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Example 4: Decision making about implantation of cardioverter defibrillators (ICDs) and deactivation during end of life care

About the research

Lead researcher: Professor Richard Thomson, Newcastle University.

Funder: National Institute for Health Research (NIHR) Health Services and Delivery Research (HS&DR) Programme.

Project aim: To explore the views of patients, family members and clinicians around making decisions about both implantation of cardioverter defibrillators[1] (ICDs) and deactivation at the end of life. The aim is to improve the information and support given to patients and increase their participation in making these decisions.

Type of research: Clinical research.

Duration: Two years - started May 2013.

Who we spoke to

We interviewed Dr Kerry Joyce, a Senior Research Associate working on the project. Her comments are in blue below.

About the involvement

How patients influenced the research question

The research team submitted three separate grant applications before this study was funded. The third and final version included recommendations from an experienced carer which changed the focus of the project and ensured the research question directly addressed patients' needs.

> "The first two applications focused solely on decision making around implantation of ICDs. They were rejected. Some of the feedback said this was not an area of significant interest or patient need. We took this on board and at

[1] An ICD is a small device which can treat people with dangerously abnormal heart rhythms (from British Heart Foundation website accessed 16/10/13) www.bhf.org.uk/heart-health/treatment/implantable-cardioverter-defib.aspx

> the suggestion of one of the cardiologists on our team contacted Trudie Lobban MBE, founder and trustee of the patient organisation, Arrhythmia Alliance (the Heart Rhythm Charity).
>
> Trudie helped us think through the most important issues for patients and family members. She encouraged us to change the focus of the study to cover decisions around deactivation as well as implantation. She raised the issue of the timing of these decisions, explaining that patients want to talk about deactivation in advance. This way deactivation is addressed as a hypothetical scenario rather than leaving it until the end of life, when it's an emergency situation. If left until then it is often the family / carers who are faced with making the decision rather than the patient themselves causing even more distress at an extremely emotional time. If we hadn't changed the focus of the study, we may not have got funded. ” **Kerry**

Patient / carer involvement prior to applying for funding

Trudie became a member of the grant writing team and contributed to drafting the funding application in the same way as other team members. In recognition of Trudie's important contributions, she became a co-applicant on the grant.

Trudie was offered payment for her time spent in telephone meetings and reading drafts of the grant application. However she did not take up this offer. She was already working in a paid role in the charity.

Impact of the early involvement

Trudie's involvement at the early stages ensured the project was **relevant and meaningful** to patients. This reassured the researchers that their work was genuinely worthwhile.

Her contributions to the grant application **strengthened the patient voice** throughout.

> “ The final application was stronger as a result, as Trudie was able to advise on how to incorporate the patients' views and to emphasise the potential for patient benefit. Specifically she helped write the lay summary and sections on patient and service need. ” **Kerry**

Continuation of involvement following funding

Trudie has joined the Advisory Group for the project along with another representative from her organisation.

Lessons learnt

> “ It's about having a conversation at the outset. If we had engaged Trudie when we were putting the first grant application together then we might have saved a lot of time and effort, and got it right at the beginning.
>
> It takes time to establish relationships, to get beyond the superficial to really identify what's important. It's about having ongoing conversations and

establishing a dialogue, not just emailing a draft and saying 'What do you think about this?' You also have to listen to people's comments and remain open, not being blinded by what you think as a researcher. ”**Kerry**

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References:

Joyce, K.E, Lord S, Matlock DD, McComb JM, Thomson R. Incorporating the patient perspective: a critical review of clinical practice guidelines for implantable cardioverter defibrillator therapy. J Interv Card Electrophysiol. 2013; 36(2):185-97.

This example is one of a series of examples of public involvement in research funding applications. To find out more and view the other **examples**

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planning a meeting of members of the public
INVOLVE Briefing note eight: Getting started

Costing and budgeting for public involvement in your study
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Reference: INVOLVE (2013) Examples of public involvement in research funding applications: Decision making about implantation of cardioverter defibrillators (ICDs) and deactivation during end of life care