

# Advance Care Planning, DNACPR & ReSPECT

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# Aims

- Advance care planning - evidence base
- Spotlight on DNACPR decision-making
- ReSPECT – process; feedback so far; progress

# Advance Care Planning: the evidence

- Methods/tools and outcome measures used in existing studies variable.
- Need for well designed RCTs with standardised outcomes that examine the economic impact of ACP, its effect on quality of care and experiences of patients/families.
- Improves EOLC, pt family satisfaction and bereavement process.
- Reduced hospital admission.
- ACP over time > effective than written documents alone.
- 60–90% of public supportive of ACP but uptake only 8%.
- Most HCPs positive towards ACP but reservations about the applicability/validity of ACP documents.

Brinkman-Stoppelenburg et al (2014)

Weathers et al (2016)

Detering et al (2010)

RCP Concise Guidance to Good Practice (2009)

# Spotlight on DNACPR

- DNACPR decisions: historically have been separate from advance care plans.
- Fixation on CPR often at the expense of loss of focus on overall priorities of care for an individual.
- Discussions/decisions associated with misunderstandings, negative clinicians' perceptions, complaints and litigation, negative media reports.

# Spotlight on DNACPR

- ‘Time to intervene’ – NCEPOD, Nov 2012.
- Case law: [Tracey \(2014\)](#) and [Winspear \(2015\)](#) - conversations that need to take place before decisions are taken not happening.
- [Waters \(2015\)](#)- determinations as to when CPR may be appropriate made on the basis of unjustified assumptions as to disability.
- House of Commons Health Committee report: EOLC – March 2015.
- Revised 3<sup>rd</sup> edition of BMA/RC(UK)/RCN guidance – June 2016.

# DNACPR: an evidence synthesis

## complaints & incidents

4500 incidents related to DNACPR (<0.5% of total number), ~1/3 causing harm.

Perkins et al, 2016  
Fritz et al, 2013

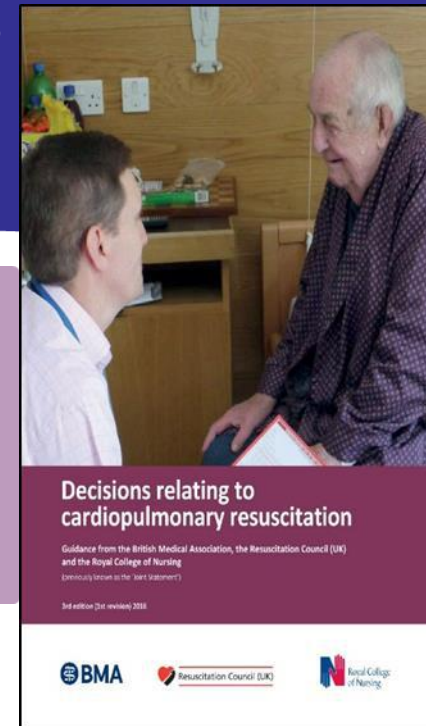
- Failure to anticipate need for DNACPR decision
- Disagreement with DNACPR decision
- Confusion over process for decision-making
- Poor communication
- Poor handover between settings, need for review following change in patient status
- Poor record keeping
- Inconsistent terminology and forms (25% using RC(UK) form)
- Inconsistent decision maker
- Poor guidance on process for patients who lack capacity
- Lack of portability between settings
- Negative impact (escalation, observations, basic care, pain relief, fluid intake)

# DNACPR: an evidence synthesis

## Factors that improve outcomes:

- Review by specialist teams at time of acute deterioration (critical care outreach, SPC, care home admission)
- Structured discussions at the time of acute admission
- Discussing CPR as part of overall treatment plans
- Standardised documentation for decisions

“...there are clear benefits in having (CPR) decisions recorded on standard forms that are... recognised across geographical and organisational boundaries within the UK.”



# ReSPECT

[www.respectprocess.org.uk](http://www.respectprocess.org.uk)

## Recommended Summary Plan for Emergency Care and Treatment

- Integration of DNACPR decisions with ACP.
- Steering group co-chaired by RC(UK) and RCN, initiated Spring 2015. Wide representation – GMC, BMA, CQC, RCs, patient / public, academic institutions, clinical specialties, ambulance service etc.
- Sets out recommendations for clinical care *in emergency situations* where obtaining consent not possible.
- Starts not from ID of specific interventions, but preference of pt re whether their priority is to sustain life or prioritise comfort.
- ReSPECT can be complementary to a wider process of advance/anticipatory care planning.



# RESPECT

Tools to enhance / support clinician decision making and raise public awareness

<http://www.respectprocess.org.uk/>

Web APP: very good and raises the understanding of the process and the use in different settings and backgrounds.

<http://www.respectprocess.org.uk/learning>

- Terms of use
- Clinician's guide
- Leaflet and poster
- Implementation plans
- Patient, parent, young persons info
- Teaching slides
- FAQs

The screenshot shows the 'What should happen to you in an emergency?' section of the RESPECT form. It includes a header with the RESPECT logo and title. Below the title, there are several sections with questions and checkboxes for 'Yes', 'No', or 'Not sure'. The questions cover topics like: 'What is it?', 'Who is it for?', 'How does it work?', 'What does it cover?', 'Why is this available?', and 'What else can I do?'. Each question is followed by a brief explanation and a set of three checkboxes. The form is designed to be filled out by a clinician to document a patient's preferences for emergency care.

This is a leaflet titled 'What should happen to you in an emergency?' from the RESPECT project. It provides a clear, step-by-step guide for clinicians on how to complete the RESPECT form. The leaflet is divided into several numbered sections: 1. Personal details, 2. Summary of relevant information for this plan, 3. Personal preferences to guide this plan (when the person has capacity), 4. Clinical recommendations for a similar acute care event, and 5. A Clinical recommendation for a similar acute care event. The leaflet includes practical advice, such as 'Ask the person (or if they cannot answer ask their family or other carer) the names of the people you would like to be called' and 'Priority for working life...'. It also features a small illustration of a person at a computer and a QR code for more information.

This is an NHS leaflet featuring a testimonial from Sheila Burt. The text reads: "I definitely don't want to die at home because I don't want to be a burden on my husband". Below the quote is a photograph of Sheila Burt. At the bottom of the leaflet, the RESPECT logo is displayed, along with the text: "You've been making decisions all your life. Talk to a professional about your care and medical treatment preferences for when the going gets tough. Watch Beryl and Sheila's story at www.respectprocess.org.uk".

Preferred name

**1. Personal details**

Full name				
NHS/CHI/Health and care number				

Date of birth
Address

Date completed
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**2. Summary of relevant information for this plan (see also section 6)**

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

**3. Personal preferences to guide this plan (when the person has capacity)**

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort	Prioritise comfort, even at the expense of sustaining life
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Considering the above priorities, what is most important to you is (optional):

**4. Clinical recommendations for emergency care and treatment**

Focus on life-sustaining treatment as per guidance below clinician signature	Focus on symptom control as per guidance below clinician signature
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Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended Adult or child clinician signature	For modified CPR Child only, as detailed above clinician signature	CPR attempts NOT recommended Adult or child clinician signature
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**5. Capacity and representation at time of completion**

Does the person have sufficient capacity to participate in making the recommendations on this plan?  
**Yes / No**

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**  
If so, document details in emergency contact section below

**6. Involvement in making this plan**

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

**A** This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.

**B** This person does not have the mental capacity to participate in making these recommendations. This plan has been made in accordance with capacity law, including, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

**C** This person is less than 18 (UK except Scotland) / 16 (Scotland) years old and (please select 1 or 2, and also 3 as applicable or explain in section D below):

**1** They have sufficient maturity and understanding to participate in making this plan

**2** They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.

**3** Those holding parental responsibility have been fully involved in discussing and making this plan.

**D** If no other option has been selected, valid reasons must be stated here. Document full explanation in the clinical record.

Record date, names and roles of those involved in decision making, and where records of discussions can be found:

**7. Clinicians' signatures**

Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC Number	Signature	Date & time

Senior responsible clinician

**8. Emergency contacts**

Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend/other			
GP			
Lead Consultant			

**9. Confirmation of validity (e.g. for change of condition)**

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/HCPC number	Signature

# ReSPECT

- Aim was to adopt nationally from February 2017
- NIHR funded study (Warwick University) – assess effects of ReSPECT in acute settings (n=6) over 3 years (2016-2019)
- Alongside this it is now moving into the next phase in which health and care communities wishing to adopt ReSPECT can be offered access to the materials that they will need to start planning implementation. Interested organisations should join the Implementation Network.

# ReSPECT

## Positive

- Embedding DNACPR in wider discussions re priorities of care.
- Places pt at centre of care.
- Lay opinion that beneficial to pt care.
- Standardised document.
- Potential for improved communication between healthcare professional and patients and across boundaries; community and acute trust and between trusts.
- Ultimately changing the culture so these conversations become the norm and aren't left to a point of crisis.

## Negative

- Dislike of the form
- Many places are already using ACPs and DNACPR forms that are integrated and working well - this form may not in its current form, replace those items in use without risk.
- Multiple stakeholders.
- Version control.
- No electronic version available.
- Information sharing.
- Suitability across all settings- ED, paed.
- Training in competencies.
- Patchy implementation.
- Several different forms - AMBER care bundle, DNACPR and now ReSPECT - clarity needs to be provided of when each is used.

### Feedback from Warwick:

- Engaging all local providers.
- Patient voice.
- Local IT solution.
- Funding.
- Establishing a Working Group which includes representatives from the Trusts and Community.
- Education.
- Identifying champions of ReSPECT in all of these areas.
- Support and a desire to want to implement this process – all healthcare sectors.
- National mandate.
- Electronic system.

Lead: Janni Hodgson, Resuscitation Services Manager RSCH

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- RSCH introducing ReSPECT 1/4/2018. For new patients - old red forms will still be recognised.
- In-house training to start this month and oncology plan to use in outpatients.
- A proposal submitted to the STP for funding for a project lead to drive and support the implementation across Surrey Heartlands has been approved; lead being recruited.
- SECAMB in support of the process : it will assist in making timely decisions according to the patients expressed wishes.
- GP's / community nurses / palliative teams / paramedics G@W CCG to receive early training to support this.
- Patient information campaign.



# How will ReSPECT fit in with PACE?

- G&W: > Proportion of patients dying in the community than neighbouring CCGs - this trend needs to continue. Still some cases of inappropriate escalation of care: PACE not always updated; OOH GPs time restrained; EOL drugs not available in home.
- In the emergency situation, paramedic or OOH GP needs readily available information in an easily recognisable format. In this way, ReSPECT document offers additional benefits.
- Important to establish which pts have just a RESPECT and which also have PACE, and how these interact.
- PACE time-consuming, but its remit wider, > holistic. For some patients, likely to be a place for both.

QUESTIONS?



# References

- The effects of advance care planning on end-of-life care: A systematic review. Arianne Brinkman-Stoppelenburg, Judith AC Rietjens and Agnes van der Heide. Palliative Medicine (2014) Vol. 28(8) 1000–1025
- Advance care planning: A systematic review of randomised controlled trials conducted with older adults. Elizabeth Weathers, Rónán O’Caoimha, Nicola Cornally Carol Fitzgerald, Tara Kearns, Alice Coffey, Edel Daly, Ronan O’Sullivan, Ciara McGlade, D.William Molloy (2016), <https://doi.org/10.1016/j.maturitas.2016.06.016>
- The impact of advance care planning on end of life care in elderly patients: Karen M Detering, Andrew D Hancock, Michael C Reade, William Silvester,
- BMJ 2010;340:c1345. Single centre Prospective RCT
- R (David Tracey) v (1) Cambridge University Hospitals NHS Foundation Trust (2) Secretary of State for Health (2014)
- Winspear v City Hospitals Sunderland NHS Foundation Trust [2015] EWHC 3250 (QB); [2015] WLR (D) 468
- Time to Intervene. A review of patients who underwent cardiopulmonary resuscitation as a result
- of an in-hospital cardiorespiratory arrest. A report by the National Confidential Enquiry into Patient Outcome and Death (2012)
- House of Commons Health Committee. End of Life Care. Fifth Report of Session 2014–15
- Decisions relating to cardiopulmonary resuscitation. Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing. 3rd edition (1st revision) 2016
- Perkins GD, Griffiths F, Slowther A-M, George R, Fritz Z, Satherley P, et al. Do-not-attempt-cardiopulmonary-resuscitation decisions: an evidence synthesis. Health Serv Deliv Res 2016;4(11).