

# Patient and family experiences of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) discussions: an integrative review of the literature

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## Background

- DNACPR communication and decision making has relevance in all areas of clinical care.
- In the UK an advance decision not to attempt CPR is taken if such an attempt is deemed futile or if the patient does not wish it to occur.
- An English Court of Appeal ruling led to revised national guidance emphasizing good practice with regards to engaging with patients and families.

*“Causing patient ‘distress’ per se is now not reason enough to not discuss implementation of a DNACPR decision”*  
(Tracey vs. Addenbrookes Hospital Trust 2014)

- A light touch review of the NHS Scotland policy on DNACPR decision-making and communication highlighted the need for an overview of the evidence in this area to inform good practice guidance.

## Aims

- To identify patient, family or carer experiences and expectations of DNACPR discussions.

## Methods

- We searched 7 databases using the keywords: ‘CPR’/‘DNR’/‘DNAR’/‘NFR’/‘DNACPR’ discussions ‘Resuscitation orders’, ‘DNR order’, ‘Allow Natural death order’, ‘CPR conversations’, ‘Patient and Carer experiences of discussing resuscitation’, ‘Patient, family carers’ perceptions/perspectives on CPR discussions’.
- We included papers from all settings which focused on DNACPR discussions.
- We excluded papers which did not focus on patient or family experience or expectation of DNACPR discussions; papers pre-2004; opinion pieces; case note reviews and where abstracts only available.
- **Coding system:** devised to assess topic relevance; validated for inter-rater reliability.



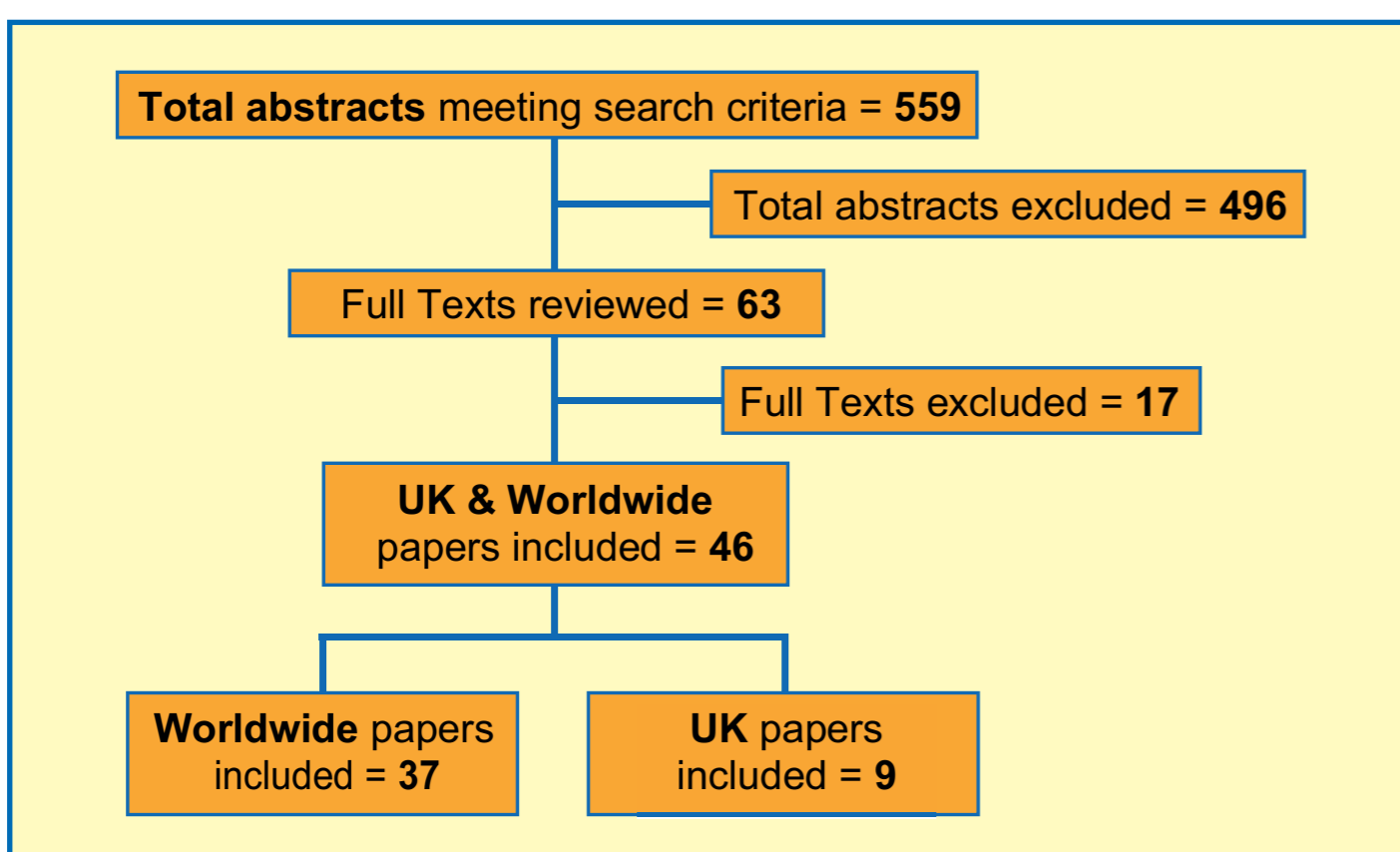
Theme 1: Who should initiate / be present during DNACPR discussions?	
UK Papers	Worldwide Papers
<ul style="list-style-type: none"> <li>• Discussions should be led by someone known to the patient.</li> <li>• <b>GP if at home</b> or if in hospital: a consultant or specialist nurse.</li> <li>• <b>Someone trusted</b> as well as...</li> <li>• <b>Trust built up over time</b> is perceived to be important in creating the environment in which the communication necessary to underpin ACP/DNACPR discussions can take place.</li> </ul>	<ul style="list-style-type: none"> <li>• Most would prefer their family physician to hold resuscitation discussions.</li> <li>• One of the top ‘most favorable’ factors for DNR discussion scenarios is <b>discussion held by attending (consultant)</b>.</li> <li>• Staff who have formed a relationship with the patient may initiate the discussion</li> <li>• “Trust in my doctor”, “my doctor seeing me as a person” are important facilitators to EOL communication.</li> <li>• However, trust in the patient’s doctor or family may lead to patients wishing to engage less in ACP discussions.</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Importance of FAMILY presence</b> during DNACPR discussions and the importance of family understanding.</li> <li>• Family presence may mean the patient feels their wishes are more likely adhered to.</li> <li>• A strong feeling that patients and their relatives wish to be involved in the discussion of CPR.</li> <li>• Concern that involving family may be a burden on them.</li> <li>• Males are more likely to feel resuscitation should be a medical decision, whereas females more likely to wish for family involvement.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients in assisted living facility wish carers to be involved in EOL decision making</li> <li>• Many patients have talked about EOLC preferences with family but very few have discussed this with their physician.</li> <li>• Emotional involvement of nominated family member can be problematic.</li> <li>• Family lean towards a physician decision where the patient was autonomous before admission, but a family decision was more likely when the patient had been dependent before admission.</li> <li>• Family members with higher education prioritised family involvement in the DNR decision.</li> </ul>

Theme 2: When/Where should DNACPR discussions take place?	
UK Papers	Worldwide Papers
<ul style="list-style-type: none"> <li>• Early in the disease and continue throughout.</li> <li>• Relatives felt that discussions should take place much closer to death.</li> <li>• Discussions close to diagnosis or starting treatment were less favorable for cancer patients.</li> <li>• Discussions require time and privacy.</li> </ul>	<ul style="list-style-type: none"> <li>• Doctors expressed difficulty in finding the appropriate moment to discuss resuscitation.</li> <li>• Establishing patient’s preferences should be ongoing process.</li> <li>• Some patients feel earlier discussion is better to allow them to finalise affairs and while cognitive state is better.</li> </ul>
<ul style="list-style-type: none"> <li>• Discussions held during acute admissions (such as exacerbation of COPD) may not be recalled after discharge.</li> <li>• The best time to discuss DNACPR preferences for these patients is at home or in the GP surgery soon after an acute admission.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients may not recall, or may recall different components of the discussion compared to their physicians.</li> <li>• Preferred setting would be their physician’s office (GP surgery). Home is more preferable to the hospital setting.</li> </ul>
<ul style="list-style-type: none"> <li>• Early EoL discussions can enable people with life limiting disease to include dying as part of life.</li> <li>• Leaflets giving information on CPR to hospice patients are acceptable but should be followed up by an individualised discussion.</li> </ul>	<ul style="list-style-type: none"> <li>• Around half of primary care patients would prefer DNR discussions while healthy.</li> <li>• A scripted intervention about CPR and ventilation could be useful at the time of admission.</li> </ul>

Theme 3: How/What should a DNACPR discussions occur/ include?	
UK Papers	Worldwide Papers
<ul style="list-style-type: none"> <li>• Patients prefer discussions to be individualised, empathetic, honest, straightforward and balanced. They should include information on risks involved and low chances of success.</li> <li>• Discussions should include details of prognosis and quality of life (QOL) and be held with patient and NOK. They should consider levels of education and literacy.</li> <li>• QOL is a key factor in the decision making process.</li> <li>• Initiating resuscitation discussions enables patients to begin to address issues related to EOL and dying.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients valued discussions including assurance of: pain relief, non-abandonment, information on hospice care, and honesty about prognosis.</li> <li>• Discussions should be individualised regarding content and timing and focus on patient’s knowledge of prognosis, goals for the future and desire for life prolonging treatments.</li> <li>• Professionals should review past experiences/fears of death &amp; dying and assess whether they accept dying as a likely outcome.</li> <li>• Ending the discussion with a question or a recommendation are both acceptable.</li> </ul>
<ul style="list-style-type: none"> <li>• Patients found discussing CPR as part of a ‘Treatment Escalation Plan’ (TEP) a good idea, and this caused no excess of anxiety.</li> <li>• Patients feel that discussions re. CPR in the wider context of a TEP make them feel: “looked after” “reassured”, caused them to “to face reality” and “put things in to perspective”.</li> </ul>	<ul style="list-style-type: none"> <li>• Few patients find the topic of DNACPR stressful when addressed by questionnaire or when addressing CPR as part of a Physician Orders for Life Sustaining Treatment POLST document.</li> <li>• Patients felt listened to and that the provider cared about the decision making process.</li> </ul>
<ul style="list-style-type: none"> <li>• Shared decision making is important for cancer patients.</li> </ul>	<ul style="list-style-type: none"> <li>• Shared decision making between patients and doctors is the patients’ preferred model.</li> </ul>

## Conclusions

- Minimal original research in the last 10 years. Conclusions based on UK papers alone are not appropriate due to the low numbers.
- Cultural variance make certain conclusions from worldwide papers less applicable to UK papers, however there were many overlapping themes falling in to three categories.
- All DNACPR discussions should be individualized in terms of: timing, level of understanding, past experience, expectation, goals and fears.
- Patients prefer to hold DNACPR discussions with someone known, trusted and knowledgeable: in many cases this should be their own GP.
- Discussion of CPR in the context of a wider discussion around EOL preferences is acceptable, and does not cause excess distress.
- More original research is needed in this area to enable development of an evidence-based approach to the most effective communication methods.



## Results

- The literature search from the last 10 years identified a lack of UK data in areas of 1. Experience of DNACPR discussions (5 papers) and 2. Expectations of DNACPR discussions (4 papers).
- Worldwide literature showed a similar trend.
- Cultural variances in worldwide literature are acknowledged.
- We identified 3 themes which are summarized in tables 1-3.

### References:

Decisions relating to cardiopulmonary resuscitation. (2014) Guidance from the British Medical Association (BMA), the Resuscitation Council (UK) (RC (UK)) and the Royal College of Nursing (RCN).  
Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). An integrated Adult Policy, decision-making and communication (2012) NHS Scotland and Scottish Government.