

# Serious Illness Care Programme UK: Implementation of a communication model for patients with advanced cancer, a feasibility study.

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## Background

Improving the way in which clinicians initiate and engage in important conversations with patients with serious illness and their families is imperative.<sup>1</sup> The Serious Illness Care Programme (the programme), developed in the US by Ariadne Labs<sup>2</sup>, is a 'systems wide' complex intervention to support communication and individualised care planning, between clinicians and patients with serious illness. In collaboration with Ariadne Labs the programme has been developed for use within the UK, with pilot implementation funded by NHS England. Within the programme, clinicians are trained in use of a Serious Illness Conversation Guide (the guide), to structure conversations with patients/families.

A feasibility of the UK programme is underway, within one North West cancer centre.

## Aim

Assess the acceptability and feasibility of the Serious Illness Care Programme UK when implemented within one cancer centre within the North West of England.

## Methods

Data on the use and experience of the UK programme, from the perspective of clinicians and patients

### Quantitative Data: Questionnaires:

Clinicians - pre/post training: 1) Self Efficacy in Palliative Care; 2) Thanatophobia Scale; 3) acceptability of serious illness care programme and training

Patients - pre/post serious illness conversation: 1) Quality of clinical communication; 2) Quality of life at the end of life questionnaire 3) Anxiety scale; 4) depression scale.

### Qualitative Data: In depth interviews:

Clinicians: experience of the UK programme, education and training and engaging patients in serious illness conversations

Patients: experience of engaging in serious illness conversations, including their acceptability of the approach

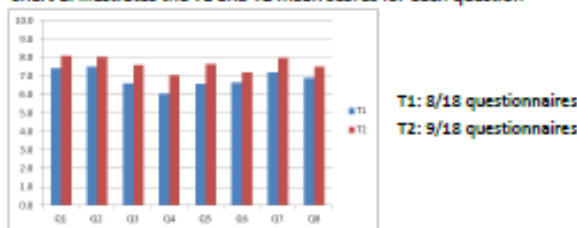
## Results

### Quantitative Data: Clinicians

Overall 50% (9/18) of clinicians returned at least 1 questionnaire Pre and Post training in the Serious Illness Care Programme

### Self Efficacy in Palliative Care

Chart 1: illustrates the T1 and T2 mean scores for each question



Encouragingly, clinician confidence was rated higher at T2 for all questions on confidence around caring for palliative care patients.

### Thanatophobia Scale

Table 1: Thanatophobia Scores

Statement	T1	T2
7) participants assessed at T1, 8 participants at T2	% Strongly Disagree/Disagree (score 1 or 2)	
1. Dying patients make me feel uneasy	43%	50%
2. I feel nervous when talking to dying patients	33%	38%
3. It is frustrating to have to continue talking with relatives of patients who are not going to get better	40%	30%
4. Managing dying patients' families is too	20%	30%
5. It makes me uncomfortable when a dying patient wants to say goodbye to me	43%	63%
6. I don't look forward to being the personal physician of a dying patient	57%	20%
7. When patients begin to discuss death, I feel uncomfortable	33%	30%

T1: 7/18 questionnaires  
T2: 8/18 questionnaires

- Overall, the greatest positive shift was found for statement 2, which rose by 29 points to 88% at T2.
- It is encouraging that majority of statements saw an increase in positive scores between T1 and T2.

## Results (cont.)

### Acceptability of Serious Illness Care Programme and Training

(n=7 clinicians who had conversations)

- 100% said it made their patient's emotional state 'Much Better/Better';
- Over two thirds (71.4%, n=5) felt discussing the issues within the guide 'Increased/Greatly Increased' satisfaction with their role in their patient's care;
- Anxiety about having these discussions was made 'Much Better/Better' through use of the guide (71.4%, n=5)

### Quantitative Data: Patients

22 patients approached to take part 45% have gone on to complete study measures at T1 (5/22 patients were unable to be contacted)

10 returned questionnaires at T1; 60% so far returned questionnaires at T2

Table 2: Generalised Anxiety Disorder (GAD-7); Depression Scale (PHQ-9)

GAD-7 Scores	T1		T2	
	n	%	n	%
0-4 (none to mild)	2	20%	2	20%
5-6 (moderate)	1	10%	1	10%
7-9 (moderate to severe)	7	70%	8	80%
Mean Score	5.5		5.5	

- Majority of patients scored between 0-4 (90%, n=9) at T1 on the GAD-7, indicating 'no general anxiety'.
- 1 patient increased their GAD-7 at T2, from 1 to 2. This still illustrates very low levels of general anxiety
- 50% (5) indicated no depression at T1. The remaining 5 had a range of scores from 'mild' to 'severe'.

- All patients decreased in depression severity. The majority (83%, n=5) now scored between 0 and 3 ('none')

### Quality of Life at the End of Life (QUAL-E) Scale

- Majority rated 'overall quality of life' as 'good/excellent' at T1 and T2 (T1 80%; T2 77%); which perhaps reflects the aim of the programme to identify patients where active treatment may not be aim, but the patient is 'stable'.

### Quality of Communication / Patient Evaluation Questionnaire

- An Overall mean score of 8.6 (10 'absolutely perfect') for 'quality of communication' indicates that patients rated the skill of participating clinicians very highly for this conversation
- 100% (6) found it 'Very Worthwhile' to talk to their clinician about these issues
- 83.3% (5) stated that 'Worries about your illness' decreased a little/a lot after the conversation

### Qualitative Interviews—Patients

- Patients overwhelmingly valued the conversation and the attention to their 'holistic' needs, rather than just talking about their diagnosis and treatment;
- Knowing that the clinician was using the guide was identified by some to be a signifier of 'good care' – that the clinician was 'doing their best' to make sure they covered everything that was important;
- Some described feeling like the 'door was opened' to have conversations with their loved ones, where they may not have had these conversations before;
- Talking about limited prognosis proved a challenge for some: many patients stated they 'still felt well' and that perhaps they may react 'differently' to the conversation should they become 'less well'.

## Conclusion

Interim results show positive results for the feasibility study, both for the acceptability of the serious illness care programme and the ability to collect meaningful data on the use and experience of the programme. Patients found the conversation to be beneficial, and for some this provided a 'line in the sand' to ensure that everyone was on the same page. Opening up wider conversations with family members is also a prominent theme from these interim results. Further data collection and in depth analysis is ongoing, and will be reported into the next financial year.

## References

- Gawande A (2014) *Being Mortal: Medicine and What Matters in the End*. Profile Books: London
- Bernacki R et al (2015) Development of the Serious Illness Care Program: a randomized controlled trial of a palliative care communication intervention. *BMJ Open* 5(10): e009002. doi:10.1136/bmjopen-2015-009002

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