

Event report

The Facts of Death: ReSPECT NEWS2 - A progress update

17 October 2018



West of England
Patient Safety Collaborative

Working together to build a culture
of continuous learning and improvement

Introduction

ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) is a process that creates personalised recommendations for a person's clinical care in a future emergency in which they are unable to make or express choices. It provides health and care professionals, responding to that emergency with a summary of recommendations to help them to make immediate decisions about that person's care and treatment. ReSPECT can be complementary to a wider process of advance/anticipatory care planning.

The ReSPECT plan is created through conversations between a person and their health professionals. The plan is recorded on a form and includes their personal priorities for care and agreed clinical recommendations about care and treatment that could help to achieve the outcome that they would want, that would not help, or that they would not want.

ReSPECT can be for anyone, but will have increasing relevance for people who have complex health needs, people who are likely to be nearing the end of their lives, and people who are at risk of sudden deterioration or cardiac arrest. Some people will want to record their care and treatment preferences for other reasons.

The logo for ReSPECT features the word 'ReSPECT' in a bold, purple, sans-serif font. The letter 'e' is replaced by a yellow heart shape.

Recommended Summary Plan for
Emergency Care and Treatment

The ReSPECT form and further
information can be accessed at
www.respectprocess.org.uk

The principles of ReSPECT are:

A desire to ensure patients get the care and outcomes they value by:

- Encouraging patients to think about and communicate what outcomes they value and which ones they fear the most
- Facilitating clinicians to make and record recommendations for care and treatment based on these patient preferences
- Ensuring that these clinical recommendations are summarised in a plan for emergency care and treatment
- Ensuring that the recommendations are recognised and respected by pre-hospital, primary and secondary care

ReSPECT

Anne Pullyblank, Clinical Director of the West of England AHSN welcomed everyone to the second ReSPECT event and reviewed the reasons why we were gathering. She summarised how the project had developed since the last ReSPECT event in June, emphasising the need for a cultural change in the system. Anne outlined the strategy to improve communication including an education arm, public awareness campaign and encouraging patient and public involvement (PPI).

The event was attended by 105 delegates representing patients and carers, primary care (in and out of hours), community services, mental health services, hospices, the ambulance service and acute care.

All three of the regional Sustainability and Transformation Partnerships (STPs) were well represented across 52 different organisations that attended.

Part of the initial mapping exercise was to establish where and what population would benefit most from creating an Advance Care Plan. Dr Lucy Pocock introduced attendees to the end of life research she has been doing. The research project is a realist evaluation of the Electronic Palliative Care Coordination System (EPaCCS) project in Bristol, North Somerset and South Gloucestershire.

Lucy's work spanned the three STPs in the West of England and although focused on End of Life, gave us an interesting insight into the current situation. The work suggested that in the West of England, the number of people dying in hospital was between 40 and 46%, just below the national values. 20-27% died at home and between 18-31% died in a care home. However, whilst this may suggest people are not dying in their preferred place, 73% of relatives believed their loved ones died in the right place.



Another surprising figure saw dementia as the leading cause of death followed closely by Ischaemic Heart Disease based on the official register of deaths. The work also looked at the relationship between age and death and number of admissions in last year of life. She highlighted the great work that is being done across the region including the use of (EPaCCS), the Poor Prognosis Letter (PPL) alerting GPs to patient's likely to be in the last year of life, Care Coordination Centres which aim to coordinate care for patients at the end of their life and the broader approach of developing compassionate communities. The work concluded that most people die in old age, of non-malignant disease, in hospital following at least one admission in the last 12 months.

Lucy suggested that improvements for the future should include a focus on older adults, using unplanned admissions as a trigger for advance care planning, engagement with care homes and education and training for healthcare professionals.



We then heard the moving and inspiring story from Stephanie Nimmo whose daughter Daisy was born with a life limiting condition and whose husband was sadly diagnosed with metastatic bowel cancer. As her story unfolded, she shared with us amazing insight into the carer's experience highlighting key concepts necessary for any healthcare provider to consider when caring for patients with life limiting conditions or at the end of life. The importance of seeing her daughter as a little girl, not as a syndrome or a diagnosis; having open, honest conversations; being given the space and time to make memories; becoming the parent expert; the importance of living rather than waiting to die.

Stephanie is dedicated to improving patient experience by sharing her story with many organisations and is the author of "[Was this in the Plan?](http://www.wasthisintheplan.co.uk)"*. Her work supports the aims of ReSPECT and we thank her very much for her poignant contribution to our event.

Delegates then had the opportunity to participate a world café event with eight different themes. Following feedback from the previous ReSPECT event the idea for a world café emerged so that delegates would have the opportunity to explore different aspects of the implementation process. It was an opportunity to share existing practice looking at what works well and how participants had overcome barriers. A full description of the content and the outcomes of each workshop can be found in Appendix 1.

Before breaking for a networking lunch, the three STPs had the opportunity to provide an update.

Bristol, North Somerset and South Gloucestershire (BNSSG) STP Bridget James

BNSSG have had their first meeting where Terms of Reference were discussed and agreed, and the driver diagram and project plan were reviewed. A request was made to organisations to identify available data. The approach to a launch was discussed and suggestion of a soft implementation in certain areas such as care homes was raised. This would be supported by the creation of an educational pack and communication strategy from system wide processes.

Action Points from the Meeting:

- BNSSG members to contact Kate Rush directly to discuss implementing ReSPECT in their specific areas and compile own implementation plans and next steps.
- To set up a task and Finish Group meeting to discuss the digital version of the ReSPECT form and it's adaptation on to EPaCCS- linking with digital lead at WEAHSN.
- To set up task and finish meeting to discuss how BNSSG STP implements ReSPECT across the STP.
- To look at an education pack to raise community awareness and create community strategy.

Bath and North East Somerset (BaNES), Swindon, Wiltshire (BSW) STP

BSW have held an initial meeting in October and are recruiting staff to be part of the project team, and further updates will follow.

Gloucestershire STP Hannah Williams and Andrew Foo

A reflective presentation was delivered giving us the story of how Gloucestershire have taken steps to improve their end of life care and how ReSPECT will complement it.

Following poor feedback from the CQC and their own reflections, a system wide strategy was developed, an STP end of life care clinical programme group was set up, needs were assessed and the service was redesigned. Quality Improvement methodology was employed throughout and evaluation and review carried out.

The aim of the group was shared: **“The Gloucestershire End of Life Clinical Programme aims to deliver county-wide provision run by kind, compassionate and competent staff, which supports people to have the best possible death”.**

There is recognition that ReSPECT will complement the strategy developed and key stakeholders were acknowledged. The Implementation strategy included recruiting champions in each area, teaching and awareness, implementation ward by ward with feedback before rolling onto the next ward. The plan is to have the form alongside the UP form with the implementation date February 2019.



NEWS2

Emma Redfern welcomed delegates to the second part of the day and the focus on the National Early Warning Score 2 (NEWS2) and outlined the programme for the afternoon.

Following the successful implementation of NEWS across the region, Alison Tavaré GP Clinical Lead West of England AHSN talked us through the transition to NEWS2. The two additions are the assessment of new onset confusion and a second SpO2 scale.

There was opportunity to debate what constituted new confusion and what happened if a patient has fluctuating lucid periods as seen for example, in patients with dementia and mental health problems.

The delegates also discussed the criteria for when a patient could be placed on scale 2 and who the competent decision maker can be. Alison also gave a helpful explanation of the difference between hypoxic and hypercapnia respiratory drives.

Various examples were given of poor identification of and communication regarding patients with Type 2 respiratory failure. These included:

- ambulance crews being unable to access clinical information rapidly enough;
- patients arriving in ED drowsy and requiring ventilator support due to High flow O2;
- and target saturations not recorded on the patient discharge summary.

North Bristol Trust is working on a hypercapnia leaflet for patients, exploring re-launching the BTS oxygen alert cards and looking at how we can make oxygen sensitivity more visible on discharge information. Please contact Seema Srivastava (Associate Medical Director & Consultant Physician, NBT) for more information: Seema.Srivastava@nbt.nhs.uk

Nathalie Delaney then asked delegates to feedback on a flowchart to help decision making regarding Scale1 or 2.

James Merrell Lead Nurse Governance, Quality and Sepsis, then shared his experience of implementing NEWS2 at Weston General.

Initially a steering group was set up with the focus of standardising care across the trust. Staff training was a key driver and was rolled out over 6 weeks. Key findings following implementation:

- Patients inappropriately placed on to scale 2.
- Not adding up NEWS scores correctly.
- Outreach teams workload increased by 0%.
- There were no problems reported regarding new confusion.
- There has been an increase in patients being screened for sepsis.
- This provided a focus for where to target further training.

Hein Le Roux (Clinical Lead, West of England AHSN) then asked the stakeholders to provide updates on their Trusts/organisation's implementation of NEWS2:

- (North Bristol Trust and University Hospitals Bristol Trust were implementing on the day of the event).
- Medvivo have started to implement.
- There was no update from Musgrove Park Hospital.
- Bristol Community Health has not started yet, but have a NEWS2 group set up, which includes North Somerset Community Partnership.
- Avon and Wiltshire Mental Health Partnership Trust have started to implement.
- 2gether Mental Health are in the planning stages and are aiming to launch in 2019.
- Wiltshire Health and Care are aiming to launch in Q3 or Q4.
- Royal United Hospitals Bath are launching on the 7th November 2018
- Gloucestershire Hospitals launched in June 2018 and have ongoing issues with Scale1/2.
- Swindon Community Health Service launched in June and have issues with Scale1/2.
- South West Ambulance Service shared that they should be implementing NEWS2 8 weeks from the event (12 December 2018).

David Partlow (Clinical Medical Director, SWASFT) then gave us an update on the South West Ambulance Trust's implementation of NEWS2. He explained to us how the electronic Patient Care Record ePCR had been rolled gradually out across seven counties since 2014. He showed us a graph showing the increase

in NEWS score completion since its introduction in 2016 and the electronic form that clinicians complete, now modified for NEWS2.

The focus then shifted to the health of people with learning disabilities. Alison Tavare (Clinical Lead, West of England AHSN) shared Toby's story highlighting the poor care he received possibly due to healthcare staff lack of understanding, inaccurate assumptions and possible prejudices. She also shared that by teaching Toby's parents how to do a NEWS score, they were able to communicate their concerns about his deterioration to healthcare staff much easier, and Toby was subsequently diagnosed as having sepsis secondary to pneumonia.

Kevin Elliott (NHS England, Transforming Care Team) then shared that, despite great steps forward being made regarding inclusion, value and choices, and recognition of the fact that people with a learning disability (LD) are not a homogenous group, the figures are stark:

- People with an LD have poorer physical and mental health than other people.
- The average age of death for people with LD is 65 for men and 63 for women as opposed to 78 for men and 83 for women in the general population.
- 37% of people with an LD die from avoidable causes compared with 8.8% of the general population.
- There is low uptake of annual health checks, health promotion and screening, and prolonged psychiatric hospital stays for assessment and treatment.

The recommendations from the Confidential Inquiry into Premature Deaths of People with Learning Disability (CIPOLD) are:

- Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans.
- People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome.
- Clear identification of people with learning disabilities on the NHS central registration system and in all healthcare record systems.

Other publications from Public Health England highlighted the need for a structured approach, referring to five determinants:

- Social determinants.
- Genetic and biological determinants.
- Communication difficulties and reduced health literacy.
- Personal health behaviour and lifestyle risks.
- Deficiencies in access to and quality of health provision.

It is the differential exposure to each of these five determinants that, for any person with a learning disability, predicts that they will suffer health inequalities in comparison with the majority of the population.

The way forward:

Campaigns aimed at raising awareness of being on a GP register and attending annual health checks. The target audience

including people with an LD, their families, their supporters and the health staff they might come in contact with.

Resources:

For more information on NHS England's Learning Disability Programme

www.england.nhs.uk/learning-disabilities

Mencap 'Don't miss out' www.mencap.org.uk/advice-and-support/health/dont-miss-out/dont-miss-out-guides

NDTi & VODG guide for Social Care staff

www.ndti.org.uk/resources/publications/better-health-for-people-with-learning-disabilities

RCGP Step by Step guide www.rcgp.org.uk/clinical-and-research/toolkits/health-check-toolkit.aspx

National Learning Disability Health Check

www.england.nhs.uk/gp/gpfv/investment/gp-contract/

People with learning disabilities: health checks audit tool

www.gov.uk/government/publications/people-with-learning-disabilities-health-checks-audit-tool

NHS Quality Checking draft toolkits

www.england.nhs.uk/learning-disabilities/projects/nhs-quality-checking-draft-toolkits/

Closing Remarks

Our events are reliant on teams sharing and collaborating to help spread information and learn about excellence across organisations. We were really grateful for the representation from all disciplines in the room, working together and sharing ideas on how best to achieve this shared outcome.

It was so valuable to hear from Dr Lucy Pocock, outlining the leading causes of deaths in the West of England region and providing us with the challenge of how we can improve deaths for the ageing population. Of course, Stephanie Nimmo blew us away with the life changing story of her daughter and husband's end of life experiences and deaths. It really brought home to us the challenges we face as health and care organisations and how small differences can make a huge impact.

In the afternoon, it was helpful to hear from all the represented organisations about their progress on NEWS2, which organisations have launched, and to share the learning from Trusts which

have implemented NEWS2. We are hugely thankful to all our presenters but especially appreciate James Merrell's (Governance, Quality Improvement and Sepsis Lead Nurse, Weston Area Trust) candid presentation about his organisations experience of the roll out of NEWS2, the training sessions that were provided to staff, and challenges that were faced (i.e. locating lost records in a refrigerator!)

There have been a few changes in the project team within West of England AHSN since the last event so as the new ReSPECT Project Lead I look forward to working with you, hearing your views and walking alongside you through this journey to implement ReSPECT. Hannah Little will also be joining us in mid-November, as Project Lead for the Deteriorating Patient work stream, which includes NEWS, and we're looking forward to welcoming her to the team.

Helen Eddison
West of England AHSN



Appendix 1

ReSPECT Event 17th October 2018 World Café Sessions

Workshop A - ReSPECT and the DNACPR Wristband

Workshop Lead: Lydia Newton, Core Surgical Trainee, North Bristol NHS Trust

This workshop discussed the Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms used in North Bristol Trust where a survey of up to 150 junior doctors at the Trust looked at how to identify patients who are 'not for resuscitation' through the use of wristbands.

Following the survey, it was found that patients supported the form, with the use of the DNACPR wristbands providing clarity for patients, and assurance that a decision on CPR would not be taken without their knowledge.

A DNACPR sticker with symbol is placed on patients' records, and to prevent accidental labelling, the wristband is signed by two clinical professionals.

A pilot is planned for use in North Bristol Trust.

Some discussion points during the workshop included:

- A decision on resuscitation needs to be instant, and the DNACPR wristband helps this decision.
- DNACPR is "an easy conversation if you are willing to have it" with the patient on admission.
- Issues with the DNACPR form are that:
 - o patients move around the hospital a lot
 - o there are issues with finding a specific DNACPR form depicting patients' wishes.

There were some concerns expressed on the use of DNACPR forms, which were that the patient experience group of the initial survey is not the same as actual patients across the Trust.

There were concerns at losing the paper form of the ReSPECT form, and that yellow stickers are also used in patient notes within Community Healthcare.

There were concerns that patients might remove the wristband, and all hospitals have had incidents related to inappropriate resuscitation, as recorded by the Mortality Surveillance Group.

Workshop B - ReSPECT and the “Purple Butterfly” Approach to End of Life Care in Acute Hospital

Workshop Lead: Dr Clare Kendall, Consultant in Palliative Medicine, North Bristol NHS Trust

This workshop discussed the Purple Butterfly approach; a system to empower staff across the organisation to deliver high quality, personalised, compassionate end of life (EOL) care.

Starting on a pilot ward in Southmead Hospital, staff worked with patients, families and the wider hospital team to improve the provision of EOL care. Improvements included:

- The Purple Butterfly sign (on patient doors, drug charts, and staff lanyards) to improve the visibility of EOL patients to all healthcare staff.
- A new Purple Butterfly menu, created in partnership with EOL patients and the trust’s catering team
- Redesigned paperwork for EOL patients
- Specific trolleys with Purple Butterfly resources

Training was provided to staff at all levels and in different roles on wards, along with sessions at junior doctor training, and acknowledged that a fundamental part of EOL care is ensuring that it is tailored to the individual and their family.

The main themes that came out of this workshop were:

- That the scheme aimed to improve patient focused care and deliver a system to support passionate care.
- The scheme can be audited to track and monitor care and triangulate against patient complaints.
- The Purple Butterfly scheme encourages communication across care of patients’ needs.
- That Purple Butterfly improves the visibility of end of life patients – door signs, drug chart stickers, lanyard.
- That Purple Butterfly helps raise awareness of individual care plans
- That the Purple Butterfly symbol stops unnecessary moving procedures for end of life patients.
- That Purple Butterfly helps refocus on patients in a busy setting and improve systems which have not changed for 50 years.

Other ideas that came out of the discussion were:

- The Purple Butterfly icon could be used on paper notes.
- An ‘after-death staff huddle’ to talk through what went well and what could be done differently.
- The usability of the ReSPECT form for dyslexia.
- Potential issue that the Purple Butterfly form and the ReSPECT form are both purple.
- The potential to copyright the Purple Butterfly system and icon to roll out to other Trusts/care homes, which could be adapted nationally.

Workshop C - ReSPECT and the Red Bag

Workshop Lead: Hein Le Roux, GP Clinical Lead, West of England AHSN

This workshop focused on the Red Bag scheme which provides a transfer pathway designed to ensure care home residents receive safe, coordinated and efficient care should they go into hospital in an emergency. The scheme was started three years ago in Sutton South West London.

Discussions in the workshop included:

- Suggested Next steps:
 - o To embed Red Bag across the region.
 - o To ensure all Acute Trusts are aware.
 - o To collate evidence from ongoing pilots.
 - o A checklist for the Red Bag contents held within the Orange Folder would be useful (Gloucestershire use an orange folder for people with complex needs, including those living independently in their own home).
 - o To learn from Swindon – do it on a big scale!
 - o Should probably provide a folder as well as Red Bag.
 - o Should all Red Bags contain a completed ReSPECT form?
- Questions:
 - o Can families /patients buy their own Red Bag? Signposting families to Red Bag?
 - o Could patients wear a wristband to identify that patient has a Red Bag? (the wristband is kept in the Red Bag until use).
 - o Could the Red Bag include something personal (e.g. photos)?



For more information on our work in this area please see the reports on our frailty webpage at: www.weahsn.net/what-we-do/enhancing-patient-safety/collaborating-in-the-community/frailty-community-practice/

Workshop D - ReSPECT and the Poor Prognosis Letter

Dr Miranda Flory, Consultant in Supportive and Palliative Care, University Hospitals Bristol NHS Foundation Trust.

This workshop focused on the Poor Prognosis Letter, an initiative developed by North Bristol Trust in 2013 to provide electronic prognostic information from secondary care specialists to GPs to help them identify patients approaching the end of life.

This was included as a case study in the recent RCP publication "Taking About Dying"

Dr Flory explained elements of the Poor Prognosis letter, including:

- The Poor Prognosis Letter is used as a starting point for GPs in having the conversation on end of life care with patients.
- 30-50 Poor Prognosis Letters are completed each month.
- The Poor Prognosis letter acts as a reminder to patients of the prognosis conversation that has taken place.
- The Poor Prognosis Letter enables further discussion of the patient's needs.
- More patients died 'not in hospital' who had a Poor Prognosis Letter in place (2015 – 36%).
- Death is occurring on average 31 days after a Poor Prognosis Letter is given – this is too late!
- However, patient notes need to be specific: it does not mean that when a patient "needs a Poor Prognosis Letter, they are for end of life discussion" – which is not very useful with regard to conversations to be had with the patient around end of life decisions and preferences, or the completion of a ReSPECT form.

Suggested next Steps:

- Are to 'normalise' the conversation of death to improve cultural change.
- And to improve delivery and performance to enable a Poor Prognosis Letter to be issued sooner in the patient's pathway.
- The Poor Prognosis Letter should be included in and with a ReSPECT form for compatibility.
- What is the 3am test for the Poor Prognosis Letter and ReSPECT combined?
- Designing guidelines for junior doctors on the Poor Prognosis Letter and the ReSPECT form's use and consideration.

Questions:

- How many admissions are recorded after a Poor Prognosis Letter is issued for a patient? What is the nature of readmissions?
- Did the issuing of a Poor Prognosis Letter reduce admissions?
- Does readmission increase the uptake of a Poor Prognosis Letter?
- How will out of hours GPs / SWAST be aware of PPL? Plan for recording PPL on EPR (electronic patient record)
- Could the Poor Prognosis Letter be married with ReSPECT to act as a nudge to completing the form with the patient?
- Will the Poor Prognosis Letter be kept with the patient on their person? How will paramedics know that a patient has a Poor Prognosis Letter?

Workshop E - ReSPECT and the Experiences of Advance Care Planning

Tom MacConnell, Consultant Cardiologist and End of Life Lead, Musgrove Park Hospital

This workshop considered the plethora of Advance Care Planning in the region and discussions around having open conversations with patients on their preferences, and the use of the ReSPECT form.

Discussions included:

- The difference between ReSPECT and the Treatment Escalation Plan (TEP Form): a TEP form is a medical document which does not reflect the preferences of the patient or family; the ReSPECT form captures and reflects the wishes and preferences of the patient.
- Some patients are already too sick to interact with the process - conversations need to be had earlier and the patient's family need to be aware of the situation when the patient is at end of life.
- There is a need to have a 'brave conversation' at the right time early in the patient's 'journey'.
- Is there an opportunity to start the conversation with patients on options for an advanced care plan as part of the conversation around diagnosis?
- Acute Trusts and consultants need to offer their opinion on where their patient is at on the 'pathway' to identify the earliest opportunity for the conversation to be had with the patient.
- End of life advance care planning holds stigma and is fearful – when is the right time to start end of life conversations? People are more resilient when they know where they stand!
- There is a need to share the patients conversation captured through the ReSPECT process widely so that we all know where the patient is in their 'journey' along the care path
- Dementia Memory Clinics would be a good place to have the initial ReSPECT conversation
- End of Life Doulas – link with community networking = joined up working to provide holistic support to patient

Suggested next Steps:

- There is a need to agree the terminology and description of the ReSPECT form across all systems and practices.
- Everybody should move away from "you are probably going to die" to " you are going to die" and have realistic conversations with patients – healthcare professionals should internally 'celebrate' when a good death occurs (when patient preferences and wishes are recorded and acted upon).

Other considerations:

- Other countries embrace patient preferences around end of life care plans – we need to get better at this! What can we learn?
- Patients should be able to access and amend their own records as and when they want.

Workshop F - ReSPECT and the Death Café

Nathalie Delaney, Patient Safety Programme Manager, West of England AHSN

This discussion featured around the growth of Death Cafes and the increase in open conversations around death taking place in the public space. Death Cafes provide a safe and welcome environment to discuss death freely, to educate and help others becoming more familiar with the end of life.

Discussions in the workshop covered topics such as the need to have open conversations about end of life and options for recording those conversations relating to the preferences for end of life. There were also discussions on the language used to describe death, and the use of euphemisms to 'protect oneself' from talking about death: passing away, gone to a better place.

Further discussion was had on the use of the term 'Death Café' and how this had negative connotations to people wanting to join, and it was suggested that organised conversations around death held in pubs could be called 'last Orders', which was not as 'off putting' as the term Death Café'.

Some links and useful websites were shared including:

['What on earth is a death café?'](#)

DeathCafe.com

Workshop G - ReSPECT and the End of Life Doula

Arabella Tresilian, End of Life Doula, End of Life Doula UK

Suggested resource: 'With the End in Mind' by Kathryn Mannix

Arabella Tresilian is a trained End of Life Doula and mediator, and this workshop focused on the support Doulas provide end of life patients and their families, and their unique position to be able to have conversations around patients and their families' preferences.

Doulas are trained in supporting people at the beginning (birth doulas) and end of life. 'End of Life Doulas' walk alongside the individual, their family and their community as an informed companion. They are sensitive to practical, emotional and spiritual needs and are a consistent and compassionate presence, with knowledge, experience and understanding.

Discussion points focused on:

- The number of doulas available nationwide;
- The understanding of available care packages by Doulas;
- Whether an End of Life Doula is financed by the patient.
- The process to develop doula practice and numbers.
- How quickly could a doula attend a patient?

Questions were raised and answered around the following:

- How do doulas overcome natural barriers?
 - by 'holding the space' so families can be proactive with care; this is adjusted on a case by case basis; Doulas also help provide a vigil for when patients die without their family and friends present.

- How many Doulas are available nationally for patients to employ for support at their end of life?
 - there is no 'raft of doulas' available, it is an 'organic growth' in development, and it is not a speedy process to develop doula practice and numbers.
- How quickly could a doula attend a patient?
 - that depends, as there are not enough Doulas trained; but it is important to create relationships between doulas and NHS organisations to spread the word and raise the profile of Doulas available.
- How long is Doula training?
 - about 20 days, which is accredited – Arabella Tresilian's website lists local doulas, but best to contact them directly.
- Are doulas vulnerable legally through their work?
 - an insurance package has been rigorously developed and accredited training is intensive.
- What is patient and family feedback like?
 - it is important to get Doulas on people's radar with case evidence and feedback; however, it is a 'quiet growth' and there is a driving need to 'get it right'.
- What about the governance behind doulas? i.e. access to medical records, etc.
 - Doula advocacy is 'light', and the main objective is to help people organise their thoughts and getting them to think about questions they have not considered.
- What about Doula training?
 - Doulas work within a family system, not just with the individual and generate a level of calm – the training is theoretical, spiritual and emotional.
- How would you introduce an End of Life Doula to a patient?
 - Local Death Cafes are good access points to Doulas, or complete a form on the Living Well Dying Well website.
- What is the guidance for maximum /minimum time a Doula would spend with a patient?
 - This is tailored to the individual, including those interacting with those people who are living in social isolation (i.e. engaging with neighbours); it's about building the relationship and learning where gaps are in support for patient, such as family; if the Doula is a volunteer then the amount of time spent with patient is agreed beforehand; Doulas can also engage with the patient on family disputes, consent, helping to write letters, etc.

Workshop H – Just In Case Drugs / End of life Ambulance Staff
Ali Mann, Senior Project Manager, West of England AHSN

This workshop focused discussion on anticipatory prescribing; a process that is designed to ensure that there is a supply of drugs in the patient's home, combined with the apparatus needed to administer them, with the intention that they are available to an attending clinician for use after an appropriate clinical assessment.

Some discussion points included the following:

- First Responders are called out of hours to 70% of end of life cases.
- There is a need for patient families to understand ReSPECT and what it means for patient outcomes (families are complex!)
- There exist often incorrect assumptions across services, so there driving need to make sure that conversations with patients are captured across the full Care Pathway, through Acute and Community Care.
- There is a need to be careful not to raise unrealistic expectations – Just in Case Drugs may be held with the patient, but can they access the services to administer them?
- Education and training should be a priority.
- There is a need for consistency of the ReSPECT form to ensure it details how out of hours and end of life services can be accessed by the patient – this is really important for First Responders that cross localities.
- A dichotomy exists for First Responders as they are ‘trained to treat’, but need conversations on how ‘not to treat’ patients when working with a patient who holds a ReSPECT form – the outcome of death is perceived as a failure by medical colleagues – “There is no such thing as withdrawal of care in medicine, there is only redirection of goals” Sam Ghali.
- There exists a lot of focus on whether Just in Case Drugs are in place, but there has been no sense check on whether a conversation has been had with the patient about whether it’s the right thing to do.
- Consideration should be given to options for ‘self-care’ in the community; however, palliative care is always the priority within the community.
- There is a driving need to solve the interoperability issue of a digitized version of the ReSPECT form, accessible to all services.
- Need to find appropriate ‘touch points’ for patients to have ReSPECT conversations, i.e. Memory Clinics, COPD Clinics, etc.

Ideas, suggested actions:

- Undertake ReSPECT conversations in Memory Clinics.
- Learn from paediatrics and family carers, and from other countries, such as Australia.
- Question on advanced technology – do the clinicians need to be with the patient when completing the form?
- End of life care requires the right care in the right order at the right speed.

Next Steps:

- What can we learn from paediatrics?
- What can we learn from other countries (i.e. Australia)
- Involve whole family
- Training GPs to increase confidence and competence
- Maintain consistency and communication
- National standard – minimum requirement