



1 **Survivors Quality Standard:**
2 **Meeting the care and rehabilitation needs of cardiac arrest**
3 **survivors and their key supporters**

4

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32

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33 **2. Introduction**

34
35 Cardiac arrest affects tens of thousands of people in the UK every year. Although
36 circumstances may differ – with some people experiencing a cardiac arrest in the community
37 and others in healthcare settings – survival always depends on lifesaving interventions such
38 as early recognition, calling for expert help, cardiopulmonary resuscitation and defibrillator
39 use. Survival and recovery can be further improved via advanced life support, post-cardiac
40 arrest care, rehabilitation and follow-up. Existing quality standards currently cover
41 resuscitation practice and training in different settings but are not specific to rehabilitation and
42 the survivor’s journey post-hospital discharge.
43

44 **Definitions**

45 **Survivor**

46
47 We use the term ‘survivor’ here to describe any individual who has been successfully
48 resuscitated after a cardiac arrest and is not in a prolonged disorder of consciousness or on
49 a specialist neurological rehabilitation pathway. For this Quality Standard, the focus is on
50 Survivors who return home or are living in a community setting.

51 **Key Supporter**

52
53 The term ‘key supporter’ represents family members, spouses, partners or close friends of
54 cardiac arrest survivors who were impacted by the event (this list is not exhaustive). Some
55 within this group may also identify as ‘co-survivors’. The key supporter term is one that
56 resonated with patient and public involvement (PPI) partners as it reflects both family
57 members as well as those that may not be related but are close to the survivor.
58

59 **Scope**

60 This quality standard relates to the recovery and rehabilitation of survivors of cardiac arrests
61 that happened both in-hospital and out-of-hospital, irrespective of the cause (e.g. cardiac,
62 respiratory, traumatic, unidentified, etc). The scope does not cover addressing underlying
63 causes of the cardiac arrest. Some patients will survive with little to no impairment, most with
64 mild to moderate but some will require substantial ongoing care. This document covers the
65 period before discharge from the hospital up to the long-term follow-up.

66 By implementing the measures within this quality standards survivors and their key
67 supporters across the four UK nations will be provided with and will benefit from the following:

- 68 ● Access to a minimum standard of post-resuscitation assessment of physical, cognitive
69 and mental health needs before and after hospital discharge and signposting to
70 appropriate services where indicated.
- 71 ● Improved quality of service provision regarding the above standards.
- 72 ● Improved outcomes following successful resuscitation after cardiac arrest. These may
73 include benefits to their physical, cognitive, and mental health and health-related
74 quality of life.

75
76

77 This document provides a realistic and achievable quality standard for the provision of care
78 and rehabilitation needs of cardiac arrest survivors (the ‘survivor’) and their key supporters.

79

80 **Background**

81

82 ***“True recovery is more than having survived and being grateful”.***

83 RCUK CA Survivors Group participant

84 Cardiac arrest survivors are a highly heterogeneous population, ranging from those who
85 experience minimal long-term health impairments to those who suffer severe hypoxic brain
86 injury and never return home – e.g., due to persistent disorders of consciousness. Some will
87 have ongoing neuro rehabilitation needs with a dedicated pathway, but many will be
88 considered fit enough for discharge home.

89 Whilst most survivors are discharged to their usual place of residence, many will have
90 rehabilitation and support needs that impact their long-term health-related quality of life.
91 Following a cardiac arrest, around 50% of survivors have mild cognitive impairment, around
92 40% report limitations due to physical difficulties, around 70% suffer from fatigue, and 15-
93 30% experience emotional problems.

94

95 Whilst significant focus is on the survivor after cardiac arrest, this document also provides
96 standards for the follow-up of key supporters. They may also suffer long-term psychological
97 consequences including anxiety, depression, fear, and trauma due to having
98 witnessed/experienced a traumatic event (during resuscitation and/or hospital stay) and
99 having caregiving responsibilities in the mid to long term. They may also have difficulties
100 transitioning to everyday home life after hospital discharge and suffer a high burden of carer
101 strain due to providing support to the survivors from hospital admission through
102 rehabilitation/recovery and beyond.

103 Consultations with colleagues in Europe and North America have suggested that the
104 challenge is similar across international healthcare systems. Published data indicate that
105 consistency in standards and availability of dedicated follow-up care pathways remain elusive
106 in the UK, Sweden, Denmark, and the United States; yet all of these settings also offer

107 regionalised examples of effective care pathways. For example, informed by an early
108 intervention study tested with cardiac arrest survivors in the Netherlands, the Essex
109 Cardiothoracic Centre established the first dedicated “Care After REsuscitation” (CARE)
110 Service in the UK in 2016. CARE offers a systematic and specialised review of psychological
111 and cognitive needs, with a focus on societal reintegration. Initial evidence suggests that it is
112 possible to address unmet clinical needs with specialist diagnosis and therapy, resulting in
113 improvements to physical and mental health 6 months after discharge from hospital.

114 In the US, the NeuroCardiac Comprehensive Care Clinic (N4C) and a parallel initiative – the
115 NeuroCardiac Comprehensive Care for Co-Survivors and Family Members, or N4C-F – is
116 the first interdisciplinary clinic that aims to identify and address any
117 neurocognitive/neurological and psycho-social problem to minimize disability and facilitate
118 reintegration into the community.

119 The ‘Copenhagen Framework’ also advocates for a multi-disciplinary guideline-based
120 approach to improving cardiac arrest pathways that should include diagnostic evaluation,
121 screening of survivors and close family members, discharge planning, and both short-term
122 and long-term follow-up and rehabilitation. r

123 **Methods**

124 As details in Section 1 above, the development group included representatives drawn from
125 cardiac arrest survivors, their partners and key supporters; researchers in survivorship and
126 experts from the fields of cardiology, rehabilitation, physiotherapy, nursing, occupational
127 therapy, neuropsychology, speech and language therapy and community resuscitation. This
128 included people from the four nations of the UK, RCUK and partner organisations and
129 charities. The steering group’s focus was survivor-driven, with key representation from the
130 Sudden Cardiac Arrest UK (SCA UK) charity.

131

132

133

134 3. Core Standards

IN-HOSPITAL CARE (BEFORE DISCHARGE)	
	<p style="text-align: center;">Assessment for risk of reoccurrence</p> <p>Complete thorough diagnostic evaluations, including assessments for underlying causes and risk factors, to ensure comprehensive rehabilitation and long-term risk reduction</p>
	<p style="text-align: center;">Assessment of physical, cognitive and emotional wellbeing</p> <p>Assess cognition using a validated tool (MoCA, SDMT, ICQCODE-CA, CLCH). Assess fatigue using an appropriate patient-reported outcome measure (such as the MFIS-20). Assess anxiety, depression and symptoms of post-traumatic stress using a validated scale (e.g. HADS; PCL-5)</p>
	<p style="text-align: center;">Assessment and referral for rehabilitation and support needs</p> <p>Offer individualised, post-discharge care plans, including timely referrals to relevant medical and therapy specialists, cardiac rehabilitation programs, and a contact person for ongoing support</p>
 Key Supporters	<p style="text-align: center;">Assessment of key supporters</p> <p>Consider screening family members/key supporters for emotional distress related to the cardiac arrest. The HADS or the Zarit Burden Interview may be used</p>
	<p style="text-align: center;">Information and signposting</p> <p>Provide relevant information and self-management material on problems commonly experienced post-cardiac arrest . Signpost to national and local charities/peer support groups (e.g. Sudden Cardiac Arrest UK, Resuscitation Council, British Heart Foundation, SADS UK, etc).</p>
POST-DISCHARGE CARE	
	<p>Offer an appointment with the follow-up team to all survivors and their key-supporters within 3 months of discharge. Make this appointment at the time of discharge</p>
	<p>Offer a comprehensive follow-up appointment by 1 or 2 clinicians with the relevant skills who have close links with relevant in-hospital healthcare specialists.</p> <p>Agree an appropriate plan—including onward referrals, information provision and signposting—during the follow-up appointment.</p>
During the appointment cover the following subjects:	
<p>A. Heart function and medication</p> <p>B. Secondary prevention, including diet, smoking, alcohol and exercise.</p> <p>C. Implantable device support (if relevant).</p> <p>D. Family history and nature of the cardiac arrest.</p> <p>E. Physical recovery, including mobility, fatigue and physical activity.</p>	<p>F. Cognition, including memory and thinking skills</p> <p>G. Psychosocial well-being: relationships, intimacy, social reintegration, return to hobbies.</p> <p>H. Return to work, education or other responsibilities.</p> <p>I. Driving and occupational considerations.</p>
	<p>All key supporters should be invited to the follow-up appointment and offered an assessment of their emotional wellbeing</p>

Figure 1. Summary of Survivor Quality Standard Recommendations.

135 **3.1 In-hospital care (pre-discharge)**

136

137 **Assessment for risk of cardiac arrest reoccurrence and interventions to reduce this**
138 **risk**

139

140 1. All survivors must receive appropriate diagnostic evaluation of the underlying cause
141 of their cardiac arrest, including appropriate clinical evaluation, imaging, and
142 assessments.

143

144 2. Diagnosis and treatment may require onward referral, for example to specialists in
145 managing conditions related to electrophysiology or inherited cardiomyopathy. That
146 should mean that survivors are also considered for other elements of rehabilitation
147 and recovery while their underlying cause is addressed.

148

149 3. Identification and management of underlying risk factors (such as cardiovascular
150 disease) should also be addressed as part of their assessment. This may also include
151 diet and exercise referral, not only as part of the cardiac rehabilitation and recovery
152 but as a means of reducing risks for the longer term in those patients for whom this
153 may have been a contributing cause.

154

155 4. Survivors with no clear cause of their cardiac arrest identified (idiopathic) and their
156 family members should be considered for additional investigations. There is a
157 dedicated pathway for myocardial infarction as a cause of cardiac arrest, but for those
158 with no such obvious cause, further care is still needed. They should receive the same
159 assessment and referral to rehabilitation as any other cardiac arrest survivor and
160 should not be excluded a-priori from services (e.g. cardiac rehabilitation).

161

162 **Assessment for rehabilitation and support needs**

163

164 1. All survivors should be offered a multi-disciplinary assessment of their rehabilitation
165 and support needs. Structured questionnaires such as the Informant Questionnaire
166 of Cognitive Decline in the Elderly Cardiac Arrest version (IQCODE-CA) or the
167 Checklist Cognition and Emotion (CLCE-24) may be used.

168

169 2. This should be conducted by clinician(s) who have the skills to assess for
170 rehabilitation and support needs after cardiac arrest (e.g. specialist nurses,
171 physiotherapists, occupational therapists, or clinical psychologists – this list is not
172 exhaustive).

173

174 **Assessment of cognitive problems**

175

176 3. Survivors must be screened using an appropriate tool such as the Montreal
177 Cognitive Assessment (MoCA), the Symbol Digit Modalities Test (SDMT) or an
178 equivalent tool that is designed to detect even mild cognitive impairments. Post-
179 cardiac arrest cognitive dysfunction may be subtle in some patients, so routinely
180 screening all patients will ensure this is not missed and provides a baseline for any
181 follow-up assessment.

182

183 4. Where the screening tool indicates the survivor has fallen below an agreed level
184 (e.g. < 26 on the MoCA) **or** the survivor **or** key supporters report subjective
185 cognitive problems it is recommended that the survivor:

186

187 a. receives an assessment of 'functional cognition' in complex tasks pre-
188 discharge, so survivor and family are aware of any deficits and appropriate
189 strategies including social care if required are put in place before discharge
190 home.

191

192 b. is referred to an appropriate specialist (e.g. care of elderly, neurologist or
193 intensivist) for a more detailed neuropsychological assessment, as well as
194 involvement of specialist occupational therapy and other disciplines as required
195 to co-create a rehabilitation plan. It is recommended that the neurocognitive
196 examination be conducted by someone with an understanding of post-cardiac
197 arrest aftercare.

198

199 **Assessment of physical problems**

200

201 5. Survivors should be screened by appropriate healthcare professionals for physical
202 problems, with further specialist assessment to include mobility, strength, balance,
203 sensation, coordination, or vestibular function as required. Self-reported issues
204 relating to physical function can form part of individual assessment but should not
205 be relied upon as the only means of determining need for further support.

206

207 **Assessment of fatigue**

208

209 6. Fatigue is the most common problem reported by survivors. All survivors must be
210 assessed for fatigue. It is recommended to use an appropriate patient-reported
211 outcome measure. Scoring systems may include the Modified Fatigue Impact
212 Scale, Fatigue Assessment Scale or Fatigue Severity Scale although there is not
213 a specific recommendation for cardiac arrest survivors.

214

- 215 7. If initial assessment indicates there are fatigue issues, appropriate referral to a
216 fatigue assessment and rehabilitation service is recommended.
217

218 **Assessment of emotional wellbeing**
219

- 220 8. Screening of emotional problems such as depression, anxiety or post-traumatic
221 stress disorder (PTSD) is recommended for all survivors. Widely used measures
222 such as the Hospital Anxiety and Depression Scale (HADS) and PTSD checklist
223 (PCL5) are recommended.
224

225 **Referral for rehabilitation and support needs**
226

- 227 9. Based on the inpatient assessment, all survivors should have an individually
228 tailored plan for their post-discharge care with referrals made to the most
229 appropriate specialist teams. These include, but are not limited to, medical
230 specialities such as genetic testing, neurology, psychiatry, and therapy specialities
231 such as occupational therapy, physiotherapy, speech and language, and
232 neuropsychology.
233

- 234 10. Referral to cardiac rehabilitation programmes, is recommended for all survivors
235 regardless of the cause of their cardiac arrest.
236

- 237 11. Referral to rehabilitation/support services should be made before discharge where
238 possible.
239

- 240 12. Survivors should be given the name and contact details of a key person who has
241 a copy of the tailored plan and can assist with referrals to services.
242

243 **Assessment of key supporters**
244

- 245 1. It is recommended that family members or other key supporters are screened for
246 emotional distress associated with the cardiac arrest event, as well as their ongoing
247 role as a carer and supporter. The HADS and the Zarit Burden Interview may be used
248 to this effect.
249

- 250 2. Referral to the key supporter's own GP, social worker or psychologist may be
251 appropriate.
252

253 **Information and signposting**

254

- 255 3. Before discharge, the survivor and their key supporters should receive relevant
256 information and self-management material on problems commonly experienced post-
257 cardiac arrest, including cognitive, physical, and emotional subjects as well as fatigue,
258 resuming daily activities, driving, returning to work, relationships and sexuality where
259 relevant. This should be in an appropriate format (leaflets, videos)
- 260
- 261 4. Survivors and their key supporters should be signposted to national/local charities and
262 peer-to-peer support groups, e.g. Sudden Cardiac Arrest UK (SCA UK), Sudden
263 Arrhythmic Death UK (SADs UK), Resuscitation Council UK, British Heart Foundation,
264 and Chest Heart and Stroke Scotland (this is not an exhaustive list, and there are
265 updated links available at www.resus.org.uk).
- 266
- 267 5. They should have the name and contact details of a key person who can provide
268 information by telephone or email and who also has access to their in-patient
269 assessment and tailored plan for rehabilitation and support.
- 270

271 **3.2 Post-discharge care**

272 **3-month follow-up**

273

- 274 1. It is recommended that the assessment by the follow-up team is completed by one or
275 two clinicians (e.g. specialist nurses, occupational therapists, clinical psychologists -
276 this list is not exhaustive). The team should have close links with relevant in-hospital
277 healthcare specialists such as physiotherapists, speech and language therapists,
278 neuropsychologists, and various medical specialities.
- 279
- 280 2. It is recommended that the follow-up team works as a single point of contact with a
281 dedicated team of healthcare professionals who have specific knowledge of post-
282 cardiac arrest issues.
- 283
- 284 3. An appointment with the follow-up team should be offered to all survivors and their key
285 supporters within 3 months of discharge, with the appointment made at the time of
286 discharge.
- 287
- 288 4. The appointment should be suited to their communication needs, preferably in person-
289 but maybe by telephone or video conference.
- 290
- 291 5. Survivors should be able to self-refer or be referred by other health professionals
292 including GPs to the follow-up clinic if this has not already been done by the
293 discharging hospital.

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6. The following aspects of care and recovery should be covered during the follow-up visit which should lead to an individualised recovery care plan. The plan should be a holistic approach based on the experiences of the survivor and their key supporters, rather than focusing on the domains of healthcare specialties. Recommended subjects covered at the 3 month follow-up, which include Patient Reported Outcome Measures where possible:
 - a) Heart function and medication for cardiovascular disease.
 - b) Risk factors for secondary prevention, including diet, smoking, alcohol and exercise.
 - c) Implantable device support (if relevant).
 - d) Family history and nature of the cardiac arrest.
 - e) Physical recovery, including mobility, fatigue and physical activity.
 - f) Cognition, including memory and thinking skills (assessed using the MoCA, SDMT or a similar standardised test).
 - g) Psychosocial well-being – including relationships, intimacy, social reintegration, and returning to hobbies and interests.
 - h) Return to work, education or other responsibilities.
 - i) Driving and occupational considerations.
7. All key supporters (who wish to be involved) should be invited to the follow-up appointment, offered an assessment of their emotional well-being and provided information about managing their well-being and recovery and, if required, how they can support their survivor in their recovery, including signposting to appropriate resources (see section below)
8. Survivors and their key supporters should generally be discharged by the follow-up clinic after an appropriate plan has been put in place and agreed referrals made.

324 **Long term follow-up**

325 For the purpose of these quality standards, ‘long-term’ refers to the period after the initial
326 follow-up (3 months plus).

327 Be aware that individuals may need to access different information at different time points
328 after the initial follow-up to support them in “making sense” and self-managing their condition.
329 Reasons for survivors/Key supporters to contact the follow-up team for a re-referral likely
330 revolve around information-seeking on specific issues, or the need for counselling (cardiac-
331 arrest-specific counselling services, if available) and how to access this.

- 332
- 333 1. Survivors and their key supporters should be made aware they can self-refer back to
334 the follow-up clinic if there is a cardiac arrest-related issue that has emerged later on

335 that they would like to be addressed. These referrals should then be screened for
336 'appropriateness' by the 'follow-up' team.

337 **4. Organisational standards**

- 338
- 339 1. The ownership for pre-discharge assessment and follow-up care of all survivors must
340 be agreed upon at a local level. For cardiac arrest survivors, there is the potential for
341 confusion as to which speciality or hospital provider will ensure follow-up and
342 rehabilitation.
- 343
- 344 2. It is recommended that there is a clearly identified role providing leadership at a senior
345 (strategic) level to provide resources for the care of cardiac arrest survivors and this
346 may be determined by the acute care provider's Resuscitation Committee.
- 347
- 348 3. Organisations should consider using the services that already exist locally for similar
349 patient groups (post-intensive care, traumatic brain injury, stroke, and cardiac disease)
350 to deliver services for cardiac arrest survivors. Solutions include upskilling existing
351 staff and expanding referral criteria to current services to accept cardiac arrest
352 survivors.
- 353
- 354 4. Organisations should ensure that healthcare professionals who undertake and
355 interpret standardised assessments receive appropriate training to do so (if required)
- 356
- 357 5. Appropriate systems should be in place to initiate referrals and escalation pathways
358 to other medical/therapy specialists.
- 359
- 360 6. Organisations should ensure that there is a nominated recovery programme lead to
361 champion cardiac arrest recovery. This is a key role to oversee the programme at a
362 service delivery (day-to-day) level, from in-hospital assessments to outpatient follow-
363 up.
- 364
- 365 7. Appropriate space, technical support and facilities should be made available.
- 366
- 367 8. Organisations should undertake appropriate audit of service delivery.
- 368
- 369
- 370
- 371
- 372

373 **Supporting information**

374

375 Cardiac Risk in the Young

376 <https://www.c-r-y.org.uk/>

377

378 Sudden Cardiac Arrest UK

379 <https://www.scauk.org/get-support/>

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381 Sudden Arrhythmic Death UK

382 <https://www.sadsuk.org.uk/>

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