

Serious Illness Care Programme UK: assessing the ‘face validity’ and acceptability of a Serious Illness Conversation Guide

McGlinchey T¹, Mason S¹, Coackley A², Maguire M², Roberts A¹, Maloney F³, Sanders J³, Paladino J³, Block S³, Kirkbride P², Ellershaw JE¹

¹Marie Curie Palliative Care Institute Liverpool, University of Liverpool, ²Clatterbridge Cancer Centre NHS Foundation Trust,

³Ariadne Labs, Brigham and Women’s Hospital, and Harvard T.H. Chan School of Public Health, Boston, Massachusetts

Background

Improving the way in which clinicians initiate and engage in important conversations with patients with serious illness and their families is an imperative.¹ The Serious Illness Care Programme (‘the programme’) is a multi-component, systems-based intervention developed by Ariadne Labs in the United States (U.S.) to improve the care of all persons with serious illness². It employs clinical tools, training programmes, and workflow innovations to promote shared decision making regarding future care and treatment between clinicians and patients through timely high quality communication. The Serious Illness Conversation Guide (‘the guide’) is the evidence-based ‘clinical tool’ used to structure clinician led conversations. Preliminary work in the U.S. Demonstrates positive impacts of the intervention on the frequency, timeliness, and quality of conversations with seriously ill patients, as well as their positive impact on patients and families.

NHS England has funded a pilot implementation of the programme within the UK. Prior to the pilot, work was undertaken to adapt the programme to the UK setting, including a qualitative research project to assess the ‘face validity’ of the guide for a UK context.

Aims

- Examine ‘face validity’ & acceptability of the guide within the UK from the ‘user’ perspective: Patient Public Representatives; Clinicians
- Develop Serious Illness Conversation Guide UK

Methods

Method	Sample	Objectives
Step 1: Nominal Group Meeting ^{3,4} Expert Group Consensus Meeting	14 participants in 3 ‘expert’ groups: 1. 5 Oncology Consultants 2. 4 Palliative Care Experts – 3 Consultants, 1 Palliative Care Specialist Trainee 3. 5 Communication Skills Experts	<ul style="list-style-type: none"> • Review the guide; recommendations for improvements • Consensus; whether the guide could be used in the UK.
Step 2: Cognitive Interviews ^{5,6} - ‘Think Aloud’ Technique ⁷ Explore how respondents answer prompts within the guide	6 patient and public representatives recruited from a North West Cancer Centre	<ul style="list-style-type: none"> • Understand how respondents perceive and interpret prompts in the guide • Assess format, context and language

Results

Nominal Group

14 participants were in attendance, and consensus was gained: the guide would provide support for clinicians to initiate difficult conversations. Minimal amendments were suggested. Overall findings centred on the following:



- Robust programme of education and training is key
- Continued training and support throughout the implementation period;
- Systems innovations essential to underpin use of the guide and support clinicians to have conversations with their patients.

Cognitive Interviews



- The views and perceptions of 6 patient and public representatives were sought;
- Thematic analysis was undertaken, using the “substance of the interview” to generate key themes, to interpret

Led by:

Results (cont.)

- Overall concept: standardised approach to communication, was valued by all; Use of the programme promotes a ‘partnership’ approach to care planning:

“...it starts a conversation...” (P1)

“it’s a partnership...I suppose the doctor...is wanting to see what it is the patient is concerned about...” (P1)

- ‘Formality’ of some words/phrases a concern for some, particularly use of the word ‘goal’. Participants worried this could hinder rapport and the ‘natural’ and ‘personal’ feel of the conversation:

“goal is a funny word isn’t it...it’s not a goal, no I don’t like goal...not quite the right word...it doesn’t have a feeling of wanting to see my first grandchild, that’s not a goal...” (P5)

- Attention to the patients ‘holistic’ needs as an individual, rather than exclusively focussing on their ‘disease’ was valued:

“It’s seeing the person as an individual and that they’ve got a life”. (P2)

- Education and training key; concerns use of the guide has the potential to create an artificial ‘interview’ situation, highlighting use of the guide must enable flexibility:

“...I think sometimes using these words just makes it sound like a formal interview...you need to...be able to put the patient into a situation where they feel comfortable to...open up with their concerns”. (P1)

- All participants agreed the final phrase in the guide, “we’re in this together”, could undermine the patient centred aim: consensus that this prompt be removed:

“you’re not actually in it together...you’re not, I mean yes put some comforting words there but...we’re in it together is hardly comforting, when you know it’s not true.” (P5)

Conclusion and Future Work

Both clinicians and patient representatives felt the guide would aid communication, and the systems-wide approach was valued by all. Small amendments to the guide were identified and 5/11 prompts were changed. A revised guide for the UK has now been developed.

Future Work

NHS England has funded a National pilot to implement the UK programme at three NHS sites. Exploratory research is underway in one North West cancer centre, to assess the implementation and use of the UK programme ahead of further roll out. Future plans include research protocols to investigate feasibility of the implementation and use of the UK programme, in order to guide wider use and roll out.

References

1. Gawande A (2014) Being Mortal: Medicine and What Matters in the End. Profile Books: London
2. Bernacki R et al (2015) Development of the Serious Illness Care Program: a randomised controlled trial of a palliative care communication intervention. *BMJ Open* 5(10): 5:e009032. doi:10.1136/bmjopen-2015-009032
3. Delbecq AL and Van de Ven AH (1971) A Group Process Model for Problem Identification and Program Planning. *Journal of Applied Behavioural Science*. 7: 466
4. Delbecq A L, Van de Ven A H and Gustafson D H (1975) Group techniques for program planning: a guide to nominal group and Delphi processes. Glenview, Illinois: Scott Foresman and Company.
5. Campanelli P (1997) Testing Survey Questions: New Directions in Cognitive Interviewing. *Bulletin de Méthodologie Sociologique* 55(1):5-17
6. Presser S et al (2004) Methods for Testing and Evaluating Survey Questions. *Public Opinion Quarterly* 68(1): p. 109-130
7. Czaja R (1998) Questionnaire pre-testing comes of age. *Marketing Bulletin* 9: 52–66
8. Oliver DG, Serovich JM, Mason TL (2005) Constraints and Opportunities with Interview Transcription: Towards Reflection in Qualitative Research. *Social Forces* 84(2): 1273-1289

