

# A qualitative study of decision-making about the implantation of cardioverter defibrillators and deactivation during end-of-life care

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## Plain English summary

### Cardioverter defibrillators at end of life

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## Plain English summary

Patients with heart problems may be at risk of sudden death and can be protected from this by an implantable cardioverter defibrillator (ICD). An ICD monitors the heart. If a life-threatening rhythm occurs, the device will deliver electrical shocks to restore the natural rhythm. ICDs can improve survival, but some patients can experience unnecessary shocks or develop psychological problems. Patients close to the end of their lives can experience unnecessary pain and distress from shocks, and turning off the ICD (deactivation) will prevent shocks and make the patient more comfortable. Shared decision-making involves patients making decisions about their treatment in partnership with clinicians, after the risks and benefits of different options have been explained to them, and enables them to make a choice that reflects what is important to them. It is not clear if patients are appropriately supported to make an informed decision.

We observed consultations in three hospitals and conducted 80 interviews with patients, their relatives and clinicians to understand how best to improve the engagement of patients/relatives in decision-making with clinicians about putting in ICDs and deactivating them towards the end of life. Patients had varying knowledge about their heart condition and the function of ICDs. Clinicians often found it difficult to explain fully the function of an ICD and its risks and benefits. The risk of a patient developing psychological problems and the negative impact of the ICD on body image were rarely discussed. Patients/relatives wanted to be involved in implantation decisions, with deactivation discussed at the same time. Clinicians were anxious about early deactivation discussion. Opportunities throughout the pathway were identified for discussion about the appropriateness of continued ICD therapy and deactivation.

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