

Evaluating ReSPECT in Primary Care

Topic guides for Interviews and focus groups

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care

Draft Topic Guide for Public members Focus Group

The focus group topic guide will be further developed and refined during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. What are the benefits for patients, carers, the health service, and wider society of ReSPECT ?
2. What are the disbenefits, or disadvantages, of ReSPECT ?
3. What gets in the way of implementing, or putting into practice, ReSPECT in a way that maximises its use and value?

Prompts:

- Access to forms
 - Transfer of forms between health and social care organisations involved in care and treatment
4. How can the disbenefits or disadvantages of ReSPECT, and challenges to using ReSPECT, be mitigated?
 5. Any other comments

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care

Draft Topic Guide for Faith Leader Interviews

The interview topic guide will be further developed and refined during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. What do you think are the benefits for patients, carers, the health service, and wider society of the implementation of ReSPECT?
2. What do you think are the disbenefits or disadvantages of ReSPECT?
3. What do you think gets in the way of implementing, or putting into practice, ReSPECT in a way that maximises its use and value?

Prompts:

- Access to forms
 - Transfer of forms between health and social care organisations
4. How can the disadvantages of implementing ReSPECT, and challenges to its use, be mitigated?
 5. I'd like to hear about your views on how the values embedded in ReSPECT sit with the key values of your faith, for example in relation to:

Prompts:

- Treating people with dignity
 - Respecting people's autonomy
 - Appropriate use of modern medical technologies
 - Prevention of unnecessary harm and suffering
6. Do you think there are areas where the faith's teaching supports the premise of ReSPECT, or could cause challenges for people following that faith?

Prompt:

- Any thoughts on how to mitigate these challenges for both patients and clinicians?
7. Any other comments

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Draft Topic Guide for GP Interviews

The interview topic guide will be further developed, refined, and piloted during the study in collaboration with our clinical co-investigators and PPI advisory group.

Topics for discussion:

1. Understanding of the ReSPECT process and form

Draft prompt questions:

- What does the ReSPECT process mean to you?

2. Account of up to 3 ReSPECT processes that you were involved in (including the ReSPECT process for a patient participant in the study if you were involved in completing the relevant form)

Prompts (for each account):

- Why you decided to start each process?
- How you set up the process?
- Your experience of any conversation(s) with the patient and family.
- Your experience of completing the form.
- Views on form storage and accessibility for future reference.
- Views on how and when the completed ReSPECT form is reviewed.
- How the ReSPECT form influences the care that is provided for the patient.

3. How your GP practice organises the ReSPECT process?

4. Thoughts and feelings that arose for you from your involvement in the ReSPECT process.

Prompts:

- Whether the ReSPECT process changed how you viewed your patients, and/or yourself?
- Whether you think it resulted in a change to the care and clinical interventions provided, and how you view these?
- Whether you think there was any impact on the trust between patients and yourself, or the health service more generally.
- Whether you trust that the ReSPECT form will receive attention within general practice and other parts of the health service once completed.
- Views on how the ReSPECT process could be improved.

5. Views on factors that affect the implementation and embedding of the ReSPECT process in general practice, including:

Prompts:

- Clinical and organisational pressures that may affect opportunities to initiate ReSPECT discussions.
- Uncertainty about prognoses that affects decisions as to whether to initiate conversations about the ReSPECT process.
- Patient and family/carer responses to initiating conversations about the ReSPECT process.
- Clinical and organisational factors that may prevent carrying out planned patient preferences.
- Any other factors

6. Whether you have been involved in any other types of advance care planning discussions and your experience of these compared to ReSPECT .

7. Whether COVID-19 has had any impact on your thinking about ReSPECT or advance care planning in general.

8. Any other comments.

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Draft Topic Guide for Care Home Manager Interviews

The interview topic guide will be further developed, refined, and piloted during the study in collaboration with our clinical co-investigators and PPI advisory group.

Topics for discussion:

1. Understanding of the ReSPECT process and form

Prompt:

- What does the ReSPECT process mean to you?

2. Your role in the ReSPECT process

Draft question/prompts:

- Do you initiate the process by suggesting it to a resident/family member or GP?
- Are you involved in ReSPECT conversations between residents and their doctor or nurse?
- If a doctor or nurse is visiting a resident do you refer them to the ReSPECT form?

3. How the GP practice(s) organises the ReSPECT process in relation to the nursing/care home

Draft question/prompts:

- How does the GP practice(s) organise completion of ReSPECT forms for residents?
- How does the home store the form(s) and use them when the resident is ill?
- How do doctors attending residents when they are ill use the ReSPECT form?

4. Changes in thoughts, feelings or behaviours arising for you from involvement in the ReSPECT process

Draft question/prompts:

- Perceptions of any impacts on residents or staff of the ReSPECT process
- Has being involved in the ReSPECT process for residents changed how you think about the residents' health/illness/treatment?

5. Involvement in any other advance care planning discussions

Draft question/prompts:

- Do you have experience of other types of advance care planning with your residents?
- How do these other forms of ACP compare with the ReSPECT process?

6. Whether COVID-19 has had any impact on your thinking about ReSPECT or advance care planning in general.

7. Any other comments.

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Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care

Draft Topic Guide for Health and Social Care Professionals Focus Groups

The focus group topic guide will be further developed and refined during the study in collaboration with our clinical co-investigators and PPI advisory group.

Topics for discussion:

8. What are the benefits for patients, carers, the health service, and wider society of the implementation of ReSPECT ?
9. What are the disbenefits of ReSPECT?
10. What gets in the way of implementing ReSPECT in a way that maximises its use and value?

Prompts:

- Access to forms
 - Transfer of forms between health and social care organisations
11. How can the disbenefits of ReSPECT, and challenges to its use, be mitigated?
 12. Any other comments.

ReSPECT in Primary Care

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Topic Guide for Home Care workers focus groups.

Topics for discussion:

1. Can you start by telling us about your experience of ReSPECT in the context of your work ?

Prompts:

How have you used ReSPECT in the course of your work/how do you come across it in your work?

How relevant is it to you in your work?

How does the ReSPECT process happen in your work?

Who is involved in the ReSPECT process in the context of your work? How are you/they involved?

2. Have you seen or experienced any challenges in ReSPECT being implemented?/in the form being used by health and care professionals?

Prompts:

Access to forms?

Awareness/understanding of forms?

Confidence acting on the form?

3. Are there specific challenges for home care workers?
 - a. Why? Can you explain these challenges?
4. How could these challenges be overcome/mitigated?
 - a. For home care workers
 - b. For health and care professionals generally
5. Do you think ReSPECT and the concept of Emergency Care Treatment Plans more generally is a good idea?
 - a. What are the benefits for people? Carers/families? Health and care professionals? The health and care service? wider society?
6. Do you think there is anything that is undesirable/not good about the idea of ReSPECT, and of Emergency Care Treatment Plans more generally?
 - a. How could these be improved? /What would make it better?
7. Any other comments

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Draft Topic Guide for Patient Interviews

Interview 1

The interview topic guide will be further developed and refined during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. Recollection of any ReSPECT conversation

Draft prompt question

- Do you have a copy of your ReSPECT form?

2. Understanding about the ReSPECT process and form

Draft prompt question:

- What does the ReSPECT form mean to you?

3. Description of the ReSPECT process from when it was first considered or mentioned, through to completion of the form, and any updating of the form.

Draft prompt questions:

- Can you describe the conversation with your doctor/nurse about the ReSPECT form?
- What did they tell you about the form?
- What kind of questions did they ask you?
- Who else was involved in the conversation?
- What happened to the form after it was filled in?
- Do you know if your doctor has referred to the form when deciding about your treatment when you are ill?

4. Views on the ReSPECT process

Draft prompt questions:

- When do you think people should have conversations about these kind of issues?
- Who do you think should keep the ReSPECT form?
- When do you think the ReSPECT form should be reviewed?
- Who should initiate this review?
- When and how it should the recommendations be acted on?

5. Thoughts and feelings that arose involvement in the ReSPECT process.

Prompt questions:

- Did the process change how you thought about yourself, your health/illness, and the prospect of your death?
- Do you think the ReSPECT process resulted in a change to the care and treatments you received,
- Has it made you think differently about your treatments?
- Do you think going through the ReSPECT process has made you trust your doctors and nurses more? Less?
- How confident are you that the recommendations on the form will be acted on
- Can you think of how the ReSPECT process or form can be improved?

6. Involvement in other advance care planning conversations

Draft prompt questions

- Have you had any other conversations about making plans for your future care and treatment and care?

7. Whether COVID-19 has had any impact on thinking about ReSPECT or advance care planning in general

Draft prompt questions

- Has COVID made you think about these kind of things more than before? If so in what way?

8. Any other comments

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care

Draft Topic Guide for Relative Interviews

Interview 1

The interview topic guide will be further developed and refined during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. Recollection of any ReSPECT conversation

Draft prompt question

- Do you/does your relative have a copy of your ReSPECT form?

2. Understanding about the ReSPECT process and form

Draft prompt question:

- What does the ReSPECT form mean to you?

3. Description of the ReSPECT process from when it was first considered or mentioned, through to completion of the form, and any updating of the form.

Draft prompt questions:

- Can you describe the conversation with your relative's doctor/nurse about the ReSPECT form?
- What did they tell you and your relative about the form?
- What kind of questions did they ask your relative? you?
- Who else was involved in the conversation?
- What happened to the form after it was filled in?
- Do you know if your relative's doctor has referred to the form when deciding about their treatment when they are ill?

4. Views on the ReSPECT process

Draft prompt questions:

- When do you think people should have conversations about these kinds of issues?
- Who do you think should keep the ReSPECT form?
- When do you think the ReSPECT form should be reviewed?
- Who should initiate this review?
- When and how it should the recommendations be acted on?

5. Thoughts and feelings that arose involvement in the ReSPECT process.

Prompt questions:

- Did the process change how you thought about your relative, their health/illness, and the prospect of their death.
- Do you think the ReSPECT process resulted in a change to the care and treatments your relative received,
- Has it made you think differently about their treatments?
- Do you think going through the ReSPECT process with your relative has made you trust your doctors and nurses more? Less?
- How confident are you that the recommendations on the form will be acted on
- Can you think of how the ReSPECT process or form can be improved

6. Involvement in other advance care planning conversations

Draft prompt questions

- Have you had any other conversations about making plans for your relative's future care and treatment?

7. Whether COVID-19 has had any impact on thinking about ReSPECT or advance care planning in general

Draft prompt questions

- Has COVID made you think about these kind of things more than before? If so in what way?

8. Any other comments

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care Draft Topic Guide for Patient Interviews

Interview 2

The interview topic guide will be further developed, refined and piloted during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. Major changes to the patient's circumstances, health, and any illness/treatment events since the first interview

Draft prompt questions:

- How has your health been in the last six months?
- Have you had any admission to hospital?

2. Any further experiences with the ReSPECT process/review since the first interview

Prompt questions:

- Has your ReSPECT form been updated or changed in the last six months?
- If so, What circumstances led to this; who initiated the review/process; when and how was it acted on?
- Have you thought about the form or the process at all in the last six months? If so, how have your views about it changed?

3. Perceptions of the influence of the ReSPECT process on any illness/treatment events

Draft question prompts:

- Thinking about any illness episodes in the last six months, did your doctor or nurse refer to the ReSPECT form?

4. Changes in thoughts and feelings about the ReSPECT process since the first interview

Prompts:

- Last time we talked about whether the ReSPECT process had changed the way you think about yourself and your health/illness. Has that changed at all in the last six months?
- We also talked about whether you thought the ReSPECT form/process made a difference to the care and treatments you receive. Has that changed at all in the last six months?
- We also talked about whether the ReSPECT process made you trust your doctors and nurses more. Has that changed at all in the last six months?
- How confident are you that the recommendations on the form will be acted on
- Can you think of how the ReSPECT process or form can be improved?

5. Any other comment

ReSPECT in Primary Care

Evaluating the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) in Primary Care Draft Topic Guide for Relative Interviews

Interview 2

The interview topic guide will be further developed and refined during the study in collaboration with our PPI advisory group.

Topics for discussion:

1. Major changes to the patient's circumstances, health, and any illness/treatment events since the first interview

Draft prompt questions:

2. How has your relative's health been in the last six months?
3. Have they had any admission to hospital?

4. Any further experiences with the ReSPECT process/review since the first interview

Draft prompt questions:

- Has your relative's ReSPECT form been updated or changed in the last six months?
- If so, what circumstances led to this; who initiated the review/process; when and how was it acted on?
- Have you thought about the form or the process at all in the last six months? If so how have your views about it changed?

5. Perceptions of the influence of the ReSPECT process on any illness/treatment events

Prompts:

- Thinking about any illness episodes in the last six months, did your relative's doctor or nurse refer to the ReSPECT form?

6. Changes in thoughts and feelings about the ReSPECT process since the first interview

Prompts:

- Last time we talked about whether the ReSPECT process had changed the way you think about your relative's health/illness. Has that changed at all in the last six months?
- We also talked about whether you thought the ReSPECT form/process made a difference to the care and treatments your relative receives. Has that changed at all in the last six months?
- We also talked about whether the ReSPECT process made you trust your relative's doctors and nurses more. Has that changed at all in the last six months?
- How confident are you that the recommendations on the form will be acted on
- Can you think of how the ReSPECT process or form can be improved?

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Topic Guide for Parent/Carers of people with learning disabilities Focus Group

We want to discuss with you about what would work well for you in an Emergency Plan for care or treatment and what is good about what happens now or how can it improve?

1. Under what circumstances do you think you would need to consider making an Emergency Care/Treatment plan?
2. Why might someone with a learning disability want or need an emergency care treatment plan?
 - a. What might be the positives/ benefits? How might it help them?
 - b. What are the challenges eg; the parent/carers views may be different to those of the person with learning disabilities or the person with learning disabilities may not want a plan, Do Not Resuscitate wishes?
3. How do you usually find out the views of the person with learning disabilities you care for?
 - a. What tools, strategies, resources, technology do you use at home?
4. Optional – Have you ever made an emergency care treatment plan?
 - a. What was the outcome of doing an Emergency Care/Treatment Plan or what can they expect following a completion of a plan. What happens next?
5. How might the person's learning disability influence what you put in the form/the recommendations you would like to see put in the form?
6. How does your role as carer influence what recommendations you would want to see in your own personal form?
7. When do you think it's a good time to talk about having an emergency care treatment plan:
 - a. for the person you care for?
 - b. for yourself?

8. Who do you think should initiate the conversation for the person you care for?
 - a. E.g. you, your doctor, a nurse, a care worker? Why?
 - b. Is there a particular health or care professional or support organisation / individual you would want to have this conversation with? Why?
 - c. Would you want anyone else to be involved? Who?

9. Who would you like to initiate the conversation for your own emergency care treatment plan if you were to have one? Why?

10. How confident are you that the emergency care treatment plan would get implemented by the right people at the right time?
 - a. for the person you care for?
 - b. for yourself?

11. What would you need to see happen for you to feel confident that your plan would be carried out as you or the person with learning disabilities wished?
 - a. Can you think of anything that might help address some of the issues you identified [make specific to the issues they raised]
 - b. What could be improved?

12. Do you think there are benefits of having emergency care treatment plans for people with learning disabilities to the health and social care system?
 - a. Do you think there are benefits of emergency care treatment plans to other support services/help you might receive/other agencies you interact with?

13. To summarise, revisit question do you think emergency care treatment plans overall are a good idea?

14. What else would you like to discuss?
 - Death & Dying Matters Trusts and Wills Power of Attorney
 - Advanced Care Planning Arranging Funerals Other