



**BIOMEDICAL & SCIENTIFIC RESEARCH ETHICS COMMITTEE
(BSREC) APPLICATION**

**NATIONAL INSTITUTE OF HEALTH RESEARCH HEALTH SERVICES AND
DELIVERY RESEARCH PROGRAMME**

**DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION (DNACPR)
DECISIONS**

PROJECT REFERENCE 12/5001/55

STUDY PROTOCOL

VERSION 2.0

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PROJECT LEAD

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1. Title

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions.

2. Name of project team and project 'lead'

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Conflicts of interest:

GDP is a volunteer member of the Executive Committee of the Resuscitation Council (UK). RC(UK) have produced national guidance on Do Not Attempt Cardiopulmonary Resuscitation decisions. Phillip Satherley is employed by Compassion in Dying and Dignity in Dying. The other authors declare they have no conflicts of interest.

2. Lay Summary

When someone suffers sudden cardiac or respiratory arrest, CPR may restart their heart and breathing. CPR interventions are invasive and include chest compressions, electric shocks, injection of drugs and artificial ventilation. If attempted promptly, CPR has a reasonable success rate in some circumstances. Generally, however, CPR has a very low success rate and the burdens and risks of CPR include harmful side effects such as rib fracture and damage to internal organs; adverse clinical outcomes such as brain damage due to lack of oxygen and other consequences for the patient such as increased physical disability.

If the use of CPR is not successful in restarting the heart or breathing, it may mean that the patient dies in an undignified and traumatic manner. National guidelines exist describing the context, setting and process for making informed decisions to omit CPR in certain circumstances. These are known as “Do not attempt cardiopulmonary resuscitation” (DNAR / DNACPR) decisions and are made as part of an overall treatment plan of a patient prior to a cardiac arrest occurring.

In brief there are three situations where a DNACPR decision is appropriate

– (i) when a patient makes an informed decision to decline CPR (ii) in situations where CPR is known to be ineffective (iii) when the doctor and patient (or relative if they are unconscious) together feel the burdens of CPR would outweigh the potential benefits. Getting it right is so important. For people close to death with an irreversible condition or when CPR would be ineffective a DNACPR decision facilitates a natural, dignified death. Applying a DNACPR inappropriately may deny the patient the chance (however small) of surviving a cardiac arrest.

Several recent high profile cases in the media

highlight evidence of inconsistency and poor implementation across NHS Trusts. This highlights the urgent need for a review of current evidence, policy and practice.

This project seeks to summarise the research evidence around DNACPR decision, identify the reasons why conflict and complaints arise and identify inconsistencies in implementation of national guidelines across NHS Acute Trusts. To ensure the project remains focused on the issues that are important to patients, relevant to NHS staff and incorporate ethical and legal frameworks, the project will be overseen by a stakeholder group comprising healthcare users, providers, ethicists, legal personnel and policy makers.

Our approach includes a systematic search and detailed synthesis of published research, assessment of the extent of the problem through reviewing NHS complaint registries and enforcement notices, measuring inconsistency in implementation of current guidelines across acute NHS Trusts. We will use case studies to explore health providers' experiences and views around DNACPR decisions to identify the practical difficulties of implementing policy in practice.

Guided by our steering group, we will synthesis the findings from this scoping exercise into a report that summarises the important issues and includes recommendations for policy. We have identified robust pathways for the dissemination of the output of this work through peer review publications, education (integration with Resuscitation Council (UK) National Resuscitation Training Courses; National End of Life Care Education Pathways), patient and professional organisations and linkage to policy makers.

3. *Summary*

When someone suffers sudden cardiac or respiratory arrest, cardiopulmonary resuscitation (CPR) may restart their heart and breathing. CPR interventions are invasive and include chest compressions, electric shocks, injection of drugs and artificial ventilation. If attempted promptly, CPR has a reasonable success rate in some circumstances. Generally however, CPR has a very low success rate and the burdens and risks of CPR include harmful side effects such as rib fracture and damage to internal organs; adverse clinical outcomes such as brain damage due to lack of oxygen and other consequences for the patient such as increased physical disability. If the use of CPR is not successful in restarting the heart or breathing, it may mean that the patient dies in an undignified and traumatic manner. Prolonged attempts may be distressing for the family.

National guidelines exist describing the context, setting and process for making informed decisions to omit CPR in certain circumstances. These are known as “Do not attempt

cardiopulmonary resuscitation” (DNAR/DNACPR) decisions and are made as part of an overall treatment plan of a patient prior to a cardiac arrest occurring.

Epidemiological data indicate that the majority (>75%) of people who die in hospital do so with a DNACPR order in place). In brief there are three situations where a DNACPR decision is appropriate

- (i) When a patient makes an informed decision to decline CPR
- (ii) In situations where CPR is known to be ineffective
- (iii) When the doctor and patient (or relative if they are unconscious) together feel the burdens of CPR would outweigh the potential benefits.

Getting it right is so important. For people close to death with an irreversible condition or when CPR would be ineffective a DNACPR decision facilitates a natural, dignified death. Applying a DNACPR inappropriately may deny the patient the chance (however small) of surviving a cardiac arrest. Several recent high profile cases in the media highlight evidence of inconsistency and poor implementation across NHS Trusts. This highlights the urgent need for a review of current evidence, policy and practice.

This research seeks to summarise the research evidence around DNACPR decisions, identify the reasons why conflict and complaints arise and identify inconsistencies in implementation of national guidelines across NHS Acute Trusts. To ensure the project remains focused on the issues that are important to patients and their families, relevant to NHS staff and incorporate ethical and legal frameworks. A stakeholder group comprising healthcare users, providers, ethicists, legal personnel and policy makers will oversee the project.

The research will include a systematic search and detailed synthesis of published research, assessment of the extent of the problem through reviewing NHS complaint registries and enforcement notices, and measuring inconsistency in implementation of current guidelines across acute NHS Trusts. We will use case studies to explore health providers’ experiences and views around DNACPR decisions to identify the barriers and facilitators to implementing policy in practice.

The findings from the scoping exercise will be synthesized into a report that summarises the

important issues and includes recommendations for policy. We have identified robust pathways for the dissemination of the output of this work through peer review publications, education (integration with Resuscitation Council (UK) National Resuscitation Training Courses; National End of Life Care Education Pathways), patient and professional organisations and linkage to NHS commissioners and policy makers.

4. *Research aim*

To summarise the research evidence around do not attempt cardiopulmonary resuscitation (DNACPR) decisions, identify the reasons why conflict and complaints arise and identify inconsistencies in implementation of national guidelines across the NHS and examples of best practice.

4.1 Objectives

- i. To review and summarise the published evidence base informing DNACPR policy and practice
- ii. To identify the themes of current complaints / conflict in relation to DNACPR decisions and explore local solutions developed to tackle these problems
- iii. To explore health professionals experiences of DNACPR policy and practice
- iv. To examine current acute hospital, community and ambulance service policies to identify inconsistencies and examples of best practice across NHS organisations
- v. To summarise, prioritise and disseminate findings from this research.

5. *Background*

Each year around 285,000 people die in acute hospitals. The National End of Life Care (EOLC) Strategy aims to bring about improvement in access to high quality care for all adults approaching the end of their life. However less than one fifth of people who die in hospital are recognised to be at the end of their life and enrolled in EOLC Pathways. This suggests the majority of deaths occur in those with an acute illness where discussions about EOLC and care pathways is less clearly defined, or that doctors are bad at recognising when patients are approaching the end of life and/or addressing and documenting these issues.

Cardiac arrest is the final common step in the dying process. In the right context, resuscitation can reverse the dying process, yet success rates are low. However CPR is a highly invasive medical treatment which if applied in the wrong setting can deprive the patient of dignified death. Do not attempt cardiopulmonary resuscitation (DNAR or DNACPR) provide a mechanism through which decisions to withhold CPR can be taken prior to a patient sustaining a cardiac arrest.

Despite the presence of national guidelines on DNACPR decisions, recent evidence suggests wide variation in NHS organisation policies and poor implementation of policy into practice. The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) report in 2012 focused on cardiac arrest. This review of patients' notes from 460 hospitals in the UK identified substantial gaps between optimal care and real life practice. Key findings were a frequent failure to consider resuscitation status, a high number of futile resuscitation attempts in frail patients with substantial comorbidities, limited engagement of families and patients in reaching DNACPR decisions and 52 cases where CPR was performed against the expressed will of the patient. Current guidelines are informed primarily by ethical and legal considerations with little focus on the available research evidence. Our scoping review of the literatures suggests substantial published evidence on DNACPR but a lack of a high quality, comprehensive systematic review that could support policy makers by summarising the best evidence. "How people die remains in the memory of those who live on" are the opening words of the DH National End of Life Care Strategy and serve to remind us of the importance of getting end of life care right. This research will produce rigorous and relevant evidence relevant to DNACPR decisions. It will summarise existing research, measure the quality, access and organisation of DNACPR decisions in the UK, explore healthcare providers experience of DNACPR decisions and identify exemplars of best practice.

The research is aligned to the strategic objectives of the National End of Life Care Strategy and seeks to raise the profile of EOLC, improve identification of people nearing the end of their lives, support care planning and coordination, summarise research and identify future research needs to ensure the highest quality of care can be delivered to all as they approach the end of their life. The evidence summarised above and the recent publication of the NCEPOD report highlight the urgent need to improve DNACPR policy and practice in the UK

6. *Work packages*

The programme of work will be divided into five work packages. The associated research methodology for each work package is detailed in section seven. In brief:

- Work package (WP) 1 will synthesise existing research evidence for DNACPR decisions through a systematic review of the literature, thematic review and meta-analysis (if possible)
- WP 2 will identify the themes behind why DNACPR processes fail by examining Coroner Article 43 notices; incidents, serious untoward incidents, complaints and enquiries from NHS providers and a data from a patient/relative helpline
- WP 3 will identify current NHS practices through a review of local Trust DNACPR policies and procedures mapped against national guidelines. It will seek examples of best practice alongside looking for evidence of inequality and inconsistencies
- WP 4 will obtain health service providers perspectives on current process. We will use focus groups to identify understanding of current guidelines and the practical difficulties of implementing policy in clinical practice
- WP 5 will pull packages 1-4 together to produce and disseminate a final report. This will be facilitated by a consensus conference with the stakeholder group and representatives of policy makers, patient and professional organisations and those responsible for education and development, to consider the how these findings will impact on future policy and research in the UK. Following this we will summarise and disseminate the findings of the project, setting out the recommendations for best use of available evidence to direct policy and practice, highlighting gaps in the evidence base and indicating prioritised future research needs.

7. *Research methods*

7.1. WORK PACKAGE 1: Synthesising the evidence for DNACPR decisions

A systematic review will be conducted to identify, categorise and summarise research evidence on DNACPR decision-making and implementation. The areas of most interest will be variability in DNACPR practice, reasons for variation including attitudes, communicating DNACPR decisions, identifying decision-makers and implementers, determining appropriateness of DNACPR.

We will search a range of databases, including Medline, Embase, ASSIA, all sections of the Cochrane Library, CINAHL, PsychInfo, and Web of Science. Our expectation is that indexing of qualitative studies is still less well-developed than indexing of quantitative studies. We expect titles may not be informative, that there may be no abstracts or key-words, and that we will have to obtain full copies of many papers in order to assess for inclusion. Searches will err on the side of sensitivity, and we accept that manual checking will be time-consuming. We will restrict searches to English language, initially for the last 10 years, but going back 20 years if we find insufficient recent studies. We will search grey literature, check references in key papers, and seek comments from experts.

Studies will be selected according to pre-defined inclusion/exclusion criteria. Studies will be read, categorised as useful, not useful or borderline. All borderline studies will be read by at least two people. However if we find a large number of useful papers, and then find that we reach saturation points, the review of those topics will end there.

We will assess the quality of evidence using standardised quality assessment tools appropriate to the study design. Common themes will be identified and tabulated. We will identify areas of consistency and non-consistency across studies and examine reasons for the latter. Results will be synthesised as appropriate. If there are quantitative data (for example from intervention studies on implementation of DNACPR decisions), these may be summarised in a meta-analysis, depending on heterogeneity of settings and interventions. When meta-analysis is not possible or not appropriate, results will be summarised in an interpretive review. Several team members will do this independently and interpretations will be discussed.

Our scoping searches have identified 11 intervention studies ranging from documentation methods to staff education. If possible, (depending on the heterogeneity of settings and interventions) data from interventional studies will be pooled in a meta-analysis. Where this is not possible a narrative synthesis of the results will be produced.

Our scoping search identified 17 qualitative studies, and full searches may find more. Our approach to the qualitative studies will be to undertake a thematic analysis (Dixon-Woods 2004). Consideration will be given to developing a meta-ethnography[1,2] if further searches and scrutiny of papers suggest that a higher-order analysis might be productive, for example using a lines-of-argument synthesis[3].

The systematic review protocol will follow the PRISMA guidelines and has been registered on the PROSPERO database (CRD42012002669#). It will be updated as the review progresses.

7.2. WORK PACKAGE 2: Assessing the cause and extent of the problem

We will seek published information to assess both the extent and causation of problems relating to DNACPR and data from an information and advice line for patients. We will obtain information from the following sources:

(i) HM Coroner Rule 43 Notices

HM Coroners are tasked with investigating deaths. If the coroner feels that the evidence gives rise to a concern that circumstances creating a risk of other deaths will occur or continue to exist, he/she may make a Rule 43 report which is sent to the organisation which has responsibility for the circumstances. Summaries of Rule 43 Notices are published at <http://www.justice.gov.uk>. A search of this database has identified four cases related to DNACPR decisions. Full inquest details have been requested from the respective Coroners. We will summarise the key issues from these cases.

(ii) NHS Incident Reporting and Complaints

We will apply to a representative sample of NHS acute, community and Ambulance Trusts to identify the number of incident reports / complaints. We have developed and tested a series of questions with the NHS Information Governance Manager at Heart of England NHS Foundation Trust that will be used to obtain data under the Freedom of Information Act.

We will ask Trusts:

- a) How many incidents, serious untoward incidents and ombudsmen investigations your Trust had in the last two financial years (April 2010-April 12)
- b) How many incidents, serious untoward incidents, complaints and ombudsmen investigations were related to do not attempt resuscitation (DNAR / DNACPR) decisions over this time frame
- c) Please send a summary of the investigation findings and any recommendations for practice / change in policy that occurred as a consequence.

In the event that this approach does not yield sufficient information we will undertake Key Informant interviews with one person (Executive Director for Health Care Governance or their Nominee) in a Trust that is able to provide an overview of all complaints. We will interview the Key Informants about the nature of complaints received about DNACPR in their Trust and the Trust responses to these. We will interview until data saturation, when no new DNACPR issues are reported. However, we will interview at least 15 key informants so we have sufficient data from across the country so we are able to report our findings whilst also guaranteeing anonymity for the Key Informants and their Trust. Data will be analysed thematically. We will apply for ethical approval to approach and interview key informants at a later stage if the FOI requests do not provide the required information.

(iii) End of Life Rights Information Line Registry (via Compassion in Dying).

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing advice and information around their rights and choices. The charity runs a freephone End of Life Rights Information Line that is available during office hours to the general public. The majority of calls and emails come from individuals who are currently 'well', but want to plan for their future. However, patients about to go into hospital for treatment, carers, solicitors and health and social care professionals also make regular contact. Providing packs for making Advance Decisions (which can include a Do Not Attempt Resuscitation decision) is one of the key activities of the information line. The Information Line already has in place a system of monitoring the number of calls they receive, the initial reason given for the call, other topics discussed and the caller type (see attached). One of the conversation topics recorded on their monitoring form is DNAR (Do not resuscitate). The Information Line will note the nature of the conversation and the context in which DNAR was mentioned. The Information Line team will record these issues during or immediately after the

call, by hand on the back of their monitoring form. Examples from their experience of receiving calls include: having a heart attack in public and not wanting to be resuscitated, and making sure their wishes are respected when in transit between care-settings. The research team will not have access to this data. The Information Line team enter the data from their monitoring form into a spread sheet. They will make an additional entry to record to topics that were discussed in relation to DNAR. The process for deciding on the topics to be recorded is detailed below. The Information Line team will then provide the research team will a summary of:

- The total number of calls during the period of data collection
- The number of calls where DNAR was raised
- The number of calls where each topic related to DNAR was raised

No personal identifier information will be provided to the study team. The data will be anonymous aggregate data.

From the experience of the Information Line team we know that DNAR is raised only occasionally (estimate less than five per month). We therefore plan to continue the data collection on the details of the issues raised about DNAR until all other data collection in the project is complete and analysis is being finalised or until data saturation is reached or until the Information Line team are no longer able to sustain the additional work, whichever comes first.

The topic list for the spread sheet will be developed as follows. Mr Philip Slatherley from Compassion in Dying is a member of the research team and joins our monthly research team meetings by telephone. During one of the team meetings Mr Slatherley will have available the first five to ten monitoring forms where DNR has been recorded. He will summarise for the team the topics covered on the monitoring forms. The team will ask questions about the topics based on their experience of DNAR and of qualitative methodology. At no point will the text recorded on the monitoring forms be revealed to the wider research team. The team will agree a list of topics for use in the Information Line spread sheet.

The process of data collection and the topics will be reviewed at each monthly team meeting. Mr Slatherley will monitor the data collection process on a day to day basis and report any concerns to the research team and alert the team to new topics at the monthly meetings.

7.3. WORK PACKAGE 3: Identifying current NHS practices

We will obtain DNACPR policies and forms from NHS acute trusts using the approach successfully pilot tested in the West Midlands region. We will develop a data extraction tool,

with input from the expert advisory group to map these policies in relation to their coverage and concordance with relevant legal requirements and national guidelines. Issues likely to be included are:

- a) Assessment of capacity
- b) Consultation guidance - patient
- c) Consultation guidance – relatives / IMCA
- d) Validity of decision
- e) Involvement of multi-disciplinary team
- f) Relationship to ambulance DNACPR policies
- g) Relationship to community DNACPR policies
- h) Patient information leaflet
- i) DNACPR form
- j) DNACPR audit
- k) Equality and diversity assessment
- l) Differing cultural / religious views.

We will tabulate and summarise consistency and differences between organisations DNACPR policies, exploring in particular differences at the interface between services. We will include specific examples as case studies within the report of innovative solutions developed by NHS organisations.

7.4. WORK PACKAGE 4: Obtaining service providers perspectives on current processes

Focus groups are an established method for collecting data from health professionals on their experiences of policy and practice and opinions, and how through discussion health professionals develop or construct their knowledge and understanding of an issue [4,5]. In relation to decisions concerning the end of life, Dalkin et al [6] are using health professional focus groups to investigate how a new integrated care pathway for individuals with life-limiting illnesses requiring palliative care worked in practice; Gélinas et al [7] used focus groups to explore the stressors faced by nurses providing end of life care in intensive care units; Thompson et al [8] used focus groups to explore health professional views on advanced directives.

There has been considerable interest in the gap between evidence and practice, policy and practice, and knowledge and practice in recent years. In situations where the care of patients is compromised, qualitative methods can be used to identify gaps between policy and practice which can then be used to identify why policy is not being implemented [9]. However, Greenhalgh and Wieringa [10] challenge our current understanding of what they call the know-do gap suggesting that we should adopt a broader, more critical view of how we understand this, acknowledging the construction rather than production of knowledge.

Health professional experience of DNACPR will rarely be in isolation, and particularly where there have been difficulties with the process, DNACPR is discussed with health professional colleagues, formally or informally. Focus groups will facilitate similar discussion by encouraging the sharing of and reflection on experiences and the development of ideas and views on policy and practice. When policy and practice have particular ethical significance, as in DNACPR the integration of ethical analysis with standard qualitative data analysis can provide both descriptive and normative insights [11].

Design

Focus groups will be carried out to access health professionals' experiences and views of DNACPR evidence, policy and practice. We have modified the focus groups from the traditional design to maximise participation of clinicians from the relevant health service contexts, ensure we are including clinicians with a range of experience of DNACPR, and to preserve anonymity for the participants. Focus group attendees will be assured that the focus group discussion will be kept confidential to the research team. They will also be assured that their data will not be recognisable in the research report including any quotations from the focus group data. With a small number of focus groups which aim for extensive discussion of an issue, it can be difficult to preserve anonymity whilst also demonstrating the provenance of the research. We will therefore aim for short focus groups with facilitated in depth discussion of one vignette (see below) but will undertake focus groups until we are confident we have achieved both diversity of participants and contexts and data saturation (we estimate up to 30 focus groups with 6-8 participants in most groups but more in some – see below). We will stop recruitment earlier if we reach data saturation and are confident we have data from a diversity of health professionals and contexts. With this in mind we will try to achieve a high yield from the data by encouraging careful reflection and wherever possible we will aim for longer focus groups that allow for the discussion

of more than one vignette and for in depth reflection but we are mindful of the difficulties of engaging health professionals in focus groups.

Participants

Hospital staff (doctors and nurses), paramedics, palliative care nurses, community nurses and GPs who identify themselves as in a position to and with the experience of making DNACPR decisions, will be invited to participate in focus groups. Senior and established staff are more likely to deal with DNACPR decisions than junior staff/staff in training. We will aim to recruit participants from at least two Regions (West Midlands and London), aiming to engage clinicians from diverse contexts (Trusts or CCGs/seniority/teams/settings) so they are likely to have diverse experience and views of DNACPR. Post graduate health care students attending a critical care module at WMS will also be included in the focus groups. Through holding some focus groups at relevant national meetings (e.g. Intensive Care Society Annual Conference, Society of Acute Medicine, College of Emergency Medicine), we will also recruit clinicians from across the country, with sufficient interest in the topic to join a focus group during a conference/national meeting.

Recruitment to focus groups

We will contact medical and nursing directors or appropriate individuals, in all Trusts and CCGs within the two regions and through them approach the relevant staff to be involved in the educational sessions. Our aim is to take the focus group to clinicians rather than invite clinicians to a focus group. This will maximise engagement with the research particularly among clinicians without a particular interest in the topic. Each focus group will be arranged within or alongside an existing meeting of clinicians, for example resuscitation training, Clinical Quality Improvement meetings, Trust mandatory training, Directorate meetings, Audit meetings, GP protected learning time sessions, senior nurse meetings.

We will negotiate with those leading these meetings to appropriately integrate the focus group with their normal activities. At national meetings we will negotiate with the meeting organisers to run focus groups alongside parallel sessions and advertise them to all participants.

At least two focus groups will be recruited from each of the following professional groups:

GPs, paramedics, community nurses, palliative care professionals, senior hospital doctors in a range of specialties, senior hospital nurses in a range of specialties, PALs/patient experience teams / chaplains. We have focussed on senior doctors and nurses as they are more likely to have experience of or be in a position to make DNACPR decisions. We would include specialist registrars in our senior doctor group. In the event that we do not have complete coverage at national meetings, we will use regional meetings to fill any gaps in professional groups.

Format of focus groups

A set of six vignettes will be constructed from initial data collected in WP 1 and WP 2. The vignettes will be reviewed by the Stakeholder Group and piloted with academic clinical colleagues. Each vignette will represent a real example of the gap between evidence, policy and practice. There will be vignettes relevant to each type of NHS health professional and clinical context involved in this study. Usually, only one vignette will be discussed in a focus group. The allocation of vignette to focus group will be random. We do not intend to match the vignette to the participants/setting of the focus group as we want to hear discussion of vignette by health professionals who might be involved in the vignette, but also from those who may only communicate (directly or indirectly) with those involved.

Focusing on one vignette will allow for depth of discussion and reflection. If appropriate a further vignette may be introduced to prompt discussion. Where possible focus groups will be audio recorded. However, data collection will be adapted to the context. For example, during a GP protected learning session (often 50+ attendees), a vignette may be presented, discussion encouraged with their neighbours, then the GPs are asked to write their thoughts on the back of the standard evaluation form for the session, and hand it. Each focus group will be conducted by a facilitator and observed by a researcher.

One of the project researchers will be trained in facilitation, and where appropriate (e.g. at a large GP meeting), the PI or a co-app will support the facilitation. Information about the research will be provided to participants at the selected events (meeting, training etc.) prior to commencement of the focus group. Consent to the research will be collected from all participants. Where someone is present for the event who does not wish to participate in the research, they will be invited to remain but not contribute to the discussion. The purpose of the focus group will be introduced by the facilitator along with assured confidentiality and anonymity.

Questions and prompts to facilitate discussion will include: first reactions to the vignette, experiences and values that inform their response, and their own understanding of policy and practice relating to the vignette. The facilitator will encourage a conversational style, engagement of all focus group members, personal reflection and group interaction and development of ideas and views. The facilitator will prompt for background to the experiences and opinions expressed. Participants at large meetings will be asked to complete a brief questionnaire at the end of the focus group indicating their health professional role, gender, length of time working as a health professional (total), length of time working in current role, and (where possible) how many of the other focus group members they have worked/are working with (e.g. in the same team, on the same ward). In smaller focus groups this information will be collected and audio recorded at the beginning of the discussion.

The precise duration of focus groups will be determined by the experienced facilitator leading each session and will be responsive to the discussions within the focus group. The minimum duration will be 20 minutes but we anticipate that in most cases it will be longer.

Data management and analysis

Data will be transcribed verbatim and uploaded into the analysis software NVivo to aid data handling. During analysis we will take account of the composition and context of each focus group. For example, where most focus group members are working in the same team, we will be aware a team view may have existed prior to the focus group. Where a group includes a number of different professions, we will be aware of possible influence on discussion of hierarchy of roles. The focus group transcripts will be thematically analysed for pertinent themes relating to the views and experiences of health professionals towards the gap between evidence, policy and practice relating to DNACPR.

We will also endeavour to capture examples of best practice. A realist approach will be adopted, which assumes that the views people articulate in language map onto their experience[36-38] rather than a constructionist perspective where meaning and experience are believed to be created through language [12]. Furthermore, transcripts will be analysed inductively, where the derivation of themes is data rather than theory driven [13]. Analysis will involve iteration between the focus group data and a) legal and ethical frameworks [11, 14,15], b) policies and procedures (WP 3), and c) relevant social and behavioural science literatures such as that on

decision making in the context of multiprofessional team working in end of life situations [16,17] and palliative care [18,19]. R&D approval will be sort through relevant Ambulance, Hospital, Primary Care and Community Trusts.

7.5. WORK PACKAGE 5: Summary, final report and dissemination

On completion of WPs 1-4, a consensus conference will be held with representatives of policy makers, patient and professional organisations and those responsible for education and development, to consider the how these findings will impact on future policy and research in the UK. We will present the study findings to this group and test that the conceptual framework we have developed captures the key outputs from the various WPs.

We will use an electronic voting system to capture the group's priorities on issues for consideration by policy makers (e.g. changes to policy, what information should be included in patient admission records regarding patient wishes) and to prioritise areas for future research. Following this we will summarise and disseminate the findings of the project, setting out the recommendations for best use of available evidence to direct policy and practice, highlighting gaps in the evidence base and indicating prioritised future research needs.

7. *Ethical Considerations*

The study will examine the views of staff. The unified GafREC guidelines specifically exclude work of this type from requiring review by an NHS Research Ethics Committee. We will apply instead to the University of Warwick Biomedical and Sciences Ethics Committee and obtain Trust R+D Departments for access to their staff when the research is to take place on NHS premises. Ethical approval will be sought once confirmation of award comes through.

Informed Consent

We will ensure all participants are freely giving fully informed consent to participate in this study by ensuring they have signed the participant consent form. They will also be given the information sheet which provides all the details of the study and what is required from them.

Participant Confidentiality and Data Security

The qualitative data we will collect will not contain identifiable characteristics. Each participant will be coded, for example participant a, b, c. The data will be recorded conversations which will then be manually transcribed. The project team will retain the study data, and all associated forms for the life of the project – 1 year and then 10 years following completion. To take into account and amendments that have to be made following publisher and funder comments. The data and forms will be retained in electronic format (all forms scanned) in password protected files. The originals will be destroyed using the confidential waste process at Warwick Medical School. The data will be stored on the project team shared drives (password protected to team members only) at the University of Warwick.

Right of Withdrawal

Participants will have the right to withdraw from the research process at any time. Participants will be able to withdraw their data up until the point at which data synthesis begins. Then data withdrawal will no longer be possible. The participants can request withdrawal by contacting the lead researcher (whose details will be shared at each focus group) if they wish to withdraw after the focus group. If they wish to withdraw before hand they can inform the administrator who invites them to the focus group.

Benefits and risks

Although there are no direct benefits for the participants for taking part in this research the findings will inform best practice in the NHS. Participants will be asked if they would like to receive a final copy of the project report or executive summary upon completion. The project team envisage no risks to the participants over and above what they would experience in a 'general' staff meeting.

8. *Expertise in this project team*

Gavin Perkins is Professor of Critical Care Medicine, in the Division of Health Sciences at the University of Warwick. A former NIHR Clinician Scientist (2007-12) he is now Co-Director of Research for the Intensive Care Society (UK) and Chairman of the Resuscitation Council (UK) Advanced Life Support Group. These links provide access and dissemination pathways to acute healthcare professionals in the UK. He has an extensive portfolio of health service research (NIHR HTA, RfPB, SDO, charity funded) and has a special interest in resuscitation research. As a member of the Resuscitation Council (UK) Executive and Chair of an Acute Trust Resuscitation

Committee he has contributed to both national and local implementation of DNACPR policies in to practice.

Barry Williams has been the Chairman of the Intensive Care Society's Patients' and Relatives' Committee since 2004 and serves as the lay and independent member on a number of clinical trials relating to intensive care. His group contributed to the decision to establish the NICE Guideline Development Group on the Acutely Ill Patient and to the production of NICE CG 50. He has also served as member on NICE CG 83 on Rehabilitation following treatment in intensive care and on the NICE Clinical Guideline Group on Organ Donation. He has experience of intensive care both as a patient and a relative. It was as a relative that he became involved in discussions with the medical team treating his wife about the appropriateness of CPR in the event of a cardio respiratory arrest.

Frances Griffith is Professor of Medicine and Society and general medical practitioner. She has experience working with interdisciplinary research teams on clinical issues. She has published extensively from ESRC and NIHR funded research on sociology of medical technology, patient illness experience and the clinical consultation. She has expertise in qualitative and mixed methodology and Research User involvement

Ann-Marie Slowther is Associate Professor of clinical ethics in the Division of Health Sciences at the University of Warwick and a clinical ethicist at University Hospital Coventry and Warwickshire NHS Trust. She is also chair of the UK Clinical Ethics Network which provides education and support for clinical ethics committees (CECs) in NHS Trusts. CECs advise Trusts on ethical issues in policy and guideline implementation hence this link provides a further dissemination pathway to NHS Trusts. She has conducted research on clinical ethics support and ethical decision making in clinical practice, including work for the General medical Council. She has published on a range of ethical issues in health care practice including DNACPR decisions.

Rob George is Professor of Palliative Care at the Cicely Saunders Institute, KCL and Consultant Physician in Palliative Care at Guy's and St Thomas' NHS Foundation Trust. He is Clinical Lead for Palliative and End of Life Care NHS London and is leading a complementary project for the National End of Life Care Programme to develop a web resource that will summarise the challenges of CPR decision-making at the End of Life and provide a central repository of policies, documentation and educational resources relevant to CPR, Emergency and Advance

Care Planning. He was involved in developing the guidelines for and the passage of the Mental Capacity Act 2005 and has published on various aspects of Ethics at the End of Life. He collaborates on a number of Health Service Research projects to do with End of Life Care.

Professor Waugh graduated from Edinburgh Medical School, and did general training in anaesthetics (DA), general medicine (MRCP UK), geriatrics and general practice before doing specialist training in public health medicine (MPH and MFPHM). He became a consultant in public health Medicine in Tayside 1986 and then Grampian 1993. Several spells as acting DPH, Tayside January to April 1993, Grampian and Shetland most of 1999. While in Grampian, he set up and directed the first Scottish HTA centre, SHPIC. Moved to Southampton in 2000 where he directed the Southampton Health technology Assessments Centre from set-up in 2000, to departure in November 2002. Appointed Prof of PHM in University of Aberdeen December 2002, and led the Aberdeen HTA Group till end March 2011. Member of NICE Appraisal Committee 2001 to 2005. Joined Warwick Evidence in June 2011.

Ms Amy Grove has a back ground in Health Psychology and graduated from Coventry with an MSc (hons) in Health Psychology 2007 and BSc (hons) in Human Psychology from Aston University in 2006. Since then she has worked as a researcher in the field of health services management. She has worked at both Coventry University in the Applied Research Centre Health and Life Sciences on a project focused on quality improvement in stroke services, and The University of Warwick at WMG on a project looking at Lean Healthcare. Amy joined Warwick Evidence in June 2011 as Project Manager. This group undertakes technology appraisals commissioned by NICE. Amy maintains her links with WMG and remains an external examiner and dissertation supervisor for the students. Amy's research interests are in Operations Management in healthcare Health Services Management and Evidence Based Management in Healthcare.

Zoe Fritz is a Locum Consultant in Acute Medicine at Cambridge University Hospitals and is about to take up a Wellcome fellowship in Bioethics, looking at the way information is shared with patients in the acute care setting, and the relationship of this with patient trust and questioning. She has conducted research assessing how DNACPR orders are interpreted, and has, with her colleagues, developed and assessed an alternative approach to DNACPR orders.

Matthew Cooke is Professor of Clinical Systems Design at Warwick Medical School; he also works at Heart of England NHS Foundation Trust as Associate Medical Director and Head of Clinical Systems Design. Until recently he was the National Clinical Director for Urgent and Emergency Care at the Dept of Health in London and a Consultant in Emergency Medicine. His research *interests and publications* include organisation of emergency care services, safer systems of clinical care, clinical systems improvement and clinical trials in emergency medicine. Since 2008 he has been leading the Support Team for the Health Foundations Safer Clinical Systems programme, developing a unique approach to improving reliability, minimising risk and reducing harm .

Sue Chambers is a registered nurse and graduated from Coventry with an MSc by Research in 2013 and BSc (hons) in Professional Studies in Nursing from Coventry University in 1995. Since then she has held a number of part time contracts at Coventry University teaching clinical skills that include CPR to undergraduate health care professionals, Sue joined Warwick Medical School in September 2013 to work on the DNACPR project, particularly WP4. Relevant expertise for this task includes experience of conducting a qualitative study during MSc, and experience of counselling developed through working as a volunteer helpline for RP Fighting Blindness.

10. *Timetable/milestones*

The project will be undertaken in phases, including: literature search, study selection, data extraction and critical appraisal, evidence synthesis, and dissemination of the results. A progress report including a draft clinical effectiveness section will be submitted on the *TBC*, this is conditional upon the rapid approval of the protocol. The final report including will be submitted on *TBC*. There will be monthly team meetings and correspondence with the advisory panel will take place throughout the project and at three formal stakeholder meetings.

Draft protocol finalised	14 April 2013
Commissioning decision	TBC
Progress report	TBC
Final report	TBC

11. *Team members' contributions*

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