

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

Principal Investigator: Prof Richard Thomson

Co-applicants: Prof Catherine Exley, Dr Stephen Lord, Dr Janet McComb, Prof Julian Hughes, Mrs Trudie Lobban

Workshop Organisers:

Darren Flynn, Practitioner Health Psychologist and Senior Research Associate

Holly Standing, Research Assistant

Lavinia Miceli, Project Secretary

3rd November 2015

What are we aiming to do in this workshop?

1) obtain your expert views on the findings of previous stages of this research study:

- observations of consultations with patients/relatives
- interviews with patients', family members' and doctors, nurses and other healthcare professionals about their views/experiences of decision making about ICD implantation and deactivation (towards end of life)

2) your ideas / expert views on how the findings can be used to support better shared decision-making about ICD implantation and deactivation

What are we aiming to do in this workshop?

1) obtain your expert views on the findings of previous stages of this research study:

- observations of consultations with patients/relatives

- interviews with patients', family members' and doctors, nurses and other healthcare professionals about their views/experiences of decision making about ICD implantation and deactivation (towards end of life)

2) your ideas / expert views on how the findings can be used to support better shared decision-making about ICD implantation and deactivation

What are we aiming to do in this workshop?

1) obtain your expert views on the findings of previous stages of this research study:

- observations of consultations with patients/relatives

- interviews with patients', family members' and doctors, nurses and other healthcare professionals about their views/experiences of decision making about ICD implantation and deactivation (towards end of life)

2) your ideas / expert views on how the findings can be used to support better shared decision-making about ICD implantation and deactivation

Summary of ICD Project

- **2-year research project funded by the NHS**
 - **National Institute for Health Research**
 - *Health Service and Research Development Programme*

Aim: To critically explore patient/relatives and healthcare professional views about, and experiences of:

- cardioverter defibrillator implantation and deactivation (towards end of life)
- how this information can be used to support shared decision-making about ICD implantation and deactivation

Methods: How we did the research

- 1. Observing discussions between patients/relatives and healthcare professionals about ICD implantation and deactivation**
- 2. In-depth interviews with individual:**
 - Patients considering an ICD (who did and did not decide to have an ICD implanted)
 - Relatives of patients with ICDs
 - Doctors, nurses and other healthcare professionals

Who did we interview?

Patient group	Numbers
Patients considering an ICD	13
Patients who decided not to have an ICD (in hospital)	8
Patients with ICDs	18
Patients with ICDs who had experienced psychological problems after implantation	3
Patients who decided to have their ICD deactivated	2
Bereaved relatives	7
TOTAL	51

Clinician group	Numbers
Implanting cardiologists (ICD Implantation Centre)	5
Cardiologists (hospitals)	5
Arrhythmia nurses (ICD Implantation Centre)	1
Heart failure nurses (hospital and community)	6
Cardiac physiologists	4
Health psychologists	2
Palliative (end of life) care doctors / nurses	6
TOTAL	29

What is shared decision making?

Who has experience of making major purchases? buying a car, a house, a holiday, a computer?

- Imagine when you went to make a major purchase the sales assistant said to you:
 - “I have chosen this car, house, holiday, computer for you as I think it is best for you”
- Would you have responded as follows?
 - “OK thanks very much - happy to go with whatever you choose for me as you know best”

- If YES – what might be the consequences?
- If NO – what would you like to say in response? What would you like to know and why?

Making a decision when there is more than one reasonable option, including doing nothing (where appropriate)

- Options have different combinations of:
 - Likely benefits (pros)
 - Likely adverse effects or risks (cons)
 - Different short- and long-term consequences
- *e.g. treatment of early stage prostate cancer, screening for genetic conditions, treating carpal tunnel syndrome*

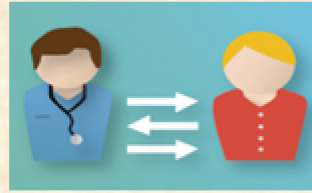
PREFERENCE-SENSITIVE DECISIONS

Ideal for Shared Decision Making!

Shared Decision Making (SDM): The Pinnacle of Patient-Centred Care

Patients and their families are involved as:

- **Active partners** with clinicians
- Meeting of EXPERTS to clarify the patient's personal:



Preference(s) for choice of treatment from the available options

Beliefs/attitudes (values) towards the **trade-offs** between the pros and cons of the available options

- **SDM helps people to make QUALITY decisions**
 - know about the options available to them (informed)
 - know what's important to them (preferences and values)
 - receive treatment consistent with their personal preferences & values

Brief discussion of findings

Implantation of ICDs

Information needs

"There'll come a point where you don't want to overload people with information and then it'll be up to people, somehow, to decide, "I don't want lots of information, give me, I don't know, the bronze information, not the silver or the gold." But I'm a gold one, I want it all 'cause it's going to be important for me. So if you can think of it and you think you should tell your patient, tell your patient. I think there's a, there will be a way to say it that is the right way for everybody. And I know not everybody wants all the information. But I need it from the medical people" (Gwen, CRT-D post-implant)

Information needs

"Perhaps there needs to be a checking of understanding... perhaps that's necessary. Because I'm sure I probably seemed awake and alert and I very quickly realised that, you know... I woke up and thought, you know, "I'm in hospital." I very quickly came, came... But obviously what I now realise that was traumatic for my body obviously and did have these effects that lasted longer than possibly it was obvious that it had done." (Isobel, post-implant, secondary prevention)

"He asked me if I had any questions, my head was too full of other things, about the state of me heart when he showed us the state of me heart, and I said, "no" as I say" (Ross, pre-implant ICD, primary prevention)

Clinician factors

"Dr Oak had a big file there, but that's all he knew of me [Yes]. Where, I mean [heart function nurse]'s seen me since I first came out of coronary care, and she knows the bits that frighten me and that sort of thing". (Bob, pre-implant ICD)

"There comes a case where you're dealing with professionals, it's like any business if you're dealing with a professional, you've got to look at his advice, weigh it up, and in the main, you should go with that professional's advice. After you've done your various... your own checks and balances. Well you must, otherwise you're wasting your time. Why go to a financial adviser if you're going to listen to him and then ignore what he tells you". (Adrian post-implant ICD)

Patient factors

"Yes, things are very different from when you're 83 from when you're 63, you know. I would've had an entirely different outlook if somebody had said, "You've got heart failure" at 63. But at 83 I think, "Well, you know, you've got to go sometime haven't you, you know?" If it's not this it would be something else. I don't want to go. I've got too much to live for. But I, I wouldn't have invasive surgery, you know, I, I've made me mind up." (Emily, pre-implant)

"So I've tried to wait to tell them about driving to the very end of any discussion. That's where I'll say, "No driving", not in the initial discussion. 'Cause if you tell them they can't drive for a year, six months, day one, first thing, that's it, they don't listen to anything else." (Mr Jasmine, physiologist)

Thoughts and reflections
on implantation decisions?

Discussions about
deactivation of ICDs

Timing of discussions

"That that be acknowledged at the time of insertion, that when they come for checks, that they're not just coming for checks of how frequently it's fired and how they're doing. Discuss the relative burdens and risks of having it and how they feel about continuing to have it." (Dr Buckthorn, palliative care clinician)

"And then Nurse Heather - and that's important - we told her that he had an advanced decision - living will - and she read it. And at that moment, she said, "Hang on. You cannot have the defibrillator, if you've made that decision, and the ICD really needs to be turned off, because it-it's a legal document...and if the defibrillator kicks in that prolongs your life." " (Janet, bereaved relative of ICD patient deactivated pre-mortem)

Clinician factors

"It's hard to say cos I think that for any given patient somebody's going to be taking the lead and it's not always clear-cut by role who that should be, so it may either be the GP, it's conceivably a heart failure nurse, it's conceivably a MacMillan nurse or our palliative care service, and I think that's probably right but there will be some situations where cardiologists are leading that, although as people deteriorate and they become housebound, that becomes a bit greyer, but I think what all of those other people need is to be able to access the cardiologists who've discussed if they're thinking of switching it off."

(Dr Mulberry, palliative care)

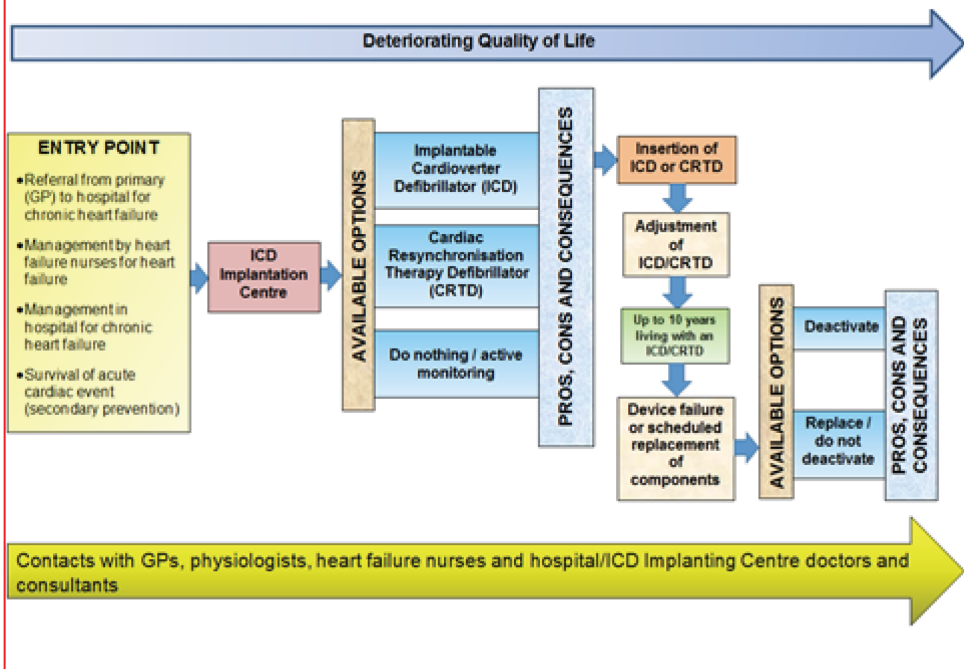
Problems with deactivation discussions

"But with a 10% ejection fraction you just think, really?! What are we going to achieve with this (ICD)? So, in many ways it doesn't surprise me that there's a reluctance to talk about that (deactivation), as with a lot of medicine then often that's kind of seen as a failure of what we've tried to achieve, whereas in palliative medicine we try to embrace it as a natural part of the life death cycle. But I don't know that that's the same view that all clinicians would hold. So yeah it doesn't surprise me that, there's a reluctance to talk about it"

(Dr Echinacea, palliative care)

Thoughts and reflections on
deactivation discussions?

Decision points and opportunities for discussions with patients/relatives about ICDs



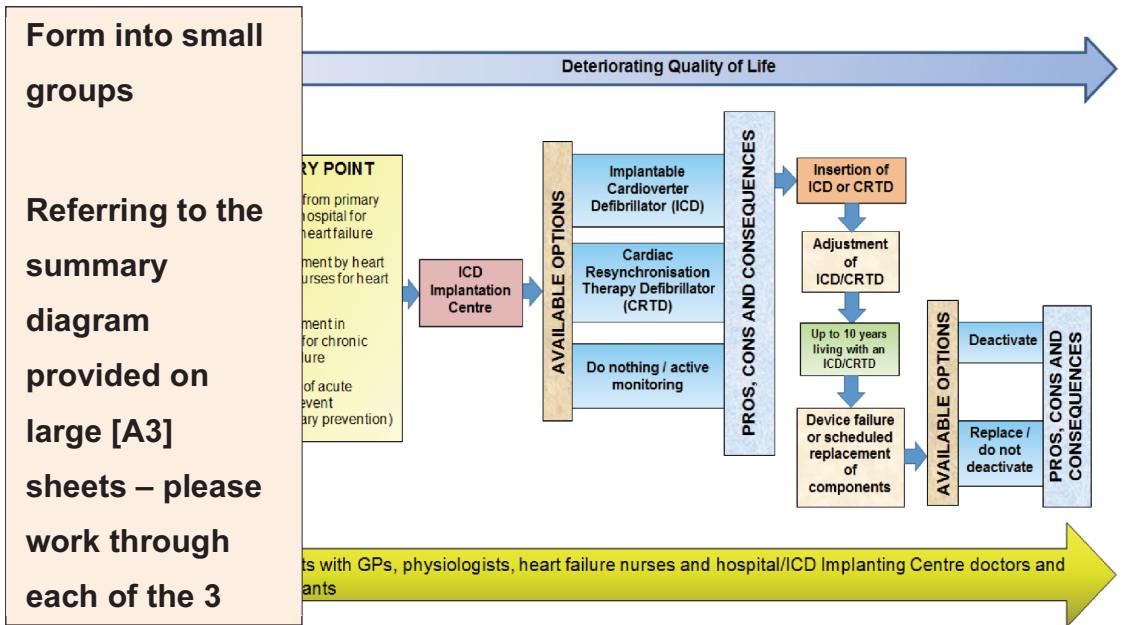
Your ideas / expert views on how the findings can be used to support better shared decision-making about ICD implantation and deactivation

Key issues:

- *What information about options (ICD, CRTD or doing nothing / active monitoring) should be provided to patients/relatives?*
- *Who should discuss the pros and cons of the options (ICD, CRTD or doing nothing / active monitoring) with patients and their relatives?*
- *When should a discussion with patients and their relatives about deactivation of ICDs/CRTDs take place?*

**Please see handout
'Structured Task'**

Structured Task



TASK 1 (15 MINS):

Individually write brief notes that relate to each of the following categories (1 item of information on each post it note)

- What information about the options (ICD, CRTD or doing nothing / active monitoring) should be provided to patients/relatives? **Green post it notes**
- Who should discuss the pros and cons of the options (ICD, CRTD or doing nothing / active monitoring) with patients and their relatives? **Yellow post it notes**
- When should a discussion with patients and their relatives about deactivation of ICDs/CRTDs take place? **Pink post it notes:**

TASK 2 (10 MINUTES)

In your small groups, collate responses for each category (and remove any duplicates) on a large piece of paper

TASK 3 (25 MINUTES)

Group discussion – one or more person from each small group shares the findings of task 2 with the other groups