

Event report

Standardising our approach to improve end of life care

7 June 2018 - Holiday Inn, Filton, Bristol



Introduction

For many years there has been debate over the use and design of Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) forms, together with a recognition of their limitations.

An approach that focuses only on withholding CPR in people who are dying or for whom CPR would offer no overall benefit has resulted in misunderstandings, poor or absent communication and poor or absent documentation.

Within the West of England, there has been growing support for improved communication and management of DNACPR and treatment escalation decisions. This is both through the regional Mortality Review Collaborative, as one of the main themes emerging from the reviews, and the Deteriorating Patient workstream, where the use of Treatment Escalation Plans for patients at risk of deterioration is a balancing measure for the wider programme.

In response to this, the West of England Academic Health Science Network (AHSN), on behalf of the West of England Patient Safety Collaborative, hosted an event on 7 June 2018 to launch a new pan-system programme looking to standardise the region's approach to treatment escalation documentation and communication.

The event was attended by 129 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 Programmes (STPs) were well represented across 54 different organisations that attended.



What our speakers said

Anne Pullyblank, Clinical Director of the West of England AHSN welcomed the delegation and presented some of the thoughts our regional stakeholders had expressed about current treatment escalation processes and practices.

Although there are some excellent examples of good practice, the absence of treatment escalation information, a lack of standardised processes, and problems communicating patients' preferences for treatment at the points of handover of care were strong themes that came through.

To address these systemic issues, the West of England Patient Safety Collaborative has supported the proposal that the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process, developed by the Resus Council, be considered for system-wide adoption. We know that our stakeholders have a range of views about ReSPECT: it encourages better conversations with patients and their families and is a nationally recognised document. However, there are a number

of reservations about it: would it pass the 3am test? Is it suited to all care settings? Staff will need more training. A new form on its own is not the solution. These topic points were addressed throughout the course of the event.

Mark Callaway and Emma Redfern from University Hospitals Bristol NHS Foundation Trust then presented the local case for change. They presented data from the work their trust had undertaken when learning from deaths using the Structured Judgement Review Method.

A toolkit for this method can be accessed at <https://www.weahsn.net/wp-content/uploads/Mortality-Toolkit-Final-June-2018.pdf>. They found that the number of avoidable deaths at their trust was very low and that the quality of end of life care was very good, even during winter pressures. However, they also found that patients were being inappropriately transferred to acute care when they were clearly at the end of life but didn't have their ceilings of care preferences or realistic clinical outcomes articulated or delivered effectively.



Gina King, Regional End of Life lead for the South West Strategic Clinical Network then explained how a programme to standardise to ReSPECT across the West of England would complement the wider end of life agenda.

This highlighted how ReSPECT addresses the Six Ambitions of the National Palliative and End of Life Care Partnership and the Government's response to the Review of Choice in End of Life Care, affirming the principle that this proposed programme would work collaboratively with other networks and their agendas.

The plenary then welcomed Catherine Baldock, ReSPECT Project Manager from the Resus Council, to deliver the keynote address. Catherine explained the background to the development of ReSPECT following the institutionally recognised failings of non-standardised DNACPR processes across the country. This involved stakeholders from 37 different patient and clinical groups, review of evidence and best practice nationally and internationally, a large number of iterations, a public consultation and extensive testing before being available for national adoption.

Since then, version two has been released which addressed some of the issues with the mental capacity section of the original form. In the spirit of quality improvement, there is likely to be further iterations of the document as it is more widely adopted and user feedback drives further developments.

Catherine gave us an overview of her experience of adopting ReSPECT across Coventry and Warwickshire and presented some compelling data. At the 14 month

audit post launch they showed 250% more ReSPECT forms than DNACPR, 60% reduction in complaints, 100% compliance with patients being involved in the decision making process when they have capacity, increased compliance with documentation across all specialities and a positive CQC review.

Catherine spoke passionately about ReSPECT and the benefits it had brought to the patient population in Coventry and Warwickshire and the support it had given staff across all disciplines. We are very grateful for the opportunity to see her presentation and for the benefit of her insight and expertise in supporting this launch event.



Recommended Summary Plan for
Emergency Care and Treatment

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

Patient and family experience

We then invited Susan and Chris Daniel to give their family's experience of DNACPR and their perspective on ReSPECT. Susan told us about her mother who had some complex health needs during the latter years of her life. She had a DNACPR in place but when she deteriorated and was transferred from her home to hospital this vital information did not transfer with her. She subsequently arrested in acute care but was resuscitated. She died a few days later.

Susan described the distress this caused to the family, particularly because her mum was not able to articulate in the few days post-resuscitation whether she understood what was going on, whether she was in pain or whether she was scared. They knew this was not the death her mother would have wanted.

Both Susan and Chris were very clear that the current system had failed both them and the medical team treating Susan's mother as her end of life care wishes had not been followed and the correct information had not been communicated between care services. Arguably, this situation could have been repeated with any treatment escalation documentation.

However, having been educated on ReSPECT and the principles that it is an improved patient centred document, the Daniels are now strong advocates of ReSPECT with the hope that this new process will avoid other families going through the confused care and pain that they suffered.

We would like to express our gratitude to Susan and Chris for taking the time to

come and speak to us at this event; for sharing their distressing and emotional experience and for reminding us that the patient and family voice must sit at the centre of this programme as it develops.

Catherine, Susan and Chris then welcomed questions from the floor. The delegates raised some interesting discussion points about the use of ReSPECT in primary care where it was noted that engagement in the process may be challenging. People also felt that the tool was not detailed enough for use in palliative care, and that there may be issues integrating ReSPECT with Electronic Palliative Care Co-ordination Systems (EPaCCS), which are in the advanced development stages in some areas of the region.

The plenary then broke out for refreshments where Gloucestershire Care Services ran a demonstration of their web-based Culture Awareness app they have developed. This app provides staff with guidance on delivering culturally competent care ensuring patients' cultural or religious needs are known and prioritised, including at end of life. You can check it out at:

www.glos-care.nhs.uk/CulturalAwareness/index.html.



Workshops

Delegates were invited to attend two of four workshops during the next session. A full description of the content and the outcomes of each workshop can be found in Appendix 1.

It was fantastic to see such positive engagement from delegates across all four workshops. There was robust debate, honest opinion and feedback but still a can-do approach. It was great to get the 'issues' out there and confront them head on. These workshops were not designed to conclude with a resolution to these issues or 'hallelujah moments'. However, the general consensus was that there is now a better understanding of the questions we should be continuing to ask ourselves as we develop this programme.

During the lunch break the West of England AHSN hosted a light-touch 'Introduction to Quality Improvement (QI)' workshop for those delegates who are not familiar with the methodology or language. We appreciate many of the stakeholders who involved in this programme may benefit from some additional support or training in QI. A good resource to support you with an introduction to QI can be found at www.qitraining.improvementacademy.org/



STP Workshops

After the lunch break, the delegates organised themselves into their STP geographies to spend an hour considering how they will collaborate across services to take this programme forward in the immediate to short term.

Each STP workshop was provided with templates of the NHS Change Model to facilitate their conversations and asked to consider their shared purpose, their shared drivers, possible measures to evidence the benefit of the change and agree on some collective pledges to take forward.

Gloucestershire STP

Gloucestershire STP has an established End of Life Clinical Programme Group which has already agreed to standardise treatment escalation documentation across the county footprint.

They used the workshop as an opportunity to have broad discussions about what currently works well within the system, what transition might look like, the need to recognise wider system teams such as fragility, complex care etc., some of the challenges around measurement and communication strategies and campaigns.

Gloucestershire STP next step pledges:

- To work together to introduce ReSPECT
- To hold another scoping workshop in Gloucestershire
- To ensure two-way leadership and communication
- To utilise a discussion forum (Life QI – administered through the West of England AHSN)
- To collectively create a Gloucestershire Driver Diagram

Bristol, North Somerset and South Gloucestershire (BNSSG) STP

BNSSG STP also has an active End of Life Care Clinical Programme Board which meets regularly and includes all relevant stakeholders from across the geography. Prior to this event, they had not collectively agreed to embark on a standardisation programme for treatment escalation procedures, but are open and receptive to a region-wide approach.

This STP agreed in the workshop that their shared purpose is a community-wide system which recognises patients' preferences and values for emergency care which is recognised by all organisations across the footprint. They agreed this shared purpose could be achieved via the ReSPECT process. They discussed the necessity to identify where the 'need' is within the system and that an initial focus should be on the drivers 'culture', 'communication (including digital)' and it becoming 'business as usual'.

BNSSG STP next step pledges:

- To take this forward as an STP
- To carry on working on our shared aim, purpose and drivers

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

BSW STP does not yet have an End of Life Care programme board and is not working collaboratively across all three CCGs on any treatment escalation programmes. So, this workshop was the first time stakeholders had come together across the wider geography with this particular shared interest.

The workshop spent a considerable time listening to all participants' individual views on what the common aim should be which was distilled broadly into the themes: the patient's voice should be at the centre of the process, there needs to be standardisation across settings and boundaries which are transferrable and the approach should be consistent. The STP also considered what their current blockages are to this programme of work and what they could do to unlock these. BSW STP next step pledges:

- To work as an STP on a standardised process
- To involve patients
- To take to all appropriate forums (not limited to End of Life Care)
- Ensure there is Executive buy-in across all organisations
- To work on communication strategies across workforce (education & training) and public
- To work further on our current blockages and what we can do to overcome them.

We are thrilled that all three STPs are willing to work collaboratively within their geographies to take forward this programme. The pace of change of each STP may vary according to their positions of readiness. However, it is clear this is a multi-faceted programme and each STP may develop slightly different strategies for their adoption of ReSPECT should they have the collective organisational buy-in to standardise to this tool. This presents us with an opportunity to observe, share and learn across the region and offers us options for some intelligent evaluation.

After everyone had fed back on the outcomes of the event workshops, the

West of England AHSN presented the proposed governance structure for the programme as we move forward. See Appendix 2. This structure mirrors the organisation of the regional Deteriorating Patient programme which proved to be successful at engaging all our regional stakeholders and driving through the agenda of the programme.

Delegates were invited to nominate themselves to either the Project Team or STP groups detailed in the structure. Nominations can still be submitted if stakeholders missed the opportunity at the event, please email ellie.wetz@weahsn.net.

Closing remarks

To sum up the event, the delegation watched a video address from Mary Hutton, Executive Sponsor for this Patient Safety Collaborative programme and Lead for Gloucestershire STP, who drew parallels between other successful regional programmes such as Don't wait to anti-coagulate for Atrial Fibrillation and PReCePT, for the Prevention of Cerebral Palsy in Pre Term Birth through the administration of Magnesium Sulphate.

Mary also stressed the importance of commissioner support to facilitate the impact of system wide change. We thank Mary for agreeing to be our Executive Sponsor for this programme and the influence she will bring to its success.

Finally, we heard from Natasha Swinscoe, Managing Director at the West of England AHSN. Natasha thanked the delegation for their attendance, their enthusiasm and

their honesty. She recognised that this will be a challenging programme but that it was good to get some of the collective apprehensions and issues voiced from the outset; to not be scared by them but to tackle them head on.

Natasha noted that the West of England AHSN will not only facilitate collaboration within and across STPs but that we can also add value in areas such as innovation and technology as the organisation has close links with industry, developers and researchers. We have the oversight and expertise to make links with these external stakeholders and our partner organisations to drive innovative ways of working into our patient safety programmes. So, if you have any ideas for technological enablers or innovations, bring them to us and we can work with you to see if there are opportunities to realise them.



On reflection

Delegates were invited to complete an evaluation form of the event and were asked their thoughts on the focus for the next collaborative event.

Delegates broadly found the themed workshops and the STP workshops the most helpful part of the day. They felt the event could have been improved by:

- Having more time to work together as an STP
- More time dedicated to workshops as they felt quite rushed
- Greater representation from Primary Care and Care Homes
- More clarity on timeframes
- A greater emphasis on the de-coupling of ReSPECT and end of life care
- More time needed to discuss individual organisation concerns
- This is useful feedback which we will note in the planning for the next collaborative event.

We asked delegates whether they were confident on how they were going to take this programme of work forward. 60% of respondents said they were confident as an STP, 60% said they were as an organisation and 70% said they were as individuals.

We will work with STPs to support their local organisations to focus on both their in-house and wider locality adoption strategies.

Looking forward

We will be forming the Project Team and STP Adoption Groups (if not already established End of Life Care programme boards/groups) over the course of the next few weeks so if you have nominated yourself to participate we will be in touch.

We want to ensure our collaborative regional events are relevant, useful and productive. To help us with this, we asked delegates to consider what themes they would like us to focus on at the next event in October 2018. The most popular were:

- Learning from other adopters
- Education and training
- ReSPECT adoption strategies
- Digital interoperability

We will work with the STPs to ensure the agenda for this event reflects these themes and any others that the local STP groups identify as a priority.

We asked delegates to consider any clinical pathways or micro-economies that may be suitable for evaluation. We received some helpful ideas which we will pass on to our evaluation partner the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care West (NIHR CLAHRC West). We also asked for recommendations of key stakeholders or people who may not yet be engaged with the programme. Thank you for your suggestions, we'll be getting in touch with them in due course.

Save the date

The next regional event for this programme will be jointly hosted with the Deteriorating Patient programme.

Wednesday 17th October 2018, Cheltenham Chase Hotel, Gloucestershire

A personal note...

I have been working on scoping this programme and organising this event since February 2018. This involved me getting in contact with every service provider in the region and attempting to gather as much information as possible on current advanced care planning practices and procedures; what works well, what doesn't and what the general feel was for the ReSPECT process before it was launched as the suggested standardised treatment escalation tool across the region.

During this period of research and scoping I spoke with a large number of truly inspirational clinicians. What you do on a day-to-day basis; the care you give to families during their most painful times, the thought and sensitivity that goes into your work blows my mind. You are all heroes working within a system that works well in pockets, but needs improving - and you recognise this.

It was fantastic to see such breadth of regional representation across a range of disciplines at the launch event. I was never bold enough to predict the outcome of the event as it was clear from my conversations with people from across the region that there may be some conflicts of opinion on how to proceed, and once you start peeling back the layers of what this project could entail it starts to become quite large and potentially overwhelming.

I was relieved that the main outcome of the event was the commitment that STPs will work with the organisations in their locality to take this forward – this is a really positive step and provides a fantastic platform of engagement for us to build on.

I've had my head in 'ReSPECT' for several months now and have been working hard to make some sense of the main drivers that could shape and define this programme. I observed many of you at the launch event grappling with the same challenge. It's tricky - this is clearly more than just introducing a new form. However, I do think that we have offered you a good starter-for-ten in the Driver Diagram we shared with you in the STP workshops (See Appendix 3) and I hope you find this useful as you consider your strategies for taking this work forward.

I would like to extend my heartfelt thanks and gratitude to all those people that helped me during the scoping period of this programme; for taking the time to talk with me, for your honesty and your ideas. Specific thanks must go to those people who helped shape the content of the workshops but particularly to Emma Husbands from Gloucestershire Hospitals who provided an inspiring and encouraging guiding hand despite being unable to attend the event!

I will be passing the baton of the management of this programme over to my esteemed colleague Joanna Garrett at the end of June but I look forward to hearing about your progress as you navigate through this challenging but potentially revolutionary system-wide patient safety programme.

Good luck!

**Ellie Wetz, Improvement Lead
(Patient Safety)**

Appendix 1

Workshop A: Why is this difficult?

Workshop Leads: Rachel Royston (Palliative Care Consultant, NBT), Tricia Woodhead (Associate Clinical Director, West of England AHSN)

This workshop was designed to tackle the systemic and cultural issues we have around ceilings of care conversations and why we often fail to have 'the conversation' with patients and their families at the right time, in the right place and with the most appropriate professional. Each table in the workshop were given a different patient scenario to review and then asked to consider some key questions such as 'what opportunities have been missed in having treatment escalation discussions?', 'why do you think these opportunities were missed?', 'what is the impact of these missed opportunities for the patient and their family?'.

The main themes that came out of this workshop were:

The conversation:

- It is not always clinically possible to identify the opportune time to have 'the conversation' with the family which means it can sometimes be missed, particularly if the patient deteriorates and no longer has capacity.
- There needs to be a sea-change to normalise these conversations so it shifts to 'life planning' not 'end of life planning'.
- We need to acknowledge that patients and their families are not always ready to have 'the conversation' and this must be handled sensitively.

Expectations:

- The expectations of patients and their families about their future treatment and care may not align with clinical opinion or diagnosis.
- Clinical opinion may be prejudiced by the patient's lifestyle, behaviour or their previous healthcare experience.

Culture:

- If we are going to adopt a new process, this needs to be accepted, supported and advocated at all levels; executive to shop floor across the system.

How can we do it?:

- We need to consider our training, education and support for staff and what resources are available to them.
- It would be sensible to start with the obvious cohorts of patients and work on the principles that practice makes perfect – the more we do it, the better we'll get at it.
- Consider the best opportunities to have the conversation. For example, it was suggested when breaking the news of an illness and the patient asks 'what does this mean...?', that this may be an opportunity to initiate the discussion.
- Look for opportunities to inform and educate our patients. Some ideas put forward were publicity campaigns across all services or targeted promotion through existing networks where we know there are touch points with appropriate patients.

Workshop B: How do we get better at it?

Workshop Leads: Alan Howe (Clinical and Quality Education Manager, NBT) and Samantha White (Lead Nurse for Specialist Palliative and End of Life Care, Gloucestershire Hospitals)

This workshop asked delegates to consider what we can do to support and enable our workforce to give them the confidence to have these difficult conversations. Alan Howe opened the session with a brief presentation introducing the concept of Human Factors, how Human Factors impact on communication, particularly impacting difficult conversations about end of life planning, and the influences of bias on these conversations.

The workshop was then asked to consider what education and training resources are already available, how they are accessed, how access can be improved and what additional resources need to be developed to support this regional standardisation programme.

The themes resulting from this workshop were:

- There are opportunities to improve training at all levels and across all disciplines – undergraduate, health and social care training, inductions to trusts, mandatory training etc. It was noted that key stakeholders need to be engaged and on board to do this such as Health Education England and trust Senior Executive Teams. There were also suggestions to draw on existing specialities to inform and support this training such as palliative and pastoral care teams.
- There were suggestions to create open spaces for discussions for the public and healthcare providers to support the normalisation of these conversations such as Death Cafes or ‘Dying to Discuss’ forums.
- A strong theme that came through was the opportunity to standardise education and training resources/materials and have a joined-up approach across our system. Some ideas for transferrable resources were video examples of good and bad conversations, role modelling tools and bite-size training packages (appropriately targeted according to the health care professional). There were also good ideas around continuous support for staff; peer mentoring and review, embedding life-long learning through clinical supervision, identifying ReSPECT champions within organisations or on wards – these were just some of the thoughts identified in this popular workshop.

Workshop C: Filling in the Form

Workshop Lead: Catherine Baldock (ReSPECT Project Manager, Resus Council)

This workshop was a practical session looking at how to fill in a ReSPECT form using case studies and role play.

Catherine Baldock kicked off the workshop with a very brief overview of what each section of the form should include (see <https://learning.respectprocess.org.uk/#module108> for an excellent resource on this). Each table was given a specific case study. One delegate was asked to play 'the patient', another 'the clinician' and enact the scenario while the rest of the table observed the conversation between the two and complete the ReSPECT form.

The main themes that stemmed from this workshop were:

- The form should be iterative and relevant to the patient at that point in their specific care plan and treatment. The patient may deteriorate, or their condition may improve. In both cases, their thoughts and preferences about their treatment in an emergency may change significantly. Clinicians need to recognise that the ReSPECT process must be flexible and evolutionary; it is not necessarily fixed once complete but should be revisited throughout the course of a patients' treatment.
- This naturally leads on to the tricky issue of version control. Care will need to be taken by adopting organisations and trusts that they have robust version control protocols in place. It also became clear through the role play that a clinician may not always have all the information necessary to fully complete a form. This may be a particular challenge for patients with long-term conditions. However, it was felt that it could be started and revisited as more information became available.
- There is a need to manage expectations – we can't promise what we can't deliver so sadly we can't always present a choice, particularly around resuscitation. The form forces clinicians to be honest with patients, irrespective of how difficult those conversations may be. This principle isn't limited to diagnosis and success of treatment; it also needs to reflect where treatment is accessible. There is little point in articulating that a patient would like palliative treatment at home if there simply aren't the primary and community services available to support that. Therefore, the commissioner contract specifications and awards may need to flex to offer greater choice to patients.
- There were some really positive observations in this workshop; it was felt the ReSPECT form supported the natural structure and flow of the conversation between the clinician and the patient and that it wasn't just a tool for end of life; it was also a tool for hope, treatment and survival.

Workshop D: How do we improve communication at handover?

Workshop Leads: Colette Reid (Palliative Care Consultant, UHB) and Kelsa Smith (IM&T Programme Lead – Digital Transformation, South Central & West CSU)

The focus of this workshop was a case study review to consider how we currently communicate treatment escalation information between services at the points of patient transfer, and whether there are ways we can improve it.

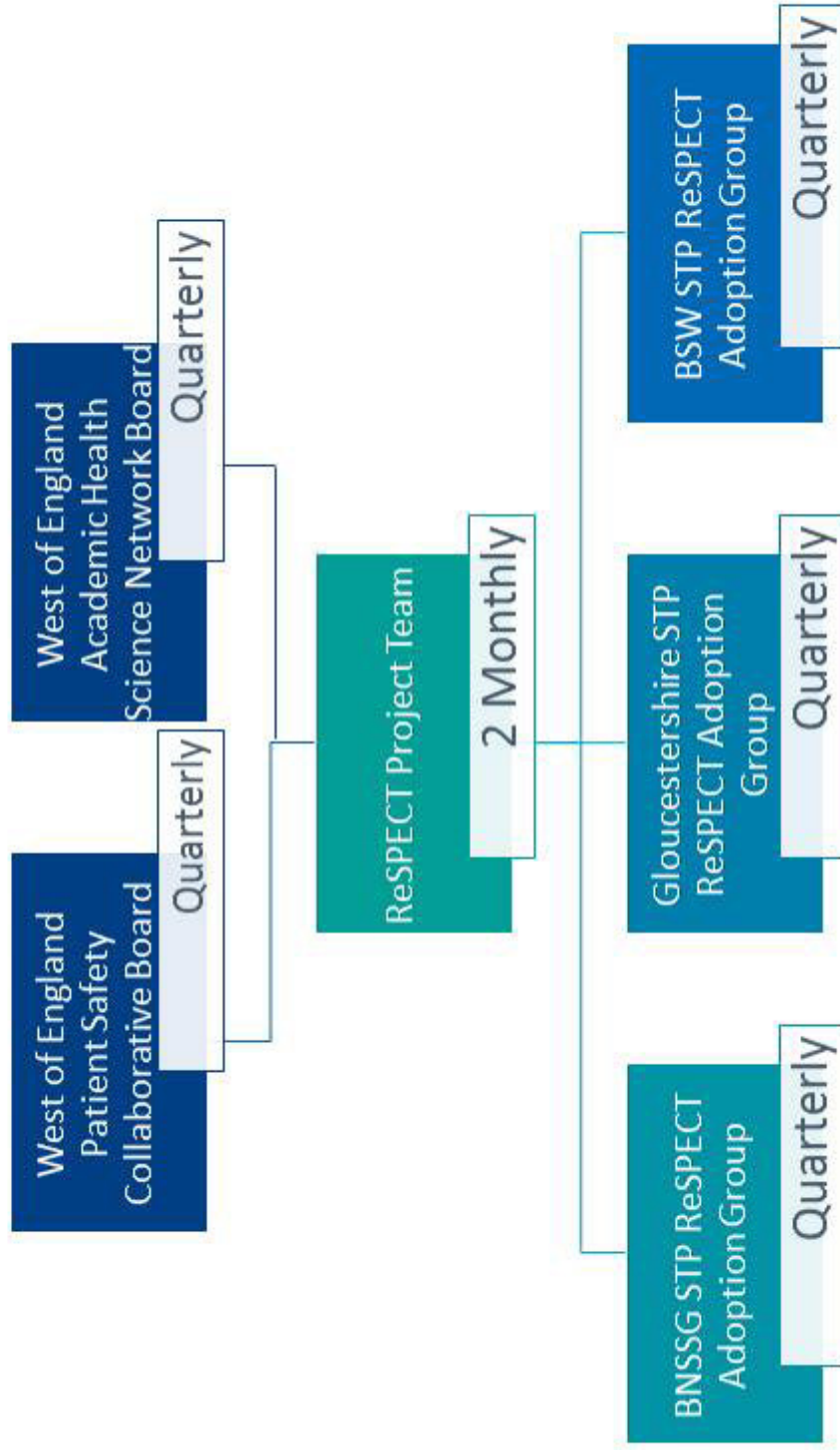
The workshop reviewed a scenario where a patient was transferred at multiple points through community to acute care and then discharged back into the community again. At each opportunity for the communication of patient information, or the physical transfer of the patient between settings, the workshop considered their current practices for communicating patient data and opened discussion for ways this could be improved.

The main themes emerging from this workshop were:

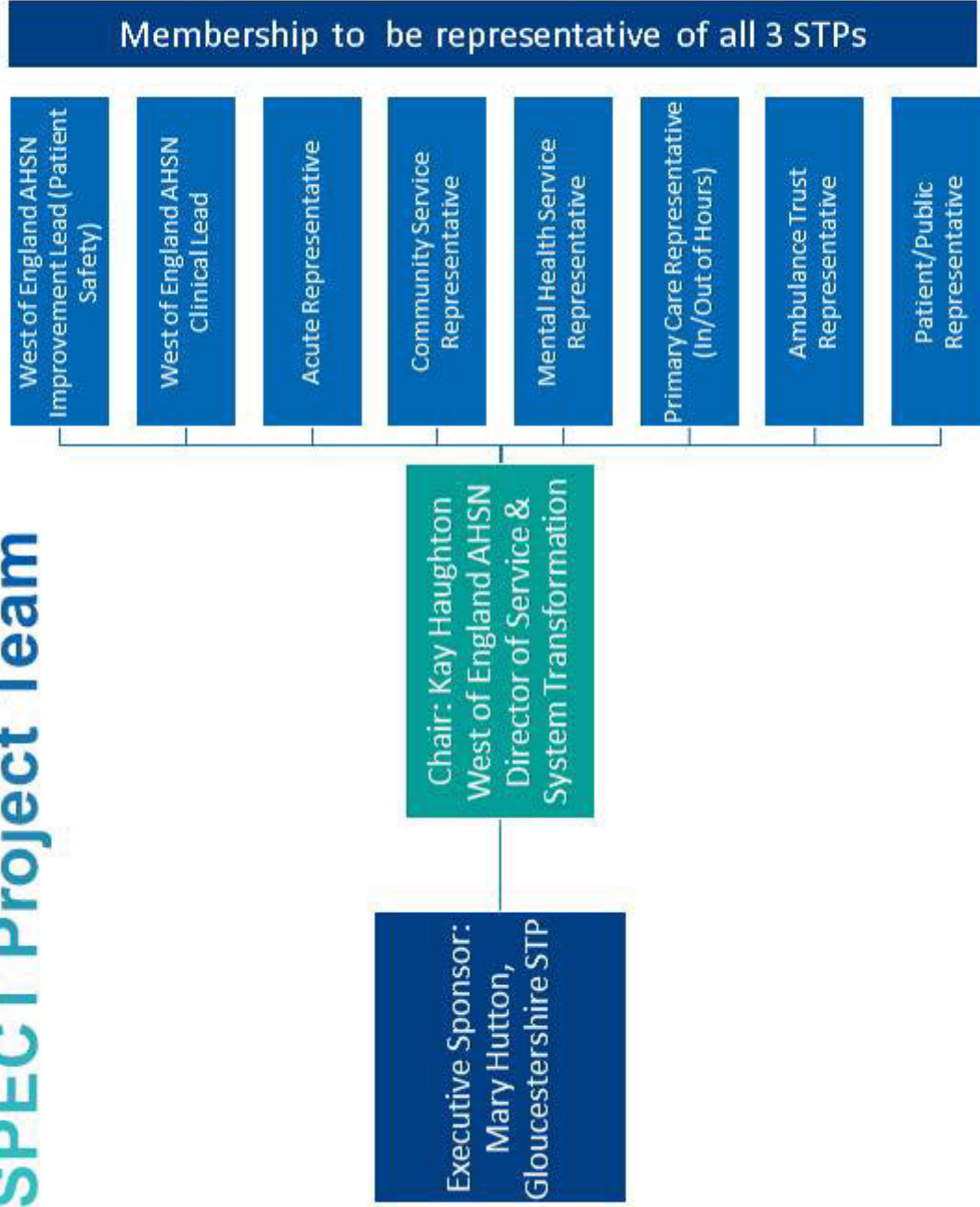
- There is too much variation within the system and too many systems where information is held. This issue is clearly not limited to the communication of patient treatment escalation information; it is a systemic issue. Wouldn't it be great if a regional ReSPECT programme could be the 'Trojan Horse' that unlocks some of these issues?
- Patient empowerment - The workshop considered other existing systems where patients retain and own their clinical information such as maternity notes. If they have capacity, then there may be an opportunity through this programme to shift the culture so patients manage their ceiling of care preferences and documentation more proactively.
- Digital enablers - Improved coding at a national and local level and increased uptake of the Summary Care Record with Additional Information could enable better sharing of information. The GDPR (General Data Protection Regulation) may also facilitate patient consent for sharing information in emergency situations.

Appendix 2

ReSPECT Programme Governance Structure



ReSPECT Project Team



STP ReSPECT Adoption Groups

- Suggested membership from within STP geography:
 - STP Leads
 - Relevant service commissioners
 - Acute Trusts
 - Community Services
 - Mental Health Trusts
 - Primary Care (In/Out of Hours)
 - Ambulance Trust
 - Care Homes
 - Hospices
 - Interoperability Leads
 - Patient/Family Representatives

Appendix 3: ReSPECT Driver Diagram

