Norfolk and Waveney
Clinical Commissioning Group

Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

Engagement on the campaign about future care preferences

Patient and Public Engagement Report – What you told us.

3 August to 14 September 2020

Executive summary

The national Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) initiative launched in Norfolk and Waveney in March 2020, just before the UK went into lockdown due to the coronavirus pandemic. Although take up of ReSPECT had started, there was still the need to raise awareness among the public about the initiative, and encourage everyone to start thinking about having 'the conversation'. ReSPECT is about articulating care and treatment preferences in the event of an emergency which may affect people with long term conditions and who may be under palliative care.

The Norfolk and Waveney team wanted to learn about how they could design a campaign to encourage people to have 'the conversation' and discuss ReSPECT with their healthcare professional. Views and ideas were gathered using a film and an online survey. The survey also asked for volunteers to come forward who would take part in structured interviews and focus groups such as cancer, we have already sought specific views from some of these groups.

Things we've learned from this survey

Anyone may have a ReSPECT form, but it can be especially relevant for those who are nearing end of life. The subject of 'palliative care' and a discussion around wishes for 'end of life' evoke very strong emotions and feelings for obvious reasons. In general, people who answered the survey fell into three groups, healthcare or ex-healthcare workers, public who'd had a good experience of the process with a loved one, or public who had had a bad experience of the process with a loved one. It is worth noting that most of those who had previously experienced the process would not have encountered ReSPECT, due to it being implemented only months before the survey was launched.

The timing of when to have 'the conversation' was felt to be really important by all, although the right time also varied case by case. However, all agreed that 'the conversation' was important to be had, and that the key people to be involved were a trusted health professional and trusted friends and/or family. In general, all thought that more awareness of the ReSPECT process was needed and came up with many suggestions about how we could improve this.

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More information about ReSPECT

What is ReSPECT?

ReSPECT is a personalised process to plan a person's clinical care in the event of a future emergency. It results in a document that contains the person's wishes and care preferences along with appropriate clinical recommendations. It will also record when a 'Do Not Attempt Cardiopulmonary Resuscitation' (DNACPR) decision has been made but it is important to note that a person can have a completed ReSPECT form and still be 'for' CPR.

For further information, including frequently asked questions, please see https://www.resus.org.uk/respect/

Who is it for?

ReSPECT can be for anyone, of any age. It is most likely to benefit people:

- with complex health needs or
- at risk of sudden collapse or cardiac arrest or
- nearing the end of their lives or
- who want to record their preferences for any reason.

Why is this being introduced?

At present, conversations with those living with serious illness tend to focus solely on decisions relating to cardiopulmonary resuscitation (CPR) which can result in misunderstandings about treatment plans. There is variation across Norfolk and Waveney in how these decisions are documented.

Few people go on to discuss what other types of care they would or would not want in an emergency situation. The ReSPECT process has been developed by the Resuscitation Council (UK) collaboratively with many organisations including patients, the public, and the Royal Colleges with the intention of designing a process that is more acceptable to patients and that standardises processes and documentation across organisational boundaries.

Which questions did we ask?

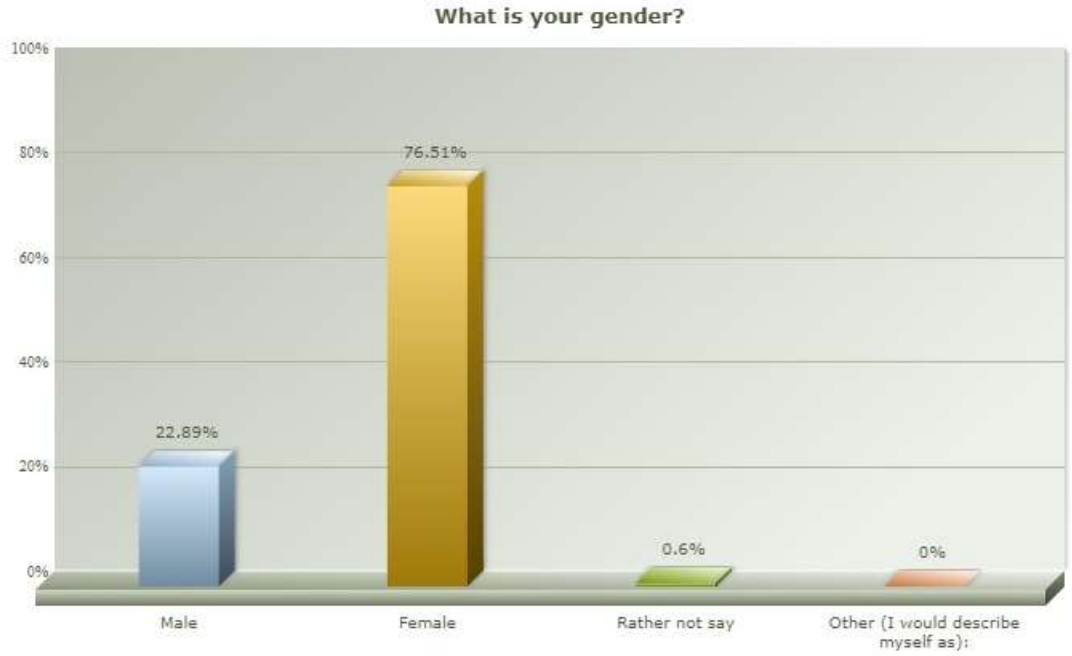
The survey was designed to find out what people think about 'having the conversation' about future care preferences, and to ask about the right messages to encourage people to talk and plan.

We were interested to know:

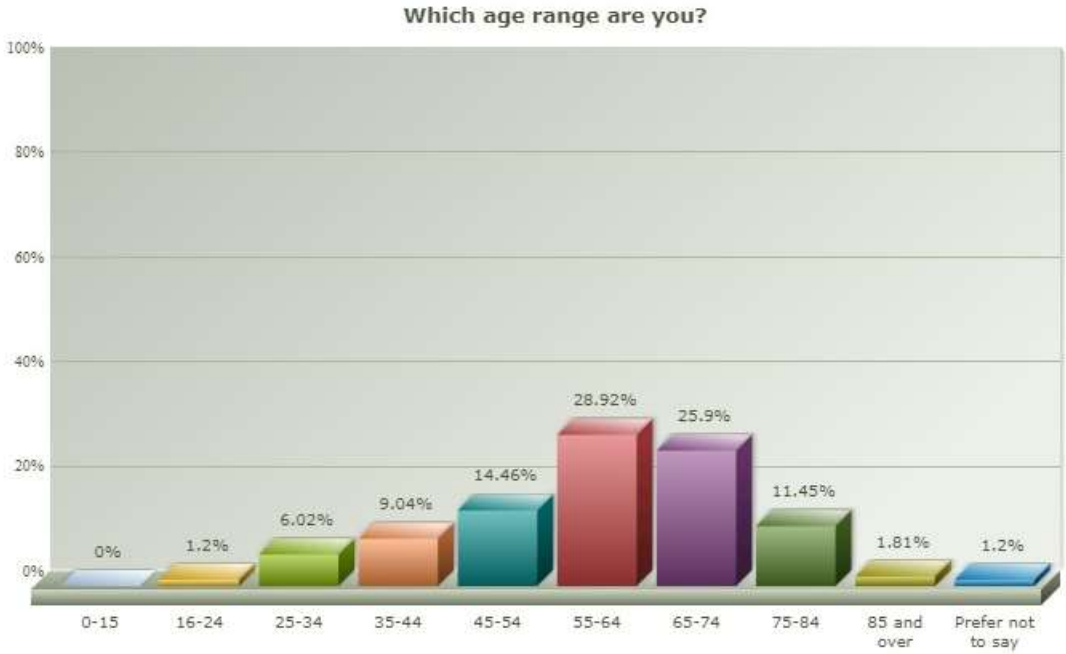
1. How aware people were about the types of language used i.e. 'advanced care plan' and Do not attempt CPR (DNACPR)?
2. Had people already had discussions about themselves or on behalf of others?
3. How should discussions about this be started?
4. How important were religious/cultural viewpoints?
5. Who people trust to deliver messages?
6. Which communications methods people felt were best, and insight into any local opportunities?

Who took part in the survey?

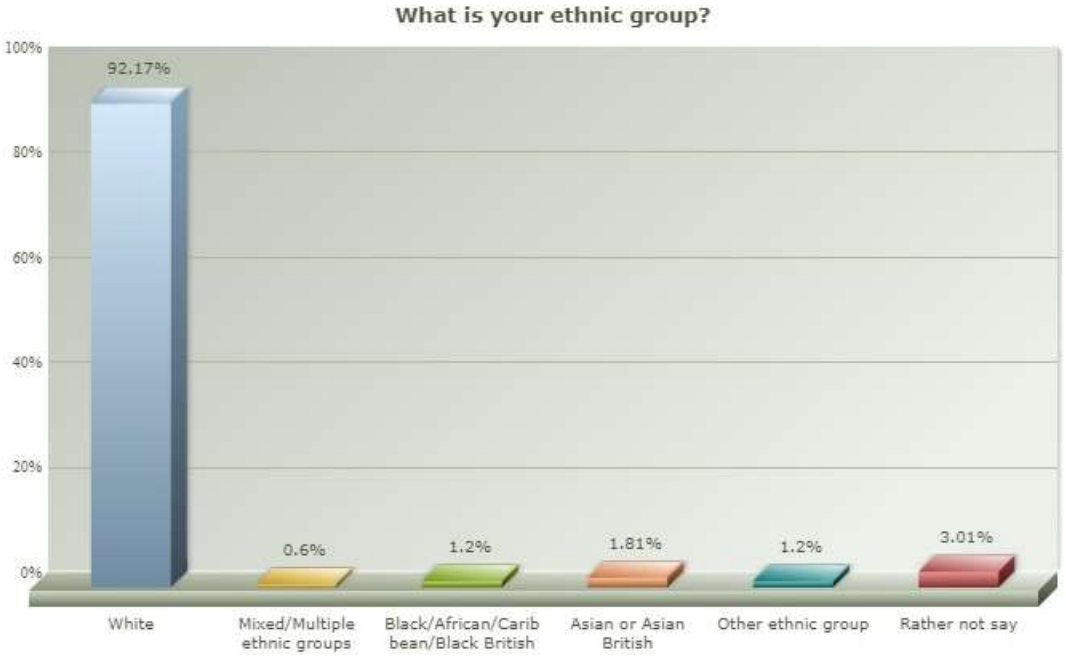
- 166 people completed the survey – 38 men, 127 women (and 1 rather not say) see below



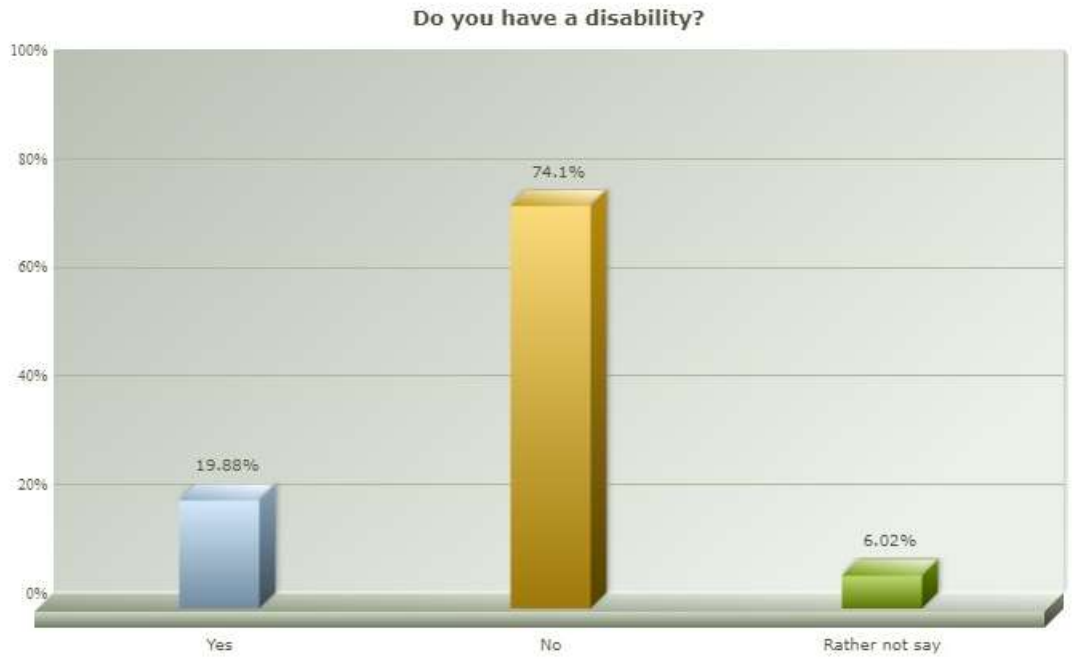
- Respondents represented a good spread of age groups although the majority of people were aged between 55 and 64 years (this group represented 48 people).



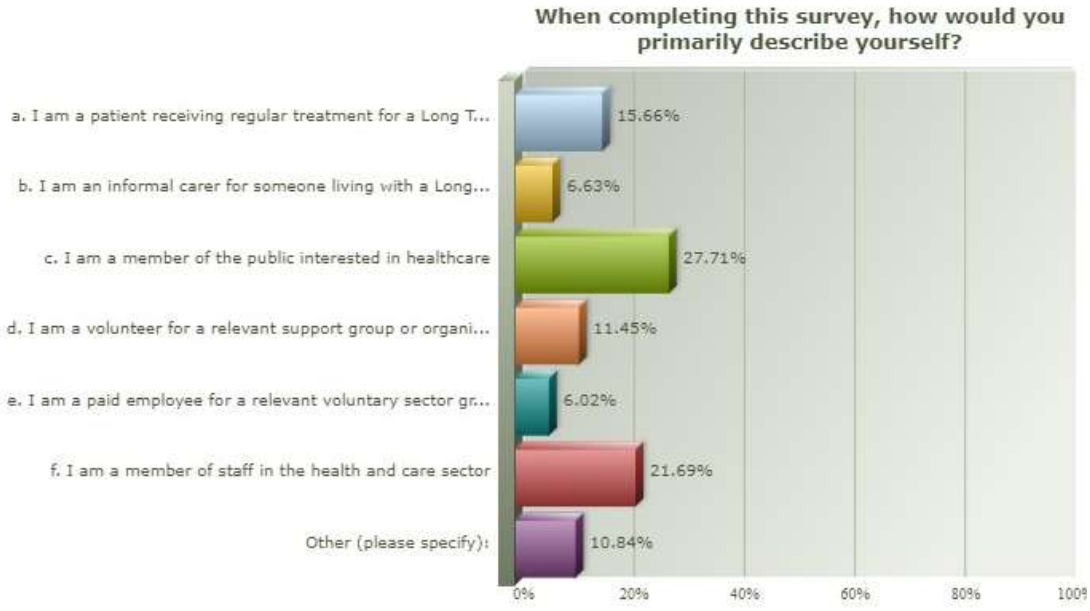
- Respondents predominantly described themselves as white – (153 (92%) out of 166) see below. This reflects the population of Norfolk which has a white population of 96.5%. (2011 Census).



- 33 respondents (nearly 20%) said they had a disability.



- The way respondents described themselves is represented by the graph below:

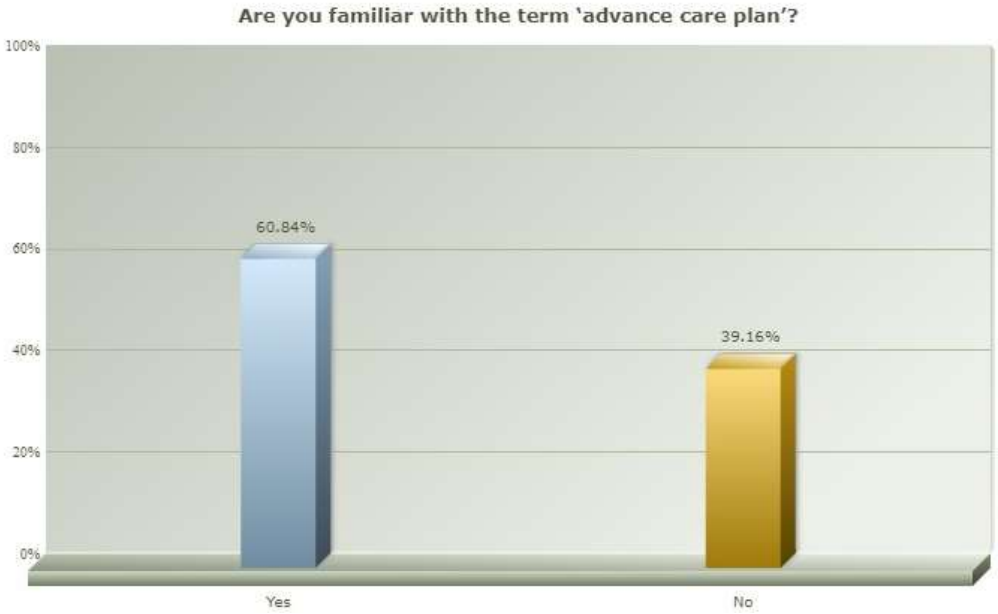


- Respondents were spread across Norfolk and Waveney their locations are represented on the map below.

What did we find out?

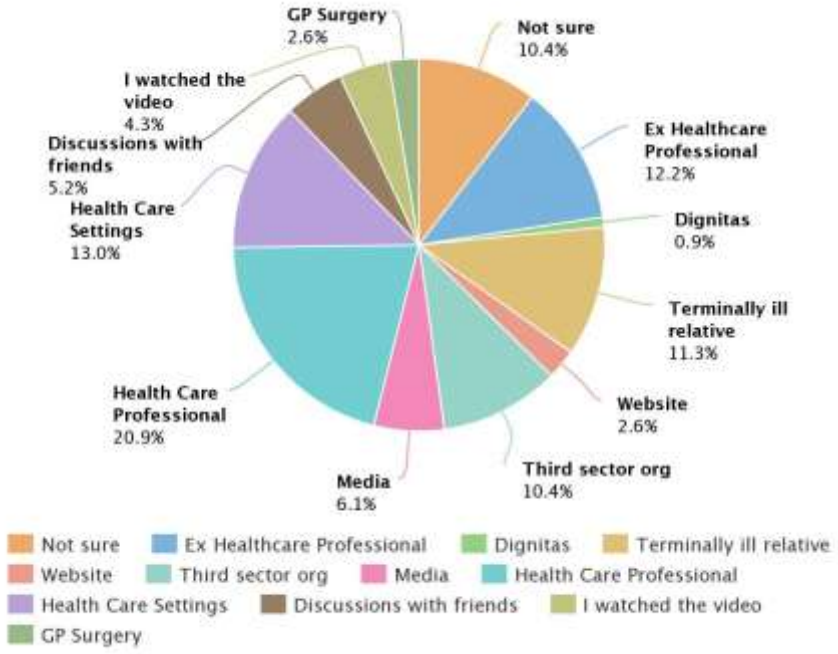
The people who responded gave us feedback which is shown below:

Question 7 | Are you familiar with the term 'advance care plan'? Yes, or no



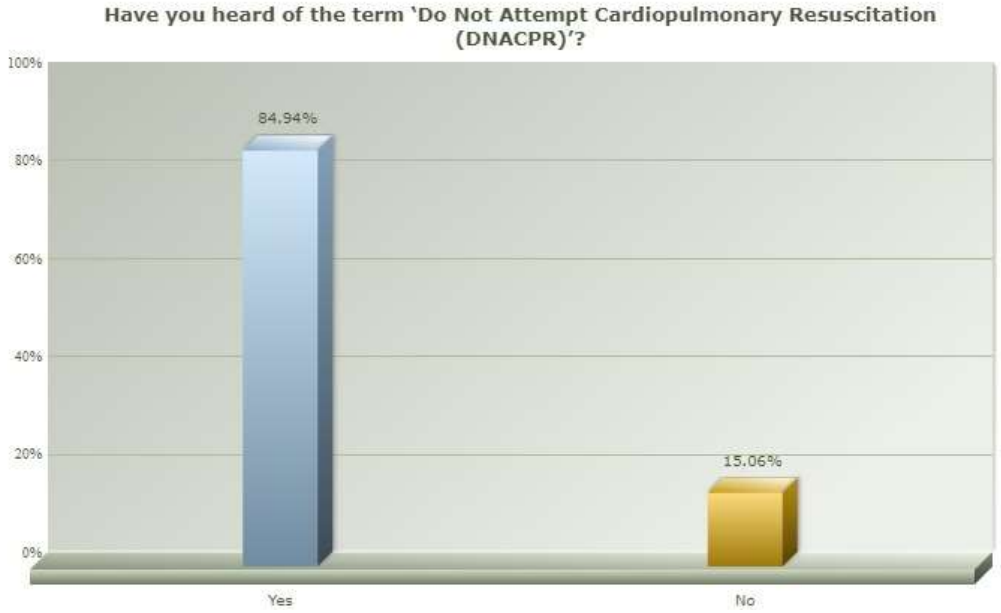
Everyone answered this question (166 people) 101 of the respondents said they had heard of an 'advanced care plan' and 65 had not.

For those who said they **had** heard of it, we asked them how they had heard about it? Their responses have been themed and are represented below.



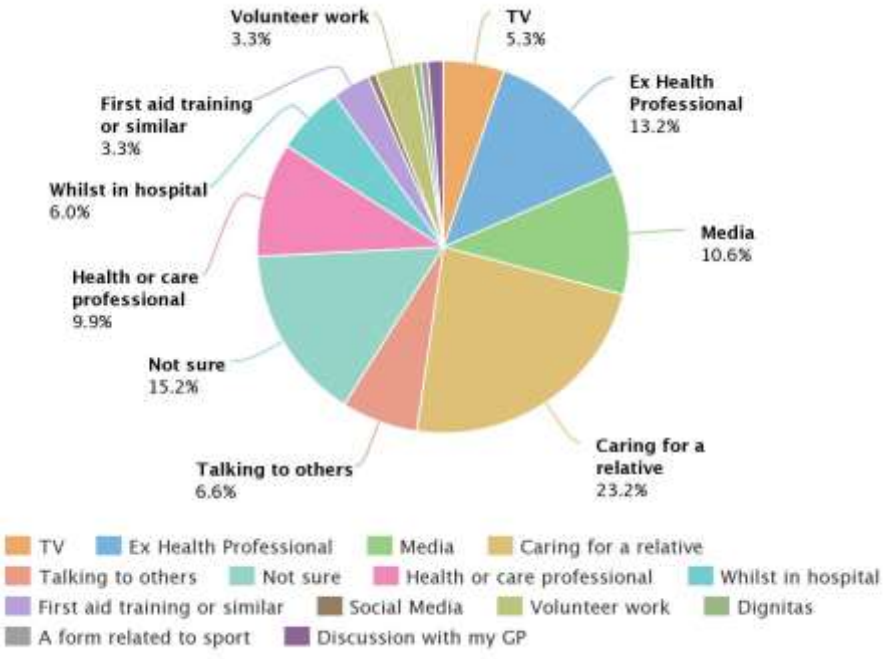
The most common ways in which respondents had become familiar with the term ‘advanced care plan’ was through currently working in the healthcare sector (24 people) or having previously worked in the healthcare sector (14), predictably the phrase had also been heard a lot in healthcare settings and commonly through having a terminally ill relative or loved one.

Question 8 | Have you heard of the term ‘Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)’? Yes, or no?

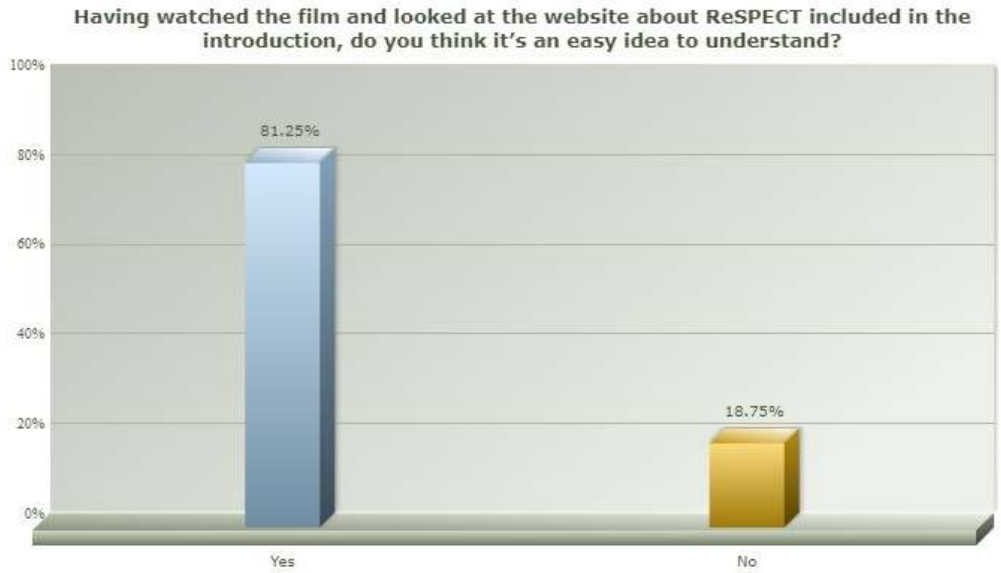


141 of 166 people said they had heard of the term ‘Do not attempt cardiopulmonary resuscitation’.

For those who said they **had** heard of the term, we asked them to tell us where they had heard it? The graph below represents the key themes. The most prominent theme was caring for a relative, 35 people had heard the term through this experience.

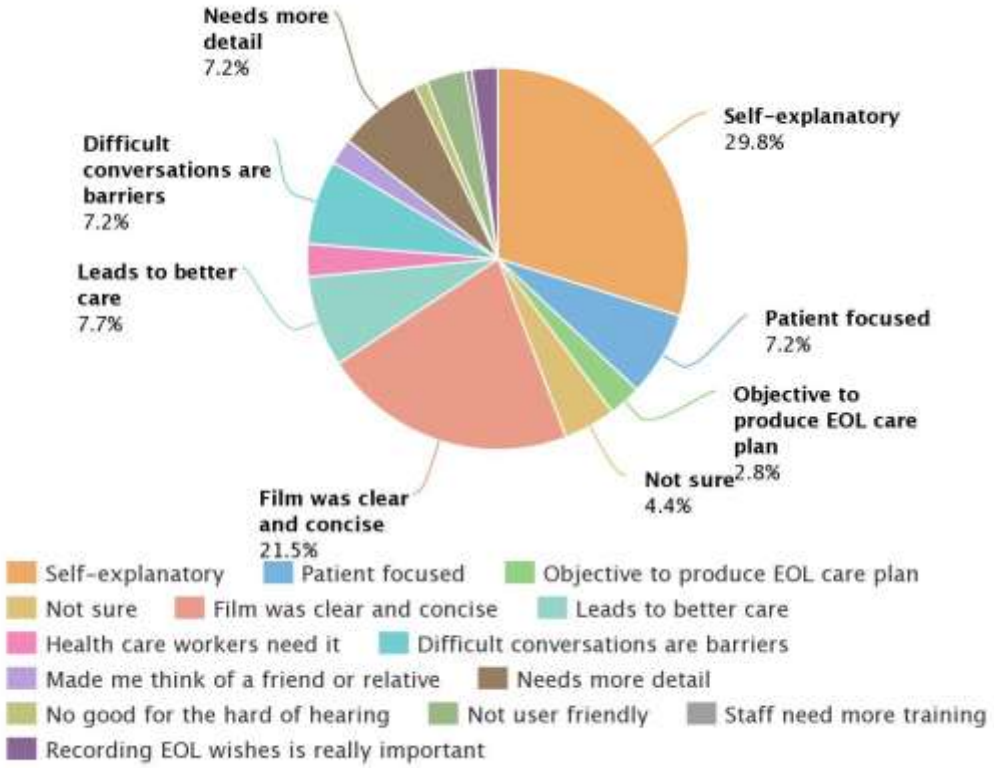


Question 9 | Having watched the film and looked at the website about ReSPECT included in the introduction, do you think it's an easy idea to understand?



130 of the 160 people who answered the question said that they thought the concept of ReSPECT was easy to understand.

We then asked people to tell us more about what they had seen. 102 people responded, the general themes are represented below:

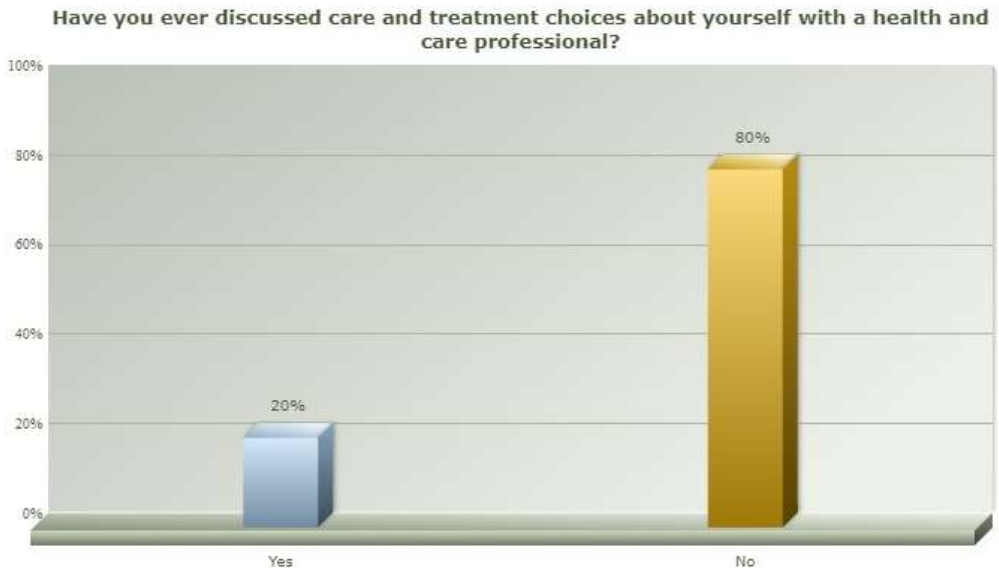


Most people thought the film was self-explanatory (54) and clear and concise (31), although several felt it was not user friendly and could be improved for the hard of hearing by the addition of BSL signed interpretation in addition to the given subtitles.

Some sample comments:

- ‘Most people that are unwell are bombarded with information as it is so easy to google symptoms etc. This could end up being just another form, more paperwork. I have already heard talk outside of work 'Doctors will now be able to put DNR on your record, without your consent'. The message you send out needs to be clear and concise, as in bullet points.’
- ‘It is easy for Hearing people and hard of hearing people but not accessible for Deaf British Sign Language (BSL) users they would need a BSL Interpreter to be able to access this.’
- ‘The film is really good and explains the rationale and process well. However, the links within the website (including the survey) are not distinctive enough.

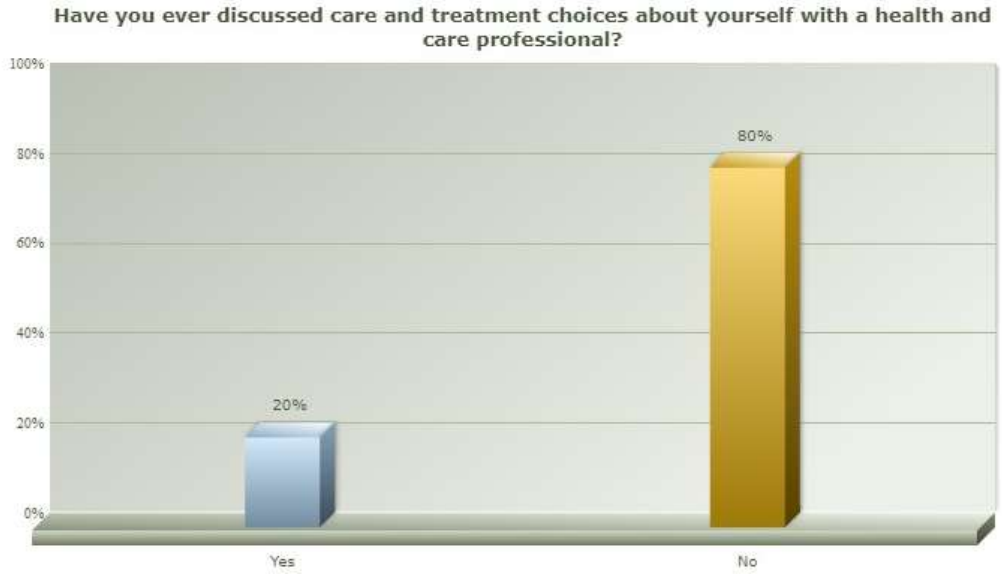
Question 10 | Have you ever discussed care and treatment choices about yourself with a health and care professional?



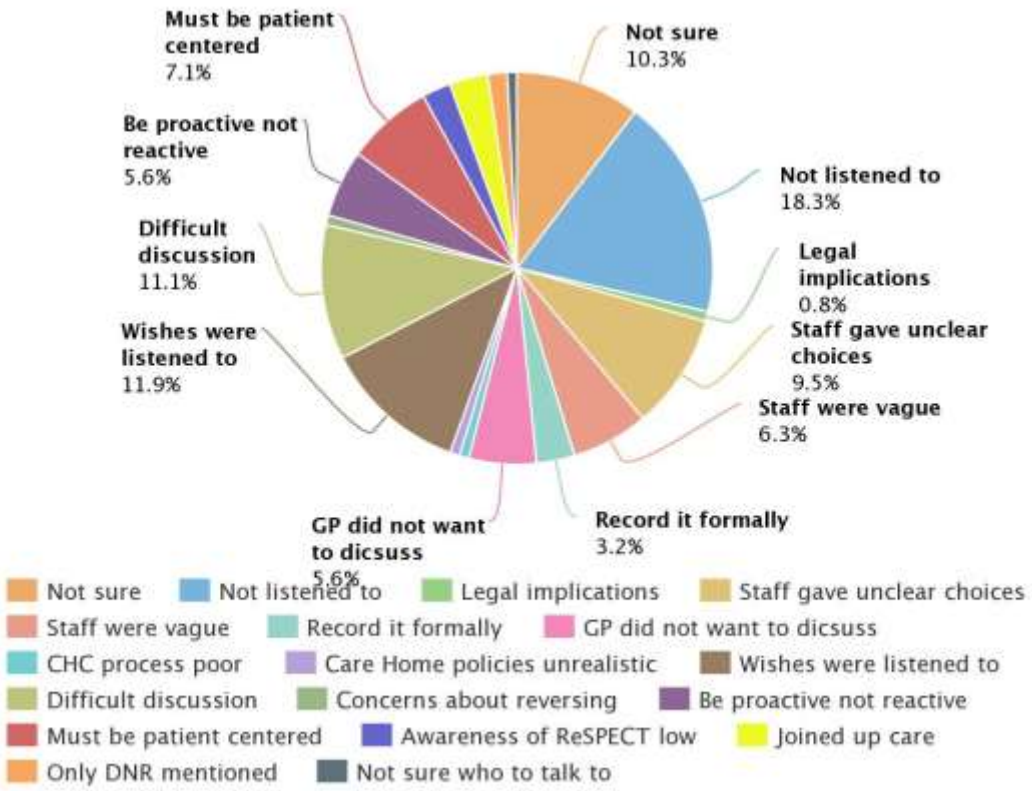
For those who answered yes (33 people), we then asked “What did you feel went well? And what did you feel did not go so well?” 36 people answered this question. In general, the feeling was that communication between staff and patients could be improved. As could the information that was given. Being listened to was the most important issue raised. Things that went badly generally related to either no confidence in NHS staff or poor communication and not being listened to. Some sample responses:

- The more senior the person I was speaking to i.e. Consultant level the less they appeared to listen to my concerns, worries or requirements. Always seemed in a hurry. I felt I always came away with lots of questions. Nursing staff always seemed supportive and understanding.
- It was about 4 years ago I approached the subject with my then named doctor and was told that it was not the time to talk about this yet
- The health care professional that I talked to listened to my views and helped me to make my own choices rather than me feel that I was being told what would happen to me.

Question 11 | Have you ever discussed care and treatment choices about someone else with a health and care professional?



For those people who said yes they had discussed care and treatment choices with a healthcare professional we then asked them what the key issues were that they talked about, and how that made them feel? There were 88 responses. Again some confusion over whether this question was about them or a relative also health professionals talking about patients. In general respondents seemed less happy about the care given to loved ones than the care given to themselves (Perhaps they felt more in control for themselves). The main themes are represented below:

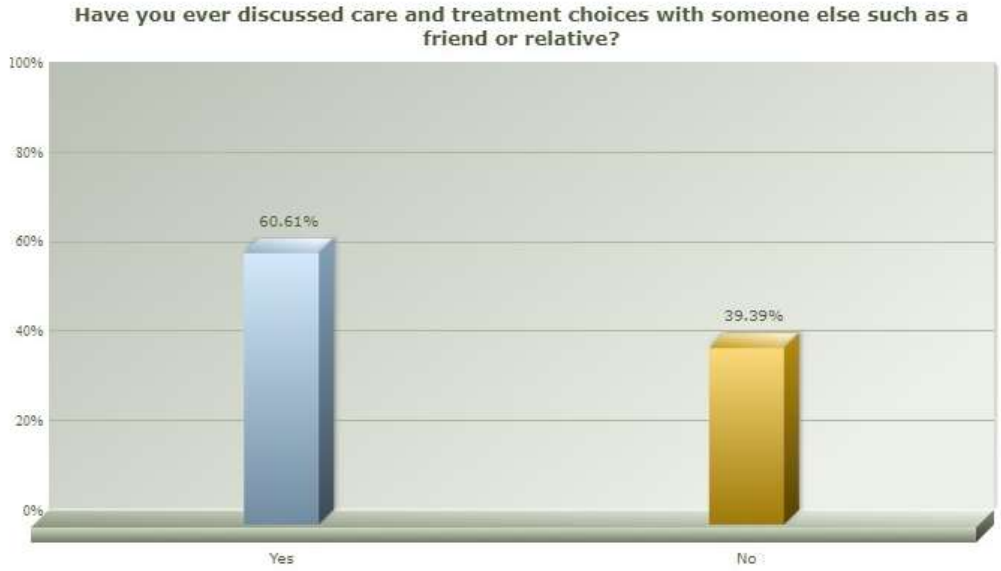


Sample comments:

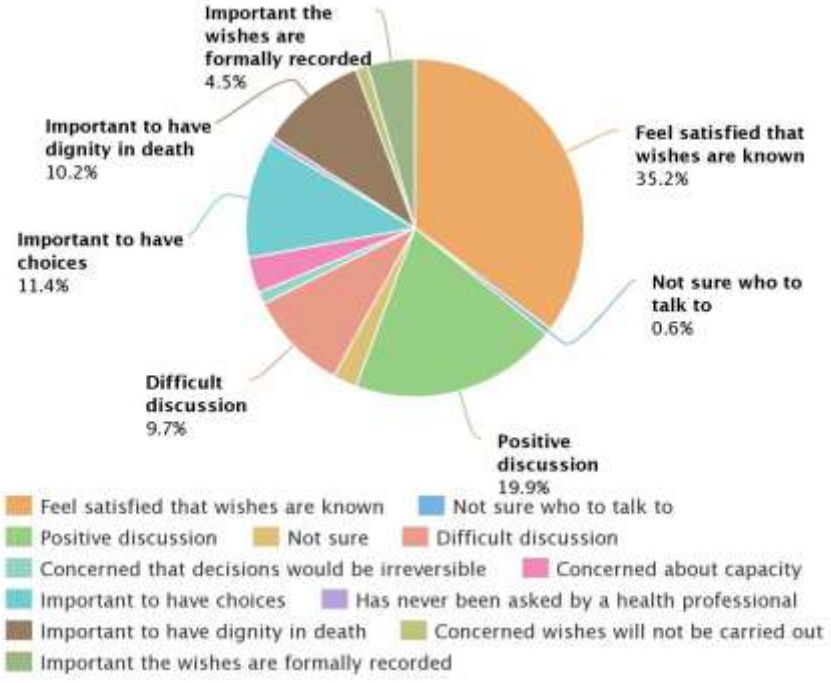
- Grandmother when in hospital and nearing the end of her life. I initiated the conversation, the hospital doctor appeared reluctant to discuss
- The NHS Continuing care process was appalling and needs to be rapidly reformed. From my own observations during my wife's latter months of life and off the record discussions with health professionals I know that this process is designed to delay any award until the patient is in the end stages of life in order to reduce the time frame that CHC will be provided.
- This was many years ago after a motorcycle accident. The healthcare professionals involved seemed interested only in the availability of organs for transplant and, in my view, it was highly unsatisfactory.
- I felt listened to. The conversation itself was open, honest and supportive. The conversation was actually had at my relatives "end of life" so the actions that were prompted as a result of the discussion were not delivered in a number of cases. I feel this was entirely down to the fact that the conversation was reactive, rather than proactive.
- I felt that the GP agreed but that the GP in attendance at the time of my 90 year old uncle who had dementia and had a sudden CVA (Stroke) and pneumonia, thought that he should Rx antibiotics against my uncles previously declared wishes. This was even though I had POA for health and finances for my uncle. Equally the nursing home and ambulance people were too scared NOT TO TAKE HIM TO A&E regardless of my explanation of my uncles wishes

A&E were furious as was I and the Consultant there asked me to sign a form stating that no further treatment would be administered and my uncle returned to the Nursing home. He died a few days later. Unnecessary distress caused to him and to me, his only relative

Question 12 | Have you ever discussed care and treatment choices with someone else such as a friend or relative?



The majority of people had discussed care and treatment choices with a friend or relative 60% (100 people), those who said they had, we asked them which issues were the most important and how that made them feel? 94 people responded. Below is a summary of the main themes with some sample comments:



We then asked: If yes, what were the issues of most importance to that person and how did that conversation make you feel? The graph above is a summary of the main themes of the answers to this question. 94 people responded.

Most people who had this conversation felt satisfied that their wishes or the wishes of their loved ones were known (62), overall the response was positive, although there were a few concerns. Some sample comments have been extracted below:

- Again only considered in relation to CPR but I know my father has often talked about what he would and would not want done for him but has never had a health care professional discuss with him the document, only us as his family.
- I had the conversation with my mum when after my dad died. Dad was her carer. Mum was happy to talk openly about how she wanted to be treated, what she would accept should things go very wrong etc. The problem I had was my siblings were not willing to do the same consequently when mum's health did go into serious decline there was a huge conflict within the family who would not believe what mum and I had discussed. It would have been so much easier if all the things we had discussed could have been recorded on a legally binding document for future proof.
- Had a conversation with my boys about not being resuscitated in the event of a major stroke again. They are young twenties and I didn't want them to have that burden or feel guilty about looking after me and giving up their lives. I felt relief for having that conversation

Observation – the majority of people answered this question in general and not from a personal perspective 'Have YOU'.

Question 13 | What in your opinion do you think helps people to start having difficult conversations like these?

152 people answered this question.

The word cloud below represents the words used in the responses:

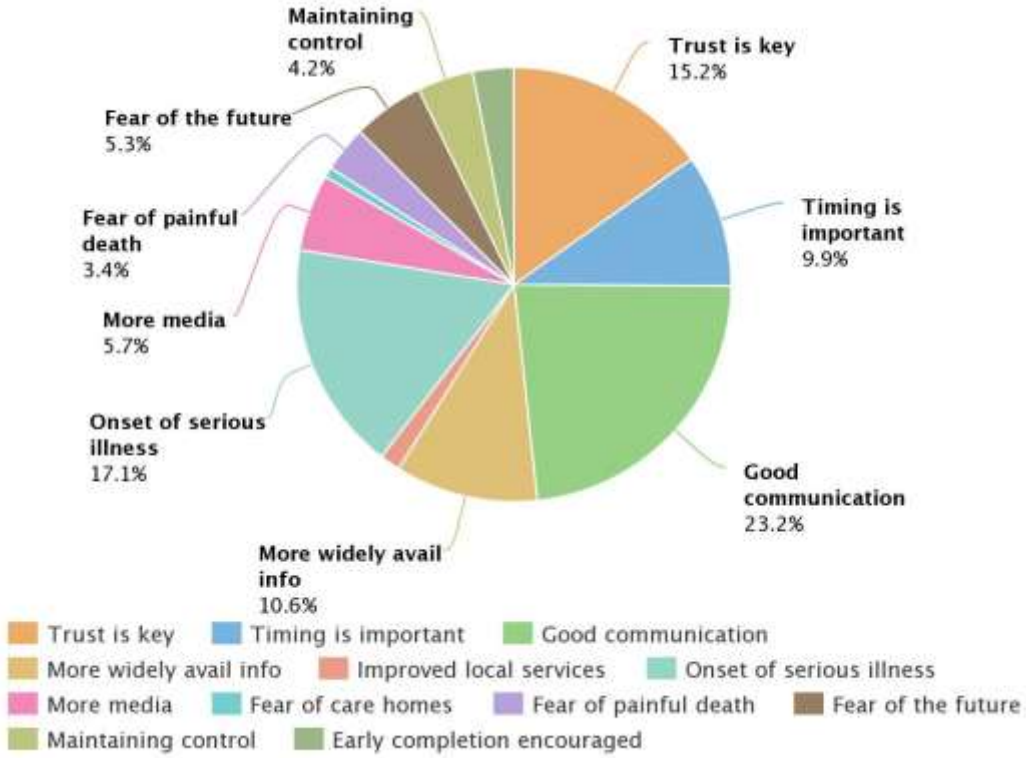
Here are some sample comments:

- People are generally unaware that the Respect process exists - or there is confusion about how this differs from DNARs. GPs and other healthcare professionals need to raise awareness of the process by speaking to patients and their families, and proactively offer

the process to patients nearing end of life care. At the moment, few people know it exists and only some GP surgeries are engaging with the process. In Waveney, it seems to entirely depend on where you live - for example, the Beccles Medical Centre are actively engaging with the Respect process and patients are offered the process and yet patients in the Kessingland/Wangford area are having to repeatedly request it and push for it.

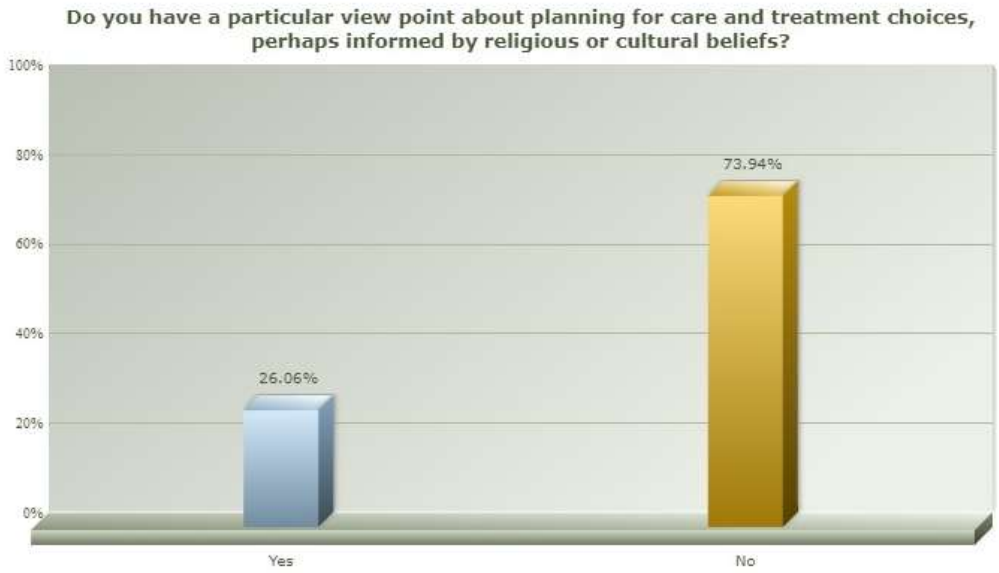
- A supportive clinician/GP who offers advice if a patient asks what's best, and someone who has time to discuss this and not rush the patient.
- These discussions, I suspect, never really take place until a person has become quite ill and is contemplating a protracted and painful demise

The graph below represents the main themes of the answers people gave. As you can see the overriding themes were that more media and awareness is needed, trust between the people having the discussion and timing is also key. Most people agreed that what usually triggered these conversations was the onset of serious illness (45 people):

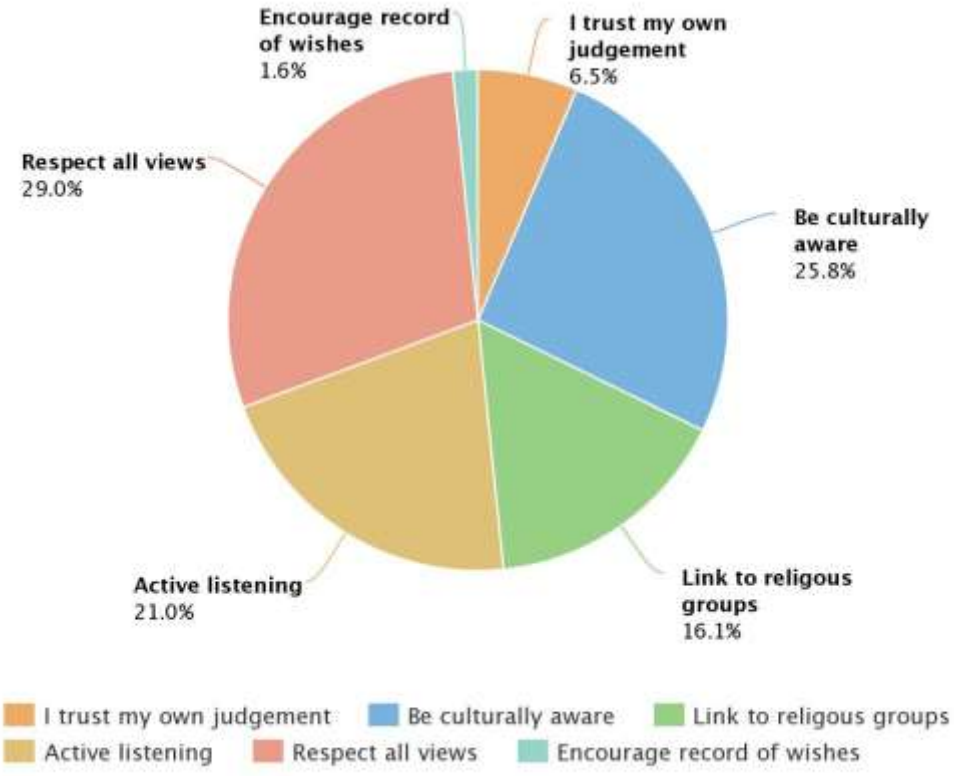


Question 14 | Do you have a particular view point about planning for care and treatment choices, perhaps informed by religious or cultural beliefs?

122 of the 165 people who answered the question said that their religious views did not impact on the decisions about care and treatment. This is represented in the graph below:



For those people who answered yes to this question we then asked how could we get these messages out sensitively? 48 people responded, their answers are themed below. In general respondents thought that all views should be respected and that it was important for staff to be 'Culturally aware', links with local religious and community groups were felt to be important to help inform understanding.

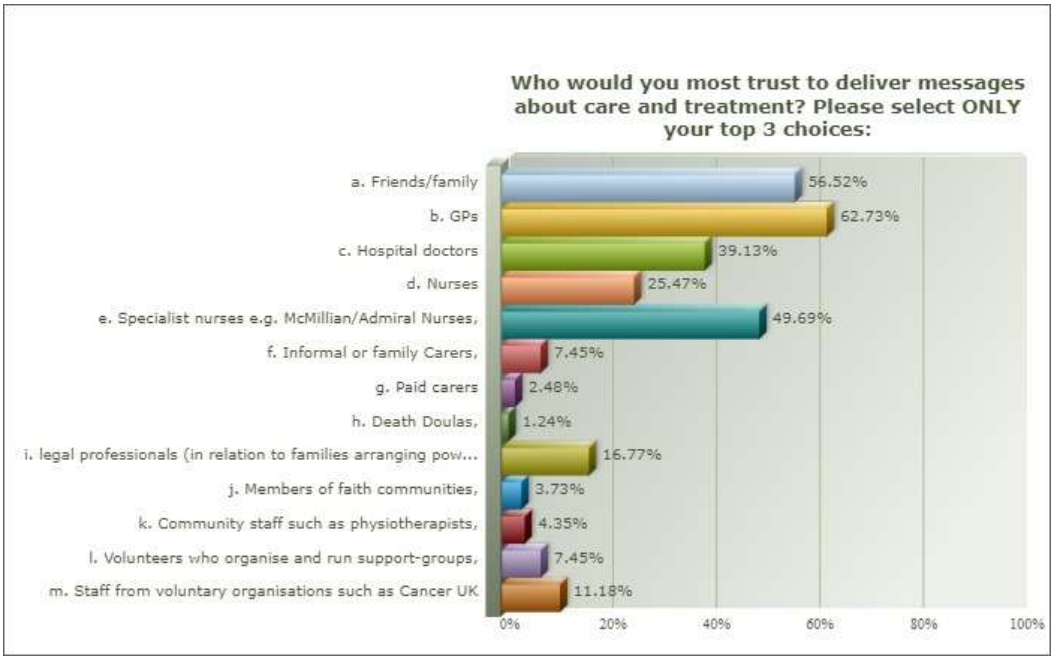


Some example answers give below:

- This implies that we should take time to understand the beliefs, of whatever kind, of the person or persons involved. This might involve group meetings that involve ethnic or faith leaders. The message must be delivered sensitively and with relevance to context.

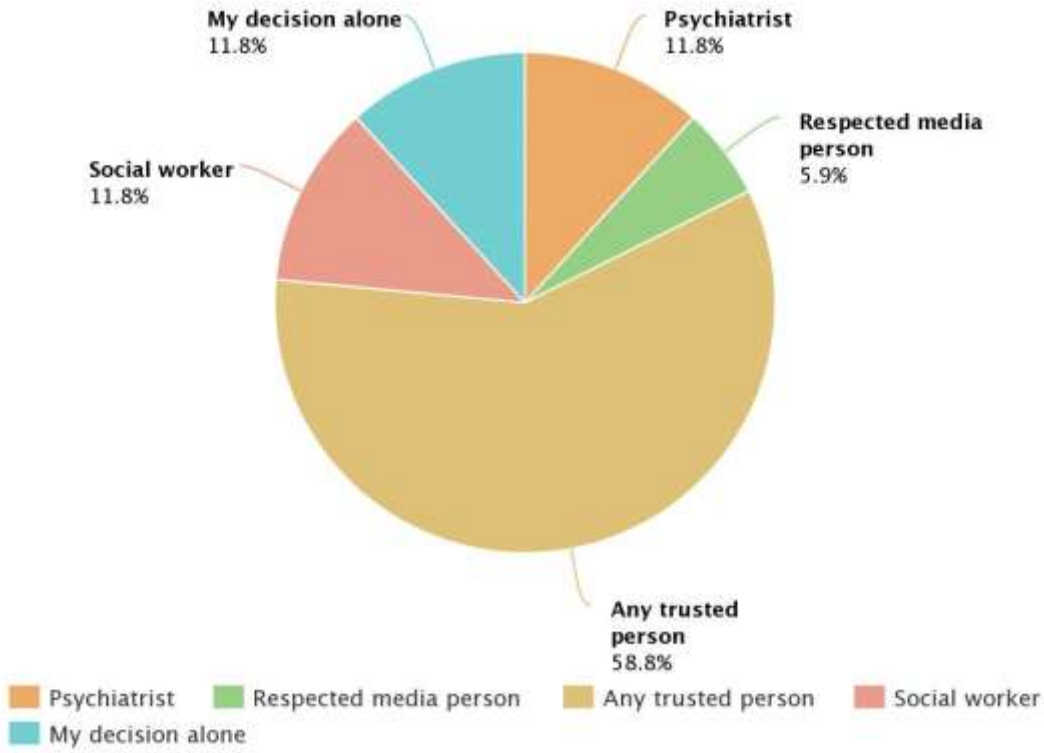
- I'd hope my cultural values are respected in my end of life care, maybe grab some examples of what's important to people so clinicians and care givers who may not be exposed to faith and cultural diversity have an opportunity to understand how these feature in people's lives... particularly the end of their lives when some people's attachment to things is stronger.
- I am a humanist and have a belief in a moral code of treating all people equally regardless of gender, race or belief system. I do not believe in an 'after life' of any description and would rather people concentrated on this life
- There is such a mix of religious beliefs in modern society that a middle way has to be found to explain the message of end of life management. The UK is now only nominally Christian and I would suggest that a multi faith seminar be called to discuss a suitable message that would not cause offence. We have communities and individuals who are Muslim - Sikh - Hindu - Buddhist - Jew - Atheists - Christian - Confucianism and even Jedi Knights (recently recognised following the last population census)

Question 15 | Who would you most trust to deliver messages about care and treatment? Please select ONLY your top 3 choices

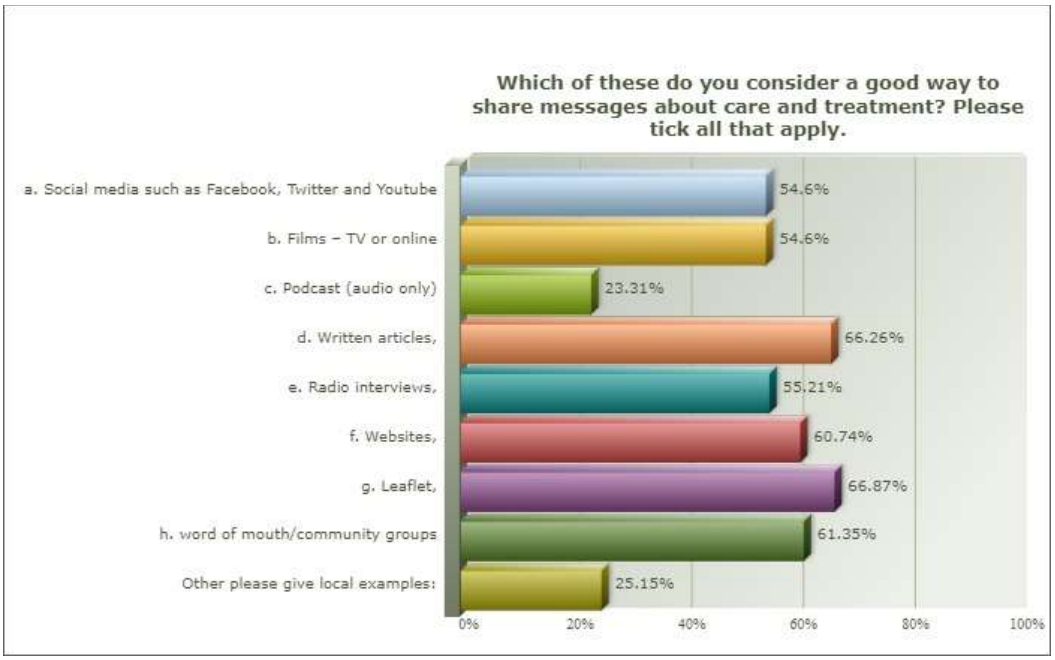


The majority of respondents who answered this question preferred that these sensitive conversations took place between themselves and family members, along with a combination of trusted professionals such as GPs and nurses.

Those who answered ‘Other’ their responses are represented in the graph below. The key theme was that the person’s role was not the most important thing, it was the level of trust.



Question 16 | Which of these do you consider a good way to share messages about care and treatment? Please tick all that apply.



The responses to this question should also be considered in the context of the average age of the respondent (55), in general it is this age group and above who are most likely to experience serious illness. The responses show that leaflets and articles were felt to be most effective, not far

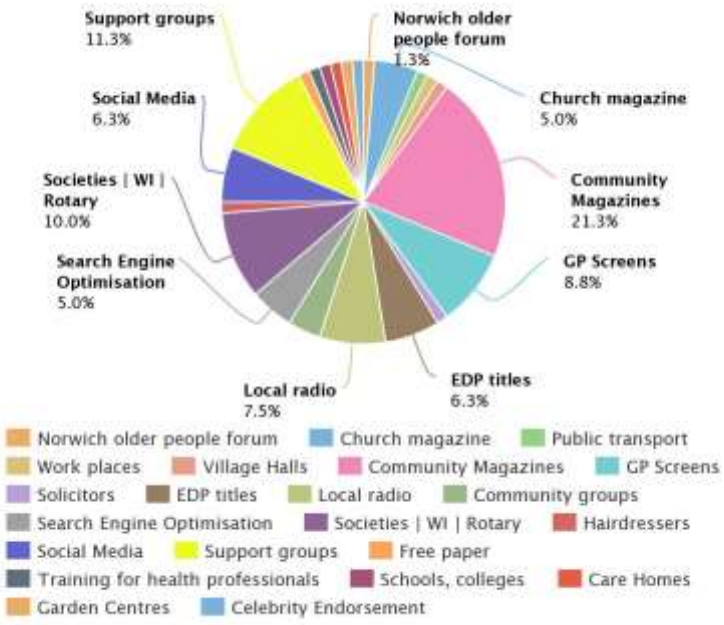
behind were face to face meetings in community groups. Social media was also felt to be reasonably effective.

Respondents to this question had lots of ideas about how to share the messages more effectively over and above those not offered as a choice above. These are represented by the word cloud below; the biggest words were mentioned most often:

Some sample comments are listed below:

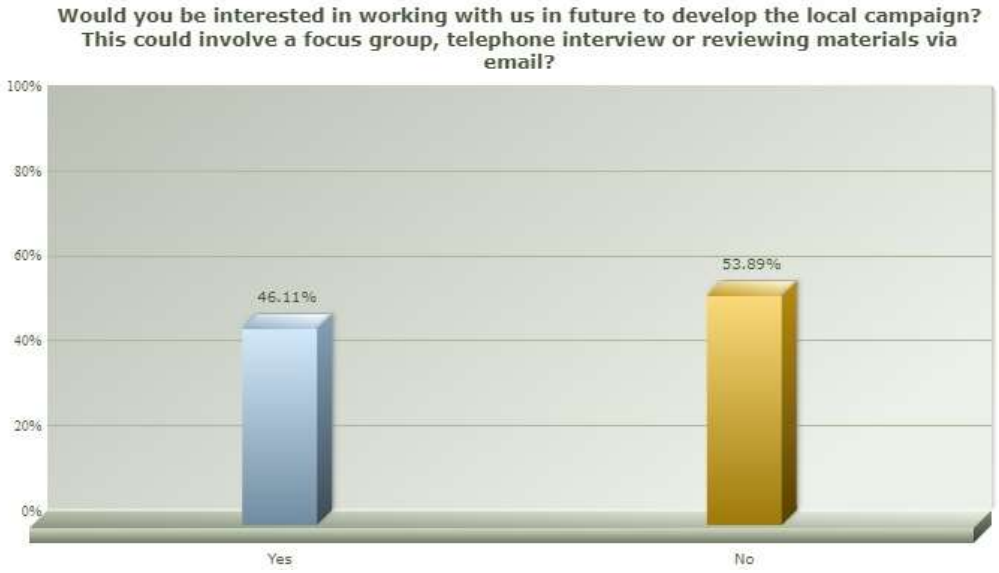
- GP surgeries, health centres, schools, colleges, universities, prisons, hospitals, faith settings (churches etc.), shops offices and other workplaces. Groups such as Compassionate Communities, trades unions, professional organisations, U3A, youth groups. Also for the issues to be raised in the media, theatre, film, literature, arts, museums.
- Quiz nights in the pub.
- Chip shop
- Market day - stall to have conversations with the public.
- Include a resource for parish councils to share in their community
- Railway / bus stations
- Resources for local businesses to use to add to their company meeting agendas.
- Local news publications (e.g. the Bugle?), pension newsletters, allow/insist that GPs send targeted info to patients. Believe it or not I think Funeral Directors (through pay schemes/insurance) should include this info. We just need to be honest and up front.

In addition, people were asked for suggestions as to where would be a good place to advertise. The graph below represents the main themes.



To view the detailed descriptions given view spreadsheet here.

Question 17 | Would you be interested in working with us in future to develop the local campaign? This could involve a focus group, telephone interview or reviewing materials via email?



What will we do as a result of what you told us?

This report will be shared with the Palliative and End of Life Care Collaborative – a group under the Norfolk & Waveney Health and Care Partnership. This report forms part of a key project under our Compassionate Communities work, where we are focussed on how we engage with the community on matters of death, dying, talking about death and advance care planning. ReSPECT is part of advance care planning and our next step is to work with you to help us to design a clear set of messages and to understand what forms of media can help convey them most effectively. We want to be able to acknowledge this sensitive subject in a meaningful way when we communicate about ReSPECT to a wider public.

The next stage of this process for us is to hold some virtual focus groups with you, where we will ask you some questions and test out some of the messages. There will also be opportunities for you to share some of your experiences with us, to help us build improvements into our work.

We will publish this report and our ongoing developments on our In Good Health website.
If you would like this document in an alternative format, for example large print or easy read, or if you need help with communicating with us, for example because you use British Sign Language, please let us know. Please email us on nwccg.communications@nhs.net