Institution: University of Cambridge		
Unit of Assessment: 2 Public Health, Health Services and Primary Care		
Title of case study: Empowering personalised discussion and advance planning about emergency treatment, resuscitation, and overall goals of care		
Period when the underpinning research was undertaken: 2008-2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Zoë Fritz [Jonathan Fuld] Simon Cohn Chris Palmer Jude Frankau Richard Parker	Wellcome Trust University Award Fellow [Associate Lecturer – Category C] University Senior Lecturer Assistant Director of Research Research Associate Medical Statistician	Feb 2018 – present Mar 2013 – present Sep 2007 – Jan 2014 Oct 1991 – Mar 2014 Jun 2013 – Dec 2013 Oct 2008 – Oct 2013
Period when the claimed impact occurred: 2017- present		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact (indicative maximum 100 words)

"Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) notices were introduced with the intention of protecting people from an invasive intervention that they would not benefit from or would prefer not to have. University of Cambridge collaborative research has identified many problems with their use in practice, and has helped develop and evaluate a new patient-centred approach – the "ReSPECT" process – to empower patients to make personalised decisions about their goals of care and preferences for resuscitation. Supported by the Resuscitation Council UK, and endorsed by the Royal College of Physicians, Faculty of Intensive Care Medicine and other major bodies, ReSPECT has replaced the system of DNACPR notices across much of the NHS. It ensures that emergency decisions reflect patients' priorities, it improves conversations around anticipatory care planning, it supports clinicians in emergency situations, and it reduces harms. ReSPECT is valued by patients and staff for its patient-centred focus and clarity about goals of care. Its positive impacts for the NHS include reduced readmissions to hospital, with associated cost-savings.

2. Underpinning research (indicative maximum 500 words)

Supporting choices about resuscitation in the event of cardiac arrest

When someone's heart and breathing stop, cardiopulmonary resuscitation (CPR) can be used to try to revive them. CPR is invasive, involving repeated heavy pressure on the chest, possible use of electric shocks, and other measures. It may not work. Even when someone is resuscitated, and especially if they are already frail, they might live for just a short time longer, and then in a state of great suffering (e.g. broken ribs) as a result of the intervention. As not everyone wants to receive attempted CPR, it is important to understand and respect people's wishes and ensure they are offered a chance in advance to make the choices that are right for them. "Do Not Attempt Cardiopulmonary Resuscitation" (DNACPR) notices were introduced with this in mind, with the aim of guiding those present on the best action to take (or not take) should an individual suffer cardiac arrest. However, University of Cambridge research showed that DNACPR notices are often variably implemented in practice, that they may have unintended negative consequences, with patients with DNACPR notices receiving suboptimal treatments, and that a new approach was needed.

A new patient-centred approach to decisions

A long-term programme of University of Cambridge research, much of it conducted in collaboration with the University of Warwick, other universities, and major stakeholders including patients themselves and leading charities such as Marie Curie and the Resuscitation Council UK, has studied DNACPR practices. It identified misunderstandings, variations, and sub-optimal practices in relation to DNACPR notices and, in response, has developed and evaluated a radically new approach to address this difficult issue.

A Cambridge-led study of a large cohort in a UK hospital was important in establishing that

DNACPR notices should not be equated with end-of-life: almost half of patients (49%) with a notice in place survived to discharge, and 17% were alive a year later [1]. Subsequent Cambridge research found, however, that rather than seeing it as a specific instruction that applied *only* in the event of a patient's heart stopping, staff were inclined to misinterpret DNACPR notices as meaning that treatments other than CPR should also be withheld – they were confusing DNACPR status with end-of-life [2]. Further research confirmed this finding and identified the potentially stigmatising effects of how DNACPR notices were documented [3]. It also found that conversations between clinicians and patients and their families about DNACPR were apt to be avoided or done poorly [3].

Prompted by this work, further Cambridge research led to the development of a new patient-centred intervention known as the *Universal Form of Treatment Options*. It was based on the principle that the patient's preferences for resuscitation should be discussed and documented in the context of their overall goals of care – not as an isolated decision. In an evaluative study, patients experienced fewer harms, and less severe harms, when the recommendation not to attempt CPR was recorded as part of the person's overall goals using the *Universal Form of Treatment Options*, rather than on a standalone DNACPR notice [4]. The study showed that the approach not only enhanced clarity about goals of care: it also changed the character of handover conversations between staff on hospital wards to focus in a more holistic way on the patient's condition and overall goals rather than their DNACPR status, suggesting that DNACPR notices were no longer being conflated with end-of-life decisions.

ReSPECT: the Recommended Summary Plan for Emergency Care and Treatment

The patient-centred principles established by the research on the *Universal Form of Treatment Options* critically informed "ReSPECT", a subsequent large-scale effort to improve treatment and care planning. It was developed to facilitate and record shared understanding of emergency care and planning with patients in a highly personalised way. With leadership from Cambridge, Warwick and others in a collaborative working group, development of ReSPECT was distinguished both by the extent of its stakeholder involvement, including patient advocates and a public consultation that drew over 1000 responses, and by its evidence-based approach [5].

Aimed at empowering patients and carers, the ReSPECT process involves focused conversations between clinicians, patients, and families, with outcomes recorded on a specially-designed form [5]. It supports high quality, patient-centred discussions about goals of care, with resuscitation recommendations for an emergency identified only after clinicians establish patients' priorities. The ReSPECT process identifies the patient's preference for the overall focus of care (e.g. life-sustaining treatment *or* symptom control), tailors clinical guidance to the individual (e.g. regarding appropriateness of hospital admission), and highlights interventions that would not help, or that the patient would not want – including, but not only, CPR. The ReSPECT process draws extensively on the *Universal Form of Treatment Options* work [4], as the only format for which good evidence exists in documenting treatment goals in this context.

3. References to the research (indicative maximum of six references)

1. **Fritz Z**, **Heywood RM**, Moffat SC, Bradshaw LE, **Fuld JP**. Characteristics and outcome of patients with DNACPR orders in an acute hospital; an observational study. *Resuscitation* 2014;85:104-108.*
2. **Fritz Z**, **Fuld JP**, Haydock SP, **Palmer C**. Interpretation and intent: a study of the (mis)understanding of DNAR orders in a teaching hospital. *Resuscitation* 2010;81:1138-41.*
3. **Cohn S**, **Fritz Z**, Frankau JM, Laroche CM, **Fuld JP**. Do Not Attempt Cardiopulmonary Resuscitation orders in acute medical settings: a qualitative study. *QJM* 2013;106:165-77.*
4. **Fritz Z**, Malyon A, **Frankau JM**, Parker RA, **Cohn S**, Laroche CM, **Palmer CR**, **Fuld JP**. The Universal Form of Treatment Options (UFTO) as an alternative to Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) orders: a mixed methods evaluation of the effects on clinical practice and patient care. *PLoS One* 2013;8(9):e70977.*
5. Hawkes CA, **Fritz Z**, Deas G, Ahmedzai SH, Richardson A, Pitcher D, Spiller J, Perkins GD, ReSPECT working group collaborators. Development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). *Resuscitation* 2020;148:98-107.*

*These publications have been peer reviewed, providing evidence of research quality.

Competitive funding supporting research

National Institute for Health Research, Research for Patient Benefit Programme:
A Universal Form for Treatment Options as an alternative to DNAR: Development and Evaluation,(2013-2019), PI: Fuld GBP249,756
Wellcome Trust Fellowship: "Developing an Ethical Framework and Practical Policy", WT100557MA (2013), PI: Fritz GBP264,479.
Wellcome Trust fellowship to the Parliamentary Office of Science and Technology, 105168/Z/14/Z (2014), PI: Fritz GBP21,401

4. Details of the impact (indicative maximum 750 words)

Advance decisions about resuscitation: a global health and ethical issue

Globally, around 60 million people die every year, including about 600,000 in the UK (World Health Organization statistics). In high-income countries like the UK, around half of deaths take place in hospital settings (Public Health England statistics). By the mid-2000s, about 80% of the people who died in UK hospitals had a DNACPR notice in place, directly affecting about 240,000 individuals every year (*Resuscitation* 2005). Yet, as Cambridge research helped to show, DNACPR notices were prone to multiple unintended consequences and were often sub-optimally implemented. This led to the recognition that a more personalised approach to making decisions was needed – one that could reflect the priorities, values and preferences of individual patients and the people important to them. University of Cambridge research has been important both in identifying problems in approaches to DNACPR notices and in developing and evaluating a practical solution – ReSPECT – now adopted at large scale in the NHS.

Empowering personalised decisions about goals of care, including resuscitation

The ReSPECT process, which links discussions about resuscitation with decisions about other aspects of emergency care and treatment, creates personalised recommendations for a person's clinical care and treatment in the event of a future emergency where they would be unable to make or express choices because their heart has stopped. It provides greater clarity about patients' priorities, it facilitates communication, and it reduces harms compared with standalone processes – such as DNACPR – that focus only on withholding resuscitation.

Impact on policy

Cambridge researchers and collaborators have worked in a highly engaged way with multiple stakeholders, including patients and families, policy-makers, clinicians, charities, and system leaders to improve processes relating to treatment decisions and to secure their implementation. For example, in January 2015 they provided written evidence on their research to the UK Parliament's Health Select Committee inquiry into end-of-life care and gave briefings to its key members, helping to stimulate understanding of the problems of DNACPR notices and the need for a process engaging broadly with patients' goals. The Committee recommended *"that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England"* [A].

The Department of Health responded positively to this recommendation for improved processes focused on patient goals**.** Later in 2015, it recorded that a *"Working Group, co-chaired by the President of the Resuscitation Council (UK) and the Head of Nursing Practice at the Royal College of Nursing has been established to look into this issue. The aim is to develop a national form that records decisions about CPR and other life-sustaining treatment in the context of a broader plan"* [B]. The working group continues to meet regularly, chaired by Dr Fritz since 2018. Dr Fritz has also presented the findings and implications of the research programme [4] to other key stakeholder groups with influence on practice – for example to the Royal College of Physicians, General Medical Council and British Medical Association ethics groups.

The ReSPECT process, designed with leadership from Cambridge, Warwick and others, supports conversations about goals of care and generates a summary of patients' wishes recorded on a specially designed form focused on patients' personal priorities for care and agreed clinical recommendations about care and treatment [5,C]. The form is intended to be used in an emergency situation where a patient is unable to make decisions. Importantly, having a ReSPECT form does not automatically mean the patient is not for resuscitation – just that their goals have been discussed and documented, forming the basis for individualised care decisions.

ReSPECT is now referenced in influential guidelines and reports. For example, the Royal College of Physicians' *Talking about dying* makes the recommendation: "*Consider using a structured tool, such as the ReSPECT process, to support conversations and documentation"* [D]. The Faculty of Intensive Care Medicine's *Care at the end of life* cites ReSPECT as a valuable resource [D]. The Resuscitation Council UK has recognised the importance of ReSPECT as a way of ensuring that individuals received appropriate CPR, and has funded a full-time clinical lead to support its adoption in England and Scotland. It writes that ReSPECT can *"change the culture of both patients and clinicians in a way that will lead to better communication between them and ultimately better person-centred care"* [E].

Changes to organisational policies

Launched in 2017, the ReSPECT process [C,F] has already replaced DNACPR notices in many NHS organisations, including hospitals, clinical commissioning groups and ambulance trusts. For example, of 227 hospital, mental health and ambulance trusts in England, 87 are now using ReSPECT and 38 are actively working towards adoption [E]. These changes have happened even though there is no national mandate or financial incentive for the process, reflecting widespread recognition of ReSPECT's value in delivering better, more patient-centred care.

Impact for patients and the public

People living in areas that have adopted ReSPECT now have the opportunity to document their preferences about goals of treatment – and the clinical recommendations which align to them – on a nationally recognised form that will be respected in an emergency. This means that people are less likely to receive treatments they do not want, and that they would have refused if they had capacity. The ReSPECT process can be used with anyone, but has special relevance for some people who may be especially empowered by being allowed to make their priorities and preferences known – for example those with complex health needs, nearing the end of their lives, or at risk of sudden deterioration [F], all groups that are rapidly growing.

Evidence from adopters of ReSPECT indicates positive impacts for patients, families and clinicians nationwide. For example, a pilot of the ReSPECT process in NHS Forth Valley [G], conducted in 2017–19 and covering 200 patients, found that it led to multiple improvements. Patients and carers felt more involved in decision-making and rated the process positively (80% rating their experience as excellent and 20% as good), and staff were better able to access the information to inform decision-making in an emergency [G]. Usha Grieve, Director of Partnerships and Information at Compassion in Dying, states:

"Evidence from our service users indicates strongly the need for a changed approach around end-of-life decision making both in terms of how wishes for care and treatment are discussed and how such wishes are recorded and communicated in emergencies. ReSPECT […] places CPR decisions within the broader framework of a person's priorities and needs. The impact of both these things is that people's wishes are more frequently discussed, more easily known about and therefore more likely to be respected in an emergency scenario, and when these things happen it ultimately results in people having a better experience at the end of life." [H]

Impact for professionals

ReSPECT minimises confusion and ambiguity for professionals, including first responders during emergencies. Most (88%) staff in the Forth Valley evaluation felt that the ReSPECT process would enable them to deliver the most appropriate care for an individual [G]. Dr Dhushy Kumar, recent chair of the Joint Royal Colleges Ambulance Liaison Committee (JRCALC), states that *"the research in Cambridge has directly contributed to an overall change in approach to and discussion and documentation of resuscitation decisions: this has made it easier for ambulance* *clinicians to deliver excellent and appropriate care for patients"* [I].

JP Nolan, head of nursing at the Royal College of Nurses from 2012-2016, states that *"utilising and disseminating the research outputs on UFTO [Universal Form of Treatment Options], significant advances in policy and practice have been achieved [… including] practice based guidance on decisions related to CPR conducted at RCN and RCN Congress [and] improvements to the regulation of Nurses and Nursing related to end of life care"* [J].

Impact for the NHS

The ReSPECT process has been adopted and welcomed across primary, pre-hospital and secondary care, and has enhanced communication between these settings [E,K]. Evidence from the Forth Valley evaluation suggests that adopting ReSPECT can also improve service-level outcomes: 27% of patients with a ReSPECT form were readmitted to hospital within three months of discharge, versus 43% of those without (a statistically significant difference), possibly because patients with ReSPECT forms have their preferred place of care recorded [G]. On average, the number of readmissions within three months of discharge per patient was 0.34 for patients with ReSPECT forms and 0.49 for those without. Assuming a national average non-elective inpatient stay cost of GBP3,076 (PSSRU Unit Costs of Health and Social Care 2019), this difference represents a cost saving of GBP461 per patient. During the Forth Valley pilot (September 2017 to May 2018), 200 patients received a ReSPECT form, an annual equivalent of 267 patients. Therefore, the total annual cost-saving associated with use of ReSPECT was GBP123,087 in this one location. Scaled across the many sites now using ReSPECT nationally, the savings amount to millions of pounds annually.

ReSPECT and COVID-19

The COVID-19 pandemic has heightened the relevance and urgency of advanced care planning and thinking about patients' priorities with sensitivity and compassion, as the potential for rapid deterioration makes anticipatory decision-making vital. ReSPECT is extensively referenced in the supporting documentation for NICE's COVID-19 rapid guideline for critical care (NG159) as a means of supporting decisions about care and treatment, and initiating conversations with patients and families in difficult situations [L]. The Resuscitation Council UK has produced a webpage to help patients and their families make best use of ReSPECT during the pandemic [L].

5. Sources to corroborate the impact (indicative maximum of 10 references)

A. House of Commons Health Committee. End of Life Care (2015), p. 45
B. Government response to the House of Commons Health Select Committee Report on End of Life Care (2015), p. 13
C. ReSPECT form v3
D. Guidelines and Reports: **(i)** RCP guidance "Talking about dying" (2018), p. 13; **(ii)** Faculty of Intensive Care Medicine, Care at the end of life, p. 39
E. Testimonial from The Resuscitation Council UK, p. 2
F. ReSPECT process: www.respectprocess.org.uk
G. A Quantitative and Qualitative Evaluation of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Process in Forth Valley. Scotland's first ReSPECT pilot: A Case for Change (2019), p. 7
H. Testimonial from Compassion in Dying, January 2020.
I. Testimonial from Joint Royal Colleges Ambulance Liaison Committee, January 2020.
J. Testimonial from Royal College of Nursing
K. Map of ReSPECT adoption sites
L. **(i)** Supporting implementation of NICE Critical Care Guidelines (NG159), pp. 3, 4; **(ii)** COVID-ReSPECT-FAQs