

ReSPECT Autumn Event

Wednesday 18th September 2019

Kings Weston House, Bristol BS11 0UR



@WEAHSN #ReSPECTWest #haveaconversation

We talk of ReSPECT, but what does that mean?
We'd like to begin by setting the scene:
What's happened so far and what we can do...
We'll hope things get better – and often they do.
But what if they don't; and things start to change?
When bloods start to fall outside normal range,
Or you're feeling weaker and getting quite frail
Then what should your future ideally entail?
We'll talk through the options of what could help now,
Find balance between treatment and comfort somehow;
Reverse what we can and support all the rest,
Consider each drug, intervention and test.
Together we'll plan for what lies ahead,
With both of us crystal clear in our head,
That all that's important was thought of and checked
And decisions were made with mutual ReSPECT.

Dr Rachel McCoubrie, <https://rachelmccoubrie.blogspot.com>

West of England

**Patient Safety
Collaborative**

Overview: The West of England Academic Health Science Network

The West of England AHSN is delivering positive healthcare outcomes locally and nationally by driving the development and adoption of new innovations and making a meaningful contribution to the economy.

Established by NHS England in 2013, we are one of 15 AHSNs across England established to spread innovation at pace and scale.

As the only bodies that connect NHS and academic organisations, the third sector and industry, we are catalysts that create the right conditions to facilitate change across whole health and social care economies, with a clear focus on improving outcomes for patients.

The AHSN is working with the Bristol, North Somerset and South Gloucestershire (BNSSG) STP (Sustainability and Transformation Partnership), the BNSSG CCG (Clinical Commissioning Group), and the Gloucestershire ICS (Integrated Care System) to support the adoption of ReSPECT (Recommended Summary Care Plan for Emergency Care and Treatment) in NHS Services and Care Homes across the footprint of the BNSSG CCG and the Gloucestershire ICS.

ReSPECT will be launched in the BNSSG STP and Gloucestershire ICS on 10 October 2019, where ReSPECT conversations will start to take place between patients and Health Care Professionals and Clinicians to discuss and record patients' end of life care plans, treatments and preferences. These will be recorded on a ReSPECT form, and this information will support clinical decisions in the case of emergencies.



About the event

The ReSPECT Autumn event was designed to deliver a series of three workshops that provided further understanding and confidence in supporting the adoption of ReSPECT in NHS Services, organisations and care homes.

The workshops included opportunities for attendees to develop their knowledge of the ReSPECT process and the value of the process to benefit patients, their families, health professionals and clinicians in primary, secondary, and community care services settings.

The workshops consisted of the following:

Workshop 1 – Confidence: this workshop provided an opportunity to share learning, experience and best practice from early adopters from Worcestershire NHS Trust and Hull NHS Trust, where ReSPECT has been adopted.

Workshop 2 – Data and Measurement: this workshop gave attendees an introduction to the [Seven Steps for Measurement](#), provided an exercise in identifying what data is, and provided an exercise in identifying data and metrics available in local settings and organisations.

Workshop 3 – Conversations: this workshop gave an insight into the benefit that earlier conversations with patients on their end of life care and treatment provides for the wellbeing of patients and their families in identifying their health care preferences. Attendees were provided with the opportunity to witness a series of conversations between clinicians and actors who played the role of various patients, and enabled interaction from attendees to stylise and influence conversation outcomes.



Attendees

The event was attended by over 150 health practitioners and clinicians from Primary, Acute and Community Care Services across BNSSG CCG and Gloucestershire ICS, as well as a contingent of representatives from care homes

Attendees included representation from the following:

Primary Care, BNSSG CCG	Primary Care, Gloucestershire ICS
Acute Care, BNSSG CCG	Acute Care, Gloucestershire ICS
Care Homes, BNSSG CCG	Care Homes, Gloucestershire ICS
BaNES (Bath and North East Somerset)	Wiltshire CCG

Plenary Session

The plenary session consisted of introductions from our speakers on their experience of supporting the adoption of ReSPECT in Worcestershire NHS Trust, Hull and East Yorkshire Hospitals Trust and South Central NHS Trust.

We also heard from Anne Pullyblank (Medical Director, West of England AHSN), who talked through the delivery of adopting ReSPECT in the BNSSG CCG and Gloucestershire ICS.

Dr Andrew Appleton (BNSSG CCG Digital Clinical Lead & CCIO) then presented the EMIS template to attendees using a live version of the template, which had been pre populated with example patient information. This was incredibly useful as attendees could see how the resulting ReSPECT form was created through the template.

The Resuscitation Council has been consulted on the EMIS template to ensure it meets criteria and requirements. The EMIS template is being tested in local GP practices to ensure the patient information it contains flows through to Connecting Care, where it can be accessed by Community Health, Out of Hours GPs and Acute Care colleagues. GPs can complete the ReSPECT form digitally in consultation with the patient, and a hard copy can be printed and handed to the patient to be kept in case of emergencies. This form can then be emailed immediately to the South Western Ambulance Service and Out of Hours GPs.

NB: Since the event, Standard Operating Procedures have been drawn up, and information and guidance has been shared with GP practices in time for the roll out of the EMIS template, which will take place after the 10th October in BNSSG CCG and Gloucestershire ICS.

Jon Bradley (Macmillan Cancer Care Development Facilitator, South Western Ambulance Service) advised that SWASFT crews and call handlers have received awareness training on ReSPECT, and that ReSPECT has been included in clinical guidelines. Jon advised that emergency crews and paramedics are prepared to recognise ReSPECT forms across the West of England, in the same way that existing Advance Care Plans and Treatment Escalation Plans are recognised. The ReSPECT form will enable clinical decisions to be made on patient care.



Workshop 1 – Confidence

This workshop provided the opportunity for our early adopters of ReSPECT to deliver a more in depth presentation on their experience of adopting ReSPECT within their specific localities.

ReSPECT: Worcestershire NHS Trust

“In the three years of ReSPECT usage there have been two near misses and no adverse effects recorded.”

(Sam Skillbeck, Macmillan ReSPECT Project Manager, Worcestershire Health and Care Trust)

Joanne Hodgetts (Macmillan ReSPECT Project Lead, Worcestershire Health and Care Trust) and Sam Skilbeck (Macmillan ReSPECT Project Manager, Worcestershire Health and Care Trust) delivered an informative introduction to the work delivered in [Worcestershire NHS Trust](#) to adopt ReSPECT through a Macmillan funded project that launched on 1st July 2019.

Jo informed attendees that ReSPECT was adopted in a hard copy form across the area, as the infrastructure was not yet in place to support a digital version of ReSPECT. ReSPECT was adopted across all care settings including the ambulance service. The project team is currently working in Year Two₁ of the two year project, and focus is now upon commencing quality monitoring of the project outcomes.

Jo also informed attendees that plans are in place to start public engagement from October 2019. The ‘go live’ of ReSPECT was supported through a range of monitored clinical training and consisted of a full set of Standard Operating Procedures adopted across all health care settings.

[Age UK](#) and [Care UK](#) were both included in the Project Board, and the [national training app](#) (from the Resuscitation Council) was used to disseminate learning, which was tailored to meet local policy and ethics. The project team has monitored how many people in each organisation were trained in order to assess risks and issues prior to ‘go live’. The e-learning training consisted of the three levels derived from the Resuscitation Council resources that are suited to authors and responders of the ReSPECT form.

The project was delivered with the principle that any patient who may want a ReSPECT form should have one, which initiated earlier conversations.

Jo Hodgetts advised that there was an expectation₁ when ReSPECT was launched in Worcestershire NHS Trust₁ that there would be issues with version control or the duplication of ReSPECT forms, but this has not proven to be the case.

Worcestershire have over 3000 staff following the ReSPECT process, and there are current challenges with training Acute Care staff, with a target of 75% of staff trained, but only 20% received training before ReSPECT went live.

ReSPECT: Hull and East Yorkshire Hospitals NHS Trust

Anna Folwell, a consultant geriatrician then delivered a brief presentation on the delivery of ReSPECT through the FIT Programme in Hull and East Yorkshire Hospitals NHS Trust. The project went live on April 18 2019, and consists of a hard copy paper ReSPECT form, as there is no digital availability yet to deliver in any other way. A consideration was made on the risk of version control of the ReSPECT form, but to date there have been no incidents reported. There was an identified need for focused training to equip users to have the ReSPECT conversation with patients early.

ReSPECT was delivered in the form of a 'big bang' on 18 April, as it was recognised that a roll out of ReSPECT in smaller pockets of trials would not work to the satisfaction of all concerned. The project developed a good outreach programme with patients, families and carers across care homes to promote the uptake of ReSPECT in care home settings. Collected data has identified an 11% reduction in admissions from care homes where ReSPECT is being used.

ReSPECT: South Central NHS Trust

Sara Constantine, Medical Director for AWP, was involved in the adoption of ReSPECT in South Central NHS Trust, and gave a good representation of some of the challenges and successes in adopting ReSPECT.

This project delivered huge value for patients with dementia. The main challenges identified included the 'piecemeal' approach to adoption across the area, as ReSPECT was initiated in one acute setting that had not fully informed other services that this was being adopted.

There was an identified issue and risk in the existence of two types of purple forms, as the existing DNACRP form was also purple. The risk also recognised that patients residing on the border with the Trust may go to a health care setting that did not recognise ReSPECT, and the two similarly coloured forms may be confused, where ReSPECT may be recognised as a DNACRP form only.

A broad discussion with questions and answers presented to the panel of early adopters closed the workshop, where attendees' questions and concerns could be aired.





Workshop 2 – Data and Measurement

This workshop provided attendees with the opportunity to identify the data and metrics that are available in their particular local settings, with recognition that the adoption of ReSPECT from the 10th October will consist of a Quality Improvement approach that will improve systems and processes to support ReSPECT.

The workshop began with a brief exercise that provided an opportunity to identify what data and measurement is, and this helped emphasise the variance of the quality and availability of ReSPECT data across local sessions.

The workshop consisted of four separate groups throughout the day, and the discussions had in each session have been recorded below for information.

Group 1

Feedback on the group exercise

A discussion took place around which staff groups were to complete ReSPECT forms, when this should best take place, and at which point a ReSPECT form might be suitable to be updated. There is a learning pack available on the [West of England AHSN website](#), which is available for all colleagues to access, which includes training on completing ReSPECT forms. A useful data set to identify and collect for all organisations and systems would be the number of staff that have had training to complete the ReSPECT form.

Group 2

Feedback on group exercise

Feedback from the exercise identified that the decision on the data available, and how best to measure this data and the frequency of measurement, needs to be made locally.

Group 3

Feedback on group exercise

It was discussed that data can be difficult to identify and measure as each setting is different, and there is not one standard data set to measure. This emphasised the need for local settings to identify the most suitable data that would best enable the adoption of Respect, using quality improvement methodology.

Another concern considered the turnover of staff being high in certain settings, and identified the need to train new staff to ensure consistency, therefore, keeping the gathering and collection of data as simple as possible, and relevant to staff duties, is important; as well as keeping accurate records. Another discussion included the measurement of confidence, as this can be very specific to a setting, and it was suggested that using the [West of England ReSPECT Confidence Survey](#) within organisations may be the best approach to this, as the results can be granulated for specific organisations and reported anonymously by the AHSN.

Group 4

Feedback on the group exercise

The discussion included the identification that measuring patient outcomes is difficult due to the variables involved, but that a standardised patient and family feedback on the ReSPECT process would be useful to identify some of the patient outcomes relating to the use of a ReSPECT form.



Workshop 3 – Conversations

This workshop aimed to provide further confidence for attendees to recognise opportunities to have earlier ReSPECT-related conversations with patients. The workshop consisted of a 'swimming pool exercise' to help attendees identify their confidence levels in having

conversations with patients. A mingling exercise then took place, to encourage conversations with those colleagues who identified as having more experience in end of life conversations, and to identify suitable times and opportunities to have conversations with patients in different settings.

The workshop concluded with examples of (acted) patient and clinician conversations on end of life preferences to provide the opportunity for attendees to witness how these conversations are more difficult for the patient, their family and often the clinician when no previous conversations have been had on health care or treatment preferences.

Swimming Pool Exercise

This exercise asked attendees to place themselves within a defined area of the room which represented their level of confidence in having end of life conversations with patients. Some of the results and conversations recorded

- **Deep End:** (Confident in having conversations with patients)
 - 'I have conversations with patients on end of life preference as part of a daily clinical practice'
 - 'I am personally confident'
- **Diving Board:** (Ready to Go!)
 - 'I know my patients very well. We know what they want. We're used to processing forms and ReSPECT will help formalise those conversations that we already have with patients'
- **Kiddies' Pool:** (not at all confident, need more practice)
 - 'Not knowledgeable enough'
 - 'Need more confidence with working alongside others in ReSPECT process'
- **Changing Rooms:** (not even in the swimming pool / ReSPECT yet) nobody placed themselves in the changing room
- **Sun Loungers:** (taking a watching brief on what is happening in BNSSG CCG and Gloucestershire ICS) 'We do end of life chats but are struggling to get GPs on board with ReSPECT'; 'I feel confident talking to staff in social care settings but do they have confidence in having ReSPECT conversations?'
- **Shallow End:** (nearly ready to adopt ReSPECT, but need more confidence to enter the Deep End)
 - The majority of attendees placed themselves in this area of the pool

The final part of the workshop consisted of a roleplay with actors playing patients in conversations with clinicians. Some of the observations, suggestions and considerations that came from the discussions are recorded below:

- 'When a patient is in denial, respect their position at that time and come back to it later'
- 'Could signpost them to someone else – spiritual?'
- 'Could ask them what their priorities are right now'
- 'Signpost to hospice care/support group for the condition (i.e. cancer support workers)'
- 'Could have family member with patient at GP appointment. Could have district workers nurse there'
- 'Could have conversations at patient's home instead of clinical setting'

- 'The patient has had 5 admissions but says he's alright! Should you ask "do you think there might be a time when you won't be alright?"'
- 'After 5 admissions it's a bit late to be starting this conversation and why isn't there a discharge letter?'
- 'Asking patient to think of how his condition is progressing?'
- 'Know when to stop the conversation and when to come back and progress the conversation'
- 'Asking how would he like his next admission to be and helping the patient to think of the future'
- 'What is the patient's biggest concern for the future?'
- 'Recommend Winston's Wish regarding how a patient's children can be supported'
 - The Rainbow Centre – Bristol
 - The Hope Charity – Gloucestershire
- 'Establish a timeframe to give people enough time to process the conversation and for it to sink in'
- 'Clinicians can often hide behind terminology when they're scared. If we use clearer language its harder for us, but it is easier for patients to understand'
- 'As a clinician I want as much information as possible before having conversations, but you don't have all the answers'
- 'Could focus on symptom control'
- 'Find a fine balance'
- 'You have to take the cues from the person in front of you'
- 'A Clinical Nurse Specialist would be good in this situation to be referred to'
- 'Inform yourselves as clinicians as much as possible'
- 'You wouldn't have the ReSPECT conversation now, the patient and family will only hear 'cancer' and 'death' so you need to let the news settle in'
- 'ReSPECT helps balance of care, but what are the patient's priorities?'



Workshop 4 – Round up of the day

Kevin Hunter (Associate Director for Patient Safety & Programme Delivery, West of England AHSN) delivered a brief roundup of the day's workshops and outcomes, which included a reminder for delegates to access the range of ReSPECT resources to be found at the [West of England AHSN ReSPECT](#) webpage.

Kevin Hunter thanked the speakers, many of whom had travelled a great distance to be at the event, and the actors who delivered the conversation workshop roleplay.

Emma Redfern (Consultant in Emergency Medicine & Associate Medical Director for Patient Safety, West of England AHSN) read a poem written by Dr Rachel McCoubrie (Palliative Care Consultant, University Hospitals Bristol), reproduced on the cover of this report.



Workshop 5 – Primary, Acute Care, Community Care Services and Care Homes

The final workshop of the day asked attendees to gather in groups within their own services, with Primary Care, Acute Care, Community Care colleagues discussing the learning and outcomes from the day, and especially considered the next steps for adopting ReSPECT in their particular settings.

A number of considerations were discussed in the round-table talks, some of which have been captured here:

'We'd like easy-read ReSPECT resources' (signposted to the [ReSPECT website](#), where an Easy-Read ReSPECT leaflet can be downloaded, or contact Respect@weahsn.net)

'We'd like a platform to be able to share great news stories from care homes. All you ever hear is the negative' (signposted to the [hyvr platform](#), where discussions on ReSPECT can take place among clinicians and health care professionals)

'We'd like nursing agencies to know about ReSPECT' (phase 2 of the adoption of ReSPECT in BNSSG CCG and Gloucestershire ICS will engage with nursing agencies from the 10th October)

‘Have you thought about domiciliary carers?’ ... ‘They build long-term relationships with people with life limiting conditions. They are in a great position to initiate the very first stages of the ReSPECT process’ (*Domiciliary care organisations will be engaged to support the adoption of ReSPECT after the 10th October*)

‘Where can I obtain access to the online training?’ (The [West of England AHSN website](#) contains access to the three levels of ReSPECT training: Level 1 – Awareness; Level 2 – Action; and Level 3 – Conversations)

Outcomes and next steps

The EMIS template for creating digital ReSPECT forms in Primary Care will be tested prior to the ‘go live’ date on 10th October for BNSSG and Gloucestershire CCG, and should be gradually rolled out across GP Practices from that date. Any GP practices that would like to start the ReSPECT process with patients and complete forms, can obtain hard copy forms via EROS using the ReSPECT form code RVJ2091, and come in pads of 55 forms; you can also order directly from the supplier [LG Davies](#).

Resources:

BBC Horizon ‘We Need to Talk About Death’

<https://www.bbc.co.uk/programmes/p06yc17v> (4 minute trailer)

<https://www.dailymotion.com/video/x716d04> (full film)

BBC Radio 4 ‘We Need to Talk About Death – My Dying Wishes’

<https://www.bbc.co.uk/programmes/m0001ygy>

‘We need to talk about dying’ – Jo Withers TEDxNewnham

https://www.youtube.com/watch?v=8zOi6Z_0au8

‘ReSPECT Process – Person Centred Emergency Care Planning’ – NHS Forth Valley

https://www.youtube.com/watch?v=7tThnoOd_Ms&feature=youtu.be

Dying Matters – “I Didn’t Want That”

https://www.youtube.com/watch?v=Z_qIR7mLoEq

East Sussex Hospital Trust’s education film for the ReSPECT process and form

<https://www.esht.nhs.uk/caring-for-you/recommended-summary-plan-for-emergency-care-and-treatment/>

[West of England ReSPECT webpage](#)

[Resuscitation ReSPECT website](#)

Thank you to everyone involved in the day!