

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

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### Workshop Facilitators:

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## Workshop Aims

### 1) obtain your views on findings of previous phases of this study:

- observations of ICD consultations across the care pathway
- interviews with patients', family members' and clinicians' about their views/experiences of decision making about ICD implantation and deactivation (towards end of life)

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

<b>Welcome and Introductions</b>	<b>6.40pm</b>
<b>Overview of ICD project and Shared Decision Making</b>	<b>6.45pm</b>
<ul style="list-style-type: none"> <li>• Aims and objectives</li> <li>• Brief overview of SDM</li> <li>• Generic chronic heart failure pathway</li> </ul>	
<b>PPT presentation - summary of findings</b>	<b>6.55pm</b>
<b>Plenary – thoughts and reflections on summary of findings</b>	<b>7.20pm</b>
<b>Small group work</b>	<b>7.40pm</b>
<ul style="list-style-type: none"> <li>• <i>How can patients and their relatives be better supported to make informed 'values-based' decisions about ICD implantation / deactivation in partnership with clinicians?</i></li> </ul>	
<b>Plenary with spokesperson from each group sharing key thoughts/ideas</b>	
<b>Summary and reflections</b>	<b>8.20pm</b>
<b>Close</b>	<b>8.30pm</b>

## Overview of ICD Project and Shared Decision Making

## Overview of ICD Project

- **NIHR Health Service and Research Development Programme**

- HS&DR - 11/2004/29:

**Aim:** To critically explore lay and professional views about, and experiences of, cardioverter defibrillator (ICD) implantation and deactivation (towards end of life) and to examine how this information can be used to support shared decision-making

## Methods

### **1. Observations: Non-participant observation**

- The nature of ICD consultations
- The nature of decision making interactions
- The patient's journey through the care pathway

### **2. Individual in-depth interviews**

- Patients
  - Relatives
  - Clinicians
- Data collection and analysis followed principles of the constant comparison method

Patient group	# interviewed
Pre-implantation (secondary care)	4
Decliners (secondary care)	5
Pre-implantation (tertiary care)	9
Decliners (tertiary care)	3
Post-implantation	18
Post implant (experience of psychological sequelae)	3
Prospective deactivation	2
Bereaved relatives	7
<b>TOTAL</b>	<b>51</b>

Clinician group	# interviewed
Implanting cardiologists (tertiary care)	5
Cardiologists (secondary care)	5
Arrhythmia nurses (tertiary care)	1
Secondary care and community heart failure nurses	6
Cardiac physiologists	4
Health psychologists	2
Palliative care clinicians	6
<b>TOTAL</b>	<b>29</b>

What is shared decision making?

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

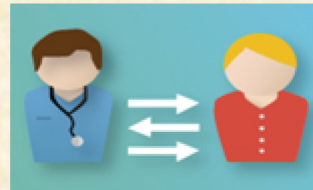
## PREFERENCE-SENSITIVE DECISIONS

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 enables 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

### 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)

Deactivation discussions



## 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

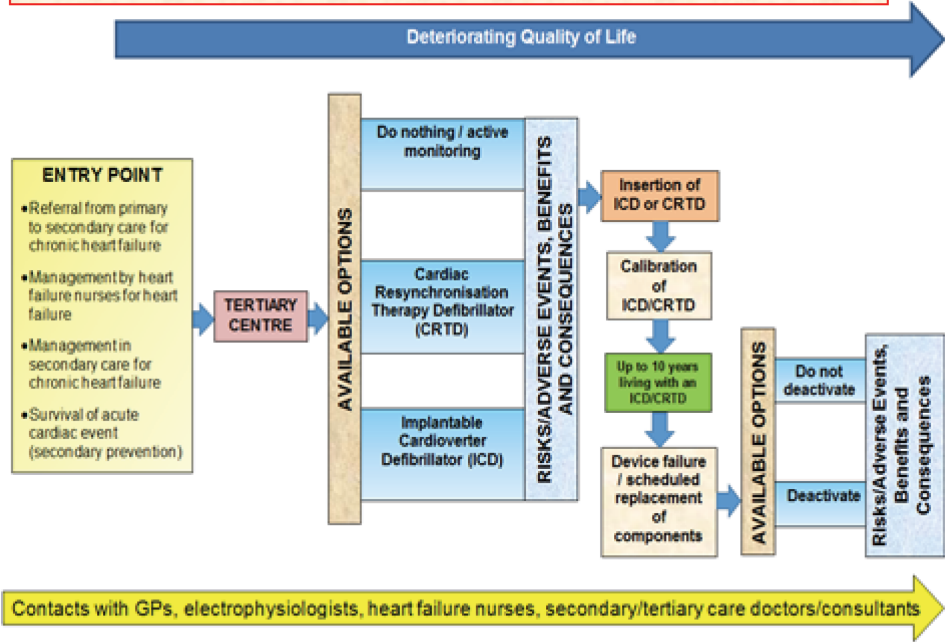
*"But with a 10% ejection fraction you just think, really?! What are we going to achieve with this (ICD)? So, in many ways it doesn't surprise me that there's a reluctance to talk about that (deactivation), as with a lot of medicine then often that's kind of seen as a failure of what we've tried to achieve, 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)

## Decision making

- **Actors involved**
  - Patient
  - Other patients
  - Significant others
  - Clinician patient relationship
- **Influences on decision-making**
  - Choice
  - QOL vs living longer
  - Feelings about surgery
  - Effect on significant other(s)
  - Previous experiences
  - Driving
  - Age
- **Timing of deactivation discussions**
  - Implantation
  - Check-ups
  - Trigger points

**Chronic heart failure pathway showing preference-sensitive decision points and opportunities for discussion with patients/relatives**



**Plenary – thoughts  
and reflections on  
findings**

## Small Group Work

How can patients and their relatives be better supported to make informed 'values-based' decisions about ICD implantation / deactivation in partnership with clinicians?

***Issues you may wish to consider in your small groups:***

- *Who should discuss pros and cons of ICDs with patients/relatives?*
- *When should a discussion about the pros and cons of ICDs with patients/relatives take place?*
- *What information should be provided to patients/relatives?*
- *How could specific barriers to SDM be overcome?*

**Then plenary with spokesperson from each group sharing key thoughts/ideas**