TheAHSNNetwork

NHS Improvement

Event report

Learning and Sharing ReSPECT Spring Event

Clevedon Hall, Clevedon | 20 March 2019

West of England
Patient Safety Collaborative

Working together to build a culture of continuous learning and improvement

Introduction

On 20 March the West of England Academic Health Science Network opened the third ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) event at Clevedon Hall, which was attended by 98 attendees from across the West of England who took part in informative plenary presentations and engaging workshops.

The event aimed to provide an update on the adoption of the ReSPECT form and process across three Sustainability and Transformation Partnerships (STPs) in the region, and gave attendees an opportunity to attend workshops to improve their confidence and understanding of how to implement ReSPECT in their own organisations and services.

There were attendees from a wide range of services within the region who contributed to discussions on delivering ReSPECT, adopting and defining best practice and identifying opportunities to begin the conversation with patients about ReSPECT.

The event was opened by Natasha Swinscoe, Chief Executive of West of England AHSN, who welcomed attendees and asked them to use the day to consider how best they can take part in implementing and adopting ReSPECT in their organisation and service within their own area. Natasha also asked attendees to consider why the region is adopting ReSPECT, and identified that ReSPECT improves patient care and enables opportunity for conversations to take place around patients' end of life choices.

During the opening plenary sessions, the question 'where are we now' was presented by a number of speakers who provided an overview of the system-led interventions for ReSPECT in a primary and community setting, and an acute and ambulance emergency setting, which included an overview of the cross-cutting themes of delivering ReSPECT and the expected outcomes.

The eight workshops provided attendees with further information and guidance - from measuring impact and gathering data; using Quality Improvement (QI) methodology and tools to implement change; guidance and advice on having conversations with patients; identifying patients who are appropriate for a ReSPECT form; and how to recognise the legal status of the ReSPECT form through a consideration of the Mental Capacity Act (MCA).

Following the workshops, Natasha Swinscoe asked all attendees to consider their next steps in adopting and implementing ReSPECT, and linked the day back to the plenary presentations 'where are we now?' The event concluded with three workshops that focussed upon the implementation of ReSPECT within Gloucestershire ICS, BSW CCG (BaNES, Swindon and Wiltshire) and BNSSG CCG (Bristol, North Somerset and South Gloucestershire). These workshops provided a good understanding of the progress of ReSPECT within these areas and identified concerns and issues to adopting ReSPECT across services.

What our speakers said

Welcome from Natasha Swinscoe (Chief Executive, West of England Academic Health Science Network)

Natasha welcomed attendees and highlighted the need for the adoption of ReSPECT in the region with a patient perspective, by sharing a short film from NHS Forth Valley.

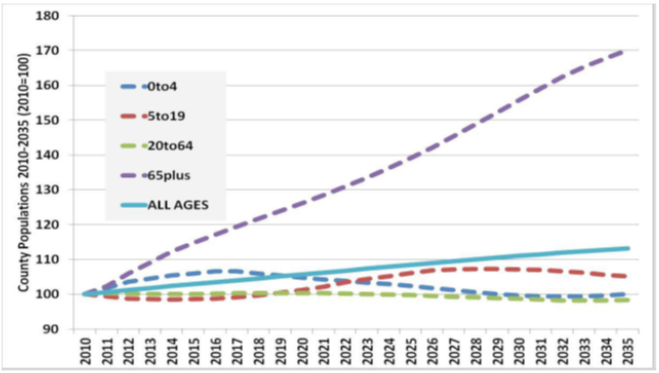
By highlighting the level of care and consideration made in planning and preparing for a birth, marriage, and even a funeral, most people do not plan for their end of life care and wishes. Natasha asked the audience to consider the ReSPECT form and process to be important to patients particularly in their last 1000 days of their lives, rather than the last 100 days, and thanked them for supporting ReSPECT.

Natasha went on to describe the AHSN's Implementation Plan which supports the roll out of ReSPECT across the three CCGs, and asked attendees to recognise the ReSPECT form across all services from the 20th March as a beginning to adoption in all services and areas, closing with "we know that the implementation of the process of conversations, and communicating the form, will take time".

ReSPECT: Where are we now? Primary and Community Care - Hein le Roux (GP Gloucestershire CCG / ReSPECT Clinical Lead West of England AHSN)

Hein recognised the ageing population in Gloucestershire and the need for the ReSPECT form and process within the CCG as a "case for change". He asked attendees to consider that patients do not experience good quality of care if their wishes are not respected, and when the "tracks do not line up" poor patient care is delivered.

Ageing population in Gloucestershire (source: JSNA)



Hein went on to describe how a recent patient, who was diagnosed with terminal cancer, was not asked about their end of life wishes until it was very late. This was despite many opportunities for health professionals to have had the conversation with the patient at a number of "touch points". The ReSPECT form, he stated, would have provided an opportunity for any number of conversations to be had by many health professionals during that patient's diagnosis and treatment.

Hein also placed emphasis on the inclusion of ReSPECT into GP contracts; and highlighted the benefit of the evolution of Primary Care Networks as the means to provide the greatest opportunities to improve patient care.

The presentation closed with Hein's description of how the Safety & Autonomy For Every Resident (SAFER) programme delivered through the Care Homes Collaborative would provide improved patient care, and many opportunities for the conversation on a patient's end of life wishes to take place, and be recorded on a ReSPECT form.

ReSPECT: Where are we now? Acute and Emergency Care – Emma Redfern (Consultant in Emergency Medicine & Associate Medical Director for Patient Safety, West of England AHSN)

Emma gave an update on where the acute trusts in the BNSSG CCG were with the adoption of ReSPECT, and advised that the acute trusts support the move to ReSPECT in principle. However, considering the logistics of adopting ReSPECT across a trust and ensuring it is recognised within community health and primary care, a cultural change is required. Within the BNSSG CCG, North Bristol Trust, Weston Area Health Trust and University Hospitals Bristol are planning to implement ReSPECT together at a set date.

A comparison was made to the adoption of ReSPECT as being similar to the adoption of NEWS (National Early Warning Score), and Emma emphasised the benefits for the adoption of a standardised approach and form. As the adoption of ReSPECT will require a cultural change across services, Emma recognised that conversations need to happen early in order to provide patients with improved care.

Emma recognised that there are sticking blocks over who is best placed to have conversations on ReSPECT. It was suggested that there is no one group of people responsible to have the initial conversation with patients, but that a number of conversations should be had with patients over a period of time. These would come from a number of areas and involve the number of health professionals who are engaging with patient care.

Emma asked attendees to recognise that the ReSPECT form is not a Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) form, but that it records patients' wishes in the event of an emergency, including their wishes for or against DNACPR. ReSPECT is more than a form, however, as it is an iterative process, starting with having the conversation with patients as early as possible.

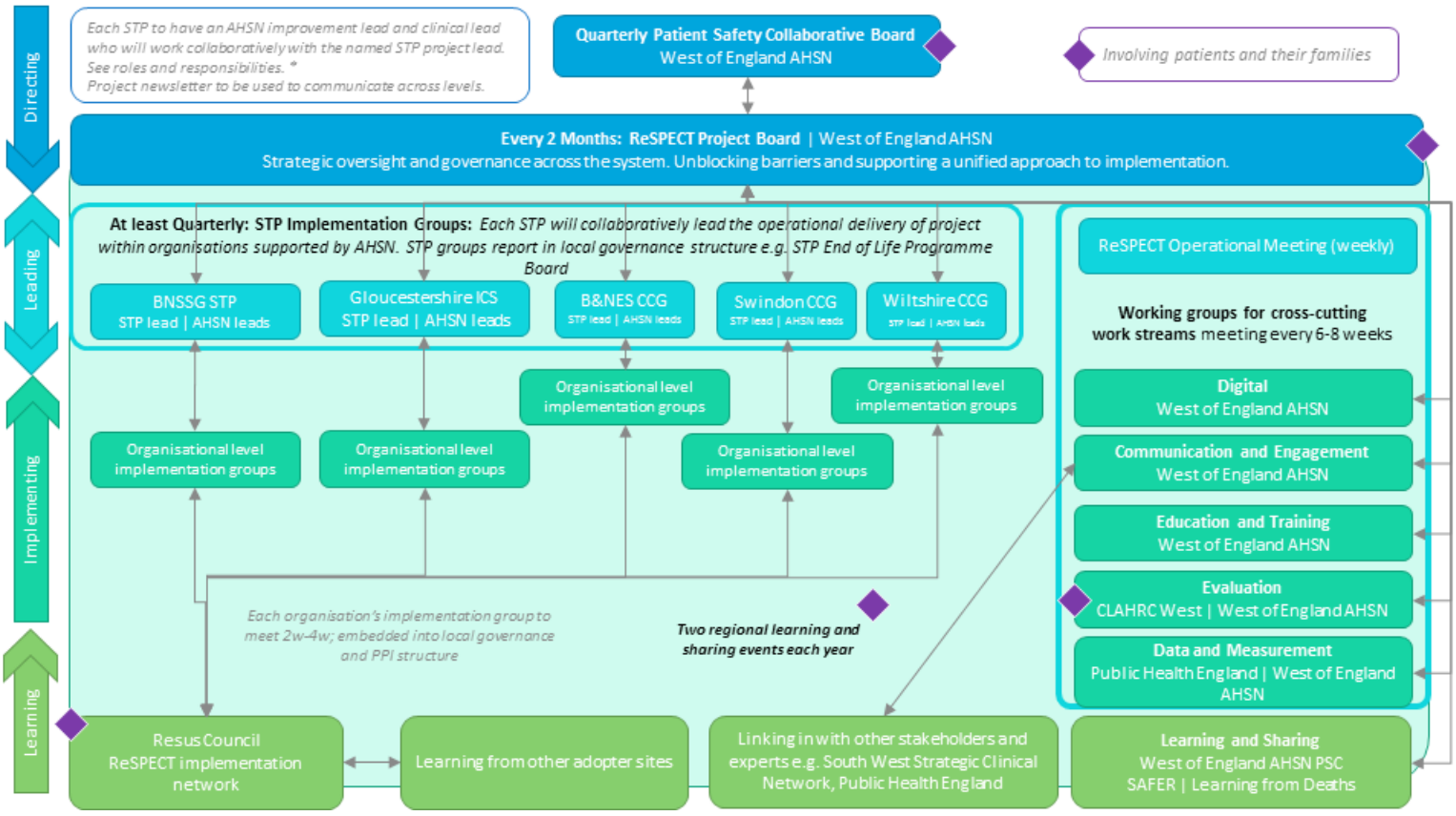
Emma also suggested that poor prognosis letters written by a patient's GP should be completed within the last year of life, and not the last month as currently happens. This would provide a greater opportunity to have the conversation on ReSPECT with patients at an earlier date.

The presentation closed with the acknowledgement that the position of Medical Examiner will include the review of patients' end of life plans, and provide opportunities for improvement, providing improved patient care.

ReSPECT: Where are we now? Cross cutting themes – Nathalie Delaney, Programme Manager, West of England AHSN

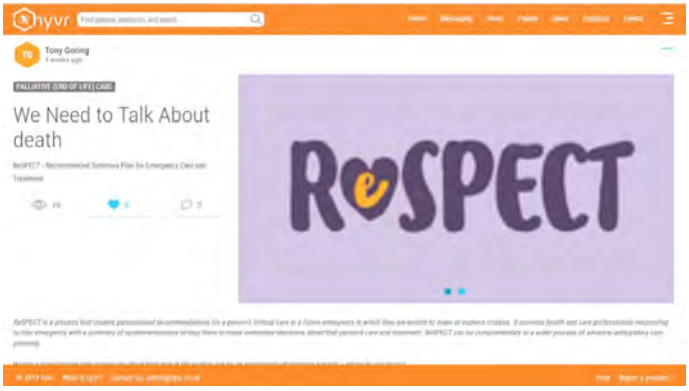
Nathalie began with a quote from one of the designers of the ReSPECT form, Ivor Williams, who said that "we didn't redesign a form, we redesigned a relationship". Nathalie recognised that the adoption of ReSPECT is about a cultural change, and is not all about the form; but relates to the need for conversations with patients at an earlier time in their prognosis. She emphasised that "ReSPECT is not a form - ReSPECT is a process of conversations, communication, and taking action on those conversations."

Nathalie went on to describe the cross cutting work streams and reiterated the challenges for all working groups. This was followed by the presentation of the Education Pack produced by the AHSN which offers three levels of training available to ensure a good understanding of the ReSPECT form and process is achieved across all levels of services.



ReSPECT Level 1	Awareness	Training to teach staff how to recognise the form, and what it stands for • What is ReSPECT and how is it different to what we have already? • Who is ReSPECT for? • What does the form look like?
ReSPECT Level 2	Action	Training for staff who will need to recognise the form, and act on the recommendations • As above plus • How to care for someone with a ReSPECT form • During an emergency where a person is unable to make or express choices • When to update the form
ReSPECT Level 3	Conversations	Training for staff who will be initiating or carrying out conversations with patients and their families about treatment escalation, DNACPR, and the ReSPECT process • As above plus • Having a conversation about ReSPECT • Completing the form • Communicating the form • The ReSPECT form, legal status and relationship with other areas

Nathalie advised that the AHSN has placed the Resuscitation Council ReSPECT resources on a FutureNHS Collaboration Platform ('Kahootz'), which includes those resources shared by early adopters of ReSPECT, such as Kent, Surrey and Sussex AHSN. The Kahootz work space includes links to the Resuscitation Council e-learning resources and scenarios. All attendees to the event have been invited to access the Kahootz online platform, and a request for access can be made to Respect@weahsn.net.

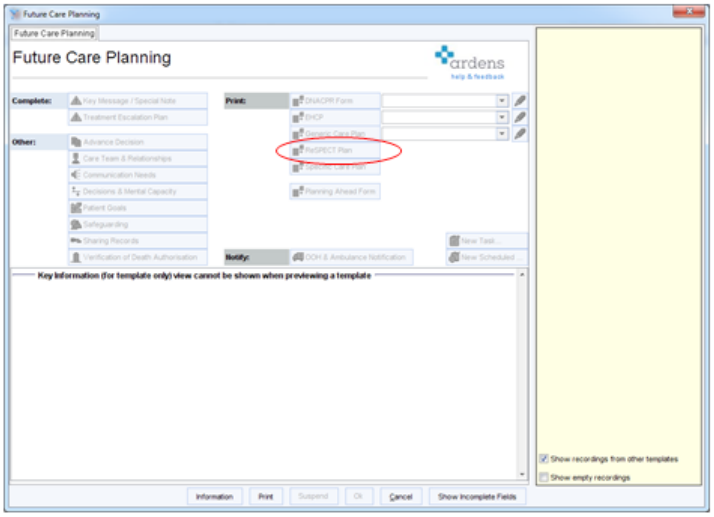


Nathalie highlighted the development of hyvr (Have Your Vision Realised) by the AHSN, which is an online platform where discussions on the adoption of ReSPECT can take place. Please email Respect@weahsn.net to join the hyvr online platform.

Dying Matters Awareness Week (13th – 19th May #areweready) was highlighted as a suitable touch point for starting conversations on ReSPECT, and will be the launch date for Gloucestershire ICS to roll out ReSPECT locally.

Nathalie discussed the need to gather data pertinent to measuring the adoption and impact of ReSPECT in the region, and across services and trusts. She emphasised that data and measurement used ought to go beyond measuring place of death, and include qualitative as well as quantitative data. National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West) will be collecting qualitative and quantitative data from care homes in the region to compliment the evaluation of the adoption of ReSPECT.

The presentation addressed the digital interoperability of ReSPECT, and this was recognised as being a "hard nut to crack". The AHSN is leading on finding a remedial solution and developing a series of "work arounds" to enable ReSPECT forms to be digitised and shared around services, community health, and primary and secondary care. Nathalie advised that SystmOne users across Gloucestershire, BaNES, Swindon and Wiltshire will have access to Ardens templates, which include ReSPECT forms, and asked attendees to advise the AHSN if access is required to these via SystmOne.



The ReSPECT form for EMIS platform is available to be installed via Template Manager or Resource Publisher at www.qmasters.co.uk/respect

Nathalie recognised that a digital solution to link the ReSPECT form among services will take considerable time to process, and advised colleagues not to rely upon a digital 'solution' to sharing the ReSPECT form and process, but to focus on using the paper form of the form. This is also the advice of the Resuscitation Council.

The presentation closed with the ask for attendees to consider that the adoption of ReSPECT will be an iterative process across the West of England, where a series of stages will deliver what is required through the development and adaptation of the process to fit the many layers of NHS services in the region.

Talking About Dying - Sarah-Jane Bailey (Health Education England Quality Improvement Fellow 2018/19 & ST6 in geriatrics and general internal medicine, University Hospitals Bristol NHS Foundation Trust)

Sarah-Jane began by addressing the issue of patients being inappropriately readmitted to hospital in 2018, and reiterated that these were situations which should not have happened or have got that far. Sarah-Jane noted that this is a poor example of patient care and went on to highlight the Royal College of Physicians' 'Talking About Dying' report, which shows that there are on average three and half times more admissions for patients to hospital in their last year of life. Sarah-Jane commented that this equates to three and half times more opportunities to have the conversation on ReSPECT. She emphasised that these conversations need to be "honest, informed and timely" to make the difference in improving patient care.

The presentation went on to note that the NHS Constitution for England enshrines the importance of a patient's right to be involved in the planning and decisions around their health and care, which includes end of life care. The need to have 'opportunity-based conversations' to ensure end of life care is improved was reiterated by Sarah-Jane, who called on colleagues to identify opportunities to have numerous conversations during a patient's healthcare journey, and emphasised that this was not one person's responsibility, but the responsibility of all health care professionals.

It was acknowledged that there is a myth that people do not want to talk about death; and Sarah-Jane stated that 77% of the public in England stated they would want to know if they had less than a year to live. Sarah-Jane highlighted that there are many cultural barriers to talking about death, which include medical practitioners' reluctance to talk about death with patients due to their professional striving to sustain life, and cultural and religious considerations when discussing death with patients.

It has been acknowledged in the' Talking About Dying' report that disclosing a diagnosis of a terminal illness can help patients to feel more empowered about care and decision making. However, health professionals are often reluctant to initiate conversations on end of life choices, and this is likely because they may be uncertain that a patient will die within 12 months, and that doctors tend to overestimate prognosis.

Sarah-Jane went on to acknowledge the increased confidence and benefits to patient care that can be provided by completing the ReSPECT form through a series of conversations with the patient. The 'Talking About Death' report acknowledges that patients often do not want to die in hospital, however the preferred place of death varies among patients. The National Survey of Bereaved People notes that 74% of respondents felt hospital was the right place to die, despite only 3% of respondents stating that patients wanted to die in hospital. Death at home can provide familiarity, dignity and comfort, but can also pose challenges depending on the availability of community health resources.

Highlights:

- The case for change: 1 in 3 adults and 80% of care home residents admitted to hospital in their last year of life.
- Patients receive better, coordinated end of life care if they are identified early as being in the last year of life and included on the GP palliative care register but only 25% of eligible patients are captured – this allows conversations about ReSPECT to take place earlier.
- Those with a non-cancer diagnosis (heart failure, COPD (Chronic Obstructive Pulmonary Disease), dementia, frailty) are least likely to be identified.
- National End of Life Care Audit: only 4% of patients had documented evidence of any sort of advance care plan or discussion of their preferences prior to hospital admission.

Q&A session:

Some of the questions put to the panel of speakers included:

- Issues with finding the time to have conversations with patients on their end of life wishes when pressure is upon primary and secondary care.
- Continuous conversations by medical practitioners with patients being documented on ReSPECT forms leads to issues with version control.
- Can Treatment Escalation Plan (TEP) forms and ReSPECT form be used successfully in tandem?

Workshop outcomes

Workshop Session 1:

Who? Which patient groups to start the ReSPECT conversation with? Emma Redfern, Hein le Roux, Tony Goring (West of England AHSN), and Gina King (Quality Improvement End of Life Lead, Thames Valley and South West Regions)

This workshop considered how to identify which people a ReSPECT conversation would be appropriate for, and help locate any 'triggers' that might provide opportunities for having the conversation with the patient earlier.

The groups considered which patients and patient groups should be identified to begin conversations early, and which health professionals might be best placed to have the opportunity for a series of conversations around ReSPECT with that patient.

Each group of participants identified a potential patient from a photograph, and using an empathy map, created a persona and backstory to identify how the patients' feel about their condition, what they see, hear and say regarding their condition, and their 'gains' and 'pains' – their positive and negative influences.

With this tool, the groups then placed that patient within their own services and identified the required touch points for having a conversation about completing a ReSPECT form. The groups also identified which health professionals would be best placed to engage the patient in a series of conversation around ReSPECT.

The workshop was summarised with the following areas identified:

- Conversations need to be patient focussed.
- Conversations need to start early.
- Communications with patients need to be standardised to provide clear and concise information and guidance for patients and health professionals.
- There is a need to standardise the transfer of information between different settings to ensure everybody knows everything that is important to the patient.
- There is a need to reduce mixed messaging.
- Conversations with the patient are an ongoing process.
- There is a need to identify the touch points within the system.
- Where appropriate, ask yourself the question "would you be surprised if this person were to die in the next 6-12 months" as a prompt to have the conversation on ReSPECT.

The outcome of the workshop provided the participants with a clearer understanding of a patient's pathway within community, primary and secondary care; and helped the groups agree on a set of actions to take away to identify which patients can be recognised for initial ReSPECT conversations.

QI Clinic - Dave Evans (Programme Manager, West of England AHSN)

This workshop was a refresher on Quality Improvement (QI) methodology and tools to support the successful implementation of ReSPECT, led by Dave Evans, West of England AHSN.

The attendees used some interesting and engaging methods and tools as examples of Quality Improvement processes, 'Plan, Do, Study, Act' and the practical use of the Institute for Healthcare Improvement (IHI) Model for Improvement. The workshop also provided an introduction to measurement for improvement using run charts.

The feedback from the workshop was positive, and participants particularly enjoyed making marmalade sandwiches as a tool for using improvement processes. Participants took away a clearer understanding of how to apply QI methodology to the adoption of ReSPECT within their service.

Legal Aspects – Dr Sophy Gretton and Katie Versaci (St Peter's Hospice)

This workshop considered the legal status of the ReSPECT form and how to apply the MCA when having conversations and using the process of completing a ReSPECT form. Attendees discussed the role of those who may hold a Lasting Power of Attorney (LPA), and including them in those who need to be made aware of the ReSPECT form and its use. There were 25 attendees from acute, community, mental health services and safeguarding professionals, who were provided with a presentation of the MCA and its application to the completion of a ReSPECT form by Dr Sophy Gretton, Consultant in Palliative Care, St Peters Hospice.

The workshop reiterated that the ReSPECT form is not legally binding, and is a recommendation for treatment. The workshop learnt that the ReSPECT form is a process of discussion between individuals and their families and professionals providing care. Not everyone will want to have these discussions and they are allowed to delegate them – e.g. to a family member. You cannot force people to have this discussion (if they are capacious).

A further discussion was had on the legal aspect of versions of the ReSPECT form and how best to manage version control, including the legal acceptance of digital copies of ReSPECT forms, which is an ongoing conversation at North Bristol NHS Trust (NBT) currently.

The workshop was concluded with a question and answer session (see below), and a discussion on the legal elements and differences between the Mental Capacity Act, Power of Attorney and Advance Decision to Refuse Treatment (ADRT).

Q&A Section

Q: What is the involvement of family in the process of completing a ReSPECT form?
A: See section 6 of the ReSPECT form.

Q: Do you have to share any ReSPECT process or ACP (Advanced Care Plan) with family members?
A: No, if a patient has capacity - but it defeats the purpose of having Advance Care Plans. However, confidentiality must be upheld (see ReSPECT FAQs page). Family may know about forms and advance care plans but may not agree with them, which makes it difficult for clinicians.

Q: What to do when there is profound disagreement between a clinician and patient?
A: It depends how hard-nosed you want to be. The General Medical Council supports you in making best interest decisions. Getting a second opinion on this can help.

FAQ – Ellie Wetz and Greg Harris (West of England AHSN)

This workshop was an interactive session that considered the ReSPECT FAQs and outstanding challenges, with shared problem solving on issues that still need to be clarified.

The workshop groups shared questions and identified issues that still need to be clarified by the cross-cutting work streams.
Some of the concerns and considerations around ReSPECT, with responses discussed in the workshop:

How will emergency staff know that a patient has a ReSPECT form in place?

- The digitisation of the ReSPECT form and sharing of patient information digitally will take time.
- Paper ReSPECT forms should be used until a digital version is created that can be shared through all services as IT interoperability is an issue.
- The paper ReSPECT form remains with the patient.

A change of culture is required to make the adoption of ReSPECT a success.

- Engage staff through training opportunities, such as the Resuscitation Council e-learning, to develop staff understanding of the ReSPECT form and process.
- Familiarity and use of the form will increase confidence.

"...it won't work unless every CCG or provider in England does it"

- Start small and implement in key areas, ensuring education and training is given.
- Share best practice across systems – a useful resource is the FutureNHS Collaboration Platform for ReSPECT (email respect@weahsn.net for access)

Who is responsible for having the conversation?

- This is an iterative process; a number of opportunities will enable conversations to take place with the patient.
- Identify opportunities to have the conversation, and everybody has responsibility to have a conversation to provide good patient care.

Version control of ReSPECT form.

- It is recommended not to photocopy the ReSPECT form, but if it is, the form should be clearly marked "COPY ONLY – NOT FOR CLINICAL USE", this is to try to avoid a situation where an original ReSPECT form has been cancelled and replaced because of changed circumstances.

Should ReSPECT be a patient-focussed or system-focussed procedure?

- Do not expect one system to fit all circumstances.
- Local policies for delivery can be created to ensure successful adoption and implementation in variant services.
- However, not to let the delay in creating local policies affect having the conversation with patients early – these can happen now.

How will ReSPECT be prioritised and resourced?

- There must be a dedicated lead in delivering ReSPECT locally and in services.
- ReSPECT Champions must see conversations as a process and willing to share learning.

What we wish we knew earlier? - Natasha Swinscoe (West of England AHSN) and Catherine Baldock (Resuscitation Council)

This workshop provided an opportunity for questions from the audience and comments from Catherine Baldock on the delivery of ReSPECT in other geographical areas of England, and a highlight of lessons learnt.

Some of the discussion points included:

- West Midlands Ambulance report shows reduced number of conveyances as a result of better information provided by the ReSPECT form to enable decision to be made by ambulance crews.
- There has been a decrease in complaints around poor terminology use by patients and their families.
- At the last count, Gloucestershire had 15 different types of TEP (Treatment Escalation Plan) forms in use, and ReSPECT is an opportunity to move to one uniformed form, which is a positive selling point for adoption. However, the yellow sticker is still used and is recognised across the system, but the appetite to keep yellow sticker is being considered across the area.
- Q: There is a concern from many organisations about the extra information that is required to complete the form. Is there a potential that the form will change?
- A: Catherine Baldock: there is a documentation group that is seeking feedback, which has recently been set up.
- It was recognised that the ReSPECT process and conversation often starts in acute care, but the focus needs to be on whole system to ensure people's wishes are met (i.e. a patient can be offered the choice to die at their care home (normal residence), but care home staff need to be supported to provide end of life care for the patient.)
- Gloucestershire CCG have commissioned services to 'plug the gap' until services at home can be arranged.
- Gloucestershire reviewed who has completed existing TEP forms, which is mostly palliative care specialists and a few geriatricians. Just introducing the ReSPECT form is not a solution, and a process of education to increase confidence needs to be addressed.
- Bespoke template on SystmOne has supported conversations for some time in Gloucestershire.
- Q: Bristol GP: "There's poor understanding in Primary Care about ReSPECT". A: Nathalie Delaney - "From today we plan to start an awareness campaign, but it is up to the individual system to decide what order" (to be discussed in Workshop 3).
- Q; What is the appetite of GPs within the BNSSG CCG? A: The AHSN have supported an event in conjunction with St. Peter's Hospice, and there is a good appetite among GPs for using the form.
- Q: What is the biggest national barrier for GPs in adopting ReSPECT? A: The digital integration has caused significant delay, but this is improving
- GPs have wanted financial incentives to complete the ReSPECT form and have conversations with patients, but this is not appropriate.
- There is a recognition that additional time and resources needed to complete longer appointments and consultation.

- Q: How do we promote ReSPECT through public engagement? A: Catherine Baldock: there is a national working group looking at this, but this has been previously left to each locality adopting ReSPECT to reduce the risk of mixed messages.
- There is a misconception that patients don't want to talk about end of life, but evidence suggests that is not the case
- Q: "Do you think there should be a regional media campaign?" A: Catherine Baldock "This has been done in other areas."
- Messages should include how the individual has choice and control.
- However, there is a need to ensure that the public are made aware know that even if they are personally not for resuscitation, they will receive other care and treatment.
- Q: Is there a national update to the adoption of ReSPECT in other areas? A: Catherine Baldock: by the end of 2019 approximately 100 organisations will have adopted the ReSPECT process.
- Different areas have approached adoption in different ways, however the Resuscitation Council is now seeing a joined up approach.
- A key message is that there are lots of resources, but there is a need to decide what works best for your area. Don't forget to engage the public!
- In some areas Allied Health Professionals have set up clinics with 40 minute appointments for advanced care planning.
- Care Quality Commission (CQC) still need to understand ReSPECT.
- Catherine Baldock: there have been two national critical incidents where it has been assumed a patient is not for resuscitation as they had a ReSPECT form is in place (no harm incidents).
- It takes at least 12-18 months to develop a change in culture to recognise that the form is about choice and not confirming a patient's end of life decision.
- Emma Redfern: "BSW CCG has a 'mixed bag' of organisations across the region. Part of the benefit of ReSPECT is the common language which will be lost if all organisations don't move forwards. There is anxiety that more risk could be introduced into the system if a form is introduced in part."
- Catherine Baldock states that some regions have decided not to adopt ReSPECT, and this has been decided as a region.

Workshop Session 2:

Talking About Dying – Sarah-Jane Bailey, Helen Meehan and Rachel Davies (Royal United Hospital, Bath)

This workshop reflected on the challenges faced by healthcare professionals in having conversations with patients about ReSPECT, ways these challenges can be overcome with confidence.

Workshop attendees discussed case studies and identified the key skills required in communicating sensitive information. They also looked at the training resources available to support the development of these skills in their organisations. The workshop concluded with the formation of an action plan for developing these skills and adopting them in organisations and across systems.

What and How? – Hein le Roux and Nathalie Delaney

The workshop considered how to create an action plan for the implementation of ReSPECT across organisations using the ACT+ADOPT checklist (adoption, dissemination, systems and documents, policies, teaching and training, implementation, monitoring and review).

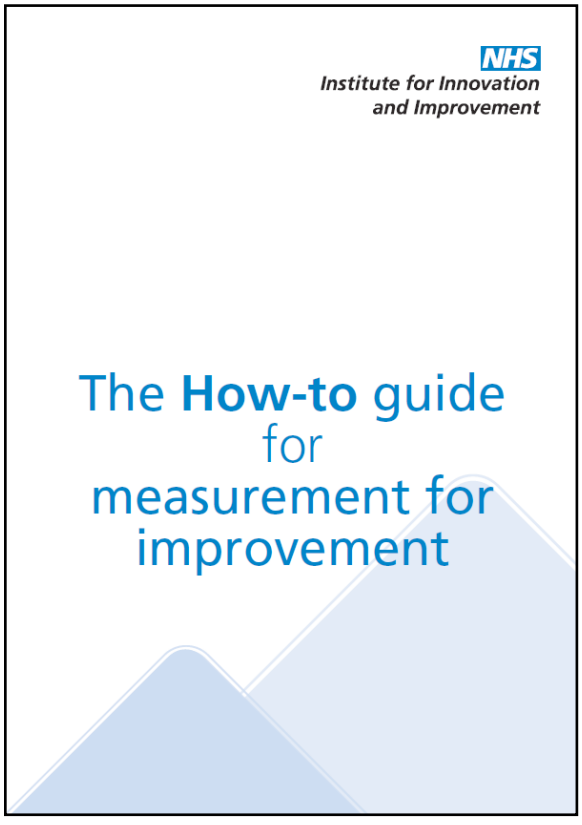
Workshop attendees looked at examples of completed ReSPECT forms and the specimen copies to consider how the forms can initiate conversations with patients and be completed across systems and organisations. Finally, attendees created process map scenarios to help identify processes required to adopt the ReSPECT form and identify any issues or barriers.

Measuring the Impact – Kevin Hunter, Melody Moxham and Tony Goring (West of England AHSN)

This workshop reviewed the existing data and measurement strategies available, and considered the next steps to identifying and collecting the required data for implementing ReSPECT in organisations and across services. The outcome from this workshop was to discuss and agree a data and measurement strategy for your organisation.

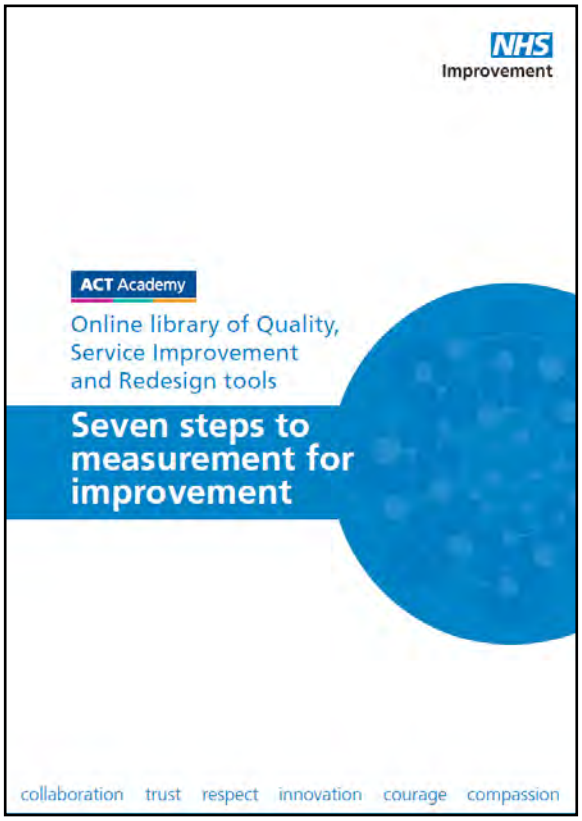
The data and measurement tools examined during the workshop included:

- Seven steps to measurement for improvement.
- Ask 5 tally charts.
- Measurement Plans.
- Measurement Strategy Tables.
- An introduction to Run Charts.



Some of the discussion points included the following:

- "measure what we value, don't value what we measure";
- "don't prioritise 'place of death' as an outcome measure" and consider how best to identify and collect qualitative data;
- a discussion on the data available for measuring the adoption of ReSPECT and impact, and the 'ReSPECT Data and Measurement Briefing' document;
- a consideration on what the key questions should be before data is collected;
- be clear about what you're trying to achieve: i.e. communicating with patient about their last few hours or days of life and what their wishes are in an emergency.



Workshop Session 3:

The third workshop sessions provided an opportunity for the three CCGs to meet and discuss their next steps in adopting ReSPECT, with consideration of the findings taken from the event.

Bristol, North Somerset and South Gloucestershire (BNSSG) STP/CCG

The discussion around the adoption of ReSPECT focussed mostly on the timescales and readiness of services to 'go live'. Emma Redfern suggested that North Bristol Trust (NBT) and University Hospitals Bristol NHS Foundation Trust would like to begin the roll out of ReSPECT through a geriatric ward, via CALS (Complex Assessment and Liaison Service) in elderly care wards, and ICU / deteriorating patient. NBT plan to adopt ReSPECT prior to the next intake of Junior Doctors in August 2019, with training and education, to assist with implementation, to begin in next couple of months.

Further discussion was had on the engagement of primary care to ensure that there is full awareness and support for adopting ReSPECT. Nathalie Delaney advised that the ReSPECT education pack will be sent to GPs in the BNSSG footprint, and ReSPECT is on the agenda of local GP Forums. GPs are being engaged with training and education on completing the ReSPECT form through the Health Learning Partnership sessions taking place across the footprint, the first of which is 22nd May. Hein le Roux reiterated the value of the Primary Care Network in assisting with the adoption of ReSPECT and gave his opinion on the increasing awareness and interest of GPs wanting the ReSPECT form in place as this improves patient care.

Further discussion took place over the adoption of ReSPECT within Community Healthcare, and the consideration of the data that should be collected now in order to establish a baseline of data for measuring the impact of implementing ReSPECT in the community. Nathalie advised that the West of England AHSN would be happy to support any training requirements required around data and measurement, and are happy to advise on the source and type of data that can and should be collected for measurement.

The next steps were identified as taking a number of forms:

- The West of England AHSN will assist with supporting the CCG's dissemination of the ReSPECT Education Pack to acute, primary and community care.
- The BNSSG STP Working Group will discuss further requirements for delivering ReSPECT at the next meeting held on 22nd May.
- The West of England AHSN will work with Bristol Community Health to identify required and available data for measurement, and support any measurement training requirements.
- The West of England AHSN will also support the promotion of ReSPECT during Dying Matters Awareness Week (13th to 19th May) within BNSSG to raise awareness.

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

The BSW STP area discussions were led by Emma Higgins, who acknowledged that BaNES, Swindon and Wiltshire CCGs have differing Governance arrangements around end of life care planning and whilst the three CCG areas are working to align decision-making, each CCG remains responsible for its' own governance process. It was discussed that there is an existing TEP in place across the system, which is working well although further understanding about the quality of the completion of the forms would be helpful.

The group also acknowledged that Salisbury Hospital Foundation Trust (SFT), Royal University Hospital Bath (RUH), Great Western Hospital (GWH) and Community Services across the STP recognise the TEP currently in place, although SFT do not currently initiate the forms. The group discussed that BaNES CCG is supportive of a move to ReSPECT, but Great Western Hospital and Swindon CCG are not currently planning to adopt it.

Wiltshire CCG is currently facilitating a Quality Impact Assessment regarding adoption of ReSPECT across the STP area. The joint assessment has identified some risks in relation to adoption of ReSPECT and whilst mitigating actions have been agreed (a shared policy, development of a local 'part 2' of the ReSPECT form, shared training and communications messages), it may not be the right time to adopt ReSPECT across BSW if providers believe it would potentially be a backwards step.

Following discussions about the learning from the event, the group's view was that the existing TEP is working, and that it may be appropriate to move as a whole system to ReSPECT following the publication of Version 3, which the Resus Council are currently working on in response to feedback. The evaluation and evidence base should also be available at this time to support informed decision making.

The group also agreed that it was essential to start raising awareness with staff regarding ReSPECT and to agree to recognise and honour any ReSPECT forms which accompany patients using BSW services (for example; visiting patients usually resident outside of BSW).

Emma Higgins advised she would represent the views of the Group at the Wiltshire End of Life Programme Board, and the subsequent STP ReSPECT working group and liaise with B&NES and Swindon CCGs.

The group agreed topics for further discussion and development which will be picked up in the ReSPECT steering group.

Gloucestershire ICS

The discussion around the adoption of ReSPECT in Gloucestershire ICS considered the next steps. The group considered which single idea or learning point taken from the event would help inform the next steps to implementation. It was agreed that the West of England AHSN ReSPECT event had highlighted that Gloucestershire is at a different place than other STPs and CCGs. The group considered the questions 'what mistakes have been learnt' and 'what has not yet been done in the process of adopting ReSPECT'.

It was agreed that Gloucestershire are delivering the adoption of ReSPECT in two waves, and are currently delivering on the second wave of delivery. End of Life systems in Gloucestershire have listened to carers, families and patients, which has been critical to the delivery of ReSPECT, and has helped develop the strategy for adopting ReSPECT.

The ReSPECT Implementation Group is in place, which has also informed the STP Executive Group. Chief Executive officers have agreed to implement ReSPECT, including ambulance services and care homes.

Currently in place are ReSPECT Clinical Leads, a Care Homes Representative, a Domicile Care Representative, a Hospices Representative, and a GP interface. Attendees were asked to advise Hannah Williams of any gaps.

ReSPECT is to be officially launched cross Gloucestershire during Dying Matters Awareness Week (13th – 19th May). The Gloucestershire end of life website will be live shortly. The Risk Register has helped form the project plan.

It was recognised that Primary Care is not using any TEP form, and that there is a general consensus to move straight to using the ReSPECT form in Primary Care. However, there is concern over the current Patient Treatment Option form being misplaced by patient – this has been recorded on the risk register – and there was a suggestion to continue to use this form until it is replaced by a ReSPECT form.

Closing Remarks

Natasha Swinscoe led the closing remarks, and she asked attendees to consider bringing the discussion on adopting ReSPECT back to the initial question raised during the opening of the event – why are we adopting the ReSPECT form? This is to improve patient care and ensure that conversations around end of life choices take place earlier. Natasha asked attendees to remember the last 1000 days of a patient's life when considering ReSPECT, and the positive impact that has been experienced by other geographical areas that have adopted ReSPECT early.

Colleagues from the three CCGs present at the event were asked to consider their next steps and reflect on anything new that they had gained from attending the workshops.

Natasha thanked everybody for attending, and thanked the plenary speakers and workshop facilitators. She asked attendees to note the date of the next ReSPECT event to be held on 18th September, where it is hoped health professionals will be presenting and discussing their delivery and adoption of ReSPECT that will take place over the next few months.

The next ReSPECT event hosted by the West of England AHSN will be on Wednesday 18th September 2019 09:30 – 16:30 at Kings Weston House, Kings Weston Lane, Bristol BS11 0UR.

You can reserve your place via Eventbrite.
https://www.eventbrite.co.uk/e/autumn-respect-event-tickets-58587014337

Watch a video of some of our attendees' views on ReSPECT from the event at https://vimeo.com/326331399

Appendix 1 - ReSPECT in your area

Dr Kate Rush. Bristol, North Somerset and South Gloucestershire STP, kate.rush2@nhs.net

Kate is Associate Medical Director at BNSSG CCG and has been clinical lead for End of Life care for the area. As a GP Kate became passionate about EOL being everyone's business - training at St Peter's Hospice and supporting patients in Primary Care to have choice in a situation where there can seem very little. As a commissioner Kate would like to see EOL considered more widely by all partners to ensure people's needs and wishes are considered in any decision making.

Emma Higgins, Quality Lead, Wiltshire CCG, emma.higgins1@nhs.net

Emma has been the chair for the BaNES, Swindon and Wiltshire Community Transformation Group for around two years. The group was invaluable in bringing people together to implement the National Early Warning Score and continues to focus on NEWS2 and implementation in care homes and primary care. The ReSPECT workstream has also been added to the remit of this group. The BSW STP are working together to align approaches and share ideas.

There is a ReSPECT Steering Group, which meet regularly. The group has acknowledged that the there are concerns regarding the current ReSPECT form versus the current well-embedded community and acute TEP form and the potential risks and impact of moving to from one to the other. Therefore, a Quality Impact Assessment is being carried out jointly, to understand the risks and to identify mitigations.

Several things have been agreed across the STP area: a) that there will be a shared policy, b) that there will be the same training across providers, c) that there will be measures to monitor during implementation, and d) that the Steering Group will develop an 'appendix' to the ReSPECT form which will be implemented alongside it.

Whilst this last point is not the 'ideal' approach, it will mean that all providers will be aligned, which is a step forward from each of us developing our own versions. We are hoping in this way to achieve 'sign off' of the move to ReSPECT and to influence those providers in our system which are yet to agree the change.

Hannah Williams, Health and Social Care Commissioning Manager – End of Life Care and Community Nursing, Gloucestershire ICS, hannah.williams17@nhs.net

Hannah is a Senior Quality and Commissioning Manager at Gloucestershire Clinical Commissioning Group and is responsible for leading the End of Life Care Clinical Program Group and its associated improvement work and deliverables.

Hannah is passionate about improving quality of care and experience for all at the End of Life. She is committed to a co-productive approach, ensuring everyone's voice is heard, valued and listened to.

Appendix 2 - Films

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

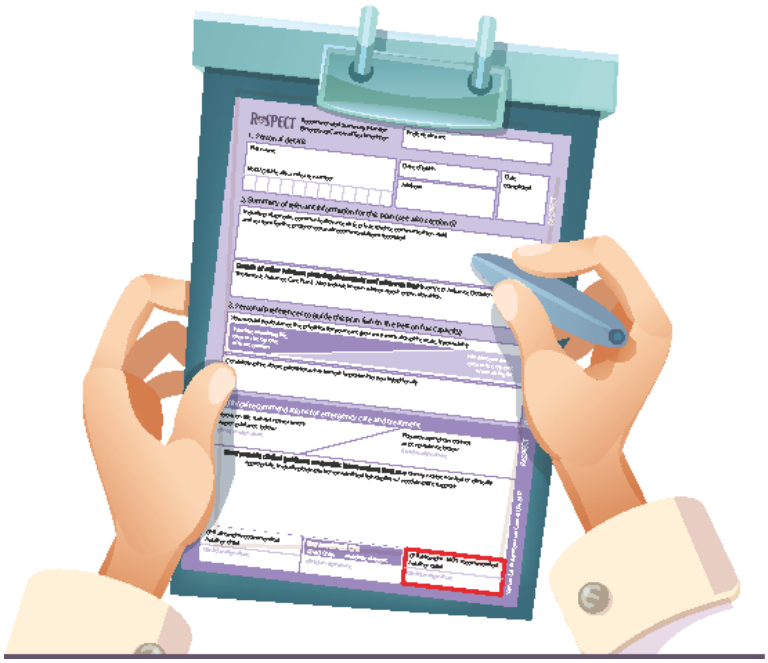
'We need to talk about dying' - Jo Withers TEDxNewnham
https://www.youtube.com/watch?v=8zOi6Z_0au8

'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_qIR7mLoEg

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/

'Endgame – Changing the way we think about living and dying' (Netflix)
End Game is about one thing we all share as human beings—the experience of death and dying.
The discussion booklet to accompany the film is available at:
http://endgame-documentary.com/wp-content/uploads/2019/02/EG_Guide_web.pdf?mc_cid=cb3aa79cab&mc_eid=bf49cd0783



Appendix 3 - Digital implementation

Sharing information across systems: The near future

Summary Care Record with Additional Information
(SCR with AI)
SNOMED-CT Code indicates patient has
ReSPECT Form

Primary Care:
ReSPECT form coded with
SNOMED-CT Code
(EMIS/SystmOne)

First responders:
View SCR with AI from ePCR
Know to look for ReSPECT
Form with patient

Issues:

- Access can to SCR with AI can be very slow
- Not practical in an emergency response
- Dependent on patient consent to share records through SCR with AI
- Patient may not have ReSPECT form with them despite SCR with AI indicating one exists

Sharing information across systems: Our plans for the future!

Local Health & Care Record
(LHCR)

Local Interoperability
(Connecting Care / JUYI)

Ambulance ePCR
Integrated with LHCR
Flags critical patient information is
available i.e ReSPECT form
Direct link in ePCR to ReSPECT
form in Interoperability Systems

ReSPECT form uploaded to
Patient Record
(EMIS/SystmOne)
PDF or embedded template

Appendix 4 - Implementation plan