SERIOUS ILLNESS CARE

Programme UK

Better Conversations Better Care

Patient-centred
Systems-integrated
Evidence-based

Report for the Phase One Pilot

October 2017

SERIOUS ILLNESS CARE
Programme UK

Table of Contents

Foreword by Atul Gawande

The thing I didn't understand, even after years of surgery practice, was what it really means to be good at caring for people facing the consequences of unfixable problems--an incurable cancer, organ failure, advanced age. What I learned from my palliative care colleagues, some of whom co-authored this report, is that our key mistake is failing to recognise that people have goals and priorities for their care besides just living longer. To learn what those are, we have to ask. But mostly, we don't. When we don't, the care we provide is often out of alignment with what matters most to people. The result is suffering.

When clinicians do ask, however, and align their care with people's goals and priorities, the results can be remarkable, according to the evidence - less suffering, less non-beneficial treatments, more control, and equal or longer survival. Despite clinicians' best intentions, several barriers limit their ability to effectively communicate with patients in ways that meet this standard. We haven't been trained to communicate in this way; we don't have systems in place to make patients expect these conversations and to consider them normal; we don't have a ready place to record and find the goals and priorities in the patient's voice. In patient safety, we know it takes a system to enable clinicians to do the right thing every time for every patient. This is true of serious illness communication too.

The report that follows describes the efforts over one year of a team of people who are making this possible. Their ultimate goal is to ensure the highest quality communication for every seriously ill patient in the UK, starting with their home institutions. This is no easy task and this team has faced - and overcome - many challenges. Our group at Ariadne Labs, where I am executive director, developed the Serious Illness Care Program and worked closely with our UK colleagues to support their efforts. We have learned many things from each other. And I'm encouraged by the team members' perseverance and results. I think readers of this report will see how their progress stands to benefit the patients of the NHS. Readers will also understand that there are many things left to learn about making progress happen at large scale. The signs are, however, that we have an approach that holds promise for delivering care that meets the priorities of some of our most vulnerable patients.

This work has transformed my practice. I think it will change your care for the better, too.

Atul Gawande, MD, MPH
Executive Director, Ariadne Labs
Professor, Harvard T.H. Chan School of Public Health
Surgeon, Brigham and Women's Hospital, Boston, United States

Executive Summary

The Serious Illness Care Programme UK aims to improve the lives and personalise the care of all people with serious illness through meaningful conversations about their goals and priorities. This report describes the implementation and evaluation of a 15 month NHS England funded national pilot of the Programme. It reports the positive impact of the Programme on clinicians and their patients and presents preliminary evidence that this innovative approach can improve care delivery for seriously ill patients in the NHS.

Introduction

Serious illnesses include those conditions, such as cancer, cardiopulmonary, respiratory or motor-neurone disease, that burden patients and families, and for which the risk of mortality is high. Among the evidence-based interventions known to improve the care and well-being of patients with serious illness and their families, communication receives the least attention. It is arguably the most important intervention because communication enables shared decision making and personalised care, whether or not a patient's disease is curable. The literature demonstrates the positive impact of communication on patient and family coping, utilisation of hospice care, quality of life and well-being, and care aligned with patient preferences. However, such communication is often absent, late, or fails to address the goals, values, and priorities that lend meaning to patients' lives and direction to clinician's care. It places patients at risk of receiving aggressive, costly, questionably beneficial, undesired interventions and therefore low-value care at the end of life.

The systematic delivery of high quality communication has been shown to improve the quality and value of patient care. A US-based randomised controlled trial of The Serious Illness Care Programme demonstrated more frequent, earlier, and higher quality conversations with seriously ill patients. Patients experienced reduced anxiety and depression and described being better prepared for the end of life. In another trial of the Programme in primary care patients, use of hospice care increased while hospitalisation and overall healthcare costs decreased. Clinicians, whose standard medical training leaves them ill-prepared to engage patients in such discussions reported greater communication self-efficacy and satisfaction as a result of the intervention.

Healthcare systems seeking to meet the quadruple aims of improved population health, better patient care, greater provider and patient satisfaction and quality-driven reductions in cost should rate the delivery of high quality communication among their highest priorities.

What is the Serious Illness Care Programme?

The Serious Illness Care Programme is a system-level intervention designed to improve the lives of people with a serious illness by optimising the timing, frequency and quality of serious illness conversations. Comprising clinical tools, training, support, and systems innovations, the Programme empowers patients to actively participate in planning for the future with their illness. It enables clinicians and other professionals in the wider healthcare system to personalise care according to the goals and priorities of individual patients.

The Department of Health has highlighted the Programme as a model for improving the delivery of personalised care and endorsed the approach to training and evaluation, that are core features of the Programme.

The UK Programme partnership is based on the pioneering work of Ariadne Labs, a leading health system innovation centre based at the Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health (Boston, USA). The Programme is a partnership led by The Clatterbridge Cancer Centre NHS Foundation Trust (Merseyside, UK), with The Marie Curie Palliative Care Institute, Liverpool (University of Liverpool, UK) and Ariadne Labs.

This collaboration supported the development of core capabilities that enabled implementation and evaluation of the Programme in multiple sites in year one.

Core Capabilities

✓ Comprehensive stakeholder engagement

✓ International collaboration

✓ Research

✓ Implementation

✓ Monitoring and evaluation

✓ Technological expertise

✓ Training and coaching

✓ Communications

✓ Governance and risk management

The UK Phase One Pilot

NHS England funded a 15 month implementation pilot of the Programme in 2016. The NHS Clinical Commissioning Groups at Airedale, Wharfedale and Craven (AWC) Yorkshire and Southend-On-Sea in Essex were selected to join The Clatterbridge Cancer Centre as the first sites.

During the pilot year, Ariadne Labs trained four UK Master Trainers and supported the training of 59 clinicians. The UK team independently trained six trainers from across the different locations.

Together the three pilot sites screened 2000 patients and offered a serious illness conversation to 295 patients (14.75% of patients screened). Clinicians completed 220 conversations (74.58% conversion rate).

Key Patient Related Outcomes

• All patients completing an evaluation reported feeling that the conversation was worthwhile

• 87.5% reported feeling "very satisfied" with the conversation. Patients highly rated the skill of their clinician in leading the conversation (mean score 8.5/10)

• 89% reported reduced levels of depression and no patients reported increased depression

• Patients and their families reported less anxiety and improved quality of life

• A majority (60%) of patients reported increased rapport with their clinician, greater control over their medical decision making, improved understanding about what their health might be like in the future, and more hopefulness about their quality of life

Key Clinician Related Outcomes

• Clinicians valued the way in which a structured Conversation Guide helped them talk with patients about their goals, values, and priorities

• Clinicians reported increased confidence, knowledge and skill as a result of the training

• Clinicians described the unanticipated and overwhelmingly positive impact of structured conversations on their relationships with patients

Key System Related Outcomes

• We adapted systems and employed a population-health approach to serious illness care, utilising systematic patient identification strategies and workflow adaptations that enabled clinician triggering and conversations

• We modified two different electronic health records to capture and share information about patients' goals and values with providers in multiple care settings

• We developed a comprehensive, bespoke tracking and reporting infrastructure for the UK Programme that enables real-time data outcome reporting and mapping. The system can flex and adapt to fully support implementation, expansion and all research activity

• We developed training capacity to support implementation of the Programme at additional sites

Summary

Pilot data from the Programme evaluation described herein suggests that the Serious Illness Care Programme UK enables clinicians and their seriously ill patients to engage in high quality conversations about goals, values and priorities more often and earlier in the course of an illness. The implementation of the Programme in three demographically distinct settings demonstrates positive healthcare outcomes for patients and benefits for clinicians.

An economic analysis was not a feasible component of this programme evaluation. However, there is reason to believe that in aligning patient care with their preferences and goals, the Serious illness Care Programme UK may reduce hospitalisations, enhance use of community-based care, and reduce inappropriate use of expensive, marginally effective, and possibly undesired medical treatments in the later stages of serious illness. This is an area for future research.

Next Steps

1. Obtain funding to support implementation and evaluation of the Programme as part of a research strategy to establish a robust UK evidence base. This includes submission to the NIHR for a large robustly designed cluster randomised trial across ten cancer centres.

2. Pilot a training programme focused on the multidisciplinary team.

3. Evaluate the impact of the serious illness conversations on specific patient groups.

4. Further evaluate the impact of the Programme on patient and clinician outcomes.

5. Evaluate the impact of the Programme on the utilisation of healthcare services.

6. To disseminate findings at a national and international level through peer-reviewed manuscripts.

1. Overview

The Serious Illness Care Programme UK aims to transform the patient experience and enhance clinical care and support for people with a serious illness. The Programme is based on Ariadne Labs' pioneering work in the United States,[1] which is demonstrating that structured, meaningful conversations about a patient's goals and priorities enhances their experience of care, quality of life, and sense of control, while also reducing depression and anxiety.

The UK Programme is a partnership led by The Clatterbridge Cancer Centre NHS Foundation Trust (Merseyside, UK), with The Marie Curie Palliative Care Institute, Liverpool (University of Liverpool, UK) and Ariadne Labs, a health systems innovation centre at the Brigham and Women's Hospital and the Harvard T.H. Chan School of Public Health (Boston, USA). The Clatterbridge Cancer Centre is the national coordinating centre for the UK Programme.

The Serious Illness Care Programme UK is a multi-component system level intervention designed to improve the lives of all persons with serious illness. It systematically deploys clinical tools; education and training, and systems innovations to optimise the timing, frequency and quality of serious illness conversations (see Figure 1). The Programme supports people with a serious illness by helping them and their clinician focus on what matters most in their life. This empowers a patient to feel more in control, to plan for all stages of their illness and enables the clinician to personalise care to the goals and priorities of the individual patient.

In 2016, NHS England funded a 15 month implementation pilot of the Serious Illness Care Programme. NHS Clinical Commissioning Groups (CCGs) in Airedale, Wharfedale and Craven (AWC) in Yorkshire and Southend-On-Sea in Essex were selected to join Clatterbridge as sites for the Phase One Pilot.

The Department of Health has highlighted the Programme as a model for improving the delivery of personalised care.[2] They have endorsed the approach to training and evaluation which are core features of the Programme.[3]

This report describes the development of the Programme and implementation at the three pilot sites. We hope that the results presented here serve as an impetus for the NHS to provide future funding for the UK Programme. We believe that this is the best approach for improving care for seriously ill patients in the NHS.

The Mission Statement of the UK Programme is:

To improve the lives and personalise the care of all people with serious illness through meaningful conversations about their goals and priorities.

FIGURE 1

Key Components of the Serious Illness Care Programme UK

Tools

Education

Master Faculty Training		Clinician Training			Train Future Trainers	
Course 101	Course 201	Primary Clinician Training (1 day)	Coaching		Course 101	Course 201

System Changes

Patient Identification	Reminder System	Conversation Using the Guide	Document Conversation	Patient & Family Support

Meaurement and Improvement (QI)

2. Programme Rationale

Serious illnesses put increasing demands on the National Health Service

Serious illness is defined as "a health condition that carries a high risk of mortality and negatively impacts a person's daily function or quality of life, excessively burdens their caregivers, or both."[4] Approximately 2.6 million people over the age of 50 live with a serious illness in England, almost 14% of the entire population. This percentage is expected to rise over the next ten years, and some models estimate that nearly 3.4 million individuals over the age of 50 will be seriously ill by the year 2025.[5] The three most common causes of death for men and women are cancer, diseases of the circulatory system, and diseases of the respiratory system[6] Each of these carries a substantial burden of physical and emotional suffering, and place a strain on the health system by increasing the use of emergency, hospital and primary care services.

As patients and families often wish to avoid intensive end-of-life treatments, policy makers promote advance care planning as one method of ensuring that patients receive care that aligns with their preferences.[7]

Improving serious illness care requires improved serious illness communication

The delivery of high-quality, person-centred healthcare requires service providers to understand and incorporate patients' preferences into the process of shared decision making.[8, 9] This is especially true when patients are seriously ill, because healthcare decisions carry the risk of increased suffering and mortality. A growing body of evidence from multiple countries suggests that timely, high quality communication improves health outcomes for seriously ill patients.[10-16]

Despite this evidence, clinicians frequently fail to engage patients with serious illness in meaningful discussions about their goals and preferences regarding current and future care. [13-16] As a consequence they limit opportunities to promote shared decision-making and risk exacerbating patient and family distress.

Improving serious illness communication demands a systems-based approach

Clinician training alone is insufficient to address these deficits.[12] An effective approach to improving serious illness care must address multiple barriers that limit clinician capabilities to engage their patients in effective and timely communication. Data from US-based studies of the Serious Illness Care Programme, including a large cluster-randomised controlled trial in cancer patients and a pragmatic trial in primary care patients, demonstrates significant improvements in frequency, timing and quality of conversations.[17, 18] Results from a recent study submitted for publication demonstrate acceptance by both clinicians and their patients, and improved patient quality of life.[19]

Serious illness communication differs from but enhances Advance Care Planning

Advance Care Planning (ACP) is the iterative process by which patients outline their preferences for types and location of care in the event that they lose decision-making capacity in the future. The NHS End of Life Care Programme promotes ACP as a key process in the care of the patients with life limiting illness,[7] yet clinicians remain uncertain about for whom ACP is most appropriate and when is the right time to discuss. In the UK, ACP often happens late

leaving patients unable to express their goals, values, and preferences or without the opportunity to achieve their goals or influence their treatment.

The Serious Illness Care Programme UK focuses specifically on optimising the timing, frequency and quality of serious illness conversations. We know that there is significant scope for improvement in such communication between patient and healthcare professionals and that when we get these communications right patients are more able to make the choices in their life that they would like and receive the personalised care they want. Figure 2 illustrates a framework for communication tasks in later life, during a serious illness and in end of life care.

In focusing on improving serious illness conversations through the systematic deployment of clinical tools, education and training and systems innovations, the Serious Illness Care Programme UK has the potential to support improved outcomes for patients with long-term conditions, to improve and to begin the process of Advanced Care Planning and, in turn, to lay the foundations for better care at the end of life.

FIGURE 2 Conceptual Framework of Communication Tasks in Advance of Death

Late Life

Serious Illness

End of Life

Preparation in the event of unanticipated catastrophic illness

Serious Illness Conversations

Advance Care Planning

"In the moment" decision making

Home, Community or Hospital Settings
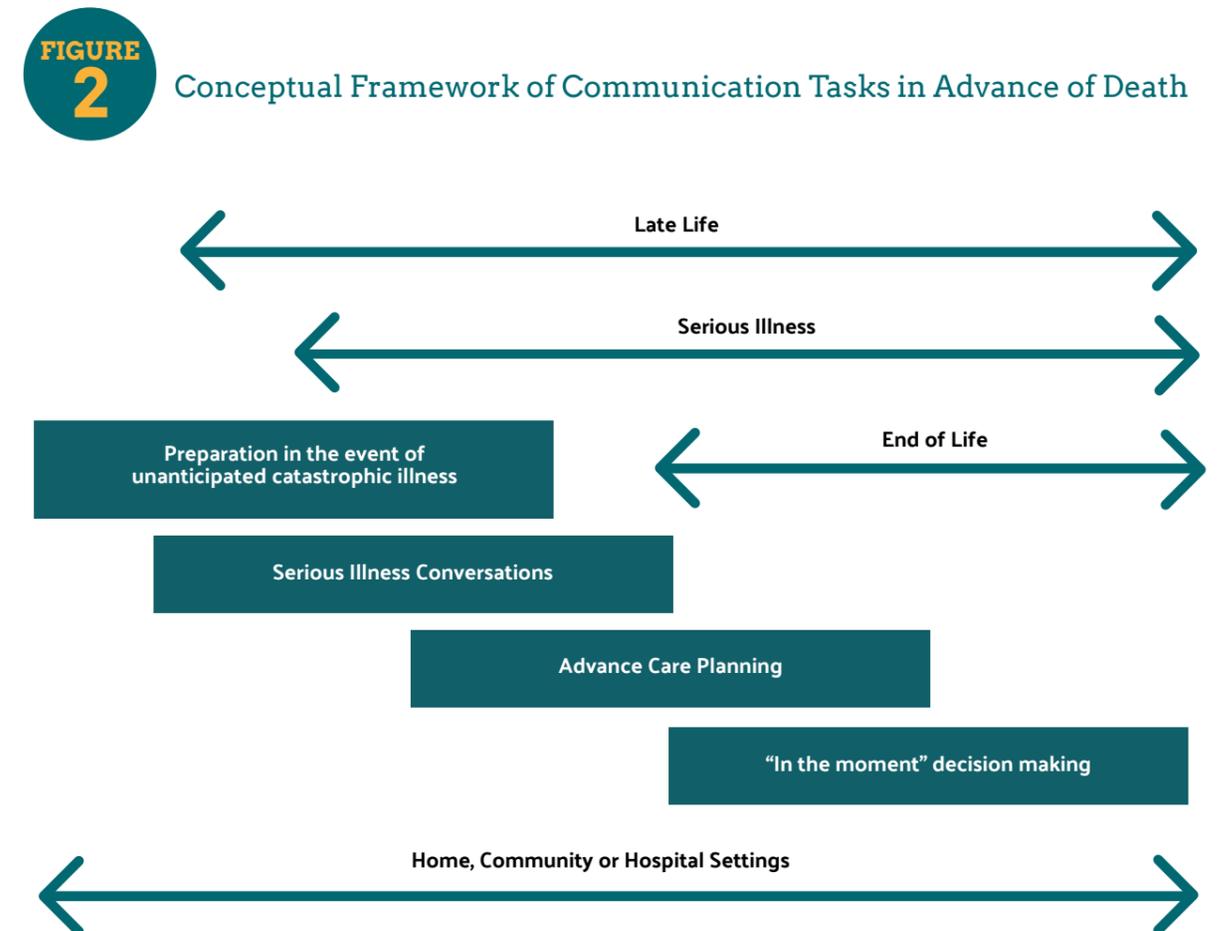
3. Core Capabilities

To transform serious illness care and ensure successful implementation, the Serious Illness Care Programme UK Team developed core capabilities which we describe below:

1. Comprehensive Stakeholder Engagement
2. International Collaboration
3. Research
4. Implementation
5. Monitoring and Evaluation
6. Technological Expertise
7. Training and Coaching
8. Communications
9. Governance and Risk Management

3.1. Comprehensive Stakeholder Engagement

We engaged a diverse key stakeholder group consisting of high-level clinicians, administrators, research experts, communication training experts, communication strategists and members of the US-based team. We collaborated to articulate the mission and vision of the Programme, and to monitor progress. This group will continue to meet in subsequent phases of the Programme to identify synergies with similar work in this field, discuss risks, oversee mitigation plans and ensure successful implementation.

We also engaged patients, carers and the public throughout the Phase One pilot as members of the UK Programme Steering Group and pilot site implementation teams. They participated in the research to determine the applicability of the UK Conversation Guide, approved its content and validated patient and family/carer supporting materials. Patients completed questionnaires and face-to-face interviews as part of the feasibility study. An engagement event for patients and carers was held at one of the participating pilot sites.

3.2 International Collaboration

The Serious Illness Care Programme was developed at Ariadne Labs, a health systems innovation centre founded by Atul Gawande, MD, MPH and based at the Brigham and Women's Hospital and Harvard T.H. Chan School of Public Health in Boston, MA, USA. Expertise was developed through implementation of a large single-centre cluster randomised controlled trial at the Dana-Farber Cancer Institute and an implementation trial in primary care at Brigham and Women's Hospital. Over the past two years Ariadne Labs has contracted with five health systems in the US and internationally, including The Clatterbridge Cancer Centre in the UK, to advance its understanding of implementation and the impact of the Programme in different settings. With core capabilities in implementation science, monitoring and evaluation, training, coaching, and programme management, Ariadne Labs engages with sites around the multiple aspects of the Programme, including adaptation and adoption of clinical tools, training programmes, and workflow innovations.

NHS England is one of a handful of international health systems implementing the Programme and the only health system currently working in close partnership with Ariadne Labs. The Canadian provinces of British Columbia and Ottowa have undertaken steps to implement the programme along with sites in Hong Kong, South Africa and Sweden. The NHS is at the forefront of an international movement to improve serious illness care through this approach.

The Phase One pilot serves as a model for international collaboration, as Ariadne Labs has strengthened the core capabilities of the Serious Illness Care Programme UK through specific activities detailed in Appendix A. (available at www.betterconversations.org.uk)

3.3. Research

3.3.1. Internationally Renowned Research Scientists

Our collaborative brings together nationally and internationally renowned clinical investigators, including teams led by Dr Peter Kirkbride at The Clatterbridge Cancer Centre; Professor John Ellershaw at the Royal Liverpool and Broadgreen University Hospitals; Professor Susan Block at the Dana-Farber Cancer Institute and Harvard Medical School and Professor Atul Gawande of Ariadne Labs and Harvard Medical School. This team has developed and begun to execute a multi-year research strategy, described below, to develop the UK evidence base for the Programme.

3.3.2. The UK Research Strategy

Implementation of initiatives to improve care for seriously ill patients in several countries has not dispelled concerns about their safety and effectiveness.[20] Clinicians and policy makers need confidence that programmes and initiatives, promoted as best practice, have sufficient evidence to justify their costs.

Implementation of the UK Programme is underpinned by a robust research strategy (See Appendix B) which compliments on-going research in the United States and has a number of key objectives including:

1. The development of UK-based evidence for the positive impact of the Programme.

2. Driving effective, evidence-based implementation across multiple sites.

The Programme's research strategy includes three phases:

Phase 1: Adaptation:
From March to September 2016, our team conducted a rigorous assessment of the 'face-validity', applicability and relevance of the Serious Illness Conversation Guide for use within the UK health care setting.

Phase 2: Feasibility:
From September 2016 to June 2017, our team investigated the feasibility of the Programme within The Clatterbridge Cancer Centre, in accordance with the Medical Research Council (MRC) framework for complex interventions.[21] We used this opportunity to optimise outcome measures and examine the impact and safety of the UK Programme, as the foundation for the third phase of research.

Phase 3: Efficacy:
In collaboration with the MRC North West Hub for Trials Methodology Research, we submitted an outline application in June 2017 to the National Institute for Health Research - Health Technology Assessment funding stream to conduct a mixed-methods, multi-site, cluster randomised controlled trial in cancer centres across the UK. We aim to investigate the efficacy of the Programme on improving patient and health system outcomes.

3.3.3. Adapting the Serious Illness Conversation Guide for Use in the UK

Prior to pilot implementation of the Serious Illness Care Programme in the UK, we conducted research with the specific aim of assessing the appropriateness, acceptability and relevance of the Serious Illness Conversation Guide (The Guide or The Conversation Guide) for use in the UK setting.

We used multiple methodological approaches and engaged a wide range of stakeholders. These included healthcare professionals and members of The Clatterbridge Cancer Centre Patient and Public Involvement (PPI) group.

The results of this research have been presented at national and international meetings and are available to view in further detail in Appendix C. They suggested the following:

• **The Conversation Guide promotes shared decision making:** The Conversation Guide is an appropriate tool to support clinicians to have conversations with patients with a serious illness regarding their current and future care. Participants view the Guide as promoting a partnership approach to care planning conversations and shared decision making.

- **The Conversation Guide promotes a holistic approach:** The Conversation Guide can empower the patient to think about and talk through what is most important to them in relation to their current and future care. It focuses on exploring the 'holistic' needs of individuals, rather than the disease process.

- **The Conversation Guide works best as part of a natural conversation:** It is important for clinicians to have the flexibility to incorporate the Guide prompts as part of a natural conversation.

- **Effective use of the Conversation Guide requires education and training:** A robust programme of education and training must accompany implementation of the Programme. Continued training and support throughout the implementation period, via coaching and mentoring, is essential to overcome initial anxieties and challenges related to integrating the Conversation Guide into practice.

- **Effective use of the Conversation Guide requires systems innovations:** Adherence to the systems innovations (infrastructure and monitoring) is essential to underpin use of the Conversation Guide and support clinicians to engage in conversations with patients.

- **Robust research and evaluation** alongside pilot implementation is essential.

- **The Conversation Guide is applicable for use in the UK:** The Conversation Guide has only minor changes to the wording of some prompts and the final affirmation statement.

3.4. Implementation

Implementation refers to a "span of activities from the initial agreement through the process of integrating the Programme into an organisation or healthcare system and continuing with long-term improvement."[22] The Serious Illness Care Programme UK utilised a four-phase implementation roadmap, (see Figure 3) adapted from that developed by our US colleagues, to guide the planning and delivery of the pilot.

Phase 1: Building the Foundation
Phase 1 aims to build a supportive environment and readiness to implement the Programme. Specifically, this phase leads teams to understand the core components of the UK Programme, clarify the needs of the local healthcare system and organisations, and align one to the other.

Phase 2: Planning Implementation
Phase 2 focuses on creating a detailed plan to implement the Serious Illness Care Programme. It sets in motion the people, processes and structures necessary to ensure that clinicians and staff are trained and supported to deliver high quality conversations and care. The UK team developed the training plan for clinicians and due to time constraints of the one year pilot, future trainers were recruited and trained at the end of the period.

Phase 3: Launch Pilot Sites
Phase 3 puts into action the plans developed in Phases 1 and 2 and included clinician training and pilot site launches. Ongoing monitoring and evaluation support the effective implementation of the Programme and necessary adaptations. Close work with clinicians identifies specific training and workflow issues, including uptake of the Conversation Guide and use of the documentation template. Feedback gained through informal contact and formal coaching improvesd processes and ensured successful implementation.

Phase 4: Sustaining and Expanding
Phase 4 focuses on embedding the Programme within the organisational culture of the healthcare system so that clinicians continue to have high quality conversations with the appropriate patients, at the right time. This phase includes strengthening the infrastructure of the UK Programme and reaching out into new populations.

SERIOUS ILLNESS CARE
Programme UK
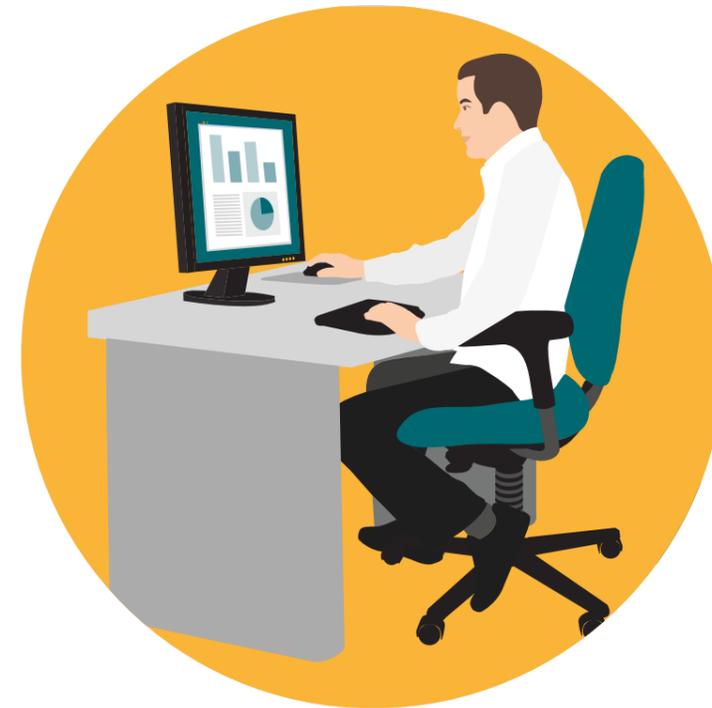
FIGURE 3 UK Implementation Roadmap

PHASE ONE Build a Foundation

Set up Implementation Group ← Access Readiness ← Engage Leader and Colleagues

Determine Programme Goals → Construct Budget and Obtain Approval →
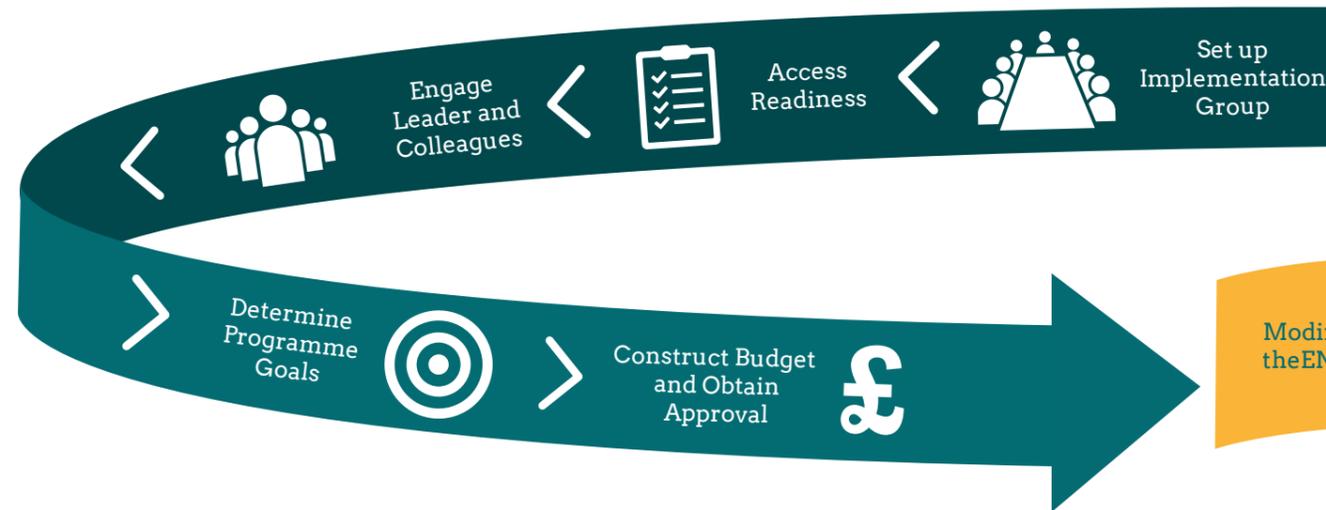
PHASE TWO Plan Implementation

Modify theENR → Recruit Clinicians → Align Outreach and Comms Strategy with UK Programme

Plan for Performance Improvement ← Prepare for Quality Control ← Prepare for Monitoring & Evaluation ← Customise Clinic Workflow for Conversation

PHASE THREE Launch Pilot Sites

Initate Promotional Events and Activities ← Begin Clinician Training ← Identify Clinic Level Team Champions

Implement and Refine Clinic Workflow → Debrief and synthesise lessons learned → Create a Plan for Programme Expansion

Promote the Programme → Coach, Debrief & Improve → Train the Trainers

Plans for Sustainbiliity ← Evaluate Impact
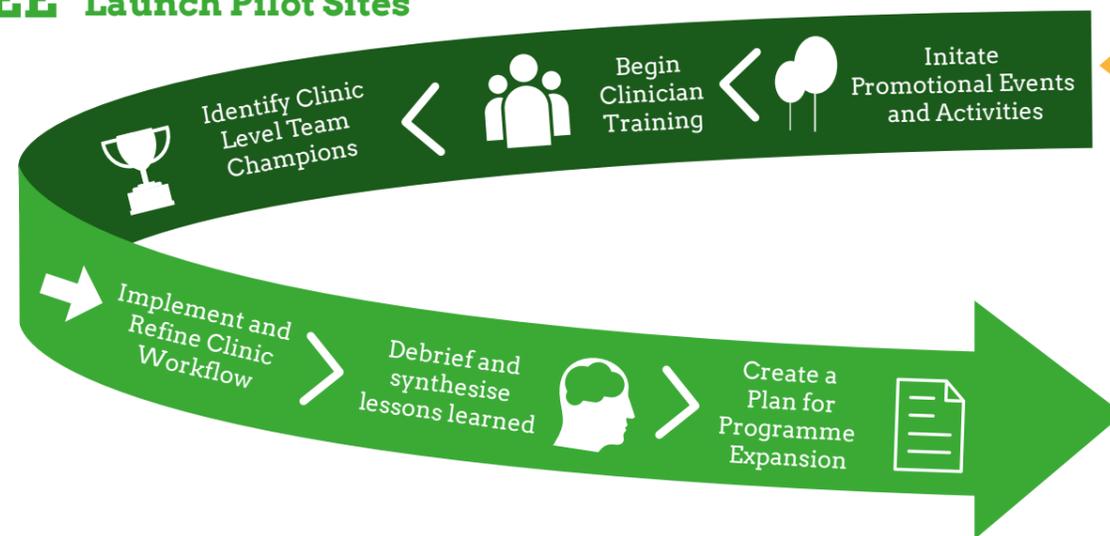
PHASE FOUR Expand, Support & Evaluate

3.5. Monitoring and Evaluation

Our Monitoring and Evaluation team established governance procedures and the definition of process and outcome metrics. They ensured that there was a plan for data capture and procedures in place to measure progress against the metrics and for subsequent evaluation of the Programme. A risk assessment and mitigation document was used as a reference to assure an implementation at pace under governance.

We identified four essential reporting areas, which formed the basis of downloadable reporting by and for pilot sites:

1. Participant identification and registration.
2. Demographics, site, GP or clinic associated with the participant.
3. Screening and conversation record.
4. Evaluation consent, uptake and completion at GP sites.

We developed a bespoke Clatterbridge Cancer Centre (CCC) monitoring and evaluation system, using the National institute for Health Research (NIHR) EDGE platform, to support implementation through capture and reporting of relevant metrics.[23] This includes a robust data capture, data management and monitoring plan with associated Standard Operating Procedures. All attributes and output reporting has been validated to support the tracking and oversight requirements of the UK Programme. The CCC EDGE system facilitates real-time monitoring at all levels, including patient identification and clinician conversation activity. The system has key metric reports programmed for standard monthly reporting, allowing issues to be identified and addressed as they arise. The pilot sites have been able to track progress using the system. The existing data architecture will support implementation of the Programme at additional sites.

The infrastructure and system is flexible and may be configured to support the next stages and expansion of the UK Programme. A full description of the monitoring and evaluation plan is contained in Appendix D.

3.6. Technological Expertise

Documentation of serious illness communication in an accessible location within the Electronic Health Record (EHR) is essential to ensure that clinicians align the patient treatment with their stated values and goals. Working directly with Information Technology experts at the pilot sites, we successfully implemented Conversation Guide-based templates in two different electronic health record systems- MediTech and SystmOne. Each Conversation Guide prompt is coded, facilitating systematic and in-depth monitoring of a serious illness conversation. The infrastructure may now be easily utilised by other sites joining the Programme.

FIGURE
4
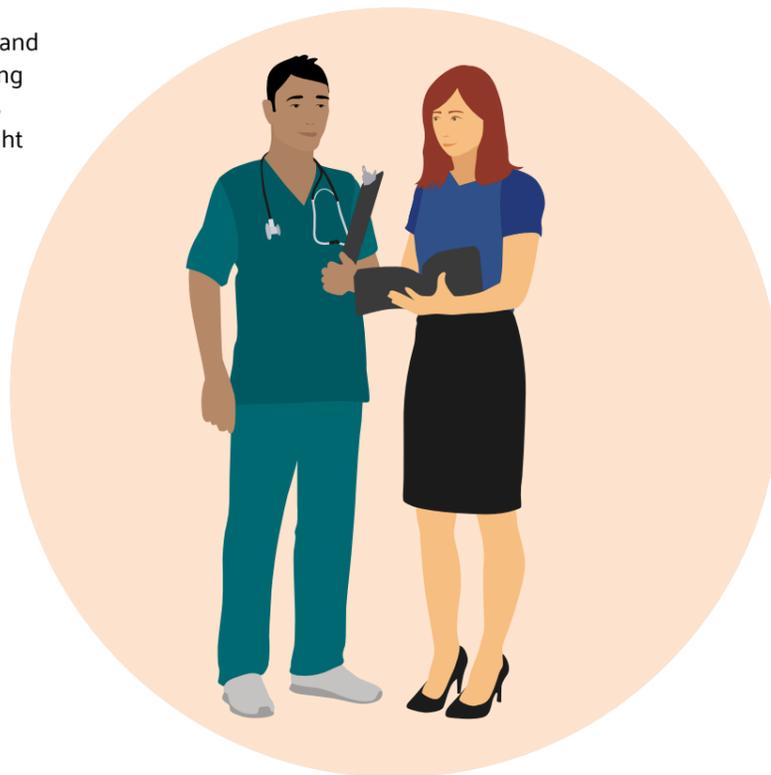
Section of EHR Template Used for Documenting a Serious Illness Conversation

3.6.1. Electronic Health Record Module

The EHR module is a structured template to support clinicians' documentation of serious illness conversations. It reinforces use of the Conversation Guide by mirroring the structure and language, whilst also allowing clinicians to enter free form text.

The module has nine prompts including: understanding, information preferences, prognostic communication, goals, fears and worries, strengths, functional abilities, trade-offs and family involvement.

Figure 4 illustrates part of the EHR template used at The Clatterbridge Cancer Centre.

For SystmOne, the EHR module was developed as a questionnaire template and the same template added to the electronic system used in each participating practice in Airedale and Southend. At The Clatterbridge Cancer Centre, we developed and implemented a questionnaire on the Meditech system for clinicians who had completed the training. Completed questionnaires are viewable by all clinicians. Electronically generated letters containing details of the serious illness conversations were sent to GPs and other relevant healthcare professionals.

We linked the Serious Illness electronic record to related templates already in use at the pilot sites, including DNACPR (Do Not Attempt Cardiopulmonary Resuscitation) and PPC (Preferred Priorities of Care).

3.7. Training and Coaching

The Serious Illness Care Programme UK, along with its US-based collaborators, includes internationally and nationally recognised medical educators and employs a pedagogical approach, grounded in adult learning principles and refined over many years. Dr Susan Block, Professor of Psychiatry and Medicine at Harvard Medical School, and Senior Advisor to the Serious Illness Care Programme, is considered one of the founders of the US palliative care community, and is among the leading serious illness communication

experts globally. She and her husband, Dr Andrew Billings, developed the Palliative Care Education and Practice (PCEP) course, a flagship educational offering of the Harvard Medical School Center for Palliative Care. This course has trained palliative care clinicians and educators from around the world for more than 15 years and has directly contributed to the growth of the field internationally.

Anita Roberts, Senior Lecturer at the Marie Curie Palliative Care Institute is among the most well-established communication trainers in the UK. She is a senior member of the team that established and implemented the National Advanced Communication Skills Training Programme (Connected), and has trained thousands of clinicians in more than 30 years of work in palliative care. As the Education & Training Lead, Anita led the adaption of the US-based Serious Illness Care Programme's Teaching and training materials for use in the UK.

3.7.1. Master Faculty Training

Two members of the UK team undertook Course 101 in April 2016 in Boston, MA. This training focuses on use of the Conversation Guide and includes the primary clinician training. They subsequently trained two master trainer candidates. Over the next three months the master trainer candidates used the Conversation Guide in their clinical practice prior to taking Course 201. The Ariadne Labs master faculty conducted course 201 in July 2016 in Liverpool. This course focused on the pedagogical approach to teaching communication skills and use of the Conversation Guide. Master trainer candidates led a practice reflection, applied techniques to create safety during role play sessions, facilitated skills practice sessions on the use of the Conversation Guide, and provided effective feedback to learners on their communication skills and responding to clinicians' concerns.

We adapted three case scenarios from those used in the U.S. training, and developed two additional scenarios such that three relevant case histories were available to suit the specific needs of GP and Oncologist participants.

FIGURE 6 Clinician Training Day Agenda

09.30 – 10.00	Introductions Expectations
10.00 – 11.00	Overview of Serious Illness Care Programme UK Evidence Base
11.00 – 11.15	**Coffee Break**
11.15 – 12.30	Presentation introducing the Conversation Guide Video Demonstration of Conversation Guide in Practice
12.30 – 13.00	**Lunch**
13.00 – 14.45	Small Group Working: using the Conversation Guide and documenting outcomes
14.45 – 15.00	Participants Agenda
15.00 – 15.15	**Coffee Break**
15.15 – 16.00	Local Workflow and System Ongoing Support Next Steps
16.00	**Close**

FIGURE 5 Training Pathway to Support Implementation of the UK Programme

Master Faculty Training: Course 101 → Course 201

Clinician Training: Primary Clinician Training (1 day) → Coaching

Train Future Trainers: Course 101 → Course 201

Education and training related to the Phase One pilot focused on four key elements: master faculty training; clinician training; provision of on-going coaching; and training future trainers. Figure 5 illustrates the training pathway.

3.7.2. Clinician Training

We trained clinicians in cohorts of nine or 10 by running two onsite trainings at each pilot site. We developed a six-hour study day to ensure that pilot site clinicians had sufficient time to complete training that includes role play with feedback, as well as to learn about the programme, local implementation arrangements and the monitoring and evaluation process.

We received six Category 1 CPD (Continuing Professional Development) credits from the Royal College of Physicians for the UK course to incentivise clinicians to participate in the training. Figure 6 illustrates the agenda for a UK clinician training day.

We developed a UK facilitator guide, adapted PowerPoint presentations, participant hand-outs, a clinician reference resource, and produced a 12-minute video to demonstrate successful clinician use of the adapted UK Conversation Guide. (Figure 7).

FIGURE 7 UK Training Video

3.7.3. Coaching

The use of coaches in UK clinical practice is relatively new. The programme utilises a "coaching" approach to support trained clinicians in effective use of the Conversation Guide and troubleshooting of challenges that arise related to implementation or communication. Our team has developed vernacular, tools, and processes to help systemise coaching within the UK context. For example, we created a coaching template that facilitates discussion between the coachee and coach based on the coachee's stated goals. (See Appendix E) These tools are easily adapted to meet the needs of each implementing organisation.

All participating clinicians were offered coaching following the training. The coaching aimed to reinforce best practices in having serious illness conversations and to support clinicians who were having difficulties, while also providing an opportunity to celebrate successes and to maintain motivation for the project. We conducted joint coaching sessions and completed summary forms that they shared with the clinician. Sessions were conducted by telephone, email or in person per the preference/availability of the clinician. Each session lasted approximately 30 minutes.
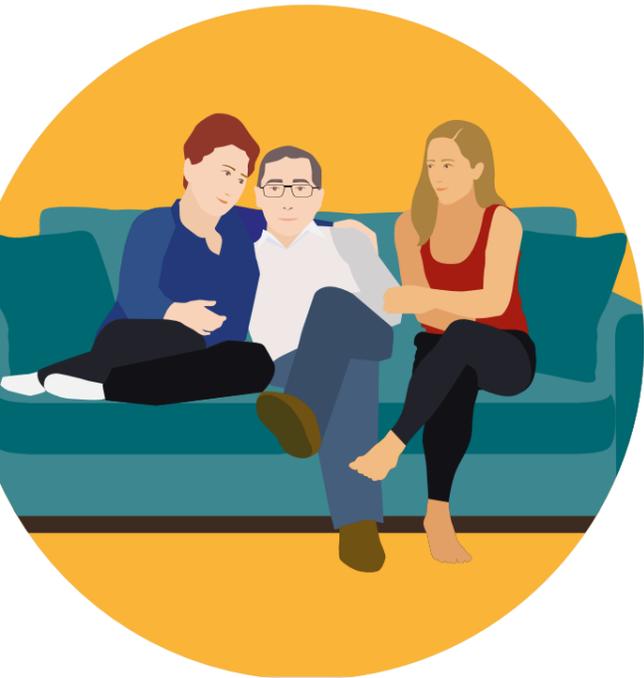
Ariadne Labs provided support to the UK programme coaches by providing scheduled and ad hoc sessions to review coaching aims, challenges and opportunities.

3.7.4. Training Future Trainers

Master Trainers conducted a train-the-trainer programme with clinicians from each of the three sites. As maintaining the quality of training is paramount, a specification was developed to ensure that potential trainers had the requisite skills and attributes (see Appendix F).

We trained six clinicians as UK trainers: two Palliative Care Consultants, two GPs and two Oncologists; (three from Airedale, two from Clatterbridge and one from Southend). All six participants had undertaken the initial clinician training in autumn 2016 and had actively used the Conversation Guide in their clinical practice.

3.8. Communications

We developed a detailed and robust strategy to enable effective communications and engagement with key stakeholders and others with an interest in serious illness care. Our multi-institutional communications team developed a branding strategy; national website; media outreach materials and a range of Programme resources. The national website (see Figure 8) is available at www.betterconversations. org.uk. Examples of branded materials are available in Appendix G.

Although the UK Programme is not specifically focused on end-of-life-care, the strategy took account of media and public sensitivities in this policy area. The communications strategy will support on-going expansion of the UK Programme.

FIGURE **8** National Website Home Page
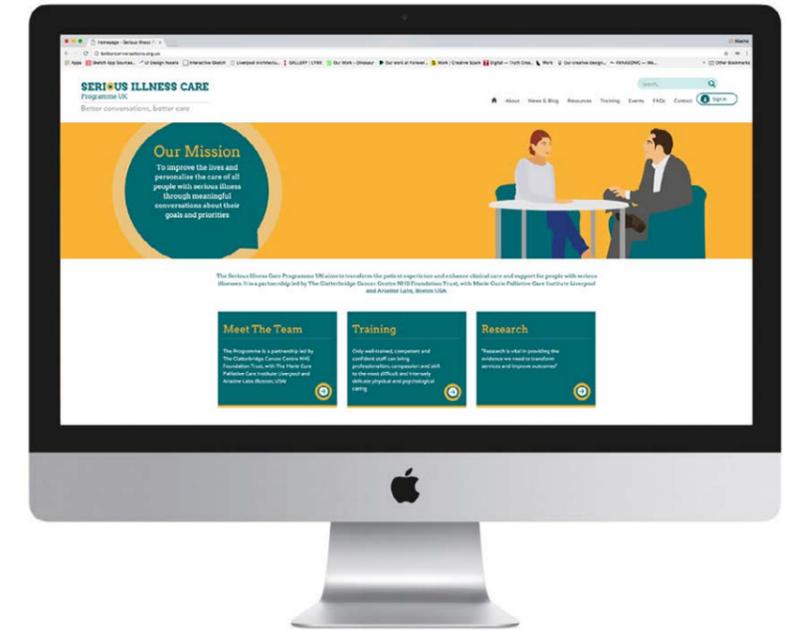
3.9. Governance and Risk Management

The governance and risk management strategy describes a framework to support decision making within the Serious Illness Care Programme UK. Figure 9 illustrates the organisational structure. A full description of the governance framework, its components, underpinning core principles, key work streams and the risk register are available in Appendix H.

FIGURE 9

Organisational Structure for the Serious Illness Care Programme UK

Oversite

UK Steering Group

Ariadne Team

5 Key Work Streams
National Development
Conversation Guide Validation
Education & Training
Pilot Site Implementation and Coordination
Evaluation & Research

Project Management Group

Key Members
Clinical Lead
Coordinator/ Administrator/ IT Representative
Executive Member
Clinician Representative
R&I Representative
Patient/Carer Representative
Communications Representative

Pilot Site Implementation Team

Delivery

Clinical Manager

Patient & Families

Frontline Clinical Teams

4. Funding, Site Selection, and Site Descriptions

4.1. Funding

The Serious Illness Care Programme UK aligns to business plan deliverables for the New Models of Care Programme (specifically, 'delivering a modern model of integrated care'), and supports the key objectives in the NHS England Business Plan.[24,25] Following a national workshop held at The Clatterbridge Cancer Centre in July 2015, and discussion with NHS England's Director of Long Term Care and Integrated Care Pioneer Programme, a Phase One pilot was established under the auspices of NHS England to provide formal training in the use of the Serious Illness Conversation Guide.

4.2. Site Selection

A request for applications was sent to sites participating in the NHS England Integrated Care and Support Pioneer Programme.[26] This is a national initiative to improve the quality, effectiveness and cost-effectiveness of care for people whose needs are best met when the different parts of the NHS and local authority services work in an integrated way. In January 2015, the pioneer initiative was incorporated into the wider New Models of Care Programme.[27]

NHS England coordinated the site selection process, and sought applications for review by members of their team. Selection criteria included high level support from key stakeholders and commitment to evaluation and knowledge transfer across sites. Southend-on-Sea and Airedale, Wharfedale and Craven (AWC) were selected as the two pioneer sites to join The Clatterbridge Cancer Centre as Phase One pilot sites. (Figure 10).

FIGURE 10

Locations of Phase One Pilot Sites

The Clatterbridge Cancer Centre

Airedale, Wharfedale and Craven

Southend-On-Sea

4.3 Site Description

Figure 11 gives demographic details about each of the three pilot sites; the clinical environment; strategic aims, and local initiatives which are synergistic with the Serious Illness Care Programme UK.

FIGURE 11 Site Descriptions, including Existing Initiatives with which the Serious Illness Care Programme UK provides Synergy.

NHS Southend Clinical Commissioning Group	**NHS Airedale, Wharfedale and Craven** Clinical Commissioning Group	**NHS The Clatterbridge Cancer Centre** NHS Foundation Trust
Southend-On-Sea is a well-known seaside resort located on the north side of the Thames estuary, 40 miles east of central London. It covers 16 square miles. The Southend CCG serves a population of 185,000, approximately 30% of which are over the age of 65. Adults living with a long-standing health condition comprise approximately 56% of the population.[28]	Airedale, Wharfedale and Craven (AWC) CCG is located in North Yorkshire and is part of the Bradford and Airedale Palliative Care Managed Clinical Network. It serves a population of 156,000. 23% are aged 65 or older and living in urban or rural areas. [29]	The Clatterbridge Cancer Centre (CCC), one of the largest networked cancer centres in the UK, delivers specialist cancer care to a population of 2.3 million people across Merseyside, Cheshire and surrounding areas, including the Isle of Man. It provides non-surgical cancer care e.g. chemotherapy and radiotherapy, for solid tumours and from 2017 also provides treatment for haematological malignancies.[30]
Clinical Environment		
Clinical sites: 10 primary care practices Number of clinicians trained: 20	Clinical sites: Two primary care practices Number of clinicians trained: 19	Clinical sites: One tertiary cancer centre Number of clinicians trained: 20
Strategic Aim		
To redesign, integrate and remodel existing services to increase the number of people supported to remain in their home and community setting and to achieve their preferred place of care during final stages of life.	To improve the quality of care and outcomes for individuals through their New Models of Care – 'Complex Care' Model, which focuses on a person-centered approach.	To promote a culture of engagement of professionals with patients and the delivery of compassionate patient centered care.
Synergistic Local Initiatives		
• Dedicated Care Home Service • Community Recovery • Electronic Palliative Care Coordination System (EPACCS) [31] • Complex Care Service	• Gold Standard Framework [32] • Electronic Palliative Care Coordination System (EPACCS) [31] • Shared Electronic Health Record across care settings • The Gold Line [33]	• Gold Standards Framework [32] • AMBER Care Bundle [34] • Enhanced Supportive Care [33]

5. The Return on Investment: Findings from the Phase One Pilot

NHS England investments need to optimise the value of care, by improving quality and, where possible, reducing costs in ways that reflect patient choices rather than system mandates. The following summary highlights key findings from the evaluation of the Phase One pilot, including baseline assessments, reach metrics, training evaluation, clinician evaluation of the Conversation Guide, and findings from the feasibility study. Additionally, we highlight examples of case studies collected from patients and clinicians. This pilot also adapted and tested the UK version of the Conversation Guide which is discussed in Section 3.

In the absence of an economic analysis, which is unfeasible at this stage of UK Programme development, the following data demonstrates increased frequency, demonstrates increased frequency and quality of the type of communication that is associated in the literature with decreased utilisation of costly, potentially non-beneficial therapies. A full analysis on return of investment could only be properly undertaken as part of a wide reaching research study. As described in other sections, we are establishing a foundation and application for this to begin.

Detailed tables and figures are available for review in Appendix J and full details of the UK Programme outputs to date are listed in Appendix K.

5.1. Baseline Analysis

In order to understand the quality and frequency of discussions between patients and clinicians about the patient's wishes, goals and needs in their last year of life, we conducted a retrospective audit at each of the three pilot sites of 50 randomly selected case-notes of patients who had died within the previous 12 months using a standardised data collection form.

Findings: The frequency of documentation of prognosis discussion and patient understanding varied across the three sites (range 50-86% and 40-66%, respectively). There was infrequent documentation of discussion of goals, sources of strengths, trade-offs, and critical abilities, although there was some variability between the three sites.

5.2. Reach Metrics

Reach metrics describe the extent to which the implementation resulted in screening of and communication with seriously ill patients as well as our success in training clinicians. Table 1 highlights pilot site reach data from October 2016 to June 2017.

Table 1 Reach Metrics for Phase One Pilot				
	Airedale	**CCC**	**Southend**	**Total**
Patients identified as potentially suitable for a serious illness conversation	500	1225	184	1909
Patients offered serious illness conversation	104	135	56	295
Patients who completed a serious illness conversation	102	60	54	220

We trained 59 clinicians across the three pilot sites: 18 GPs and one Palliative Medicine consultant from AWC CCG; 18 GPs and two Palliative Medicine consultants from Southend CCG; 20 Consultant Oncologists from The Clatterbridge Cancer Centre. Forty-three of 56 (77%) non-palliative care doctors conducted 220 conversations during the pilot. Three of the thirteen trained doctors who had no subsequent conversations were unable to participate in the project due to long term illness or excessive workload. Active doctors averaged 4.8 conversations (median=4) over the pilot period.

5.3. Training Day Evaluation

We used a pre and post-course self-assessment questionnaire and a clinician acceptability questionnaire adapted from the US programme. Data from the evaluation of the training day is reported separately for the two primary care sites and The Clatterbridge Cancer Centre. A full report of the training evaluations for all three sites is available in Appendix L.

Doctors rated the training highly and almost universally felt that the course fully or mostly met all learning objectives. Clinicians reported increased confidence across all domains of serious illness communication with the most substantial increases relating to focusing on patient goals and values and responding to patient emotion. Clinicians noted that the training enabled them to improve their care of seriously ill patients and enhanced their understanding of how this initiative could potentially reduce anxiety, depression, and unnecessary admissions. All trainees highly rated the master trainers, noting that they fully or mostly presented information clearly, treated individuals with respect, and demonstrated mastery of content.

5.4. Clinician Evaluation of the Guide and Conversations

We used a postal questionnaire to understand trained clinicians' perspectives regarding the usefulness of the Conversation Guide. Nearly 80% of the 32 responding clinicians were using the Conversation Guide in their clinical practice. On average, these clinicians agreed or mostly agreed that use of the Guide helps build a trusting patient-clinician relationship, provides information that helps them understand their patients, allows them to gain important information, and is easy to use.

In assessing the emotional impact of the conversation on patients, 63% of doctors reported the conversation having an improvement on their patient's emotional state; and no doctors reported the conversation having a negative impact on their patient's emotional state. Eighty-five percent reported feeling that their conversations improved their own satisfaction with their role in the care of the patient and all clinicians noted a reduction in their anxiety related to these types of conversations.

5.5. Feasibility Study

In parallel with the implementation and evaluation in AWC and Southend, we conducted an in-depth study at The Clatterbridge Cancer Centre (CCC) to assess the acceptability and feasibility of both the Programme itself and of measurement strategies that might be used for future evaluations or research studies.

We undertook quantitative and qualitative measurement. Our sample included trained clinicians at CCC and their programme-identified patients. We asked clinicians to complete questionnaires before and after training and patients to complete questionnaires before and two weeks after the conversation. A detailed list of measures is listed in Appendix M. Additionally, we asked patients and clinicians to participate in a single narrative interview using a phenomenological approach to gain a deeper understanding of their experience of engaging in serious illness conversations.[36, 37, 38] During the interview, we explored thoughts and feelings engendered by participation in the serious illness conversation, and the emotional impact. We interviewed clinicians within two months of their training and patients within two months of the recorded serious illness conversation.

5.6. Summarised Results

- Clinicians had sustained increases in confidence related to every aspect of communication assessed by the Self-Efficacy in Palliative Care (SEPC) Questionnaire, [39] including discussing the effects of cancer, issues of death and dying, and communicating prognosis.

- As assessed by Thanatophobia scores,[40] clinicians reported less helplessness with terminally ill patients, less frustration with speaking to terminally ill patients, less trauma related to managing dying patients, less discomfort with dying patients who wish to say goodbye.

- Interviewed clinicians described feeling that the conversations were challenging but beneficial to patients, and "worth it"; that it was useful to "stop, think, and reassess" with patients, and that the conversation opened the door for future such conversations, and served as a useful "reference point." They described challenges related to identification of patients (time consuming) and to logistics of scheduling and coding.

- Eighty percent (80%) of patients reported no reduction in quality of life following the conversation; 89% reported reduced levels of depression and none had increased levels of depression. On average, patients rated clinician skill in having serious illness conversations at 8.5/10.

- One hundred percent (100%) of patients reported that the serious illness conversation with their clinician had been worthwhile and 87.5% reported feeling very satisfied with the conversation.

- Over 60% of patients reported an increased rapport with their clinician; a greater sense of control over their medical decisions; better understanding of what their health might be like in the future, and feeling more hopeful about their quality of life.

- Interviewed patients overwhelmingly valued the conversation, noting the benefit of having "time to talk" with their consultant. They felt that the conversations were holistic and compassionate, focusing not exclusively on diagnosis. They noted the benefit of good rapport; the "natural" flow of the conversation, and some felt the use of the Conversation Guide signified "good care," and that the clinician was "doing their best." Some reported feeling like the "door had been opened" to future conversations with their loved ones.

> " ...it almost took a weight off your shoulders...something that was always there, you know, just behind you; suddenly it was here and you were talking about it, and you were talking quite normally if you want...in a very open and clear way. Discussing it openly with somebody, and although it was emotional... it wasn't painfully emotional. "

5.7. Case Histories

We received several case histories from clinicians participating in the Programme and have included two examples below. Further case histories can be found in Appendix N

Case A

My 72-year-old patient was diagnosed with Motor Neurone Disease 11 months ago. We had the serious illness conversation the day before she moved to a new house, as she was keen to get her views down, before having to re-register with a new GP.

I was rather anxious as this was my first serious illness conversation but I knew her well. She attended with her daughter and she was totally aware that her life was limited but she didn't want to dwell on this; she wanted to talk about how she can continue to live a fulfilling life. We discussed what was important to her such as being treated and cared for with dignity and respect, as she can no longer feed herself, spending time with family and friends and continuing with social activities such as gardening and singing.

I found the conversation quite challenging. She was particularly tearful when talking about how her daughter would cope in the future when she was gone. It helped me understand how simple practical things can make a huge difference to her life, such as the position of her bed in her new flat, getting the room set up for when she becomes bedbound. We did not discuss any of the usual topics such as DNACPR.

I left the conversation feeling very positive and upbeat despite the highly emotional subjects covered. By using the framework provided by the Conversation Guide I feel like I have made a real difference to her quality of life by allowing her time to talk and think about it. I am certain, that without using the Guide, I would not have found out about these very practical considerations that are incredibly important to her.

It was one of the most satisfying consultations for some time but I needed a cup of tea afterwards!

Case B

I met with a family: a pregnant daughter, wife, and terminal husband. He had always been a man who had a garage and loved to make and mend things. Since his diagnosis he had got up very early and spent several hours in his garage. This was upsetting his family who wanted to spend what they saw as precious minutes with him, and they were also scared he would hurt himself as he had experienced periods of confusion.

We reviewed his medication as some of his confusion had been due to overuse. We were able to discuss why his garage time was so important for him and how he wanted to make some things for his new grandchild who he was aware he may not meet.

He agreed to reduce his time a little as he realised what his family wanted from him, and they agreed to support his garage time; as they realised why he was doing it and why it was important to him -- "when I'm in my garage I'm me -not an old man dying of cancer"

Both cases are examples of the Programme achieving its mission to improve the lives and personalise the care of all people with serious illness through meaningful conversations about their goals and priorities. The first case resulted in a conversation around practical matters that the patient wished for her clinician to know. Whilst admittedly difficult, the clinician also acknowledged the conversation was "one of the most satisfying consultations" in some time.

The second case highlights the way that serious illness conversations can bring a patient, their family and clinician together. This includes discussing potential medical treatments and importantly, things that matter most to the patient. These, along with the other case examples found in Appendix N, give the context behind a small fraction of the conversations that occurred during the course of our pilot.

5.8. Summary

The evaluation and feasibility study in the Phase One pilot demonstrated positive effects of the Serious Illness Care Programme UK on patient satisfaction, quality of life and clinician experience. We found that conversations happened more often, earlier in an illness and were of better quality. Two large studies in the U.S. have also shown the impact of the Programme on timing, frequency and quality of conversations.[12, 19]

A comprehensive Return on Investment Analysis was not part of this Phase One pilot.

We consulted experts from the Operational Research and Evaluation Unit at NHS England for their advice on evaluation in Phase One and in the future. They concluded the following:

- The UK Programme has a good evidence base to work from.

- Cost reductions demonstrated by U.S trials are difficult to translate into UK context, though NICE costing tools may provide a generic figure on switching from hospital care to home care.

- Information about the mechanism and outcomes of the UK Programme will support its spread.

- Outcomes, cost impact and health economics will be important in future phases.

- A control group may help to determine the outcomes which can be attributed to the conversation.

Table 2 summarises some of the potential benefits and cost savings from implementation of the Programme in the UK. If we conservatively extrapolate preliminary findings from the high-risk primary care setting in the United States, we can forecast savings that might result from implementation of this Programme. We know that patients and their families prefer their care close to home and that this Programme is likely to deliver that care. According to a report by Marie Curie,[41] care in the community costs approximately one third the cost of care in the inpatient setting. When people with a serious illness have the opportunity to express their values and goals in a timely way and with a realistic understanding of prognosis, this will influence their decisions about their care. It is reasonable to expect savings that result from avoidance of hospitalisation as a direct result of these decisions.

The Marie Curie report noted that there is the potential to reduce the cost of care by £280 per day by avoiding hospital admission or reducing the length of unnecessary stay. It suggests that a reduction in the length of a hospital stay by four days for 30,000 people would result in a potential saving of £34 million. There are more than 300,000 people in the UK with palliative care needs which equates to potential cost savings of £340 million.

Modelling work to assess the economic impact of changing patterns of service/resource utilisation as a result of the Serious Illness Care Programme UK intervention is an important component of Phase Two. We know that Return on Investment analysis will involve key people and require adequate resource. Personnel include:

1. Finance: track the investment/cost of the Programme.

2. Clinical, quality and patient safety leads: identify quality indicators that will be affected by the Programme.

3. Statisticians, data analysts, and programmers: help the clinical staff estimate changes in the identified indicators using data available from the hospital/care setting and relevant information from other sources.

4. Consultants for training and statistical analysis related to quality improvement.

Table 2 Potential Benefits and Cost Savings of Serious Illness Care Programme UK		
Care Delivery	**Care Quality**	**Potential Cost Savings**
Care delivered closer to home via community based services in line with the goals and wishes of the patient Helping to enhance and perhaps extend (e.g. by training other clinicians / healthcare professionals - community matrons, practice nurses etc.) existing advanced care planning and end of life care provision. Ensuring that primary/community-based interventions and services become a genuine and viable alternative to planned & unplanned hospital admission, or long-term care for patients with a serious illness diagnosis.	Patient satisfaction Clinician satisfaction Better quality of life Reduced depression and anxiety	Reductions in the number of A&E attendances Reductions in placements to nursing and residential care homes/hospice Reductions in elective/non-elective hospital admissions Reduction in the number of unnecessary days people stay in hospital Reduction in the number of outpatient appointments Reduction in the number of unnecessary days people stay in hospital

6. Lessons Learned

A key return of this 15 month pilot is the lessons that will inform future implementation of the Programme. A complete list of lessons learned, by category, is included in Appendix O.

Below we summarise some of the most impactful lessons learned from this first year of the Programme:

1. Information provided to interested sites should be comprehensive, including: i) requirements for all phases of the Programme; ii) participation in monitoring and evaluation, and iii) required membership of national UK Programme for Quality Assurance.

2. In depth meetings with the central team are essential for interested sites to develop an understanding of:

    ✓ The Programme

    ✓ The commitment required

    ✓ The impact and benefits for patients

3. All participating sites must complete a readiness assessment (gap analysis) to ascertain their capacity for change given current:

    Motivation: perceived incentives and disincentives that contribute to the desirability to use the intervention. Components of motivation include beliefs about and support for the intervention -- such as collective expectations, attributes of the intervention, anticipated outcomes of the intervention, pressures for change, and emotional responses.

    General Capacities: maintaining a functioning organisation (e.g. sufficient staffing, effective organisational leadership) and connecting other organisations and the community. Components of general capacity should include:

    ✓ the culture of the organisation: how it functions

    ✓ climate: how employees collectively perceive, appraise, and feel about their current working environment

    ✓ organisational innovativeness: general receptiveness toward change

    ✓ resource utilisation: how resources are devoted to interventions

    ✓ leadership: whether power authorities articulate and support organisational activities

    ✓ structure: processes that influence how well an organisation functions on a day-to-day basis

    ✓ staff capacity: general skills, education, and expertise that staff possess

    Serious Illness Programme UK Specific Capacity: human, technical and fiscal conditions important for successful implementation of the Serious Illness Care Programme. Components of the Serious Illness Programme UK Specific Capacity should include knowledge, skills, and abilities needed for the Programme (e.g. strong clinical engagement and senior management support from commissioner and provider organisations); key stakeholder(s) who support an intervention through connections, knowledge, expertise, and social influence; project management, data management, and IT personnel who have the capacity to dedicate to the Programme.

4. The Central Team should be involved in preparing the specification for successful sites and in the final selection of sites.

5. Local implementation teams should be multidisciplinary in nature, comprised of an executive member, clinical lead, project manager, communication lead, data manager, and administrative manager as a minimum.

6. Early and ongoing engagement with key stakeholders and frontline clinicians is important, including one-on-one meetings, site visits, and phone calls. Early engagement must include buy-in, identification of trainers, and identification of local coaches.

7. The developed research methodology can provide meaningful data on the effect and impact of the UK Programme on patient care. It is important that a full clinical trial is conducted to establish a UK centric evidence base that will support the wider adoption and rollout of the UK Programme.

7. Meeting the Key Objectives

At the start of the Phase One Pilot 10 key objectives were agreed by The Clatterbridge Cancer Centre and NHS England. All objectives were achieved. Full details are available in Appendix P.
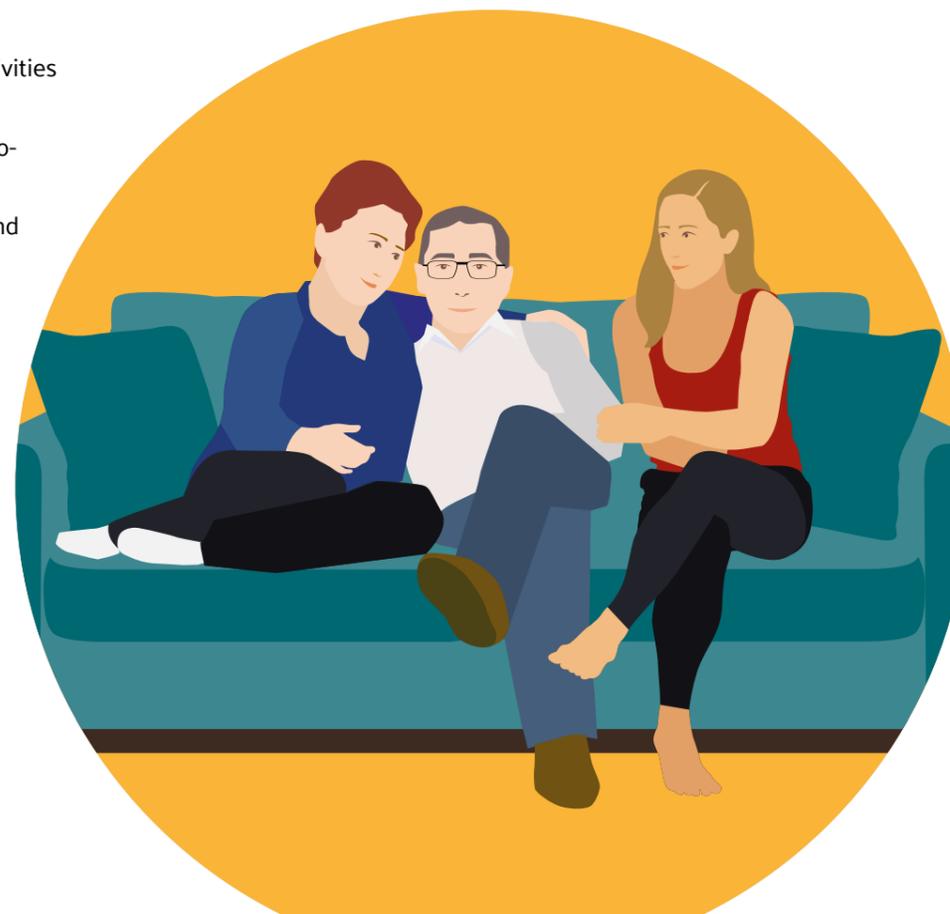
8. Conclusions and Next Steps

8.1. Conclusions

The primary goal of this Phase One pilot was to develop an infrastructure for the Serious Illness Care Programme UK, to implement the Programme in three sites and to evaluate the impact for patients and clinicians. Despite marked challenges inherent to the temporal and geographical constraints, we effectively achieved this goal, built and nurtured local and system capacities, and learned lessons that will enhance the efficiency and quality of future implementation efforts.

Building on the work of Ariadne Labs, who had demonstrated the benefits of using a Conversation Guide in the US, we found that the Serious Illness Care Programme UK provides a scalable framework to support UK clinicians in conducting more, earlier and better serious illness conversations with patients who are at high risk of dying. By triggering the conversations early in the course of an illness, patients and those important to them are able to consider decisions about their lives and medical care with adequate time for reflection and discussion.

The Conversation Guide has a structured format which clinicians valued as it helped them talk with patients about what matters most to them. We demonstrated that training and support enhances clinician confidence, knowledge, and skill and improves the quality of the conversation. Patients and their families told us of the benefits they gained from participating in these structured conversations, how it improved their emotional state, reduced anxiety and had a positive impact their quality of life. Clinicians were also overwhelmingly positive about the benefits of the conversations on the doctor-patient relationship, and fears about the potential negative impacts proved unfounded.

We showed that adaptation of the electronic health record within different organisations or healthcare settings is achievable. We showed that the electronic health record (EHR) template provides an important source of information about patient goals and values that is easily accessible by other healthcare professionals, especially at critical times.

We found that the unique system innovations in identification, scheduling and workflows facilitate the change in practice that can be absent in other initiatives and learned ways to streamline and improve upon these processes for the next phase of implementation. We showed that the Programme may be used in different care settings, is flexible to adjust to the needs of different organisations, and can be used with a range of patient populations.

It is likely that use of the Conversation Guide may have positive benefits in terms of reducing the inappropriate use of valuable healthcare resources in the later stages of the lives of people with serious illness. At present, we are unable to definitely state that use of the Conversation Guide will lead to less hospital admissions, fewer terminally ill patients being managed in intensive care settings or a reduction in the use of potentially toxic chemotherapy drugs at the end of life; further work on this is both required and planned. Nevertheless, the Serious Illness Care Programme UK may plausibly enhance the quality of life of patients with serious illnesses, whilst reducing healthcare spending. Future studies of the Programme will specifically examine these issues.

We believe that this innovative UK Programme enables patients with serious illness and clinicians to discuss preferences and wishes more often, earlier and more effectively. Ultimately, and most importantly, these discussions ensure that healthcare provision is more closely aligned with what matters most to each patient.

8.2 Next Steps

Over the past 12 months we have created a strong foundation for future implementation of the Serious Illness Care Programme across the UK. We will continue to work on implementing the Programme across the UK in parallel with establishing a robust UK evidence base.

We will explore options for extending involvement to other key professionals within multidisciplinary teams caring for patients with serious illnesses.

We will look to evaluate the benefits of using the Conversation Guide in specific groups of patients with serious illnesses, such as those with cancer and renal failure. We will evaluate the impact on different outcomes and the utilisation of health care services.

We will continue to collaborate with expert colleagues, exchanging ideas and experiences relating to implementation and evaluation, and disseminating our findings to a national audience.

9. Acknowledgements

Lead Authors	
Dr Peter Kirkbride	National Lead for the Serious Illness Care Programme UK, Medical Director, Consultant in Clinical Oncology, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Dr Alison Coackley	Clinical Lead for the Serious Illness Care Programme UK, Consultant in Palliative Medicine, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Dr Justin Sanders	Assistant Director of Innovation, Serious Illness Care Program, Ariadne Labs US, Consultant in Palliative Medicine, Dana Faber Cancer Institute, Boston, US.
Professor Susan Block	Senior Advisor, Serious Illness Care Program, Ariadne Labs US; Consultant in Psychosocial Oncology and Palliative Care, Professor of Psychiatry and Medicine, Harvard Medical School, US
Anita Roberts	Education and Training Lead, Director of the Centre for Communication Skills, Education and Training; Senior Lecturer, Marie Curie Palliative Care Institute, Liverpool, UK.
Dr Stephen Mason	Research and Development Lead, Marie Curie Palliative Care Institute, Liverpool, UK.
Professor John Ellershaw	Director, Marie Curie Palliative Care Institute, Liverpool; Consultant in Palliative Medicine, Academic Palliative and End of Life Care Department, Royal Liverpool and Broadgreen University Hospitals NHS Trust, Liverpool, UK.
Alexa Traynor	Communications Lead, Director of Communications, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Ben O'Brien	Communications Lead, Associate Director, Policy & Communications, Marie Curie Palliative Care Institute, Liverpool, UK.
Dr Maria Maguire	Monitoring and Evaluation Lead, Research Manager, The Clatterbridge Cancer Centre NHS Foundation Trust, UK
Tamsin McGlinchey	Research Assistant, Marie Curie Palliative Care Institute, Liverpool, UK.

Lead Authors	
Karen Ross	Project Coordinator, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Francine Maloney	Implementation Specialist, Serious Illness Care Program, Ariadne Labs, Boston, US.

Contributors	
Neil Wolfenden	Lead Development Manager, Integrated Pioneer Support Team, New Models of Care Programme, NHS England.
Mark Dines-Allen	Lead for Serious Illness Care Programme UK, New Models of Care Programme, NHS England.
Dave Allen Smith	Head of Clinical Systems, NEL Commissioning Support Unit, Essex
Mehreen Hussain	Communications Manager, NHS England
Jiri Chard	Senior Evaluation Lead, Operational Research and Evaluation Unit, Analytical Services, NHS England.
Lynda Appleton	Research Nurse, The Clatterbridge Cancer Centre NHS Foundation Trust, UK
Dr Helen Bonwick	Master Trainer, Associate Specialist in Palliative Medicine, Marie Curie Hospice, and Liverpool Heart and Chest Hospital NHS Foundation Trust, Liverpool, UK
Dr Anthony Thompson	Consultant in Palliative Medicine, St Helens and Knowsley Teaching Hospital NHS Trust, Merseyside, UK
Tony Murphy	Patient and Public Representative, Steering Group, Serious Illness Care Programme UK, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Su Winter	Patient and Public Representative, Steering Group, Serious Illness Care Programme UK, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Emer Scott	Associate Director of Communications, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Dr Rosemary Lord	Member of Steering Group, Research Lead, Consultant in Medical Oncology, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Barney Schofield	Member of Steering Group, Director of Transformation, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Joan Spencer	Member of Steering Group, General Manager, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Dr Ernie Marshall	Member of Steering Group, Clinical Director for Chemotherapy, Consultant in Medical Oncology, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Joanna Paladino	Associate Director of Implementation, Serious Illness Care Program, Ariadne Labs, Boston, US.

Contributors	
Pauline Vickers	Information Management and Technology Project Manager, The Clatterbridge Cancer Centre NHS Foundation Trust, UK
Itamar Frenkel	Electronic Patient Record Analyst, The Clatterbridge Cancer Centre NHS Foundation Trust, UK.
Jo Shakeshaft	Data Manager, The Clatterbridge Cancer Centre NHS Foundation Trust, Liverpool, UK
Dr Helen Livingstone	Clinical Lead, Serious Illness Care Programme UK, NHS Airedale, Wharfedale and Craven Clinical Commissioning Group, Consultant in Palliative Medicine, Sue Ryder Manorlands Hospice and Airedale NHS Foundation Trust, North Yorkshire, UK.
Rebecca Hewitt	Project Manager, Serious Illness Care Programme UK, NHS Airedale Wharfedale and Craven Clinical Commissioning Group, North Yorkshire, UK.
Dr Helena Rolfe	GP Lead, Serious Illness Care Programme UK, NHS Airedale Wharfedale and Craven Clinical Commissioning Group, General Practitioner, Ilkley Moor Medical Practice, North Yorkshire, UK.
Dr Andrew Daley	Consultant in Palliative Medicine, Bradford Teaching Hospitals NHS Foundation Trust, North Yorkshire, UK.
Dr Pat Ahlquist	Clinical Lead, Serious Illness Care Programme, NHS Southend-On-Sea Clinical Commissioning Group, Consultant in Palliative Medicine, Havens Hospices, Westcliff On Sea, Essex.
Ingrid Harvey	Project Support Officer and Data Manager, Serious Illness Care Programme, Commissioning Support Manager, Integrated Commissioning Team, NHS Southend Clinical Commissioning Group and Southend-On-Sea Borough Council, Essex
Dr Sharon Hadley	GP Lead, Serious Illness Care Programme, NHS Southend-On-Sea Clinical Commissioning Group; General Practitioner, St Lukes, Southend-On-Sea, Essex.
Tracy Harris	Strategy and Commissioning Manager, Older People, Carers and Physical/Sensory Impairment, Integrated Commissioning Team, NHS Southend-on-Sea Clinical Commissioning Group, Essex, UK
Nick Faint	Programme Manager, Southend-On-Sea Borough Council, Essex.
Matt Mint	Commissioner for Older People and Carers, Integrated Commissioning Team, NHS Southend-On-Sea Clinical Commissioning Group, Essex, UK.
Shidaa Adjin Tettey	Strategy and Commissioning Manager, Older People, Carers and Physical/Sensory Impairment, Integrated Commissioning Team, NHS Southend-on-Sea Clinical Commissioning Group, Essex, UK
Bill Murphy	Patient and Public Representative, NHS Southend-On-Sea Clinical Commissioning Group, Essex, UK.

10. References

1. Ariadne Labs. Serious Illness Care. [Internet]. [cited 2017 Sept 18]. Available from: https://www.ariadnelabs.org/areas-of-work/serious-illness-care/

2. The Choice in End of Life Care Programme Board. What's important to me. A review of choice in end of life care. [Internet] February 2016.[cited 2017 Sept 18]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf

3. Department of Health. Our Commitment to you for end of life care. The Government Response to the Review of Choice in End of Life Care. [Internet]. July 2016. [cited 2017 Sept18]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf

4. Kelly AS. Defining "Serious Illness." *J Palliat Med* [Internet] 2014. [cited 2017 Sept 18]; **17(9)**.

5. Beach B. Serious illness in the over 50s. International Longevity Centre [Internet] 2015. [cited 2017 Sept 18]. Available from: http://www.ilcuk.org.uk/index.php/publications/publication_details/serious_illness_in_the_over_50s

6. Office for National Statistics. United Kingdom Health Statistics. Edition 4. [Internet] 2010. [cited 2017 Sept 18]. Available from: http://webarchive.nationalarchives.gov.uk/20160107053721/http://www.ons.gov.uk/ons/rel/ukhs/united-kingdom-health-statistics/2010/index.html

7. National Health Service End of Life Care Programme. Advance Care Planning: A Guide for Health and Social Care Staff. [Internet].2007. [cited 2017 Sept 18]. Available from: http://www.ncpc.org.uk/publication/advance-care-planning-guide-health-and-social-care-staff

8. Department of Health. Equity and excellence: liberating the NHS. CM7881. [Internet]July 2010 [cited 2017 Sept 18]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213823/dh_117794.pdf

9. Coulter A, Collins A. No decisions about me, without me. Making shared decision-making a reality. The Kings Fund, [Internet].2011. [cited 2017 Sept 18]. Available from https://www.kingsfund.org.uk/sites/default/files/Making-shared-decision-making-a-reality-paper-Angela-Coulter-Alf-Collins-July-2011_0.pdf

10. Jacobsen J, Jackson V, Dahlin C, Greer J, Perez-Cruz P, Billings JA, et al. Components of early outpatient consultation in patients with non small cell lung cancer. *J Palliat Med 2011*; **14(4)**:459-464.

11. Billings JA, Bernacki R. Strategic Targeting of Advance Care Planning Interventions: The Goldilocks Phenomenon. JAMA Intern Med [Internet] 2014 [cited 2017 Sept 18]; 174(4):620-624. Available from: https://www.researchgate.net/publication/260091374_Strategic_Targeting_of_Advance_Care_Planning_Interventions_The_Goldilocks_Phenomenon.

12. Bernacki R, Hutchings M, Vick J, Smith G, Paladino J, Lipsitz S, et al. Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. BMJ Open [Internet] 2015[cited 2017 Sept 18]; 5(10):e009032. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4606432/

13. Wright AA, Zhang B, Mack JW, Trice E, Balboni T, Mitchell SI et al. Associations between end of life discussions, patient mental health, medical care near death and caregiver bereavement adjustment. *JAMA* [Internet] 2008 [cited 2017, Sept 18]; **300(14)**:1665-1673. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2853806/

14. Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. *J Clin Oncol* [Internet] 2010 [cited 2017 Sept 18]:**28(7)**:1203-1208. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2834470/

15. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC et al. Healthcare costs in the last week of life: associations with end-of-life conversations. *Arch Intern Med* [Internet] 2009 [cited 2017 Sept 18]; **169 (5)**:480-488. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2862687/

16. Epstein AS, Prigerson HG, O'Reilly EM, Maciejewski PK. Discussions of Life Expectancy and Changes in Illness Understanding in Patients with Advanced Cancer. *J Clin Oncol* [Internet] 2016 [cited 2017 Sept 18]; **34 (20)**:2398-2403. Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4981977/

17. Lakin JR, Koritsonsky LA, Cunningham B, Maloney F, Neal BJ, Paladino J et al. A Systematic Intervention to Improve Serious illness Communication in Primary Care. *Health Aff* 2017; **36**: 7258-7264.

18. Paladino J, Bernacki R, Hutchings, M, Lipsitz SR, Neville BA, Gawande A, Block S. Effect of conversations about values and goals on anxiety in patients. *J Clin Oncol.* 2015; **33**(suppl 29S; abstr 9).

19. Bernacki R, Paladino J, Neville B, Hutchings M, Kavanagh J, Lakin J, Miranda S, Sanders JJ, Lamas D, Gass JD, Stuart L, Gawande AA, Block SD. Impact of the Serious Illness Care Program: Results of a randomized controlled trial in outpatient oncology. *J Clin Oncol* (Unpublished).

20. Beernaert K, Smets T, Cohen J, Verhofstede R, Costantini M, Eecloo K, Van Den Noortgate N, Deliens L. Improving comfort around dying in elderly people: a cluster randomised controlled trial. *Lancet* 2017; 390: 125–134.

21. Medical Research Council. Developing and evaluating complex interventions: new guidance. [Internet] 2006. [cited 2017 Sept 18]. Available from: https://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/

22. Ariadne Labs. Serious Illness Care Program. Implementation Toolkit. 2016[Unpublished]

23. University of Southampton. EDGE [Internet] [Updated 2017; cited 2017 Sept 18]. Available from: http://www.edgeclinical.com/.

24. National Health Service. Five Year Forward View. [Internet] October 2014. [cited 2017 Sept 18] Available from : https://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

25. National Health Service. Next Steps on the Five Year Forward View. [Internet] March 2017. [cited 2017 Sept 18]. Available from: https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf

26. National Health Service England. Integrated Care Pioneers. [Internet] 2017. [cited 2017 Sept 18]. Available from: https://www.england.nhs.uk/integrated-care-pioneers/

27. National Health Service England. New Care Model: Vanguards-developing a blue print for the future of NHS and care services. [Internet] September 2016. [cited 2017 Sept 2017]. Available from: https://www.england.nhs.uk/wp-content/uploads/2015/11/new_care_models.pdf

28. National Health Service. Southend Clinical Commissioning Group. Operational Plan 2015-2016 [Internet] 2015. [cited 2017 Sept 18]. Available from: http://southendccg.nhs.uk/about-us/key-documents/ccg-publications/964-nhs-southend-ccg-operational-plan-refresh-2015-16/file

29. Bradford District and Craven Health Care Economy. Five Year Forward View (2014-2019) [Internet] [cited 2017 Sept 18] Available from: http://www.airedalewharfedalecravenccg.nhs.uk/wp-content/uploads/2014/08/Bradford-and-Craven-five-year-forward-view.pdf

30. The Clatterbridge Cancer Centre NHS Foundation Trust. Annual Report and Accounts 2015-2016. [Internet] [cited 2017 Sept 18]. Available from: https://www.clatterbridgecc.nhs.uk/application/files/2714/7461/9943/The_Clatterbridge_Cancer_Centre_NHS_FT_-_Annual_Report_Annual_Accounts_and_Quality_Report.pdf

31. Public Health England. National End of Life Care Intelligence Network. Electronic palliative care coordination system national data set project. [Internet]. 2013.[cited 2017 Sept 18]. Available from: http://www.endoflifecare-intelligence.org.uk/resources/publications/epaccs_nat_data_proj

32. The Gold Standard Framework [Internet] 2017 [cited 2017 Sept 18]. Available from: http://www.goldstandardsframework.org.uk/

33. Airedale NHS Foundation Trust. The Gold Line [Internet] 2017. [cited 2017 Sept 18]. Available from: http://www.airedale-trust.nhs.uk/yourhealth/services-and-support/gold-line/

34. Guy and St Thomas NHS Foundation Trust. AMBER care bundle [Internet] No date [cited 2017 Sept 18]. Available from: http://www.ambercarebundle.org/homepage.aspx

35. National Health Service England. Enhanced supportive care. Integrating supportive care in oncology. [Internet] 2015 [cited 2017 Sept 18]. Available from: https://www.england.nhs.uk/wp-content/uploads/2016/03/ca1-enhncd-supprtv-care-guid.pdf

36. Kvale, S. Interviews: An Introduction to Qualitative Research Interviewing. 1996. London: Sage.

37. Polkinghorne, D. E. Narrative knowing and the human sciences. 1998. Albany, W. State: University of New York Press.

38. Van Manen, M. From Meaning to Method. Qual Heal Res, 1997:7(3): pp. 345-369.

39. Mason, S., Ellershaw, J.E. Assessing Undergraduate Palliative Care Education: Validity and Reliability of Two Scales Examining Perceived Efficacy and Outcome Expectancies in Palliative Care. *Med Ed*, 2004; 38: 1103–1110.

40. Merrill J, Lorimor R., Thornby J, Woods A. Caring for Terminally Ill Persons: Comparative Analysis of Attitudes (Thanatophobia) of Practising Physicians, Student Nurses and Medical Students. *Psychol Reps*, 1998; 83:123–128.

41. Addicott R, Dewar S. Improving choice at end of life. Descriptive analysis of the impact and costs of the Marie Curie Delivering Choice Programme in Lincolnshire. [Internet] 2008. [cited 2017 Sept 18] Kings Fund. London. Available from: https://www.kingsfund.org.uk/sites/default/files/improving-choice-end-of-life-descriptive-analysis-impact-costs-marie-curie-choice-programme-lincolnshire-rachael-addicot-steve-dewar-april-2008.pdf

11. Glossary

Algorhythmic approach: using a set of rules for accomplishing a task in a certain number of steps.

Clinician Reference Guide: Available to support clinicians through all aspects of the serious illness conversation. It provides detailed information about how to introduce the conversation, example language to use, and tips for navigating common patient scenarios.

Coaching: Helping people get better at something they already know how to do by observing, asking questions, and allowing them to self-reflect on ways to improve their performance.

Coding: transformation of healthcare diagnosis, procedures, medical services, and equipment into universal medical alphanumeric codes. The diagnoses and procedure codes are taken from medical record documentation e.g. transcription of clinician notes, laboratory and imaging results.

Continuing Professional Development (CPD): a continuing learning process that enables clinicians to maintain and improve their performance across all areas of their professional work and is a key component of revalidation for doctors.

Data architecture: models, policies, rules or standards that govern which data is collected, and how it is stored, arranged, integrated, and put to use in data systems and in organisations.

DNACPR: Do Not Attempt Cardiopulmonary Resuscitation

EDGE: an innovative cloud based research management system created by the Clinical Informatics Research Unit at the University of Southampton. It supports a wide range of functions and allows organisations to actively manage research within a single system so that information can be better organised and analysed in real-time.

Family Communication Guide: Designed for the patient, to help them talk with their family and those important to them about the same topics discussed during the serious illness conversation. Like the clinician materials, it provides language for the patient to relay information to their family.

Hospice Care: seeks to improve the quality of life and wellbeing of adults and children with a life-limiting or terminal illness, helping them live as fully as they can for the precious time they have left. It aspires to be accessible to all who could benefit and reflect personal preferences and needs. Hospices offer wide-ranging, personalised care which is provided by a versatile team of different professional staff and volunteers. As well as taking care of people's physical needs, they also look after their emotional, spiritual and social needs. They support carers, family members and close friends, both during a person's illness and during bereavement. Hospice care is free for everyone, and can be provided in a wide range of settings, not just hospice buildings. These include day services, care homes and people's own homes.

Iterative development: methodology is based on a cyclic process of prototyping, testing, analysing, and refining a product or process. Based on the results of testing the most **recent iteration** of a design, changes and refinements are made.

Meditech: a US based company that provides electronic health record (EHR) systems for use in hospitals.

New Models of Care Programme: a NHS England initiative as part of the Five Year Forward View for the NHS. Focuses on: clinical engagement, patient involvement, local ownership and national support. Co-design approach and identifies replicable standards, tools and methods. National package of support and uses transformation fund to maximise progress and pace. Clear evaluation process to support testing and rapid learning with inbuilt sharing of learning.

Patient Identification: A systematic process used to identify patients with serious illness who would benefit from a serious illness conversation. Often a combination of algorithmic (i.e. filtering patient with only high risk conditions) and clinician approaches. (Would you be surprised if this patient died in the next 1-2 years?).

Patient Preparation Materials: A letter designed to prepare patients for a serious illness conversation with their clinician. It includes topics for patients to think about in advance, reinforces the importance of the conversation, and reassures patients that talking about the future need not impact their treatment plan.

Palliative Care: an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, for example physical, psychosocial and spiritual. Palliative care is delivered in a variety of settings, including hospices, hospitals and in the community.

Palliative Medicine: the branch of medicine involved in the treatment of patients with advanced, progressive, life-threatening disease for whom the focus of care is to optimise their quality of life through expert symptom management and psychological, social and spiritual support as part of a multi-professional team. Palliative medicine specialists may work in hospital, in the community and in hospices or other specialist palliative care units.

Preferred Priorities of Care (PPC): is a document to write down wishes and preferences during the last year or months of your life. It aims to help you and your carers plan your care when you are dying.

Proxy: the authority to represent someone else, or a figure that can be used to represent the value of something in a calculation.

Quality assurance is maintaining a high quality of health care by constantly measuring the effectiveness of the organisations that provide it.

Quality Improvement: is the systematic and continuous actions that lead to measurable improvement in health care services and the health status of targeted patient groups.

Rapid cycle improvement: use of standard quality tools to achieve breakthrough improvement in performance within a rapid time frame. One example is the Plan-Do-Study Act (PDSA) cycle.

Readiness assessment reviews if the need for change is clear to people, the process is understood and that individuals are positive. A successful change readiness assessment will alert to any adjustments before implementation and help manage the risk of failure.

Reminder system: A systematic process for reminding patients to have a serious illness conversation with patient who have been identified as "eligible" for a conversation.

Roadmap: a process to help in the planning and implementation of the Serious Illness Care Programme within an organisation or system.

Screening: the process of identifying people who may be at increased risk of disease or condition or event.

Serious Illness: Conditions that carry a high risk of mortality and negatively impacts on a person's daily function or quality of life; excessively burdens their caregivers, or both. Examples of such conditions include, cancer (metastatic or haematological), renal failure, dementia, advanced liver disease or cirrhosis, diabetes with severe complications (ischemic heart disease, peripheral vascular disease, renal disease), amyotrophic lateral sclerosis (ALS), acquired immune deficiency syndrome, severe chronic obstructive pulmonary disease or interstitial lung disease and severe congestive heart failure.

Serious Illness Care Programme UK: Population health management initiative that includes six key intervention steps: (1) a system to identify appropriate patients, (2) training and coaching, (3) a prompt for clinicians to conduct serious illness conversations at the right time, (4) a short, simple serious illness Conversation Guide, (5) suggestions to help patients discuss preferences about care with their families, and (6) a system for documenting personalised patient goals and priorities in the electronic health record.

Serious Illness Conversation: A structured conversation between a clinician and a patient that addresses the patient's understanding of their illness, preference for information, preference for family involvement, personal life goals, fears and anxieties, and trade-offs they are willing to accept.

Systems innovations: set in motion the people processes and structures to ensure successful delivery of the programme. They include customising the workflow and modification of the EHR.

SystmOne: centrally hosted clinical computer system developed by The Phoenix Partnership. It is used by healthcare professionals in the UK and is one of the accredited systems in the government's programme of modernising IT within the NHS.

Workflow: is the sequence of processes that need to happen to allow a serious illness conversation to take place and the information to be communicated. It includes the following steps: screening scheduling, conversation preparation and documentation.

SERIOUS ILLNESS CARE
Programme UK

12. List of Appendicies

The following appendices are available online at www.betterconversations.org.uk.

www.betterconversations.org.uk