Serious Illness Care Programme UK: Assessing the 'face validity' and acceptability of the Serious Illness Conversation Guide for use within the UK health care setting.

SERIOUS ILLNESS CARE Programme UK

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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 an imperative. 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 achieve these outcomes. The Serious Illness Conversation Guide ("the guide") is an evidence-based clinical tool to improve the quality of clinician-led conversations, promoting shared decision making and future care planning. 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 project to assess the 'face validity' of the guide for a UK context.

## Aims

- Establish face validity and acceptability of the serious illness conversation guide for use within the UK
- Incorporate any suggestions for amendments into a UK version of the Serious Illness Conversation Guide

### Methods

Nominal Group Meeting<sup>3,4</sup> Sample: three 'expert' groups:

 5 Oncologists, 5 Communication Skills experts, 4 Palliative Care specialists



The objectives of the meeting were to:

- Review the guide; recommendations for improvements
- Reach consensus as to whether the guide could be used in the

Cognitive Interviews<sup>5,6</sup> - 'Think Aloud' Technique<sup>1</sup> Sample: 6 patient and public representatives: Objectives:

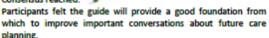


- Understand how respondents perceive and interpret prompts in the guide
- Assess format, context and language.

# Results

Nominal Group

Consensus reached:



Participants felt it was important to wait for the findings from the patient and public representatives before making improvementations for amendments

## Results (cont.)

Cognitive Interviews

Overall, participants felt the guide was a useful 'conversation piece', empowering the patient to think about, and talk through, what is most important to them in regards to their future care:

"...as a conversation piece...I think it's ok..."

"...it starts a conversation..."

Participants valued the attention to the patients 'holistic' needs as an individual, rather than

exclusively focussing on their 'disease':

"It's seeing the person as an individual and that they've got a life"

Participants highlighted a concern that the conversation could create an artificial 'interview' situation, highlighting clinicians should be able to 'adapt' the language and format to be more responsive:

> "... 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".

One major recommendation from the both cognitive interviews and the Nominal Group, was; it is imperative clinicians can integrate the prompts within the guide into a 'natural' conversation.

### Conclusion

In response to the findings from this project, 5/13 prompts were amended. Results from this study suggest the guide (UK version) study to the suggest the guide (UK version) further research regarding its use should be undertaken as part of a feasibility study prior to



recommendation for roll out to further sites. Research is now underway to explore the 'user experience' of the guide in practice, including both qualitative and quantitative research methods.

## References

- Gawande A (2014) Being Mortal: Medicine and What Matters in the End. Profile Books: London
- Bernadd R et al (2015) Development of the Serious lineus Care Program: a randomised controlled trial of a pallistive care communication intervention. BMJ Open 5(10): 5xx009032. doi:10.1136/bmjopen-2015-009032
- 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 Delph processes. Glenview, Illinois: Scott Foresman and Company.
- Campanelli P (1997) Testing Survey Questions: New Directions in Cognitive Interviewing. Bulletin de Méthodologie Sociologique 55(1):5-17
- 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

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