Appendix O
Lessons Learned

1. Adapting the Serious Illness Conversation Guide for Use in the UK	
1.1	Clinicians, patients and public representatives welcomed the Serious Illness Care Programme UK and highlighted its potential to improve communication and care planning for patients with a serious illness.
1.2	The Serious Illness Conversation Guide language translates well to the UK with minimal adaptation.
1.3	Patient and public representatives endorsed the likely utility of the Serious Illness Conversation Guide in initiating and sustaining dialogue between clinicians and patients about the latter's hopes and wishes for future care.
1.4	Clinicians, patients and public representatives recommended further research to establish an evidence base around the implementation and impact of the Programme.
2. Implementation	
2.1	A comprehensive implementation team should include the following key roles: executive member, clinical lead, project manager, communication lead, data manager, administrative manager, and patient and carer.
2.2	Early recruitment of Implementation Team members, including a Data Manager and Project Manager, aids implementation.
2.3	Implementation Team members require protected time in their job plans to allow successful role fulfillment.
2.4	Project Managers and Data Managers may need support, in addition to the detailed Gantt charts and projects plans provided, to clearly understand the timelines and content for some outputs required e.g. future planning, design of workflows, tailoring the electronic healthcare system. This should be supported by effective site project management.
2.5	Early site visits from the central team aids implementation, facilitates discussion and encourages recruitment.
2.6	Implementation Teams should hold monthly minuted meetings and include a central UK team member by telephone or in person.
2.7	Readiness assessment provides a focus for the site Implementation Team.
2.8	Weekly contact between site leads and the central team throughout the implementation are essential.
2.9	GPs are typically well-compensated for additional or unusual work. Engagement and drivers for uptake should be reviewed in Phase 1.

2.10	Information provided to interested sites should be comprehensive, including requirements for all phases of the Programme.
2.11	Early engagement of clinicians in relation to clinical workflows aids integration of the Programme
2.12	Inconsistent coding limits effective patient screening.
2.13	Primary care sites require less frequent screening reports compared to secondary or tertiary care sites, due to the limited number of patients with a serious illness.
2.14	Project Managers require a clear plan and timeline for project outputs.
2.15	Future primary care pilots may be better started in summer months to avoid winter pressures. Locum cover should be considered for clinicians with heavy caseloads.
2.16	All systems should be checked before starting clinician training i.e. alerts, report generation, linkage of templates to the clinical trees.
2.17	Identification algorithms miss seriously ill patients, so ad hoc patient identification should be encouraged.
2.18	Expansion and sustainability planning should start early. Sites should be encouraged to have a forward vision.
2.19	Funding streams that can support expansion should be identified as early as possible.
2.20	Shared learning between participating sites is a key component of the Programme. Innovative and effective ways of sharing learning should be encouraged
2.21	Participating sites should be expected to join the national UK Programme for ongoing Quality Assurance.
3. Monitoring and Evaluation	
3.1	Consistency of reporting and screening depends upon appropriately high level administrative rights to implement and maintain protocols across multiple sites. Involvement of personnel locally with high level multisite access would make ongoing EHR processes and changes easier to manage e.g. support from CSU although this would require resource.
3.2	Some sites within a locality were reluctant to give the Data Manager access to their electronic system. This requirement is crucial for the project. Sites should be selected on clear infrastructure and ability to engage and work on the pilot.

3.3	The EDGE system and infrastructure is governance based, linked to reports on project outputs and management by the central team. It is important that there is acknowledgement and engagement at all participating sites that the data supplied is available for full evaluation of the project.
3.4	Local site teams and Data Managers should understand how to use the patient tracker system and be able to utilise the option of direct entry to EDGE to reduce workload.
3.5	The EDGE system is the project reporting system for implementation of the UK Programme. It gathers the information to support the outputs which are predetermined. It is important that sites can report on all of the project fields.
3.6	Refresher training on the use of EDGE may be required during implementation for some sites.
3.7	Non-clinical, non-practice staff were required to access patient records on the electronic healthcare system. Process planning needs to include consideration of this for future sites and all selected sites must be able to support this
3.8	IT Managers/ Practice Managers/administrative staff should be engaged as early as possible. Their support is essential for encouraging clinicians to continue with conversations, and other ad hoc tasks.
3.9	The IT skills of staff in practices/organisations may vary. When registering for the Programme, sites should be responsible for the skill set of their teams.
3.10	There were essentially two research streams - evaluation at GP sites and the feasibility study within CCC. This caused a delay in application for REC approval, which was made in September rather that July. REC approval was given in November 2016. The number of evaluation streams should be considered with care.
3.11	The evaluation process aimed to be set up before clinicians started having serious illness conversations with patients. Due to delay in the HRA approval process which was outside the control of the central team, patients were not asked to consent to the evaluation for the first 3 months. Sites were unable to include the early conversations and this meant a reduced evaluation pool.
3.12	All participating sites need to: agree to engage in research/evaluation; understand the demands required and have the capabilities to participate. Patient evaluation may be delayed without satisfactory completion and return of documentation

3.13	The reporting system by definition must be anonymised. The project protocol and the EDGE system can facilitate this requirement.
3.14	Sites were given training and trackers to match patient evaluations, and back flow charts were developed which were REC approved. This process must be blinded to the GPs for full impartiality. It is important that sites can adhere to this process.
3.15	Involving patients too often, or for too long would not be appropriate. Built in and ongoing feedback should be favored rather than in depth feedback from a few. The pilot implementation at pace allowed for patients to be contacted once for the evaluation.
4. Technology Expertise	
4.1	Early involvement of local IT expertise is essential.
4.2	There should be early engagement with those who need to approve the new EHR module. An invitation to the training day may be helpful.
4.3	Systems must be set up in advance of clinician training. It is important to have a "dry run" using all IT systems in advance of the Go Live date.
4.4	Data Managers need access to the systems in different practices. Getting permission can take time.
4.5	VPN access is complicated due to multiple agencies involved and local firewalls.
4.6	Training and support post-training, for Data Managers and other key people in the organisation is important e.g. practice managers, secretaries etc.
4.7	The Programme website should have a demonstration video with clear signposting to additional help and support.
4.8	If there are multiple primary care practices within one locality, this can lead to disparate data and tracking. All practices within one locality should be using the same electronic healthcare system.
5. Electronic Health Record Module	
5.1	SystmOne does not permit a search for any patient who has been offered a conversation but has since died. This has to be done manually, meaning EDGE data may not be complete. There is potential to send an evaluation form to a patient who had died although this did not happen during the pilot. This risk is reviewed by the REC and mitigated by patient selection for the conversation.
5.2	It is important that participating sites are able to align EHR system changes for implementation and evaluation.

5.3	Deceased patient records are treated differently on SystmOne and do not appear in searches and reports and the record cannot be accessed for further data. A bespoke report will be required.
5.4	Small changes to the template on SystmOne meant that it created a second version of the template and then did not allow reports to be run on the first version. For SystmOne - ensure short cut link from clinical tree.
5.5	SystmOne does have an off-line mobile working option including the questionnaire which means a paper version isn't required. However the questionnaire can be printed from SystmOne for completion off site.
5.6	The template should be linked to clinical letter generation as this will aid communication.
5.7	The template should be linked to other local Advance Care Planning documents.
5.8	The search function on SystmOne should be enabled for all patients who have had a serious illness conversation.
5.9	Clinicians should be reminded that they need to finalise the conversations on the template before it can be viewed. Alternatively the template should be built so that it is viewable prior to finalisation.(SystmOne)
5.10	Changing the version of the questionnaire template will affect reporting functionality.
5.11	Consistency of reporting and screening depends upon appropriately high level administrative rights to implement and maintain protocols across multiple sites. Involvement of local personnel with high level multisite access is key.
5.12	Methods of access to the electronic healthcare system in use should be considered in advance as there are often local differences. Involvement of personnel with high level and easier access to the system would help in overcoming local differences.
6. Education and Training – Clinician Training	
6.1	Some participants had limited understanding of the UK Programme and implementation plan prior to attending the training. Specific pre-course packs for all participants (clinical and non-clinical) should be made available.
6.2	Support staff, including site team members, had limited understanding of the Programme and their role in supporting it. Future rollout should include support staff in training that is relevant to them.

6.3	The Training Day should include more role play with feedback and more practical implementation tips. Reducing the time allocated to Programme overview and the evidence base may be necessary. This information could be included in the pre-course materials described above. Training should include more time for discussion of practical aspects e.g. screening process, using EHR templates.
6.4	Engaging clinicians to initiate conversations is challenging. Consider issuing the Certificate of Training after a clinician has had a minimum number of conversations.
6.5	Some clinicians remain unconfident in having serious illness conversations post-training. Consider offering extra sessions if required. Other options include: opportunities for further practice as part of the coaching framework, observation, peer review, etc. Webinars could also provide information and support post- training.
6.6	Trained clinicians may benefit from peer support. A local or national community of practice should be in place.
7. Coaching	
7.1	It was difficult to engage some clinicians in coaching. Appointments for first coaching sessions could be made at the clinician training .The website should be developed to support the coaching programme.
7.2	Master trainers were geographically remote from some implementation sites. Local coaches would be helpful.
7.3	Need to improve and maintain clinician confidence re having conversations following the training. Consider developing local peer observation as part of the coaching programme.
7.4	Coaching is time consuming and requires on-going commitment. Need to factor time demand of coaching into the business case/ project budget.
8. Training Future Trainers	
8.1	Training trainers too early introduces potential for diminished training quality. The timing of the Training the Trainers course should be linked to clinician training to ensure new trainers are running training days as soon as possible. Ensure that all trainers attend an annual Trainers Meeting.

8.2	Training local trainers can be problematic. If the local implementation is limited (e.g. no ongoing funding/support) there is a greater risk of dilution of knowledge and skill impacting on quality of the training/ programme. Consider a different model of training. It may be more effective and cost efficient to develop a central cohort of UK Trainers rather than isolated local trainers. New trainers should be observed delivering their first training by at least one Master Trainer.
8.3	It is helpful for Trainers to have local knowledge and relationships. If central Master Trainers are used, local champions could be developed to be part of the training team for a specific location which would provide local intelligence and support. If local Trainers are used, they should be trained at the beginning of the roll out and should co-train local clinicians with Master Trainers until they are competent and confident in the role.
9. Funding, Site Selection and Site Description	
9.1	The UK Central team should be involved:- a) in preparing the specification for successful sites b) In the final site selection
9.2	Site selection should consider requirements for increasing the evaluation and understanding of applicability of the UK Programme.
9.3	A clear understanding of how involvement in the Serious Illness Care Programme UK will benefit what is already happening locally is important (e.g. developing new (integrated) models of care; population health management; Sustainability and Transformation Plans; Accountable Care Organisations.
9.4	It is essential to have strong clinical engagement and senior management support for the UK Programme amongst commissioner and provider organisations from the outset.
9.5	Successful sites benefit from:- - a track record of special interest in supporting serious illness care - a desire to change practice
9.6	Participating sites must identify the key personnel with capacity to dedicate to the Programme. There is a particular need for project and data management skills, and ongoing IT support.
9.7	Sites should be encouraged to have a forward plan for implementation and sustainability across a wider footprint following completion of the pilot.

9.8	If implementing in a primary care setting, successful sites should agree to target a specific cohort of clinicians across a small number of practices. This helps to create an informal local support network and can also foster a positive climate of competition. It enables more effective communication between local and central teams and makes it easier to address any challenges that arise during implementation e.g. establishing and modifying workflow, data access/ consent/ IT/ clinical systems issues.
10. Feasibility Study	
10.1	Patients and clinicians are very willing to participate in evaluation.
10.2	Rich qualitative data from both clinicians and patients provided valuable insights about the impact of the Programme and ways to develop implementation.
10.3	The design of the feasibility study is suitable for a larger definitive clinical trial.
10.4	Organisational infrastructure for the Programme must pay specific attention to how and when serious illness conversations happen, and allow clinicians the 'time' and 'space' with which to conduct them.