

**Appendix**

Appendix table 1 - results from CASP checklist for randomised control trial studies

Author	Year Published	Did the study ask a clearly focused question?	Was this a randomised controlled trial?	Were participants appropriately allocated to intervention and control groups?	Were participants, staff and study personnel 'blind' to participants' study group?	Were all of the participants who entered the trial accounted for at its conclusion?	Were the participants in all groups followed up and data collected in the same way?	Can the results be applied to your context?	Were all clinically important outcomes considered?
Goldstein <i>et al</i>	2019	yes	yes	not clear	yes	yes	yes	yes	yes

Appendix table 2 - results from CASP checklist for qualitative studies

Author	Year Published	Was there a clear statement of aims of the research?	Is the qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Is the data collected in a way that addressed the research issue?	Has the relationship between the researcher and the participants been considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?
Fluur <i>et al</i>	2013	yes	yes	yes	yes	yes	yes	yes	yes	yes
Fluur <i>et al</i>	2014	yes	yes	yes	yes	yes	yes	yes	yes	yes
Hill <i>et al</i>	2019	yes	yes	yes	not clear	yes	not clear	yes	yes	yes
Kramer <i>et al</i>	2013	yes	yes	yes	no	yes	yes	not clear	yes	yes
Kutcher <i>et al</i>	2020	yes	yes	yes	yes	yes	not clear	not clear	not clear	yes
MacIver <i>et al</i>	2016	yes	yes	yes	yes	yes	yes	yes	yes	yes
Lee <i>et al</i>	2016	yes	yes	yes	not clear	yes	not clear	yes	yes	yes
Mueller <i>et al</i>	2011	yes	yes	yes	yes	yes	not clear	not clear	yes	yes
Raphael <i>et al</i>	2011	yes	yes	yes	yes	yes	no	not clear	yes	yes
Stoevelaar <i>et al</i>	2020	yes	yes	yes	no	yes	yes	yes	yes	yes
Ali-Ahmed <i>et al</i>	2019	yes	yes	not clear	yes	yes	no	not clear	not clear	yes
Conelius <i>et al</i>	2013	yes	yes	yes	no	yes	not clear	yes	yes	yes
Hill <i>et al</i>	2018	yes	yes	yes	yes	yes	no	not clear	yes	yes
Hjelmfors <i>et al</i>	2014	yes	yes	yes	yes	yes	no	yes	yes	yes
Miller <i>et al</i>	2019	yes	yes	yes	yes	yes	not clear	yes	yes	yes
Mooney <i>et al</i>	2019	yes	yes	yes	yes	yes	not clear	not clear	yes	yes

Appendix table 3 - results from CASP checklist for cohort studies

Author	Year Published	Did the study address a clearly focused issue?	Was the cohort recruited in an acceptable way?	Was the exposure accurately measured to minimise bias?	Was the outcome accurately measured to minimise bias?	Have the authors identified all important confounding factors?	Were confounding factors taken into account in the design and/or analysis?	Was the follow up of the subjects complete or long enough?	How precise are the results?	Do you believe the results?	Can the results be applied to the local population?
Buchhalter <i>et al</i>	2014	yes	yes	yes	yes	not clear	not clear	yes	yes	yes	yes
Pasalic <i>et al</i>	2016	yes	yes	not clear	yes	not clear	not clear	yes	yes	yes	yes
Thompson <i>et al</i>	2019	yes	yes	yes	yes	yes	not clear	yes	yes	yes	yes
Thylén <i>et al</i>	2014	yes	yes	yes	yes	yes	yes	yes	yes	yes	yes
Trussler <i>et al</i>	2019	yes	not clear	yes	not clear	no	no	yes	not clear	yes	yes

Appendix table 4 - details of all included studies

Author	Country	Aim of study	Study design	Participants	Relevant Findings
<b>Ali-Ahmed <i>et al</i> (2019)</b>	North America	(a) How physicians are incorporating SDM in counselling patients about ICD candidacy and implantation, (b) what SDM tools are used for that purpose, (c) whether physicians are aware of sex- and race-based differences in perceptions of ICD implantation, and (d) If physicians change their SDM approach based on the patients' sex and race.	Survey	Healthcare professionals	The vast majority of cardiologists and electrophysiologists who implant ICDs engage in shared-decision making (SDM) during the general consent process for ICD implantation. However, under two-thirds use SDM to address ICD deactivation. The most popular SDM tool was Colorado tool. Despite this, there is a strong need for more data-driven SDM tools that can be customized to fit different populations.
<b>Buchhalter <i>et al</i> (2014)</b>	North America	To describe features and outcomes of patients who underwent cardiovascular implantable electronic device deactivation.	Retrospective review of medical records	Patients	The review found that patients who made the decision to undergo device deactivation were more likely to involve palliative medicine than patients whose surrogates made the decision. This finding might reflect the shared decision-making process between a clinician and an autonomous patient with decision-making capacity. In addition, the review showed that despite more than half the patients having an advanced directive only one addressed ICD deactivation. It is recommended from this review that any patient with an ICD engage in advanced care planning. This approach may reduce ethical dilemmas and moral distress among surrogates and care providers when it comes to end-of-life care.
<b>Conelius <i>et al</i> (2013)</b>	North America	To develop and evaluate the psychometric properties of the Attitude Towards Advanced Directive Survey and investigate the reliability and validity from its use among ICD patients.	Survey	Patients	Using a survey the study found participants had a limited understanding of their condition and did not have confidence in healthcare providers to decide on their treatments. Most participants claimed that their healthcare providers rarely have conversations regarding advanced directives. In addition it was reported that some healthcare providers either do not understand the advanced directives themselves or do not believe they are useful. The results from this survey conclude participants would like to discuss advanced directives when they are first diagnosed with their heart problem requiring the ICD and at every subsequent office visit.
<b>Fluur <i>et al</i> (2013)</b>	Sweden	To explore patients' experiences of complex issues of battery replacement and deactivation of the ICD.	Qualitative Interviews	Patients	Results from qualitative interviews showed that end-of-life discussions were rare and none of the patients had early conversations regarding end-of-life. The majority of patients were reluctant to discuss ICD deactivation and most would choose to replace ICD battery at end-of-life. When asked patients would prefer to leave deactivation discussions until end-of-life became a reality. This was mainly because that it was difficult to talk about death; it was energy consuming and shifted focus from what patients considered important; living in the present.

<b>Fluur et al (2014)</b>	Sweden	To explore future reflections of spouses living with an implantable cardioverter defibrillator recipient with focus on the end-of-life phase in an anticipated palliative phase.	Qualitative Interviews	Family member	Qualitative interviews with spouses described how they felt left out related to fundamental information about the device and the partner's illness trajectory. They were rarely offered verbal or written information about what to expect and how they missed such targeted information. For many of the relatives it came as a shock that the device could be deactivated. From this information it is recommended initiating early conversations with patients and their spouse, continuing this dialogue over time and establishing collaboration with counselling professionals when needed, can help the couple to handle life with an ICD.
<b>Goldstein et al (2019)</b>	North America	To determine if a clinician-centered teaching intervention and automatic reminders increased ICD deactivation discussions and increased device deactivation.	RCT	Healthcare professionals	The randomised control trial showed there was no difference in ICD deactivation conversations in patients cared for by clinicians who underwent the communication training intervention compared to control group. However, Patients cared for by clinicians who underwent the intervention training were more likely to have a goals of care conversation compared with patients cared for by clinicians in the control group who had no communication training.
<b>Hill et al (2018)</b>	UK	To explore patient and professional factors that impact perceived likelihood and confidence of healthcare professionals to discuss ICD deactivation.	Survey	Healthcare professionals	This survey found that the majority agreed it should be cardiologist or specialist nurses who should initiate conversations about ICD deactivation. Nurses were in favour of discussing deactivation prior implantation whereas physicians preferred when care became more palliative. The presence of a deactivation policy was not associated with the likelihood of discussing deactivation; however, healthcare professionals were more confident in making this decision when a deactivation policy was present. The overall results from this study agreed that patients should be informed about deactivation before implant and periodically during the disease trajectory, as per clinical guidelines. Furthermore, the decision to deactivate an ICD was deemed to require agreement between the cardiologist, patient, and his/her family.
<b>Hill et al (2019)</b>	UK	To explore patients', family members' and healthcare professionals' perspectives and attitudes towards discussing ICD deactivation	Qualitative Interviews	Patients	Results from the interviews showed a number of patients stated they were aware that aspects of their illness and future management had not been disclosed, and they questioned the rationale for this. Many healthcare professionals believed it was appropriate to wait until the patient broached the subject of deactivation. Furthermore, neither patients nor family members could comprehend that a shock could be inappropriate. Healthcare professionals supported the positive aspect of a shock and it wasn't until the patient was seen as end-of-life could they comprehend deactivation. Overall, the majority of patients wanted to be involved in the decision to deactivate their device; however, they agreed that a medical professional should make the final judgement. A proactive approach to discuss deactivation would enable shared clinical decision-making in the advanced stages of illness.

<b>Kramer <i>et al</i> (2013)</b>	North America	To identify nurses' concerns about the clinical, ethical, and legal aspects of deactivating cardiovascular implantable electronic devices	Qualitative Interviews	Healthcare professionals	Qualitative interviews with nurses showed the nurses noted that conversations before device implantation were largely physician driven. Patients were told about the benefits of the device, but equal time was not given to discussing options such as forgoing a device or later deactivation. In addition, physicians' failure to consider the psychosocial, economic, and advance care planning aspects of living with a device. The nurses believed that lack of advance care planning may have led to reactive decision making and was an avoidable stress for patients, families, and healthcare professionals. The interviews suggested frequent revisiting of advance care planning, particularly as part of a strengthened outpatient care practice, would further support efforts to better match patients' goals with the functions of their ICD. A team-based approach involving nursing and other healthcare professionals could enhance the conversation before implantation by informing patients in a comprehensive fashion about the risks and benefits of receiving an ICD.
<b>Kutcher <i>et al</i> (2020)</b>	North America	To better understand the experiences of family caregivers of a terminally ill patient who received hospice care at home and chose deactivation of a pacemaker.	Qualitative Interviews	Family member	Interviews with family members showed lack of understanding and support from medical professionals, who showed great enthusiasm for inserting a pacemaker but great reluctance when considering its deactivation. Without the support and understanding of the medical team, the caregivers felt lost and helpless, and they were forced to navigate alone through a difficult health-care situation alone. As a result, caregivers need to have easy access to information so that they can understand the process of deactivation. Healthcare professionals should be encouraged to involve the healthcare professionals throughout the decision making process.
<b>Hjelmfors <i>et al</i> (2014)</b>	Sweden	To describe HF nurses' perspectives on, and daily practice regarding, discussing prognosis and end-of-life care with HF patients in outpatient care.	Survey	Healthcare professionals	Most of the nurses in the survey had reported discussing prognosis or end-of-life issues with patients with an ICD. However, more than half said they felt hesitant due to uncertainty when answering the patient's questions. As a result nearly all the nurses reported a lack of education into how to approach deactivation and end-of-life conversations. From this result it is important to provide training for nurses to improve their ability to communicate with patients and families regarding end-of-life care. This would be supported by communication tools to help initiating these conversations earlier in the disease trajectory.

<b>MacIver <i>et al</i> (2016)</b>	Canada	To determine patient awareness, preferences and timing of implantable cardioverter-defibrillator deactivation discussions.	Qualitative Interviews	Patients	The interviews generated a mixed response, some of the patients recalled having conversations about device deactivation however others could not remember. There was a mixed response to whom should initiate conversations from physicians to nurses to the patient themselves, as they felt if the physician initiated the discussion before the patient was ready, it would increase emotional distress. The overall results from the interviews suggested: prior to implantation, patients explained how they wanted to know the ICD could be deactivated but did not want to engage in lengthy discussions about their preferences. The majority of patients expressed a preference for comprehensive ICD deactivation discussions when their condition deteriorated but while they remained of sound mind to engage in a discussion and communicate their preferences
<b>Lee <i>et al</i> (2017)</b>	North America	To explore family members' experiences of patients with ICD making decisions at EOL. Understanding the decision-making of patients with ICD at EOL can promote informed decision making and improve the quality of EOL care.	Qualitative Interviews	Patients	Family members in this study reported that patients prefer a shared decision-making style with family members. Family members having direct conversations with patients regarding their end-of-life wishes experience more confidence in patients' decision compared to relying on a written advanced directive only. Family members valued open, honest communication patients. Therefore, health-care providers should encourage direct conversation even when patients have advanced directive. Providers should encourage patients to discuss their advanced directive with their family members to promote the understanding of their end-of-life wishes.
<b>Miller <i>et al</i> (2019)</b>	North America and Australia	To determine the association of health literacy with experiences, attitudes, and knowledge of the ICD at EOL.	Survey	Patients	The survey found that health literacy placed no role in influencing the decision to deactivate the ICD. However, increasing ICD knowledge reducing the number of participants choosing to retain their defibrillation at end of life. Improving ICD knowledge may have a meaningful impact on risk reduction and interventions to improve ICD knowledge may help to decrease unnecessary invasive procedures for generator replacement and shocks during the active dying phase, thus improving both the quality of life and the quality of the death experience for ICD recipients.
<b>Mooney <i>et al</i> (2019)</b>	Ireland	Investigate patients' knowledge and opinions about their ICDs during life, illness and at the time of death and the factors that might influence these.	Cross-sectional, correlational, non-experimental study – using a validated 39-item questionnaire	Participants	Of the 30 participants in this study, 59% had sufficient knowledge about ICDs. There was no relationship between knowledge and time since implantation ( $p=0.11$ ). A relationship existed between knowledge and age; those that were older were better informed ( $p=0.008$ ). The authors conclude that patient education and communication are essential for patients with ICDs to enhance decision-making about ICD management at the end of life.

<b>Mueller et al (2011)</b>	North America	To identify themes associated with role conflicts and moral distress experienced by cardiovascular implantable electronic device (CIED) industry	Qualitative Interviews	Healthcare professionals	Industry-employed allied professionals (IEAPs) described situations in which they received little support from clinicians and were given the responsibility of informing patients and their loved ones about the process and outcomes of ICD deactivation. Most reported little or no training and felt unprepared for their first deactivation. IEAPs request that only physicians, nurses and other healthcare professionals be involved in the communications and initiation of ICD deactivation discussions. IEAP should only be involved in the technical aspect.
<b>Pasalic et al (2016)</b>	North America	To review the EOL experiences of patients who underwent CIED deactivation assessing the content of palliative care consultations and outcomes for this group compared to patients who did not receive this intervention	Retrospective review of medical records	Patients	The review showed that less than half patients had palliative medicine consultations and only two-thirds of these addressed ICD deactivation: this could have been because this was not specifically requested on referral or patients and/or family did not seek this advice. These consultations addressed multiple topics including goals for care, symptom management, discussion of hospice and community resources.
<b>Raphael et al (2011)</b>	UK	To look at when end of life and device deactivation should be discussed with patients and how much patients want to know prior to ICD implantation	Qualitative Interviews	Patients	These interviews highlighted a mixed response to patient's desired involvement in ICD deactivation. Some patients were determined to be involved from the start, prior implantation. Others felt that device deactivation should not be routinely discussed with patients, reasons given were that the information may be confusing, that the decision is best left to the doctor, and that switch off may prematurely shorten life. Therefore, the review suggests ICD deactivation discussion need to be tailored to patient preferences.
<b>Stoevelaar et al (2020)</b>	Netherlands	To explore the experiences of patients having advance care planning conversations about implantable cardioverter defibrillator deactivation.	Qualitative Interviews	Patients	These interviews highlighted a mixed response to ICD deactivation. Some patients wanted to be involved in discussions, other would prefer to decision to deactivate to be left to clinicians. Most patients agreed family should be involved in the decision making. Not everyone was in favour of recording their preferences about ICD deactivation in a document, because they were not sure what they would want when their disease would progress. Therefore, it is recommend healthcare professionals to explore the patient's readiness to talk about end-of-life and ICD deactivation, so that information can be tailored to the needs of the patient.
<b>Thompson et al (2019)</b>	Sweden	To describe experiences, attitudes, and knowledge about the ICD at EOL in ICD recipients and to compare experiences, attitudes, and knowledge in ICD recipients with and without heart failure (HF).	Survey	Patients	The survey found factors associated with having a deactivation discussion were primarily ICD related, including a history of an ICD shock and having high levels of ICD concerns. The other predictor was symptoms of anxiety, which has been known to have a significant relationship with shared decision-making and how patients interact with their providers. These associations are crucial to understand because they may indicate avenues for discussions about end-of-life discussions, and times most appropriate for broaching the subject.

<b>Thylén <i>et al</i> (2014)</b>	Sweden	To develop and evaluate respondent satisfaction and measurement properties of the 'Experiences, Attitudes and Knowledge of End-of-Life Issues in Implantable Cardioverter Defibrillator Patients' Questionnaire'	Survey	Patients	The survey found when it came to the participants' attitudes on discussing deactivation and end of-life issues, a third of patients were unwilling to have such conversations, two-thirds stated that the question should be raised in connection with the ICD-implantation, and the majority during the last days of life. Despite the recommendations that ICD deactivation be discussed prior implantation this survey data highlights the importance of being aware of the patient's unique preferences and needs.
<b>Trussler <i>et al</i> (2019)</b>	Canada	To investigate how device deactivation in patients with terminal illness is occurring at our tertiary care hospital; Kingston Health Sciences Centre (KHSC) in Kingston, Ontario, Canada.	Retrospective review of medical records	Patients	The review found that only one-third of patients received ICD cardioversion/defibrillation therapy deactivation as part of their end-of-life care. Under half of patients who died with an ICD and a terminal diagnosis had a DNR order from a physician. Of these DNR patients the majority underwent device deactivation as part of their end-of-life care plan. Therefore, suggested as a minimum active ICDs should be recognized and discussed by clinicians when a patient opts to become DNR

#### Appendix 5 – Search Strategy Example for Medline

##### Population Terms

"Implantable cardioverter defibrillator" [MeSH]

"ICD" [MeSH]

"automatic implantable cardioverter defibrillator" [MeSH]

"AICD" [MeSH]

"implantable defibrillator" [MeSH]

##### Outcome

"Communication" [MeSH]

"health communication" [MeSH]

"consult\*" [MeSH]

"inform" [MeSH]

"mention" [MeSH]

"discuss" [MeSH]

"verbalis\*" [MeSH]

"talk to" [MeSH]

"vocalis\*" [MeSH]

"converse" [MeSH]

“address” [MeSH]

“advance care planning” [MeSH]

“advance directive” [MeSH]

“end of life planning” [MeSH]

**Filters Activated**

English Language

Last 10 years

Adult Population (18 years and over)

Publication date from 2010-2020

\*Search terms and strategies will be adapted to database: Embase, PsycInfo, CINAHL