Appendix D
Monitoring and Evaluation Plan

1. Background and Rationale

We implemented the Serious Illness Care Programme UK across primary and secondary care sites in geographically disparate sites across England. Given the complexity of such an effort and the necessity of consistent data input, we required a robust and user-friendly monitoring and evaluation infrastructure. Members of our Monitoring and Evaluation work stream developed a bespoke EDGE-based [1] system to provide a secure web-based infrastructure to monitor all aspects of Programme implementation. Concurrently, we developed a project risk assessment and mitigation plan to assure delivery of programme components and enhance identification of issues that required further discussion and mitigation by the UK Programme Steering Group.

2. System Design and Infrastructure

We undertook a full review of outputs and reporting metrics in order to define the parameters and data inputs needed to monitor Programme delivery and uptake. This led to the construction of the Data Capture Plan for the sites, describing the process, essential fields to be recorded and full site requirements. We developed a bespoke patient tracker for sites to code patient screening, identification, acceptance by patients, appointment booking, conversation completion and documentation.

Once we had defined the required data, we developed User Specific Requirements for the EDGE system and began an initial programme build. We needed to link participant entry data to a specific site and clinician while maintaining anonymisation of any participant identifiers to the Programme team at CCC. Only programme specific unique alphanumeric identifiers were entered into the EDGE system.

We identified four essential reporting areas:-

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

We built, tested and validated the bespoke system, which enabled the following parameters to be inputted and assessed *via* downloadable reports into Excel spreadsheets:

- ✓ Number of patients screened each month per site
- ✓ Number of patients identified as high risk and therefore eligible for a Serious Illness Care Programme
- ✓ Number of new conversations taking place per clinician per site
- ✓ Number of follow-up conversations taking place per clinician per site
- ✓ Number of patients that declined a conversation per clinician per site

The data allowed for real-time progress monitoring and flagging in the event of low participation rates from trained GPs and clinicians or evidence of implementation delay. The following information could be recorded into the system:

- ✓ Date patient identified as high risk
- ✓ Date of initial conversation or date patient declined

- ✓ Date conversation recorded in the electronic health records
- ✓ Date of follow-up conversation or date patient declined follow-up conversation
- ✓ Date of patient death.

The patient evaluation was also tracked using the EDGE system:

- ✓ Patient consented to take part in the evaluation (enabling the number of patients consented versus number of patients having the conversation to be evaluated).

The system design also enabled tracking of the following:

- ✓ Number of patients where consent was requested
- ✓ Number of patients who gave consent to take part in the survey
- ✓ Number of patients declined
- ✓ Number of patients completing the survey
- ✓ Number of patients withdrawing
- ✓ Number of patients who did not return the survey but did not withdraw

We produced and delivered instructions in the use of the EDGE system to involved staff.

3. Evaluation

3.1 Baseline review

Each of the three pilot sites completed a baseline review to determine current practice for benchmarking against the Programme following implementation. We used Excel spreadsheets to standardise reporting across practices and sites. Information was anonymised to the Programme Teams. The following information was captured and analysed at CCC.

- Demographics.
- Prognosis and understanding.
- Patient focused goals of care discussion.
- Care related to treatment.
- Any tools used by the Clinician/ GP.

3.2. Patient Evaluation at GP sites

A Patient Evaluation Survey was adapted from one used by Ariadne Labs. The Health Research Authority (HRA) [2] and Research Ethics Committee approved a research protocol and related consent documents.[3] All aspects of the process, from patient approach to informed consent, survey completion and returns were mapped through the EDGE system.

4. Summary

The Monitoring and Evaluation work stream established governance procedures and defined process and outcome metrics. It developed a plan for data capture and procedures to measure progress against the metrics and to evaluate the Programme. We used a risk assessment and mitigation document as a reference to assure implementation at pace under governance. The infrastructure and EDGE-based data system is flexible and ready for further configuration to support future Programme expansion

5. References

1. University of Southampton .EDGE [Internet] [Updated 2017; cited 2017 Sept 18]. Available from: http://www.edgeclinical.com/.
2. NHS Health Research Authority. HRA Approval. [Internet] No date. [cited 2017 Sept 18]. Available from: http://www.hra.nhs.uk/about-the-

hra/our-plans-and-projects/assessment-approval/

3. NHS Health Research Authority. Research Ethics Committee. [Internet] No date. [cited 2017 Sept 18] Available from: http://www.hra.nhs.uk/research-community/applying-for-approvals/research-ethics-committee/