the shared vision and values, strong local leadership, and local workforce commitment for creating a collaborative culture has been demonstrated. The success of KSPCS has been attributed to the Kerry community, knowing how to adapt a National Strategy and

effectively engage with the national system. Local culture encourages the public to contribute and invest in local initiatives to support the community. Kerry being a small community with homogeneous population features also creates an environment with little community tension pulling in different directions. One of the recognised success factors of the KSPCS has been the capacity of local leaders to channel this capacity into fundraising activities led by the Kerry Hospice Foundation. Due to the local community involvement in the fundraising, there is an ownership perception and pride towards the KSPCS in the community. The availability of local funds enabled the creation and development of the KSPCS, leverage local resources and negotiate with regional and national representatives to meet local needs. One prime example of this negotiation and collaboration between local leaders and national representatives led to the building of the inpatient unit which allowed to have the service in place much earlier than if it was dependant on the national roll-out only. This innovative collaboration to fund local services has been recognised as a key factor in the development of KSPCS and a model that can be replicated in other settings in Ireland.

All the local characteristics that have enabled the development of the KSPCS would not have been possible without adherence to a national level guidance and commitment by the Government to develop palliative care services in the country. The Report of the National Advisory Committee on Palliative Care published and signed by the Government in 2001 has been a reference document for the development of the KSPCS. It is still considered one of the most progressive documents in palliative care nationwide in which there was a clear commitment to person-centred care, the importance of the volunteer sector and integrated care with enhanced community care. The national integrated programme report, approved in 2015 and published in 2019 is the new reference for current development. The next national integrated programme report is due for revision in 2024.

Despite all the success factors identified above, our study identified key challenges that are limiting the capacity of the KSPCS to continue its development in their vision and ambition to create an integrated palliative care service. Local effort can only do so much if there is no whole system approach. The service is just one service in the local health and care system and limited by the boundaries set by the HSE and national level policies.

Several system level challenges have emerged during this evaluation. One, even though national level policy is aligned and guides the vision for integrated palliative care in Ireland, national and regional level stakeholders are not always fully engaged. This “bottleneck” from national level vision to local capacity is sometimes difficult to overcome for local leaders in the context of lack of resources and plan for national level implementation. National and regional political priority shifts, and governance and leadership changes have also a great impact in the development, continuity, and sustainability of local initiatives. National and regional level fragmentation in the

governance and payment does not facilitate integration between services either. One of the examples of this fragmentation are the community and hospital services, where staff of the KSCPS lie under different structures and local teams need to make an effort to create a collaborative culture in spite of the fragmentation. KSPCS has also clearly identified gaps in the service provision that are dependent on the HSE resources and are necessary to guarantee continuity of care.

Another significant system level challenge is the data sharing and safety, and digital and technology solutions development. The digital innovation was perceived as the weakest element of integrated care by the stakeholders participating in the SCIROCCO self-assessment exercise, and this was confirmed during interviews at all levels. Local health and care services have very limited margin to develop local solutions as the policies about data sharing and safety, digital solution development and resources for their integration are managed at the national level within the HSE. Low capacity for data sharing between services and care settings, and low digital innovation intake have been identified as significant limitations for integrated care. There is also a significant difference in the capacity to access digital resources between the hospital and community services, with a clear gap and lack of resources in the community. The timing of this evaluation allowed to capture a dichotomy around data and digital innovation in Ireland. On the one hand, the COVID-19 pandemic amplified the need for digital solutions to overcome face-to-face contact restrictions. At the same time, the HSE in Ireland suffered a major ransomware cyberattack that showed the fragility of the existing digital environment. The need for national level development of a safe and innovative data sharing and digital environment was identified as a major component to continue working towards integrated care.

The quantitative analysis of the data collected at the service complemented the limitations for evaluation that emerged in the qualitative research. On the one hand, there is no systematic approach to evaluation at the national or local level and therefore, the systematic learning and improvement based on evidence is quite limited. The Key Performance Indicators are fragmented and do not represent the user journey, access to services or quality of the service provision. There is a national plan to shift to new indicators, but the implementation plan is still under development.

7 Future development opportunities

This research evaluation has allowed the identification of some opportunities for future steps to continue in the development of an integrated palliative care service.

7.1 Local level

- **Greater user, family and public involvement and engagement**
  There is a great opportunity to involve and engage with users, families, and community in the discussion and decision-making of the planning, commissioning, delivery, and evaluation of integrated palliative care in Kerry. There are several enabling elements that can facilitate this step. First, the credibility and respect Kerry Hospice Foundation has in the community can facilitate reaching local community. Second, there is a well-organised initiative at the national level in Ireland to support users and the public to advocate meaningfully for palliative care by preparing them to be active members of the boards and forums by increasing their health literacy, empowerment, and preparation. And finally, the KSPCS team is open~~ed~~ to innovative approaches to include the voices of the users, public and staff in the discussions for continuous improvement. There is still a margin to work towards people-driven palliative care, where the services are designed and delivered with the "people" and not "for" the people, by progressing from informing and consulting with people to engaging, co-designing and co-producing the service. Understanding people's and staff's experience can feed the service in a more responsive way to create a learning process at the service and organisation level.

- **Advocate for advance care planning**
  The KSPCS and Kerry Hospice Foundation could have a very prominent role in informing and advocating for palliative care services and advance care planning in the community. There is a natural resistance to palliative and end-of-life care which is explained by the cultural beliefs and experience of death. In this sense, there is resistance and avoidance to palliative and advance care planning conversations that could be introduced in the community to improve palliative care experience in the community. There ~~had~~ been experimentation with some experiences such as "Death Cafe" before COVID-19. There is an opportunity to explore the impact KSPCS together with the Kerry Hospice Foundation could have in the cultural change in the community.

- **Greater and better structured integration of community care**
  KSPCS has made a huge effort to get the highest level of integration with GPs and PHNs to provide person-centred care in the community. There is an opportunity to continue broadening the area of influence including all the services, organisations, and programmes in the community, statutory and non-statutory in their highest capacity where specialist palliative care would act as a reference for highly specialised or complex care.

7.2 Regional and national level

- **National guidance and political commitment**
  Regional and national leaders must provide guidance and ensure political commitment to deploy person-centred and community-led integrated palliative care in Ireland. There is a high expectation in the new national integrated programme report which is due for revision in 2024 to provide the guidance for the next iteration of integrated care development.
  On the other hand, and even if this report has highlighted the importance of local leadership and availability of funds to enable local development, the differences between regions can produce significant inequalities of palliative care service provision nationwide. Regional and national leaders should support all regions to ensure everybody in the country has access to high quality integrated palliative care.

- **Enhance regional level collaboration**
  Regional and CHO level collaboration can provide with new opportunities to strengthen local palliative care services. Even though there is already a high level of collaboration at clinical level, there is still opportunity for collaboration with other levels of care, and between statutory and non-statutory organisations. A Regional Development Group could facilitate development of palliative care from the regional perspective, give opportunity to collaborate with Community Care Networks and cross-pollinise with other community programmes. It would also be beneficial to understand and co-design palliative care services that fill the requirements and expectations of palliative care in the Community Care Networks or other community programmes.

- **Overcome limitations by the fragmented governance structures**
  Fragmented national or regional structures can pose challenges in the development of integrated care services. There is also a recognition that system wide restructuration and

integrated governance may be very difficult, more considering the existence of different levels of governance (e.g., managerial, operational, clinical). There is a need to create innovative solutions to overcome the limitations of national or regional structures locally or by areas of interest. Whatever the construct, there could be an oversight group that ensures all the representatives of all the players are involved in the revision of the service. This solution has been proposed for KSPCS during the research evaluation where each service would continue reporting to their respective governance bodies and the oversight group would revise the whole process.

- **Digital infrastructure**

  Digital and data sharing infrastructure development and resources for their integration are managed at the national level within the HSE. The need for national level development of a safe and innovative data sharing and digital environment has been identified as a major component to continue working towards integrated care. Part of the necessary IT and data sharing infrastructure and the electronic health records allow for a more consistent and coherent data and information collection and sharing. Information sharing among all the care services and practitioners is one of the fundamental aspects that can facilitate transitions, care continuity and integration. One step forward that could be considered in the development of the HER is for the patients or users to access their own data which could support self-management, and even control and ownership of their won data.

- **Progress and impact**

  One of the most important mechanisms to assess impact in a continuous learning culture is the capacity to measure progress towards an agreed goal or population health outcomes. There is a need to develop capacity and resources at the national level to measure the quality of the palliative care services provided and allow collection of standardised and comparable information on all users. Collected data should also represent and provide information about the user journey, the staff and service organisation around the care of people, and the understanding of how the services are impacting the public and population health outcomes. Sound evidence to guide palliative care service development is essential. Providers, funders and other stakeholders should support the development of a programme of well-designed research studies to assess the development, implementation and outcomes of services. There is a future development opportunity locally and nationally to develop a systematic research evaluation process and integration of data to support a continuous learning culture.

In summary, KSPCS is an example of a service with a vision to provide integrated palliative care that provides and has clear values around person and family centredness. Local leadership, community involvement in fundraising and ownership of the initiative, and the collaborative culture of the workforce coupled with adherence to a clear national blueprint have delivered this service and continues to improve the care experience of the users. Significant effort is being made at the service and community level to maximise integration. There are opportunities for future development of KSPCS to continue building an integrated palliative care service, such as having a greater and better structured integration with all the community care programmes and organisations, increasing the engagement with users and the public, and to act as a reference service for other settings and areas on how to build person- and family-centred integrated care services.

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