A Quantitative and Qualitative Evaluation of the ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) Process in Forth Valley

Scotland's first ReSPECT pilot: A Case for Change

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Contents

Report Authors:

Lead Authors

Dr Lynsey Fielden
Ageing & Health Consultant/Hospital Palliative Lead
ReSPECT Project Lead
NHS Forth Valley (FV)
Email: lfielden@nhs.net

Deborah Lynch
Senior Quality Improvement Facilitator
NHS Forth Valley
Email: deborah.lynch@nhs.net

Contributing Author

Karen Petrie
ReSPECT Nurse
NHS Forth Valley
Email: karen.petrie@nhs.net

Report approved by the

Clinical Outcomes Group Forth Valley

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Executive Summary

This executive summary highlights the key findings of the pilot of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process in NHS Forth Valley (NHS FV) and provides the context and evidence for adopting a more person-centred and standardised approach to emergency/anticipatory care planning across all care settings.

Introduction

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions are commonly made in healthcare but have been associated with wide variation in practice, negative perceptions, poorer outcomes, complaints and litigation. Evidence suggests that there is an over focus on discussion and decision making around Cardiopulmonary Resuscitation (CPR), when such discussions should be considered as part of an overall treatment plan.[1] Further, wider emergency care planning provides an opportunity to focus on realistic treatment goals that *should* be considered not only those that *shouldn't*.

The ReSPECT process[2] was created following a systematic review of DNACPR decisions and documents in 2015 and has been developed with wide stakeholder engagement and is endorsed by the Resuscitation Council (UK). The process prompts and facilitates individualised anticipatory care planning and results in a summary document with personalised and realistic recommendations for a person's clinical care in the event of an emergency when they are unable to make or express choices. The process is intended to both respect patient choice *and* clinical judgement and promotes shared decision making. A ReSPECT document is the emergency care planning component of wider Anticipatory Care Planning (ACP) e.g. My Anticipatory Care Plan.

ReSPECT documentation is *never* intended to replace a conversation in an emergency situation when it is practicable and appropriate for this to take place. However, in an emergency setting, the form could become an essential tool to guide the individuals and teams caring for that person, to deliver the right treatment at the right time in the right place in accordance with that person's previously stated preferences for care. As described by a carer in our pilot feedback "*it gives the person a voice and a choice*" even if they are unable to express their wishes in that moment.

Context in NHS Forth Valley

A high quality, effective and more person-centred approach to anticipatory care planning remains a local and national priority as highlighted in the Forth Valley Health Care Strategy[3] and is aligned with the ethos of Realistic Medicine.[4] Timely and focused conversations with people, their families and carers by appropriately skilled individuals to plan for their future care and support is essential. A standardised process to facilitate and record such discussions is of particular value in reducing variation in practice and to enable a more joined up way of working particularly at the interfaces of care. This is of particular importance at the end of life as outlined in the Strategic Framework for Action on Palliative and End of Life Care[5] and guidance on decision making from the General Medical Council.[6]

DNACPR decision making and documentation is common place since the launch of the NHS Scotland DNACPR policy in 2010, occurring daily in a variety of care settings. DNACPR decisions should be discussed with the patient and/or those close to them, with few exceptions, as outlined in the DNACPR revised policy (2016)[7] in view of recent case law. Involvement of these key individuals is vital, however, when it does not take place it can lead to distress, misunderstanding and complaints. A local baseline audit revealed 80% of such DNACPR decisions involved the patient and/or those close to them and identified further work was required to improve patient and family involvement in crucial emergency care planning.

In March 2017, we conducted a point prevalence study of DNACPR documentation across the acute and community hospital wards with over 900 case notes reviewed.[8] More than a third of patients had an NHS Scotland DNACPR form present, with a point prevalence of up to 90-100% in some community wards caring for frail elderly patients. However, a smaller study performed showed that a minority have emergency/anticipatory care plans (less than 1 in 10) and where present there was no standardised approach for documenting goals of care and a shared decision making approach was not always evident. This is of particular importance for those patients nearing the end of life, where interventions, such as CPR or hospital admission, may be increasingly burdensome and of little value to that person's quality of life. More importantly, we were not capturing 'what matters to them' in their health and social care.

A local audit 'The NHS Forth Valley Resuscitation Service Report' in 2017[9] identified that 32% of cardiac arrests, resulting in CPR, were potentially avoidable: 6% of patients had an unrecognised pre-existing DNACPR decision; 18% of patients were deemed appropriate for DNACPR and 8% had no clear escalation plan in place. Survival to discharge after a cardiac arrest was noted to be 22% for all patients.

In primary care, GP's utilise the Key Information Summary (KIS) in agreement with the patient to record discussions about ACP. This enables GP's to update information electronically as the patient's wishes or condition changes over time. The '*special note*' section of KIS is ordinarily where GP's can update information about emergency care planning. This is added in a free text format with previous evidence showing that this can be variable in structure, content and usefulness[10]. Thus, there is no standardised framework for documenting decisions for an emergency situation including preferences for treatment, preferred place of care and ultimately preferred place of death. Emergency care planning utilising KIS alone also immediately limits the number of clinicians who can record treatment plans across all care settings, for example, clear documentation about priorities for care in an emergency, is of vital importance in an acute and community hospital setting. Furthermore, a significant proportion of health and social care professionals *cannot* access KIS in an emergency situation even in a read-only format.

A pilot of the ReSPECT process was proposed in 2017 to facilitate individualised care planning including CPR decisions in NHS FV. We are the first health board in Scotland to trial this approach to emergency care planning.

Key Aims of the Pilot

The overall aim of the pilot was to test the potential of the ReSPECT process over existing systems/processes:-

1. To increase emergency/anticipatory care planning and ensure this is useful, accessible and up to date.
2. To facilitate person-centredness and shared decision making.
3. To provide a more standardised approach to emergency care planning across a variety of settings including primary care, secondary care and the hospice.

Methodology

A ReSPECT steering group was initiated in 2017 and the initial pilot was conducted between September 2017 until May 2018. The ReSPECT process was utilised in 4 pilot areas: older adult (>75's) acute medical ward; older adult (>65's) acute mental health ward; Strathcarron day hospice and in primary care (2 General Practitioner's in different practices). ReSPECT documentation was utilised alongside DNACPR forms, due to an initial small test of change as the ReSPECT form has a '*CPR attempts recommended*' and '*CPR attempts not recommended*' option. The existing electronic systems were harnessed and optimised, thus enabling the scanning and uploading of the ReSPECT form as a clinical ALERT on Clinical Portal, increasing visibility to care teams looking after that person in an emergency. We adapted a trigger tool (BMJ Practice Pointer)[11] to prioritise emergency/anticipatory care planning in a hospital setting.

We evaluated the ReSPECT process by reviewing:-

- The ReSPECT process and quality of associated documentation
- Patient outcomes including preferred place of care
- Key Information Summary
- Qualitative feedback from patients, carers and staff

Summary of Key Findings

Over 200 people experienced the ReSPECT process during the pilot period. At the time of compiling this report, more than 700 patients have now been involved.

Graph 1: ReSPECT forms uploaded to Clinical Portal
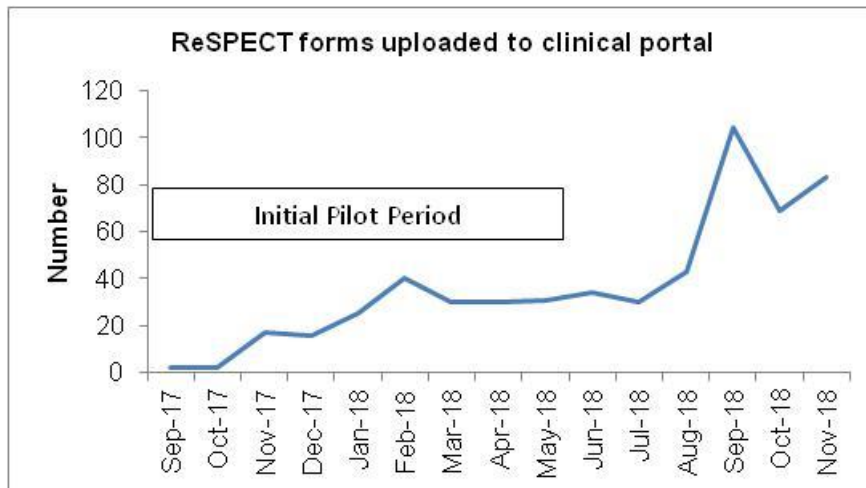
The ReSPECT process can be utilised for anyone but is of particular relevance for those with lifelong conditions or complex health needs, living in a care home setting or at risk of a future health crisis. It is of the utmost importance for patients with life limiting conditions and those nearing the end of life including the main disease trajectories of advanced cancer, organ failure or frailty/dementia. The mean and median age of the patients in this pilot was 82 years of age.

Our quantitative and qualitative evidence points towards the ReSPECT process being superior to existing processes, primarily DNACPR documentation. At the heart of this evaluation lies the person-centred approach. The feedback received from the pilot has been overwhelmingly positive, both formally and informally. The process prompts conversations which may not have otherwise taken place and ensures appropriate planning is in place in the event of a health crisis.

ReSPECT facilitates person-centred anticipatory care planning and promotes shared decision making.

In the initial analysis of ReSPECT forms, 100% of key individuals were involved in decision making. The process promotes patient involvement in their own treatment planning, with more than 70% of patients asked about their priorities of care during the process. Nearly 75% of patients and/or those close to them wished to prioritise comfort over life sustaining measures in their treatment preferences. There is no comparable standardised process for facilitating person-centredness in emergency care planning. All patients and their loved ones rated the ReSPECT process positively, with 80% rating their experience as excellent, and 20% rating their experience as good. Everyone who provided feedback on the process felt that ReSPECT considered 'What matters to you'. 94% of staff questioned felt ReSPECT considered the patient and/or family in decision making. Staff felt empowered to deliver the right treatment at the right time for the patient in accordance with their wishes. In terms of shared decision making, patients and carers felt they received a good explanation of options for care and treatment and

were aware that the plan can be reviewed as the situation changes. All felt they were asked about their views on treatment and approaches to care. They also felt that conversations were 'open and honest' and this enabled them to 'make informed family decisions' based on the advice of health care professionals. Our staff evaluation highlighted the importance of framing the often challenging and difficult conversation(s), particularly agreeing treatment preferences and realistic goals which need to be communicated sensitively and effectively.

ReSPECT increases anticipatory care planning which is up to date and useful in an emergency.

A key aim of the pilot was to increase the % of patients with an ACP which was also useful in an emergency and up to date. Significantly more patients with a ReSPECT form had a KIS, 68% compared to 40%. The information contained within the KIS is more likely to be useful in an emergency once the patient has been through the ReSPECT process. 89% of KIS were found to be useful when a ReSPECT form was in place versus 43% with no form in place. More patients with a ReSPECT form also had an up-to date KIS. This enables more staff to have access to useful information when treating a patient in an emergency. 88% of staff questioned felt that the ReSPECT process would enable them to deliver the most appropriate care for that person. Treatment plans were recorded which included decisions beyond CPR including hospital admission, critical care admission, non-invasive ventilation and non-oral nutrition. Staff identified that the form guided them in decision making in an emergency when the patient was unable to express their wishes.

The ReSPECT process improved patient outcomes, particularly for those nearing the end of life.

Our early evidence shows that patients who have been through the ReSPECT process in this pilot are more likely to still be at home 3 months following a hospital admission (73% with a ReSPECT form, compared to 57% without a ReSPECT form). Further, it helps to support people to die in their preferred place of care. For nearly 75% of patients where this was achieved, less than 10% died in an acute hospital setting. Overall, 42% of patients with ReSPECT in place died in a homely setting (either their own home or a care home) compared to 26% without this. 54% of patients with ReSPECT in place compared to 74% with no ReSPECT in place, died in a hospital setting. This makes the suggestion of the ReSPECT process as a tool to support good end of life care particularly compelling. However, such conversations and decisions about treatment and care should ideally be taking place even earlier not only in the last days and weeks of life.

A more sustainable electronic and ultimately digital solution for the ReSPECT process is required to support the project both locally and nationally.

Challenges with sharing information across interfaces of health and social care are an ongoing local and national priority. The ReSPECT pilot exposed, rather than created, the current challenges across interfaces of care and this was an issue identified early in the pilot study. The electronic process has been further refined during the pilot but continues to create challenges for clinicians and has been identified as a potential barrier for future wider roll-out in Forth Valley, particularly primary care. Only 79% of ReSPECT forms were electronically uploaded, 75% were specifically communicated in the Immediate Discharge Letter (IDL) if completed in a hospital setting. Further, only 64% of patients had their KIS updated within 1 month

of a hospital discharge, to reflect the discussions recorded in the ReSPECT process. This is expected to improve as the process evolves and beds in. Informal feedback from primary care colleagues, suggests that the ReSPECT process is not currently in an electronic format which can intuitively support the use of KIS, although the latter also has its own limitations.

Next Steps

Ongoing

1. ReSPECT continues to be a strategic priority for the organisation including e-health planning to support the wider roll out of the process across Forth Valley, enabling the transition completely from DNACPR documentation particularly in a primary care setting. ReSPECT continues to be aligned with Realistic Medicine locally.

2. Develop work with NHS Education for Scotland (NES) Digital Service to create a more sustainable digital form to support the ReSPECT process, particularly in primary care, and which will allow citizens to access their own electronic health record. Integration into current systems e.g. Trakcare is already underway.

3. Continue to regularly sample completed ReSPECT documentation to promote safety and high quality communication across all care settings.

4. Further develop the operational policy for use of the ReSPECT process in a variety of care settings. Promote and develop the educational resources available on the staff intranet ReSPECT webpage including the educational app.

5. Utilise a variety of ACP trigger tools to identify patients who may benefit from the ReSPECT process e.g. SPICT-4-ALL which can be used by family and carers, not only care professionals.

6. Raise public and staff awareness about the ReSPECT process utilising the NHS Forth Valley video and sharing the positive local patient, family, carer and staff experience.

7. Promote excellent communication skills training which promote shared decision making and consider the time and workforce planning required to deliver the ReSPECT process in all health and social care settings.

8. Further qualitative feedback from primary care, including care homes.

9. Further evaluation of paramedic and emergency response teams' access to emergency care planning documentation.

10. Further project support to deliver this will be required to enable the complete transition to the ReSPECT process including an education lead, dedicated project improvement (QI) lead, and ehealth project support.

Future

11. Consider mapping the patient pathways, at an individual and local population level.

12. Integrate the ReSPECT process into existing processes and pathways e.g. My Anticipatory Care Plan, Frailty Initiative, Scottish Patient Safety Programme Deteriorating Patient, Nursing Home Local Enhanced Services (L.E.S), Scotland's House of Care.[12]

13. Further qualitative analysis on mapping any potential gaps in health and social care provision required to deliver on patient preferences and supporting those who wish to die at home.

14. Support patients who may have impairment of mental capacity e.g. learning disability or dementia utilising the locally developed decision making pathway.

15. Evaluate Patient Outcome Reported Measures (PROM's) focusing on value based care at an individual level.

Introduction

People are living longer and in better health due to improvements in health and social care. This is predicted to result in more than double the number of people aged 85 years and over by the year 2031. Around two million people, 40 per cent of the Scottish population, have at least one long term condition and one in four adults over 16 report some form of long term illness, health problem or disability.[13]

For the majority of individuals, healthcare treatment aims to prolong life or return the individual to near or as near their pre-illness health as possible. For those individuals living with a chronic or life limiting condition it is important to start to plan for the future as early in the journey as possible. Further, there will be more people living with terminal and progressive life limiting conditions where the priorities of care may shifts towards those which impact quality of life and address symptoms rather than those which can prolong life. Life sustaining treatments in this context may be deemed increasingly burdensome by that person and may no longer be wanted or appropriate. The value of sensitive, high quality, individualised care planning has never been more crucial with so many people living with multi-morbidity, complex conditions, frailty and mental health challenges. The importance of sensitive and effective communication which helps to individualise, plan and support people and those close to them at the end of life is outlined in the Strategic Framework for Action on Palliative and End of Life Care.[5]

ACP is a proactive 'thinking ahead' approach which puts the person at the centre of decision making and outlines their needs and realistic preferences. Evidence shows that patients would like to be more involved in decisions about their care and treatment, as they should be, and that this contributes to improved outcomes and experience of care.[14] The role of families and carers, where the individual has agreed to their involvement, is often vital for holistic care planning.

There has generally been a lack of progress in fully involving people in decisions about their health and care, however, more than ever there is a much needed growing emphasis on person-centred care and a shift in the balance of decision making as outlined in Realistic Medicine.[4] Shared decision making can improve patients' knowledge and help patients develop realistic expectations about options and help them clarify their preferences. It may reduce overuse of interventions with minimal or no expected benefits and underuse of beneficial interventions.

The ReSPECT process is the emergency care planning component of a wider ACP. It has the potential to harness and facilitate high quality ACP communication and decision making, resulting in a summary plan listing clinical recommendations for a future emergency when that person is unable to make or express preferences for treatment. Capturing advance patient preferences has traditionally proved challenging due to a number of reasons including time/resource pressures, lack of confidence or engagement in having such conversations and uncertainty about an individual's prognosis. An emphasis on open, honest and earlier conversations is essential whilst acknowledging the uncertainty and complexity of decision making with the person at the very centre of this.

Background

A high quality, effective and more person-centred approach to individual care planning remains a local and national priority. The importance of ACP was outlined in the NHS Forth Valley Health Care Strategy.[3]

Person-centred care is underpinned by 4 principles; treating people with dignity, respect, compassion; offering co-ordinated care and support; tailoring care and treatment to that individual and their own health and social context; and enabling individuals to be participants in their own care. As part of the person-centred care strategy, shared decision making with the patient about their anticipated preferred treatment when they become unwell is a key priority, and helps health and social care professionals do the right thing in an emergency potentially reducing under or overtreatment, reducing variation in practice and improving patient and carer experience.[15]

A shared decision making approach enables the people we care for and support and professionals to work in partnership, making decisions based on the best clinical evidence, making sure that people are fully informed about risks and benefits, and combining this information with the person's values and preferences.

Forth Valley Context

A DNACPR point of prevalence study carried out in NHS FV In March 2017, scoped the extent of DNACPR decision making across all of our acute and community wards (>900) patients.[8] 1 in 3 patients had a DNACPR decision documented; the highest incidence was found in the community hospital setting. The majority of these patients were frail elderly with DNACPR prevalence reaching 90-100%. In contrast, a smaller study revealed that emergency/anticipatory care planning was inconsistently documented (<10%), often lacked patient/next of kin involvement and was not always easy to access in an emergency situation due to the lack of a standardised approach. This is of particular relevance in a community hospital setting, when nursing staff utilise the emergency GP team when a patient becomes unwell out-of-hours. The NHS Forth Valley Resuscitation Service Report' in 2017[9] identified that 32% of cardiac arrests resulting in CPR were potentially avoidable: 6% of patients had an unrecognised pre-existing DNACPR decision; 18% of patients were deemed appropriate for DNACPR and 8% had no clear escalation plan in place. Survival to discharge after a cardiac arrest was noted to be 22% for all patients.

Evidence shows that 1 in 3 patients will die within 12 months of a hospital admission and 1 in 2 people aged 85 years and over.[16] Previous research has shown that 70% of patients express a wish to die at home at the end of life, however, only 1 in 5 patients actually end up dying at home and this is least likely in patients over 85 years of age.[17] A clear emergency care plan would empower all staff in such situations to ensure the right treatment is given at the right time in the right place in accordance with that person's wishes as far as possible. Many local GP practices have signed up to Nursing Home L.E.S with 6 monthly ACP reviews for nursing home residents. There had been no specific recommendations about the content or scope of this. A previous study, evaluating the quality of the KIS, identified that even when KIS information is recorded, it may not be a useful guide for a clinician in an emergency situation.[10]

DNACPR discussions must involve the patient and/or those close to them (if mental incapacity) in accordance with the updated national DNACPR policy.[7] There are a few exceptions to this but when not communicated appropriately this has resulted in distress, mistrust, complaints and litigation. We found previously in a small local study that only 80% of such decisions adhered to the national policy for communication.[8]

We also reviewed the communication systems utilised in Forth Valley to support advance decision making and noted that at least 6 electronic systems would need to be updated to be inclusive of all relevant care professionals involved in that person's care - Clinical Portal, KIS, EMIS, Midas, Docman and Crosscare.

In summary, the baseline evidence suggests:-

- We are identifying where CPR may be unwanted or not of benefit, this reduces burdensome interventions and inappropriate CPR attempts.
- CPR discussions are not taking place universally in the context of wider emergency care planning.
- Care planning may not be as person-centred as it could be, this needs to be better evidenced and a framework provided.
- There is a lack of evidence around how much shared decision making takes place in such discussions.
- There are significant gaps and overlaps in existing processes and pathways. Information is not always up to date, useful or accessible and may not be available in an electronic format or across all care settings. Thus, DNACPR decisions and anticipatory care plans are not always visible and can be missed in emergencies and at the interfaces of care. Many staff providing emergency care cannot view emergency treatment plans including KIS.

In light of the local context, a pilot was proposed for a new approach to emergency care planning utilising ReSPECT, a process endorsed by the Resuscitation Council (UK).[2] The ReSPECT process starts with a conversation and results in an anticipatory emergency care plan, designed to be used as a guide for health and social care professionals in the event of a clinical emergency or deterioration which renders a person unable to make or express their wishes. Its overall aim is to establish a shared understanding of the person's current condition, the likely course and prognosis of any illness if known, and which forms of treatment that person would or would not want to be considered in an emergency. Treatments discussed will depend on that person's situation but may include CPR, admission to intensive care, organ support, intravenous fluids or antibiotics. The discussion may also include whether that person would wish admission to hospital in an emergency, this is particularly important for those who may be approaching the end of life. Following discussion(s), the person's preferences are then recorded on a ReSPECT form in combination with the clinical recommendations for emergency care that are realistic for the patient and care teams looking after them.

The overall aim of our pilot was to explore the ReSPECT process as a potential tool for the right standardised framework in our health board for emergency care planning, thus removing the need for DNACPR documentation. We evaluated this, by the following:-

1. Reviewing the overall process and the quality of ReSPECT documentation in a variety of care settings.
2. Measuring patient outcomes including their preferred place of care.
3. A comparison of the KIS of all patients who had a ReSPECT form completed during the pilot, and patients without a ReSPECT form who had triggers present in ward A11 pilot.
4. Qualitative Feedback from patients, carers and staff about the ReSPECT process.

Implementing the ReSPECT process in Forth Valley

Methodology & Process

Preparation for the pilot was guided by the ReSPECT Implementation Roadmap shown below.[2]

Figure 1: Implementation Roadmap
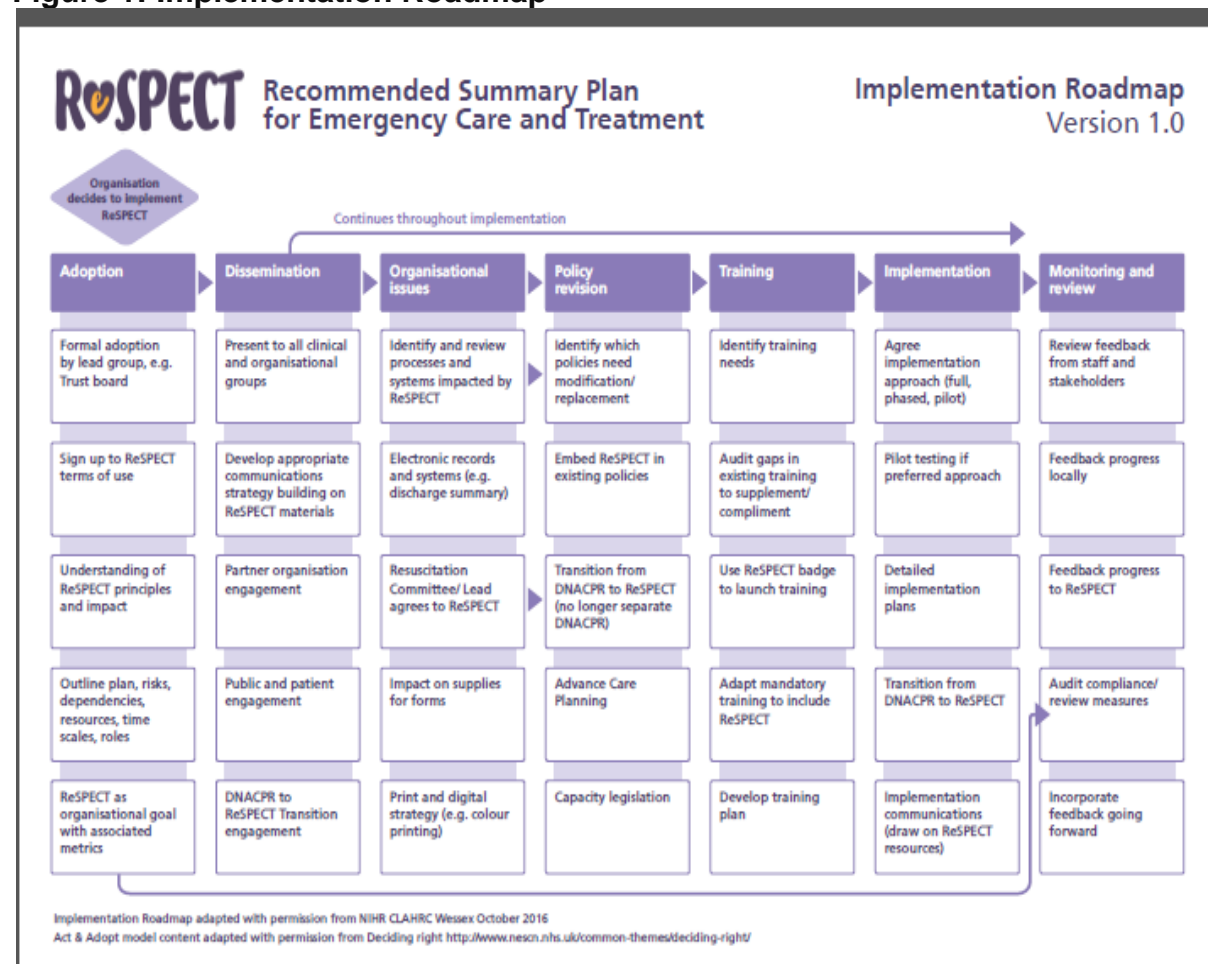
Location

The pilot commenced in September 2017 and was introduced in 4 key areas; acute older people's ward A11 Forth Valley Royal Hospital (FVRH) (>75's), acute mental health ward 4 FVRH (>65's), Strathcarron day hospice and in primary care (2 General Practitioner's in different practices).

Process

An initial small test of change was proposed; as such ReSPECT had to be used alongside DNACPR documentation where appropriate to communicate decisions. As ReSPECT may document both decisions *for* CPR as well as *not for* CPR and this was felt to pose too high a clinical risk for patients if the document was not recognised and decisions inadvertently not adhered to. Colour ReSPECT paper forms were used; either handwritten or in a writeable pdf format and then printed in colour. The location of where the form was stored was dependent on the care setting.

Preparation for the pilot included harnessing the electronic clinical systems already in place. Completed forms were 'scanned-to-me' on a printer and sent to a local email inbox respect@nhs.net. The IT team then made this available as a black and white pdf in the ALERTS and Clinical Communication section of Clinical Portal to view across a variety of care settings with access to this system within the health board. During the pilot, the ALERTS became colour coded to increase visibility (shown below in Figure 2).

Figure 2: ALERTS screen on Clinical Portal

If for any reason the ReSPECT document required updating or was removed the old or revised form was scored through and scanned to the generic ReSPECT email box. The status of the old form in the Clinical Communication section then changed to 'non-current' and was not removed but kept as part of the clinical record. The new updated and scanned in form was then viewed in the ALERT and Clinical Communication section as before. An email receipt was then emailed back to the sender and any changes or queries dealt with by the EDMS IT team managing the inbox. DNACPR documents could also be uploaded in the same way. Clinical Portal does not link with KIS and a prompt for the GP practice's to update KIS was required when this was initiated in a hospital/hospice setting at discharge (see Appendix 1 for the full ReSPECT process in FV).

Education

Awareness raising about ReSPECT across the health board was essential prior to the pilot commencing and educational sessions for staff were offered during the pilot in addition to use of the ReSPECT Learning Web-application.[2]

ReSPECT team

A ReSPECT strategic project team was developed with key stakeholder involvement, meeting every 3 months to evaluate the progress of the project. Regular operational meetings took place on a usually weekly basis. The overall project lead clinician time exceeded the 4 hours designated per week and similarly for the primary care lead clinician. The project was supported by a ReSPECT education nurse for 1 day per

week in the acute hospital setting, incorporated in to nurse education role's in palliative and end of life care in community hospitals and in a primary care setting and aligned with local resuscitation and communication training.

Evaluation

- We evaluated the use of ReSPECT in a variety of care settings - hospital, care home, patient's own home and day hospice. We reviewed all completed ReSPECT forms for quality of documentation and compared content with the KIS for each patient
- We measured the following outcomes for patients discharged from a hospital with a ReSPECT form: 7 day, 30 day and 3 month readmission, subsequent length of stay (LoS) on readmission, place of death and KIS updated within 1 month of discharge. We assessed whether the person's preferred place of care was recorded and if they actually died in their preferred place of care
- We also looked at the impact of ReSPECT on the quality of KIS for emergency care. We compared outcomes in this group of patients (with ReSPECT form) with patient's discharged from hospital who triggered for ReSPECT (see table 1 below) but did not have this at discharge (no ReSPECT form)
- Qualitative feedback was obtained utilising questionnaires (available on request) adapted from the National Patient Experience Survey, from patients and carers (family members) after they had been through the ReSPECT process; and an informal carer support group. Feedback was also obtained from staff in a variety of care settings (questionnaire available on request)

ReSPECT in the hospital setting

Although only two acute hospital wards were identified for the pilot, we anticipated that there would be a need for a wider adoption of the ReSPECT process in other ward areas. As the pilot evolved, patients were being transferred to other acute or community hospital wards with a ReSPECT document in place or being readmitted to any adult hospital ward with the document in place.

Triggers for a ReSPECT discussion

Although anyone could potentially benefit from the ReSPECT process, a targeted approach was used in the hospital setting to identify those people who should be prioritised for emergency care planning, mainly in view of time/resource challenges. We developed a trigger tool adapted from BMJ Practice Pointers[11] (see Table 1 below) to support identification of patients although this was often quite apparent to the clinical team. Suitable patients were identified at the weekly multi-disciplinary team meetings, daily ward round or safety huddles. The screening process was also beneficial when comparing patient outcomes which will be discussed later in this report. The NEWS (shown in Figure 3 below) was utilised to align with the Deteriorating Patient work[18] for clarification of treatment planning and for appropriate escalation or limitation of clinical interventions.
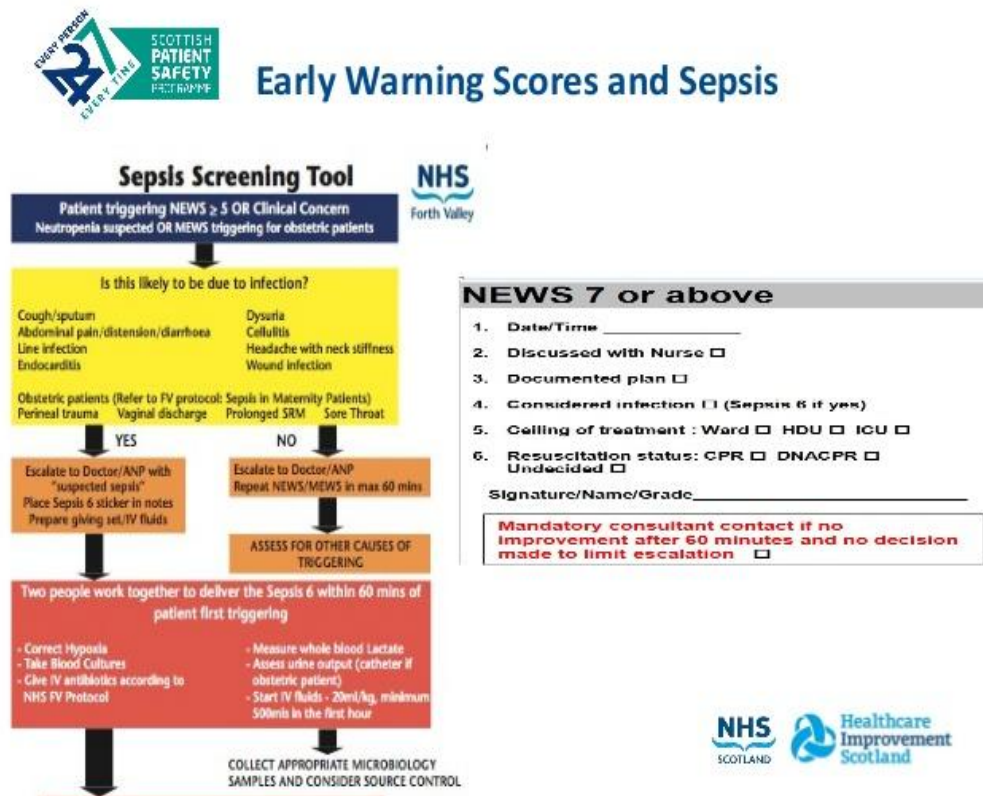
Figure 3: National Early Warning Score (NEWS)
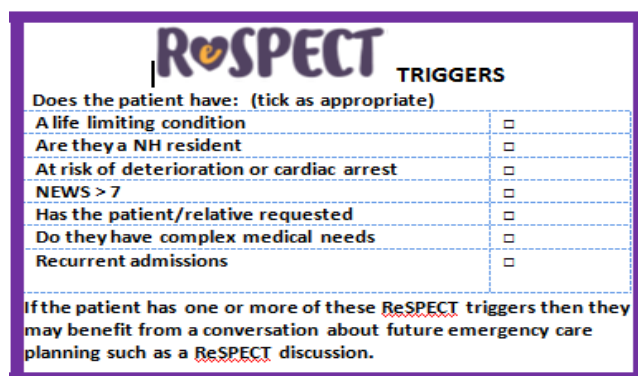
Table 1: Triggers for ReSPECT
Life limiting condition
Care home resident
Identified risk of acute deterioration, cardiac arrest or death including increasing NEWS
All patients with NEWS>7
Requests by the individual/family to record preferences
Long term / complex health needs
Recurrent Admissions

A prompt (seen in Figure 4 below) was then placed in the clinical notes for consideration of the ReSPECT process at the next opportunity.

Figure 4: ReSPECT triggers sticker


The triggers enable staff of different grades and specialties to highlight appropriate patients for a ReSPECT discussion. These conversations were often prompted by nursing, more junior medical staff member and allied health care professionals. Staff in every area of the hospital could recognise patient's suitability for the ReSPECT conversation in view of this.

During the pilot in ward A11, 331 patients were screened using triggers for discussing ReSPECT, and 63% (n=207) were identified as having one or more triggers. This figure correlated with those screened for frailty using a pre-existing frailty tool, this was not developed further due to ongoing discussions on agreed frailty criteria for another project.

Graph 2: Triggers for ReSPECT
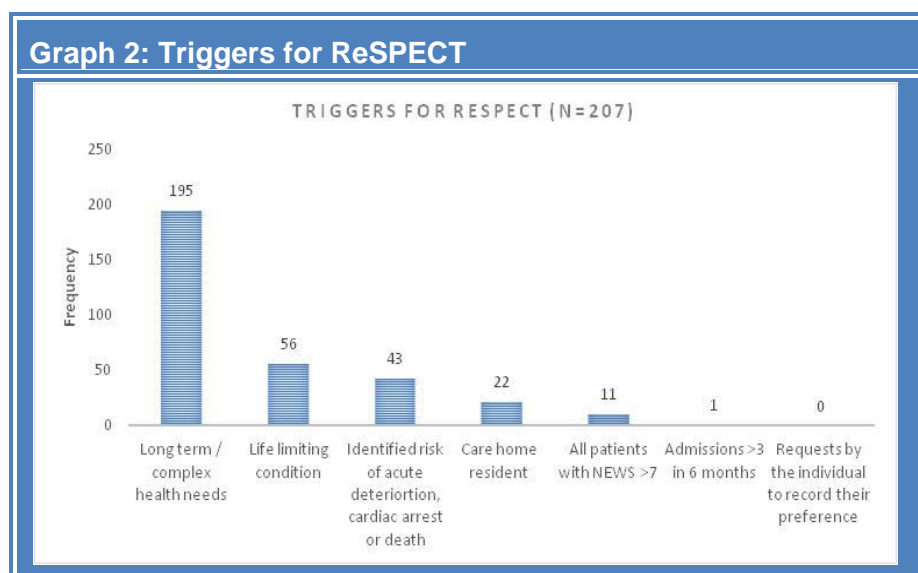
Graph 2 above shows the frequency of the triggers recorded for patients during the A11 pilot. The overwhelming majority of these patients were identified as having long term/complex health needs.

Graph 3: ReSPECT forms completed in ward A11 during the pilot

RESPECT FORM IN PLACE (N=207)
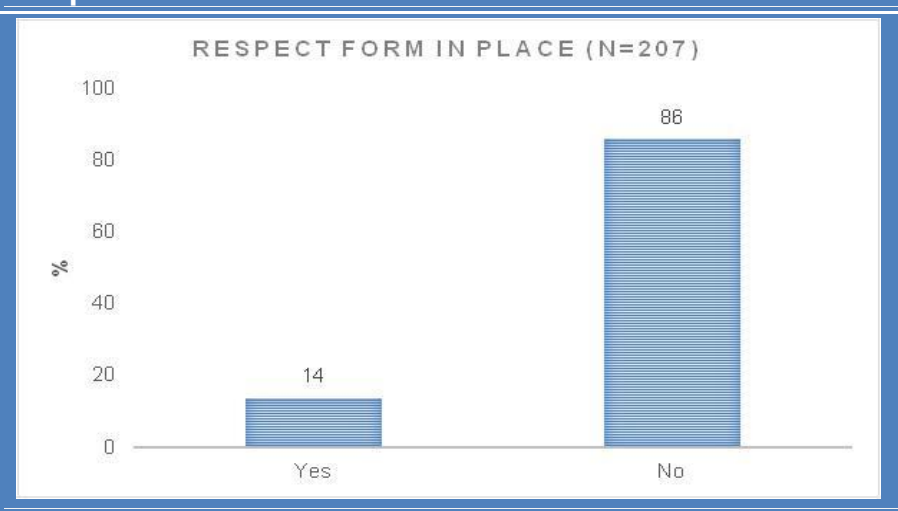
14% (n=29) of patients identified as having one or more trigger for ReSPECT had a ReSPECT form completed in ward A11. Of the 86% (n=178) who did not, 7% (n=13) went on to have a ReSPECT form completed during a subsequent admission to hospital or in the community by a GP.

It should be noted that the data that informs the graphs above was only collected when the ReSPECT nurse was on duty. We know from the forms that were uploaded to the ALERT section on Clinical Portal that 57 ReSPECT forms had been completed in ward A11 during the same time period (September 2017 and April 2018).

The Conversation and Decision-making

The ReSPECT conversation was, in the majority of cases, initiated by a member of the medical team. Sometimes, the specialist nurse or advanced nurse practitioner with the appropriate skill mix also took forward these conversations. Although discussions are often best to have when someone is stable and at home prior to a health crisis, often more urgent conversations are required due to a sudden deterioration in someone's clinical condition or if they have had a prolonged hospital admission. Under the guidance of the senior clinician (consultant in the hospital setting), suitably skilled junior medical staff often took forward the ReSPECT discussion with the patient and their family. The senior clinician agreed the overall treatment plan and ideally signed off the document. The essential part of the process was the conversation and the collaboration between the health care team, patient and their family. It was important to ensure everyone involved in the discussions had a clear understanding of the treatment recommendations agreed within the document. If the patient did not have capacity to be involved in the decision making process then the discussion involved the Power of Attorney/Guardian/next of kin in line with Adults with Incapacity (Scotland)[19] legislation as per the framework in the document. Families and patients have informally fedback that they were grateful for the discussions about their loved ones future emergency care, as difficult as the conversations were at times. Families reported previously feeling the burden of decision making for a family member where preferences were not known or discussed.

Conversations with patients and families often occurred over a few consultations before ReSPECT documentation could be completed, depending on the urgency of the situation. It was vitally important to review documentation if there was a change in condition or care setting. If a patient had temporary mental incapacity e.g. due to delirium and could not initially engage in discussions, then decision-making would need to be re-explored when their condition improved and they regained capacity. Inclusion of the family/carers in discussions was usually routine whether the patient had capacity or not as, in this pilot, patients were usually keen for their involvement. A patient/family information leaflet[20] was often given out prior to a fuller ReSPECT discussion after an initial explanation of the process.

Completing the ReSPECT document

Clinicians noted that the layout of the ReSPECT form provided a framework and natural flow for discussions and decision making, making it difficult not to consider someone's preferences for care and treatment, where this may not otherwise have occurred naturally in the conversation.
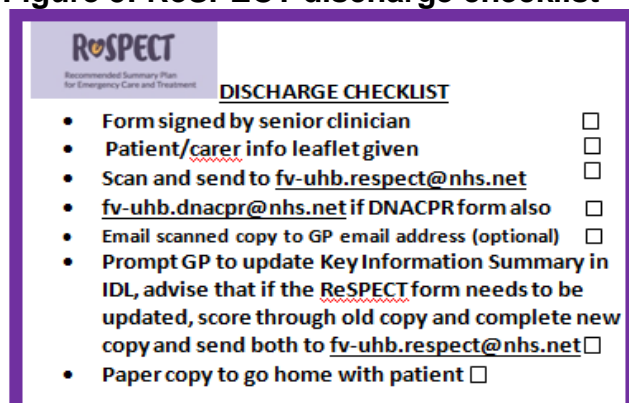
The framework for CPR decision making and discussions utilised the existing national DNACPR Scotland policy. If a 'CPR attempts NOT recommended' was recorded on the ReSPECT form, then a DNACPR form was also completed. If a patient lacked capacity, discussions were in accordance with Adults with Incapacity (Scotland)[18] guidance and as documented in the national DNACPR policy[7] and GMC guidance.[6] Paper forms were kept in the front of the patient's clinical notes, the DNACPR form first followed by the ReSPECT form as appropriate.

ReSPECT at hospital discharge

Similar to the DNACPR documentation, the paper ReSPECT form went home with the patient so that could be immediately accessible to health and social care professionals in an emergency in which the person cannot express their wishes. Prior to this, an electronic version was created as previously described.

On hospital discharge, the IDL detailed the content of the ReSPECT form and requested that the primary care team kindly update the KIS accordingly.

Figure 5: ReSPECT discharge checklist

The ReSPECT discharge checklist sticker shown here in Figure 5 was placed in the notes of the patient to ensure the discharge process and communication of ReSPECT with primary care was consistently approached.

The people, families and carers involved in the ReSPECT Process

At the centre of the ReSPECT pilot were the people, their loved ones and those caring for that person, often as they neared the end of life. The ReSPECT process was utilised in a variety of settings in the pilot and to better understand that very human process, the following stories (outlined in Box 1, 2 and 3) based on real scenarios, are outlined in a hospital, community and hospice setting.

Box 1: Hospital setting

Mrs. M is a 76 year old lady who is admitted to the emergency department with seizures which are prolonged (status epilepticus). She requires a brief period of airway support in the critical care unit until seizures are controlled with epilepsy medication. A brain scan reveals a stroke has caused the seizures.

She has a significant past medical history including previous stroke, ischaemic heart disease, depression, high blood pressure and diabetes. She has been living at home alone with support from her 3 children with recent assistance with personal care and requirement for a package of care. She mobilises with a walking frame and hasn't been out in the last 3 months due to recurrent falls and loss of confidence.

After regaining consciousness, she is noted to be suffering from a severe delirium in the post-ictal phase and lacks capacity for decision making about her care and treatment. The health care team looking after her feel it would not be of overall benefit for her to return to the Critical Care Unit, if a similar situation should arise again. There is no documentation of her previous anticipated preferences for emergency treatment including CPR. Her daughter mentions that no such discussions have previously taken place with her mother, this is not a topic that would have been raised or discussed.

Her daughter, who has welfare Power of Attorney, doesn't believe her mother would wish to return to the Critical Care Unit for any more invasive monitoring or intervention. This is agreed and documented by the lead clinician and the wider team, with a recommendation that treatments such as intravenous antibiotics are appropriate but not CPR or readmission to the critical care unit. A clear seizure plan is also discussed and then documented in a ReSPECT form as part of her hospital notes.

Her son arrives from England the next day and he is concerned that a 'do not resuscitate' decision has already been agreed for his mother.

The team explores the son's concerns, on further discussion it emerges that he is worried that the presence of a 'do not resuscitate' form means she is dying and will get less treatment. He is taken through the ReSPECT process with his sister present. A further discussion takes place, this includes the realistic options for treatment that can and should be offered by the clinical team and which are recorded in his mother's summary plan. The son now feels reassured that 'something will be done' if she deteriorates again. Her daughter hopes that she has made the right decision for her mother and expresses how difficult this has been for her.

Some weeks later, their mother's delirium resolves and she regains mental capacity for discussing treatment options. The treatment plan is further discussed and she fully agrees with the decisions made although can't recall her Critical Care admission. She would prefer to be cared for at home if possible but if needed would come in to hospital for appropriate treatment. The form is updated to reflect her wishes and involvement. The family are reassured that everyone is in agreement and she is discharged home with the ReSPECT form in place. Her own GP updates her Key Information Summary once she has been discharged home.

ReSPECT in a community setting

The ReSPECT process in the community pilot was primarily targeted for patients with frailty either living in their own home or in a care home setting. High Health Gain data[21] can be provided by a tool to help GP practices identify their most vulnerable patients who are predicted to have complex needs in the next 12 months. These patients are thought to have the potential for 'High Health Gain' but this was not felt to be a particularly useful tool to identify suitable patients from the GP practice's in this pilot. The final search screened for >65 years old, frail, high complex condition with 1 or more hospital admissions in the last year. The nursing home manager of the local care home was also invited to identify and approach patients and families who were interested in taking part in a wider ACP review incorporating the ReSPECT process.

Patients were identified with and without mental capacity to engage in decision making around anticipatory emergency care; the latter were supported by their families. The ReSPECT process was well received by the majority of patients and families, although some declined to participate in the pilot. It was felt that patients living in a care home setting had the most potentially to gain; some relatives of the patients were unaware that not admitting their loved one to hospital was even an option. It was felt that the ReSPECT process would only work as part of a wider ACP review for the patient, particularly where they were well known to the clinician. ReSPECT helped to prompt conversations about consideration of polypharmacy and POA, for example. There were clear benefits of having a ReSPECT form in place where hospital admission was not desired and it was noted that the process and documentation enabled this wish to be respected. Without this intervention these patients would have been admitted to hospital ordinarily in a health crisis. Patients and families felt empowered and relieved to be involved in the process and in formalising decisions, the feedback was overwhelmingly positive and can be viewed in the qualitative feedback. It was felt that a suitably skilled nurse practitioner could take this role forward in the community and allow care closer to home if desired.

Box 2: Community setting

Mr. S is 85 years old, he has kept in relatively good health besides high blood pressure, prostatic hypertrophy with raised PSA ('monitoring only') and osteoarthritis. He lives with his wife; he was driving until recently when his eyesight began to deteriorate. Mr. and Mrs. S have 2 children in their sixties, they each have their own family and live in another part of the country.

Mrs. S passes away suddenly and Mr. S becomes increasingly isolated and housebound. During a house visit following on from a recent fall, his GP who knows him well notices a significant amount of weight loss and he is more breathless since his wife died. A concerned neighbour who is in attendance, has noticed he is not able to look after the house or himself and is struggling to manage the stairs. After an initial assessment and referral for further social work and rehabilitation input - he is referred to the frailty clinic at the local hospital. Prior to being appointed, he has another fall, a probable blackout and is admitted as an emergency. After further assessment and investigation, his previously high blood pressure is now low and he is found to have 'aortic stenosis'- a severe narrowing of the valve. A cardiology referral is made after an initial discussion during his hospital admission. However, once he returns home he has a further discussion about this new diagnosis and the likely prognosis with his own GP. He decides that he would not wish any treatment even if surgery was an option, 'he has had a good life and when the time comes… just let me go'.

> **Box 2: Community setting (continued)**
>
> His GP suggests that it would be useful to capture his preferences for treatment utilising the ReSPECT document. After clarifying his wishes, Mr. S and his GP agree a plan which include that he would not wish surgery nor CPR but outlines treatments that he would wish e.g. hospital admission for antibiotics. His GP then phones his family, with Mr. S's consent to advise them of their discussion and to make them aware of the form. Mr S. later completes a wider Anticipatory Care Plan with support from his family and an ACP nurse.
>
> Over the next 6 months, Mr. S has increasing admissions with fluid overload and urinary tract infections. On the 3rd admission, his condition is worse and he is worried he will die in hospital and he wants to be at home as recorded in his ACP if he is nearing the end of life. The care team expedite his discharge from hospital, advising the family, GP and district team of the plan to support him at home for end of life care. The prognosis and course is uncertain but he is able to be supported for some weeks before he passes away at home.

ReSPECT in a hospice setting

In the pilot period, suitable patients were identified for the ReSPECT process in the Strathcarron day hospice setting. This was often prompted by a change in the person's clinical condition or care setting e.g. cessation of chemotherapy or following on from a hospital admission. The ReSPECT process was often initiated by the patient or staff member as part of a wider discussion about planning for the future.

In addition, patients in the Strathcarron hospice inpatient unit, for whom discharge was being planned, were also considered for the ReSPECT process. This allowed the team to have conversations over the course of the admission and for agreed decisions to be communicated to the wider team on discharge e.g. community palliative care team. This facilitated collaboration between care teams at crucial transition between care settings. The patients' medical notes were electronic and ReSPECT or DNACPR forms were stored in a patient folder as well as being scanned in to the electronic systems- Clinical Portal and Crosscare. The process for completing a ReSPECT form was as for other clinical settings (see Appendix 1). In each case, the GP was notified by phone as to the presence of a ReSPECT form.

> **Box 3: Hospice Setting**
>
> Mrs. R is a 42 year old lady who lives with her husband and two children, aged 11 and 17 years old. She was diagnosed with a malignant melanoma affecting her leg 1 year previously, for which she had surgery. Subsequently, she is unfortunately diagnosed with metastatic disease and she agrees to undergo targeted immunotherapy as discussed with her oncologist. Shortly after commencing immunotherapy she develops sepsis with adrenal insufficiency. She is commenced on appropriate treatment although there is a recognition that she may not survive. A DNACPR decision is agreed and documented following discussion with Mrs. R. Her condition then improves and she is transferred to Strathcarron Hospice for ongoing symptom management. Mrs. R is distressed that her family had been preparing for her death but now she has improved. She does not wish them to go through this repeatedly, and has decided that she doesn't wish any further cancer treatment. On further reflection and discussion with her family and hospice staff, she decides that treatment may give her quality time with her children - this is of the utmost importance to her. She is commenced on a lower dose of immunotherapy. Her anticipated health problems include adrenal insufficiency and infection. She wishes further active

Box 3: Hospice Setting (continued)

treatment if there is a possibility of more quality time with her family. A ReSPECT form is completed, to guide clinicians when she may be unable to express her wishes in an emergency. The recommendations include ongoing immunotherapy and active treatment of infection, including central venous access, as appropriate, in accordance with her wishes. The specific risks of her treatment are discussed and contact details for key professionals involved in her care are completed. Mrs. R has an admission to the acute hospital approximately a month following this. She is too unwell initially to be involved in decision making and treatment is guided by the ReSPECT form. She is treated actively with IV antibiotics, fluids and steroids. She responds well to this and is able to spend four more months at home with her family. Her disease sadly progresses with further complications and a more symptomatic approach is now preferred by Mrs. R. ReSPECT documentation is updated to reflect this approach. One month later she passes away peacefully in a hospice setting with her husband and sister at her bedside.

Results

Section 1: Demographics

This section of the report presents demographical information for all patients with ReSPECT forms that were uploaded to the ALERTS section of Clinical Portal, during the pilot period (September 2017 to May 2018).

ReSPECT form completion

Graph 4: Number of ReSPECT forms uploaded to Clinical Portal
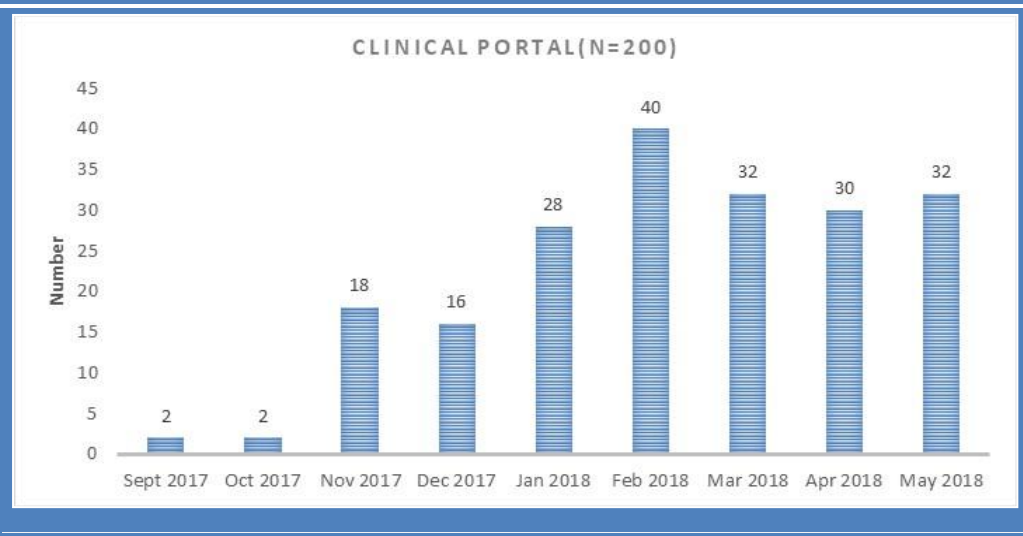
200 ReSPECT forms were uploaded to the ALERT section of Clinical Portal from September 2017 to May 2018. This involved a total of 198 patients, 2 patients had their ReSPECT forms revised with a new form replaced on Clinical Portal.

This is an underestimate of the actual ReSPECT forms completed in the pilot period. There were an unknown quantity of forms completed in the community setting with a paper document only, this was usually because it was not practicable to scan the form, in some cases this was because the patient was at the end of life and this could not be removed from their homely setting. This is an important consideration when creating a sustainable plan for ReSPECT documentation in a variety of care

settings, out of hours teams including paramedic teams need to be aware of such documents which would enable the right treatment at the right time in the right place for that person.

Location of ReSPECT form completion

Graph 5: Care setting where forms were completed

LOCATION (N=200)
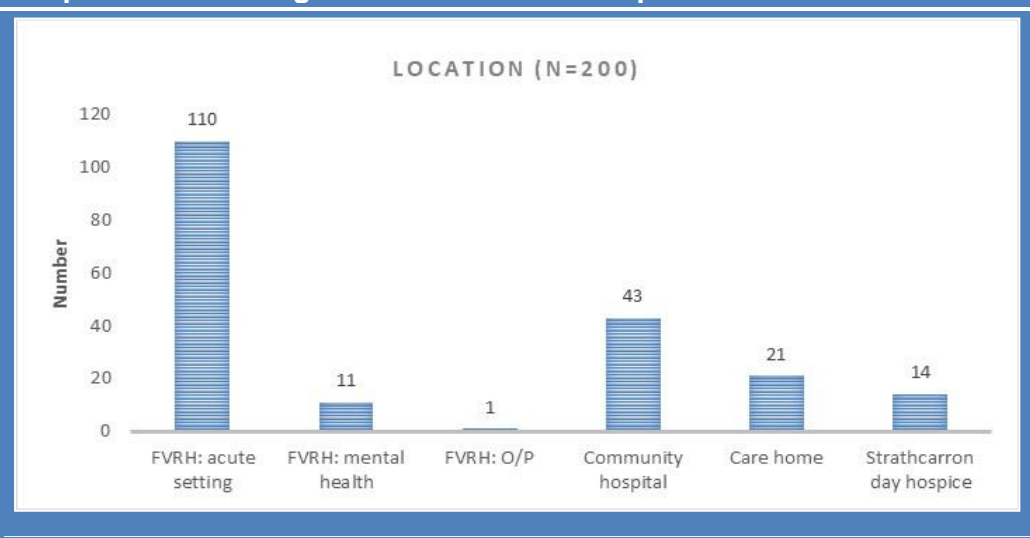
83% (n=164) of forms were completed in a hospital setting, most commonly in an acute setting. A full breakdown of the location of forms completed can be viewed in Appendix 3. 37% of forms (n=60) were completed within the main pilot ward A11 during the pilot period. Demand for ReSPECT documentation increased as the pilot progressed and this can be observed in the range of settings where documents were completed.

Patient demographics

Graph 6: Gender

GENDER (%)

- Female ■ Male

Graph 7: Age

AGE (%)

■ 41-60 ■ 61-80 ■ 81+
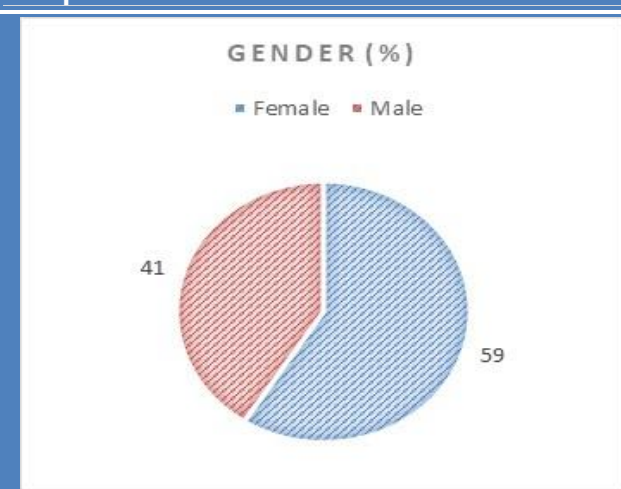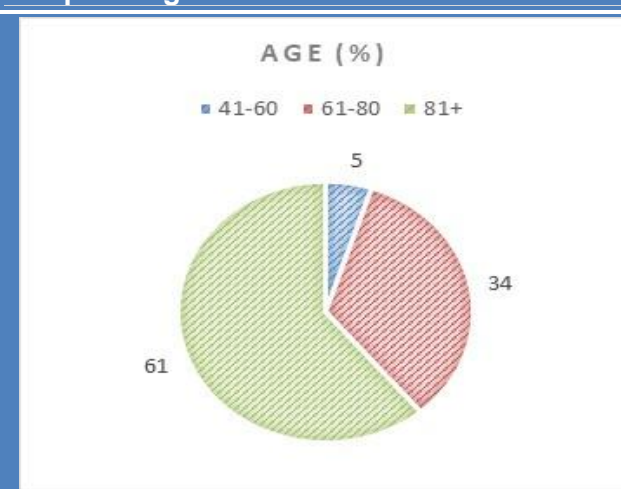
59% (n=117) of patients were female and 41% (n=81) male. The majority of patients were over 80 years old, the average and median age was 82 years old. As a third of forms were completed in the pilot ward A11 (>75's) this result is as expected.

Section 2: Review of completed ReSPECT forms

This section of the report provides a retrospective evaluation of the quality of information recorded on 100 of the completed ReSPECT forms, within the pilot period. The data was collected by the ReSPECT nurse using a locally developed data collection tool (available on request).

The section of the form being evaluated is highlighted in red on the right beside the results obtained. It can be assumed that 100% would be the gold standard where essential information is being recorded e.g. patient information, mental capacity, lead clinician signature. Further information recorded while desirable is less likely to be at 100% e.g. prognosis, priorities of care.

Disease trajectory

This question was added after data collection had started and was collected for 60 of the 100 ReSPECT forms reviewed. Multiple answers could be given in response to this question.

Graph 8: Disease trajectory

DISEASE TRAJECTORY (N=60)
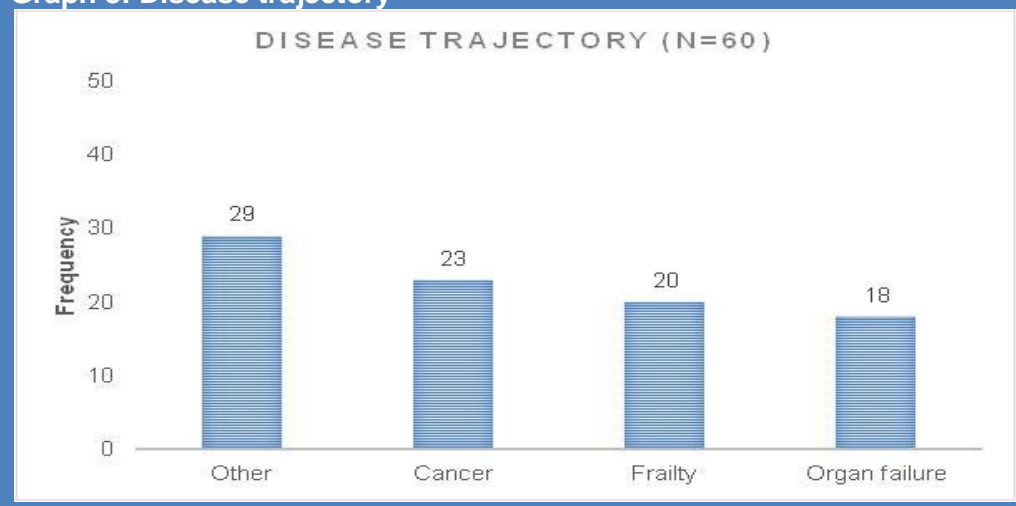
If appropriate, the disease trajectory was recorded and was varied within this pilot population. 'Other' disease trajectory included recurrent sepsis and neurodegenerative disorders.

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Patient demographics and date of completion

Graph 9: Patient demographics and date of completion

Nearly all forms contained the minimum identifiers (full name, address, date of birth and CHI number). The date of form completion was recorded on 84% of forms, feedback suggests this could be due to the location of where this information is recorded on the form and would be important to review with any future versions. The persons preferred name was recorded on 75% of forms reviewed. 100% of the forms were handwritten and legible.

Summary of relevant information

The **summary of relevant information** section of the ReSPECT form should be completed in discussion with the person (or with their family if they do not have capacity) and should include information on diagnosis, prognosis where known, communication needs and details of other relevant planning documents such as ACP, DNACPR, AWI.

Graph 10: Summary of relevant information
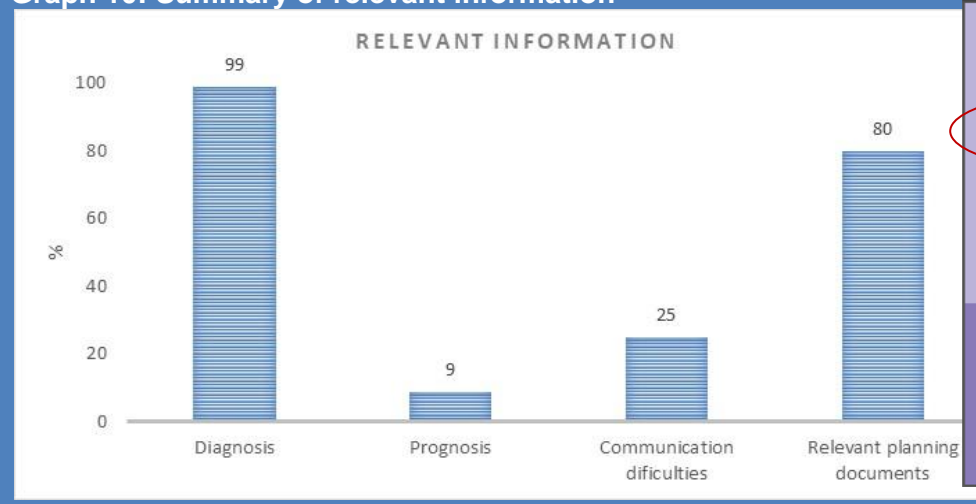
Graph 10 shows that 99% of forms contained information on diagnosis, and only 9% information on prognosis. This evaluation did not review the quality of information on diagnosis or prognosis just whether it was completed or not. The lack of documentation around prognosis likely reflects the challenges in this area particularly

with those on less predictable disease trajectories e.g. frailty/dementia and organ failure. 25% of forms contained information on communication needs. 80% of forms gave details on other relevant planning documents, and Table 2 below shows the planning documents detailed.

Table 2: Relevant planning documentation	
Planning documentation	**Frequency**
DNACPR	71
Adults with Incapacity	23
Advance Care Plan	7
Power of Attorney	2
ALFY your plan - scanned onto portal	1
Thinking ahead document - held by patient	1
Organ donation card	1

As expected, DNACPR was the most frequently recorded planning document.

Personal preferences

The **personal preferences to guide this plan** section of the ReSPECT form asks the person to describe their priorities for their care. A visual scale can be used to help them to consider what is most important to them, on the left moving towards life sustaining interventions and on the right those that prioritise comfort. The patient or family member (if lacking capacity) marks on the scale where they feel their priorities of care are focused.

Graph 11: Evidence that patients were asked about their priorities for care
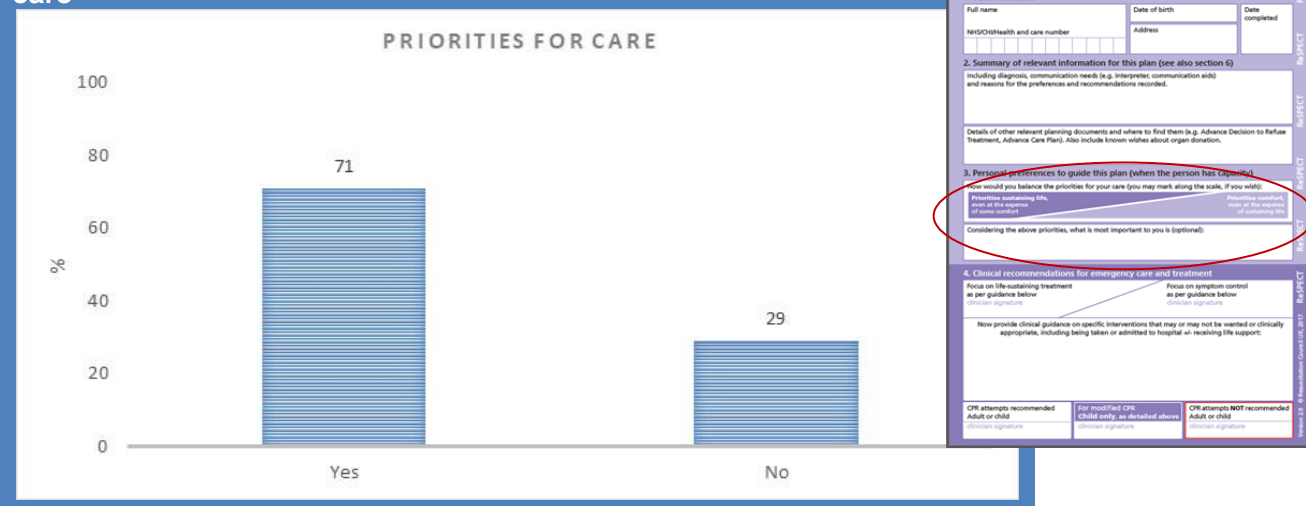
Graph 11 shows that 71% of forms contained evidence that the person was asked about their priorities of care. There was no such information recorded in the remainder of forms, this was usually due to the patient being unable to participate in this section. Some patients found this section difficult to understand even after an explanation, this is a very important section as it could potentially evidence the

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shared decision making process. This section may either need further revision in future versions or more specific guidance or pointers for completion of documentation for clinicians.

Graph 12: Priorities for care
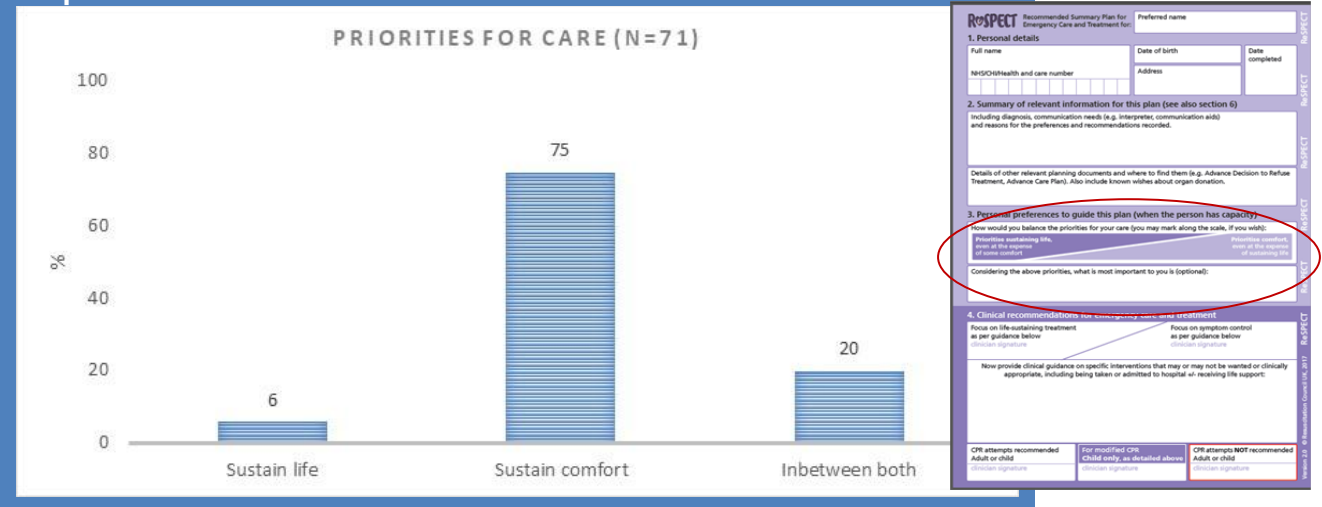
Graph 12 shows that 75% (n=53) of patients identified '*sustaining comfort*' as being their priority for care- care and treatment to control symptoms and provide comfort. 20% (n=14) of patients identified the middle point which usually reflected the wish for treatment to control symptoms in addition to some life sustaining treatment - IV antibiotics being the obvious example. 6% (n=4) wanted to be considered for life sustaining treatments even at the expense of some discomfort. It is perhaps unsurprising that so many patients chose a more symptomatic approach given the pilot areas and average age of the patients. The usefulness of the visual scale may need further evaluation and revision.

Clinical recommendations for emergency and care treatment

The **clinical recommendations for emergency care and treatment** section of the form records the recommendations to guide decision-making in a future emergency.

Graph 13: Signed by a clinician
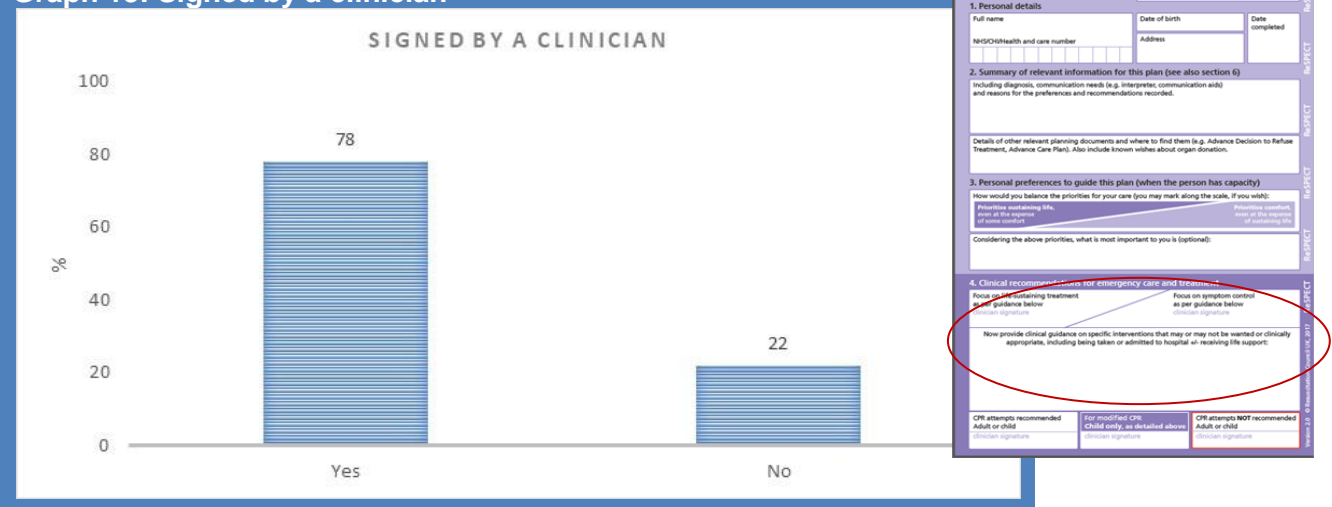
On 78% (n=78) of forms the goal of care section was signed by a clinician. The

reason for not documenting and signing this is not known for the 22% where this was not recorded, this would require a more qualitative evaluation. Informal feedback suggests that clinicians can find this section difficult to complete as the decision is more binary and does not reflect the scale for priorities of care in the patient section. This may need to be considered when considering future iterations of the ReSPECT form. Table 3 below shows the specific interventions that were agreed in the treatment recommendation section.

Table 3: Clinical guidance			
Specific interventions	**For intervention**	**Not for intervention**	**Not recorded on form**
CPR	2	92	6
Hospital admission	44	46	10
IV Antibiotics	27	37	36
IV Fluids	18	20	62
Level 3**	2	16	82
Level 2*	0	16	84
Non oral nutrition	2	11	87
Ward level care	30	6	64
NIV	0	3	97
Blood products	5	2	93
Organ support	0	2	98
Oxygen	10	0	90

* Level 2 - patients requiring more detailed observation or intervention including support for a single failing organ system or post-operative care and those 'stepping down' from higher levels of care. **Level 3 - patients requiring advanced respiratory support alone or monitoring and support for 2 or more organ systems.

Table 3 shows the most frequently recorded interventions were CPR, hospital admission and IV antibiotics- it was clearly stated on the form whether the person was for the intervention or not for the intervention. It was often less clear whether this was a patient preference which is often helpful to record e.g. decision for CPR or for surgery. This is important as a decision about not to recommend CPR may be due to the patient choice rather than the clinician. The DNACPR Scotland policy documentation is quite clear about the decision making process but ReSPECT documentation less so, unless documented in the patient notes, which won't be readily accessible in an emergency. 2 forms did not provide any clinical guidance on specific interventions besides CPR.

It also highlights the use of medical terminology e.g. level 2 care, which may not be understood in different care settings. This is an important consideration for future education. It is essential that information is clear and can be understood by any health and social care professional across interfaces of care. The information contained within the document may also needs to be sensitive to this.

Graph 14: CPR decision
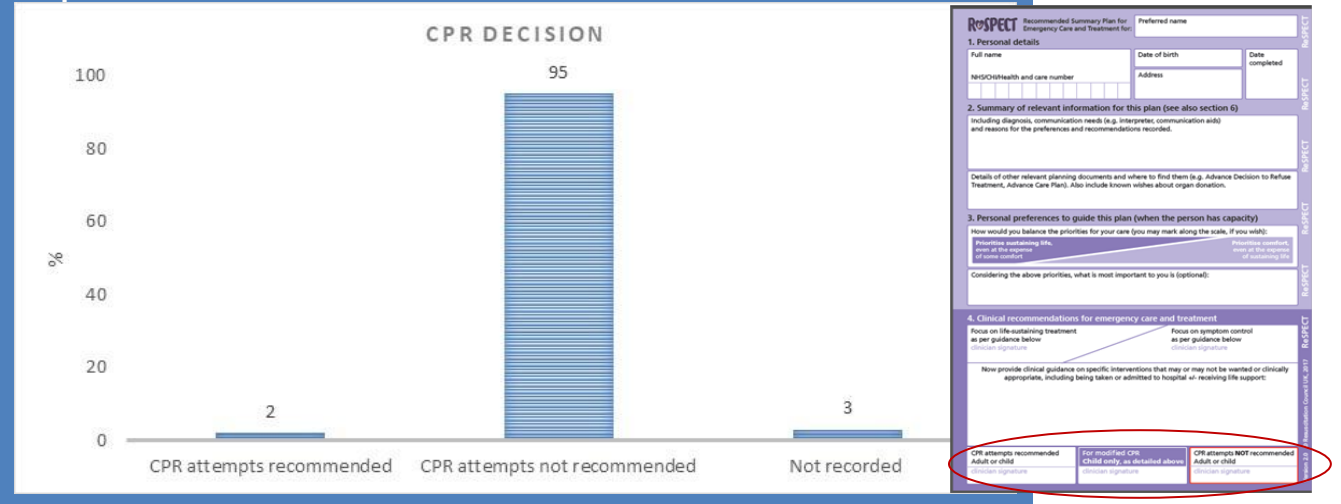
Graph 14 shows that on 95% (n=95) of forms the *CPR attempts not recommended* box had been signed on the right, on 2% (n=2) of forms the *CPR attempts recommended* box had been signed on the left, and on 3% (n=3) of forms neither of the boxes had been signed but the decision made was recorded in the Clinical Recommendations section.

Capacity and representation at time of completion

The **capacity and representation at time of completion** section of the ReSPECT document considers whether the person has sufficient capacity to participate in making the recommendations on the plan or the person has a legal proxy who can participate on their behalf in making the recommendations.

Graph 15: Capacity and representation
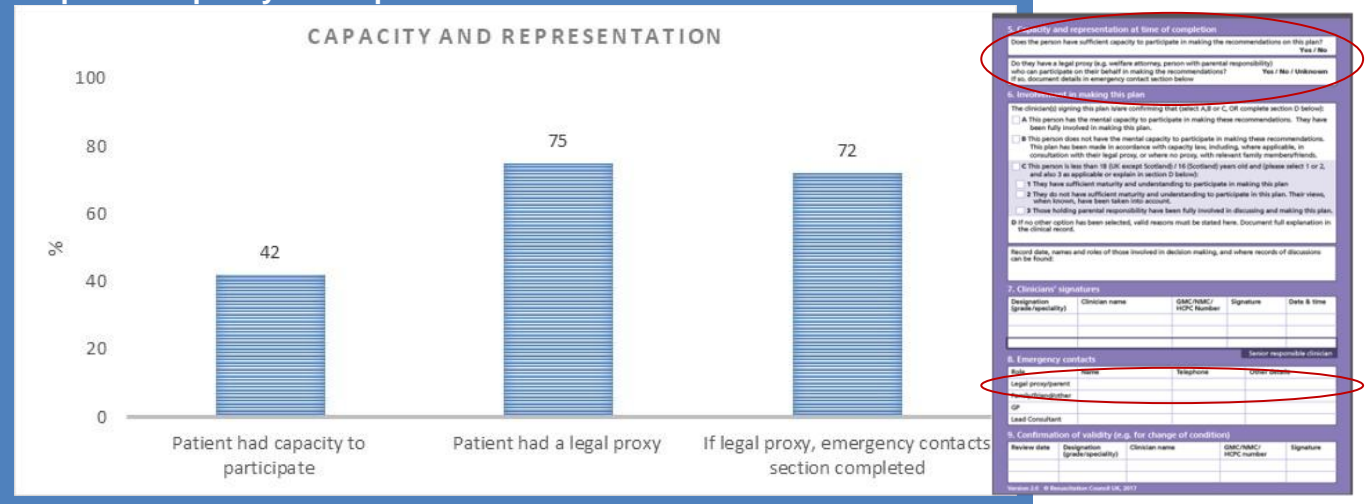
It was recorded in 42% (n=42) of cases that people had sufficient capacity to participate in making recommendations, in other words, the majority of patients did not have capacity to engage in the decision making process. It is not known whether the reason for the incapacity was a potentially reversible state e.g. delirium or a chronic mental incapacity e.g. dementia or a severe learning disability. It was recorded that 75% of people had a legal proxy who could participate in making

recommendations. It should be noted that of those who had a legal proxy, it was also recorded that 28% (n=21) had sufficient capacity to participate. Incomplete information is recorded about PoA involvement in discussions in those where capacity was present. This would routinely be recorded in section 6 but this did not always take place. If the patient had a legal proxy, the relevant details were inserted in the emergency contacts section in section 8 in 66% (n=66) of forms.

The **involvement in making this plan** section of the form prompts the clinician signing the plan to circle one of the following four statements:

- **A**: This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan
- **B**: This person does not have the mental capacity to participate in making these recommendations. This plan has been made in accordance with capacity law, including, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends
- **C:** This person is less than 18 (UK except Scotland) / 16 (Scotland) years old*
- **D:** If no other option has been selected, valid reasons must be stated on the plan and recorded in full in the clinical record

Graph 16: Involvement in making this plan
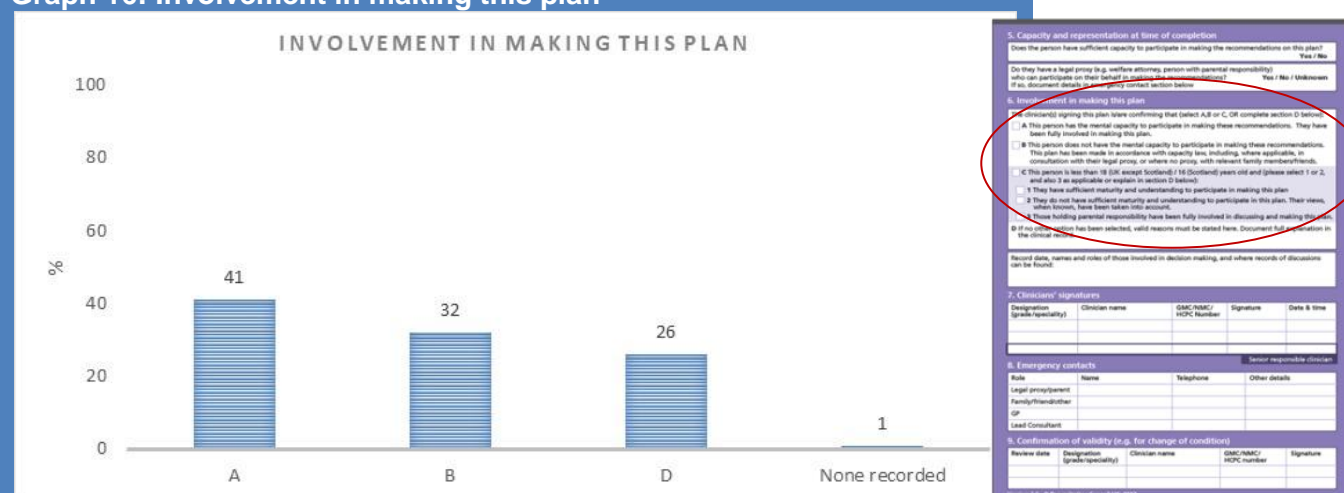
*Please note: statement C is not applicable for the pilot of ReSPECT in FV and has been excluded from the graph above

Graph 16 shows the statement that was circled to confirm involvement in making the plan. 41% (n=41) of patients had the mental capacity to participate in making recommendations and were fully involved in making the plan, 32% (n=32) of patients did not have the mental capacity to participate in making recommendations and the plan was made with the persons legal proxy or family and friends. Statement D was selected for 26% (n=26) of forms, and in 22% valid reasons were documented on the forms. Statement C was not used as this pilot did not involve minors.

Clinician's signature

The **Clinicians' signature** section of the form must be signed (inserting also the date and time of signing) by the professional who completes the ReSPECT form. If that is not the senior responsible clinician, they should review and endorse the recommendations by adding their signature at the earliest opportunity.

Graph 17: Clinicians signature
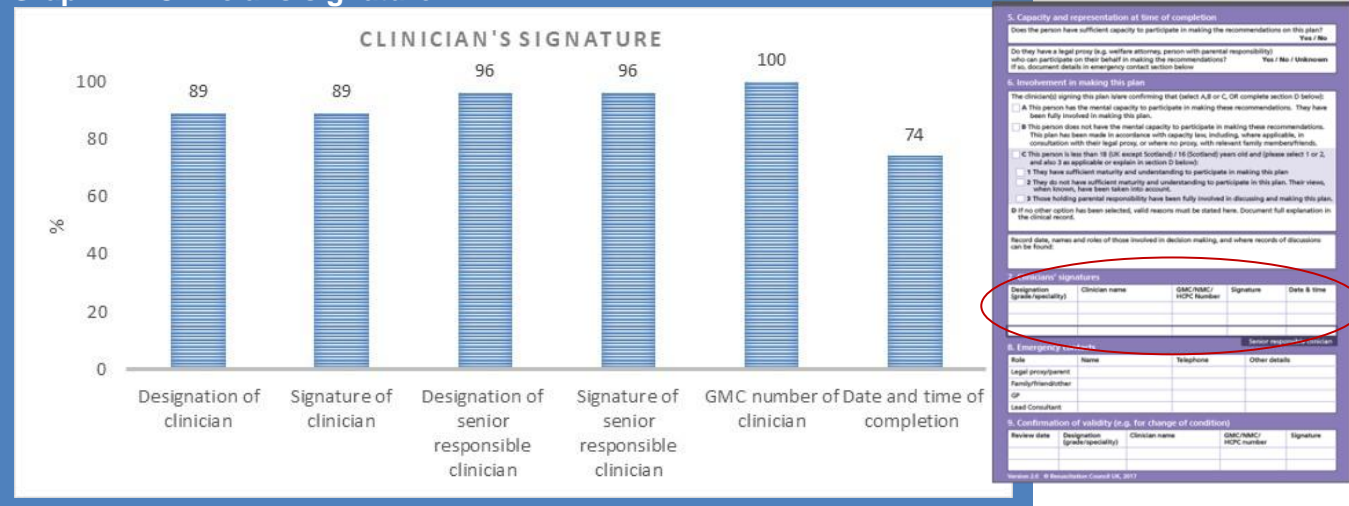
All forms were signed by a clinician and a GMC number was recorded. 96% (n=96) of forms contained the signature and designation of the senior responsible clinician. Less frequently recorded were the date and time of signing.

Emergency contacts

The **emergency contacts** section should be used to record the contact details of people who should be considered for immediate contact in the event of major deterioration that may warrant reconsideration of the previously recorded recommendations.

Graph 18: Emergency contacts
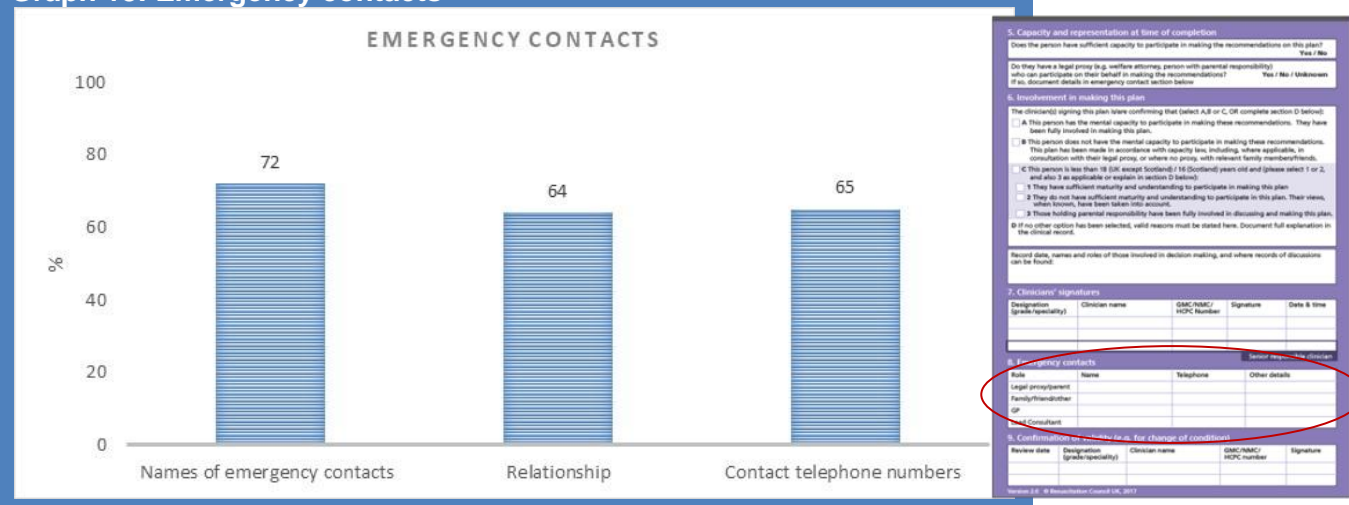
Graph 18 shows that 72% (n=72) of forms contained the names of emergency

contacts. However the relationship details and contact telephone numbers of emergency contacts were not always recorded. 28% (n=28) of forms contained no information in the emergency contacts section.

It was further noted that the ReSPECT forms would benefit from having a version number and location of form completion noted.

Section 3: ReSPECT across the primary and secondary care interface

This section reports the communication of the presence of a ReSPECT form across the primary and secondary care interface. Hospital patients discharged with a ReSPECT form should have this detailed in their IDL to prompt the GP team to update the patient's KIS, which is available to community staff including out-of-hours team's and paramedics.

Immediate Discharge Letter and Key Information Summary

The information in this section is based on the 164 patients who had a ReSPECT form completed during an admission to hospital (see Graph 5, p25). 61 patients were excluded from the analysis because 47 died during the index admission, and 14 were still inpatients. Graph 19 and Graph 20 below show the analysis for the remaining **103 patients who were discharged home or to a care home** as they would have had an IDL completed on discharge.

Graph 19: Immediate Discharge Letter
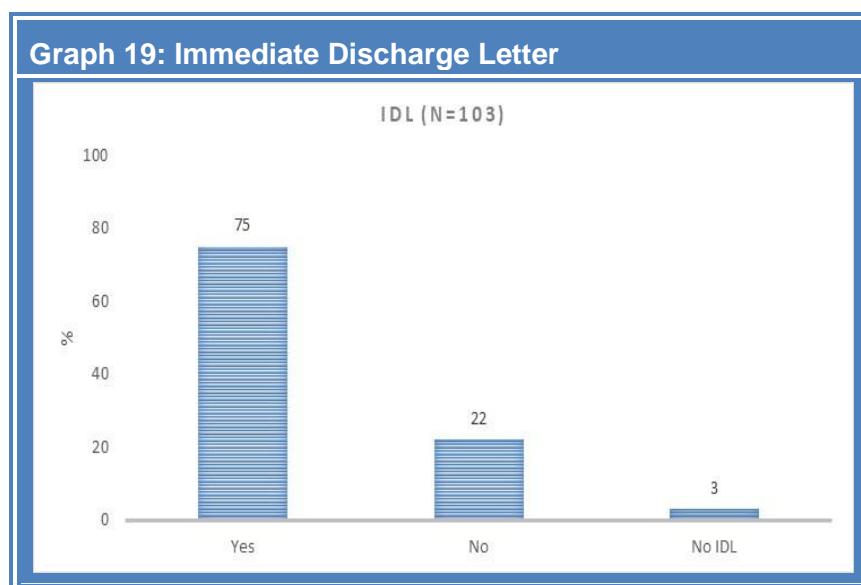
Graph 19 shows that ReSPECT was mentioned on 75% (n=77) of IDLs. 3% (n=3) of IDLs could not be found. This is expected to improve as the process beds in.

Graph 20: Key Information Summary

KEY INFORMATION SUMMARY (N=77)
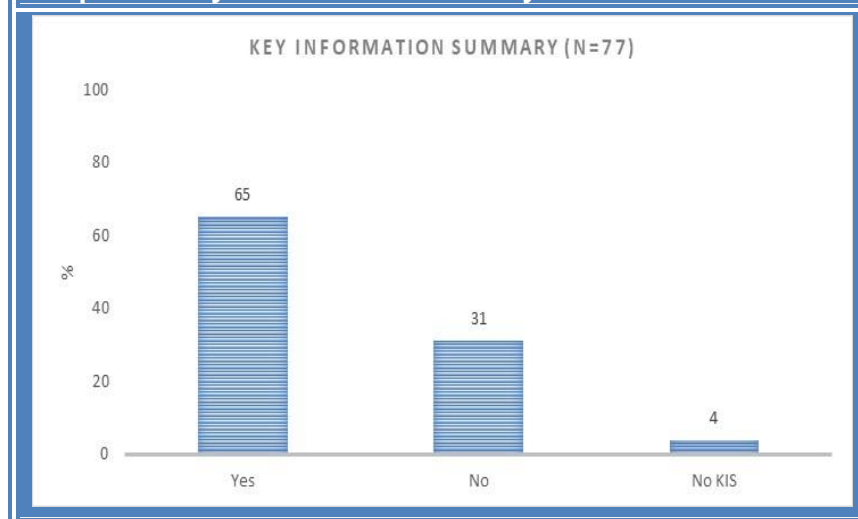
Graph 20 above shows that for those 77 cases where ReSPECT was communicated in the IDL, ReSPECT was mentioned in 65% (n=49) of patients KIS within 1 month after discharge. Again, this is likely to improve as the process beds in.

Key Information Summary

As an additional piece of work the project lead clinician compared the KIS of patients who had a ReSPECT form completed during the pilot, and patients without a ReSPECT form who had triggers present in ward A11 pilot. The rationale being that by allowing more clinicians to complete an emergency care plan then KIS information may also be more likely to be up to date and useful in an emergency. For those in a hospital setting, all patients had been discharged >1 month at the time of KIS analysis on Clinical Portal.

The inclusion/exclusion criteria for the KIS comparison can be seen in the flowchart below (Figure 6).

Figure 6: Flowchart of patients who met inclusion/exclusion for KIS comparison
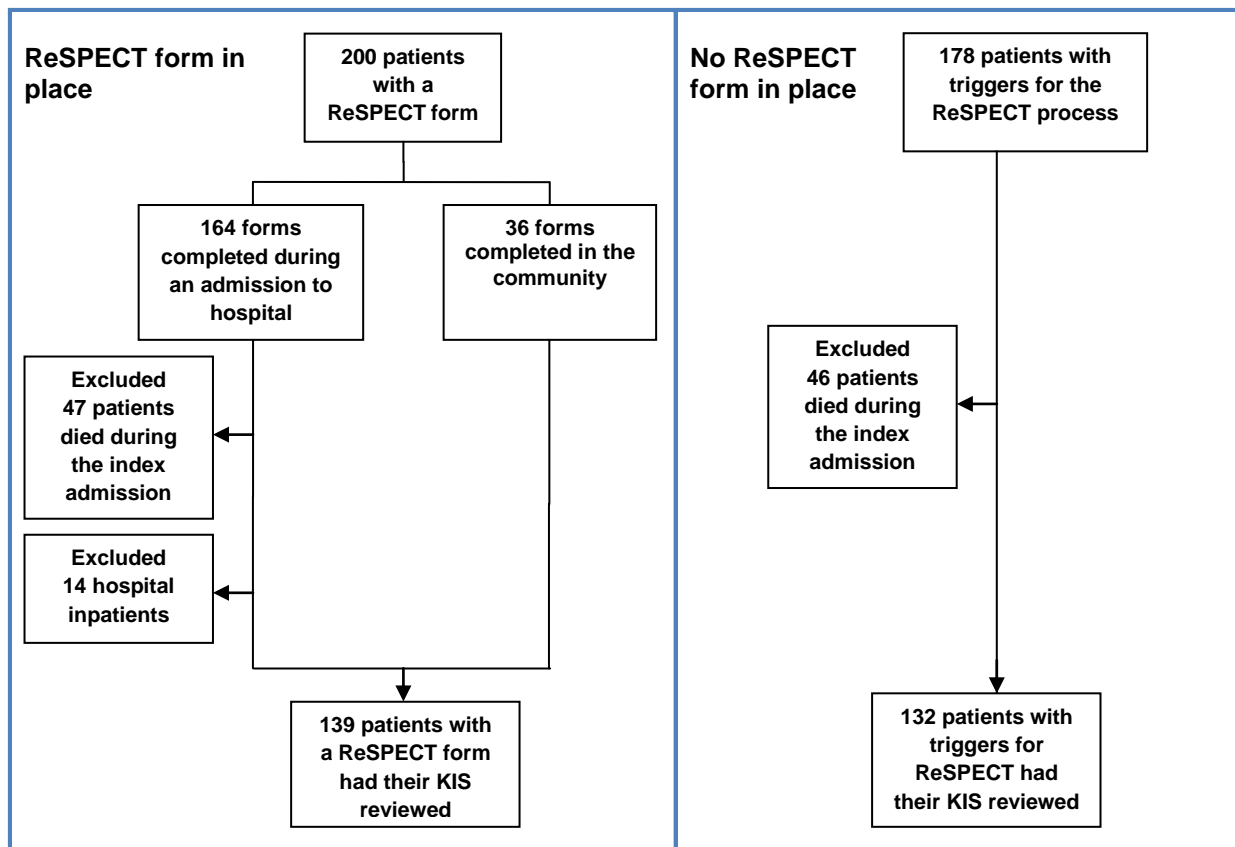
Graph 21: KIS
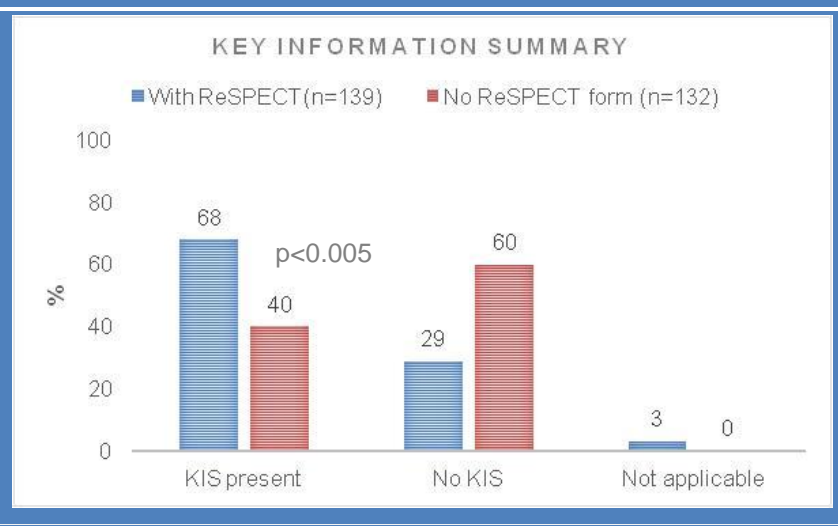
Graph 21 shows that 68% (n=94) of patients with a ReSPECT form had a KIS, compared to 40% (n=53) of patients with no ReSPECT form. If you go through the ReSPECT process then you are more likely to have a KIS, this reaches statistical significance (*chi-squared test, p<0.005).* This is important as this enables more

people to have access to guidance about emergency care including out-of-hours teams before they have visited the patient (where there will be a paper copy).

It is not clear why 29% of patients with a ReSPECT form still did not have any shareable information on KIS as they had agreed to go through the ReSPECT process and sharing of this information.

Graph 22: KIS up-to-date
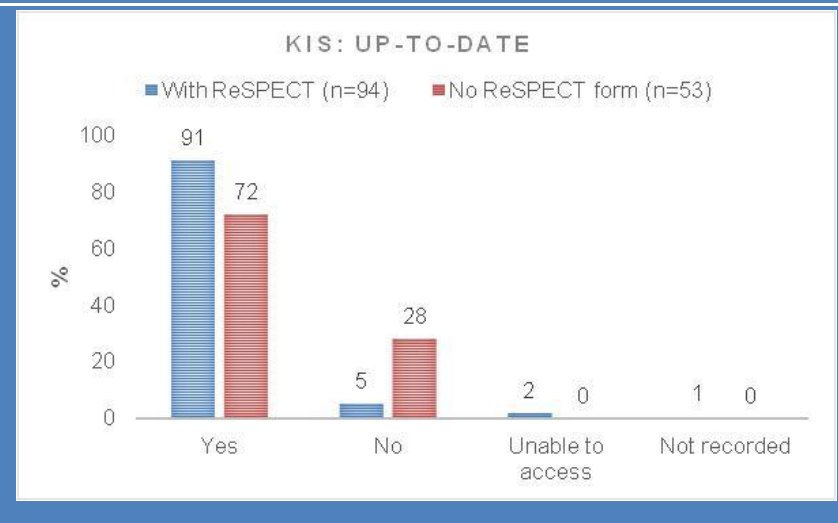
Graph 22 shows that of those patients with a KIS, 91% (n=86) of patients with a ReSPECT form have an up-to-date KIS (updated in the last 6 months), compared to 72% (n=38) of patients with no ReSPECT form.

Graph 23: KIS useful in an emergency
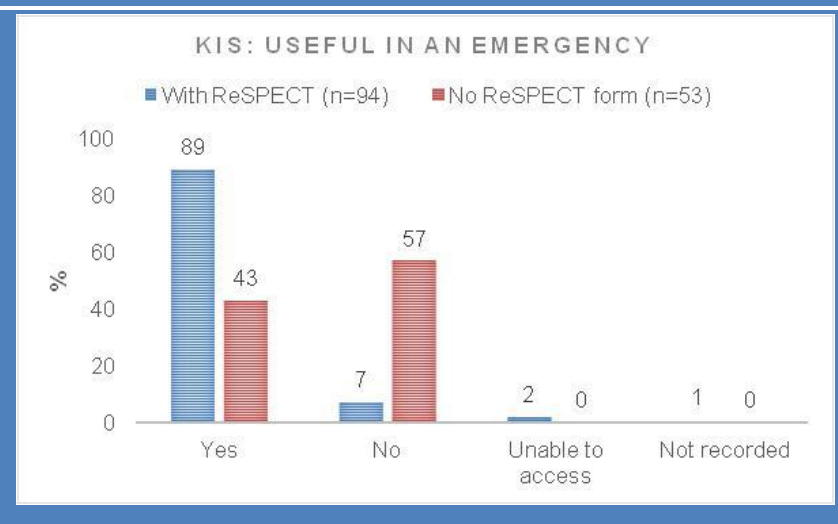
Graph 23 shows of those patients with a KIS, 89% (n=84) with a ReSPECT form had a KIS with useful information about treatment or care in an emergency e.g. preferred place of care or anticipated health crisis, compared to 43% (n=23) of patients with no ReSPECT form. This also supports the qualitative data presented later in the report that highlights that staff find the presence of a ReSPECT form would help them deliver the right care for their patient in an emergency.

Preferred place of care and actual place of death

To complete this additional analysis the project lead clinician looked at preferred place of care and compared this with actual place of death as recorded and agreed on the ReSPECT form for all patients who had died. At the time of this review, 112 of the 200 patients with a ReSPECT form had died, and the following analysis is based on those 112 patients.

Graph 24: Died in preferred place of care

DIED IN PREFERRED PLACE OF CARE (N=112)

Yes 78
No 22
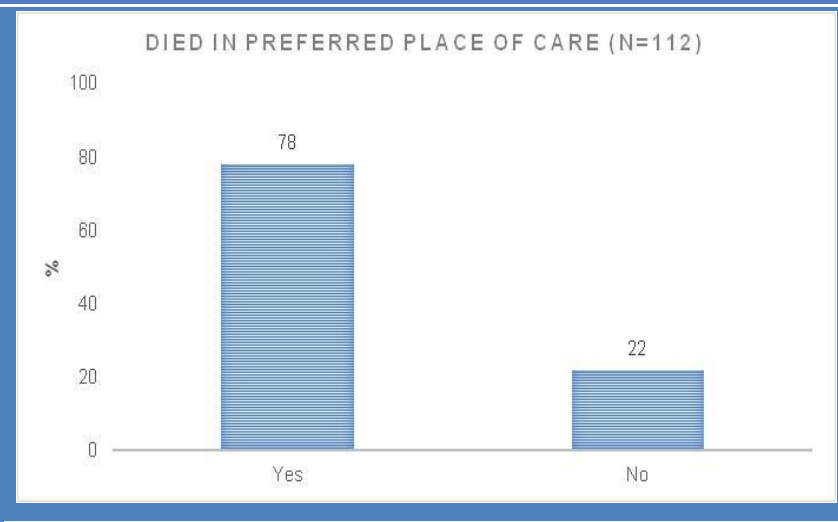
Graph 24 shows that 78% (n=87) of patients died in their preferred place of care.

Graph 25 below shows place of death for those 87 patients.

Graph 25: Place of death

PLACE OF DEATH (N=87)

Community hospital 41
Care home 23
Home 18
Hospice 10
Acute hospital 7
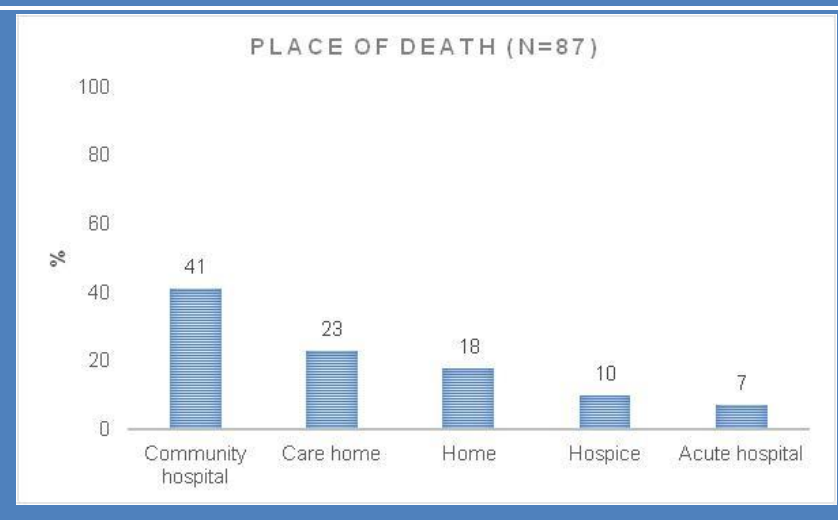
Graph 25 above shows that of those 87 patients who died in their preferred place of care, 41% (n=36) died in a community hospital, 41% (n=36) died at home or in a care home, 10% (n=9) died in the hospice, and only 7% (n=6) died in the acute hospital.

Section 4: Patient Outcomes

The results in this section of the report are based on a comparison between 110 patients, who had a ReSPECT form completed during an acute hospital admission (see Graph 5, pg 23), and 178 patients without a ReSPECT form who had triggers present in ward A11 pilot (see Graph 2, pg 16).

The decision to compare both groups was to see whether the ReSPECT process increases the likelihood of people remaining at home after hospital discharge or their place of death being at home.

Survival to discharge

Graph 26: Survival to discharge (from the acute hospital)
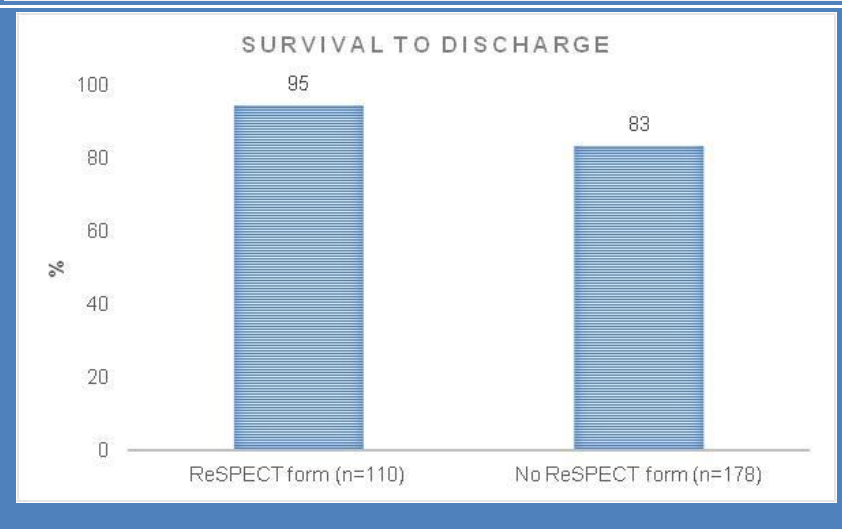
Graph 26 shows that 95% (n=104) of patients with a ReSPECT form survived that index admission compared to 83% (n=148) of patients with no ReSPECT form. This is likely due to a greater requirement for emergency care planning in those being discharged from the acute hospital to another care setting.

Those who did not survive to discharge have been removed from the following analysis.

Re-admission to hospital within 3 months

Graph 27: Readmission to hospital within 3 months

NUMBER OF PATIENTS READMITTED WITHIN 3 MONTHS

p=0.01

ReSPECT form (n=104): 28
No ReSPECT form (n=148): 63
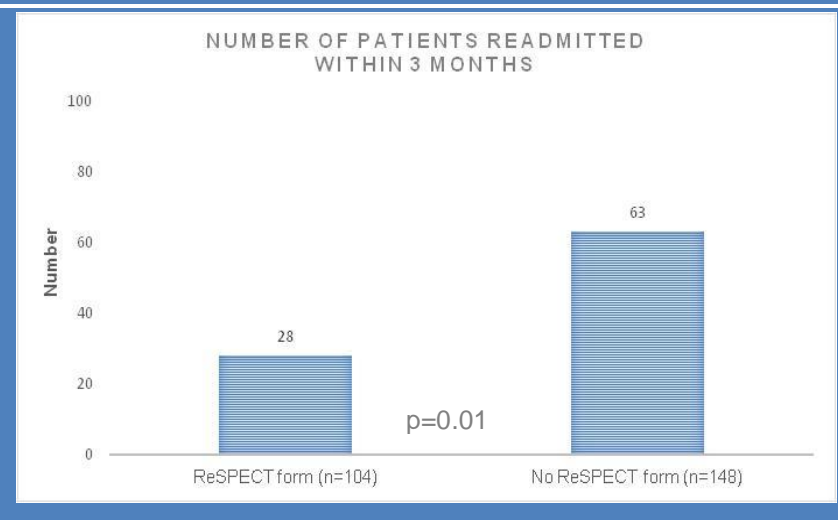
Graph 27 compares the number of people readmitted within 3 months of a hospital discharge with and without a ReSPECT discussion and form in place. Patients in both groups had previously been identified as being appropriate for ReSPECT using the trigger tool (Figure 3). 28 (27%) patients with a ReSPECT form and 63 (43%) without a ReSPECT form were readmitted to hospital within 3 months of initial discharge. Although this is only an initial analysis of the first cohort of 252 patients screened for ReSPECT, we have demonstrated a statistically significant reduction in readmission rate (*chi-squared test, p=0.01*) when the ReSPECT process is applied.

Graph 28: Number of readmissions to hospital within 3 months

NUMBER OF READMISSIONS WITHIN 3 MONTHS

p=0.01

ReSPECT form (n=104): 35
No ReSPECT form (n=148): 72
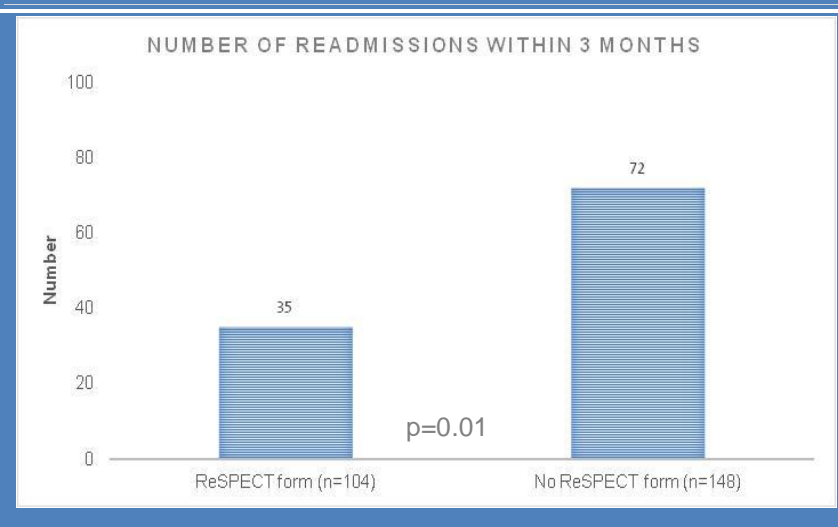
Graph 28 similarly compares the number of readmissions within 3 months (compared to *patients* readmitted in Graph 27). 35 readmissions occurred in the ReSPECT form group versus 72 without a ReSPECT form. Again this is a statistically significant reduction (*chi-squared test, p=0.01)* in number of admissions.

Table 4: No of readmissions to hospital within 3 months		
Re-admissions	ReSPECT form	No ReSPECT form
One	21	56
Two	7	6
Three	0	1
Total	28	63

Table 4 shows the number of readmissions of individual patients after discharge.

Graph 29: Breakdown of readmissions within 7 days, 30 days and 3 months
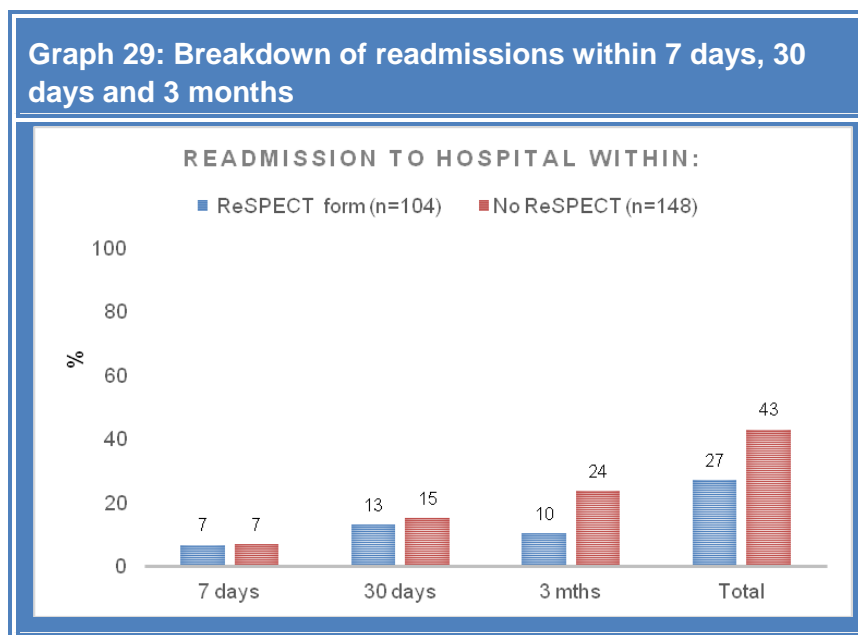
Please note: patients who died within 7 days were removed from the 30 day analysis, and patients who died within 30 days from the 3 month analysis

Of those patients with a ReSPECT form, 7% (n=7) were readmitted within 7 days of discharge from their ReSPECT admission, 13% (n=13) within 7-30 days, and 10% (n=8) within 30 days and 3 months. In total, 27% were readmitted within 3 months.

Of those patients with no ReSPECT form, 7% (n=10) were readmitted within 7 days of discharge from the admission that they met the criteria for ReSPECT, 15% (n=22) within 7-30 days, and 24% (n=31) within 30 days-3 months. In total, 43% were readmitted within 3 months.

Table 5: LoS for readmissions to hospital within 3 months		
LoS	ReSPECT form (n=35)	No ReSPECT form (n=72)
Minimum	0	0
Maximum	37	75
Mean	13.2	12.4
Median	**9**	**9**

The median length of stay for both groups was 9 days. Further analysis of LOS will

be reviewed as numbers of patients who have been through the ReSPECT process increase. LOS on subsequent readmission is felt to be more relevant as often patients having this completed on their index admission have been admitted for a substantial period of time in the community hospital. A comparison of LOS of patients only looking at those discharged from a community hospital ward may reduce this variance.

Graph 30: Kaplan Meier curve showing time to 1st readmission after surviving hospital
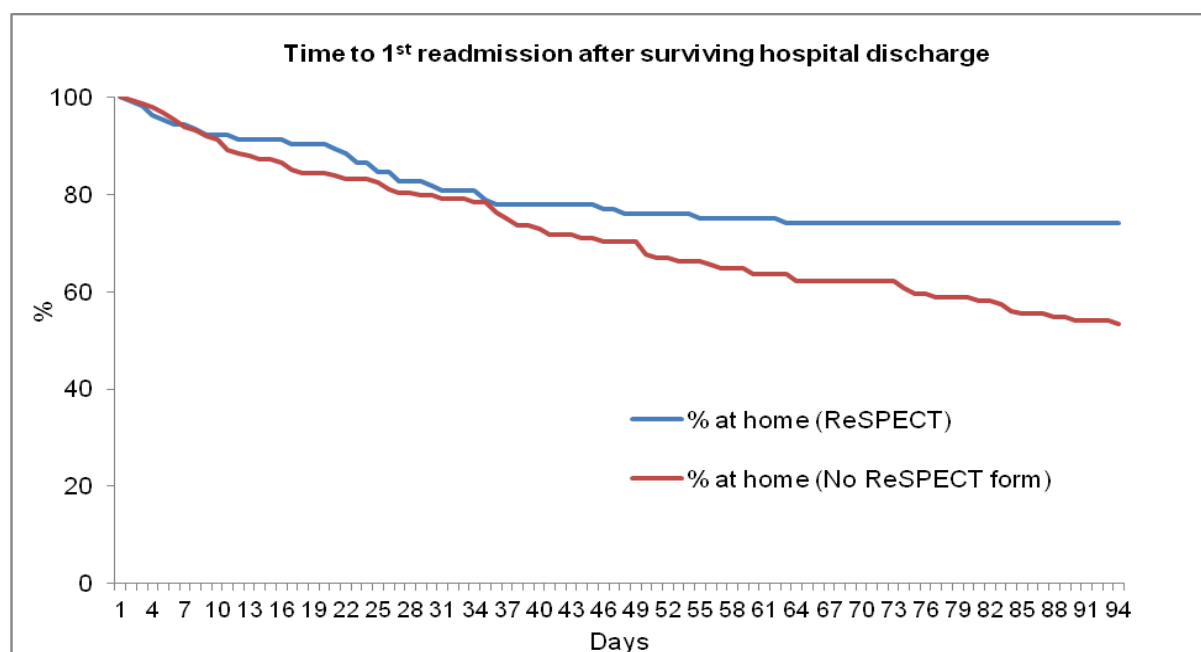
Graph 30 shows the time to readmission up to 3 months following discharge in the 2 cohorts of patients. This excludes any patients who died within this time period. 1 month after discharge the % still at home are fairly similar in both groups, however, beyond 1 month of discharge patients with ReSPECT forms in place are less likely to be readmitted. This may be due to patients with ReSPECT forms having their preferred place of care recorded. A further qualitative analysis of both groups, may identify any confounding factors e.g. disease trajectory or differences in locality.

Place of death

Graph 31: Place of death

PLACE OF DEATH

ReSPECT form (n=72)   No ReSPECT form (n=53)

Hospital setting: 54, 74
Homely setting: 41, 26
Hospice setting: 4, 0
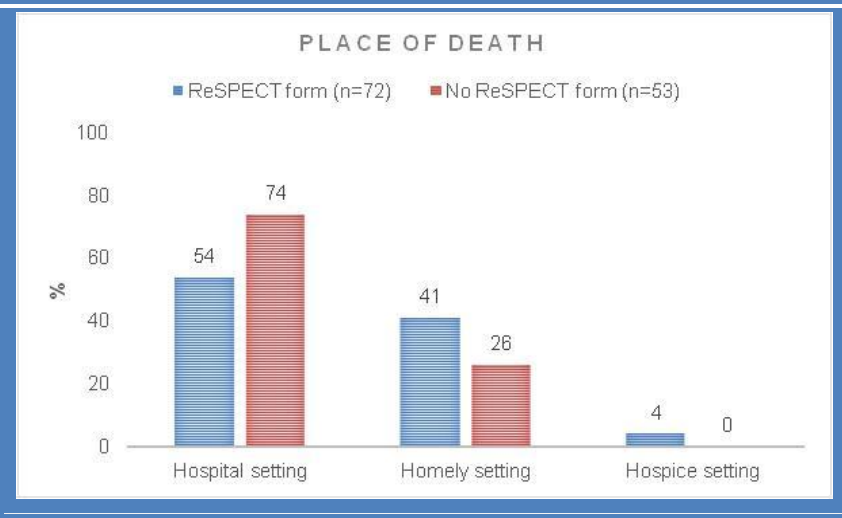
At the time of reporting, 69% (n=72) of patients with a ReSPECT form, and 35% (n=53) with no ReSPECT form had died. Graph 31 above shows that more people die in a homely setting with ReSPECT form in place. 41% (n=30) of patients with a ReSPECT form died at home or in a care home, compared to 26% (n=14) of patients without a ReSPECT form .

54% (n=39) of patients with a ReSPECT form died in a hospital setting, compared to 74% (n=39) without a ReSPECT form.

Graph 32: Breakdown of place of death

PLACE OF DEATH

ReSPECT form (n=72)   No ReSPECT form (n=53)

Acute hospital: 33, 40
Community hospital: 21, 34
Home: 19, 13
Care Home: 22, 13
Hospice: 4, 0
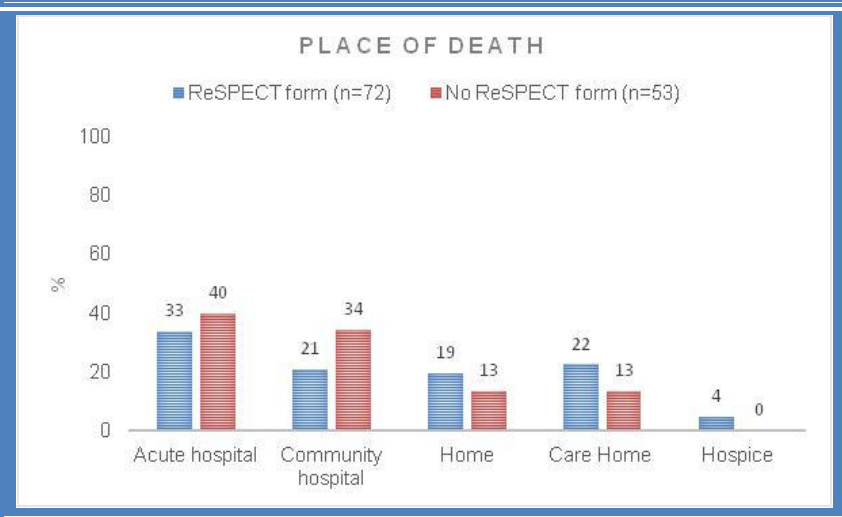
Graph 32 above provides a breakdown of place of death. Patients who go through the ReSPECT process are statistically more likely to die outside of a hospital setting (*chi-squared test, p=0.027).*

A comparison of both groups can be seen in the Kaplan Meier curve graph in Graph 33 significantly more patients with a ReSPECT form have died, however after 4 months both groups are very similar.

Graph 33: Time to death from ReSPECT trigger screening

Time to death from ReSPECT trigger screening

— % surviving (ReSPECT)
— % surviving (no ReSPECT form)
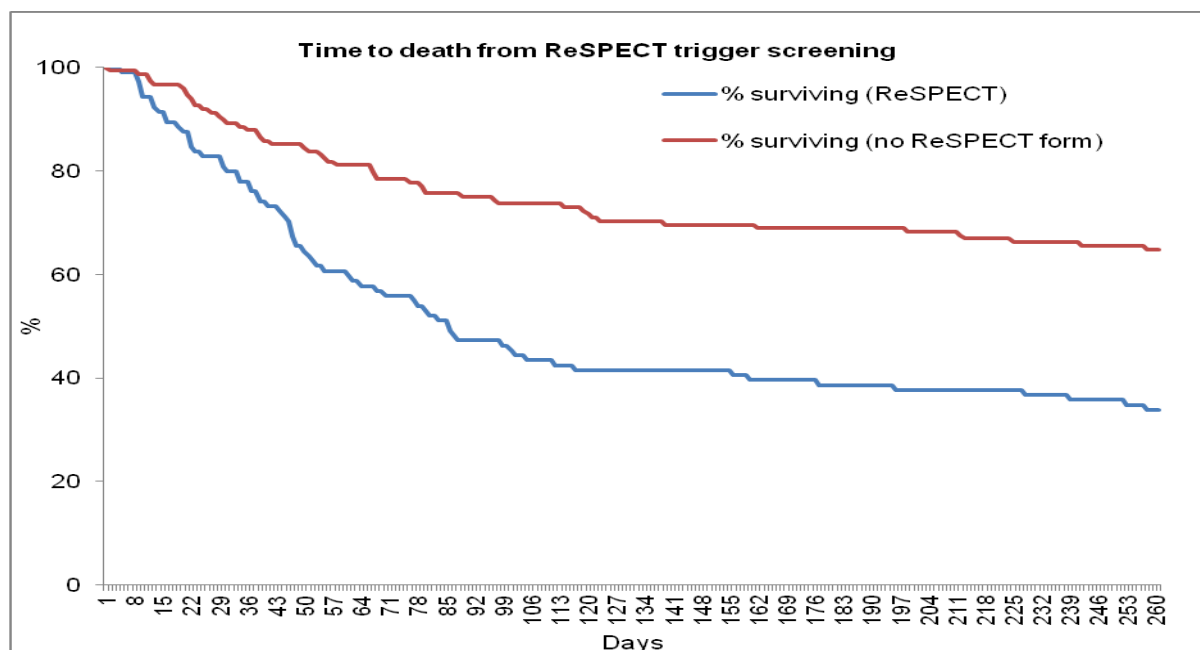
The data shows that ReSPECT is more likely to be initiated for patients in the last months of life during a hospital admission. Clinicians appear to instinctively and preferentially select these patients and a further analysis would be useful to see if they were on a more predictable disease trajectory e.g. cancer.

Although it could be considered that ReSPECT should be commenced much earlier in the patients journey, the pilot was primarily conducted in a hospital setting and evidence shows that that 1 in 3 patients will die within 12 months of their index admission and 1 in 2 >85yrs die within the same time period.[16] Anecdotally, patients who were felt to be nearing the end of life often had more specific treatment plans e.g. recording their preferred place of care and whether hospital admission would be desired. This information was not routinely recorded for those without a ReSPECT form, even where a KIS was present.

DNACPR

Graph 34: DNACPR
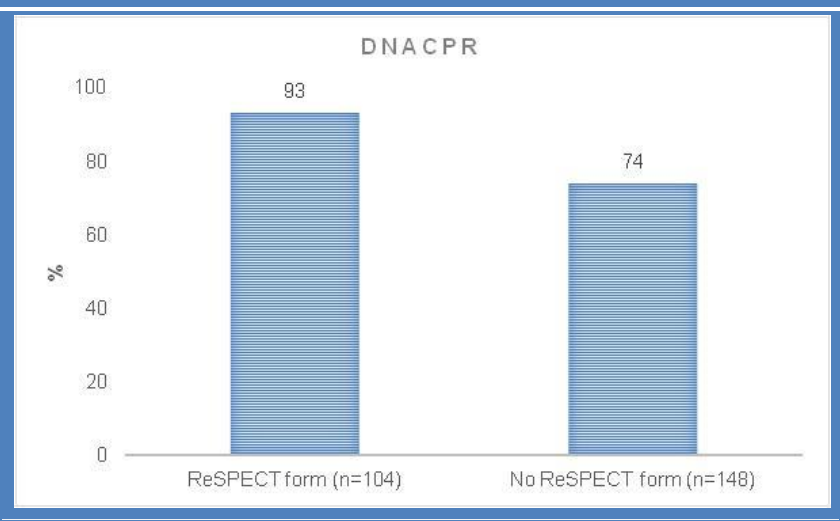
Graph 34 shows that 93% (n=97) of patients with a ReSPECT form also had a DNACPR, compared to 74% (n=110) of patients with no ReSPECT form. As this was a retrospective analysis, no further analysis was made as to whether there should have been more DNACPR decisions in the group without a ReSPECT form. It is therefore not known if patients without a ReSPECT form in place and 'still for CPR' include those who have would not wish to have this intervention in the event of a cardiac arrest but haven't specifically been asked.

Destination on discharge

Graph 35: Destination on discharge
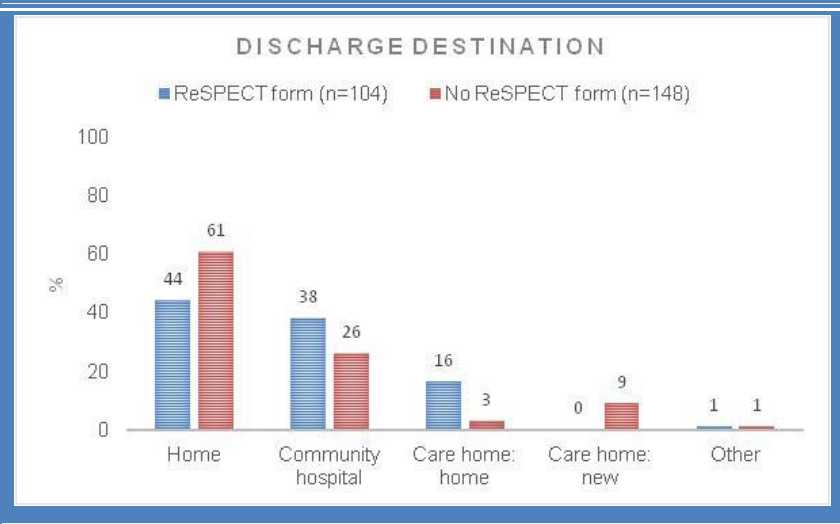
Graph 35 shows that 60% (n=63) of patients with ReSPECT, and 64% (n=95) with no ReSPECT, were discharged back to a private residence or care home setting. Interestingly, 9% (n=13) of patients with no ReSPECT form, were discharged to a care home as a new discharge destination following the admission when they were identified as meeting the criteria for ReSPECT. This would appear to be a missed opportunity for an emergency care plan to be in place when a patient is likely to have

had a lengthy stay in community hospital before discharge to a care home setting. This is an area identified for further quality improvement work. The 'other' destinations were; hospice and another hospital out with Forth Valley.

Section 5: Patient Experience and Carer Questionnaire

This section of the report gives results of the ReSPECT Patient Experience Survey, a survey about the ReSPECT form and process. The ReSPECT Patient Experience Survey was also adapted and given to an 'informal' carer support forum group for their thoughts and feedback on the ReSPECT process.

Patient experience

The patient experience survey questionnaire was given to patients and/or their relative, depending on capacity, after the ReSPECT process had been completed.15 patients and/or their relative responded anonymously: 10 were completed by the patient's relative; 3 were completed by patients and 2 were completed by both the patient and their relative.

Involved in decisions about care and treatment

Graph 36: Were you involved as much as you wanted to be in making decisions about your care and treatment?	**Graph 37: Were the people that matter to you involved as much as you wanted to be in making decisions about your care and treatment?**
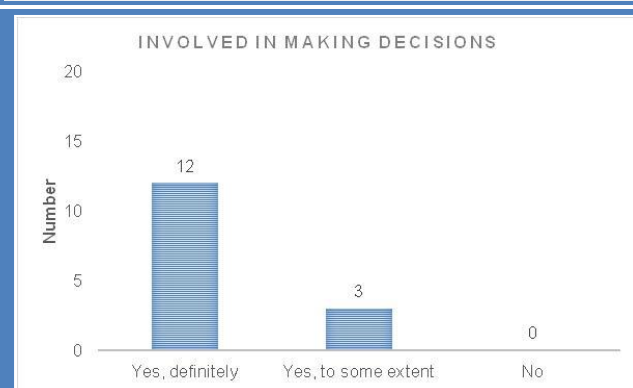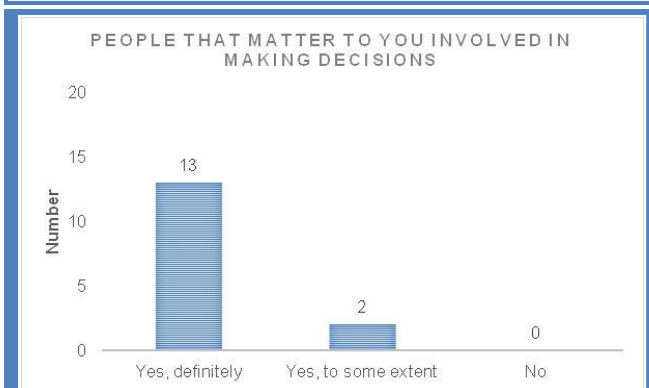
All respondents agreed that yes, definitely or yes, to some extent they or the people that matter to them had been involved in making decisions about their care and treatment.

The ReSPECT conversation

38: Do you feel that staff took account of what matters to you?	Graph 39: Do you feel you were treated with respect and dignity?
WHAT MATTERS TO YOU Yes, definitely: 15 Yes, to some extent: 0 No: 0	TREATED WITH RESPECT AND DIGNITY Yes, definitely: 15 Yes, to some extent: 0 No: 0
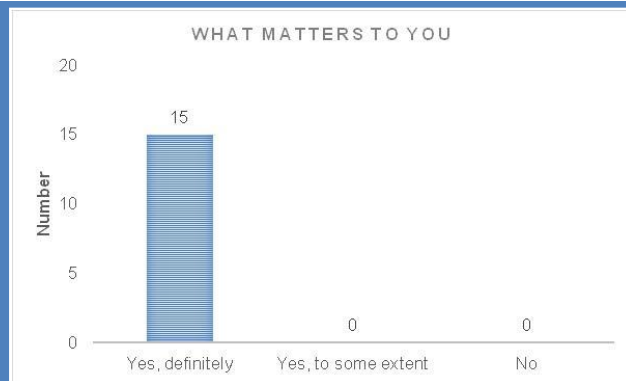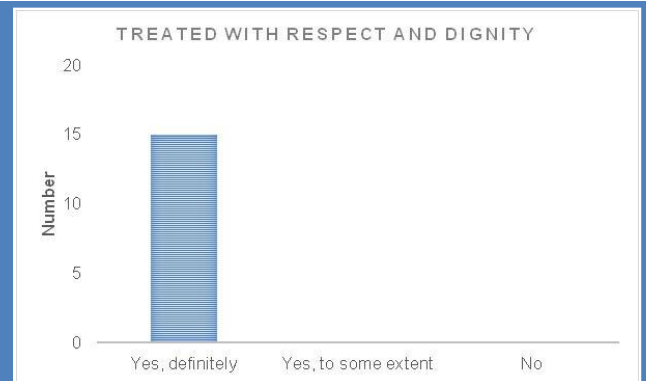
Graph 40: Do you feel that you were treated as a whole person (e.g. taking into account your beliefs, hope, traditions, customs, spirituality)?	
TREATED AS A WHOLE PERSON Yes, definitely: 14 Yes, to some extent: 1 No: 0	
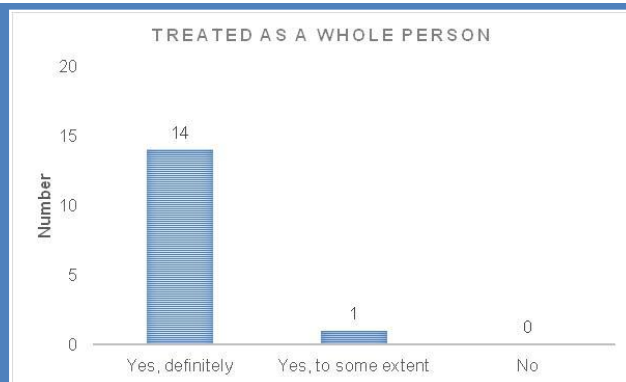
One patient who completed the survey with their relative liked the idea that the ReSPECT plan is 'person-centred'.

The ReSPECT decision-making process

Patients and/or their relatives were asked how much they agreed or disagreed with the following statements regarding the ReSPECT decision-making process.

Graph 41: I was asked to share my views about treatment and approaches to care?	Graph 42: I was given enough information to help me make informed decisions about my care and treatment options?
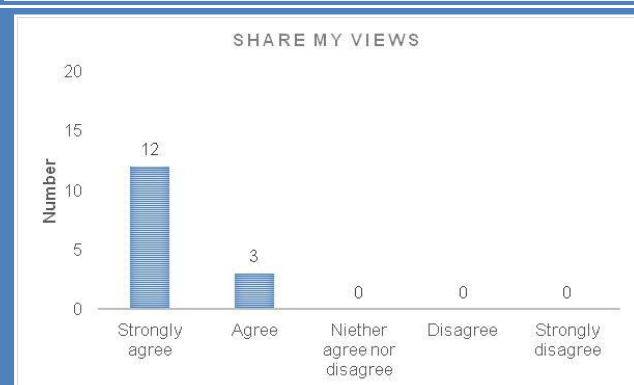
SHARE MY VIEWS

Strongly agree: 12, Agree: 3, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0

GIVEN ENOUGH INFORMATION

Strongly Agree: 13, Agree: 2, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0

Graph 43: Care and treatment options were discussed in a way I could understand?	Graph 44: I was able to communicate my wishes openly to staff?

DISCUSSED IN A WAY I COULD UNDERSTAND

Strongly Agree: 13, Agree: 2, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0

COMMUNICATE MY WISHES OPENLY

Strongly Agree: 14, Agree: 1, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0
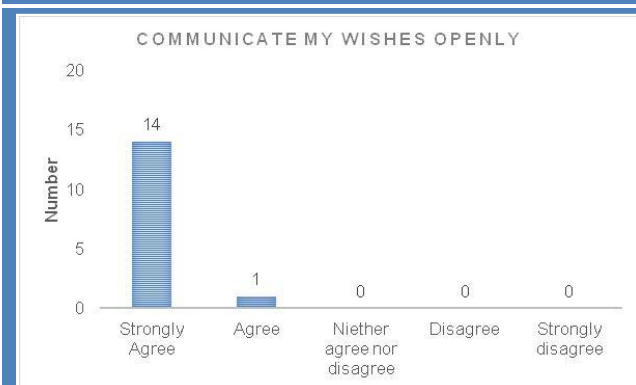
Graph 45: The emergency care planning helped me to make decisions about care and treatment?	Graph 46: Staff worked well together in organising my care?
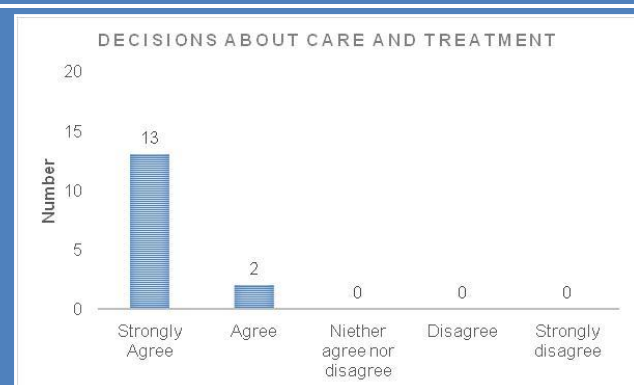
DECISIONS ABOUT CARE AND TREATMENT

Strongly Agree: 13, Agree: 2, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0

ORGANISING MY CARE

Strongly Agree: 13, Agree: 2, Niether agree nor disagree: 0, Disagree: 0, Strongly disagree: 0
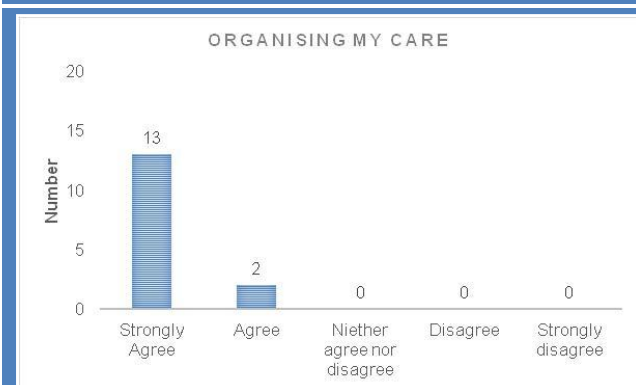
Respondents, were overall, positive about the ReSPECT decision-making process. Qualitative feedback revealed that they felt they received a good explanation of options for care and treatment that can be changed at any time. They also felt that conversations were 'open and honest' and this enabled them to 'make informed family decisions', based on advice from medical professionals.

PLAN THAT RECORDS MY PREFERENCES

Number

20

15   14

10

5

0   Strongly   Agree   Niether   Disagree   Strongly
     Agree   agree nor   disagree
              1   disagree   0   0
                          0
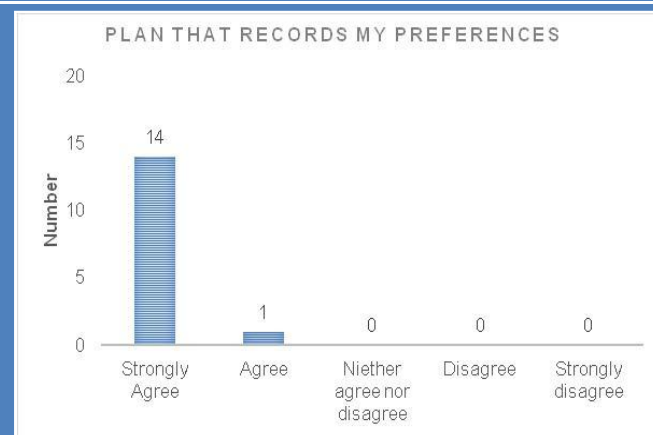
One family member went on to add that their relative 'has always been clear about end of life plans and now medical professionals have a document to show this'.

Rating the ReSPECT process

Graph 48: Overall, how would you rate the ReSPECT process?

RESPECT PROCESS

Number

20

15

12

10

5

3

0   Excellent   Good   Fair   Poor   Very poor
                          0   0   0

Overall, people rated the ReSPECT process positively; all 15 respondents rated the ReSPECT process as excellent or good.

The results of the survey would indicate that patients and their family's experience of the ReSPECT process were really positive. The word cloud in Figure 7 below provides some qualitative feedback on what people liked about the ReSPECT process.

Figure 7: What people liked about the ReSPECT process

In response to a question asking how the process could be improved, one patient felt that there was a lot of repetition in the questions that they were being asked by the doctors and the nurses that they came into contact with- this was felt to reflect the overall hospital admission rather than the ReSPECT process specifically.

Carer Questionnaire

The carer survey questionnaire was given to carers who were attending an unpaid carers forum. 12 carers returned feedback on their thoughts of the ReSPECT form and process.

Involved in decisions about care and treatment

Graph 49: Do you welcome the idea of being involved in making decisions about your care and treatment?	Graph 50: Do you feel that it is important that the people who matter to you are involved in making decisions about your care and treatment?
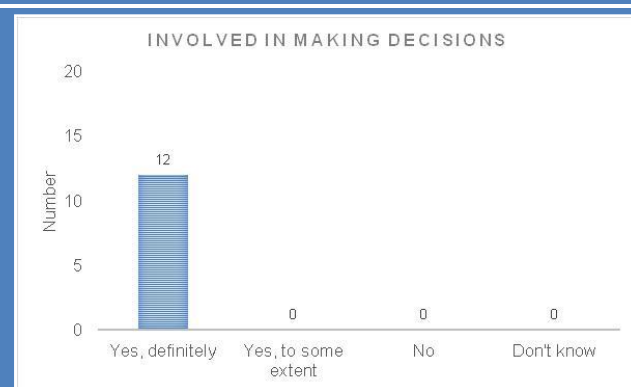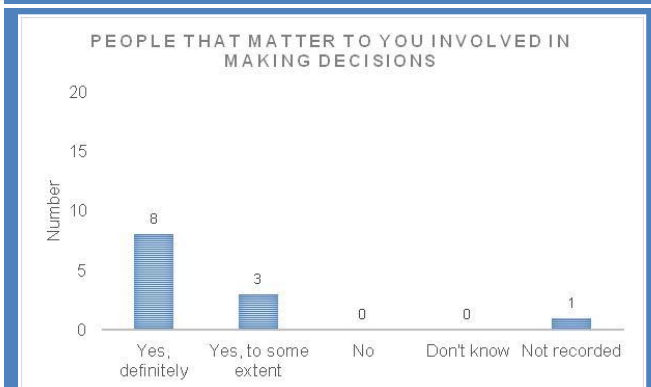
One carer went on to add that although they felt that it was important that the people who matter to them were involved in making decisions about their care and treatment, the persons wishes 'should not be overridden' and suggested putting in place a power of attorney.

The ReSPECT conversation

Graph 51: Do you feel that the ReSPECT conversation takes into account what matters to you and your loved one?	**Graph 52: Do you feel that the ReSPECT conversation is beneficial for respect and dignity?**
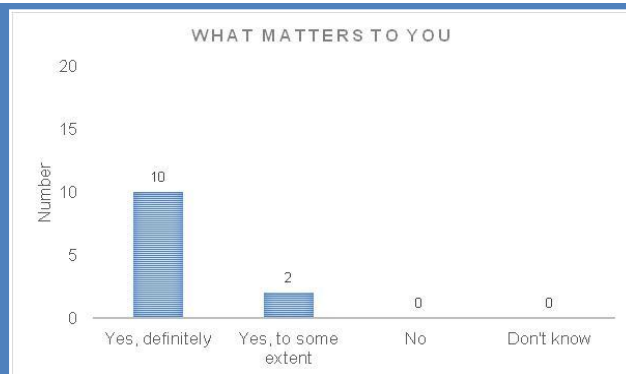
WHAT MATTERS TO YOU

Yes, definitely: 10
Yes, to some extent: 2
No: 0
Don't know: 0

RESPECT AND DIGNITY

Yes, definitely: 11
Yes, to some extent: 1
No: 0
Don't know: 0
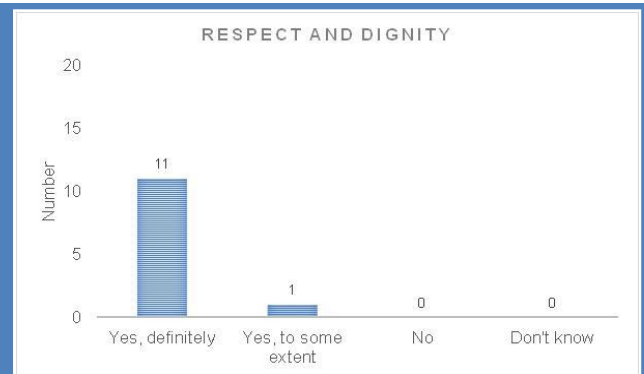
Graph 53: Do you feel the ReSPECT conversation takes into account your beliefs, hopes, traditions, customs and spirituality?

BELIEFS AND VALUES

Yes, definitely: 5
Yes, to some extent: 4
No: 2
Don't know: 0
Not recorded: 1
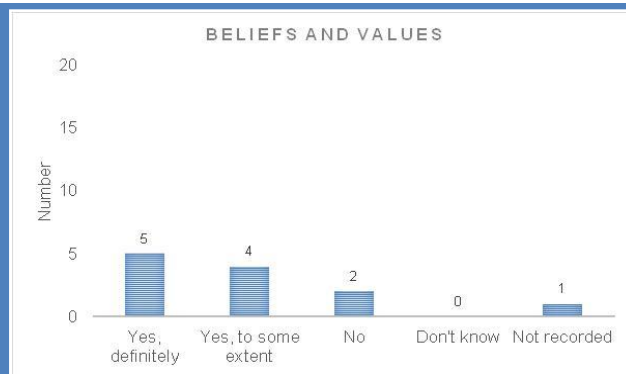
One of the carers who responded negatively to the beliefs and customs question stated that this question needed a bit more explanation. It was felt for those who had actually been through the process this was viewed more positively.

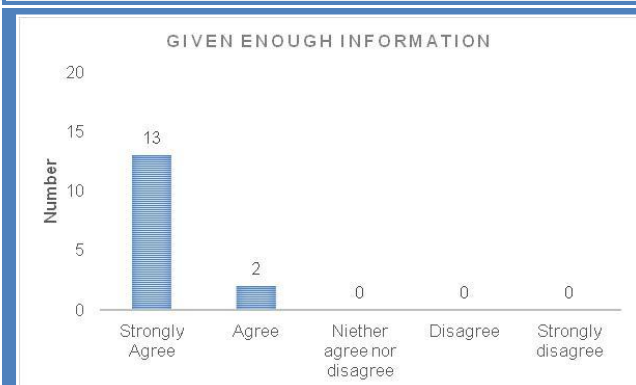## The ReSPECT decision-making process

Carers were asked how much they agreed or disagreed with the following statements regarding the ReSPECT decision-making process.

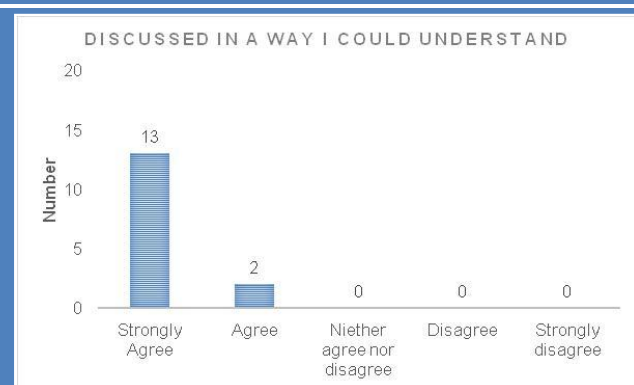| Graph 54: ReSPECT helps people to share their views about their treatment and approaches to care?	Graph 55: ReSPECT helps people to start the conversations about their wishes openly with their loved ones?
Graph 56: ReSPECT helps people to start the conversations about their wishes openly with staff?	**Graph 57: It may help staff work well together in organizing their care?**
Graph 58: It may help health professionals to have a plan that records individual preferences and recommendations for emergency situations?	
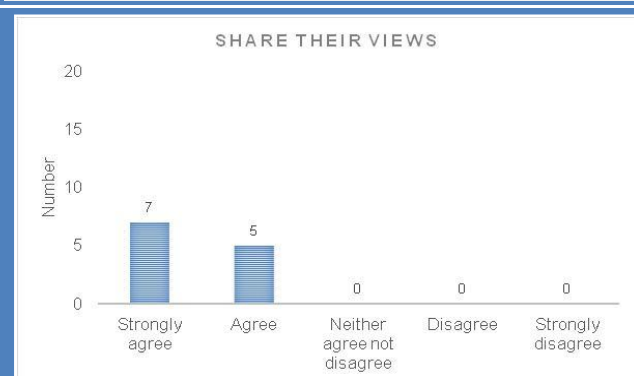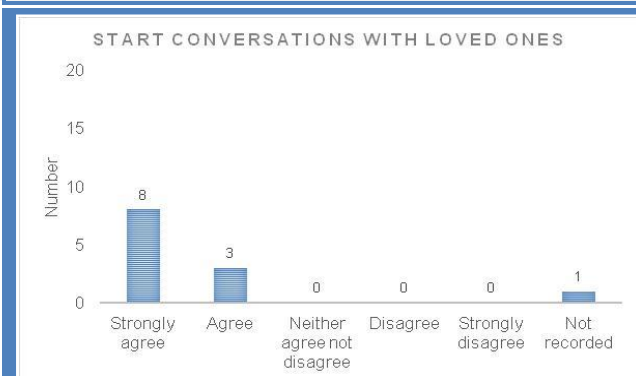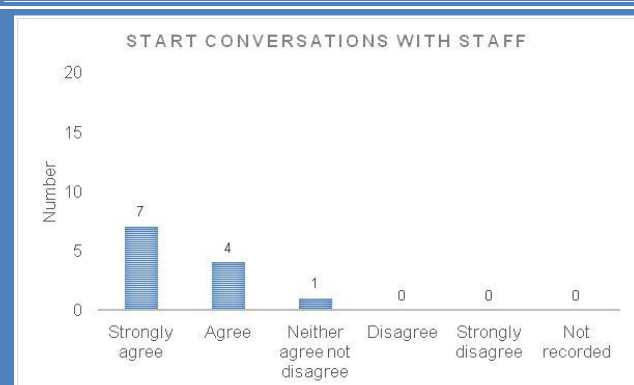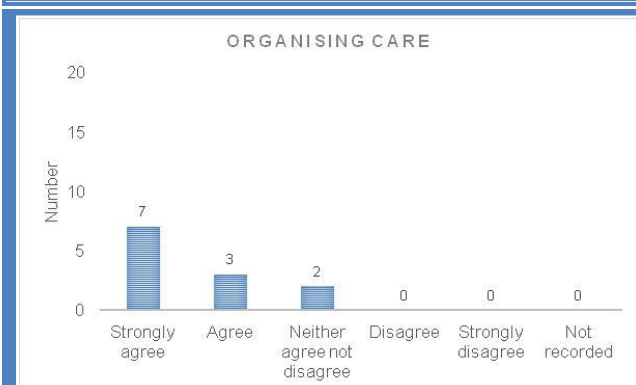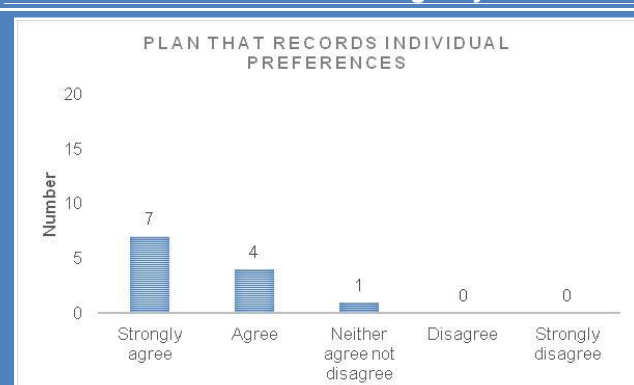
One carer went on to add that the ReSPECT process 'assists a necessary conversation', and another, that it helps 'to prepare' for an emergency situation. Carers liked that the information on the ReSPECT form can be shared between

different services and professions. They feel it is a plan that lets 'medical people' know what peoples wishes are at a difficult time.

Rating the ReSPECT process

Graph 59: Overall, how would you rate the ReSPECT process?
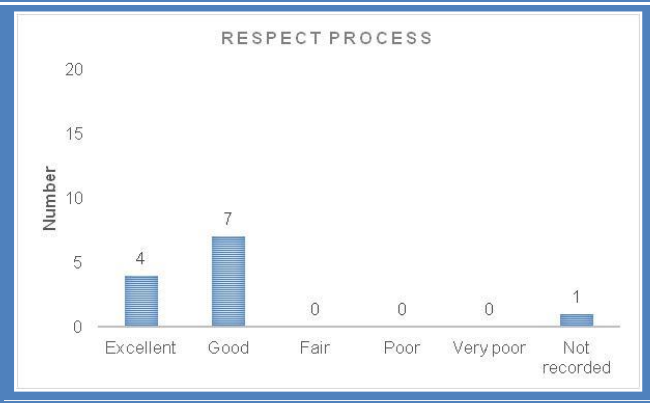
Overall, carers rated the ReSPECT form and process positively; where recorded, all respondents rated the ReSPECT process as excellent or good.

The results would indicate that carers responded positively to the ReSPECT form and process. The word cloud in Figure 8 below provides some qualitative feedback on what people really liked about the ReSPECT form and process.

Encouragingly, people rate the ReSPECT process very highly when they have actually had the experience versus those who are just considering ReSPECT in a theoretical scenario.

Qualitative Feedback

Figure 8: What carers liked about the ReSPECT process

In response to a question asking how the process could be improved, one carer found the sliding scale in the personal preferences section on the document to be a bit unclear and felt that it could be 'broken up a bit more'. This comment reflects what can often be experienced in practice when completing the form with a patient or relative. This section of the form may require further review.

Section 6: Staff Feedback

This section of the report gives the results of the ReSPECT staff survey, sent out to staff during the pilot period. The survey asked questions about education on the ReSPECT process, completing a ReSPECT form, and their opinions of the ReSPECT process. 20 members of staff have returned feedback on their experiences.

Staff Demographics

Graph 60: Designation	**Graph 61: Area of work**
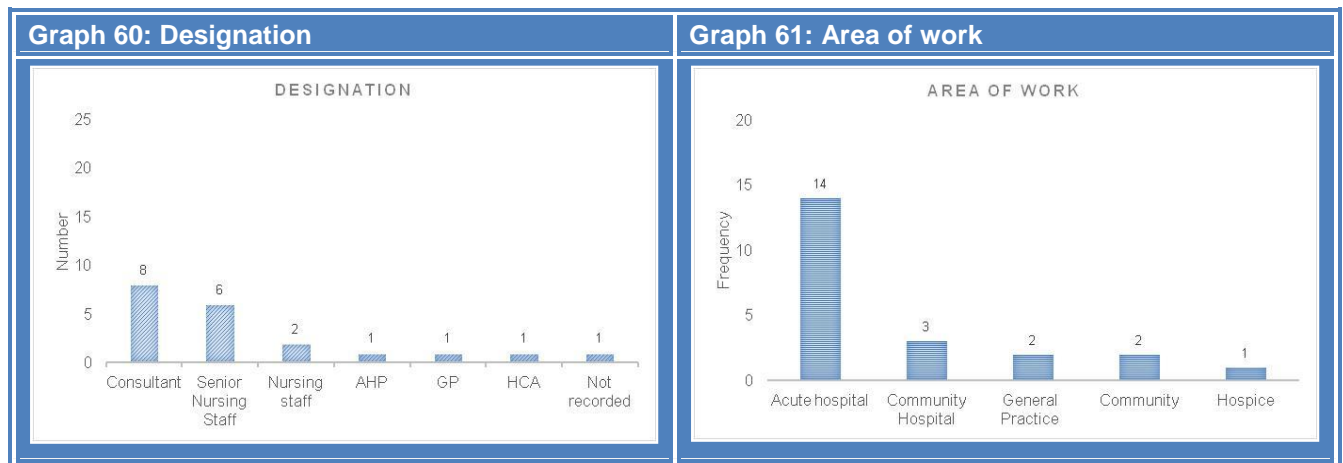
The majority of respondents were consultants and senior nursing staff, who work in the acute hospital. All respondents were aware of the ReSPECT pilot in NHS Forth Valley.

ReSPECT education

Graph 62: Have you received any education or information on ReSPECT?	**Graph 63: If yes, what type of education or information did you receive?**
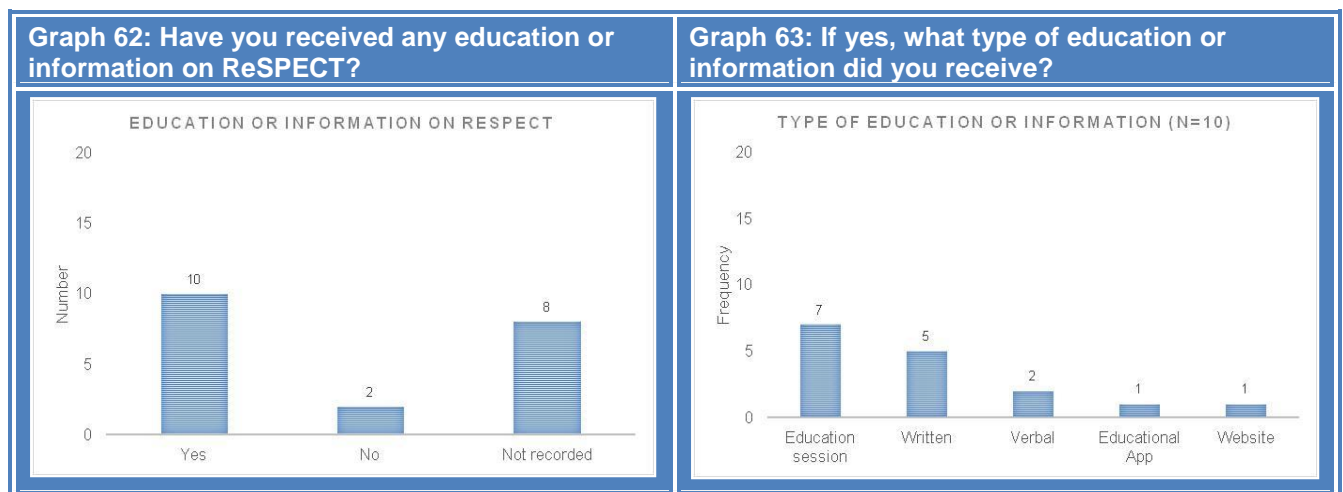
10 respondents had received education or information on the ReSPECT process, including how to complete a ReSPECT form. 7 staff had attended ReSPECT education sessions.

Completing a ReSPECT form

Graph 64: Have you completed a ReSPECT form?	Graph 65: If yes, did the education or information you received help you to complete the form?
HAVE YOU COMPLETED A RESPECT FORM	EDUCATION HELPED TO COMPLETE FORM
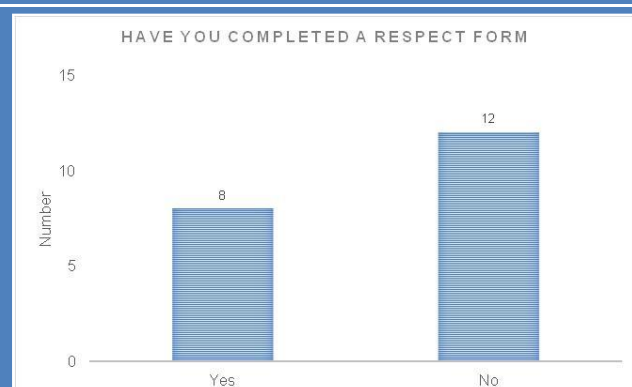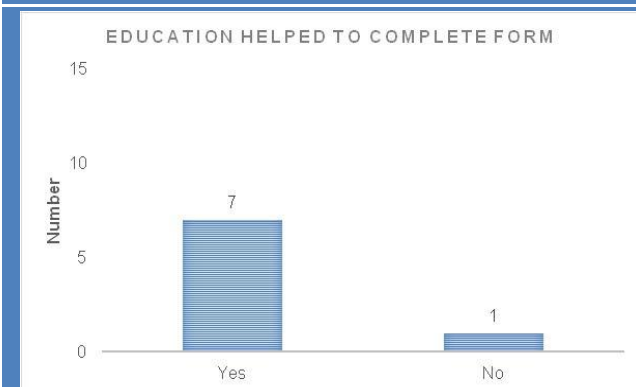
All 8 respondents who had completed a ReSPECT form agreed that the form was easy to complete. 7 agreed that the education or information they had received had helped them to complete the form. 2 nurses and the one AHP stated that although completing the form wasn't part of their role they did advise clinical teams on when ReSPECT was appropriate.

The ReSPECT process

Staff were asked how much they agreed or disagreed with the following statements thinking about the purpose of ReSPECT, and the ReSPECT process.

Graph 66: ReSPECT helps patients to identify what is important to them at an early stage	Graph 67: The ReSPECT process involves the patient and / or family in decision-making
WHAT IS IMPORTANT	SHARED DECISION MAKING
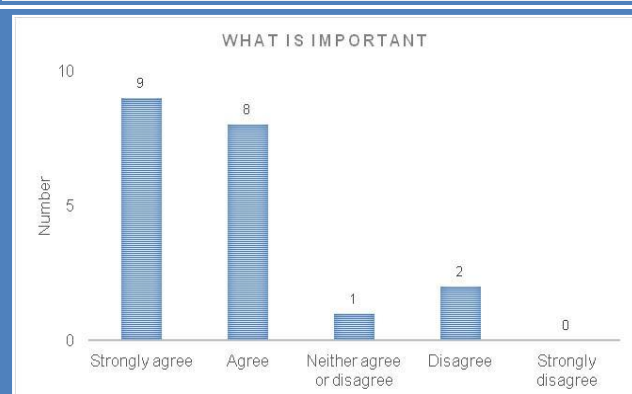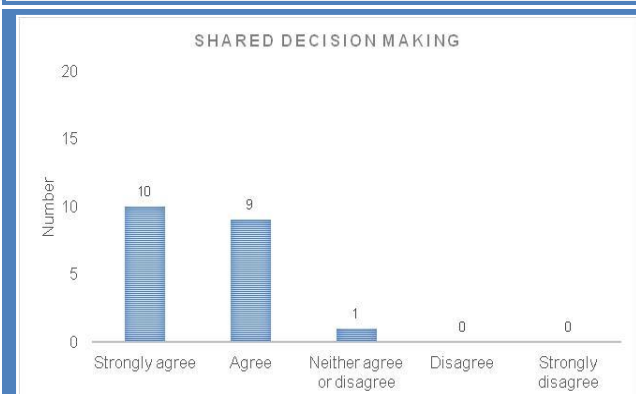
Graph 68: A ReSPECT document will help the individual/team to deliver the most appropriate care and treatment for the patient	Graph 69: I am comfortable in having discussions with patients/family about treatment/care planning
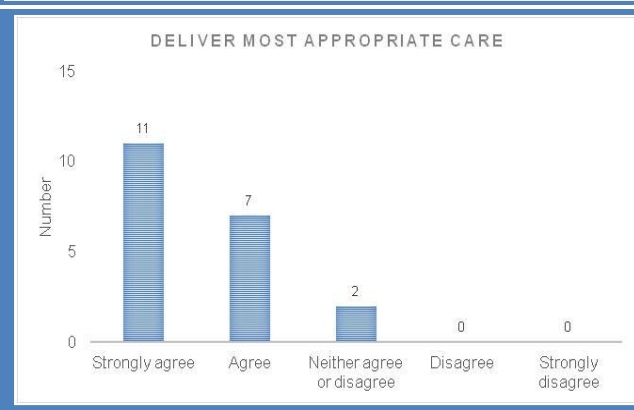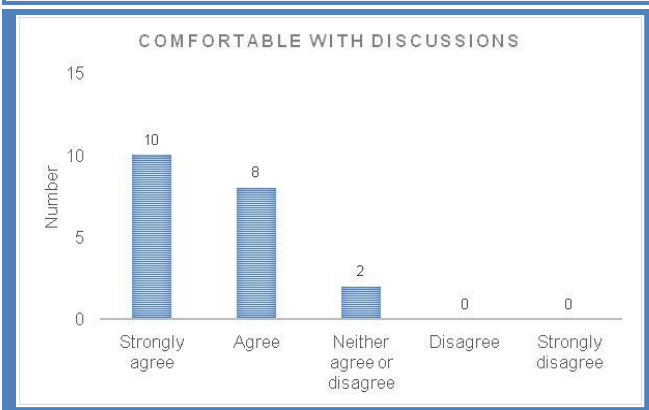
Qualitative feedback

How receptive have you found patients and carers to engage with / initiate the ReSPECT process

- Level of receptiveness is dependent on where patient is in terms of disease progression, age, level (severity) of underlying conditions. Most times when I discuss this - most are receptive
- Have only completed one which involved a receptive patient
- Most families have welcomed this however a few have declined to participate
- Unable to comment on the ReSPECT process but in general find people are comfortable and often relieved to be involved in planning what their future care and treatment will look like. The emphasis requires to be on the quality of the conversation and not on the form
- Very receptive and anecdotally very grateful families for having the discussion open and honest
- Most have been very receptive. Some people are not ready to talk about ACP.

What seems to influence the decision-making process?

- Clinical condition - response to active treatment. Family opinions. Advance decisions. Previous admissions, frailty, co-morbidities
- Clinician relationship with patient/carers, time, patients/ carers beliefs and ethical views
- Consideration of patient condition, co-morbidities prospective care, treatment and outcome of treatment
- Decision making by patient is around pre-existing beliefs. My decision to have a talk is around prognosis. I tend to do it in people with life-limiting conditions - cancer / end stage COPD/ heart failure/ dementia
- Driven by clinical need, but influenced by teams previously involved in patients care and their expectations - often unrealistic. Crisis tends to prompt discussions rather than anticipation in health
- From experience it is usually acute deterioration and a more reactive decision, compared to a planned proactive decision making process = ReSPECT
- It reassures families that we are "not giving up" on their relative and will continue to care for them as much as is appropriate

What seems to influence the decision-making process? (Continued)
- Providing people with the information they need regarding risk benefit. Using language that people understand. Ensuring that people having realistic expectations regarding treatment outcomes. Giving people time to consider and discuss options with those that matter to them, then revisiting the process. Explore previous experiences (of hospital/hospice/the possible treatments); what the patient views as an acceptable quality of life; patient having adequate information to make an informed decision

How do you think decision-making could be improved?
- By honest, transparent discussion with patient/ family. Awareness of difficult conversation but defined in a sensitive supportive manner. A discussion about what can be done, realistic medicine what is unlikely to work. Finalising a decision/ discussion about CPR
- Carried out before emergency admissions or a crisis. It needs combined with Organ/ Tissue Donor information. Clarity around which patients it is aimed at. Avoid duplication with DNACPR and ReSPECT
- Clear escalation plans at admission
- Earlier thought given to ReSPECT
- Ensuring that patients/ relatives have information provided in a timely fashion, in a format which they can understand
- General awareness of options and opportunities to discuss future care plans
- Importance of clear, constructive information and a consistent approach
- Initiated earlier in the patients journey
- Involving families earlier in the admission
- More time available to have discussion. Providing people with the information they need regarding risk/benefit. Using language that people understand. Ensuring that people have realistic expectations regarding treatment outcomes. Giving people time to consider and discuss options with those that matter to them, then revisiting the process.What is medically appropriate for the patient; previous experiences (of hospital/hospice/the possible treatments); what the patient views as an acceptable quality of life; patient having adequate information to make an informed decision.

Thinking about the ReSPECT process: What worked well?
- Completing the form and having it uploaded for all to see in a safe, accessible way
- Completion of form at least implies some of the relevant conversation has occurred
- Ease of the document to complete
- Having paper and electronic versions easily accessible to the patient, family and healthcare professionals
- Helps me to know how far to escalate the person's care. It is more succinct than the ACP
- Person-centred approach, (sliding scale/ bar). Open/ honest with patients and family/ next of kin
- Process works well at present. Have had some issues with lack of consultant signature recently which has meant delay in form going to portal
- Taking time to build rapport with patient prior to initiating ReSPECT. Discussing this in the context of making the right decisions for the person going forward - making sure their views are respected/ avoiding putting pressure on family to make difficult decisions if the person isn't able to
- The scale allows family flexibility and doesn't have such a black and white scenario. Families feel more involved
- Would think that early discussion about situation, patients awareness of condition and goals of care would be a positive for ReSPECT but no clinical experience if this occurs in practice

Thinking about the ReSPECT process: What could be improved?
- Although it's great that it's on one double sided page, possibly more room to explain decisions
- An electronic form would be good
- An increase in people who have a clear plan
- Continued awareness. Senior medical staff/ consultant training on ReSPECT to encourage culture change/ to encourage positive discussions, documentation and decision making
- Documentation of decisions - too simplistic and open to interpretation. No clarity about content of discussions leading to form completion. Goals are often unrealistic
- Filling out the form it feels rather repetitive especially on the back page
- Gaining consent from patient to have ReSPECT info on KIS. I have documented this as part of IDL as quality improvement plan
- More patient and family awareness of process and ideas behind it
- More space to write in patient's wishes re treatments they do/ don't want. Greater clarity re who can complete ReSPECT, who can sign as senior clinician
- Quite a time-consuming process. In practice I have few people who I can delegate this job too as it's so hard to get the forms completed in a timely way
- Raising awareness with all Healthcare providers
- The process needs standard questions asked of ALL patients coming to hospital & standard information passed on to Primary Care when they leave including; 1a. As well as Next of Kin - Do you have Power of Attorney? 1b. If so who are they & what powers. The process needs standard questions asked of 2. Are you on the Organ/ Tissue donor register? b. Do your NoK or PoA know? 3. Do you have an anticipatory Care Plan, DNACPR or ReSPECT document completed? Information leaflets widely available in Primary Care, outpatients & wards. Be good if it was supported nationally

Discussion

Framing the conversation

At the heart of the pilot of the ReSPECT Process, were the conversations which took place with the patient, those close to them and the health care professionals involved in their care. The challenges faced in taking forward the conversations are outlined in the staff feedback. Ideally, such conversations took place when the patient was relatively stable however often these conversations were prompted by a health crisis, anticipated or not. The patient stories are based on real clinical scenarios which take someone unfamiliar with the ReSPECT process, through the often complex and evolving discussions required particularly where the condition changes along with the goals of care. In acute life threatening scenarios, patients are often unable to participate initially in decision making and it is important to revisit these conversations if the patient becomes well enough to participate later e.g. delirium. Ideally, such decisions would be made with all of the available information available for that person including up to date diagnosis, prognosis if known and the likelihood of success of treatments including CPR. Clinicians need to be supported in having such conversations, by having access to tools and supporting information which aid treatment decisions and provides an evidence based approach where appropriate. Clinicians are often working more pragmatically where evidence for treatments may not be as well known for that particular patient and this is where shared decision making is of particular importance.

Benefits and challenges during the pilot

Benefits

The formal qualitative feedback received is only a proportion of the positive responses received; anecdotally families have been relieved and felt supported in having open and honest discussions with their loved one. There may be a presumption that patients, particularly more vulnerable or elderly patients, don't wish to be involved in treatment decisions. However, we found that, on the contrary, many often have very clear opinions on their future care. These views and opinions are not always volunteered if not asked about e.g. CPR decisions, however if not explored there may be an inappropriate presumption for treatment where this may actually be unwanted. Further, the issue of informed consent is vitally important and so no such presumptions about invasive treatments should be made.[22] The patients and families who did go through the ReSPECT process often reported feeling more content during their admission once their future emergency plan had been discussed and agreed and increased satisfaction and experience of care was observed. ReSPECT appeared to reduce levels of patient and family discontent around communication and overall, even where patients did not have a ReSPECT form in place, the ethos of the pilot ward areas was focused on establishing appropriate treatment plans and involving key individuals as early as possible. Health and social care professionals, particularly in settings such as care homes or community hospitals described feeling empowered and more secure when plans have been agreed and put in place. This reduced unwanted variation in practice and over-medicalisation where this was not appropriate. ReSPECT is also an excellent tool to advocate for patients (particularly where they lack capacity) who should be considered for interventions and who may be inappropriately at risk of not being considered for these if they were to have a DNACPR form for example. It gives an opportunity for those who know the patient well e.g. their family member or clinical specialist to advocate for them when they may not be present when the emergency takes place.

Challenges

Although the screening process highlights patients who would benefit from further discussions about their future care and preferences, in reality a ReSPECT conversation did not always follow on for a variety of reasons; time pressures, lesser priority in the acute setting, staff turnover, staff reluctance or lack of confidence in initiating such discussions. In an ideal scenario, every patient would be asked about their preferences for care and treatment. In reality, person-centred care and shared decision making does take time and a skilled workforce to deliver on this. Removing any barriers and making the process more efficient is an essential component of its future success.

Contacting relatives when appropriate who do not always reside locally and can be overseas was a challenge particularly in the care home population of patients. It was often appropriate and only feasible to have such discussions by phone, providing appropriate safeguards are in place and in accordance with capacity law.

The timing of these difficult and often complex discussions can be a challenge, initiated too early and the form needs updated and rewritten (e.g. in an admission where all of the information may not be known at that point or the patient too ill), but if delayed a further deterioration in the person's condition may result in more difficult or prolonged discussions about someone's treatment plan when they may be unable

to be involved. If the plan is not specific enough then this may not include plans for an anticipated emergency and this could potentially lead to a delay in decision making in a crisis. However, if too rigid or specific then health care professionals may feel bound by the recommendations e.g. not for hospital admission. This highlights the importance of education and not having a binary approach or being bound by the recommendations if the situation is not covered in the summary form. An example of this may be where a more symptomatic approach has been adopted but the patient may need to attend hospital if a fracture is sustained. Thus, the ReSPECT form *never* replaces a conversation whenever the patient has capacity to engage in discussions at the time of the emergency and the recommendations should be reviewed at each interface of care or change in condition to ensure the plan is relevant to that situation. Even where the clinical recommendations were not specifically related to the clinical scenario, it was felt that the earlier ReSPECT discussions ensure that the patient's voice is heard and this supports decision making for unplanned situations.

The process of uploading forms and revising copies is an interim measure. Forms can become out-of-date very quickly however the same is true of KIS and we found that this was often not up to date or relevant as evidenced in the pilot.

The ReSPECT process in its current form, works well in an acute setting and has the same potential in primary care. GP's may view this as duplication and increased time and effort as they already have KIS in place. The presence of multiple forms would further add to this concern and having one form in place would be preferable. Further, there currently is no 'Read Code' available (GP's use these to record the number of patients with e.g. a DNACPR form) specifically for ReSPECT unlike DNACPR, however there is potential for this to be developed.

In times of crisis, often DNACPR decisions need to be made where there is no one available to be contacted particularly in an emergency department setting. However, ReSPECT would be different in that it would be an emergency care plan not just a binary decision about CPR. Clinicians may be reluctant to complete a fuller plan in the absence of a discussion with loved ones and practically it will be challenging to have such discussions with every patient in a crisis unless the form can be updated in a stepwise fashion and more user friendly. This should improve with the plan for digitalisation of the form.

Conclusion

The pilot of the ReSPECT process can be regarded as a success in terms of the encouraging qualitative feedback, high quality of form completion, increased anticipatory care planning and improved patient outcomes. The number of people likely to benefit from the ReSPECT process is significant; it would be more patients than simply those who currently have a DNACPR form. It would obviously benefit patients during or following on from a hospital admission, however, ideally conversations would begin earlier in anticipation of a health crisis rather than being prompted by a crisis. Identification of such patients in primary care is likely to be more challenging than in an acute setting beyond those in need of palliative and end of life care although these patients would clearly benefit most. Tools such as e-frailty index, AnticiPal or Read codes e.g. SNO-MED CT are already used across the UK and further work in identifying individuals for wider ACP is ongoing locally. An effective roll-out would involve the gradual removal of DNACPR forms and the

digitalisation of the forms to ensure sustainability particularly in a primary care setting. Workforce challenges need to be factored in to future planning to ensure there are enough appropriately skilled health and social care professionals to deliver the process. ReSPECT conversations are often best carried out by specialist nurses who know the patient well and with the right skills and training an increasing number of health care professionals could be trained using a competency based approach. This would further maximise the potential for anticipatory care planning, particularly in a community setting.

High quality conversations and documentation takes time as evidenced by those who triggered for the ReSPECT process versus those who ended up going through the process. However, patients who were able to engage in their priorities of care now have this documented in a standardised fashion and this puts people at the centre of their care.

There is a growing body of evidence that a lack of advance decision making can have negative consequences for the patient.[23] DNACPR discussions and documentation in isolation can be associated with poorer outcomes, for example, CIPOLD (2013)[24] found that inappropriate or poorly documented DNACPR decisions contributed to premature unexpected death in patients with learning disability. More widespread implementation of the ReSPECT process will reduce the likelihood of a lack of patient and family involvement in decision making and promote earlier conversations for those not just nearing the end of life. Earlier planning and discussion should reduce ongoing inappropriate CPR attempts _and_ poor care and inappropriate escalation of care at times of crisis. Conversely those most in need will have treatment escalated in a timely fashion.

The ability to communicate robustly and seamlessly at times of crisis is essential for high quality patient care. This pilot exposes the challenges of overlapping electronic systems and processes across care settings and identified this, not only as a potential barrier for use, but as a challenge in keeping emergency care planning up to date and therefore delivering the safest and desired treatments. The ReSPECT summary form will likely require a paper copy for the forseeable future; however, the ability to share information across interfaces of care electronically requires further development locally and nationally. Digitalisation of the form as part of the National Digital Platform is anticipated with wider work currently ongoing with NES Digital Service and Forth Valley. The citizen facing component of the future digital document will be vital in truly facilitating shared decision making.

The ReSPECT process increases anticipatory care planning including having an up to date and useful KIS because of its accessibility across care settings and the ability for a variety of care professionals to participate in the process. It allows more health and social care professionals to access anticipatory care planning, this is vitally important for those at the coalface to provide the right care for that person in accordance with their wishes. We know that some hospital, care home and hospice staff cannot access KIS currently. The ReSPECT form has a more standardised format which has key consistent elements and facilitates shared decision making as well as capturing what matters to that person. Further, the process increases the likelihood of patients remaining at home following hospital discharge up to 3 months after a hospital admission. Although ReSPECT could be for anyone it clearly has particular relevance for those at the end of life and in particular may support those

wishing to die at home to do so. Many patients who went through the process were in the last days, weeks and months of life and were able to be supported in their preferred place of care, in 90% of cases this was out with an acute hospital setting.

In conclusion, the evidence shows that if done well, the ReSPECT process prompts and supports person-centredness, shared decision making and joined up working. ReSPECT also aligns with the National Health and Wellbeing Outcomes[25] framework for improving patient care through improved health and social care integration and Health and Social Care Standards[26].

The ReSPECT process ultimately has the potential to transform current practice by improving quality of care, resulting in better outcomes for patients and those close to them. A successful transition to the ReSPECT process will require the right technology, environment, time and workforce to enable a cultural shift and allow us all to *Personalise Realistic Medicine*[27.]

Next Steps

Ongoing

1. ReSPECT continues to be a strategic priority for the organisation including e-health planning to support the wider roll out of the process across Forth Valley, enabling the transition completely from DNACPR documentation particularly in a primary care setting. ReSPECT continues to be aligned with Realistic Medicine.

2. Develop work with NHS Education for Scotland (NES) Digital service to create a more sustainable digital form to support the ReSPECT process and which will allow citizens to access their own electronic health record. Integration into current systems e.g. Trakcare is already underway.

3. Continue to regularly sample completed ReSPECT documentation to promote safety and high quality communication across all care settings.

4. Further develop the operational policy for use of the process in a variety of care settings and the educational resources available on the staff intranet ReSPECT webpage including the educational app.

5. Utilise a variety of ACP trigger tools to identify patients who may benefit from ReSPECT e.g. SPICT-4-ALL which can be used by family and carers, not only health care professionals.

6. Raise public and staff awareness about the ReSPECT process utilising the NHS Forth Valley video and sharing the positive local patient, family, carer and staff experience.

7. Promote excellent communication skills training which promote shared decision making and consider the time and workforce planning required to deliver the ReSPECT process in all health and social care settings.

8. Further qualitative feedback from primary care, including care homes.

9. Further evaluation of paramedic access to emergency care plans.

10. Further project support to deliver this will be required to enable the complete transition to the ReSPECT process including an education lead, dedicated project improvement (QI) lead, and ehealth project support.

Future

11. Consider mapping the patient pathways, at an individual and local population level.

12. Integrate the ReSPECT process into existing processes and pathways e.g. My Anticipatory Care Plan, Frailty Initiative, Scottish Patient Safety Programme Deteriorating Patient, Nursing Home Local Enhanced Services (L.E.S), Scotland's House of Care.[12]

13. Further qualitative analysis on mapping any potential gaps in health and social care provision required to deliver on patient preferences and supporting those who wish to die at home.

14. Support patients who may have impairment of mental capacity e.g. learning disability or dementia utilising the locally developed decision making pathway.

15. Evaluate Patient Outcome Reported Measures (PROM's) focusing on value based care at an individual level.

Abbreviations

ACP	Anticipatory Care Plan
BMJ	British Medical Journal
CPR	Cardiopulmonary Resuscitation
CT	Computerised Tomography
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EMIS	Electronic Management Information System
GMC	General Medical Council
GP	General Practitioner
IDL	Immediate Discharge Letter
IV	Intravenous
KIS	Key Information Summary
LES	Local Enhanced Services
LoS	Length of Stay
MDT	Multidisciplinary Team
MiDIS	Multi Disciplinary Information System
NEWS	National Early Warning Score
OOH	Out of Hours
POA	Power of Attorney
PROM	Patient Outcome Reported Measures
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SPICT-4-ALL	Supportive and Palliative Care Indicator Tool

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Appendices

Appendix 1: ReSPECT form

ReSPECT — Recommended Summary Plan for Emergency Care and Treatment for:

Preferred name

1. Personal details

Full name

NHS/CHI/Health and care number

Date of birth

Address

Date completed

2. Summary of relevant information for this plan (see also section 6)

Including diagnosis, communication needs (e.g. interpreter, communication aids) and reasons for the preferences and recommendations recorded.

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life, even at the expense of some comfort — **Prioritise comfort,** even at the expense of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment as per guidance below
clinician signature

Focus on symptom control as per guidance below
clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	clinician signature

ReSPECT — ReSPECT — ReSPECT — ReSPECT — ReSPECT

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5. Capacity and representation at time of completion

Does the person have sufficient capacity to participate in making the recommendations on this plan?

Yes / No

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**
If so, document details in emergency contact section below

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

☐ **A** This person has the mental capacity to participate in making these recommendations. They have been fully involved in making this plan.

☐ **B** This person does not have the mental capacity to participate in making these recommendations. This plan has been made in accordance with capacity law, including, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

☐ **C** This person is less than 18 (UK except Scotland) / 16 (Scotland) years old and (please select 1 or 2, and also 3 as applicable or explain in section D below):

☐ **1** They have sufficient maturity and understanding to participate in making this plan

☐ **2** They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.

☐ **3** Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here. Document full explanation in the clinical record.

Record date, names and roles of those involved in decision making, and where records of discussions can be found:

7. Clinicians' signatures

Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC Number	Signature	Date & time

Senior responsible clinician

8. Emergency contacts

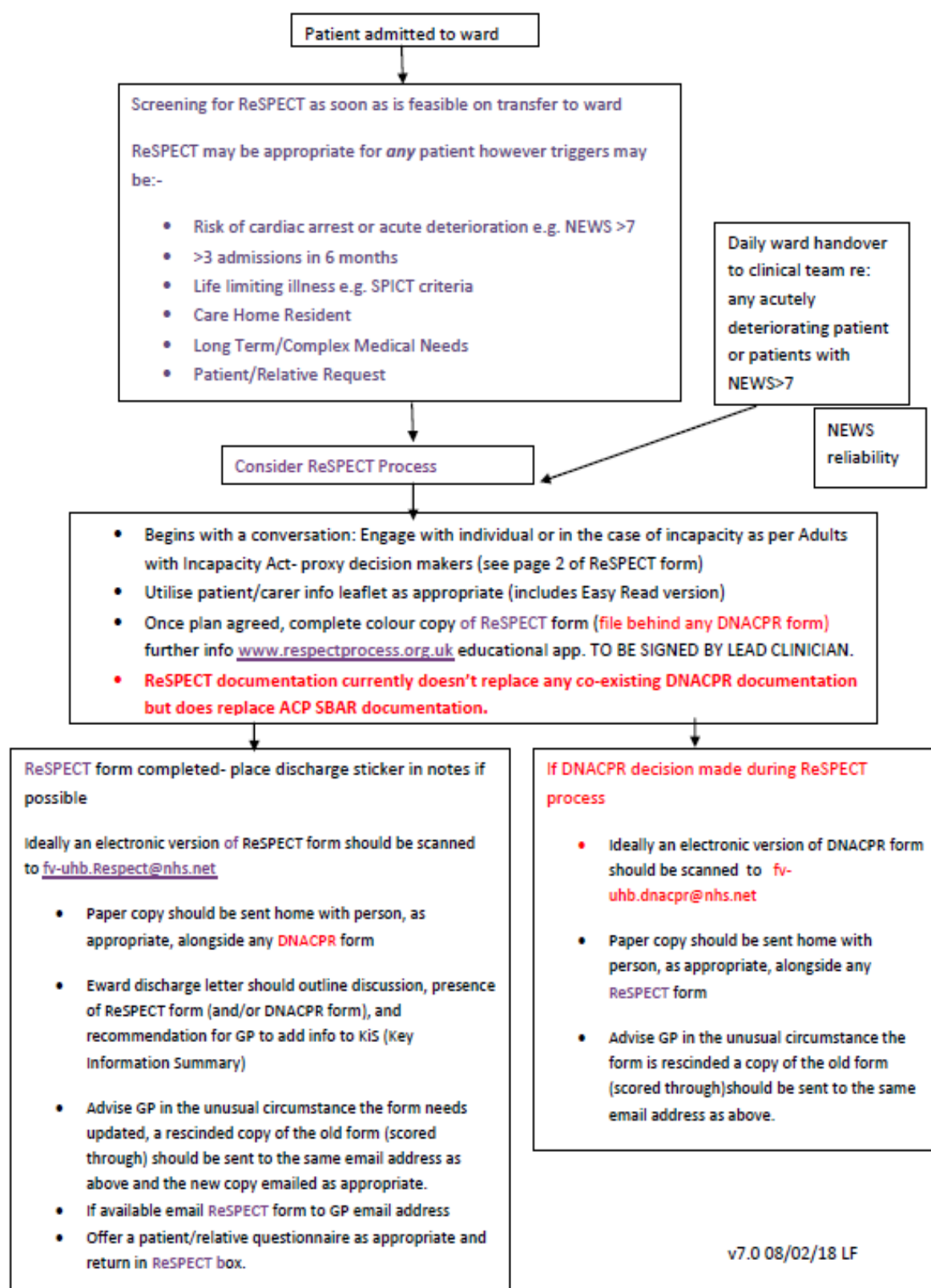| Role	Name	Telephone	Other details
Legal proxy/parent			
Family/friend/other			
GP			
Lead Consultant			

9. Confirmation of validity (e.g. for change of condition)

Review date	Designation (grade/speciality)	Clinician name	GMC/NMC/ HCPC number	Signature

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Appendix 2: ReSPECT process in FV

Flow chart: New ReSPECT document implementation

```
                    ┌─────────────────────────┐
                    │ Patient admitted to ward │
                    └─────────────────────────┘
```

Screening for ReSPECT as soon as is feasible on transfer to ward

ReSPECT may be appropriate for *any* patient however triggers may be:-

- Risk of cardiac arrest or acute deterioration e.g. NEWS >7
- >3 admissions in 6 months
- Life limiting illness e.g. SPICT criteria
- Care Home Resident
- Long Term/Complex Medical Needs
- Patient/Relative Request

Daily ward handover to clinical team re: any acutely deteriorating patient or patients with NEWS>7

NEWS reliability

Consider ReSPECT Process

- Begins with a conversation: Engage with individual or in the case of incapacity as per Adults with Incapacity Act- proxy decision makers (see page 2 of ReSPECT form)
- Utilise patient/carer info leaflet as appropriate (includes Easy Read version)
- Once plan agreed, complete colour copy of ReSPECT form (file behind any DNACPR form) further info www.respectprocess.org.uk educational app. TO BE SIGNED BY LEAD CLINICIAN.
- **ReSPECT documentation currently doesn't replace any co-existing DNACPR documentation but does replace ACP SBAR documentation.**

ReSPECT form completed- place discharge sticker in notes if possible

Ideally an electronic version of ReSPECT form should be scanned to fv-uhb.Respect@nhs.net

- Paper copy should be sent home with person, as appropriate, alongside any DNACPR form
- Eward discharge letter should outline discussion, presence of ReSPECT form (and/or DNACPR form), and recommendation for GP to add info to KiS (Key Information Summary)
- Advise GP in the unusual circumstance the form needs updated, a rescinded copy of the old form (scored through) should be sent to the same email address as above and the new copy emailed as appropriate.
- If available email ReSPECT form to GP email address
- Offer a patient/relative questionnaire as appropriate and return in ReSPECT box.

If DNACPR decision made during ReSPECT process

- Ideally an electronic version of DNACPR form should be scanned to fv-uhb.dnacpr@nhs.net
- Paper copy should be sent home with person, as appropriate, alongside any ReSPECT form
- Advise GP in the unusual circumstance the form is rescinded a copy of the old form (scored through) should be sent to the same email address as above.

v7.0 08/02/18 LF

Appendix 3: A full breakdown of the location RESPECT forms completed

Forms completed in a hospital setting

Table 6: FVRH acute setting (n=110)	Number
Ward A11	60
Ward B21/B22	11
Ward A32	10
Ward B23	6
Ward B12	5
Ward B31	5
AAU	3
Ward A12	**3**
Ward A31	2
Ward B11	2
Ward B32	2
Ward A21	1
Total	**110**

Table 7: Community hospital and ward (n=43)	Number
SCH Ward 3	15
CCHC Ward 1	8
SCH Ward 1	5
CCHC Ward 2	4
Bo'ness Ward 1	4
SCH Ward 4	3
FCH Unit 2	2
Bo'ness Ward 2	1
FCH Unit 1 FCH Unit 1	1
Total	**43**

Table 8: FVRH mental health (n=11)	Number
Ward 4	10
Ward 4	1
Total	**11**

Table 9: FVRH Outpatients (n=1)	Number
Oncology clinic	1
Total	**1**

Forms completed in a community setting

Table 10: Care home (n=21)	Number
Forthbank	16
Cunningham house	5
Total	**21**

Forms completed in a hospice setting

Table 11: Strathcarron Hospice (n=14)	Number
Strathcarron Day Hospice	14
Total	**14**