Person centred care planning
Lynsey Fielden
Consultant Geriatrician
Acute Palliative Lead

NHS Forth Valley
An introduction to RoSPECT

Recommended
Summary
Plan for
Emergency
Care and
Treatment
Overview

ReSPECT

• What is it?
• Who is it for?
• Why use ReSPECT?
• Work in NHS Forth Valley
Background: What is it?

- The ReSPECT process creates a summary of personalised recommendations for a person’s clinical care in a future emergency in which they do not have capacity to make or express choices.

- Such emergencies may include death or cardiac arrest, but are not limited to those events.

- The process is intended to respect both patient preferences and clinical judgement.

- In theory, anyone could have one......not just end of life
ReSPECT – who is it for?

• Everyone – with increasing relevance for those:
  ▫ with particular healthcare needs
  ▫ nearing the end of their lives or at risk of cardiac arrest
  ▫ who want to record their preferences for any reason

• A ReSPECT form is best completed when a person is relatively well, so that their preferences and agreed clinical recommendations are known if a crisis occurs
Why? Importance of thinking ahead

- Living longer
- Increase in long term conditions, but also complexity and multi-morbidity
- Despite medical advances we cannot stave off ill health indefinitely
- ‘Thinking Ahead’ approach
- Empowering individuals
- Enabling care teams
- Right team, right time, right decision, right outcome?
Toolbox of care planning resources
• Point prevalence DNACPR decisions
• 32% across NHS Forth Valley
• 63% community hospitals
• 80% decisions communicated
DNACPR decisions and discussions have led to:

- negative patient/public perceptions
- negative clinicians’ perceptions
- complaints
- litigation
- negative media reports
• DOES NOT REPLACE A CONVERSATION
• Not legal binding
• Should be reviewed in light of context and change in condition
• Not about preventing necessary admissions
• Lead clinician sign off
ReSPECT - aims

- More conversations between people and clinicians
- More planning in advance
- Good communication
- Good decision-making
- Shared decision-making whenever possible
- Good documentation
- Better care
Wider Context

- Realistic Medicine
- Deteriorating Patient
- Dementia Strategy
- Strategic Framework for PELC
Pilot preparation

• Set up Steering Group with wide stakeholder engagement
• Align electronic systems (EDMS/Clinical Portal to maximise transparency)
• Raise awareness of process and pilot across organisation
• Replace pre-existing ACP documents which become redundant

• QI support
• IT support (set up an email address)
• Education- signpost to educational app and process for upload
• Support team
Pilot project

- September- May 2018
- Acute elderly care ward, elderly mental health ward, day hospice, community teams
- Use alongside DNACPR where appropriate
Alerts information is from EWar and EDMS.

<table>
<thead>
<tr>
<th>Type</th>
<th>Alert</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alert</td>
<td>Patient Opted in to Butterfly Scheme</td>
</tr>
<tr>
<td>Alert</td>
<td>Do Not Attempt Resuscitation - see case notes</td>
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<table>
<thead>
<tr>
<th>Type</th>
<th>Title</th>
<th>Specialty</th>
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<tbody>
<tr>
<td>ALERTS</td>
<td>DNACPR</td>
<td>EmerMgtPlans</td>
</tr>
<tr>
<td>ALERTS</td>
<td>ReSPECT</td>
<td>EmerMgtPlans</td>
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Further information is available in the ECS/KIS tab.
Overall aims of ReSPECT pilot

• To test the ReSPECT process

- Emergency care planning
  • Up to date
  • Useful
  • Easily accessible

- Earlier conversations
  • Person centred care
  • Shared decision making
Targeted approach

- Triggers at MDT

ReSPECT TRIGGERS

Does the patient have: (tick as appropriate)
- A life limiting condition
- Are they a NH resident
- At risk of deterioration or cardiac arrest
- NEWS > 7
- Has the patient/relative requested
- Do they have complex medical needs
- Recurrent admissions

If the patient has one or more of these ReSPECT triggers then they may benefit from a conversation about future emergency care planning such as a ReSPECT discussion.
Location of ReSPECT form completion

- Clinic: 1.0%
- Hospice: 1.0%
- Care Home: 6.9%
- Community Hospital: 21.8%
- Acute Hospital: 59.4%
Patient preferences

![Graph 9: Priorities for care](image)

- Sustain life: 6%
- Sustain comfort: 75%
- In between both: 20%

Patients priority (n=71)
Qualitative feedback: ReSPECT experience

Completing questionnaire:
- Patient
- Carer/Relative
- Both
Patients/Carers after the process

- Were you involved as much as you wanted to be in making decisions about your care and treatment? 100%
- Were the people that matter to you involved as much as you wanted them to be in making decisions about your care and treatment? 100%
ReSPECT process

Overall rating

- Excellent
- Good
“Dad has always been clear regarding his end of life plans and the fact that medical professionals now have a document to show this is ideal”

“Open, honest and informative. We were included and our views sought appropriately ”

“Should be extended nationally”

“Gave me a sense of control in the planning of my future care”

“We liked that this is person centred”
Carer engagement group feedback

- Overwhelmingly positive (excellent or good)

“Excellent idea provided the health professionals adhere to it”

“The sliding scale is a bit vague, would like it broken up more”

“It’s a good thing...will be tremendously helpful at the end of life. It will take stress out of a situation. It gives everyone a voice and a choice”

“Assists a necessary conversation”
Staff questionnaires

• Staff Feedback
  - 94% felt that ReSPECT involved the patient and/or family in decision making
  - 88% felt ReSPECT would help them deliver the most appropriate care

“..Most have been very receptive.....some people are not ready to talk about anticipatory care and this is respected”

“It is gentler than DNACPR where the focus is on NOT doing something rather than what we can do with ReSPECT”

“Helps me to know how far to escalate the person’s treatment”
Community usage

- 2 small pilots done
  - patients with capacity living in their own home
  - patients without capacity in a care home

**Positives**
- Easy to complete
- Facilitates shared decision making & person centred care
- Well received by families and patients
- Carers felt empowered
- Storage within care home was easy
- Fit in easily with other discussions such as acp/dnacpr/awi

**Challenges**
- Some issues getting in touch with carers and setting up meeting/telephone
- Some carers worried about them making the decision
- More difficult on phone than face to face
- Quite complicated process re scanning and getting on clinical portal
OUTCOME MEASURES

- 450+ patients have been through the process
- Ongoing evaluation - early data
- LOS, readmissions, place of death
- Actual place of care/preferred place of care at the end of life
- %time at home in the last 6 months of life
Re-admission* to hospital within:

<table>
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<tr>
<th>Time Period</th>
<th>ReSPECT Form</th>
<th>No ReSPECT</th>
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<tbody>
<tr>
<td>7 days</td>
<td>6.7%</td>
<td>7.9%</td>
</tr>
<tr>
<td>30 days</td>
<td>13.0%</td>
<td>15.0%</td>
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<tr>
<td>3 months</td>
<td>10.4%</td>
<td>23.8%</td>
</tr>
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</table>
ReSPECT form (n=28) and No ReSPECT (n=65)
Died in preferred place of care (n=113)

- Yes: 76
- No: 24

%
Frequently voiced concerns

- Isn't it going to take forever? I don't have time!
- Is this not duplication of other work?
- Is this my role? Could somebody else be doing it?
- The process post filling out is so complicated!
Process measures

• 100% involved in discussions

• Improved communication in IDL needed

• KiS not always updated (70% at 1 month)
Benefits

- Patient preference
- Provides a standardised approach cf. KiS
- Summary
- Stays with patient
- Electronic system

- Positive feedback
- Facilitates involvement of the person and those close to them
- Accessible to more people
- Outcomes?
Challenges

• Sharing of information across interfaces of care
• Electronic version
• Duplication
• Time
• Staff turnover
• Keeping up to date
• Too vague

• Doesn’t come in to hospital with them
• Process evolved during pilot
• Resistance to change
Case study

• 86 year old lady
• Medical standby
• Care home resident
• Recently bedbound
• Dyspnoea
• Desaturated 79% OA, febrile, 150bp
• In extremis on admission
• Nil on KiS
Rewind 2 months.........

Increased confusion, weight loss 2 stone
- Abnormal CT
- Metastatic lung cancer (mediastinal invading chest wall and brain metastases)
- Resp Clinic- attends in wheelchair
  - Performance status 3- best supportive care
  - Asthma, type 2 diabetes
  - Living at home with POC
Assessment

- Chest Sepsis, AKI
- IV antibiotics
- Bedbound
- DNACPR placed
- Sepsis 6/NEWS stickers

- Day 3 Admission: ACP and return home
What were the goals of treatment?

What were the persons previously expressed wishes?
• We all grow older
• We’ll die sometime
• We don’t like to discuss death and dying
Identification

- Intuition?
- Life limiting condition
- Deteriorating patients
- Adult with incapacity/learning disability

Hospitalised and >85 Care Home Residents

SPARRA
Anticipal
SPICT/SPICT4ALL
GSF PIG
Read Codes (SNOWMED CT)
ReSPECT

- Evidence for ReSPECT versus DNACPR (transition)
- Obvious use in deteriorating patients
- Particular relevance at end of life
- Care home patients
- Guidance re use of ReSPECT and educational/communication plan
- Digital Form
Next steps

✓ Currently being rolled out across hospital, primary care, hospice
✓ Link in with Deteriorating Patient (structured response)
✓ Education and engagement events
✓ Integrated into WSW and nursing home LES
✓ Integrated into existing electronic systems
✓ Share good practice in other areas
✓ Supporting good communication

WE NEED YOU!!
Acknowledgements

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