

Appendix M Feasibility Study Measures

1. Objective

To assess the acceptability and feasibility of the Serious Illness Care Programme UK (the Programme), when implemented within The Clatterbridge Cancer Centre.

2. Specific Aims

2.1 To establish the feasibility of the research design to collect meaningful data on the implementation and experience of the UK Programme:-

- Assess proportion of patients identified as eligible for serious illness conversations that are recruited to the research
- Use data collected to illustrate any indicative improvements in communication and patient outcomes

2.2 To conduct qualitative interviews with patients and clinicians to explore perceptions of engaging in a serious illness conversation using the Guide.

3. Methods

The samples are described in Figure 1.

4. Measures

4.1 Quantitative Data: Clinician Questionnaires

Questionnaires were given to clinicians to complete at two time points: time point 1 (T1) prior to training and time point 2 (T2) following training.

Figure 1 Samples used in Feasibility Study

Clinicians	Inclusion Criteria Consultants Oncologists at The Clatterbridge Cancer Centre who had completed a one day training in the Serious Illness Care Programme, consisting of theory and practice in using the Conversation Guide. Provision of consent to participate in the Feasibility study.
Patients	Inclusion Criteria Patients identified as being suitable for a Serious Illness Conversation (diagnosed with advanced incurable cancer) Able to provide written informed consent.

4.1.1 Pre and Post Measures.

The Self Efficacy in Palliative Care (SEPC) Scale¹

This measure includes 23-items with three theoretically distinct subscales assessing perceived self-efficacy in:

- communication (eight items)
- patient management (eight items)
- multidisciplinary teamwork (seven items)

Only the eight item 'communication' subscale was used as these align most closely with the aims and objectives of this study.

Thanatophobia Scale²

This measure is a seven-item scale designed to assess the attitudes of health care

professionals towards caring for dying patients.

4.1.2 Post Measures (only completed at T2 - post training).

Clinician Acceptability

This study specific questionnaire has been used in previous studies of the Serious Illness Care Programme in the US. It asks clinicians to recall the last conversation had using the Guide and rate their agreement against nine items relating to how well the Guide enabled them to have a 'better' conversation with their patient. Each item is scored using a Likert scale ranging from '1' ('strongly disagree' or 'not at all') to '5' ('strongly agree' or 'a great deal').

4.2Q Quantitative Data: Patient Questionnaires

Questionnaires were given to patients to complete at two distinct time points: time point 1 (T1) - prior to a serious illness conversation supported by the UK Programme and time point 2 (T2) - within two weeks following the conversation.

4.2.1 Pre and Post Measures.

Quality of Life: Qual-E³

This measure assesses the quality of life for patients with a serious illness. It is structured into four domains (symptom impact; relationship with healthcare provider and preparation for end of life (concerns about loved ones) to measure the 'quality of life at the end of life'. The instrument includes 20 individual items, four subscale importance ratings, and one overall quality of life question. It exhibits sound psychometric properties and has demonstrated acceptability in patients with advanced cancer. It is designed for

application in palliative care, hospice or conventional medical settings.

Although all subscales within Qual-E are potentially sensitive to the intervention, the '*relationship with health care provider*' subscale includes items that directly link to the purpose and objective of the conversations supported by the Guide, such as; participating in decisions about care; knowing what to expect about the course of illness; knowing where to get answers; feeling control over treatment decisions and feeling known as a whole person.

Generalised Anxiety Disorder Assessment (GAD-7)⁴ is a seven-item self-administered patient questionnaire used as a screening tool and severity measure for generalised anxiety disorder, normally used in outpatient and primary care settings. Scores range from '0' (not at all) to '3' (nearly every day) to reflect the impact of various symptoms of anxiety.

PHQ-9 depression scale^{5,6} is an instrument for making criteria-based diagnoses of depressive and other mental disorders commonly encountered in primary care. The diagnostic validity of the PHQ has been established in two studies.^{5,6} For this study the PHQ-9, a nine-item depression module from the full PHQ, will be used. The PHQ-9 is half the length of many other depression measures and has comparable sensitivity and specificity. Scores of '0' (not at all) and '3' (every day) reflect the impact of various symptoms of depression.

4.2.2 Post Measures (only completed by patients at T2 following a serious illness conversation with their clinician).

Quality of Communication questionnaire (QOC)⁷ assesses patient satisfaction with

the quality of clinician communication about end-of-life care.

Patient Evaluation Questionnaire is a questionnaire developed for use in this study. It is designed to gather information on patient satisfaction with the serious illness conversation and the confidence they have in their clinician.

The administration of the pre and post measurement tools for clinicians and patients is summarised in Table 1.

4.3 Qualitative Data: In-depth Narrative Interviews

Qualitative Interviews were undertaken with patients and clinicians to explore their experience of engaging in conversations supported by use of the Guide. Clinician interviews occurred within two months of training. Patient interviews took place within two months of the serious illness conversation with their clinician.

A phenomenological approach was adopted to facilitate the production of ‘rich’ data regarding the ‘lived experience’ of engaging with the Serious Illness Care Programme.⁸ Patients and clinicians were recruited to participate in a one-off narrative interview, which promoted a ‘conversational’ style.^{9, 10} The interviews explored the thoughts and feelings engendered by participation in the serious illness conversation, and gauged the emotional impact, particularly for patients involved.

5. References

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Table 1 Administration of Measurement Tools for Clinicians and Patients		
Tool	Pre Conversation (T1)	Two weeks post conversation (T2)
Patients		
Qual-E	✓	✓
Generalised Anxiety Disorder Assessment (GAD-7)	✓	✓
PHQ-9 depression scale	✓	✓
Quality of Conversation scale (QOC)		✓
Patient Evaluation Questionnaire		✓
CLINICIANS	Pre training	Post training (following first conversation using Guide)
Clinician Acceptability		✓
Self-Efficacy in Palliative Care (SEPC)	✓	✓
Thanatophobia Scale	✓	✓