

# BMJ Open Quality Proactive advance care planning conversations in general practice: a quality improvement project

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**To cite:** Winniffrith T, Millington-Sanders C, Husbands E, *et al*. Proactive advance care planning conversations in general practice: a quality improvement project. *BMJ Open Quality* 2024;**13**:e002679. doi:10.1136/bmjopen-2023-002679

Received 7 November 2023  
Accepted 7 November 2023

## ABSTRACT

Advance care planning (ACP) is a process of discussion, reflection and communication, enabling planning for future medical treatment. Despite evidence of benefits of ACP to patients, families and the healthcare system, many die without an opportunity for such conversations, particularly those living with progressive non-malignant conditions. The Royal College of General Practitioners and Marie Curie Daffodil Standards launched in 2020 provide primary care with a structure for improving end-of-life care, including delivery of ACP. Proactive identification of patients is integral to the approach.

We report on a quality improvement project which aimed to assess the take-up rate and acceptability in general practice of a timely and personalised ACP conversation using a 'What matters to you' (WMTY) framework, and to ensure that different diagnostic and demographic groups were included.

Patients without previous ACP and potentially in the last year of life were offered an ACP conversation; a survey sought feedback.

81% accepted the offer and in most cases, future care guidance was documented using the recognised format in Gloucestershire for recording ACP conversations, the Recommended Summary for Emergency Care and Treatment (ReSPECT) plan. Clinician and patient satisfaction was high.

We concluded that an ACP discussion using a 'WMTY' format was highly acceptable to most. With recognised enablers in place and known barriers minimised, valuable personalised conversations occurred. Reframing the conversation to focus on how someone wants to live, while including their priorities for death, could alter how such conversations are perceived by clinicians and the public. It could remove negative associations (such as linking these conversations with an imminent death), which may increase motivation for all to initiate discussions.

ACP conversations are evidenced best practice and could become routine in general practice with adjustments to practice processes and clinician education; the Daffodil Standards facilitate continued quality improvement.

## PROBLEM

Underwood Surgery, a suburban surgery, has 12 000 patients of predominantly white British ethnicity. There are approximately 120 deaths expected each year. In 2021, an audit showed:

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Despite evidence of its benefits to patients, families and systems, many die without opportunities for advance care planning (ACP), especially those without a malignancy.

## WHAT THIS STUDY ADDS

⇒ Patients usually welcome opportunities to discuss their future care even when well; proactive identification/invitation can be highly acceptable.  
⇒ Use of 'WMTY' language and a reframing of conversations to be about living as well as dying are enablers to successful conversations.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Clinician training on ACP could be reformulated to empower clinicians to adopt 'WMTY' language rather than a typically formulaic approach to ACP which merely addresses care plan template questions.  
⇒ Cost-effective and sustainable solutions might include: the incorporation of an offer of ACP at the long-term condition review; proactive identification using 'The Surprise Question'; and use of the Daffodil Standards as a framework for quality improvement across the practice population.

- ▶ Only 83 patients (37 in care homes, 46 in own homes) had evidence of advance care planning (ACP), as measured by the presence of a Recommended Summary for Emergency Care and Treatment (ReSPECT) plan.<sup>1</sup>
- ▶ Only nine of these were on the palliative care register.

Two retrospective death audits gave findings matching previous research:<sup>2 3</sup>

- ▶ ACP conversations often occur too late to be meaningful.
- ▶ ACP conversations are more likely to occur if the diagnosis is a malignancy. Our findings: 97% of patients with metastatic cancer, 17% of those with dementia and 9% of the over 90s had evidence of ACP. In addition, our baseline results indicate an underuse of the palliative care register. Only



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patients with metastatic cancer were on it. Reasons for this could include an unwillingness to identify/label a patient as 'palliative', even though they could be living with and dying from progressive conditions. This mismatch means that no structured system existed within our practice by which to identify patients who could benefit from 'What Matters to you' (WMTY) conversations over time.<sup>4</sup>

It was the results of these audits, the demonstration of the underutilisation of the palliative care register, as well as an evolving model of best practice through initiatives such as the Daffodil Standards<sup>5</sup> that provided the impetus for our quality improvement (QI) study which was designed with the following SMART (Specific, Measurable, Achievable, Relevant and Time-Bound) aims:

- ▶ To increase the number of people offered an ACP discussion in all diagnostic and demographic groups known to predict deterioration and/or death.
- ▶ To measure the take-up rate of such an offer.
- ▶ To increase the number of people with a completed ReSPECT plan within the practice by at least 50% to 126. This figure was chosen as there are, on average, approximately 120 deaths per year in the practice.
- ▶ To assess by questionnaire the acceptability of an ACP conversation with a 'What matters to you' emphasis.

## BACKGROUND

ACP is recognised as best practice care for patients at risk of a decline in their health and/or mental capacity, and can have a positive impact on patient, carer and system outcomes. It is a therapeutic process in itself and enhances patient autonomy by ensuring that views are recorded before capacity is lost.<sup>6</sup> Family can be relieved of the burden of decision-making, resulting in reduced anxiety and guilt and improved bereavement outcomes.<sup>7</sup> There can be cost savings from reductions in 'unnecessary' interventions, and there is an increased likelihood of patients dying in their preferred location.<sup>8,9</sup>

In a 2019 systematic review of ACP interventions, barriers and enablers, Risk *et al* identified barriers at the following levels: individual (eg, perceived irrelevance, lack of patient awareness), interpersonal (eg, lack of role clarity), provider (eg, lack of time) and systemic (eg, poor system linkages between primary and secondary care).<sup>10</sup> They also found four key components to success: trained facilitators, a system for identifying eligible patients, a structured and personalised conversation and the opportunity to complete ACP documents.

In UK general practice, many of these barriers to ACP exist and many enablers are absent, which may explain why rates remain low, despite it being recommended practice for over a decade. There have been national initiatives such as the ReSPECT process and the Royal College of General Practitioners/Marie Curie Daffodil Standards, both of which encourage timely and patient-centred conversations. The 2020 COVID-19 pandemic generated new challenges and a 2021 Care Quality Commission (CQC) report concerning resuscitation recommendations made during the pandemic

highlighted poor practice, but also reinforced that this predated 2020.<sup>11</sup>

Abel *et al* explored the need to reimagine ACP during COVID-19 and beyond.<sup>12</sup> Changing ACP from being an end-of-life conversation to one about 'living with dying' was shown to concur with the principles of the Ottawa Charter for Health Promotion, with the model helping to remove some of the barriers and thus increase the completion rates of ACP.

The 2021 CQC report led to the publishing of 'Universal Principles for Advance Care Planning' in 2022 to facilitate a national approach to ACP.<sup>13</sup> This includes requirements to proactively identify patients, strengthen record keeping and improve information transferability between settings.

The palliative care amendment to the 2022 Health and Care Act<sup>14</sup> makes explicit the need to promote ACP conversations, and Ambitions for Palliative and End of Life Care: A national framework for local action 2021–2026<sup>15</sup> suggests as ambition 1:

I and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me.

The ReSPECT plan (version 3) is designed to facilitate such conversations, encouraging a shift away from a narrow focus on the recommendation around attempting cardiopulmonary resuscitation (CPR).

The expectation is therefore that more ACP conversations will take place in general practice and the Daffodil Standards QI programme provides general practice with population-based structure for identification, documentation and coordination of care to occur. However, this work needs resources not currently recognised in the core general practitioner (GP) contract.

Our project was designed to trial an intervention which incorporated as many enablers as possible and minimised potential barriers using the criteria in standards 2 and 5 of the Daffodil Standards as a template for what was offered.

## MEASUREMENT

ACP has many outcome measures, some of which require qualitative rather than quantitative evaluation. The conversations can be therapeutic and lead onto further discussions within families. The outcomes amount to more than that which is documented, and more than the decisions made, making measurements intrinsically difficult. The time limit of the project meant that some outcomes were not able to be measured. Given these challenges, data collection was limited to the following outcome measures.

### Quantitative

- ▶ Number of patients who accepted the offer of an ACP conversation.

- ▶ Total number of ReSPECT plans within the practice population, before and after the project.
- ▶ Increase in numbers of patients with non-malignant conditions who had evidence of an ACP conversation.

### Qualitative

- ▶ Results of survey on acceptability of the intervention.
- ▶ Feedback from those who elected not to attend.

### Other measures not recorded

- ▶ Balancing measures would have included measuring the impact of having a 1:1 appointment with a GP for a longer than usual duration, especially at a time when face-to-face appointments with a GP were perceived to be limited.
- ▶ Process measures such as the impact of the project on increased knowledge and confidence about offering ACP within the multidisciplinary team (MDT). We acknowledge this may have contributed to the positive outcome measures.

### DESIGN

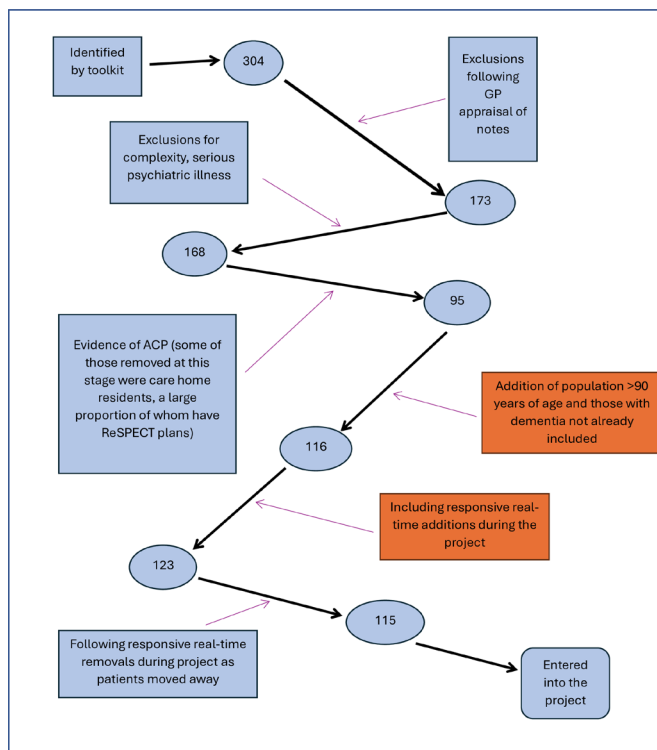
The project team consisted of the lead GP, a palliative medicine consultant and two members of the 'Ageing well' team from Gloucestershire Clinical Commissioning Group, now Integrated Care Board (ICB). Due to the sensitivity of this project, a focused consultation with the following provider partners took place:

- ▶ Age UK.
- ▶ Carers UK.
- ▶ Gloucestershire County Council Community Development Team which works with black and minority ethnic communities.
- ▶ Local care homes and assisted living facilities.
- ▶ Complex Care at Home matron.
- ▶ Resuscitation Council UK clinical lead for ReSPECT.
- ▶ Practice team at Underwood Surgery.

### Participant identification

The identification of patients who stand to benefit most from ACP is difficult due to variable illness trajectories and sudden deaths. Due to limited time, we focused on those who are most likely to die or deteriorate within a year, despite this not always being predictable. Over the last few years, several tools have emerged to try and identify patients who may be at risk of death or loss of capacity within the next 12 months. The EARLY Identification in Primary Care (EARLY) toolkit was developed in 2019–2020 and we used this because of its adoption by National Health Service England.<sup>16</sup> Over 300 patients were initially identified; in an average GP practice approximately 1% of patients (120 in Underwood Surgery) die each year. The following steps were then taken:

- ▶ **Inclusions:** The lead GP appraised the likelihood of each patient being in the last year of life or losing capacity; those in neither group (n=131) were removed. Of these, the vast majority had a diagnosis of cancer several years ago and were under 70 suggesting that the overinclusivity of the toolkit is mainly due to



**Figure 1** Flow chart showing the pathway to finalising the cohort.

the identification of people with a previous cancer but in no other high-risk group.

- ▶ **Exclusions:** Those who already had evidence of recent ACP were excluded, as were those deemed to be more suitable for a conversation with their own GP, because of complexity or severe psychiatric illness.
- ▶ **Missing patients:** An additional search was made to identify patients aged over 90 or with dementia who had not been already identified. The latter may not die within 12 months but are at risk of losing capacity. Relatively fit 90+ year-olds may well live for more than 12 months but become increasingly likely to require more care or have hospital admissions. Their views are therefore important to capture.
- ▶ **Responsive real-time additions over 6 months:** During the 6-month project, some patients were added to the list following clinical events or direct requests from the patients or families.
- ▶ **Responsive real-time removals over 6 months:** Eight patients moved away from the practice.

After exclusions and additions, the number of patients selected was 115.

The flow chart shows the pathway to finalising the cohort (figure 1).

Table 1 shows the demographics and primary diagnoses of participants.

### Contacting patients identified

A letter was drafted then modified following consultation with provider partners. It began as follows:



**Table 1** Patient demographics and primary underlying diagnoses

		Percentage
Gender	Male	36
	Female	64
Age (years)	<71	3
	71–80	25
	81–90	46
	>90	26
Ethnicity (this is representative of the practice population)	White	99
	Asian	1
Primary diagnosis	Cancer	12
	Dementia/cognitive problems	32
	Chronic obstructive pulmonary disease	3
	Cardiovascular disease/peripheral arterial disease/chronic kidney disease	32
	Neurodegenerative disease	1
	Frailty	7
	No clear diagnosis	13

We are starting a new service in which our patients will be given an opportunity to discuss their priorities for their present and future care.

During these 30–40 minute appointments with me, Dr XX, we can discuss both what is important to you now, in your current state of health, and also what you think would matter to you most in the future, should you become seriously ill or less able to make decisions for yourself about the care you would like to receive. Some aspects of the conversation will be recorded in your medical records. It can be helpful to have a family member or friend present if you wish.

The letter was sent to 5–10 patients on a weekly basis. One of the first patients contacted said that the letter made him feel ‘as if his life was nearly over’. As a result of this, the letter was changed as follows:

We are inviting you (with a family member if you wish), to have a 30–40 minute conversation with me, Dr XX, about what matters most to **you**, and about what **your** priorities are for your health and care, both at the moment and in the future.

It is hoped that this will provide an opportunity for you to consider, discuss and share with others what matters most to you, as well as any fears about the future you may have, and also to consider what choices you might make about your health and care, both now, and also if your health should at any point deteriorate. It is hoped that the process of having this conversation, will mean that **your** views are firmly at the centre of your care over time.

No more negative feedback was received, but it was noted that in a very few cases, patients attended willingly, but said that they were not quite clear what the letter was about. This reinforces the need for public education around ACP/WMTY-based conversations.

A follow-up phone call after 1 week invited the patient to an appointment. If there were capacity concerns, the next of kin was telephoned.

### Intervention

- ▶ This was a 30–40 min appointment with the lead GP, funded by Gloucestershire ICB. The GP used a ‘What matters to you’ framework, in preference to narrowly focusing on decisions around certain interventions, though a conversation about resuscitation was always offered. This meant that the conversation was about how the patient wanted to live, as much as how they wanted to die. The GP started each consultation with a structure in mind, but with continued reflection on what questions led to productive conversations, there was learning and adaptation throughout.
- ▶ If appropriate, a ReSPECT plan was generated during the appointment; where required, further appointments were offered.
- ▶ Patients were given a leaflet written by the GP and the ICB, reiterating the importance of the ReSPECT plan staying with them, of sharing the contents with family if desired and reminding the patient that it could be updated.

### Administration

- ▶ When completed and with consent, ReSPECT plans were shared with relevant hospital teams.
- ▶ Coding using an agreed Read code was completed in the GP clinical record.

### STRATEGY

The Plan-Do-Study-Act element of this project was dynamic and focused on the development of the process.

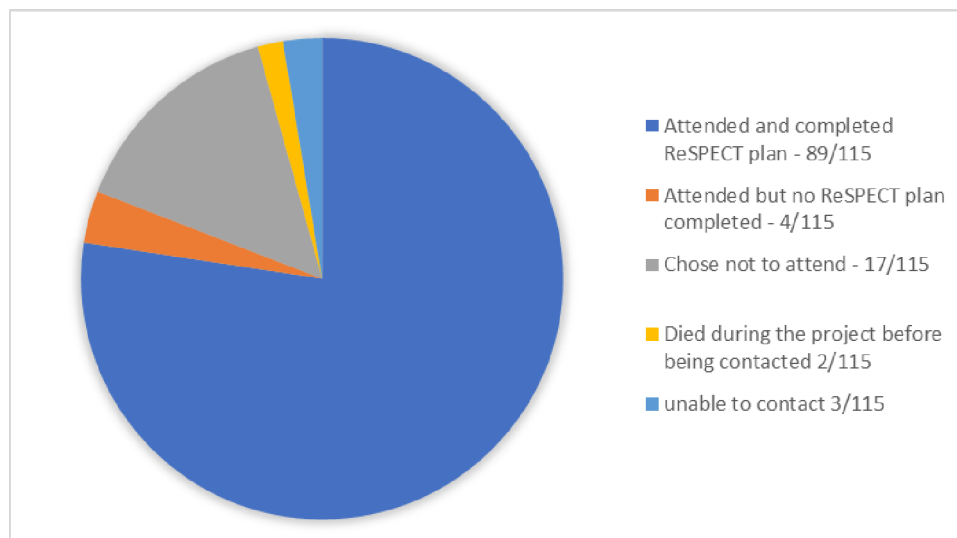
- ▶ The invitation letter was modified as feedback was received.
- ▶ There was continuous modification of the semi-structured conversation used, as the GP learnt what approaches worked well.
- ▶ The process adapted to expected challenges (some patients needing additional appointments to allow time for reflection/discussion with family) and unexpected ones (patients bringing unrelated medical problems to the consultation).

### RESULTS

#### Quantitative measurements

84 patients were seen face to face. For nine patients who were lacking capacity, a conversation was had by telephone or email, with the appropriate nominated representative.

Most consultations (96%) led to completion of a ReSPECT plan. In two of the cases in which it didn’t, these patients were deemed to lack capacity and a further



**Figure 2** Pie chart showing the results of the contact.

appointment was made for a later date, at which a best interest's approach could be adopted. In the other two cases, competing issues led to deferral of ACP.

Figure 2 presents a pie chart showing the results of the contact.

When patients or relatives declined the offer of an appointment, reasons given included:

- ▶ 'I know I should, but I don't want to.'
- ▶ 'Everything is fine thank you. We will call if we need you.'
- ▶ 'I just don't want to go there.'
- ▶ 'It is making my Mum anxious thinking about it.'

Total number of ReSPECT plans in practice at baseline: 83

Total number of ReSPECT plans in the practice population at the end of the project: 185

This represented an additional 102 plans, 89 of which were completed within the project; over 90% of these plans were in patients with a non-malignant diagnosis and all plans completed within the project were for patients not residing in care homes.

### Qualitative measurements

Four months into the project, patient satisfaction surveys were sent to all those so far contacted during the project (64 patients), whether they had elected to attend or had declined.

Response rate was 52%. No responses were received from the non-attending group.

Figure 3 shows the results of the survey (n=64).

Examples of free-text comments:

- ▶ 'Having the conversation with the doctor made it easier for me to discuss it with my family.'
- ▶ 'I was pleased to be able to discuss my future care whilst I am still able to.'
- ▶ 'I was grateful to be able to refresh and confirm previous decisions and confirm no changes had arisen since that date.'

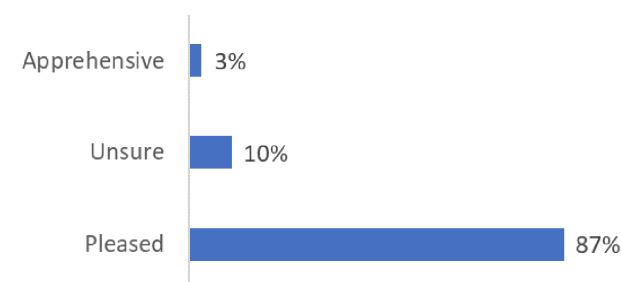
- ▶ 'Something we all have to address so it worked well.'
- ▶ 'The personal touch with a home visit and the doctor really listening to what was wanted in the way of care at home.'
- ▶ 'The freedom to talk and express thoughts and feelings.'

### LESSONS AND LIMITATIONS

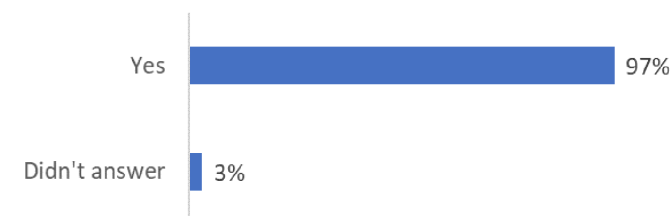
#### Strengths and unexpected benefits of the project

- ▶ Consultations were entirely patient centred, with satisfaction and experience for patients, family and the lead clinician, reflecting this.
- ▶ Proactive identification enabled ACP conversations with classically under-represented diagnostic groups.

What emotion did you feel on receiving the letter?



Was the conversation helpful?



**Figure 3** Results of the survey (n=64).



- ▶ Reframing ACP conversations by adopting ‘WMTY’ format was an enabler for conversations.
- ▶ The profile of ACP was raised in the practice among all staff. There was a promotion of discussion of patients at the end of life and openness about difficulties encountered in discussing the future, but also an increased sense of achievement and teamwork when a patient’s wishes at the end of life were upheld.
- ▶ There was a ‘trickle’ effect; it became clear that the project was discussed informally among residents of our local assisted living facility, resulting in direct requests for appointments.
- ▶ The number of patients on the palliative care register, particularly those with a non-cancer diagnosis, increased as a result of the project. This greatly improved the register’s usefulness as an anticipatory tool, by which the need for symptom control, ACP, deprescribing and additional support could be identified.
- ▶ The project results have been shared through the ICB’s End of Life Clinical Programme Group with a task and finish group established to progress clinician education on the ReSPECT process and Daffodil Standards, proactive identification of patients where ACP may have a role, as well as the public engagement around ACP. Within the practice, the cohort of patients who may benefit from ACP is now being continuously proactively identified and at monthly MDT meetings, those who have no evidence of an ACP conversation are highlighted.

### Lessons learnt during the project

- ▶ Lack of robust coding and use of the EARLY ID toolkit led to overidentification of invitees. Additional GP time was then required to confirm who should be contacted.
- ▶ Administration time was considerable. Improved coding and better recording of next of kin details would improve this.
- ▶ Mismatches between patient and GP understanding about the state of the patient’s health can impede ACP conversations. In some cases, this can be attributed to lack of shared understanding or communication between secondary care, the patient and the GP. Sharing this project with the ICB aims to try and address this challenge.
- ▶ Mismatches about (a) what an ACP conversation entails and (b) the impact and success rate of CPR can be barriers. Giving written information beforehand may have helped. However, as the response of one patient to the first iteration of the invitation letter showed, it is often hard to know how much and what information to provide, and how to nuance it to the individual.
- ▶ Sometimes it was hard to get beyond what was going on ‘in the moment’; physical or social concerns had to be addressed before the ACP conversation could progress.

This may have been influenced by the timing of the project, 20 months after the start of the pandemic.

### Limitations of the project

- ▶ The principal limitation was the fixed time nature and lack of additional cycles following modification. Iteration (having more than one conversation) is a known enabler to successful ACP and most patients in this project did not have a follow-up. In addition, more time might have enabled answers to questions such as:
  - Did having a ReSPECT plan result in avoidance of a hospital admission or in people achieving their desired place of death?
  - For those still alive, had they discussed their plan with family and was it still safe and accessible?
- ▶ A robust cost/benefit analysis of this project was not done. The economic benefits of ACP are clearly far less important than the benefits to patients, but it is important to ensure sustainability.

### CONCLUSION

#### How this study makes meaningful contribution to literature, policy and practice

Our study achieved its aims: 115 people in many different diagnostic groups were offered an ACP conversation and 81% accepted; the number of ReSPECT plans completed increased by more than 50% with a high degree of patient satisfaction. We saw an improvement in access for patients with non-malignant conditions.

Many of the results of this study concur with findings in current literature. The conversations gave high levels of satisfaction among the patients who were seen, but a small proportion of patients clearly did not want to discuss their future care for a variety of reasons. Risk *et al*’s systematic review found several studies reporting that the perceived irrelevance of ACP was a barrier, especially in those who felt well and did not have a well-defined terminal diagnosis.<sup>10</sup> However, we demonstrated a remarkable level of engagement even with a ‘well’ population.

Risk *et al* also highlight many enablers to successful ACP including the provision of education about the subject.<sup>10</sup> We found a need for education about CPR and about illness trajectories; patients were given written and visual resources after the consultation, but these may have been more impactful if provided before.

This study makes significant new contributions in the following ways: first, by showing that a proactive invitation to discuss ACP is usually welcomed; and second, by using a ‘What matters to you’ framework in the conversation and positively reframing it to being about how someone wants to live, many of the previously identified barriers (lack of understanding of disease progression, difficulties with prognostication, hesitation, denial, wish to protect others) become less of an impedance. When a conversation is about important goals/outcomes/trade-offs and not hard and fast decisions, these barriers become less relevant. The art of general practice is to enable patients to live as well as possible throughout their entire lives, and this reframing of ACP to being about exactly

this has the potential to make initiating it highly acceptable to GPs and other healthcare professionals working within primary care.

The potential of such personalised conversations to aid clinical decision-making should not be underestimated. For example, in our study, a patient expressed her fear of increasing breathlessness:

My heart doesn't function as well as it used to, and I do not like being breathless. I am afraid of being treated for an illness like a heart attack, if that treatment, brought me back to a state in which I am even more breathless than I am now...

This statement offers more nuanced guidance to clinicians than that given by dichotomous statements about resuscitation/ventilation, etc.

Our project was not sustainable in the form outlined, given the additional GP time that was required.

And yet, in line with current legislation and in preparation for the anticipatory/proactive care component of the GP contract, general practice needs to adapt so that patients who may benefit from ACP are identified and opportunities are created. Reflecting on the experience of conducting this project, we feel that QI could occur with the following changes.

#### Practice processes

- ▶ Flag in notes of patients who could be offered an ACP conversation. Our project demonstrated that under-represented groups could welcome a conversation, and flagging notes in such patients may help remind the wider primary care MDT about ACP. A similar toolkit to the one we used, or use of the surprise question 'would you be surprised if this patient died within the next year?', could be used to decide whether a flag is appropriate.
- ▶ Our project suggested a lack of knowledge about ACP and the role of CPR. Information could be provided at the 'long term condition' review in those with a flag. Normalising conversations should enable them to become easier in time for all.

#### Clinicians

- ▶ Conversations which start earlier, are about WMTY and about living well until the end, as well as dying, will work best if there is shared understanding between patient, primary and secondary care. In our project, the conversations which worked best were those in which this shared understanding was present. Any culture change among GPs needs to be mirrored in hospitals. Encouraging 'Goals of Treatment' conversations in secondary care (either inpatient or outpatient) could be a starting point for this.
- ▶ The positive feedback received in our project could be a source of encouragement to GPs, among whom confidence in how/when to initiate ACP conversations is variable. Education could focus on progressing ACP using a value-based approach and integrating conversations into 'routine' practice. Reframing the concept

of ACP from solely having a role in terminal illness to always having a role in enabling someone to live well is key to starting the conversations early, which can then be continued at intervals, with the ReSPECT plan being updated as reviews take place.

#### Service planning

- ▶ Relevant multidisciplinary practice roles such as frailty nurses/care coordinators need to be empowered to identify those in the community who may be in the last year of life but who have not had an ACP conversation.
- ▶ Use of a QI approach within practices but also across primary care networks (PCN) and integrated care systems, as well as promotion of Daffodil Standards, will ensure successes can be celebrated and momentum gained.
- ▶ Population-based dataset through an ICS (Integrated Care Systems) dashboard would support practices/PCNs alongside agreed coding dataset to monitor and build improvements and compare learning across PCNs.

Our project delivered an intervention from which there is much new learning about how to deliver medically valuable ACP conversations in primary care. The improvements in the medical model of delivery of ACP have potential to work synergistically with changes in wider society, and both could promote a culture in which people and their supportive networks could be encouraged to have and share such conversations.

**Contributors** TW was the lead GP for the project with consultation/collaboration from all other authors. The project was written up by TW and EH but has been discussed with all authors who have all submitted amendments. TW, guarantor.

**Funding** This study was funded by Marie Curie, One Embassy Gardens, 8 Viaduct Gardens, London, SW11 7BW.

**Competing interests** Dr. Tabitha Winniffrith, Dr. Emma Husbands, Jane Haros and Helen Ballinger have declared no competing interests. Dr Catherine Millington-Sanders's role as RCGP & Marie Curie national EOLC clinical champion is funded by Marie Curie; Marie Curie had no part in funding our study but they are responsible for funding the submission of the paper.

**Patient and public involvement** Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

**Patient consent for publication** Not applicable.

**Ethics approval** This was a quality improvement project rather than a research study; patients were not involved in the design, conduct or reporting or dissemination plans. Patients were recruited into the quality improvement project with full consent. Participation was entirely voluntary. There was wide engagement with provider partners prior to the commencement of the project.

**Provenance and peer review** Commissioned; internally peer reviewed.

**Data availability statement** Data are available on request.

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