



**A review looking at people's experiences of
Do Not Attempt Resuscitation (DNAR)
procedures in the Oldham area.**

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Background

Do Not Attempt Resuscitation (DNAR) has been a topic of concern with people, especially during the COVID-19 pandemic. Feedback from Oldham residents through our various channels of communication has brought to light that this is an area that we needed to understand better.

We created an online survey to try and understand people's experiences of DNAR, including, how decisions were communicated, timescales of the process and people's views on things that went as well as possible or could be improved for others in the same situation.

Disclaimer: about our research

Please note that the feedback within this report is based on subjective accounts by individuals who completed our survey online and do not represent the views of Healthwatch Oldham. Healthwatch Oldham's research is carried out in line with accredited guidelines set out in Healthwatch England's Research Governance Framework. We aim to identify what matters most to people and use our findings to ensure that people's voices influence and improve the quality of local services.

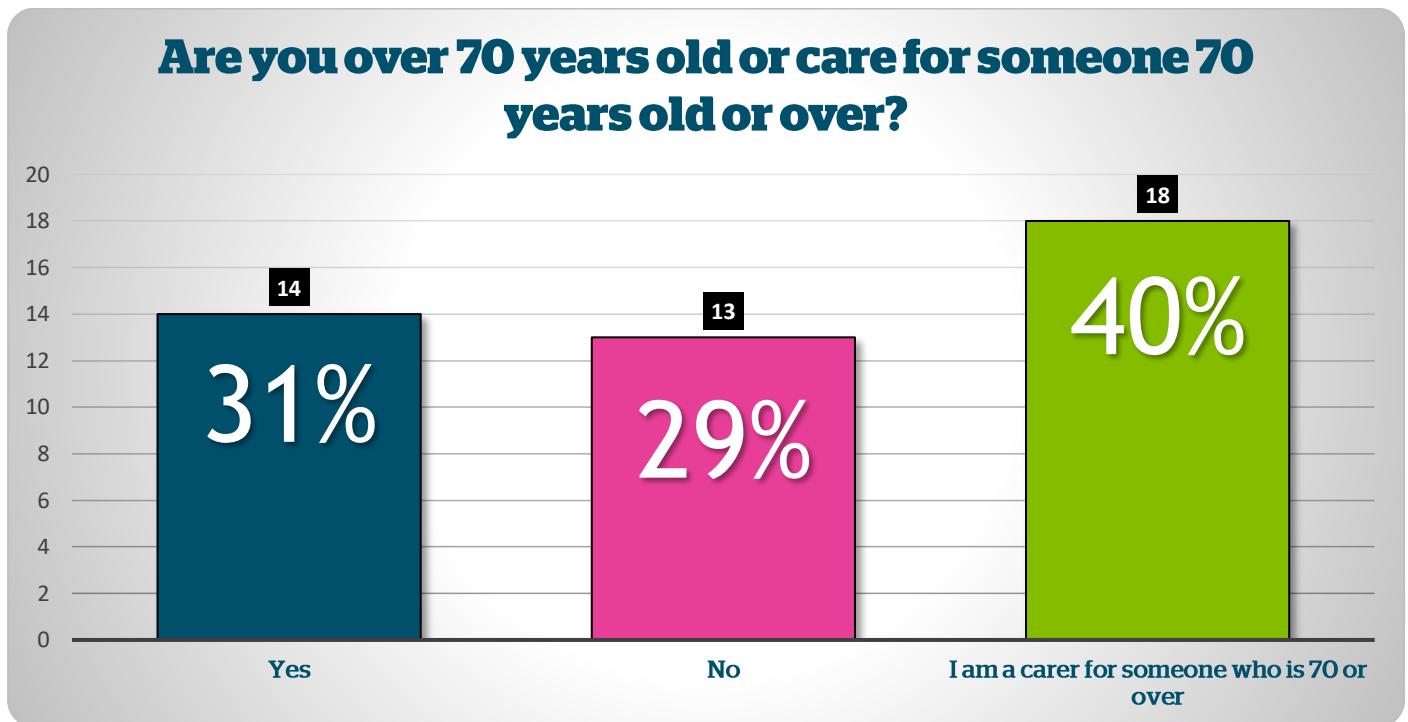
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What we did

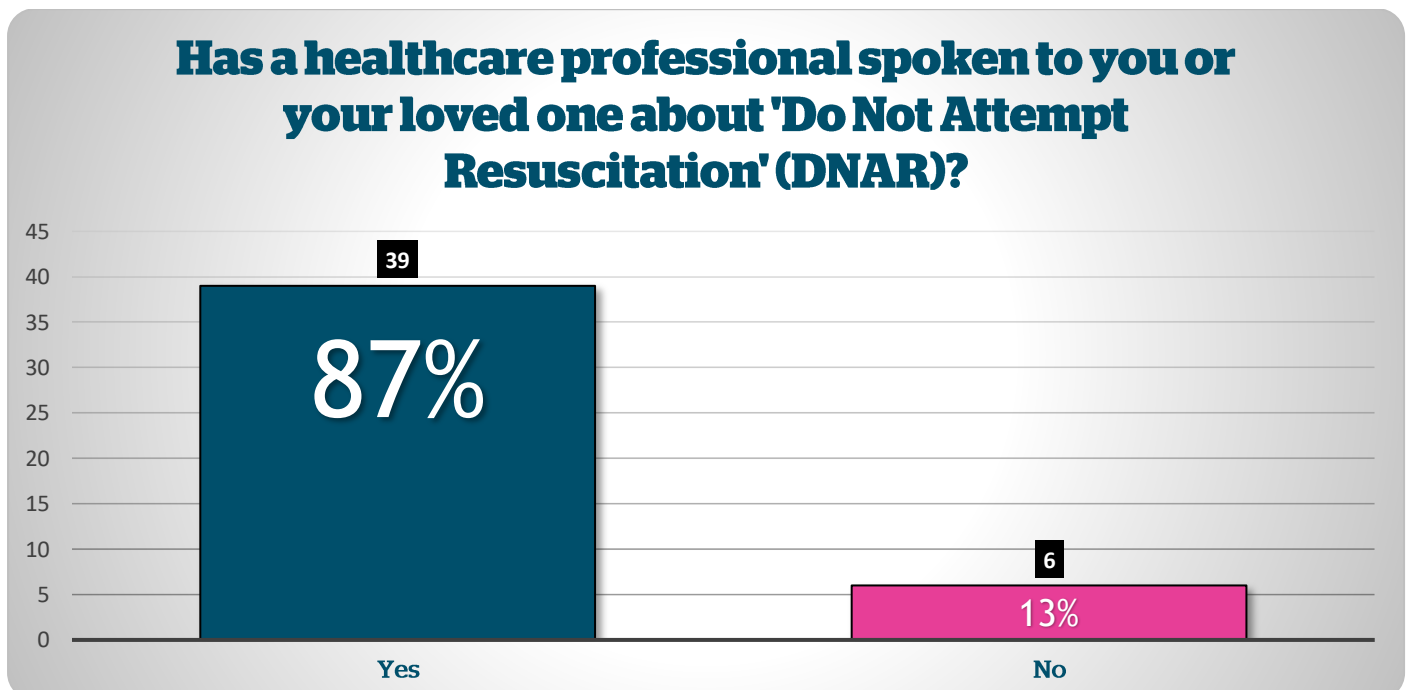
We created an online survey (see Appendix A) with a range of questions to better understand people's experiences of DNAR. Due to the COVID-19 pandemic, this survey could only be completed online. Normally when Healthwatch Oldham carries out projects and surveys, we attend community events and promote this work with all areas of the borough. On this occasion we shared the online survey with as many community groups and support pages as possible.

Key Findings

We received 45 responses to the survey and Healthwatch Oldham's analysis follows.

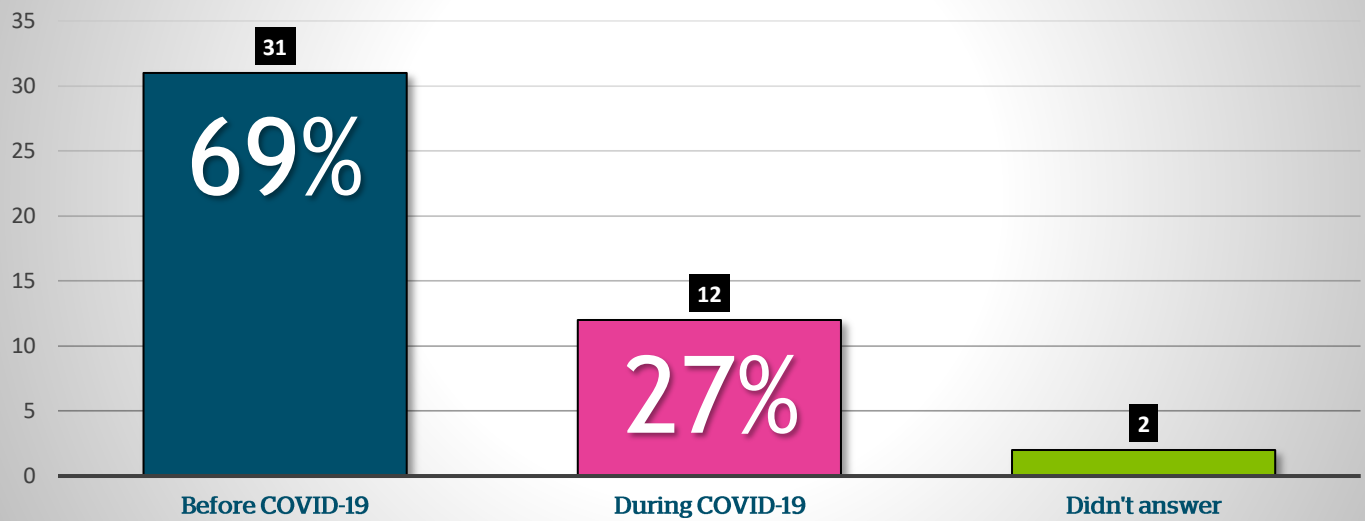


The most common answer to this question was that 40% (18 people) stated they were a carer for someone who is 70 or over whilst 31% (14 people) stated they were over 70 years old themselves. This is a notably high level of carers responses to a survey.



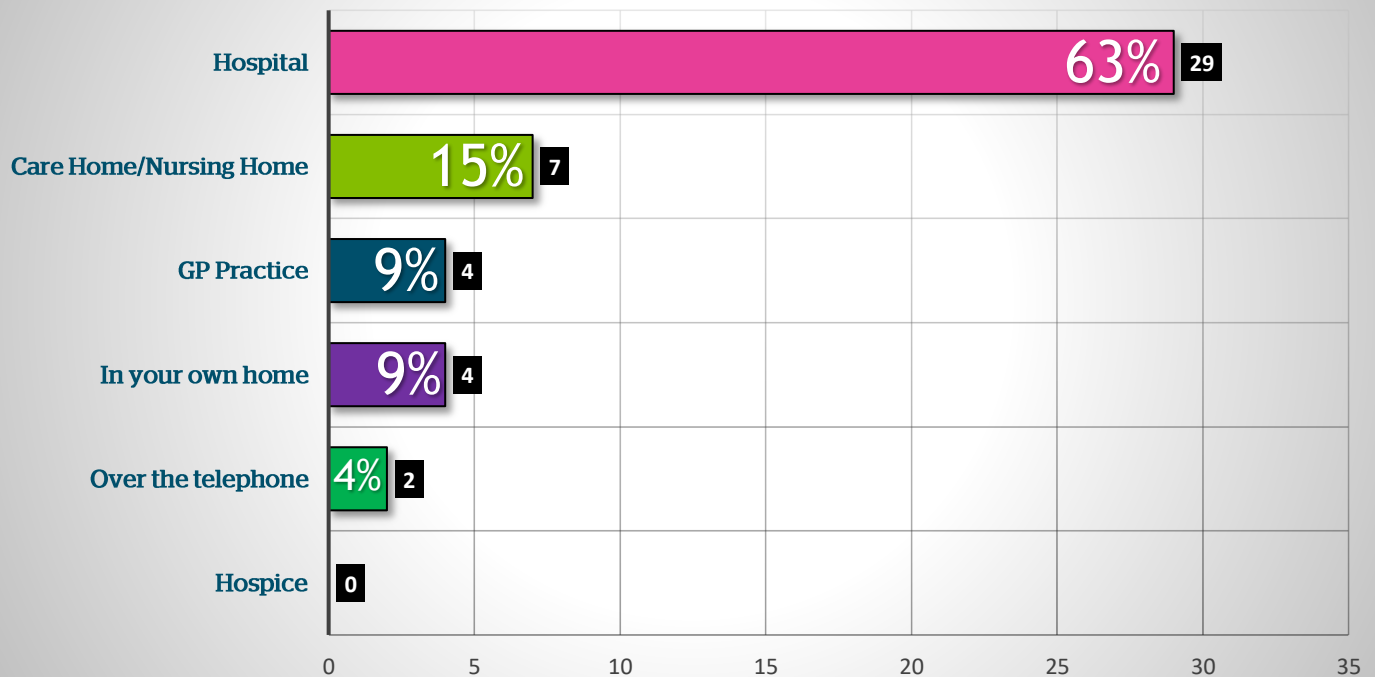
87% (39 people) stated that they had spoken to a healthcare professional about DNAR compared to 13% (6 people) who had not.

Was this before or during the COVID-19 pandemic?



69% (31 people) stated that the conversation they had with a health professional was held before the COVID-19 pandemic compared to 27% (12 people) who have had this communication during the COVID-19 pandemic.

Where was this discussion held?

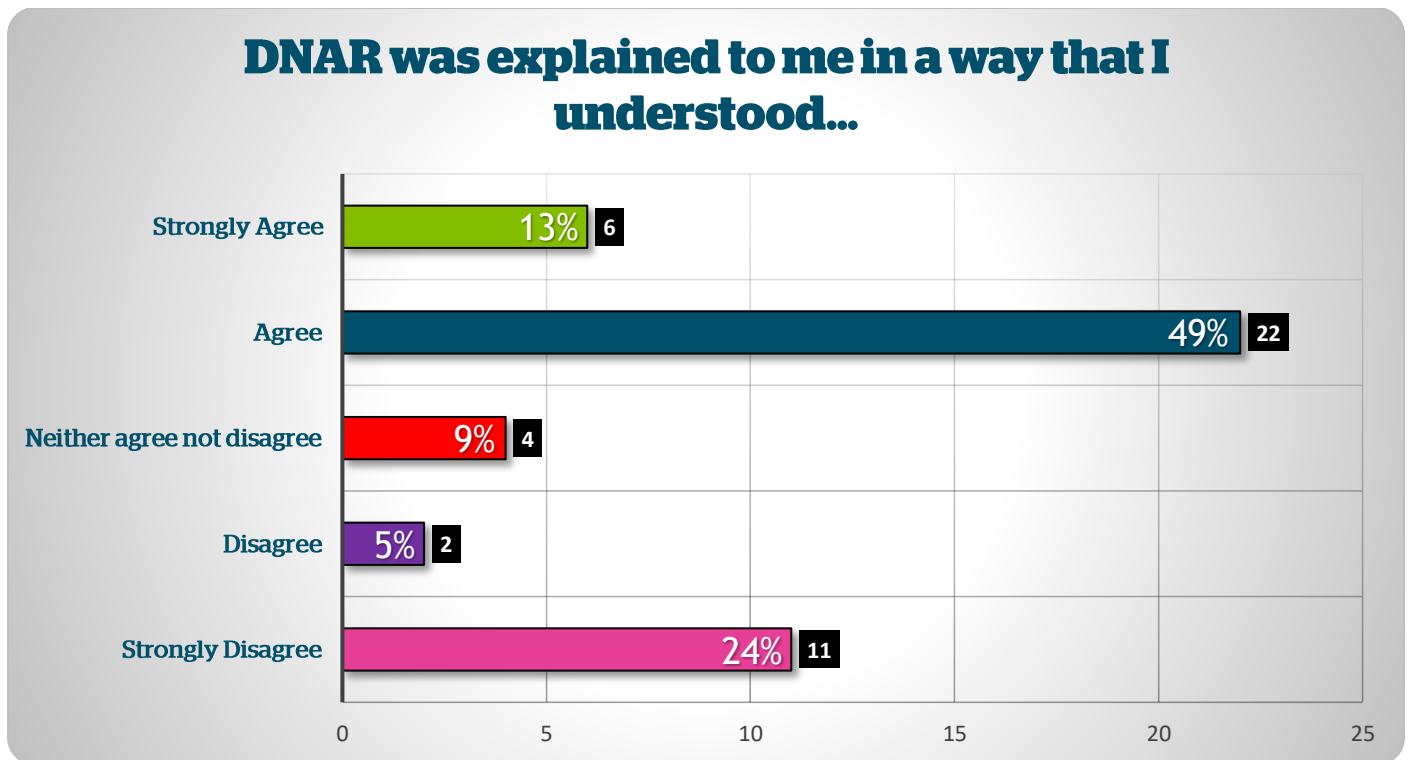


63% (29 people) stated that the most common location that this conversation took place was in the hospital. Other locations were used as a venue for this conversation, 15% (7 people) stated that the conversation took place in care/nursing homes.

Recommendation: given the low number of responses indicating that the discussion was held in a GP practice context it would be useful for Oldham CCG and the new PCNs to explore how many DNAR conversations are taking place with GPs, the experiences of all parties in this, and the support on offer to strengthen the approach in a GP Practice context.

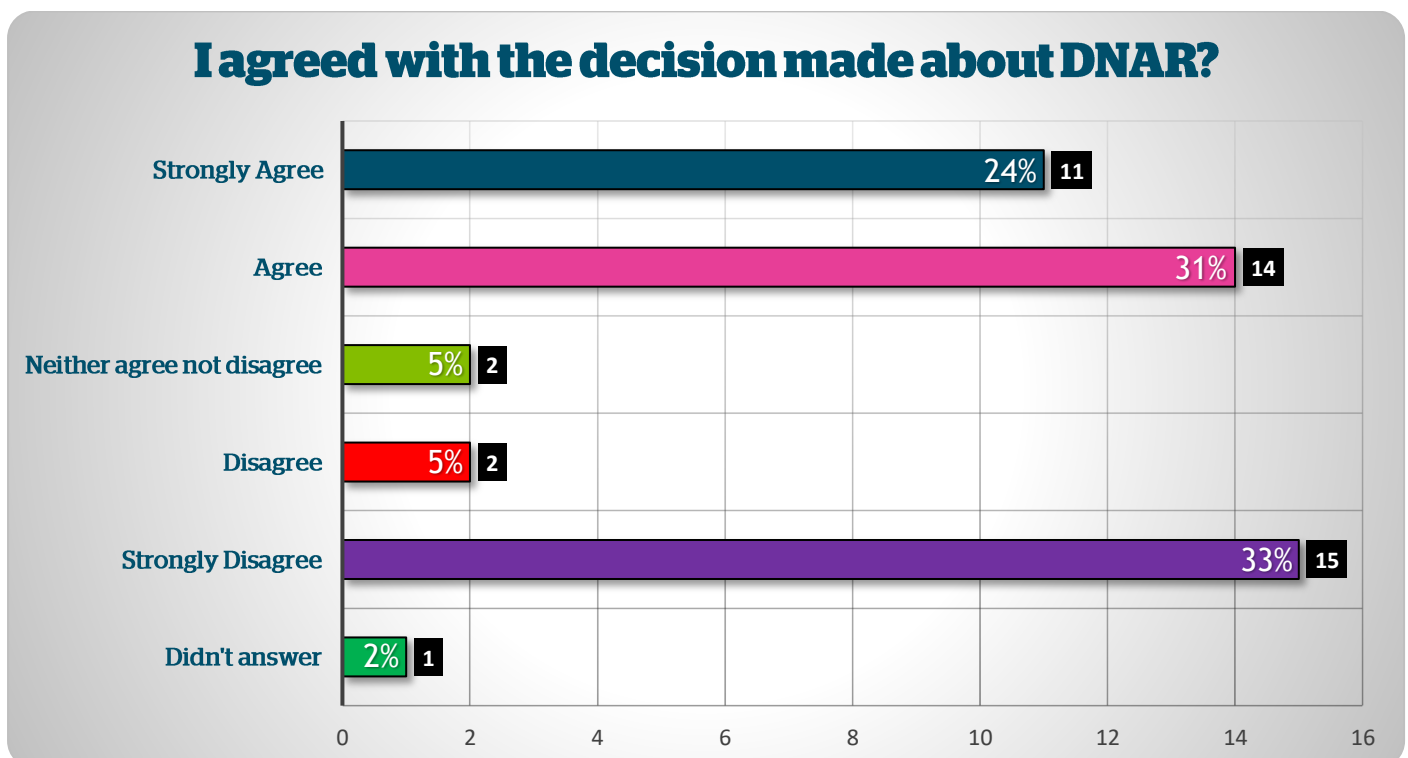
Scaled Questions

We asked a series of scaled questions asking for people to state whether they agreed with certain statements about their DNAR experience:



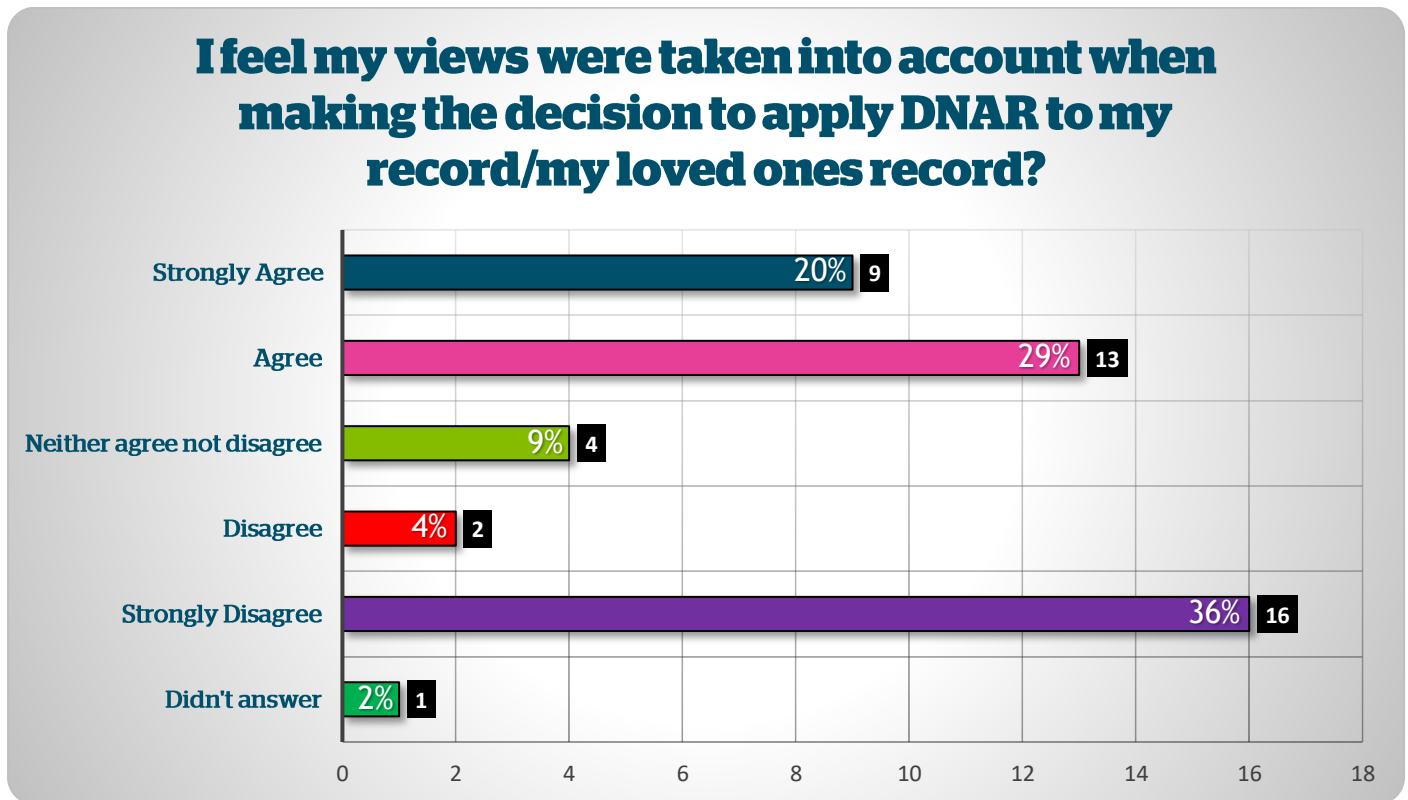
The most common answer was that 49% (22 people) felt that they agreed that DNAR was explained to them in a way they understood. However a significant minority of 24% (11 people) stated that they strongly disagreed with this. Normally strongly disagree responses are very low in our surveys and this response raises cause for concern about how well people understand DNAR conversations.

Recommendation: that all doctors are offered training in DNAR conversation best practice and that this includes input sharing the experience from a patient perspective.



The highest answer was that 33% (15 people) strongly disagreed with the decision being made about DNAR. However, 31% (14 people) agreed with the decision and 24% (11 people) strongly agreed with it. There are clearly strengths in the DNAR conversation approach to build on but again there is a very high level of strong disagreement which needs to be addressed to ensure confidence and trust from those using health and care services.

Recommendation: that processes are implemented or established for those who disagree with DNAR decisions to raise their concerns immediately and have further opportunity to address them.



The most common answer was that 36% (16 people) strongly disagreed that their views were considered when deciding DNAR. 29% (13 people) agreed that their views were considered. Once again there is a high level of strong disagreement and overall the disagreement levels with this statement are very nearly equal with the agreement levels. This is of great concern when clearly people feeling that their views have been taken into account is a critical foundation in delivering health and social care services.

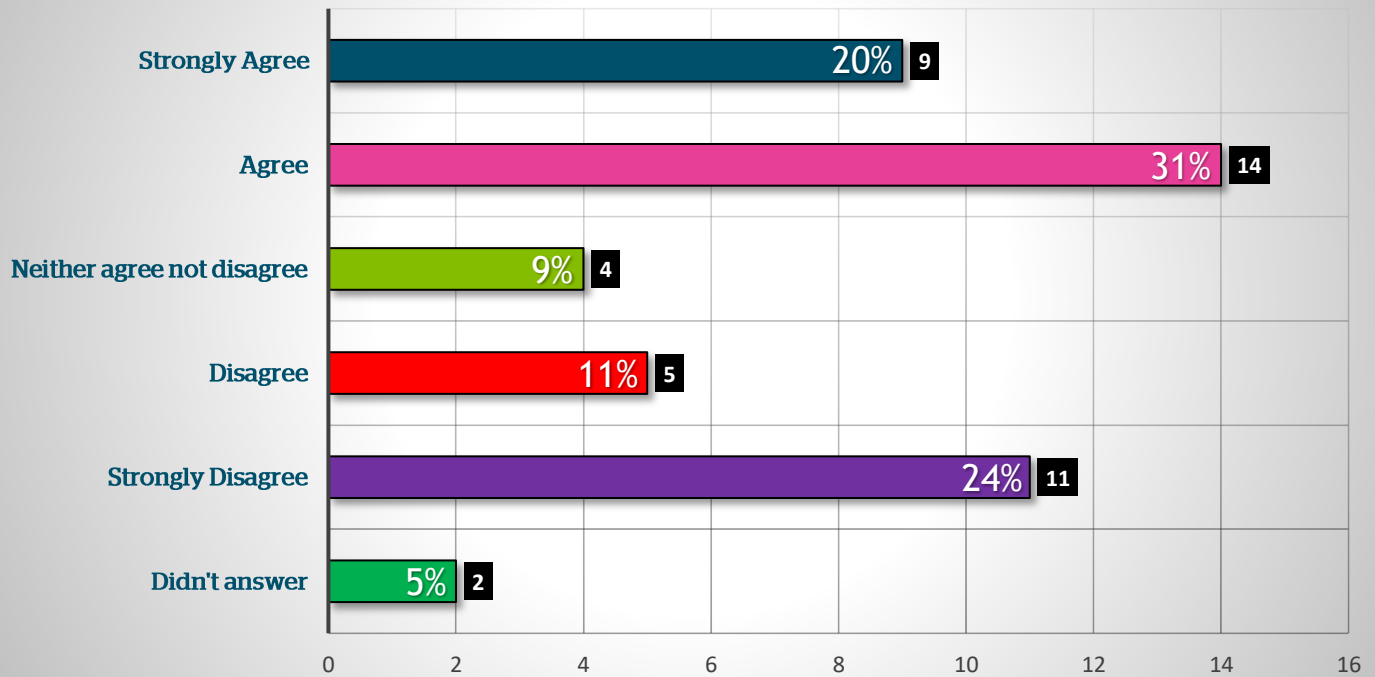
Recommendation: that processes are implemented or established to check that people do feel their views are being taken into account as part of DNAR conversations and that they can raise any concerns immediately and have further opportunity to address them.

The Northern Care Alliance NHS Group’s (NCA) DNAR Policy Summary (see Appendix B) states that if a ‘decision is not accepted by the patient, their representative or those close to them, the offer should be made to seek a second opinion’. The policy does not say what will happen in the instances when the second opinion is also not accepted.

Recommendation: that the NCA clarify the following questions related to their DNAR policy -

- What happens if a second opinion regarding DNAR is not accepted by the patient, their representative or those close to them?
- Regarding the statement from the NCA that they take a holistic approach to the decision-making process, does this take into account a patient’s religious needs and if so, in what ways?

I felt it was the right time to discuss DNAR...

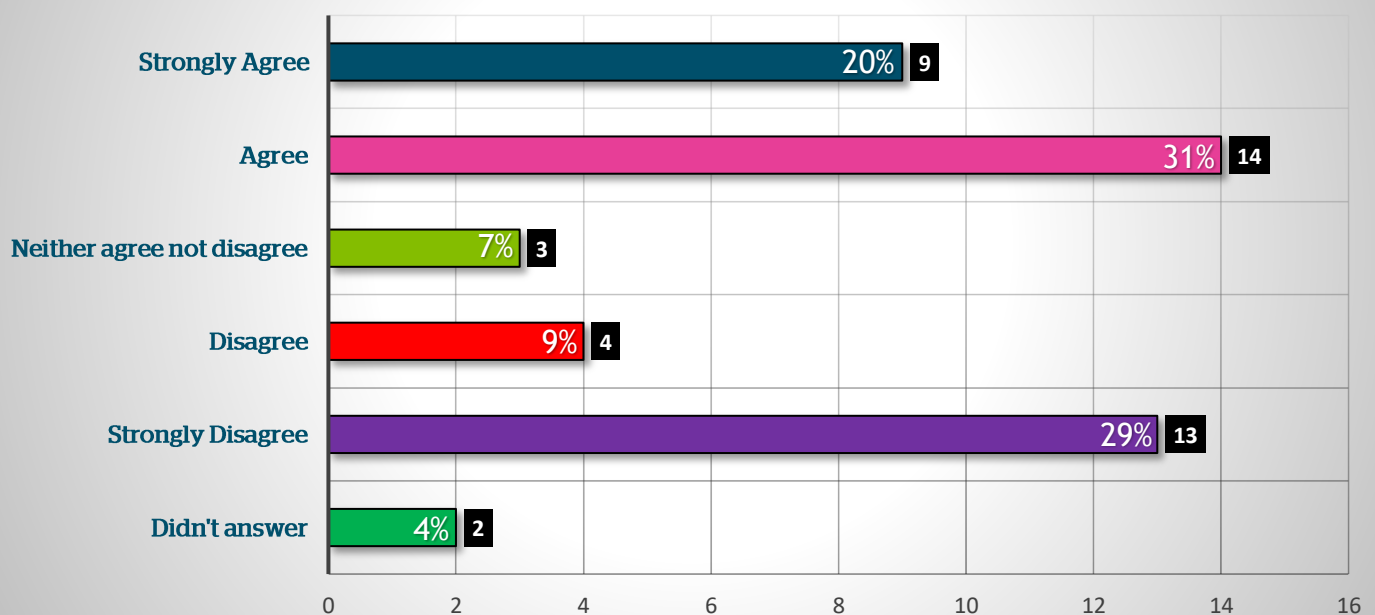


The most common answer was that 31% (14 people) felt it was the right time to discuss DNAR compared to 24% (11 people) that strongly disagreed with the timing to discuss DNAR. There are clearly successes to build on in the timing of DNAR conversations however disagreement with this remains significant and needs to be addressed.

Recommendations:

- Further consideration is given to the timing for DNAR conversations, and further research sought/undertaken to understand this area.
- Given the qualitative feedback there is a focus on ensuring more of these conversations are able to take place in a GP Practice context with support for all parties in place.

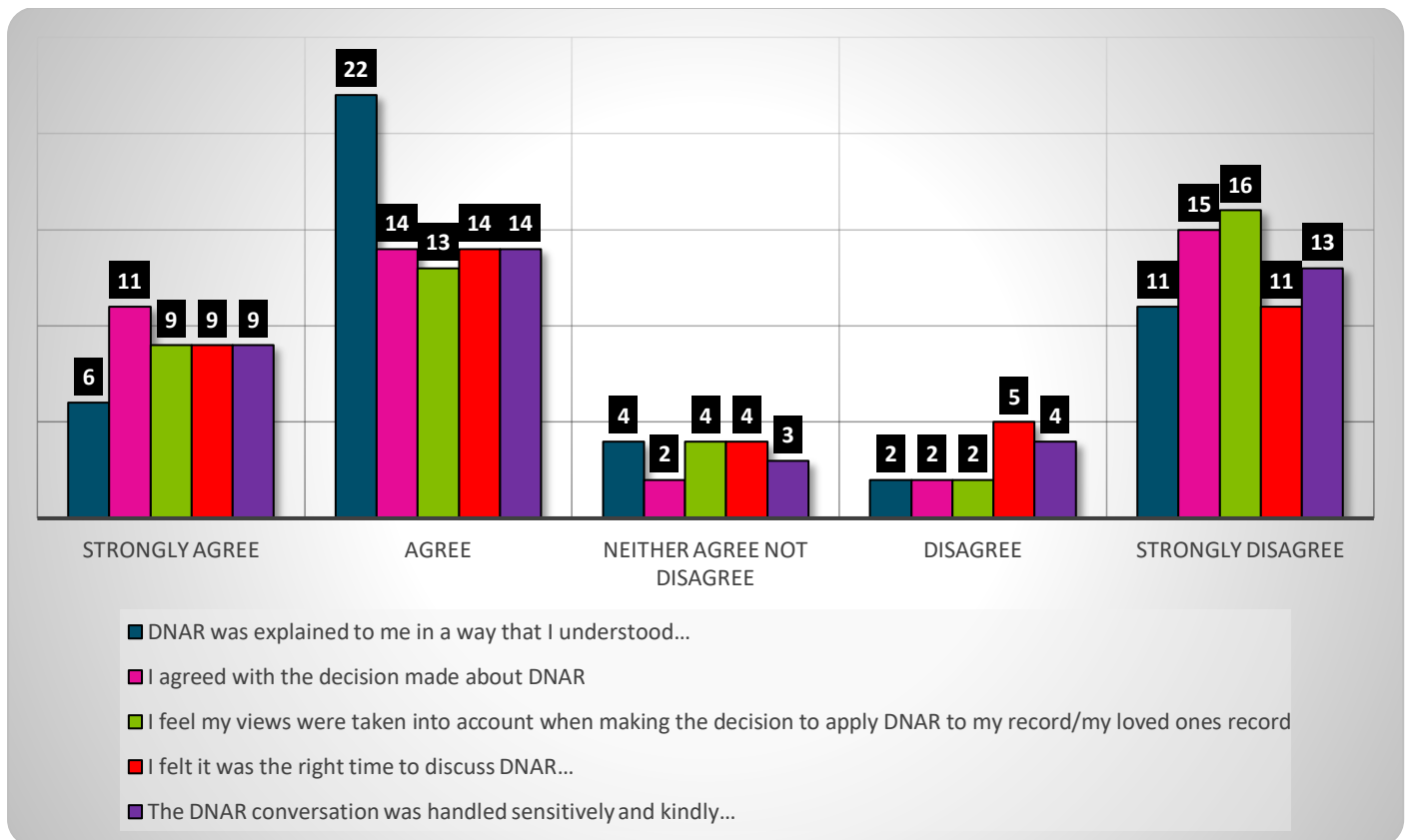
The DNAR conversation was handled sensitively and kindly...



31% (14 people) agreed that the conversation about DNAR was handled sensitively and kindly, however, 29% (13 people) strongly disagreed that this was their experience. Once more there is clearly good practice in this work that could be shared and amplified but also the level of strong disagreement is of concern. Again sensitive and kind handling of such significant topics is a critical area for improvement to ensure trust, confidence and a good reputation for our health and care services.

Recommendation: that good practice training and learning is shared amongst doctors to strengthen this aspect of DNAR conversations and that this includes input sharing the experience from a patient perspective.

We have taken these scaled questions and placed them all into one graph to give an overall picture of people’s views towards the discussions that took place regarding DNAR.



As stated above these findings show a worrying and consistent trend towards a significant minority of people strongly disagreeing with the statements made regarding DNAR. Such strong disagreement is very unusual in our surveys and indicates a system-wide challenge that needs to be addressed.

Comments

We included a section on the survey where people were able to explain more about their experiences with DNAR. These comments largely reflect the reasons why so many people strongly disagreed with the statements made in the survey.

Some comments indicated a serious concern that there was no consent for the DNAR notice to be applied but it was still added to their record:

"I felt a lot of pressure from the hospital, doctors and GP who repeatedly kept discussing DNAR with me even though they knew we were against it.

It felt like I was being harassed by Oldham hospital doctors about it and they finally made the decision to apply DNAR without my consent."

"Was constantly asked to consider DNAR. Disagreed, even though they pressured me to agree. Finally, they put the DNAR without my agreement."

"I disagreed with the DNAR because I did not think it was my decision to make. I was at the hospital, but I am not the immediate next of kin.

Until the episode in question, my elderly and rather frail grandfather had been in reasonable health and I was shocked to be asked."

"My mum is 89 and has several health issues. We were basically told that DNAR would apply to mum if it came to it.

No discussion, no option given for us to decline. Makes me angry and sad that this is the case."

"We were given no option. The DNR was forced. The lack of care and empathy was absolutely disgusting by people who should have been professionals.

It's almost like writing off a car. You're dealing with humans, not mechanical problems in a garage. I've been in and out of hospital with both my parents for the last ten years. I've seen many doctors and consultants regarding my parents health and there are good and bad doctors.

Both my parents have now passed away. My Dad was given the wrong medication before he passed away. There were many incompetent doctors and nurses leaving many mistakes overlooked.

I don't want the same to happen to anyone else. Too many ethnic minority groups experience racism within the system and their experiences are tossed aside and deemed unimportant.

This is not good enough, hence the high mortality rates of BAME groups, systematic racism affects how one is treated as well. You need to address this and retrain your staff."

Some of the comments were regarding a lack of respect from members of staff:

"Disgusting approach. No care. No compassion. No respect for the elderly. No discussion. Just we will apply DNAR and that's final."

"My father was spoken to about DNAR when delirious, the form was ticked that he had full capacity and that they had spoken to a significant other, this was not true."

"The medical staff at Royal Oldham Hospital claimed on the DNAR form that my father had capacity. His discharge form detailed confusion and delirium.

I had the DNAR removed by the doctor. My Father was admitted again, and again the same box was ticked.

My Father did not have capacity. Additionally, on this occasion, the box that the family had been informed was ticked. No one from the hospital had discussed it with any member of my family."

This comment suggests that no discussion took place at all:

"I have power of attorney over the health and wellbeing of my Father.

The first I know that the DNAR order was given from my father was on his discharge notes and had been signed off by a doctor at Royal Oldham Hospital without any discussion or permission from family.

It was a dreadful thing to see on a discharge note."

The following comment highlights that the DNAR was not sent on to the hospital by the care home:

"My auntie had advanced dementia and the DNAR conversation was of no surprise.

However, 2 months later, she got readmitted to hospital & they resuscitated as the DNAR paperwork wasn't sent by the care home.

The next and last 6 months of her life was very miserable and sad to see."

However some comments made highlighted areas of positivity, things to learn from and constructive suggestions:

"This conversation was held with my Mum present & the support of a Macmillan Nurse."

"The subject of what care people want, especially end of life care should be discussed with the GP long before the conversation is needed.

This includes any DNAR decisions - DON'T leave it until people are really ill. It could be facilitated by a nationwide advertising campaign in the first instance.

"I think this is a conversation that needs to be had with all people at varying points - to prepare people as much as possible.

My Mother, who has Alzheimer's, was taken into hospital and tested positive for Covid-19. This was the first time that this had been discussed.

This was a lot to take in as the family. Also, my Father talked about it with me right at the start of the pandemic as he is shielding due to health conditions and this was a very emotive chat to have.

How can we prepare ourselves to get people thinking about it?"

"I had power of attorney for my Father and was aware of his lung cancer prognosis and Alzheimer's. Dad was admitted to hospital with pneumonia.

The Doctor discussed very gently, the option of DNAR having seen Dads latest lung X-ray. I agreed to the DNAR as I had discussed such a situation with Dad many years ago, so I knew what his wishes were.

Dad was involved in the DNAR discussion, in that he was present (again Dad's wishes that nothing should be kept from him and he wanted me to be present when good or bad news was discussed). Although, I am not sure he could follow all the conversation due to his advancing dementia.

Despite the Doctor being sensitive, it was very emotional decision to make and it is still very clear in my memory. It was made easier because we had discussed it as a family many years ago. I feel the message you put across should be very much about families discussing issues such as DNAR and organ donation together at a quieter happier time, so they are not faced with discussing these issues when emotions are at an even higher level in an emergency medical situation."

"I have told my friends and family that I don't want to be resuscitated, but not had the conversation with a medical practitioner."

"My relative requested a DNAR. We both have a Christian faith and hope. We were both nurses and understand the implications and likely success of resuscitation.

As they are housebound with limited mobility and other health issues, they would not want to live with even less quality of life."

"DNAR orders issued by doctors/authorised medical staff, when completed require a medical professional's name and signature. Yet, there is no procedure where that a patient/or their next of kin sign, as to demonstrate that a discussion/consultation has taken place and most importantly that there has been a clear understanding as to what this means to their future treatment and treatments that may be limited.

I understand certain changes have been made within recent legislation in regard to discussion/consultation with patients and their families. However, without a procedure that records such and the patient's involvement/understanding, how is this reliable as to fully safeguard patients, who clearly at this time are extremely unwell and vulnerable?"

Conclusion

As well as analysis of our survey we have sought input and advice from Compassion in Dying (www.compassionindying.org.uk). Their feedback and research has indicated the following points which confirm many of our findings:

- We need more honest and sensitive conversations about CPR. This requires health and care professionals to listen to and understand people's priorities and concerns and then consider this in decisions and discussions. As a minimum, health and care professionals need information and guidance to enable them to explain what CPR is and why it may cause more harm than good for that particular individual. In the charity's experience most people are not distressed by the DNACPR decision but by a lack of honest and clear communication around the decision.
- CPR conversations should be everyone's responsibility and must take place sooner. When discussions are postponed or passed on from a care home to a GP to a hospital clinician, for example, the result is that a decision may need to be made in an emergency, quickly and when emotions are high.
- There is an urgent need for better public understanding of what CPR is (what it entails, what the success rates are, what recovery could be like); how CPR decisions are made; and the fact that a DNACPR decision only applies to CPR and subsequently all other appropriate care and treatment will continue to be offered.
- A significant number of people want to ensure they are not resuscitated but are not supported to get a DNACPR form. Many people are told by their GP, for example, that they aren't old enough or sick enough to think about these things. This has a significant impact on people leaving them feeling abandoned and worried about the future.
- We need to address the issue of record keeping and sharing. When a decision about CPR is made, via a DNACPR form or an Advance Decision, it must be made available across settings (care homes, ambulance service, hospitals) to prevent unnecessary resuscitation attempts and traumatic deaths.
- Done well, DNAR conversations help people understand what is likely to happen if they become unwell and give them the opportunity to ask questions and explain what matters to them.

It is important to remember that DNAR is meant to help reduce anxiety and distress at the end of life stage of care. It is an advance decision made when a person is feeling well and can make a clear informed choice of how they wish their final moments to be and it is important that this is respected. Unfortunately, sometimes the way a DNAR conversation is being held is actually causing anxiety and distress, rather than alleviating it.

When a clinician decides to hold this discussion, they should and clearly often do so taking into consideration clarity, sensitivity and timing. We recognise this isn't always possible especially when it is an emergency situation hence the need to hold this conversation earlier, in a primary care setting. Forced decisions should of course be avoided as with very unwell people adding such distress in their final days is not something anyone wants to see happen. It is clear that DNAR should be spoken about more to eliminate the fear and taboo it holds. A national campaign to raise awareness would be something that would help everyone and Healthwatch Oldham would urge NHSE and national bodies to consider this.

The results from this survey show two sides of DNAR. One is that people feel that the process has been done as best as possible given the difficulty of the situation. The other, which is of great concern given the significant minority of individuals giving this feedback, is that things have gone critically wrong at such a crucial and emotional time for families. These issues include decisions being made without the

family's knowledge, some decisions going against the wishes of the family or individual and some decisions being poorly or uncaringly communicated. Healthwatch Oldham makes the recommendations below as practical steps to help address these concerns.

DNAR Recommendations

1. Training: We recommend that all doctors, and all staff being empowered to support DNAR conversations, are offered training and learning opportunities in best practice around DNAR conversations. This should have a particular emphasis on:

- caring, kind, respectful, and sensitive conversations
- a pro-active but non-pressured and not repeatedly undertaken approach
- cultural and religious understanding
- consideration for those with additional communication needs.

Also it should include input that shares the experience from a patient/family perspective.

2. Timing and Expertise: The conversation around DNAR and the timing is paramount. This is such a serious, emotional and sensitive conversation that we would recommend only confident and well-trained staff (see recommendation 1 above) hold the discussion. Experience and knowledge help with delivery and answering queries. We recommend that more DNAR conversations are able to take place in a GP Practice context with support for all parties in place. We do recommend though in an emergency situation that it is a doctor who should hold the conversation especially if there are questions from the patient or family.

It is very concerning to read the experiences of some of the survey respondents and this should be taken on board by NHS providers in terms of the impact a poorly handled conversation can have and the long-term damage it can cause. We also recommend that further consideration is given to the timing for DNAR conversations, and further research sought/undertaken to understand this area. In particular given the low number of responses indicating that the discussion was held in a GP practice context it would be useful for Oldham CCG and the new PCNs to explore how many DNAR conversations are taking place with GPs, the experiences of all parties in this, and the support on offer to strengthen the approach in a GP Practice context.

3. Consultation: What is clear from the survey responses is that DNAR is being applied even without patient or family consultation. This is concerning as patients and appropriate family members should always be consulted on DNAR, especially as it is a legal requirement to do so. Additionally, these decisions are being made at a time when the patient is very unwell and is an added unnecessary pressure and worry. We would recommend that clinicians consider very carefully the timing of such conversations and unduly putting pressure on the patient or family. We understand that DNAR is a clinical decision and as such, when the situation presents, the attending clinicians will clinically assess whether the patient is suitable for resuscitation. Given this, we question why patients/families are pressured with an imposed DNAR when it is unnecessary.

We recommend that a process is put in place whereby a patient or their next of kin can sign to indicate that a DNAR discussion has taken place and that there is a clear understanding of what the implications are. Linked to this we recommend that processes are implemented or established for those who disagree with DNAR decisions to raise their concerns immediately and have further opportunity to address them.

We further recommend that the NCA clarify the following questions related to their DNAR policy:

- What happens if a second opinion regarding DNAR is not accepted by the patient, their representative or those close to them?
- Regarding the statement from the NCA that they take a holistic approach to the decision-making process, does this take into account a patient's cultural and religious needs and if so, in what ways?

4. Reviewing Pathway: We would recommend that the Northern Care Alliance NHS Group (NCA) and Oldham Clinical Commissioning Group (for primary care) provide a pathway on how a patient/family can go about requesting a review/reconsideration of the DNAR decision. This is especially helpful for those who objected to the DNAR being applied. The DNAR form is designed to

be reviewed so perhaps now the initial emergency response to the COVID-19 pandemic is under control, and normal services are slowly being resumed, patients/families can be provided with contact details of how they can request a review. We also suggest that a review date be added to the DNAR decision form.

We further recommend that the NCA clarify the following review questions:

- How frequently are DNAR decisions reviewed and is there is a standard timeframe?
- Who is asked to carry out reviews?
- Is there clear guidance in place for staff about the review process?
- When a person's circumstances change, is a DNAR review flagged up on that person's records? If so, what is the evidence that reviews have taken place? If not, how is a clinician to know when it is suitable to review a decision?

5. Time to Consider: If a patient is unsure about DNAR at the time of discussion, we would recommend that the staff member undertaking the conversation allow them time to think about it. They should not be pressed to decide there and then. It should also not be revisited time and again by different doctors during the same admission to hospital. This will understandably make the patient/family feel unduly pressured. Therefore, we recommend that there is a clear record that a conversation was held so that it isn't repeatedly revisited during the same admission. We would also recommend that processes are implemented or established to check that people do feel their views are being taken into account as part of DNAR conversations.

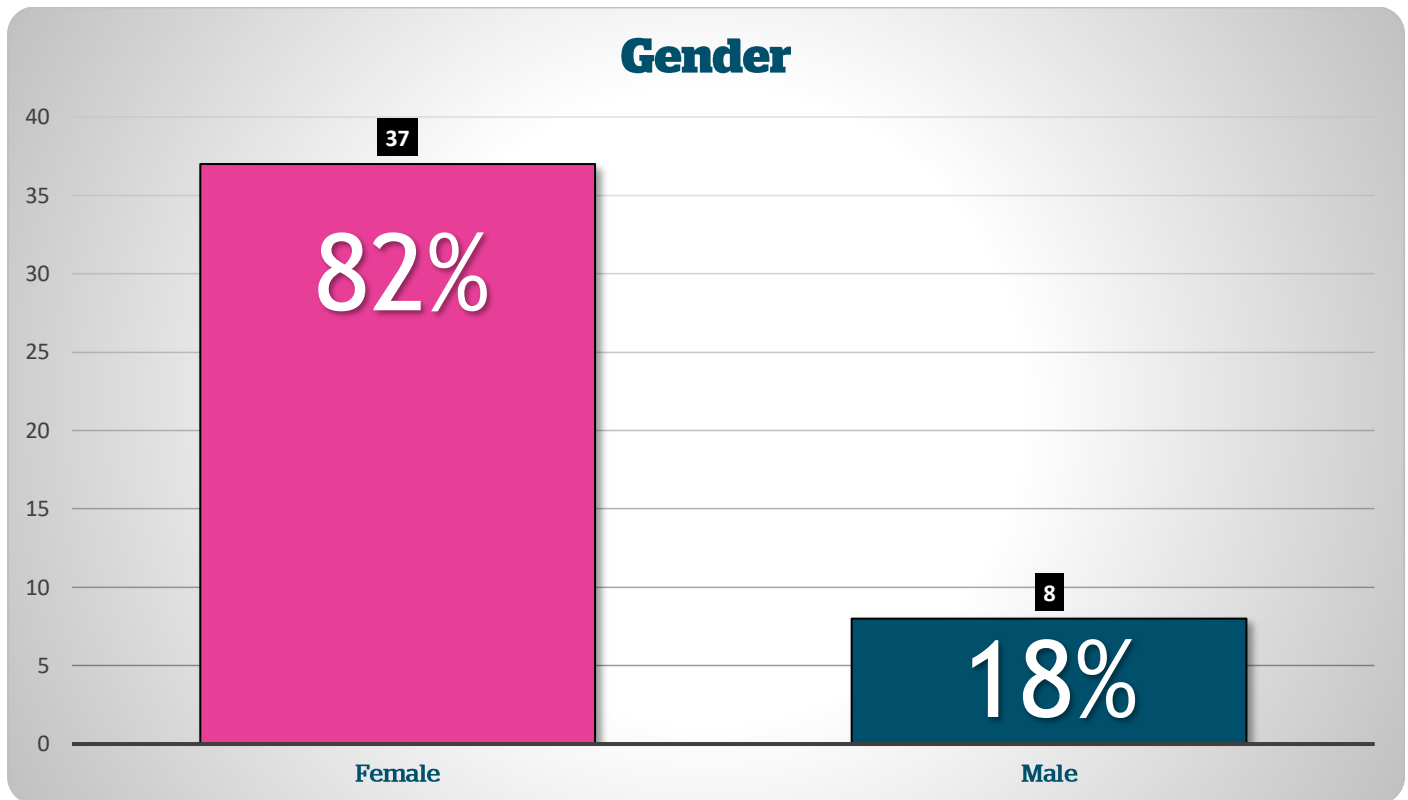
6. Clear Communication: We recommend that patients/families should also be clearly informed that the decision made is reversible and that the form can and should be reviewed as the patients' health changes. Additionally, we would recommend that patients/families should be clearly informed that DNAR does not mean the withdrawal of treatment - and explain clearly exactly what it means. It would be helpful if a leaflet could be provided whenever a DNAR discussion takes place that explains in plain English what DNAR means, where to find more information, and provides any myth busting information that may aid communication. This leaflet should also be made available in different formats and languages.

We recommend that Oldham stakeholders approach national bodies for input and support around awareness raising on these matters across the country as a number of people have commented on the importance of having DNAR conversations earlier in life. We recommend that a national campaign to raise awareness about DNAR be developed and would urge NHSE and national bodies to consider this. Also we recommend that there are assurance processes to check and ensure that records have been updated between healthcare providers.

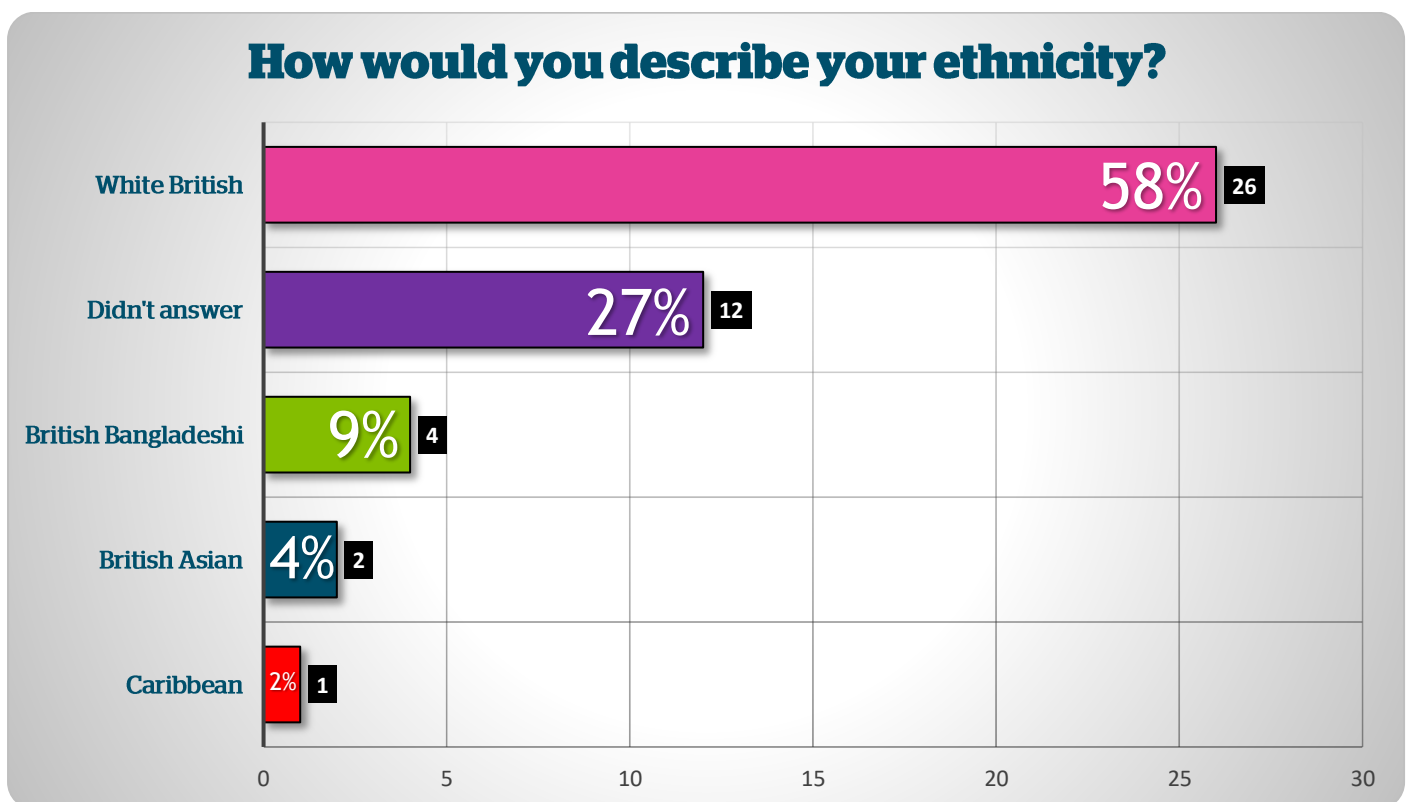
7. Crucial Impact: Some very positive experiences have been shared which demonstrates that many conversations are being handled kindly and sensitively and this should form the basis for strengths-based working in future. However when this doesn't happen, the conversations leave a very negative and lasting impact on people. Such experiences cannot be undone, but they can be learned from, so that they are not repeated. We recommendation that stakeholders collaborate on a process for capturing learning in Oldham about DNAR conversations.

8. Further Research: From the profile of respondents it is evident that further research to capture the views of more men, a wider range of people from different ethnic backgrounds, and people from some underrepresented areas of Oldham would be beneficial. We recommend that stakeholders discuss, prioritise and collaborate on further DNAR research in Oldham and that findings and recommendations from this work are added to this report.

Profile of respondents

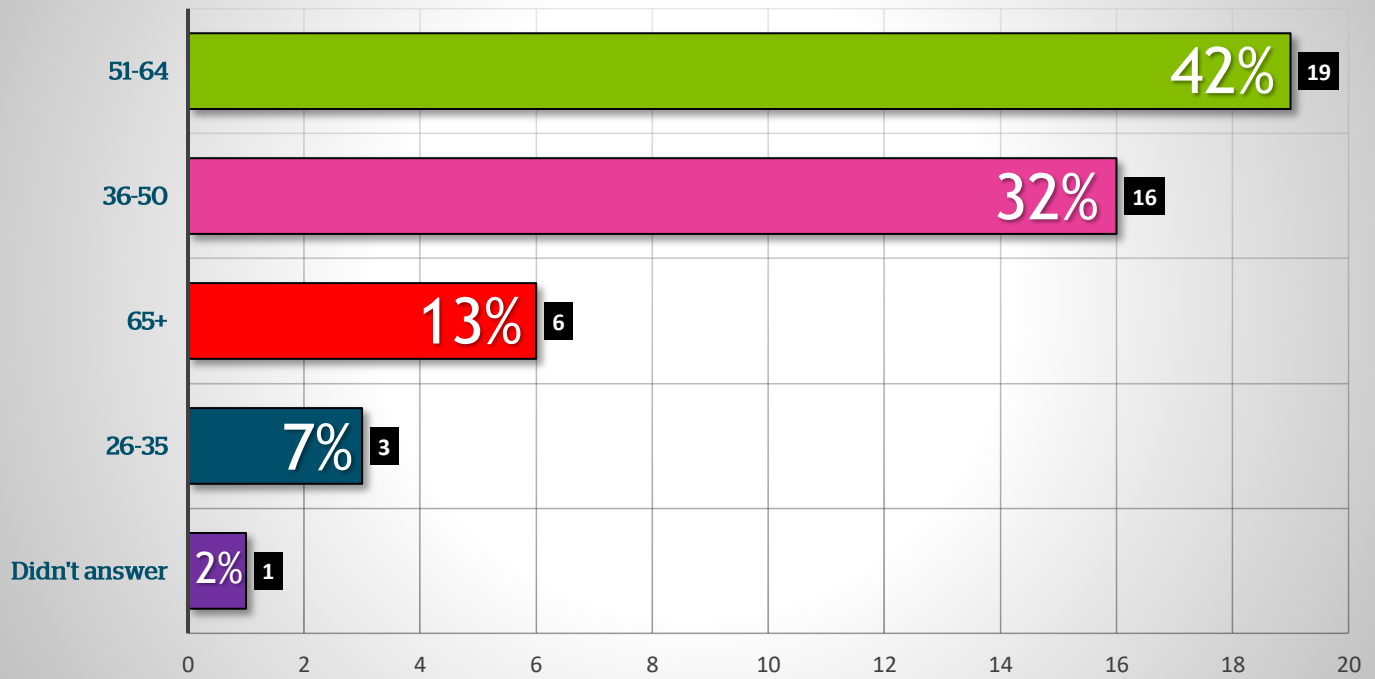


82% (37 people) who completed this survey were female compared to 18% (8 people) who were male.



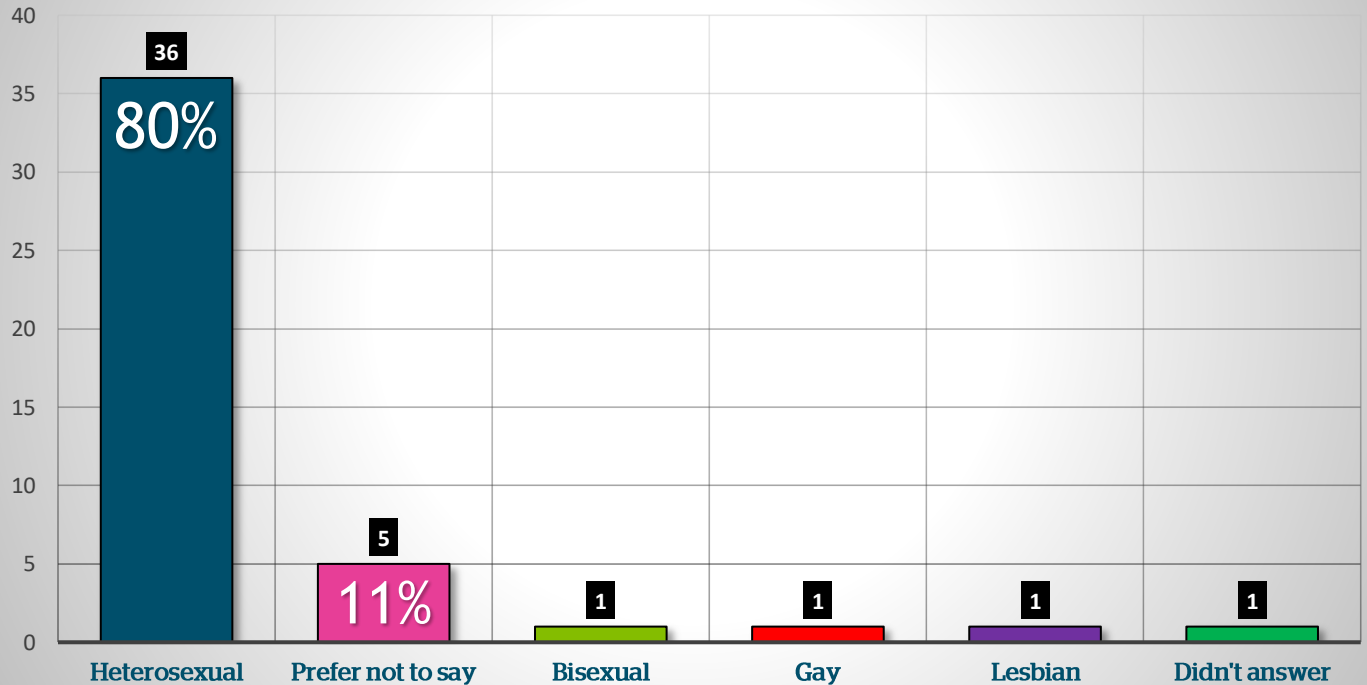
There were a range of ethnic backgrounds represented in this survey. The most common was 58% (26 people) being white British. 27% (12 people) chose not to answer this question.

Age Group



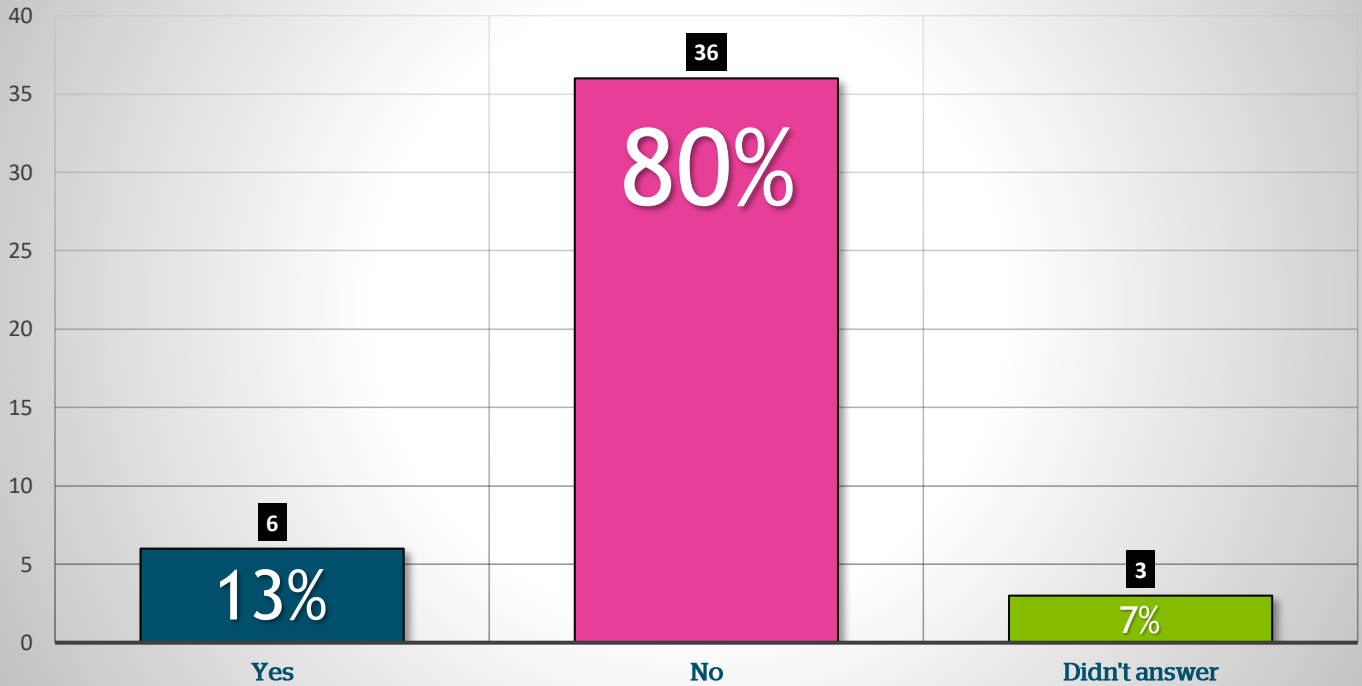
There were a range of age groups represented in this survey. The most common was 42% (19 people) who stated they were between the age of 51-64.

Sexual Orientation



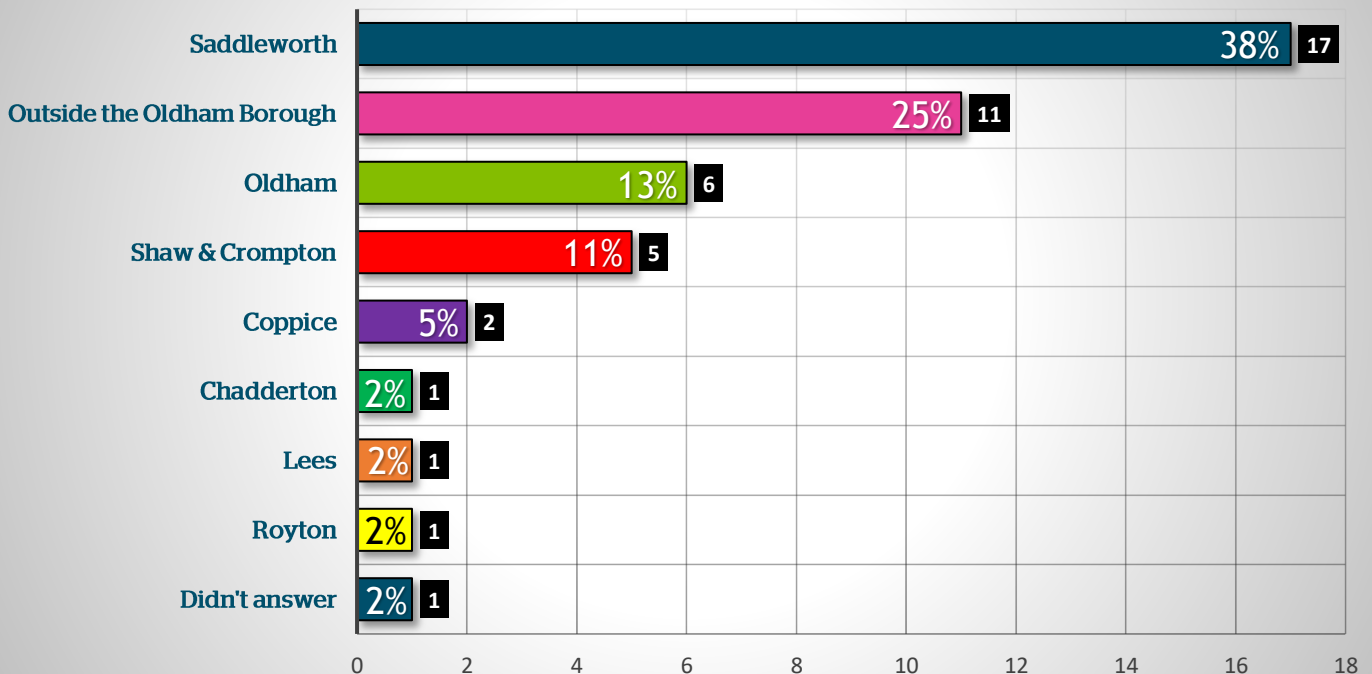
80% (36 people) stated that their sexual orientation was heterosexual. 11% (5 people) chose not to answer this question.

Do you see yourself as a disabled person?



When asked if people saw themselves as a disabled person, 80% (36 people) stated that they didn't. 13% (6 people) stated that they did see themselves as a disabled person.

Town or area you live in



The most popular location that people who completed this survey resided in was Saddleworth with 38% (17 people). Various locations across the Borough of Oldham were represented as well as 25% (11 people) who completed the survey from outside of the borough.

Appendix A: Survey Questions

1. Are you 70 years old or over or do you care for someone 70 years old or over?

- Yes
- No
- I am a carer for someone who is 70 or over

2. Has a healthcare professional spoken to you or your loved one about 'Do Not Attempt Resuscitation' (DNAR)?

- Yes
- No

3. Was this before COVID-19 or during?

- Before COVID-19
- During COVID-19

4. Where was this discussion held?

- GP Practice
- Hospital
- Care Home/Nursing Home
- Hospice
- In your own home
- Other, please specify:

5. Please indicate how much you agree or disagree with the below statements...

DNAR was explained to me in a way that I understood...

I agreed with the decision made about DNAR?

I feel my views were taken into account when making the decision to apply DNAR to my record/my loved ones record?

I felt it was the right time to discuss DNAR...

The DNAR conversation was handled sensitively and kindly...

All the above statements were followed by the following options:

- Strongly Agree
- Agree
- Neither Agree nor Disagree
- Disagree
- Strongly Disagree

6. Is there anything else you would like to add?

About You

7. Gender

- Male
- Female
- Transgender
- Prefer not to say

8. How would you describe your ethnicity? (e.g. White British) Please state below:

9. Age Group

- 11-15
- 16-25
- 26-35
- 36-50
- 51-64
- 65+

10. Sexual Orientation

- Heterosexual
- Gay
- Lesbian
- Bisexual
- Prefer not to say
- Other, please specify:

11. Do you see yourself a disabled person?

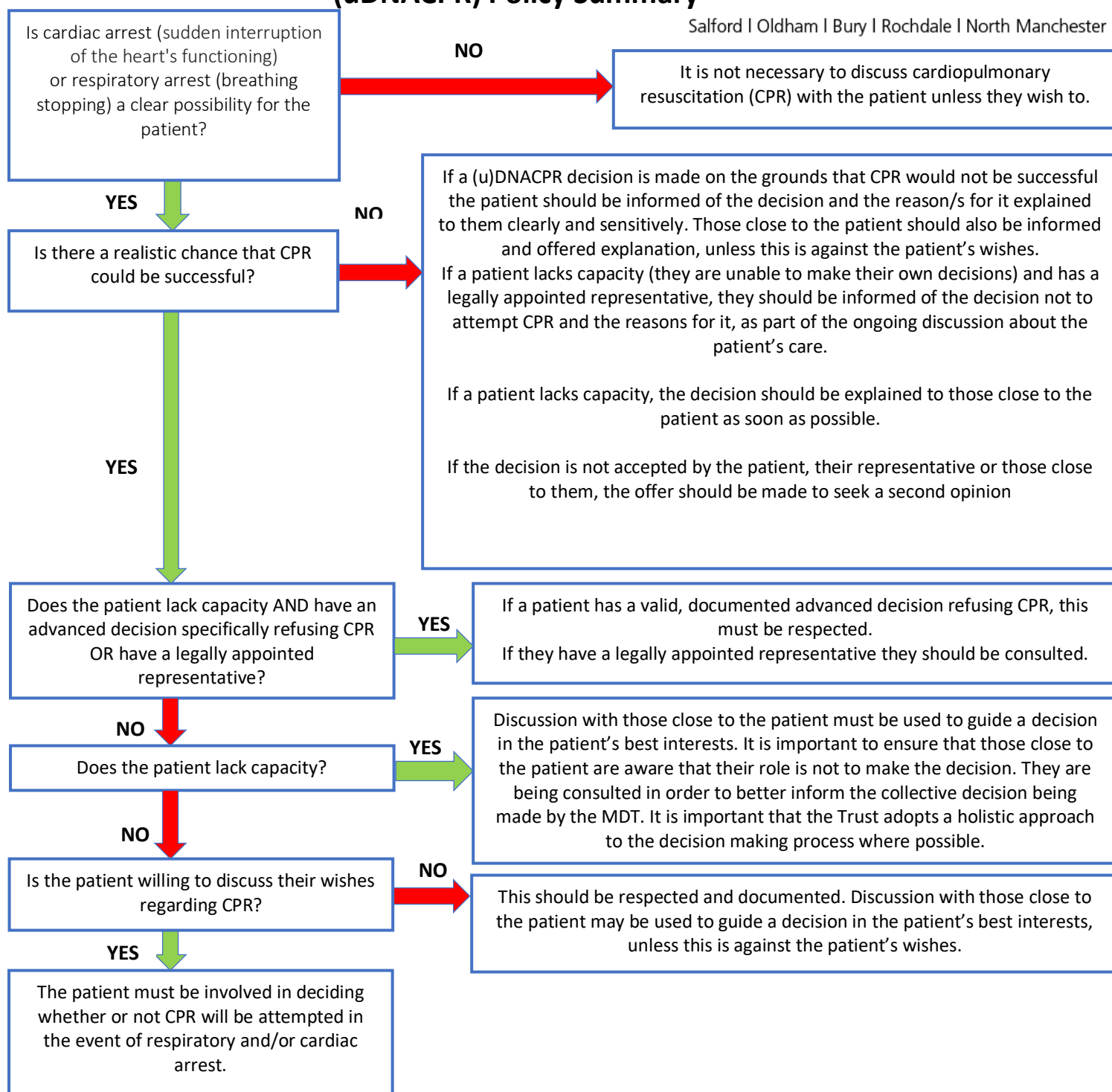
- Yes
- No

12. Town or area you live in

- Chadderton
- Coldhurst
- Coppice
- Failsworth
- Glodwick
- Lees
- Oldham
- Royton
- Saddleworth
- Shaw & Crompton
- Werneth
- Westwood
- Outside of the Oldham Borough
- Other, please specify the first part of your postcode:

Appendix B: Unified Do Not Attempt Cardiopulmonary Resuscitation (uDNACPR) Policy Summary

Salford | Oldham | Bury | Rochdale | North Manchester



- If respiratory and/or cardiac arrest occurs and there is no recorded decision, CPR should be attempted in most circumstances
- Conversations and decisions about CPR are an important part of high quality health care for people at risk of death or respiratory and/or cardiac arrest.
- A documented uDNACPR decision **does not mean** that other treatments will be stopped. Just that should the patient stop breathing/their heart stop, CPR will not be started. Decisions regarding **any** other treatment and care should be discussed and decisions made on an individual, case by case basis.
- Discussion and decisions about CPR are sensitive and complex and should be carried out by experienced and competent members of the healthcare team..
- Decisions about CPR require sensitive and effective communication with patients and those close to patients.
- Decisions about CPR must be documented fully and carefully. Decisions should be reviewed as needed on a case by case basis and if/when circumstances change.
- Advice should be sought if there is uncertainty.