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**Cardiac Arrest – COSCA Qualitative – Resuscitation WRAP Version Accepted 20/12/2019**

**MANUSCRIPT TITLE:**

**Trapped in a disrupted normality: survivors' and partners' experiences of life after a sudden cardiac arrest**

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**Key words:** Cardiac Arrest; experiences of survival; survivors; carers.

**ABSTRACT (211/250)**

**Aim of the study:** Advances in resuscitation science have resulted in a growing number of out-of-hospital cardiac arrest (OHCA) survivors. However, we know very little about the natural history of recovery and the unmet needs of survivors and their partners. This qualitative study sought to address this knowledge gap to improve understanding of the consequences of surviving cardiac arrest.

**Methods:** In-depth qualitative interviews were undertaken separately with survivors and their partners between 3 and 12-months following the cardiac arrest. An interpretative phenomenological approach (IPA) to data analysis was adopted. Developing themes were discussed between members of the research team.

**Results:** 8 survivors (41-79 years; 5 male; mean time 6.3 months post-hospital discharge) and 3 partners (1 male) were interviewed. The key (super-ordinate) theme of being 'trapped in a disrupted normality' was identified within the data. Five related subordinate themes included: existential impact, physical ramifications, emotional consequences, limiting participation in social activities and altered family roles.

**Conclusion:** Recovery for survivors is hindered by a wide range of physical, emotional, cognitive, social and spiritual challenges that disrupt perceptions of 'normality'. Survivors and their carers may benefit from focussing on establishing a 'new normal' rather than striving to achieve a pre-cardiac social and physical position. Survivor-centred assessment should support rather than undermine this goal.

## Background

Significant advances in resuscitation science and targeted efforts to improve lay resuscitation and dispatcher training have resulted in a growing number of out-of-hospital cardiac arrest (OHCA) survivors; survival to hospital discharge rates approximate 11% across most developed countries<sup>1-3</sup>. For those discharged from hospital, five-year survival rate is estimated at 81.4%<sup>5</sup>. Hence, a significant number of ‘survivors’ are living with the consequence of cardiac arrest. However, we know little about the natural history of such recoveries, or the unmet health and social care needs for this emerging group<sup>5-8</sup>, many of whom will be coping with the consequences of anoxic brain injury<sup>9</sup>.

The end goal of cardio-pulmonary resuscitation (CPR) is to restore an individual’s quality of life<sup>9</sup>, returning survivors to an acceptable level of both physical and cognitive function<sup>11,12</sup>. Whilst the initial stages of the cardiac arrest care pathway (pre-hospitalisation; emergency and initial critical care) are increasingly prescribed and underpinned by a growing evidence-base<sup>13-15</sup>, strategies for post-acute rehabilitation and long-term care are less developed<sup>16,17</sup>. Mental health, cognitive and physical impairments, affective disturbances, seizures, movement disorders, and a reduced ability to return to pre-morbid activities are increasingly recognised in survivors<sup>18-22</sup>. A recent meta-synthesis of seven qualitative studies on the topic described an array of challenges for survivors; these included experiencing a range of emotions, a disruption to perceptions of time, an altered reality, psychological difficulties and limitations in life due to a changed body<sup>5</sup>. However, few studies have sought to explore the experiences of carers or family members<sup>18-23</sup>. Given the prevalence of cognitive impairment in survivors<sup>22,24</sup>, the views of significant others may provide a crucial insight into the unmet needs of survivors<sup>25</sup> and the ‘family system’<sup>18</sup>.

Historically, the perspective of survivors has been poorly assessed in cardiac arrest research<sup>26</sup>. As survival rates continue to increase, survivor-focused assessment that takes into consideration their unmet needs and examines quality of survival is required to inform the provision and prioritisation of tailored health and social care<sup>27</sup>. We report here findings from a qualitative exploration into the unmet needs and experiences of OHCA survivors and their partners, conducted as part of a larger international study to develop a core outcome set for cardiac arrest effectiveness trials (COSCA)<sup>27</sup>.

## Methods

### *Design*

Interpretative phenomenological analysis (IPA) was selected as a recognised methodological approach for exploring specific phenomenon (‘lived world’ experience)<sup>28</sup>(Smith et al., 2009). It seeks

to understand the unique elements of an individual's perceptions and their experiences before moving to more general claims<sup>28,29</sup>(Smith et al., 2009). This study was approved by an ethics committee (13/WM/0464).

### *Sample*

To allow an in-depth exploration of how experiences may change over time, adult (18 years +) OHCA survivors, discharged from hospital and still alive between 3-12 months post-arrest, were eligible to take part. Participants were required to have cognitive capacity to provide written informed consent, with no other terminal illness. Survivors' partners were also invited to participate in separate interviews to further understand the survivor's experience.

No database of UK OHCA survivors existed at the time of the study. Therefore, participants were recruited via three routes: a) Two UK registries that include cardiac arrest survivors in their cohort - the Intensive care National Audit and Research centre (INARC: <https://www.icnarc.org>) and the Myocardial Infarction National Audit Project<sup>30</sup>; b) cardiac rehabilitation services at one hospital in England; and c) a research team screening intensive care admissions for OHCA survivors at this hospital. Recruitment took place between May-October 2014.

Potential participants were contacted at hospital discharge or by post and invited to be interviewed. For those agreeing to take part, a convenient time and location was arranged. Following the methodological approach of IPA, which seeks to obtain an in-depth understanding of people's experiences, we aimed to talk to between 7 and 10 people, an acceptable sample size for IPA<sup>28</sup>. Pseudonyms are used in the findings when referring to participants.

### *Data collection*

Semi-structured interviews are used typically in IPA<sup>28</sup>; a conversation that is flexible and allows for further exploration of pertinent topics. After reviewing published literature, we worked closely with an established Patient and Public Involvement Group (the Clinical Research Ambassador Group [CRAG] to develop topic guides (see Appendix 1). CRAG members included patients with a range of clinical experiences – encompassing cardiovascular conditions and a survivor of in-hospital cardiac arrest. Questions asked sought to gain a broad understanding of the time before to the point of arrest and afterwards. Partner interview questions focussed on the experience of the survivor.

During interviews, careful attention was paid to what participants said and, where needed, gentle prompts encouraged them to expand on responses (e.g. 'can you tell me more about your experience of coming home after your arrest?', 'what did you mean by 'feeling fatigued'?')

With the permission of participants, all interviews were digitally recorded. Additional field notes were taken to support data analysis.

### *Analysis*

IPA is an iterative approach; it aims to create a detailed, plausible account centring on experiences and patterns within the data. Data were managed using NVivo software. The first author (LW), who undertook interviews, transcribed all recordings. She then engaged in familiarisation with data (re-reading transcripts and re-listening to recordings), focusing on one interviewee at a time. During this phase of the analysis, she made descriptive, conceptual or linguistic comments on a transcript, which constituted the coding. These comments were clustered into themes for one interviewee before focusing on the next transcript. Once all transcripts had been analysed separately, patterns across interviewees were explored. At this point, other research team members read transcripts and discussed the data, exploring alternative interpretations, thus enhancing transparency and rigour<sup>31</sup>. Preliminary ideas were also shared and explored with members of an IPA support group. From this immersion in the data, super-ordinate and sub-ordinate themes were established by mapping observed interrelationships, connections and patterns<sup>28</sup>. All data was anonymised and pseudonyms allocated to participants and aligned to specific quotes

## **Results**

### *Participant demographics*

21 survivors met the inclusion criteria and were invited to participate; 10 responded, of which 8 agreed to be interviewed (5 males; mean age 62.8 years (SD 13.6); time since hospital discharge 6.3 months (SD 3.1)). Additionally, 3 partners (1 husband and 2 wives) were interviewed separately from the survivor; 2 were present at the time of the cardiac arrest and began CPR until the arrival of paramedics. The mean duration of interviews was 42 minutes (range 20 to 66 minutes).

Analysis resulted in an overarching, superordinate theme, underpinned by five subordinate themes (Figure 1).

### ***Superordinate theme: Trapped in a disrupted normality***

Throughout interview data, an overwhelming sense of being unable to move on in life was present. We therefore developed the superordinate theme of feeling 'trapped in a disrupted normality'. After creating this theme, searching for literature on the topic highlighted how it related to Sanderson et

al.'s<sup>32</sup> notion of 'disrupted normality' in a study involving patients with rheumatoid arthritis, some of whom described being overwhelmed by symptoms, making normal life impossible. For our participants, 'disrupted normality' stemmed from uncertainty surrounding their cardiac arrest, its impact on family and social life, and its resulting physical limitations. When considered together, these aspects made it hard for survivors to contemplate what Sanderson et al.<sup>32</sup> described as 'resetting normality', which involves accepting that life can evolve even with the presence of illness. Our participants painted themselves as previously healthy - not what they considered a 'typical' cardiac arrest patient. They saw their pre-arrest health as their 'gold standard', using this as a goal against which to assess their recovery. Hence, there was a wish to return to a previous standard of living:

*"I guess what I've been trying to do is to get to where I was before...one of the things they say to you is you'll feel a new person, you'll be as good as you were and actually you aren't and you're not for a long time. And this is what 8, 9 months now and I'm probably 60% back and I don't know how far that's going to go." [David]*

The existential, physical, emotional, social, and familial impact of the arrest influenced the feelings expressed by interviewees of a liminal state, whereby they sensed being unable to return to life as they knew it, but uncertain about what their life ahead held. The contribution each of these aspects makes to our superordinate theme are explored below (Table 1 provides illustrative quotations).

### ***Existential impact***

Whilst survivors were grateful for being alive, their perception of life was changed by their experience. Hence, whilst 'Cheryl' talked about being "*lucky you're still here and you've got to do something with it*", survival gave participants an increased awareness of the fragility of life and, consequently, altered their outlook for the future. The reality of death's inevitability was heightened for them. A subtle preoccupation with death appeared to interfere with a move towards a form of resetting their normality.

### ***Physical ramifications***

New physical symptoms limited what people could do in terms of mobility and interactions with others. This disrupted what they perceived to be their normal functioning. Symptoms included fatigue, pain (from ribs broken whilst being resuscitated), substantial loss of weight and muscle strength, and increased breathlessness. Cognitive functioning could also be affected leading to poor memory, difficulties making decisions, and speech problems.

### ***Emotional consequences***

Restrictions brought about by the physical limitations of having an arrest resulted in frustration among participants. Furthermore, fear and uncertainty about having another cardiac arrest pervaded interview transcripts. Loss of confidence and subsequent low self-esteem were also mentioned as emotional consequences of surviving. Dealing with these new emotional challenges made it difficult to move towards resetting normality post-arrest.

### ***Limiting participation in social activities***

Physical and emotional changes affected survivors' pursuit of leisure activities as well as voluntary and paid roles. For example, hobbies could not be undertaken due to reduced physical strength and fatigue, having an impact on socialisation. In addition, some interviewees adjusted their work arrangements as they found it difficult to complete the same tasks and hours as before. These limitations contributed to a 'disrupted normality', which affected people's social identity.

### ***Altered family roles***

Interviewees' previous social identities appeared to be disrupted specifically within the family. This happened when people were no longer able to undertake caring roles (e.g. for grandchildren or partners). Some participants mentioned strained relationships post-arrest due to a change in the survivor's personality or the burden of caring on a partner's own health.

## **Discussion**

'Disrupted normality' was a strong theme that we developed from the data. Normalisation is a concept that has been used with other chronic illnesses<sup>32-35</sup>, but not with survivors of OHCA; hence, this paper provides further insight and a novel contribution to the literature. Normalisation centres



on an individual's endeavours to live with an illness and reflects the disconnection people may encounter between body and self as a consequence. The unanticipated nature of cardiac arrest appeared to lead to a 'disrupted normality' that was challenging to overcome. This rupture touched upon all aspects of life – the existential, physical, emotional, social, and familial - affecting not just the individual survivor but also their family and social networks. This wide-reaching spread of impact suggests that a multi-disciplinary approach is needed to enable survivors to move beyond the disrupted, towards an acceptable 'new normality'.

'Disrupted normality' fits with ideas around liminality, a term from anthropology<sup>36-37</sup> that refers to the space people inhabit when they span two distinct states of being (e.g. ill/healthy). Liminality is associated with ambiguity, loss of status and marginality.<sup>38</sup> It has been linked to other conditions, such as cancer,<sup>39-42</sup> but not previously to the experiences of OHCA survivors. 'Disrupted normality' sees a fracturing between the past (perceived as predictable and understandable) and a future shaped by uncertainty and insecurity, leaving OHCA survivors unsure about how to manage the consequences of their transformed life. They may encounter ongoing concerns about having another arrest, experience their body as unreliable and previous hopes for the future may be lost. Entering a liminal state can trigger a rethinking and re-evaluation of norms and assumptions they have developed about their place in the world.<sup>42</sup> Hence, inhabiting a liminal state allows for reflection as identity undergoes a reformulation. However, OHCA survivors may require support from professionals to manage this precarious state of being; they need a facilitative environment to express difficult emotions (e.g. anger, fear) and to assimilate a change in self-identity in terms of the beliefs they hold about themselves and how they believe others perceive them<sup>43-45</sup>. Our research has highlighted that factors potentially prolonging a survivor's liminal state and perpetuating this 'disrupted normality' include ongoing concerns with death, physical limitations, emotional challenges or altered social positions.

This is the first qualitative study to interview partners of survivors of OHCA in a UK setting. Inclusion of partners' accounts supported and expanded on survivors' narratives. For example, partners mentioned changes to survivors' emotional well-being, particularly reduced confidence. 'Disrupted normality' impacted deeply upon partners. One other study that explored the perspective of significant others of survivors of a cardiac arrest reported that these individuals recounted how it represented "a threat that disrupts everyday life", since it tended to occur without warning, leading to feelings of insecurity about the future<sup>23</sup>. This underlines the importance of attending to the needs of survivors' relatives. They may not expect to receive care themselves<sup>46</sup>, yet research suggests that social support can help individuals move towards renegotiating a 'new normality'<sup>47</sup>.

Findings from our research expand on elements identified in a meta-synthesis of qualitative papers involving survivors of cardiac arrest<sup>5</sup>, and of a meta-ethnography exploring the meaning of life and death for survivors,<sup>48</sup> by identifying this unifying theme of 'disrupted normality'. It relates to earlier work on biographical disruption, whereby illness brings an end to taken-for-granted assumptions of everyday life, forcing individuals to reappraise their place in the world. It reflects how someone's life trajectory is thrown off course, and associated beliefs and expectations must be re-evaluated<sup>49</sup>.

Other authors emphasise the importance of establishing a 'new normality' when faced with significant illness, which may include developing resilience, being resolute about a condition not defining them and connecting with others who have been through the same experience<sup>47</sup>. This 'new normal' may see a shift in previously held expectations and beliefs, and can involve living with a degree of uncertainty<sup>47</sup>. A 'new normal' entails striving for 'positive living', accepting and acknowledging a changed status, and learning to cope with arising challenges<sup>50</sup>. This should be a goal for health professionals working with survivors and their care-givers, to help people reconceptualise what constitutes normal bodily experiences. They should support people to reset normality, whereby they move from being vulnerable patients post arrest, "to becoming a person again" who is able "to perceive their life as...meaningful..."<sup>32</sup>.

Some of our participants talked about re-evaluating what was important in life, yet appeared to still be hampered by anxiety and fears about the future. Resetting normality for those disturbed by illness calls for these individuals to be supported to live up to their personal values<sup>32,47</sup>. This should be acknowledged by health professionals and incorporated into goal setting as part of post-resuscitation care. For example, in some people, feeling they can contribute to family life may prove a greater priority than other objective, clinician-derived, markers of progress.

Assessment of progress among survivors should reflect where they are at that moment in time, rather than focusing on a return to a previous state of being. This may mean a shift away from a socially informed "...moral acceptance that 'normal is good' [which] places social pressure and responsibility on individuals to maintain an appearance of normality whatever the cost"<sup>34</sup>. A 'gold standard' of status prior to arrest is not helpful given that for everyone, normality is ethereal because we are all ageing and changing on a daily basis. Nothing remains static; this becomes a stark reality when faced with a sudden change in health. Consequently, any assessment that takes into consideration people's values and the notion of a new (or shifting) normal seems to be an important area for development.

Further research indicated by this study includes investigating which of the five aspects of 'disrupted normality' a clinical team should target first, or whether it is possible to address several in tandem. It

is likely that this will vary between survivors, calling for a tailored approach post-arrest. Someone who has overriding anxieties about their physical vulnerability may require psychological support before engaging in activity. Conversely, another person may need relationship counselling if a caregiver is being overly-protective. In addition, future researchers could conduct a series of interviews over a longer time period to allow for a greater understanding of how changes to 'normality' vary across recovery.

In common with other qualitative research in the field, a limitation of our study is that the views of survivors with a poor neurological outcome have not been captured. The study was strengthened by the inclusion of female survivors (37.5%). Incidence of cardiac arrest is higher in males, but previous qualitative research has been dominated by accounts from men<sup>5</sup>.

Our study highlights the wide ranging and significant impact a cardiac arrest and subsequent recovery can have on an individual and their close networks. It depicts the 'disrupted normality' that can occur, emphasising the importance of optimising provision of multi-disciplinary care for survivors and their relatives. Goals associated with progress post-discharge should focus on establishing a 'new normal', rather than trying to return to a physical and social position associated with someone's pre-cardiac arrest self. This may mean helping individuals to identify and incorporate important, personal values into their 'new normality' and into any assessment conducted by healthcare professionals.

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## COSCA Disrupted Normality

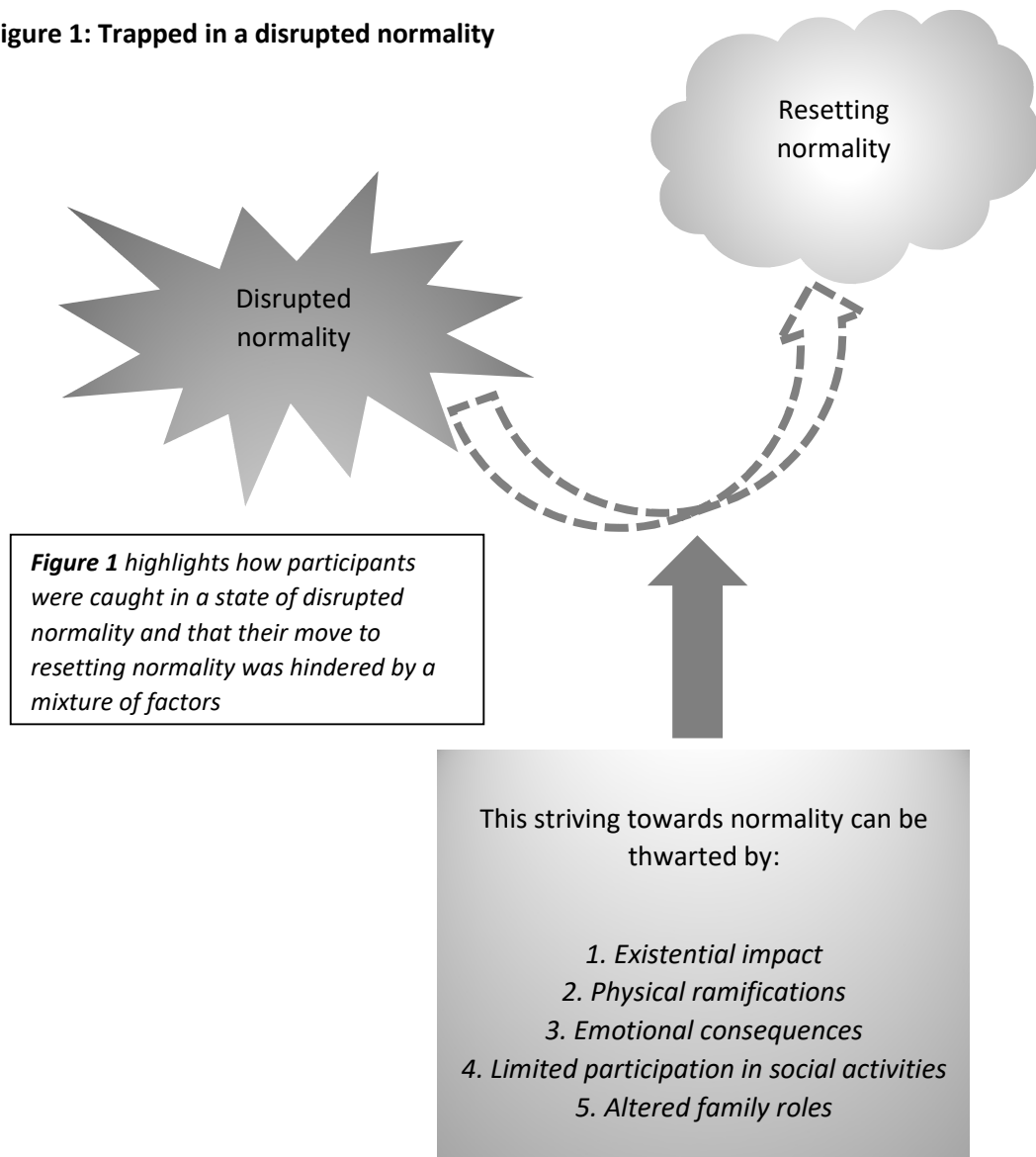
**Table 1: Illustrative quotations for sub-ordinate themes**

Sub-ordinate theme	Illustrative quotations
<b>Existential impact</b>	<p><i>"It is scary, I'm scared in case it happens again...I can't get to sleep because I'm thinking I'm not going to wake up."</i></p> <p><i>"I think it was quite frightening for quite a long time. The fact that he got no warning ... how'd you know it wouldn't happen again?" (Survivors wife)</i></p>
<b>Physical ramifications</b>	<p><i>"I just don't have the strength in my legs at the moment to even make it worthwhile, to get on a bike at all."</i></p> <p><i>"Somebody will ask me the name of something and I can't figure what it is and I'll remember it but it'll be the wrong one ... I'll get it all twisted and it'll be something totally different ..."</i></p>
<b>Emotional consequences</b>	<p><i>"I have moments when I sit thinking 'Am I having pain in my chest, is this because I've been exerting myself?' Should I be thinking more carefully about what I should be doing or does this happen to everybody and I'm now a little paranoid about what happens?"</i></p> <p><i>"...it does get frustrating when you think to yourself 'I really haven't done enough work to ... feel this tired'"</i></p>
<b>Limiting participation in social activities</b>	<p><i>"I did a lot of craftwork like these and dolls houses. I haven't got the same, I don't feel the same, I don't know why, it's just disappeared..."</i></p> <p><i>"He could not wait to get back swimming again, he really couldn't wait. And he was very disappointed when the doctor told him he couldn't." (Survivors wife)</i></p>
<b>Altered family role</b>	<p><i>"I think it was more stressful for (partner's name) than it was for me, in as much as when I was in hospital I was being looked after and I couldn't be looked after better, but when I came home the responsibility went straight back onto her shoulders ... we didn't get the support I didn't think from the community nursing that she deserved."</i></p>

	<p><i>“He’s very impatient now, he gets more impatient with people, situations, definitely got a shorter fuse than he did have.” (Survivors wife)</i></p>
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## COSCA Disrupted Normality

**Figure 1: Trapped in a disrupted normality**



## COSCA Disrupted Normality Appendices

### Appendix 1 : Topic guides

#### Topic guide for cardiac arrest patient interviews

This is a guide of topics to cover in interviews with cardiac arrest patients. There are example questions included for each topic area.

##### 1.Topics:

- Narrative
- Pre-arrest
- Post-arrest in hospital
- Daily life and activities
- Treatments management
- Messages to others
- Final questions/comments

##### 2.Question examples:

###### *Narrative*

- Could you tell me your story of your cardiac arrest?

###### *Pre-arrest*

- Can you tell me about the days leading up to your cardiac arrest?
- Can you tell me about your health leading up to your cardiac arrest?
- Were there any signs of any problems with your health before your arrest?
- What were you doing on the day of your cardiac arrest?

###### *Post-arrest in hospital*

- Could you remember anything about the arrest?
- Did experience any visions or out of body experiences?
- Can you remember and describe how you felt when you woke up/regained consciousness?
- Can you describe your time in hospital to me?

###### *Daily life and activities*

- What has life been like since your cardiac arrest?
- Where do you think you have made the most improvements since your cardiac arrest?
- What effect has the cardiac arrest had on your daily life? Work, relationships?
- Has your cardiac arrest restricted you in anyway? Have you had to make any changes to your daily routine?
- What sort of activities have you been doing since your cardiac arrest?
- Are there any activities that you are unable to do since your arrest?
- Has the arrest had any effect on your social activities?

###### *Treatment*

- What treatment options have you discussed with your doctor? (ICD, pharmacological treatments)

- Do you have any side effects from any of the treatments you have that you have started because of you cardiac arrest?

#### *Messages*

- What do you think people that make decisions in the NHS need to know about the care for cardiac arrest patients?
- What do you think people that care for and complete research on cardiac arrest patients need to know about the experience that they may not understand?
- Do you have any messages that would be useful to others that have recently had a cardiac arrest?
- Do you
- have any messages that would be useful to the family of those that have recently had a cardiac arrest?

#### *Final questions/comments?*

- We have researched the end of our interview. Is there anything else you would like to add that we might have missed out?

## Topic guide for cardiac arrest family member and carer interviews

This is a guide of topics to cover in interviews with patients and family members. There are example questions included for each topic area.

### 1. Topics:

- Narrative
- Pre-arrest
- Post-arrest in hospital
- Daily life and activities
- Treatments management
- Messages to others
- Final questions/comments

### 2. Question examples:

#### *Narrative*

- Could you tell me your story of their cardiac arrest?
- Tell me about what you were doing when the arrest happened?

#### *Pre-arrest*

- Can you tell me about the days leading up to their cardiac arrest?
- Can you tell me about their health leading up to their cardiac arrest?
- Were there any signs of any problems with their health before their arrest?
- What were you doing on the day of their cardiac arrest?

#### *Post-arrest in hospital*

- Can you tell me about when they were unconscious?
- Can you tell me about when they woke up/regained consciousness?
- Can you describe their time in hospital to me?

#### *Daily life and activities*

- What has life been like since their cardiac arrest?
  - Asking about changes to the patients and family members or carers life
- Where do you think they have made the most improvements since their cardiac arrest?
- What effect has the cardiac arrest had on daily life? Work, relationships?
  - Asking about changes to the patients and family members or carers life
- Has the cardiac arrest restricted you in anyway? Have you had to make any changes to your daily routine?
- Has the cardiac arrest made changes to their life? Have they had to make any changes to their daily routine?
- What sort of activities have they been doing since their cardiac arrest?
- Are there any activities that they are unable to do since their arrest?
- Do you think the cardiac arrest have affected their social activities?

#### *Treatment*

- Have you witnessed or been told about any side effects from any of the treatments that they have started because of their cardiac arrest?

### *Messages*

- What do you think people that make decisions in the NHS need to know about the care for cardiac arrest patients?
- What do you think people that care for and complete research on cardiac arrest patients need to know about the experience that they may not understand?
- Do you have any messages that would be useful to the family of those that have recently had a cardiac arrest?

### *Final questions/comments?*

- We have researched the end of our interview. Is there anything else you would like to add that we might have missed out?