Government of JERSEY

Health and Community Services

Deactivation of Implantable Cardioverter Defibrillators (ICD) at the End of Life

November 2021

DOCUMENT PROFILE

Document Registration	HSS-PP-CG-0466-03
Document Purpose	Organisational Policy
Short Title	Deactivation of ICD's at the end of life
Author	Sister Angela Hall
Publication Date	November 2021
Target Audience	HCS staff / Community
Circulation List	Via Intranet
Description	Policy outlining the deactivation process at the end of life
Linked Policies	P Do Not Attempt Cardiopulmonary Resuscitation DNACPR
Approval Route	Hospital Care Quality Group / Community Care Quality Group
Review Date	3 years
Contact Details	Angela Hall, 442002

CONTENTS LIST:

1. INTRODUCTION

1.1 Rationale

ICD's protect individuals at risk of sudden cardiac death (SCD) from life threatening ventricular tachyarrhythmias. An ICD has a number of key functions:

- automatic administration of defibrillation shocks to terminate ventricular fibrillation (VF) or fast ventricular tachycardia (VT)
- anti-bradycardia pacing often used after a defibrillation shock as the heart returns to normal sinus rhythm
- anti-tachycardia pacing to terminate slower VT
- cardioversion of VT

Due to guideline recommendations there has been as increase in ICD implantation rates, including in those in whom preventing SCD with heart failure due to left ventricular (LV) dysfunction is a concern (1). Devices in these patients are either ICD's or combined cardiac resynchronisation therapy with defibrillation function (CRT-D), a more sophisticated form of pacemaker with three leads used to improve the co-ordination of cardiac contractility.

The presence of an ICD can lead to dilemmas as recipient's age and are subjected to the burden of progressive disease or development of terminal conditions. Questions are then raised regarding the continuing benefit of ICD therapy which needs to be reviewed as defibrillation can cause emotional and physical distress (2). Healthcare professionals have a duty of care to consider withdrawal of non-contributors therapies and the distress caused by resuscitation measures in those nearing the end of life (3).

1.2 Scope

This policy applies to all those patients in the island who have a cardiac device implanted which has the ability to defibrillate. These numbers are growing by approximately 7-10% per annum (4) and current data identifies in the region of 120 people in Jersey with either an ICD or CRT-D device.

This applies to those in hospital and in the community and therefore affects the organisation as a whole. Senior Cardiac Physiologists provide ongoing monitoring for patients with these devices and is the Clinical Investigation Department are the first line of contact regarding device management. They work closely with the Cardiology Consultant who provides overall clinical leadership and Cardiac Nurse Specialists for support and additional advice.

1.3 Principles

The criteria for device implantation is presented in the 2014 NICE guidance on implantable cardioverter defibrillators and cardiac resynchronisation therapy for arrhythmias (TA314) (5). As guidelines are reviewed, criteria for eligibility often expands. More people survive longer with ICDs and some approach the end of their life, either due to progression of heart disease or due to development of another

irreversible terminal condition. Providing high-quality end of life care and allowing for a dignified death requires consideration and discussion of deactivation of the shock function of their ICD. If this is not done, distressing shocks from the device during the last hours of days of life may be delivered. Discussion around deactivation is therefore crucial, at time of implant and reviewed when there are changes to the patients' medical condition and at intervals during routine checks whereby the patient is reminded of the importance of discussing such matters.

A study showed that a number of patients continued to experience shocks in the last moments of life (6). 8% of ICD patients received a shock in the final moments of life and only 27% of patients had a discussion about deactivation. It is important this is addressed ideally at the time of implant (7).

The Priorities of Care document (2014) (19) deals specifically with a person who is imminently dying, i.e. death is expected within a few hours or very few days. However, it should be noted that, for people living with life-limiting illness, the general principles of good palliative and end of life care apply from a much earlier point. Advance care planning, symptom control, rehabilitation to maximise social participation, and emotional and spiritual support are all important in helping any individual to live well until they die.

This policy should be read with comprehension of the local Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) 16 years and over Policy and an understanding of matters around capacity and consent (21 22, 23, 24 and 25).

Consent related guidance can be found at:
Consent: Patients and doctors making decisions together
HCS Consent to Care and Treatment policy
Observation / Enhanced Observation Policy and Procedure

2. POLICY PURPOSE

The purpose of this policy is to provide guidance and clarification regarding deactivation of ICD devices for palliative care patients. As a result of policy implementation, the care of patients with an ICD / CRT-D device should be managed appropriately and in a timely manner so as to avoid unnecessary stress. Inappropriate therapy from the ICD should be avoided and patient's wishes and best interests must be considered. Clarification of the deactivation procedure is outlined in this policy and this applies to those which can be planned (and the ideal) but also what to do if the situation is unexpected and sudden.

Two algorithms can be seen in Appendix 1 and 2 which outline the process to be followed as per the British Heart Foundation ICD deactivation discussion document (2013) (8).

The General Medical Council (9) suggest patients are approaching the end of life when they are likely to die within the next 12 months including those whose death is imminent and those with:

- advanced progressive, incurable conditions
- general frailty and co-existing conditions meaning they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events

Decisions around device deactivation should be held during the consenting process. If this is felt inappropriate, this could be postponed until next clinical review but ideally, before clinical circumstances change and this is current practice (10, 11). A patient information leaflet can also be found on MyStates which can be downloaded and printed for patients and their carers. This has been written by the Resuscitation Council, British Cardiovascular Society, Arrhythmia Alliance, The British Heart Foundation and The National Council for Palliative Care.

2.1 When to consider deactivation

Patients with end stage disease requiring palliative and supportive care may exhibit metabolic or biochemical derangement and are at risk of developing arrhythmias that may trigger firing of the ICD / CRT-D device. Once a patient reaches the end of life, delivery of shocks will be inappropriate and can cause distress. In order to avoid this situation, the doctor caring for the patient should consider deactivating the shock function of the device (12).

The decision to withdraw shock therapy must be made by the doctor in charge of the patients care in consultation with the relevant health care professionals having first obtained a competent patients consent. Where the patient lacks capacity, an advanced decision may be prepared. This may be with the patient's notes, next of kin or solicitor. If neither is in place the decision must be based on the patient's best interests.

A second opinion may be sought where the patient's condition is complex or not progressing as expected or when the decision becomes necessary to change. This may also be requested where capacity is in question or when the views of the doctor are challenged.

2.2 Capacity

A patient with mental capacity has a legal and ethical right to request withdrawal of medical interventions, including ICD therapy, which sustains life (9, 13). Where the patient has capacity, deactivation of the device should be initiated after discussion and their agreement (Appendix 1) (8). Deactivation of the defibrillator mode does not deactivate the pacing mode and in itself does not end a patients' life but will allow for a natural death without the risk of unnecessary shocks. Where the patient lacks capacity, follow Appendix 2 (8).

Capacity must be assumed for all individuals but if loss of capacity is suspected, a two stage test of capacity is enshrined in the Mental Capacity Act (2005) (14).

A 'Do Not Resuscitate Order' must be clearly communicated and documented and updated if circumstances change.

2.3 Procedure

The procedure of deactivation should be planned where possible and the patient should attend the Clinical Investigations Department having given their consent. Deactivation of device response (shock therapy) is undertaken by a trained and competent Cardiac Physiologist.

An increased focus on assessing the need for elective ICD deactivation at the end of life may reduce the need for emergency deactivation in the community, improving the efficiency of staffing arrangements and avoiding delays that may exacerbate patient and family distress. While for some the change in condition is sudden, for others the deterioration can be anticipated and this should be taken into account.

2.3.1 in hospital

The process of ICD / CRT-D deactivation should follow Appendix 3. The decision and subsequent actions should be documented in the patients' hospital medical notes. If the patient cannot attend the department, bedside deactivation can take place.

2.3.2 in the community (including hospice, at home or in nursing or residential homes)

The medical notes available in this environment should be used to document the decision to deactivate. If the patient is at home, the GP notes should be used. Appendix 3 also outlines the procedure to follow. All personnel involved in the patients care should be aware of device deactivation.

If the patient requires transfer from one area to another, it is essential this information is clearly documented and relayed to the receiving area.

2.4 Emergency deactivation

This can be achieved with the secure placement of a magnet on the chest over the device. This may be particularly important when the ICD is repeatedly shocking someone close to death which is distressing for the patient and family. Magnets are available in the Clinical Investigation Department and High Dependency Unit on the emergency ('crash') trolleys. This is only a temporary measure and full deactivation must be undertaken as a matter of urgency.

Devices from Biotronik can be inhibited by a magnet for only 8 hours, so with a Biotronik device or if the manufacturer is unknown, the magnet must be removed for a few seconds and then reapplied every 7 hours (22).

2.5 Recommendations

Heart Rhythm UK (2013) (15) recommend the following:

- Device implantation centres are strongly encouraged to follow a local policy for the management of end of patients' life.
- All device follow up centres (including those which only follow up pacemakers) should have a policy in place for deactivation of ICD function in ICD and CRTD devices which should include the facility for domiciliary visits.
- Device therapy termination should be a consensus between the physician normally responsible for patient care, the patient and where possible a representative for the patient (e.g. a relative).
- Different levels of device therapy termination should be considered specific to the individual case and informed consent must be obtained.

The British Heart Foundation document on principles and practice of ICD deactivation (2013) (8) provide the following summary of recommendations:

- ICD deactivation at the end of life needs to be part of the pre-implantation consent and counselling process and formalised in advance care planning if the patient is agreeable (16).
- A comprehensive assessment of the overall benefits and implications of ICD therapy should be undertaken based on a patient's needs and preferences, prior to implantation.
- Shared decision making needs to take place allowing valid informed consent prior to the implantation process.
- The appropriateness of maintaining device therapy must be reviewed as part of monitoring of the patient's progressive disease trajectory, if there is any change in clinical status including the development of a life limiting disease and when the ICD generator box is considered due for replacement (17, 18).
- The development of local robust protocols for implementing ICD deactivation is essential and should refer to the multidisciplinary approach, staff training, the provision of 24 hour device-related cover and appropriate exchange of information with the patient and all involved in their care.

Important points to explain about ICD deactivation (22, 27)

- Deactivating your ICD will not cause death.
- Once your ICD has been deactivated, if you have a heart rhythm change that could cause death, your ICD will not deliver treatment for it.
- Deactivating the shock function of your ICD does not deactivate its pacemaker function.
- Deactivating your ICD will be painless.
- Near the end of your life your ICD may deliver shocks that are painful and distressing and are of no benefit. If your condition improves unexpectedly or you change your mind the ICD can be reactivated.

- It is best to think and decide about ICD deactivation in advance, rather than in a crisis. (Refer to the patient information leaflet on MyStates).

3. CORPORATE PROCEDURE

The policy will be distributed to the relevant parties for perusal and discussion. The chart below outlines personnel included and dates consulted. Amendments are made accordingly and ratification takes place in the relevant department governance meetings.

4. DEVELOPMENT AND CONSULTATION PROCESS

4.1 Consultation Schedule

Name and Title of Individual	Date Consulted
Dr Andrew Mitchell, Cardiologist	Sent 18.05.2015
Dr Ranji Thomas, Associate Specialist	30.04.2015
Sister Sinead O'Driscoll / Martine Gwinnell Palliative Care (Hospice and Community)	23.04.2015, sent 30.04.2015
Paul Roche, Senior Cardiac Physiologist	24.04.2015, sent 30.04.2015
Andrew Norman, Manager Clinical Investigation Department	20.05.2015
Pam Le Sueur, Lead Nurse Ambulatory Care	18.05.2015

Name of Committee/Group	Date of Committee/Group meeting
Cardiology Governance	20.05.2015
Palliative Care Governance	Feedback from Palliative Care 01.08.2018

4.2 Revision of Policy June 2018

Dr Andrew Mitchell, Cardiologist	Sent 28.06.2018
Dr Chris Edmond, Cardiology Clinical Fellow	Sent 28.06.2018
Paul Roche, Senior Cardiac Physiologist	Sent 28.06.2018
Andrew Norman, Manager Clinical Investigation Department	Sent 28.06.2018
Sister Lee-anne Penn, Heart Failure Nurse Specialist	Sent 28.06.2018
Imelda Noon, Palliative Care Nurse Specialist, Dr Nicky Baillache, Palliative Care	Sent 28.06.2018

Amendments following consultation:

- Hospice / palliative care input recommend having a magnet for emergency deactivation in times of need and this will be provided by the Clinical Investigation Department.
- A patient information leaflet is now available and can be downloaded from MyStates.

4.3 Revision of Policy July 2021

Dr Andrew Mitchell, Consultant Cardiologist	Sent 02.09.2021
Dr Le Page, Consultant Cardiologist	Sent 02.09.2021
Paul Roche, Senior Cardiac Physiologist	Sent 02.09.2021
Sister Sinead O'Driscoll, Heart Failure Nurse Specialist	Sent 02.09.2021
Imelda Noon, Palliative Care Nurse Specialist, Dr Nicky Baillache, Palliative Care	Sent 02.09.2021 (sent to, no returned comments)

5. REFERENCE DOCUMENTS

1. National Institute for Health and Care Excellence. (2006). Implantable cardioverter defibrillators for arrhythmias. TA95. NICE: London.

2. Cunningham D, Charles R, Cunningham M et al. (2013). Cardiac Rhythm Management – UK National Audit Report. National Institute for Cardiovascular Outcomes Research: London.

3. General Medical Council. (2010). Treatment and care towards the end of life: good practice in decision making. General Medical Council: London.

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6. Goldstein N, Lampart R, Bradley E, et al. (2004). Management of Implantable Cardioverter Defibrillators in End-of-Life Care. Annals of Internal Medicine, 141 (11), 835-8.

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18. Wright G, Klein G, Gula L. (2013). Ethical and legal perspective of implantable cardioverter defibrillator deactivation or implantable cardioverter defibrillator replacement in the elderly. Current Opinions in Cardiology, 28 (1), 43-9.

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20. Resuscitation Committee. (2017). Do not attempt cardiopulmonary resuscitation (DNACPR). Policy for Health and Social Services. Health and Social Services: Jersey.

21. Health and Community Services. (2020), Observation / Enhanced Observation Policy and Procedure available at https://soj/depts/HSS/Registered%20Documents/P%20MHCG%20Observation%20Policy.pdf#search=Mental%20Capacity%20Policy%20and%20Procedures

22. Resuscitation Council UK, British Cardiovascular Society, The National Council for Palliative Care. (2015). Deactivation of implantable cardioverter

defibrillators towards the end of life. Available at: CIEDs Deactivation.pdf (resus.org.uk)

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24. General Medical Council. (2008). Decision making and consent. Available at: Decision making and consent - GMC (gmc-uk.org)

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Further reading

Resuscitation Council (UK), British Cardiovascular Society & National Council for Palliative Care. (2014). Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death. Available at: www.resus.org.uk and www.bcs.com

General Medical Council. (2010). Treatment and care towards the end of life: good practice in decision making. Available at: www.gmc-uk.org/publications/standards_guidance_for_doctors.asp

The National Council for Palliative Care, Dying Matters and the British Heart Foundation. (2014). Difficult Conversations. Making it easier to talk to people with heart failure about the end of life. Available at: Difficult Conversations: Making it easier to talk to people with heart failure about the end of life

6. IMPLEMENTATION PLAN

A summary of how the policy will be implemented.

Amended June 2018.

Action	Responsible Officer	Timeframe
Send to those listed in the Consultation table and amend after feedback	Angela Hall	By mid July 2018
Review document with changes and re-send as required	Angela Hall	By mid July 2018
Submit to the next Cardiology Governance meeting to ratification and sign-off	Angela Hall	Next meeting
Send to Information Governance for uploading	Angela Hall	End July

Updated July 2021.

Action	Responsible Officer	Timeframe
Send to those listed in the Consultation table and amend after feedback	Angela Hall	By end September 2021
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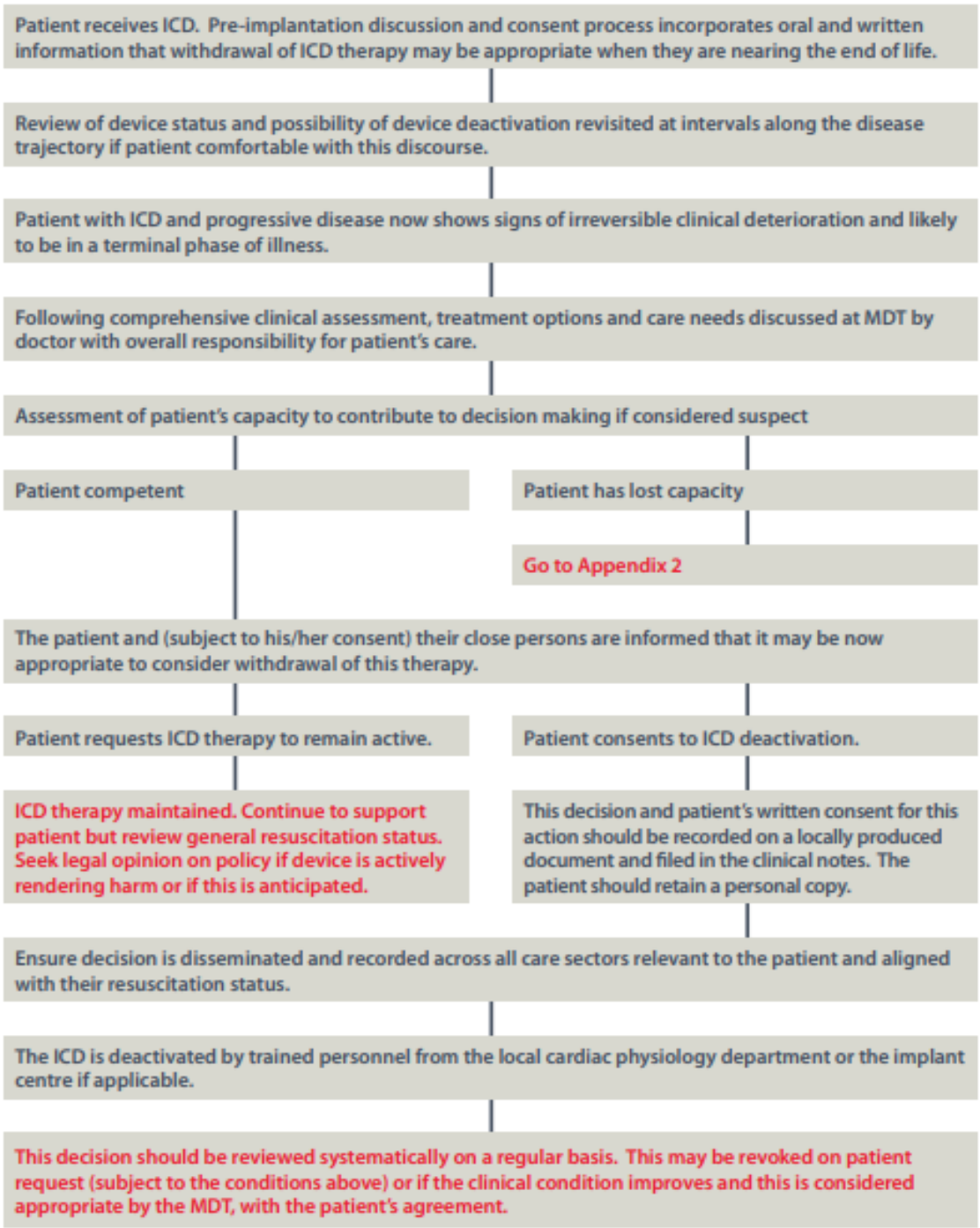
Submit to the next Cardiology Governance meeting to ratification and sign-off	Angela Hall	End September 2021
Send to Information Governance for uploading	Angela Hall	End September 2021

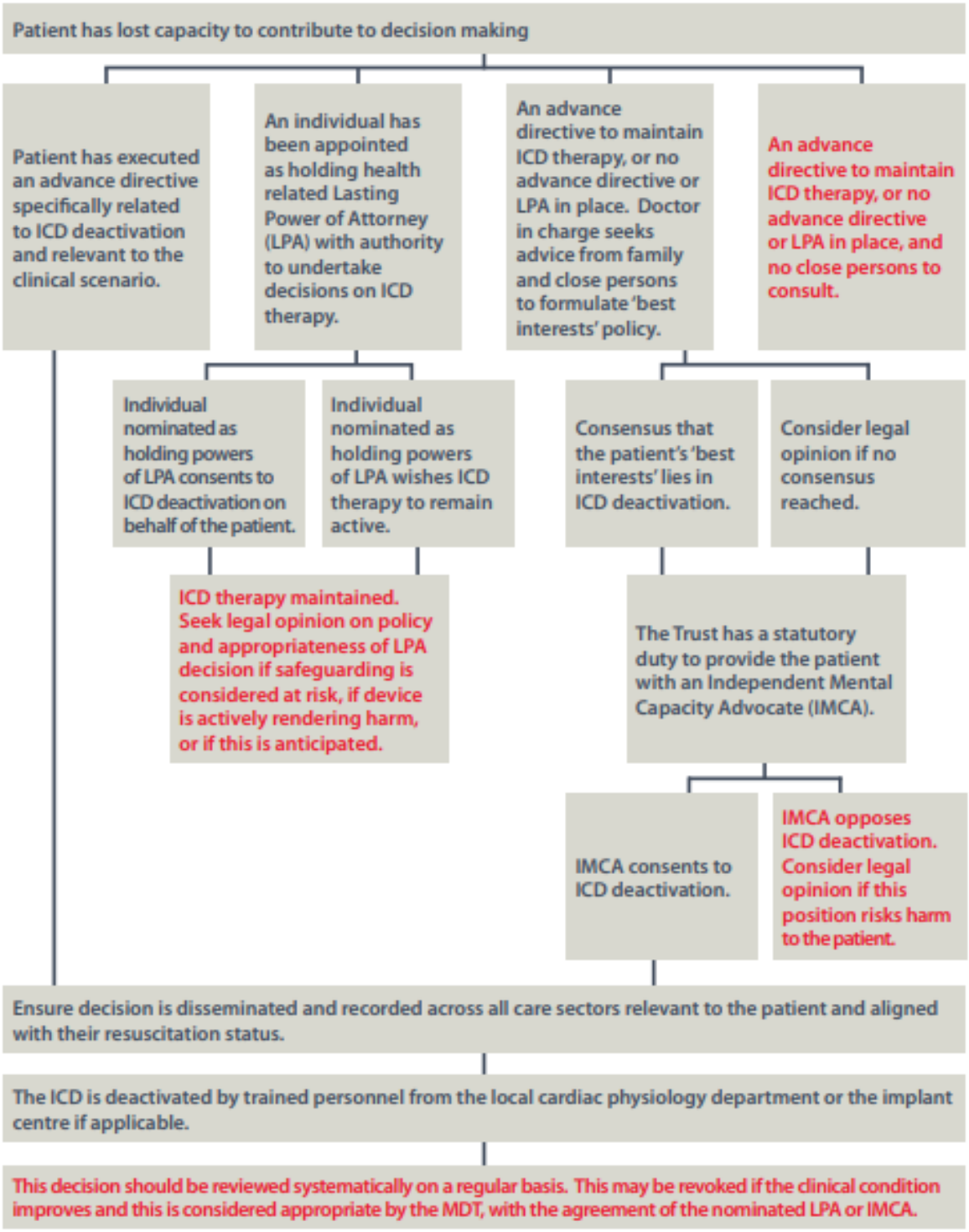
7. APPENDICES

Appendix 1: Decision algorithm for the deactivation of ICD therapy in the adult patient with decision-making capacity at the end of life

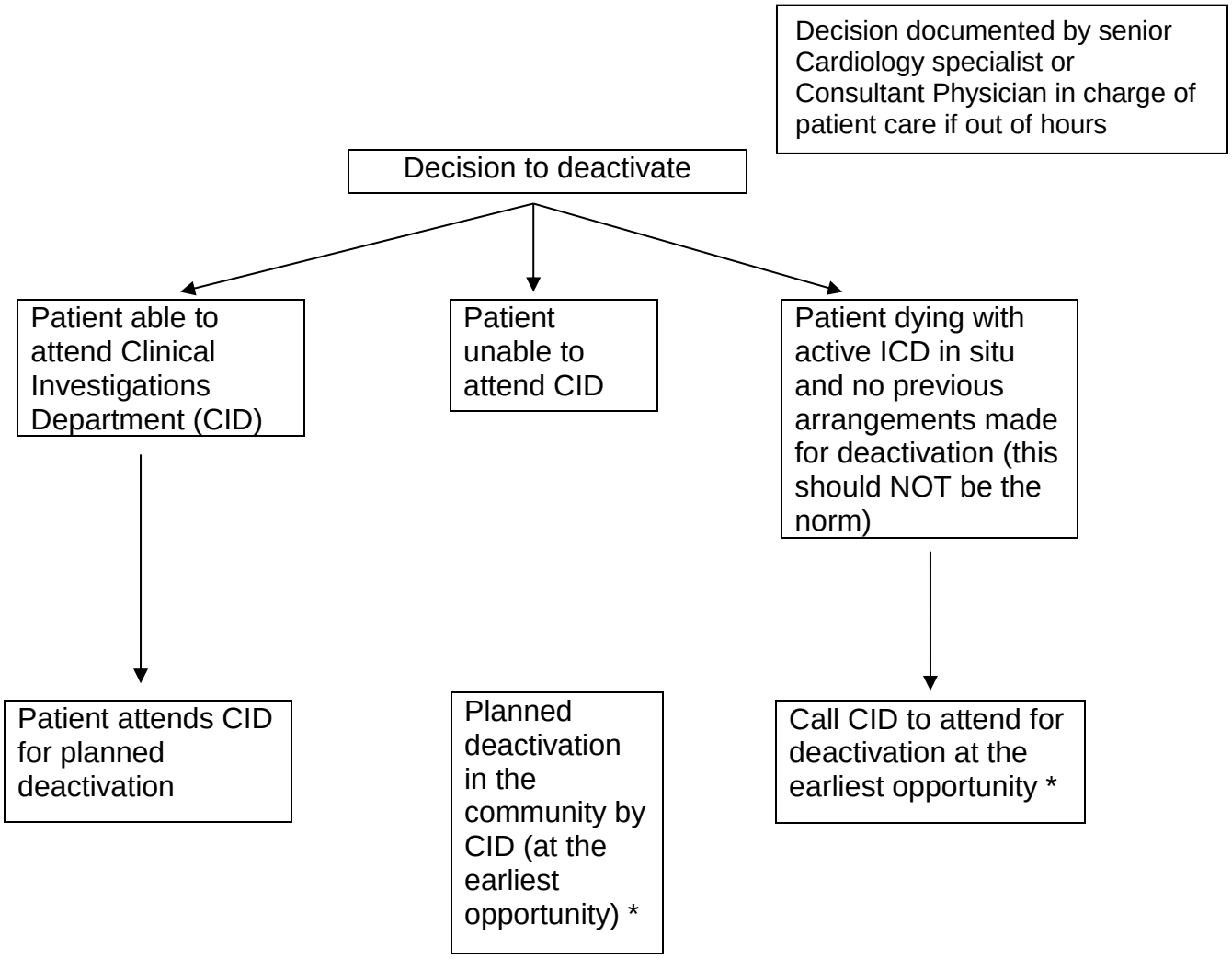


ICD deactivation at the end of life. British Heart Foundation. Beattie (2013).

Appendix 2: Decision making algorithm for the deactivation of ICD therapy in the adult patient who has lost capacity to consent (8)



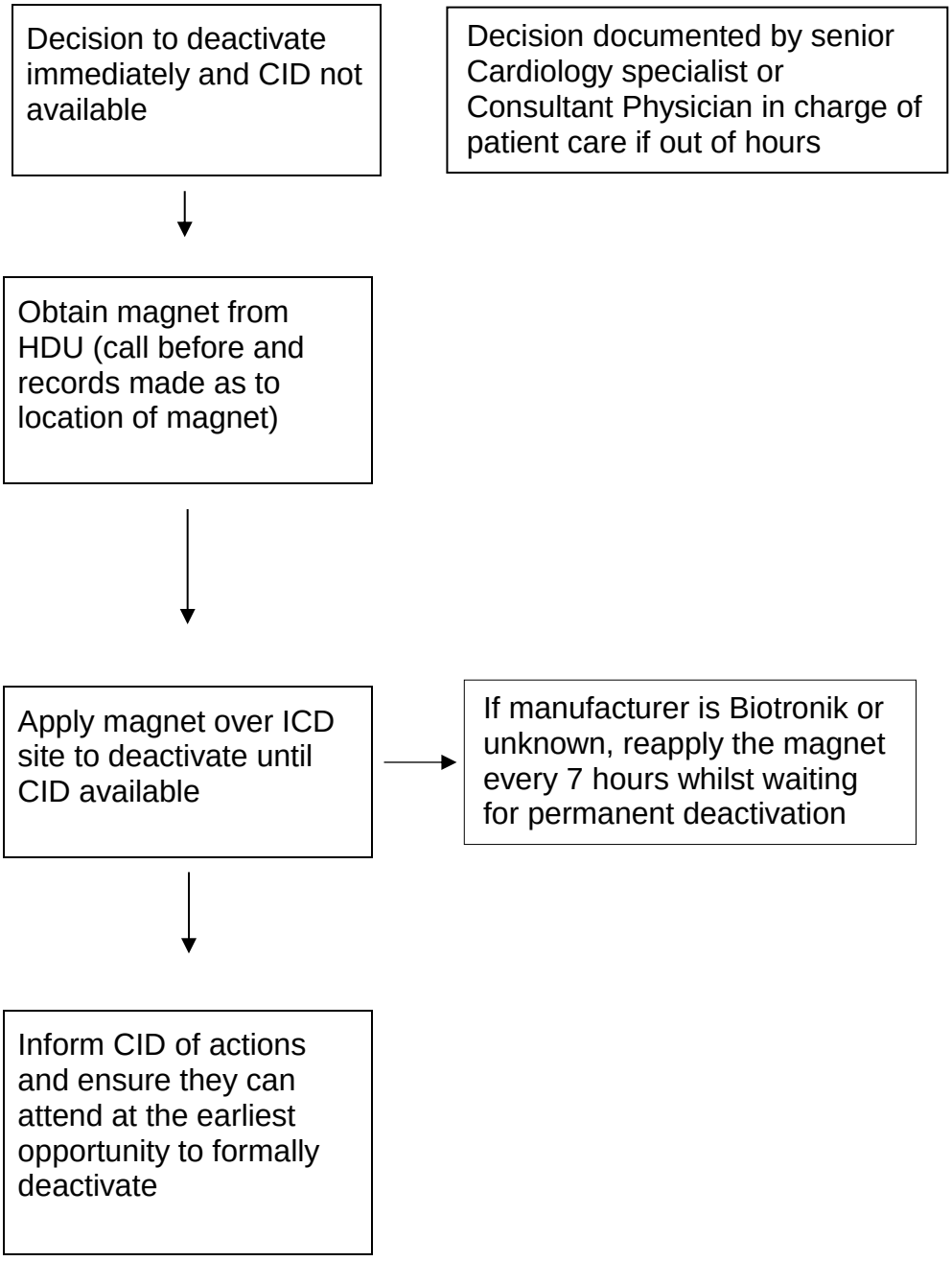
Appendix 3: Algorithm for all patients requiring deactivation



If the decision to deactivate falls outside normal working hours and it cannot wait until the next working day, a member of the Clinical Investigation staff can be contacted through switchboard. There are no formal on-call arrangements but a Cardiac Physiologist can be contacted via mobile phone who will then attempt to accommodate the request. This is only in emergency situations and every attempt should be made to contact the department in working hours and ahead of time.

If the situation requires more urgent attention, Appendix 4 should be followed.

Appendix 4: Out of hours deactivation – (when CID not immediately available and deactivation needed more urgently)



Location of magnets

Clinical Investigation Department
Crash trolley High Dependency Unit (HDU)
Hospice / Palliative Care team have access to a magnet