Dr Mike More, Chair Sustainability and Transformation Partnership
Roland Sinker, Joint Accountable Officer, STP
Jan Thomas, Joint Accountable Officer, STP
(by email)

3 December 2020

Dear colleagues,

Why ReSPECT matters to empower people towards end of life, and next steps for working together in Cambridgeshire and Peterborough
(Recommended Summary Plans for Emergency Care and Treatment)

After an exchange of observations, concerns and ideas since summer 2020, a number of us have informed this letter and will advocate it with our local Sustainability and Transformation Partners.

We are asking for a further drive to achieve a whole-community and multi-agency approach, to improve conversations about shared goals of care - progress cut short, and on occasion practice shown wanting, by the pressures of the Covid-19 pandemic.

Working urgently on this together now as services reset, will build on the partial adoption of ReSPECT policy and practice amongst our organisations. This will bring benefits to patients and families, clinical staff and even to the system finances, preventing unwanted deaths in our hospitals.

There is a historical deficit in both public and clinical engagement on end of life matters. Through years of engaging with local people who might otherwise find their voices less heard, we know that people with disabilities, or in communities more at risk of exclusion will suffer more from poor practice. It is sobering to contemplate that the gap in health inequalities may get ever larger in times of emergency or end of life care.

Have you discussed your end of life wishes with your family?
This question to 130 participants in a 2019 Healthwatch event for carers, older people, people with sensory difficulties and learning disabilities brought a very mixed response.

One person said the British/ western society have a taboo about death. Other people said they had held brief discussions but that nothing was written down.

Some had told their families about wanting to be an organ donor and others had written wills and funeral plans. Very few people said they had set up Lasting Power of Attorney or Living Wills. Nobody had made Advance Decisions or filled out a Do Not Attempt resuscitation form.

People felt that GPs should make people aware of the things they need to be talking about, possibly providing information during health checks.

Clinical barriers can be overcome
'There is still evidence of a tentativeness amongst some clinicians, following the backlash about the application of the Liverpool Pathway in some hospitals during end of life care. National guidance now exists, but it needs to be placed within a more positive framing in the whole context of shared care and decision-making.'
Clinical leader

'I was fairly recently in the presence of a nervous patient about to undergo a serious operation. A senior surgeon reading the patient's Advanced Directive was interrupted by a less senior surgeon who vigorously waved a ReSPECT form at him suggesting that it should be completed as well as or instead of the AD. After a short but tense conversation the patient was given about 10 minutes to check there were no major differences and then sign the ReSPECT form, being assured that both would be taken into account if the occasion arose. Not a good experience. This tale raises another issue about when, where and by whom the ReSPECT form should be given to/discussed with the patient.'
Community member, Peterborough

What is ReSPECT
The ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) process was developed by multiple lay and professional experts and stakeholders. Research suggested that inconsistent and poor practice and misunderstandings around DNACPR decision-making and its documentation was leading to both patient harm and a poor experience.

The evidence suggested that the way to counteract that was to develop a process that focused on overall goals of care, with the patient at the centre of the conversation.

Using ReSPECT improves patient experience and ensures that people do not get unwanted or inappropriate treatments. Despite no financial or other incentives for trusts, it has been adopted or partially adopted in 70% of counties in England.

The ReSPECT process has a well-established approach which provides a solution to many of the identified problems:

- It is person centred and encourages individualised decision making;

- It ensures that CPR decisions are contextualised within overall goals of care, minimising the possibility of misinterpretation to mean that other care should be forsaken;
- It crosses health and social care settings, supporting integrated care between care homes, hospitals and primary care.

Key to implementation is the common use of shared form in primary care, community settings and hospital to guide compassionate conversations and record people's wishes.

Equally important is the raised awareness and sensitive preparation of community members, including friends and family, for whom clarity on these matters need not be arrived at in an emergency or worse still be misunderstood or never happen.

Why we should act together now

During the Covid-19 Pandemic, many clinicians recognised the need to ensure that patients did not get inappropriate or ineffective treatments. Unfortunately, in many areas, advance care planning conversations of the kind supported by the ReSPECT process had not been embedded, resulting in an unhelpful focus on Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) decisions. In some areas there was evidence of poor practice such as 'blanket DNACPRs' being instituted.

> 'The only time the GP has got in touch with my friend is to make her sign a DNR.'
>
> 'Respect forms suddenly done on phone at start of pandemic wasn't nice at all! Should have been sent a warning letter to prepare!'
>
> Your Care During Covid, Healthwatch Cambridgeshire and Peterborough, 2020

Poor practice and opportunities for improvement is now the focus of a Care Quality Commission (CQC) thematic review. Cambridgeshire and Peterborough is selected as one of seven field sites to inform their investigation during this December and January.

The Health Select Committee are also seeking what can be learnt from the first peak of the pandemic; the poor approach to resuscitation decisions forms part of their enquiry. The Department of Health is responding to a legal challenge that information about DNACPR decisions is not adequately communicated to patients.

> 'We carry out reviews of people that have died in the Trust. It is sad to see completed ReSPECT forms that clearly state *not for readmission to hospital* and *would prefer to die in own home.* The cost of care in an expensive and inhospitable setting, in all likelihood against the wishes of the person - we have got to be better than this, working together to bring people's expectations to the fore in times of emergency.'
>
> Clinical leader

Where we had got to here in Cambridgeshire and Peterborough
Local NHS Trusts have adopted the policy over recent years. Typical practical steps may have included being incorporated into ICU admissions and transfer criteria, document approvals and printing and various internal communications.

Our CCG had implemented a care home survey project, not fully concluded.

East of England Ambulance Services Trust (EEAST) noticed improved clarity in information on their shared data systems in early 2020. They saw first-hand the positive impacts for patients and their own crew, enabling at times the early release of ambulances into service.

However, there was a drop off in this emerging good practice during the first wave of Covid-19. Lecture programmes and audits in our acute trusts were put to one side - a simple video resource hastily developed as a stop gap. Clinical leads in our CCG were rightly diverted to frontline roles. Our GPs, community and specialist services reduced face to face contact, only recently being recovered in the face of the second Covid wave with increased protection and new priority systems in place. Cambridgeshire County Council and Peterborough City Council took actions against poor practice in care homes.

What could happen next
Bringing people together from our system workforces and the public, there is an opportunity to harness people's experiences from the last nine months and powerfully inform future practice and outcomes. Learning from others about how to coordinate the next steps is key.

Norfolk and Waveney Health and Care Partnership example
The Partnership came together to focus on improving advanced care planning. Up for several awards and recognised for its quality improvement, these are some of the activities that drove their success.

- Revised documentation, clarifying legal issues, emphasis on shared understanding and more personable language
- Engagement with residents about ReSPECT and how to build a campaign reflecting that the process and documentation is commonplace in all health and care settings
- Train-the-trainer sessions to over 100 staff from 50 providers
- E-Learn and film resources

NWHCP Newsletter November, 2020

We think the components below would have impact in Cambridgeshire and Peterborough.

Recognition by our STP that this work needs to be fully adopted

Restart a ReSPECT coordinator role, with remit across the system

Joint public and clinician survey to hear our own voices feeding into Community Values Panel meeting with the clinical community to identify what matters most

Training and development opportunities for people across the STP

Campaigns using key messages and a picture of positive outcomes to change culture and practice

Summary benefits for the Cambridgeshire and Peterborough system
Simply put these are key benefits, which resonate with the emerging Integrated Care System aspirations and clinical priorities:

- Emergency and end of life care meets with people's expectations
- Tackles health inequalities
- Resources saved through shared decision making on treatments and end of life care
- Integrated care approach across all settings, with innovations in practice.

'Paramedics can potentially also be writers of the form, particularly paramedics that work in GP surgeries who can certainly help formulate some of those compassionate conversations around ReSPECT.'

Clinical leader

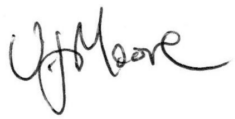
'Patients told us they want to be listened to, especially people with long term conditions who are often 'experts' in their condition and able to recognise when their health changes.'

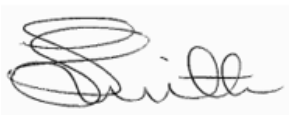
Healthwatch CEO, What would you do, NHS Long tern plan project 2019)

With thanks to our influencers

Dr Abby Richardson, GP and CCG Adviser- Daimon Wheddon, Clinical Lead EEAST- Dr Stephen Barclay, GP and CCG Adviser- Dr Zoe Fritz, Emergency Care Consultant, CUH and founder of ReSPECT - Suzanne Hamilton, Deputy Medical Director, NWAFT - Margaret Robinson, Lay member, NWAFT End of Life Care Group

Yours sincerely





Val Moore
Healthwatch Chair

Sandie Smith
Healthwatch CEO