Parliamentary
and Health Service
Ombudsman

# Do not attempt cardiopulmonary resuscitation (DNACPR)

## Survey results

January 2024

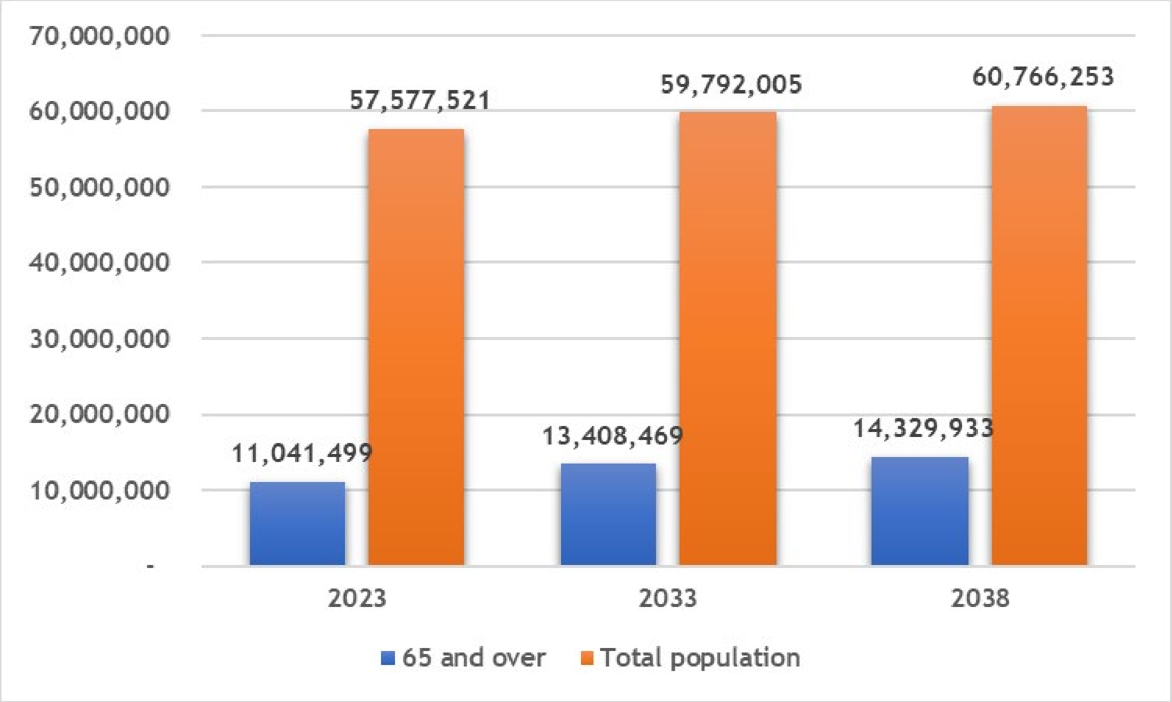
# Contents

# 1. Executive summary

## The UK's ageing population

The UK has an ageing population. In England, for example, the number of people aged 65 or over is set to increase by over 3 million in the next 15 years. This means that the proportion aged 65 or over will increase from 19% in 2023 to 24% in 2038.

**Figure 1: Population projections (England)**



**Source:** Office for National Statistics (2020)[1]

This demographic shift towards an older population has a number of implications for healthcare and, while life expectancy is expected to continue rising, there is a lower likelihood of healthy life expectancy keeping pace. In short, health conditions associated with later-life onset will affect a bigger proportion of the population and place greater strain on the UK's health provision.

## Exploring current perspectives of DNACPR processes

At present, there is widespread confusion and misunderstanding about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) processes. Attempts should be made to resolve these and minimise any unnecessary additional strain on health service provision in the future.

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[1] Office for National Statistics (2020): 'Subnational population projections for England: 2018-based', https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/bulletins/subnationalpopulationprojectionsforengland/2018based

The current research was prompted by a number of complaints we upheld about how DNACPR notices are communicated. A review of these identified potential issues with the DNACPR process. This research explored clinicians' views about how widespread these issues are.

Underlying these issues, the research also highlighted that public knowledge about DNACPR processes is often misaligned, and that public attitudes and perceptions of it do not always mirror the reality of DNACPR processes. Overcoming these misunderstandings and addressing the falsehoods which have grown up around DNACPR will be important in resolving the issues associated with it.

In our survey, respondents expressed high levels of personal experience with DNACPR decision-making processes (92%) and high awareness levels of guidance about the management of these decisions (96%). Similarly, 96% said they would be confident implementing a DNACPR decision if the situation called for it.

Consequently, only around a quarter (28%) indicated they would benefit from more guidance to add to the existing publications available from, for example, the General Medical Council (GMC) or Resuscitation Council UK.

## Managing DNACPR processes

Looking specifically at how well the DNACPR process is managed, our respondents suggested there could be room for improvement; just under half (46%) said there was good communication **most of the time** with 43% saying **some of the time**. Just 5% said **always**.

Despite this, 95% stated they were confident having discussions with patients, their families, carers and/or advocates about DNACPR decisions.

On the face of it, respondents feel confident in their knowledge of DNACPR processes and discussing DNACPR decisions with those affected. That being said, as results suggest that communications around decisions could be improved, it is possible that other factors (rather than the clinician's skills and capabilities) are influential.

To consider this further, we asked respondents if the DNACPR form they use is fit for purpose. The majority (70%) agreed that it was compared to only 13% who disagreed. There were, however, questions raised about the extent to which the wording of forms puts too much emphasis on defensive medical practice.

In addition, concerns were voiced about whether or not a single form could ever adequately cover the complexities involved in a DNACPR decision. These complexities become more acute when dealing with particular patient groups such as those with severe physical or learning disabilities, those with premature frailty or high care needs at a young age, older individuals suffering from dementia, or individuals with differing cultural beliefs about end of life care (for example, for religious reasons). Many respondents suggested that clear advice on dealing with these groups would be beneficial.

Time and resources are often in short supply within the medical profession and 87% of respondents stated that more time to follow the decision-making process would help towards resolving some of the issues with DNACPR. Some also felt that DNACPR discussions were best suited to the primary care setting. This would allow for the conversation to take place before it became a time-sensitive decision, and also for it to be held with a clinician (that is a GP) that the individual may be more familiar with and trusting of. However, it may be unrealistic to expect that a compassionate, thoughtful and open discussion about end of life care could take place at the brief amount of time allowed for in a typical GP appointment.

## Public perceptions and the reality of DNACPRs

Moreover, the greatest barrier to management of the DNACPR process according to respondents is public perceptions. This theme ran throughout much of the survey responses. Indeed, 87% stated that greater awareness among the public about why DNACPR notices are applied would go some way to addressing the issues.

Many respondents believed a mythology had grown up around DNACPR processes (fuelled in part by media depictions) which has led patients and next of kin to overestimate its effectiveness and success rate but underestimate the complications and negative effects that can result from it.

Cultural factors also play a part here and our societal reluctance to readily discuss issues relating to death and mortality can be an additional barrier to reasoned and informed discussions about DNACPR.

This led many respondents to believe that a public awareness raising campaign is essential. This could be instrumental in clarifying some of the following frequently misunderstood points about DNACPR, that:

- applying a DNACPR notice is an evidence-based decision based on the futility of the patient's recovery and does **not** equate to a withholding of other treatment
- survival rates from CPR are poorer than they are often assumed to be (somewhere between an average of 12% for out-of-hospital cardiac arrests to 24-40% for in-hospital arrests)[2]
- even where CPR is successful and the return of spontaneous circulation (ROSC) is achieved, patients will often be too ill to have an acceptable quality of life

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[2] British Medical Journal (2020): 'Patients overestimate the success of CPR', https://www.bmj.com/company/newsroom/patients-overestimate-the-success-of-cpr/

- patients and next of kin have the right to request CPR as an option, rather than it being a medical decision made by the clinician.

## The prevalence of Advance Care Planning

The Universal Principles for Advance Care Planning were developed, in part, to foster a more consistent national approach to ‘what good likes like’ in advance care planning. They are aimed at everyone involved in the process including the person affected and those important to them, and have the potential to help demystify the DNACPR process. However, from a clinicians’ point of view, there are inconsistencies in awareness levels of the principles; 53% of respondents know of the principles but only 28% think they have had a positive impact.

High awareness levels are localised around specialties which deal with end of life care on a daily basis (for example, palliative medicine) but their reach does not appear to have extended much beyond this. This means that discussions about end of life care and DNACPR do not always take place early enough and may be delayed until the patient reaches an acute setting. The impact of this, aside from placing additional burdens on clinicians within specialties associated with end of life care, is that discussions can come as a shock to patients; the emotional impact of having an ad-hoc conversation with a clinician they have previously had no contact with or built up a trusting relationship with, can make this worse.

## COVID-19 - intensifying the focus on DNACPR

The COVID-19 pandemic served to intensify the focus on DNACPR decisions. Although 23% of respondents felt this had a positive impact on the issues associated with DNACPR notices, the majority (54%) believe the impact had been negative.

On the positive side, respondents said it had led to a cultural shift which brought the concept of mortality to the forefront of people’s minds. In turn, this allowed patients to become more open to discussing DNACPRs, helped clinicians become more comfortable having these discussions, and resulted in earlier decision-making.

For those who felt there had been a negative impact, the media assertion that ‘blanket DNACPRs’ were liberally applied to particular groups resulted in a growing and enduring distrust from the public about DNACPRs.

This intensified the ‘mythology’ around DNACPRs that it can reverse a natural death, equates to a withdrawal of other treatment, and that CPR is something which can be requested as a medical procedure. The upshot has been that clinicians can feel pressured to agree to an ineffective treatment amid fears about patients and their next of kin raising a complaint against them or taking legal action.

## DNACPR processes - a public re-education

To help alleviate pressures relating to DNACPRs, the starting point (according to many of our respondents) is to re-educate the public. Further work would be required to understand the best approach to this, but respondents suggested that short, easy-to-understand pamphlets as part of a wider public awareness raising campaign would be a good start.

Similarly, shifting the focus of DNACPR from something which patients feel they may be missing out on or suggests a withdrawal of care (encouraged by the phrasing, ‘do not attempt …’) to something which they may feel more control over and investment in (for example, ‘allowing a natural death’) could also help.

There is also a part for clinicians to play so that the burden of initiating end of life care discussions is less frequently left to those in particular specialities (for example, palliative medicine). Ensuring that clinicians know how to access guidance on DNACPR processes will be useful. In addition, communication tips on how to sensitively broach these discussions would help, as would widening out the authority to sign off DNACPR notices to other medical professionals (for example, nurses).

From an administrative point of view, record management of DNACPR decisions is in need of being more joined up. Respondents noted that documentation about decisions is frequently inaccessible within and across different healthcare settings. This can lead to increased workloads for clinicians and repeated discussions being held with patients and their next of kin.

Some respondents feel a degree of frustration about DNACPR. They believe it to be a decision which – clinically speaking – should affect a small minority of patients. However, on account of misconceptions about it, DNACPR occupies a disproportionate amount of their time. Re-education of the public, improvements to administrative processes, and widening of the responsibilities for initiating DNACPR discussion would help alleviate this. And, despite not wishing to be overwhelmed by additional guidance, clear signposting to existing guidance and the introduction of nuanced support for dealing with specific patient groups would be welcomed by many respondents.

# 2. Introduction

We recently upheld a number of complaints about how decisions to apply Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) notices are communicated to those affected.

A review of these complaints and further discussions with relevant stakeholders identified some potential issues with the DNACPR process.

To gather wider evidence of the prevalence of these issues, and clinicians' opinions about the DNACP process, we developed an online survey. The survey was live for four weeks from Friday 23 June until Friday 21 July 2023 and attracted 702 responses.

# 3. DNACPR decisions

## Experience of dealing with DNACPR decisions

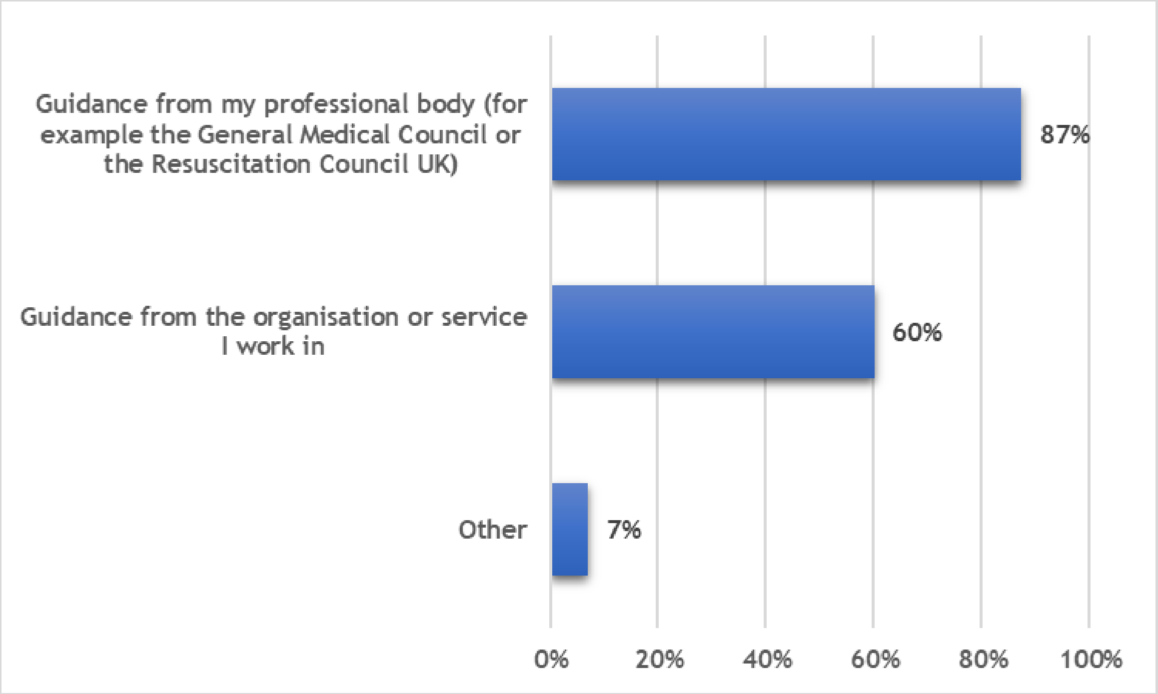
The vast majority of survey respondents (96%, n=677) have personal experience of the DNACPR decision-making process. This provides assurance that the respondents are a knowledgeable and informed group, and a valid one from which to draw conclusions about DNACPR processes.

## Guidance for managing DNACPR decisions

Similarly, the vast majority (92%, n=644) are aware of guidance for clinicians about the management of DNACPR decisions.

In terms of which guidance respondents are aware of, 87% (n=614) know of **guidance from their professional body**. As awareness of **guidance from the organisation or service they work** in is lower (60%, n=422), it is likely that this is either not deemed to be a priority for some specialties, is less well publicised or simply unavailable in many cases.

**Figure 2: Which of the following sources of guidance are you aware of?**



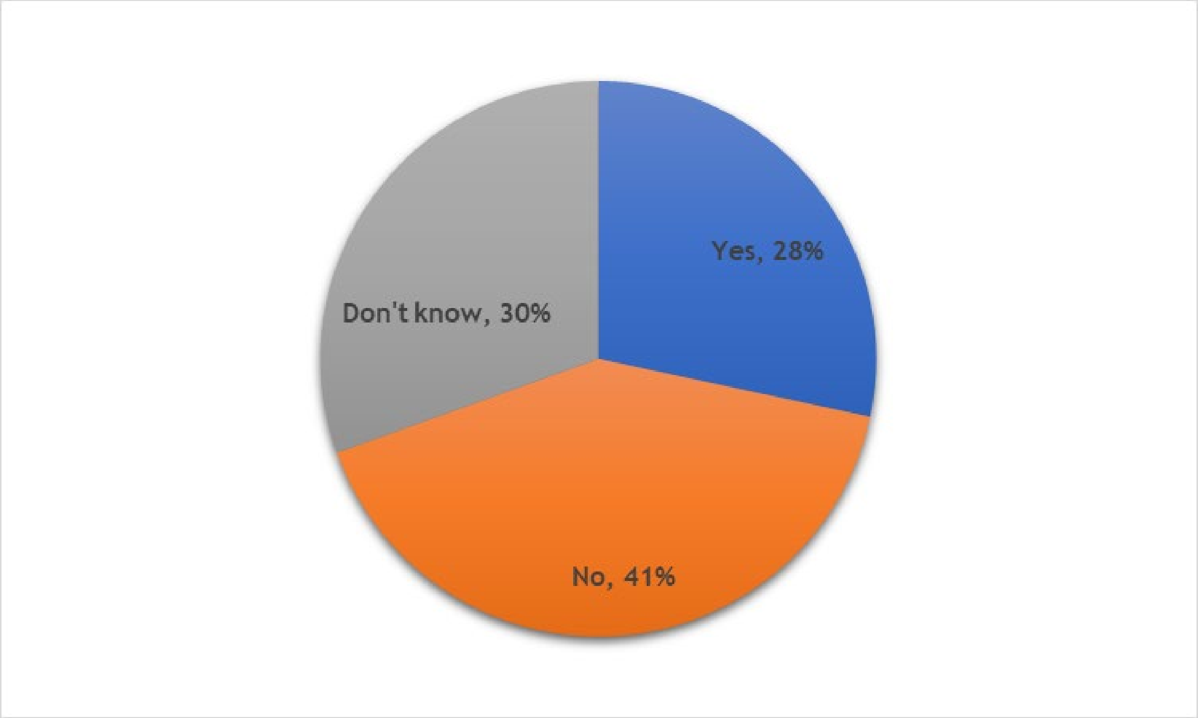
**Base: Respondents who are aware of guidance (n=644)**

Awareness levels of professional body guidance is particularly high (above 90%) for all respondents working in **dual specialties** and also for those based in **geriatric medicine**, **palliative medicine**, **clinical oncology**, and **intensive care medicine**. It is likely that clinicians with the greatest requirement for guidance (for example, those regularly dealing with end of life care) will be naturally aware of the guidance for their day-to-day work or, if not, will be more motivated to seek it out.

Confidence levels for applying this guidance is very high. 92% (n=47) for **other** guidance, 91% (n=382) for **guidance from the organisation/service**, and 90% (n=551) for **guidance from the professional body**.

Views on whether or not additional guidance would be helpful were mixed. 41% (n=289) said it would **not** be but 28% (n=199) indicated they **would** benefit from more guidance.

**Figure 3: Would you find different or additional guidance helpful?**



Respondents from some specialty backgrounds are more open to the idea of additional guidance [for example, **cardiology** (45%, n=5) or **non-clinical/no specialty/unknown specialty** respondents (43%, n=20)] and, although their views represent a minority opinion, we should be mindful that a further 30% (n=214) did not know if additional guidance would be helpful.

This indicates that, for some, further guidance could be useful depending on whether or not it adds value to the existing guidance.

Based on responses provided in the survey, respondents would appreciate greater clarity about a number of specific areas including:

- communicating DNACPR decisions effectively

- assertively dealing with patients/next of kin resistant to DNACPR (despite proven clinical futility of the process)
- de-escalation of the above to minimise complaints/legal action
- best practice approaches for dealing with specific groups (for example, those with learning disabilities or those with religious beliefs that do not align with predominant UK culture)
- clear and unambiguous clarification of legal status of DNACPR.

To elaborate, those who feel that additional guidance would be helpful mentioned various points which would benefit their development.

First and foremost, many respondents believe the root of issues is grounded in **public perceptions** of DNACPR and that guidance and education for the general public would greatly help. The reason for this, it is claimed, is there are widespread misconceptions about the process; re-educating people about it would therefore be a good starting point:

- "I think guidance for the public would be helpful, something you can refer them to if they don't understand the conversation." **Other specialties**
- "From experience, patients expect the decision regarding DNACPR to be up to them and that CPR is a choice. This, as we know, is not completely true. Patients can refuse treatment but not demand it and CPR is no different. I wish this was something that was communicated clearly to them." **Acute internal medicine**

There would also be benefits in highlighting the drawbacks of unwarranted CPR to clinicians:

- "Many members of the general public are unaware that DNACPR decisions are generally based on futility. More guidance would be helpful for the general public as well as the healthcare professionals involved on the potential harms of inappropriate CPR in those who have a low likelihood of a good outcome." **Acute internal medicine**
- "The current guidance makes it clear that DNACPR is a medical decision. But we are still offering it to patients and asking for their thoughts, even in cases where we know it will not succeed. We do this because we do not train our medical staff in the communication needed." **Palliative medicine**

Due to misconceptions around the process, **conflict** can often arise with patients or their families when a DNACPR is applied. Some respondents think that additional guidance on how to deal with this would be helpful, particularly in the case of patients with limited remaining decision skills:

- "Guidance on communication and implementation where disagreements arise with patients and family members." **Intensive care medicine**
- "The ethical dilemmas for family unacceptance of the decision for patient without capacity to consent." **Geriatric medicine**

Such points also bring into question the legal side of applying DNACPRs and some clinicians would like better advice on where they stand in this regard:

- “Legal/national guidance about what is expected in law.” **Geriatric medicine**
- “Legal implications of appropriate DNACPR decisions when family disagree, complain or threaten.” **Geriatric medicine**
- “There needs to be new work done around who has final decision making when family or patient want CPR but it is not appropriate to give clinically. This used to be a clinical decision but is now significantly muddied by the legislation. This leads to many people receiving inappropriate CPR.” **Acute internal medicine**

In addition, a few respondents mentioned that additional guidance on dealing with particular scenarios, and patients with different needs or backgrounds would be helpful:

- “Trying to minimise conflict with colleagues over differences in practice which ultimately confuse patients/relatives and cause tension. How to address conflict around DNACPR with people with different values about life and death (cultures, religions) who may not be aware of or even accept UK guidance on DNACPR.” **General (internal) medicine**
- “A more nuanced view for patients with a strong religious background - different religions have different views on what actual constitutes death.” **General practice**
- “Specific scenarios including severe disability and learning disability; more nuance about decisions for/against ICU that is accessible to juniors.” **Acute internal medicine**
- “More clarity around those with learning difficulties.” **Geriatric medicine**
- “Clarity in assessing suitability in DNAR especially for children or the very young.” **General practice**

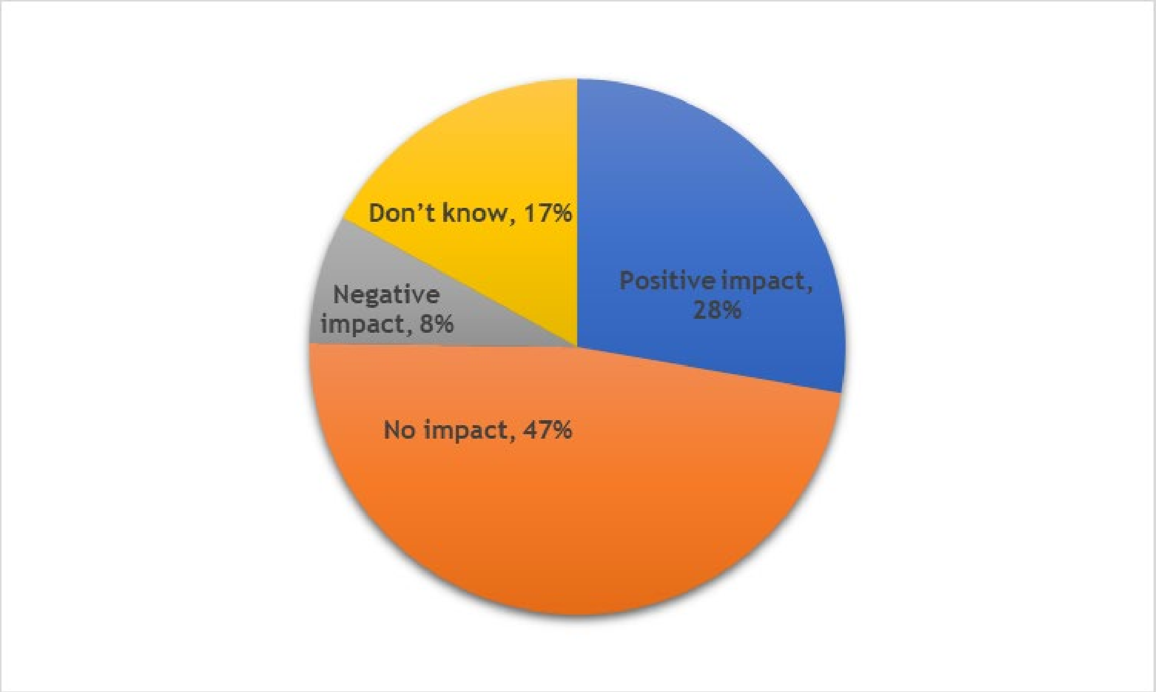
# 4. Universal Principles for Advance Care Planning

There is a relatively even split between respondents who are aware (53%, n=371) of the **Universal Principles for Advance Care Planning** and those who are not aware (47%, n=331).

Awareness levels are highest amongst respondents specialising in end-of-care and stand at 82% (n=53) for those working in **palliative medicine**.

Of those who are aware of the Principles (n=371), almost half (47%, n=176) think they have had **no impact**; far fewer than think they have had a **positive impact** (28%, n=103).

**Figure 4: What impact, if any, do you think the Principles have had on how DNACPR notices have been applied since March 2021?**



**Base: Respondents who are aware of the Principles (n=371)**

For those who believe the Principles have had **no impact**, they listed a number of reasons why they thought this was the case.

First, and as evidenced by the statistics above, awareness is relatively low:

- "I do not think there is widespread awareness of the principles. Healthcare professionals who were doing this well before the principles were published will not have changed their practice, healthcare professionals who were not doing this well are unlikely to be aware of the publication of the principles." **Geriatric medicine**

And, while knowledge about the Principles is good across certain specialties (for example, **palliative medicine**), awareness has not spread particularly far beyond these:

- “As (a) palliative medicine consultant & member of trust resus committee I am aware of these guidelines and incorporate in practice & teaching. I do not think they are widely known outside my specialty locally, despite our attempts to circulate.” **Palliative medicine**
- “The principles are fine, but were poorly publicised. I’m aware of them as a consultant in palliative medicine but I’ve never come across anyone in another specialty who has heard of them.” **Palliative medicine**
- “I do not think they have been promoted widely enough.” **General practice**

In addition, respondents felt that, however useful and well meaning, the limited time and resource available to clinicians would continue to prevent wider awareness and impact of the Principles:

- “Most would agree with and enact these principles. The issue comes with lack of time available to do this properly and lack of patient awareness of these issues.” **Geriatric medicine**
- “Unfortunately, as much as people may be aware of the guidelines, we struggle to find time to have these discussions ahead of time, before people become unwell. We also don’t continue the conversation as things change with time.” **Emergency medicine**

Similarly, some respondents felt that, as long as there were issues with public perceptions about DNACPRs, it will be difficult to move on from:

- “The principle of advance care planning as a voluntary conversation over time (often with people with incurable illness) only helps for the minority of people who take up the offer of the conversation. It does nothing to clarify for the public that resuscitation is a medical treatment which will not be offered at the point it becomes futile due to no chance of success (again thinking about terminal illness, the point where that illness naturally leads to death). The gap in public understanding is in this area, not in people’s understanding that they can opt-out of resuscitation.” **Palliative medicine**

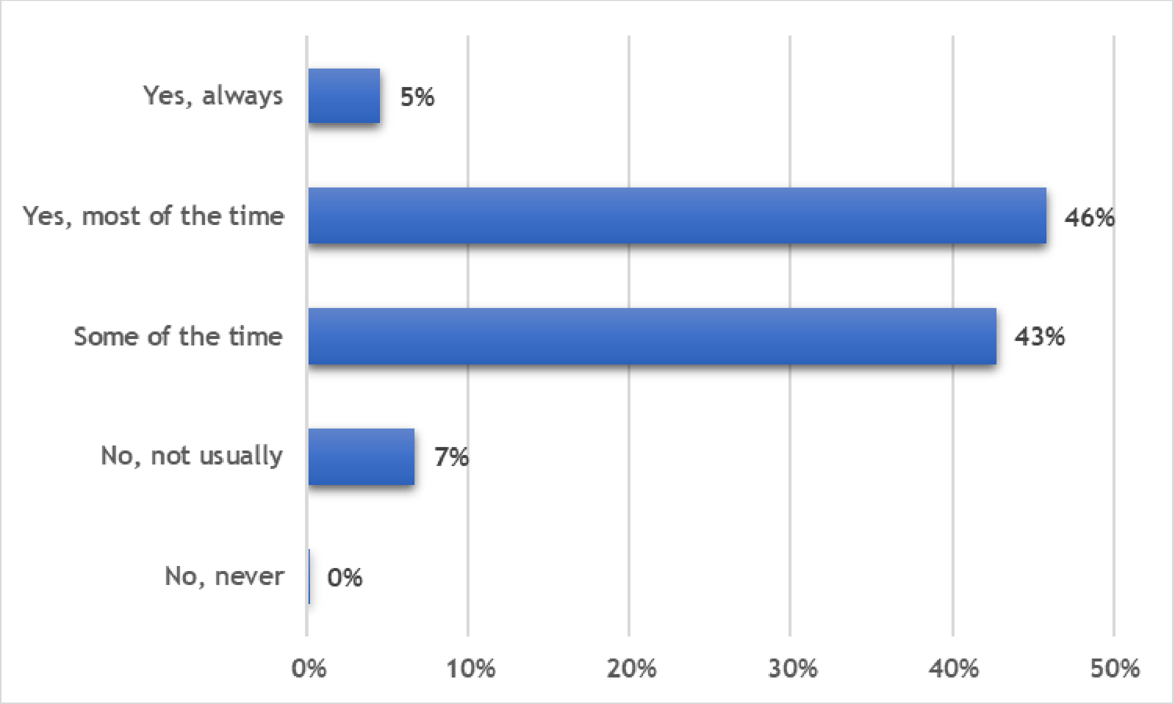
# 5. Management of the DNACPR process

## How well-managed is the DNACPR process?

When asked if there is good communication with patients and other parties when considering if a DNACPR decision should be made, respondents' results suggest there is room for improvement.

Just under half (46%, n=322) said there was good communication **most of the time** and 43% (n=300) said **some of the time**. Far fewer (5%, n=32) said **always**.

**Figure 5: When considering if a DNACPR decision should be made, do you think there is good communication with patients, their families, carers and/or advocates?**



**Palliative medicine** and **geriatric medicine** are two specialties where it might be expected that good communication about DNACPR decisions would be particularly important. However, the most common response within these specialties is **some of the time**; 62% (n=40) for **palliative medicine** and 46% (n=32) for **geriatric medicine**.

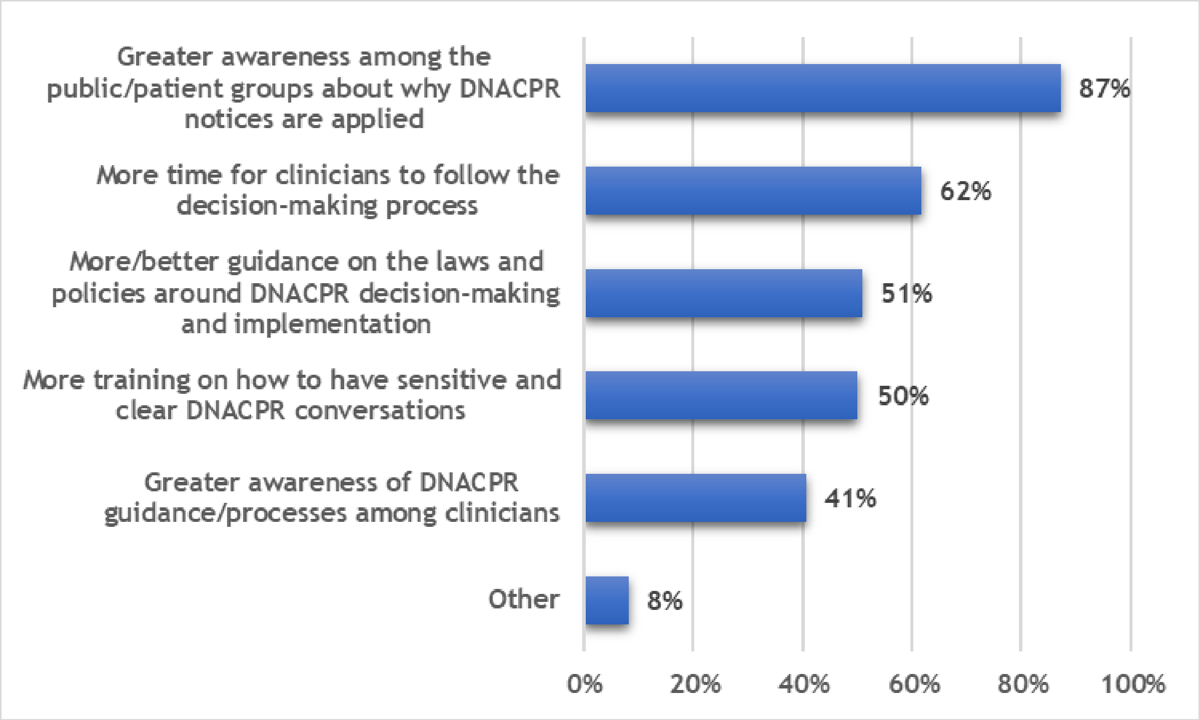
Clearly, there are particular groups among our respondents who have concerns about how DNACPR decisions are communicated.

## Addressing the barriers

When asked what might help address the issues and barriers to managing the DNACPR decision-making process effectively, **greater awareness among the public** about why they are applied was the most commonly given answer (87%, n=612), followed by **more time for clinicians to follow the decision-making process** (62%, n=433).

Around half of respondents indicated that guidance, training or greater awareness of the process among clinicians would be helpful.

**Figure 6: Addressing issues and managing the DNACPR decision-making process more effectively**



When asked what might help address the issues and barriers associated with managing the DNACPR decision-making process, respondents raised a number of points.

One of these was the underlying theme which has run throughout this research; that public understanding can make the process more difficult to manage:

- "Greater education to the public about the rights of relatives (sometimes my experience is that they believe they have a legal right to reject e.g. DNACPR)." **General (internal) medicine**

Many believe that there is considerable misinformation about DNACPRs, whether that relates to the rights of the family to determine the decision or their misunderstanding that the application of a DNACPR equates to a withdrawal of treatment:

- “Frequently see the wording of conversations implying it is the families’ decision to make which often leads to more difficult conversations.” **Respiratory medicine**
- “The public perception (not helped by much media coverage) is that DNACPR is same as stopping active treatment, rather than an acknowledgement that should death occur (cardiac or respiratory arrest) despite efforts to avoid it happening with active treatment, we are going to allow death to occur.” **Intensive care medicine**

Making the process more transparent and less complex may help towards this. There were also calls for more direction about how to de-escalate conflicts surrounding the DNACPR process:

- “There is a need to demystify the jargon in the public sphere as all too often DNACPR is perceived as a withdrawal of care, which can contribute to complaints. There is a need to have better guidance in resolving complaints locally before these are escalated to the ombudsman or GMC (e.g. compulsory PALS meeting with the family rather than just writing written responses).” **Acute internal medicine & general (internal) medicine (dual specialty)**

Without this, the upshot can sometimes be that misplaced treatment will be undertaken amid fears about litigation from clinicians:

- “Too many healthcare professionals are concerned of litigation from the courts from family members once a patient has died. Part of our decision making is litigation focused, which sometimes means patients receive CPR when we know it is not in the patient’s best interest.” **Haematology**

A key point noted by respondents was that discussions about DNACPR should take place earlier to ensure that patients and their families are fully prepared:

- “For it to be discussed much earlier when patient(s) are healthy, in conjunction with discussions around advanced care planning and ensuring people make use of LPAs [lasting power of attorney] and Advanced Directives.” **General (internal) medicine**
- “Particularly among hospital inpatients, need to promote best practice of informing those close to the patient (with patient consent, or in best interests if patient lacks capacity to give permission) at the earliest possible opportunity – to avoid ‘surprises’ later when they read the document.” **Palliative medicine**

Holding these discussions in a primary care setting would enable them to take place earlier. In addition, there is a greater likelihood they would take place with a trusted GP who knows the patient’s medical history. As is often the case though, time is in short supply and changes would be required to enable meaningful conversations to take place about DNACPR:

- “Enabling the GP workforce to maintain continuity of care to have ACP discussions over time, in a calm non-acute situation with patient, carers and family- this can be extremely time consuming to get right, particularly when a 10 minute slot is all that’s available for the discussion. It should be prioritised for the purposes of sustainable healthcare, to reduce unwanted admissions, reduce unnecessary medications and wasted resources.” **General practice**

Other respondents pointed out that they would welcome additional support when dealing with particular groups of patients:

- “Support for clinicians when managing specific groups – I’m thinking about learning disability patients and those with premature frailty/ high care needs at a young age where I think this is often handled less well. There is also something about transitions of care from children’s to adults’ services in those with short life expectancies but where patients are living to adulthood where historically they wouldn’t – adult doctors then struggle to manage decision making and I have had personal experience of a couple of truly heartrending and distressing cases for all involved.” **Acute internal medicine**
- “Published guidance on patient’s religious views around DNACPR and ethical concerns around this.” **General practice**

And there may also be specific guidance required for particular groups of clinicians:

- “Overseas doctors in particular may need focused training about the DNACPR process as it may differ between countries and cultures.” **Geriatric medicine**

Turning to procedural issues, some respondents pointed out flaws in how DNACPR is managed across the health system:

- “The lack of electronic/transferable DNACPR forms makes communication about these decisions between primary and secondary care very difficult and uncoordinated. In primary care we’ll spend a significant amount of time talking about care planning and completing a DNACPR form if necessary, only for it to be ignored/rewritten/lost when the patient is admitted.” **General practice**
- “In my experience decisions are typically made at or near admission, when the patient is acutely unwell (and often lacking capacity) and families are not reachable to discuss at the time. This is typically documented (briefly) and then rarely revisited and addressed at a later time. Again, a rigorous systems approach is needed to resolve this, rather than relying on individual teams/clinicians to pick it up.” **General practice**

And, with imminent changes to the UK’s demographic profile, there is a sense of urgency that processes need to improve sooner rather than later:

- “With the rapid increase in frail patients due to increased lifespan and the dementia avalanche starting to hit the NHS this time-consuming process needs to be addressed much more often in primary care, maybe even with a dedicated outreach team, rather a than at the crisis point of an acute admission to hospital.” **Acute internal medicine**

# 6. Experience of how DNACPRs are applied

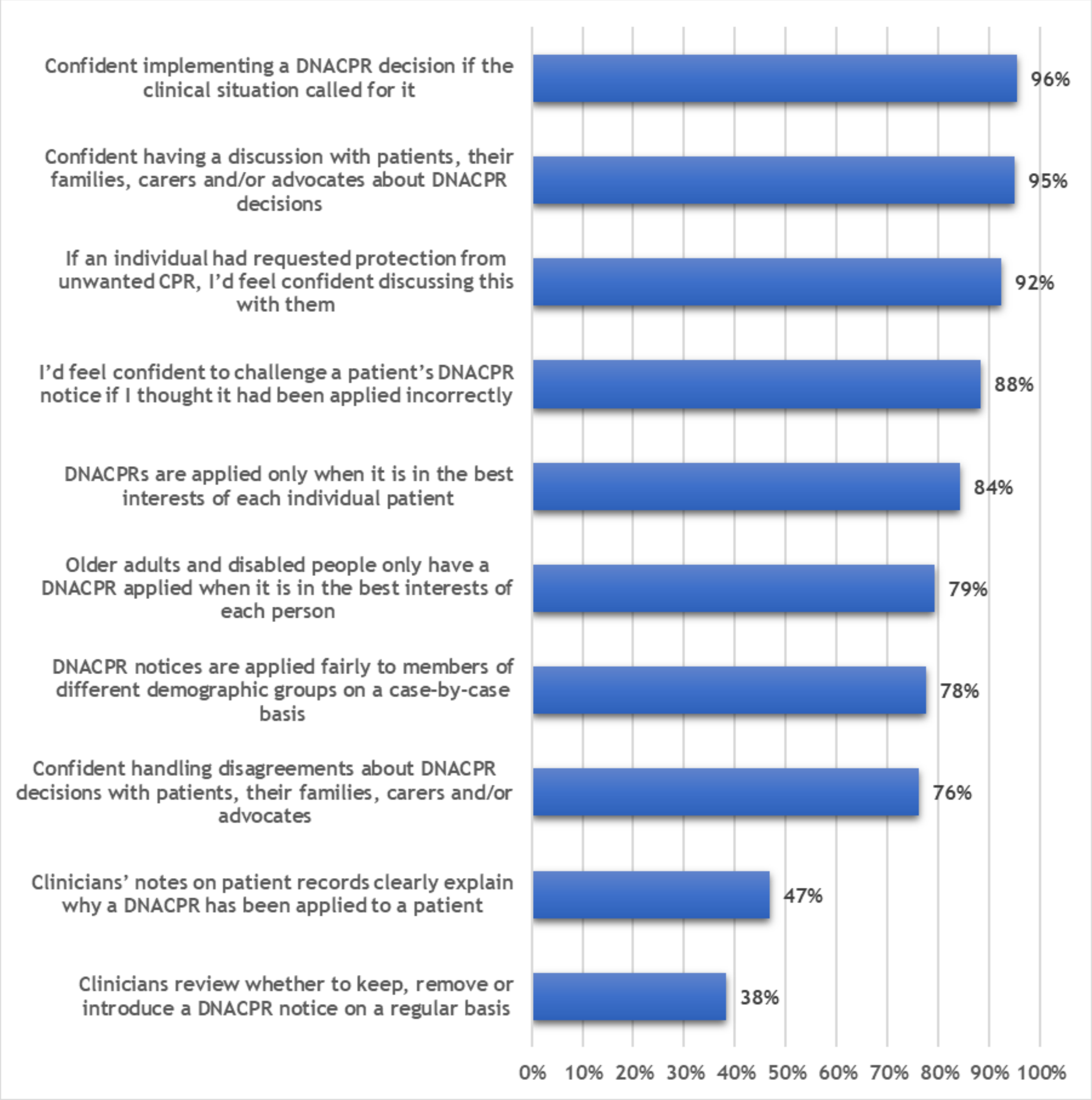
When asked to what extent they agreed with a series of statements about how DNACPRs are applied, results were largely positive.

For example, 96% (n=671) agreed that they would feel confident to implement a DNACPR decision. Similarly, 95% (n=667) are confident having discussions with patients and others about DNACPR decisions.

However, there is considerably less agreement that DNACPR notices are reviewed on a regular basis (38%, n=268) or that records clearly indicate why a DNACPR has been applied to patients (47%, n=329).

It seems likely that such problems could be minimised were there universal, easily trackable (for example, electronic) records of individual patients' end of life care wishes.

**Figure 7: Percentage of respondents who cumulatively agreed with each statement**



The reasons given about reluctance to challenge a DNACPR decision were often related to the hierarchical structure of respondents' workplaces:

- "I am happy to challenge the DNACPR decision with seniors but in my experience this is not taken seriously with due care and consideration, but a unilateral decision quickly made and not revisited/reviewed." **General practice**
- "If made by someone more senior than me." **General practice**

However, others cited additional pressures such as the threat of litigation or influence of families:

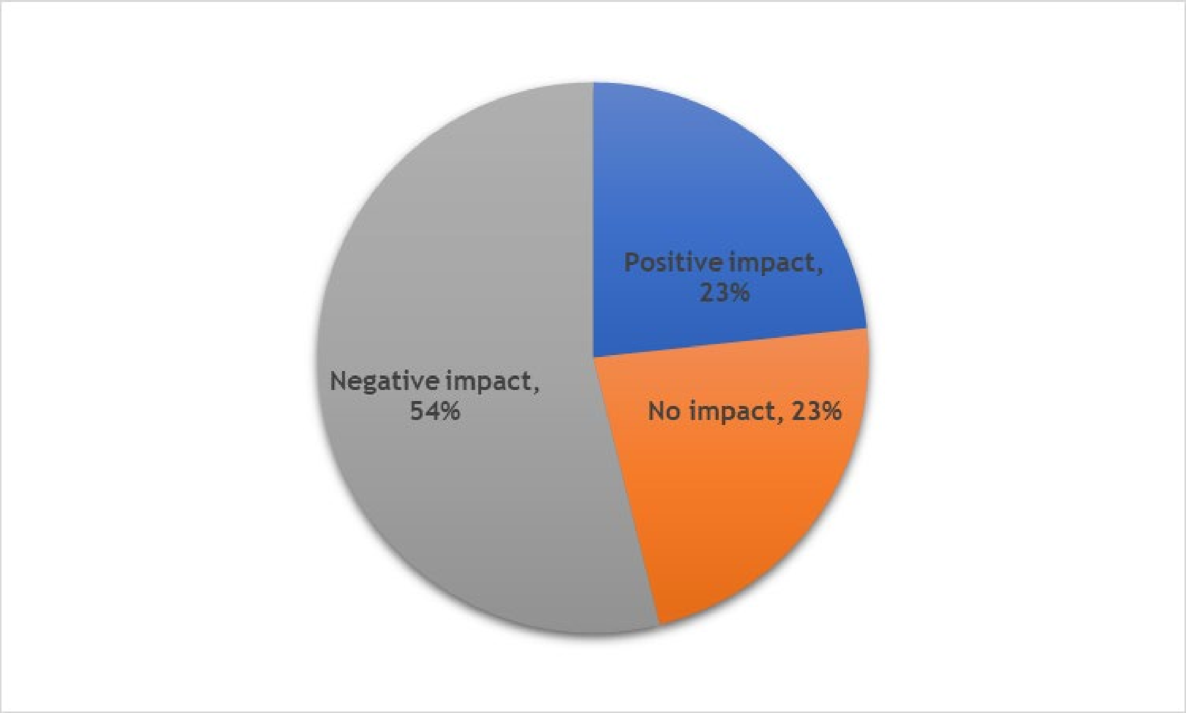
- “Workload, legal consequences, complaints from relatives, limited resources.” **Geriatric medicine**
- “The hassle of aggressive relatives in particular.” **Geriatric medicine**

# 7. Impact of the pandemic

Respondents were asked what impact the pandemic had on issues associated with DNACPRs.

The majority (54%, n=361) felt it had a **negative** impact. The remainder believe it had **no impact** (23%, n=156) or a **positive** impact (23%, n=156).

**Figure 8: Impact of COVID-19 on issues associated with DNACPR notices**



Of those who stated that COVID had a **positive impact**, some comments suggested the pandemic had helped heighten awareness of DNACPRs, resulting in earlier decision-making amongst clinicians:

- “More medical teams having DNACPR discussions earlier during a patient’s inpatient stay prior to deterioration.” **Anaesthetics**
- “Made clinicians more likely to discuss DNAR with patients well in advance where it was appropriate to do so.” **Clinical oncology**

Some felt that COVID led to a cultural shift which brought the concept of mortality to the forefront of people’s minds. This, in turn, allowed people to become more open to discussing DNACPRs:

- “Because so many people were hospitalised and became very sick, I think it is possible that the public had a greater awareness of the morbidity and mortality issues associated with the condition. Many people knew others who had become sick/died from COVID and therefore there may have been increased scope for discussions around what was possible to keep people alive, and why this wasn’t always possible.” **Other specialties**

- “It has become more of a normal thing to discuss.” **Acute internal medicine**

Similarly, a by-product of the pandemic was that clinicians became more comfortable addressing issues which they may previously have found challenging:

- “I think clinicians sadly became better at discussing end of life, as we were presented with it so much.” **Intensive care medicine**

In turn, this may have led to fewer instances of unnecessary treatment being given:

- “Clinicians became more practiced and confident at applying DNACPRs and so less inappropriate treatment occurred when people died.” **General practice**

That is not to say that, in some instances, better practice was not tempered by less welcome developments:

- “I am aware of cases where blanket application of DNACPR orders were put in place for groups of people with no individual discussion e.g. some care homes, which is clearly wrong.” **Geriatric medicine**
- “I’m aware that blanket DNACPRs were applied in the community, this is unacceptable and always needs individualised discussion and decision making.” **Geriatric medicine**

A greater number of comments were left by respondents who felt that the pandemic had a **negative impact**. But, interestingly, there appeared to be a lack of consensus regarding what happened during the height of the COVID-19 pandemic. Some of this appears to mirror the confusion and differing information discussed in the media and the ‘misinformation’ which the public have about the DNACPR process. For example, some respondents noted that blanket DNACPR notices had been placed on particular groups:

- “Some colleagues instituted blanket DNACPR instructions without personal and thoughtful discussion with patients and family members. This is NOT best practice and should NEVER happen.” **General practice**
- “Blanket DNACPR decisions made; lowering of threshold for DNACPR decisions to be made – and the issue is that many of these decisions made at the time persist and remain in place today, without review and correction.” **General practice**

Other respondents believed the opposite and felt there had been a degree of misinformation surrounding the supposed introduction of ‘blanket DNACPRs’:

- “False perception from the public that DNACPR decisions were applied indiscriminately.” **General practice**
- “Impression given to public that DNACPRs were instigated without full consideration and discussion with families- especially in those with a Learning Disability.” **General practice**

Whatever the truth behind this, it seems clear that DNACPRs were applied more liberally:

- “At the beginning of the pandemic, there was a lot of anxiety and uncertainty of how much strain the NHS will face by the ongoing wave of COVID illness. Due to these uncertainties and perceived poor prognosis patients, DNACPR decisions were made which in retrospect was not appropriate. I have encountered patients and families who have asked for these forms to be revoked and become more skeptical about having any further discussions.” **Acute internal medicine**

In short, there appears to be an acceptance from some respondents that, with the benefit of hindsight, certain policies adopted throughout the pandemic could have been approached differently:

- “GPs were asked by NHS England to make DNACPR decisions in the earlier days. They later hid their involvement in this advice and left GPs victim to negative media and family complaints about this.” **Dual specialty (other)**
- “Reluctance to resuscitate early in the pandemic due to possible risk of contracting COVID during the process.” **Other specialties**

The upshot of this has been, some believe, a growing and enduring distrust from the public about DNACPRs.

- “Blanket DNACPR decisions, which were poor practice, widely condemned particularly in the right-wing press have led to a distrust ... this makes even sensible DNACPR discussions more difficult as people’s minds are already closed before it starts. It is hard to see how this could be improved, apart from discussions about death (and CPR) being normalised in the public at large.” **Cardiology**
- “There was a chaotic approach to these decisions, and some places appeared to uniformly apply blanket decisions based on age, or frailty scores rather than individualised decisions … this sets us back years in trying to make compassionate and appropriate individualised decisions because many people are then highly suspicious of us.” **Acute internal medicine**
- “Patients and their families have lost trust that decisions are made in a considerate manner … following from that, when we want to have discussions, we face untrusting patients and families.” **Palliative medicine**

The reasons behind this were manifold but one commonly cited issue was a lack of resources to go through the DNACPR process as thoroughly as many clinicians would have liked:

- “Because we were put in position where one evening I had 30 patients severely ill none of whom had any hope of survival if they actually suffered a cardiac arrest but no time to have the relevant discussions so what was one to do - make a token effort at resuscitation leading to undignified death or cut corners in terms of discussions and documentation.” **Dual specialty (other)**

A contributory factor which compounded these practices even further was the lack of face-to-face contact at the time:

- “The lack of contact with relatives also made things very difficult-and there was often not enough staff time to communicate with relatives regularly.” **General (internal) medicine**
- “The challenge with the pandemic is that things were often done at a distance and remote. Communication would mainly be telephonic/zoom calls, etc. People were able to have sensitive DNACPR conversations over the phone but there is something about being in hospital, seeing a loved one deteriorate and understand the clinical reasoning behind why a clinical decision is made and being able to ask more.” **General (internal) medicine and geriatric medicine (dual specialty)**
- “Lack of face to face communication with patients and families. Families were subjected to conversations re CPR over the phone in the absence of seeing their relative deteriorating so hard for them to trust and contextualise the decision.” **Palliative medicine**
- “Pressure to make decisions led to out of the blue telephone conversations with zero context for patients in whom DNACPR was appropriate but who were not expecting the conversation and at a time when we were all already scared. People worried that they would have other treatments denied them.” **Palliative medicine**

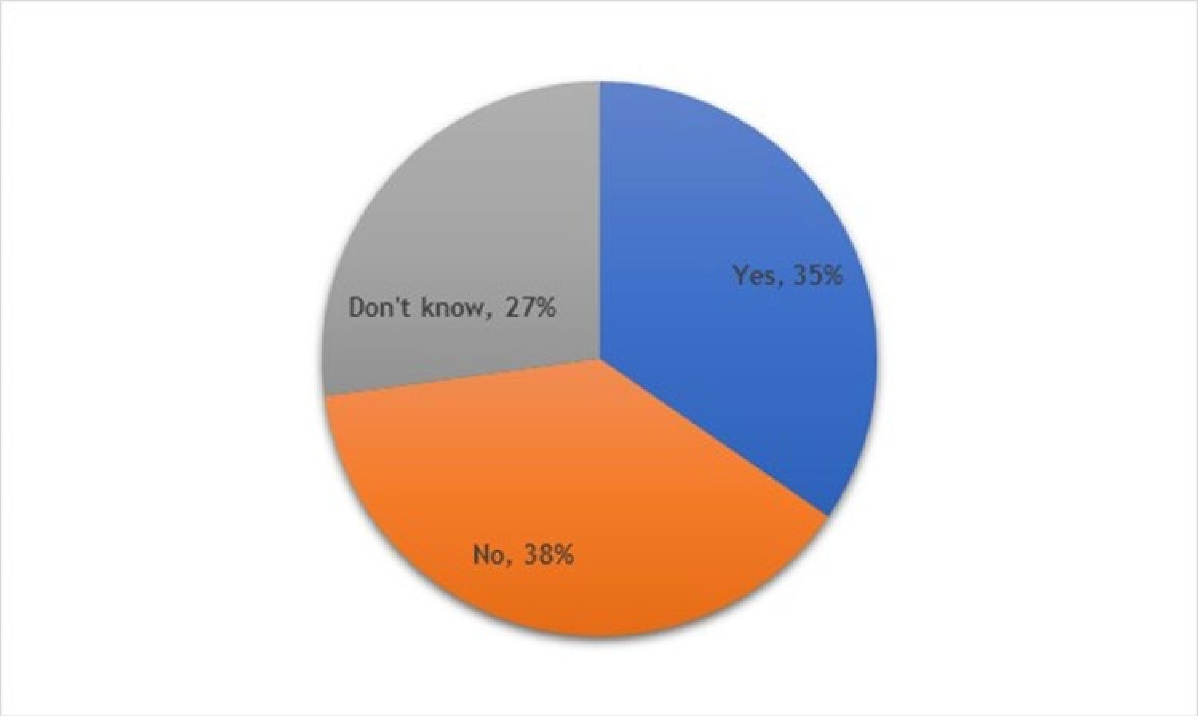
None of this appeared to be helped by the media coverage at the time which served to heighten fears, increase mistrust and perpetuate misconceptions around DNACPR:

- “Poor media coverage of what a DNACPR means, scaremongering about DNACPR.” **Acute internal medicine**
- “I believe patients and families feel DNACPR is synonymous with not for treatment - I feel this has been perpetuated by the impression treatment was withheld from particularly elderly people during the height of the pandemic.” **Dual specialty (other)**
- “Media coverage. Created a storm of indignation, when in reality almost all DNACPR orders are applied due to clinical futility, not as some conspiracy to murder.” **Geriatric medicine**

On the question of whether or not things have improved since the pandemic, there is mixed opinion.

Although 35% (n=125) think things have improved, slightly more (38%, n=138) think they have not improved.

**Figure 9: Have things improved since the pandemic?**



Respondents were invited to provide further context to their answers.

Of those who felt things had improved, there was (as noted earlier) a sense that the pandemic had heightened people's sense of their own mortality. In turn, this made them more amenable to conversations about end of life care:

- "I think more people have had a brush with mortality and have had a chance to think about advanced planning." **Haematology**
- "There is more awareness amongst the general public that hospitalisation and aggressive medical treatment may not be in the best interests of someone who is naturally reaching the end of their life." **Geriatric medicine**

More generally, the pandemic may have helped increase awareness of DNACPR processes among clinicians. Furthermore, a potential positive to emerge from media coverage of 'blanket DNACPRs' could be that this served to focus attention on particular groups of patients and made clinicians more mindful of this:

- "There was much press coverage regarding 'blanket' DNACPR decisions and this highlighted the inequalities for certain groups. I think this has made clinicians think about the process more thoroughly and document the decision-making process more clearly." **General practice**

Despite these potential silver linings, pre-existing problems such as lack of time, resources and public understanding of DNACPR persist:

- "There has been some raised awareness of resuscitation status and advance care planning, which is a positive but there is a clear need for more public education around the matter and reasoning." **Geriatric medicine**

- “Right at the start of the pandemic there was a huge time pressure to do all sorts of things. Now we have reverted to having ‘just’ the usual time pressures. We have largely returned to the pre-pandemic situation where DNACPR discussions and decisions are not happening when they should, because colleagues are too busy to consider this / too busy to have the discussions (as opposed to making too many rushed DNACPR decisions at the start of the pandemic.)” **Palliative medicine**

There were also respondents who felt that things had not improved since the pandemic. Some of them believe that the general public’s faith in medical professionals had been badly damaged:

- “Post pandemic the public view us as the enemy - social media and some news outlets have promoted such a view.” **Intensive care medicine**
- “The UK press have a lot to answer for - they make it sound like we are writing off patients when we have tools to save them, where in fact we are trying to allow patients a peaceful death where we cannot give them an extended life of any quality.” **Haematology**
- “Media hysteria has made the public worried about these decisions and therefore lots of clinicians want nothing to do with it in case they get complaints.” **Geriatric medicine**

In the absence of having the time available to labour on DNACPR decisions, solutions were offered:

- “If you make DNAR discussions overly complicated and burdensome then they simply won’t happen. A good way to reduce time taken is to make it only have to happen once, with a uniform DNAR decision that can have a review date if that’s what the patient wishes.” **Acute internal medicine**

# 8. Efficacy of current DNACPR form

70% (n=493) agree that the DNACPR form used in their workplace is fit for purpose whilst 13% (n=93) disagree.

Respondents who felt the form used was not fit for purpose provided further information to explain their reasoning.

Some believed that any attempts to summarise the complexities of the DNACPR decision into a single form would always be a difficult task:

- “No form can deal with the complexity of the issues which can be involved so can only be an adjunct to care. Current forms are a tick box exercise. Simplify them and allow back up discussion to be recorded in the notes. The form should be seen as similar to operative consent and use that model.” **Acute internal medicine**
- “Binary options currently do not balance the true meaning of the decision.” **Dual specialty (other)**
- “There is not enough space on the form to write much detail about the conversations that happen, the clinical conditions that lead to the DNACPR decision or much free text space.” **General practice**

Others felt that the forms put too much emphasis on defensive practice approaches rather than the best interests of the patient:

- “Directed at ‘defensive’ decision making / ensuring legal boxes ‘ticked’ rather than facilitating a discussion.” **Intensive care medicine**
- “Repetitive legal sounding questions that need filling in with no guidance on what to write.” **Intensive care medicine**

It was also claimed that the forms are unsuitable for different clinical settings and can fail to take into account the needs of particular patient groups:

- “DNACPR form is designed for planned detailed discussions in controlled circumstances which is not practical in the phase of the emergency admission.” **Acute internal medicine**
- “Used for all patients including day cases - not appropriate to discuss this with patients having minor surgery.” **General surgery**
- “Too long, doesn’t directly map to Mental Capacity Act, should be contiguous with the community.” **Intensive care medicine and anaesthetics (dual specialty)**

Problems can also arise due to administrative issues. For example, respondents pointed out that it can be difficult to access completed forms. This can lead to forms not being available to different healthcare providers and repeated conversations about DNACPR being held with patients:

- “There needs to be a form that is accessible by all healthcare providers (would need to be electronic) and patient or NoK [next of kin] and this would prevent discussions being unnecessarily repeated and which would encourage explicit descriptions of discussions held and clinical reasoning behind such discussion. This central form could then be reproduced in physical notes if needed.” **Dual specialty (other)**

- “The form either needs to be carried with patient or be electronic with access to all health care.” **General practice**

More generally, some respondents felt that other types of form were more appropriate as they shifted the focus for patients and - potentially - could make discussions with them more productive:

- “I think AaND (allow a natural death) form is more appropriate in terms of language used which patients and their families can understand and reduces the impact the glamourisation of resuscitation attempts in the media.” **Dual specialty (other)**
- “RESPECT form is better as it focuses on a good death rather than TEP which is a negative of taking something away from a patient.” **Dual specialty (other)**

# 9. Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process

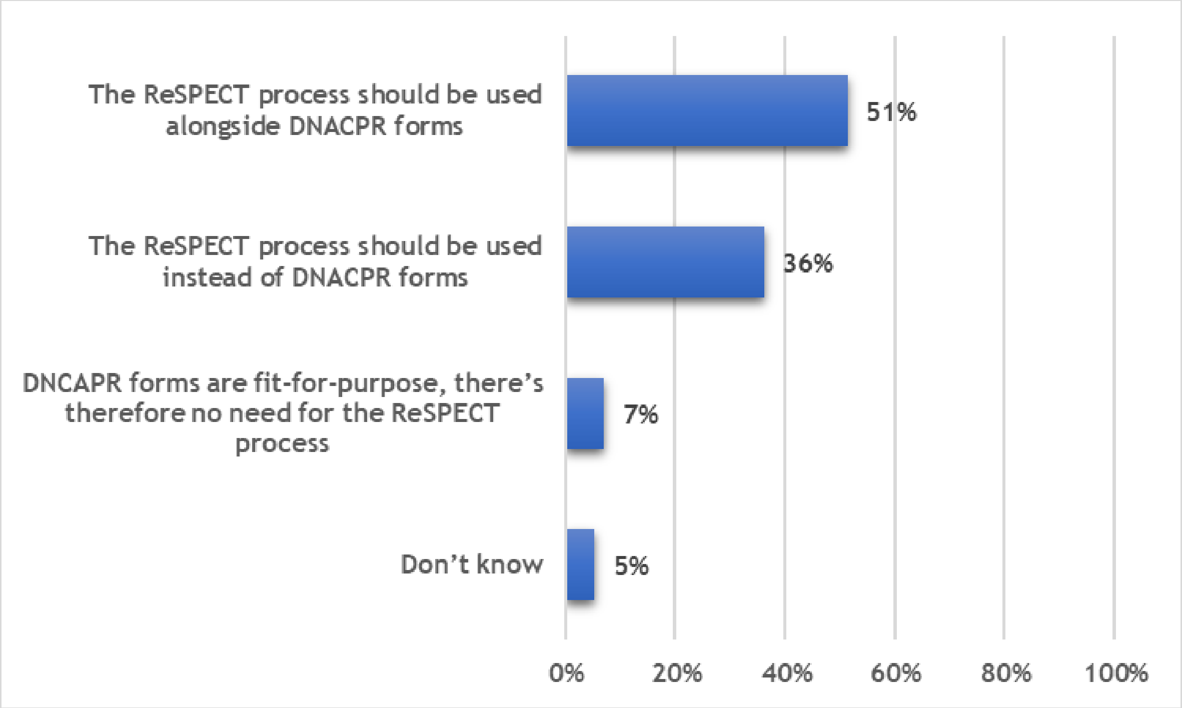
The majority of respondents (83%, n=582) are familiar with the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process.

When asked for their views on the ReSPECT process and DNACPR forms, the majority (51%, n=299) felt that ReSPECT should be used alongside DNACPR forms.

That being said, over a third (36%, n=211) believe the ReSPECT process should be used instead of DNACPR forms.

Only 7% (n=41) believe that DNACPR forms are fit for purpose and negate the need for ReSPECT.

**Figure 10: Views on the ReSPECT process and DNACPR forms**



For those who thought ReSPECT and DNACPR forms should be used in conjunction, a common observation was that they have slightly different purposes and so complement each other:

- "Respect is used to outline wishes about escalation of treatment, preferred place of care, readmission decisions etc, whereas DNACPR is very specific. They work together." **Acute internal medicine**
- "The RESPECT process is great for a 'planned death' – e.g. patients with cancer or another terminal condition with a reasonably predictable course - to allow patients who wish to do so to let us know their priorities and tell us which potential interventions they wouldn't want us to employ even if we

felt they were clinically appropriate. Because the law insists we treat CPR differently from other clinical interventions, and because CPR decisions have to be made quickly, in emergency situations, it makes sense to have a separate, clear, definite and easily spotted form for patients who don't want CPR or for whom CPR would be futile or potentially harmful." **Geriatric medicine**

Of those who said ReSPECT should be used **instead of** DNACPR forms, respondents felt that ReSPECT allows for the much more nuanced discussion and decision-making processes that end of life care deserves:

- "ReSPECT does allow a more nuanced approach to what is right for the patient." **Cardiology**

However, for it to be truly worthwhile, it would need to be properly implemented, and for clinicians to complete it in a thorough and consistent manner:

- "ReSPECT is better but only if meaningfully discussed and that takes a long time." **Other specialties**
- "ReSPECT aimed to promote a change in culture towards emergency care planning and, if implemented properly, should completely eliminate the need for a DNACPR form." **Cardiology**
- "Is a more constructive way to discuss options and less black and white than DNACPR. Allows for a more gentle introduction to the discussion and can be added to as the situation changes or as the family and patient process the clinical situation further." **Paediatrics**
- "The ReSPECT is about escalation of care as well as DNACPR. Having multiple forms leads to errors, especially if one is lost. It is better to have all the information in one place about escalation of care and DNACPR." **Paediatrics**

A minority of respondents felt that DNACPR forms are fit for purpose and there is no need for the ReSPECT process. Of this minority, some felt that ReSPECT was too vague:

- "DNACPR form is fit for purpose but needs to be part of an advance care planning recommendation that is more detailed than ReSPECT. ReSPECT tries to do too much on one form and ends up being potentially vague when a 'right now' decision is needed which is why we don't use it in our region. Paramedics said it wasn't necessarily clear enough what they should actually do." **Palliative medicine**

# 10. Conclusions

Drawing on the views of over 700 participants, this research provides valuable insight of DNACPR processes.

It has highlighted a range of clinician concerns and provided an overview of how pervasive they think the issues associated with DNACPRs are in the post-pandemic setting.

Fundamental to these are a series of misapprehensions about what DNACPR involves. These result in, first and foremost, confusion from the general public but also some differences in interpretation from clinicians about what is expected from them.

Led in part by glamourised media depictions of CPR as a universal solution to avoid death, the COVID-19 pandemic intensified the focus on DNACPR notices. Many believe this led to a growing and enduring distrust from the public which manifests itself in patients/next of kin insisting that futile CPR be undertaken despite strong clinical recommendations to the contrary.

Alongside this, the threat of complaints or litigation weighs heavily on some clinicians' minds and can lead some to reverse DNACPR decisions even if not in the best interests of the patient. It can also discourage some clinicians from initiating earlier end of life care discussions and leaves the skills and knowledge of how to deal with this appropriately in the hands of a few localised specialties in acute settings.

Faced with scarce time and resources, additional guidance which adds to the existing literature available on the topic was not universally welcomed. However, the introduction of clear signposting to existing guidance, and development of nuanced advice on dealing with specific patient groups would be useful for a substantial proportion of respondents. In particular, advice on the following situations would be beneficial:

- communicating DNACPR decisions effectively
- assertively dealing with patients/next of kin resistant to DNACPR (despite proven clinical futility of the process)
- de-escalation of the above to minimise complaints/legal action
- best practice approaches for dealing with specific groups (for example, those with learning disabilities or those with religious beliefs that do not align with predominant UK culture)
- clear and unambiguous clarification of legal status of DNACPR.

Given that the UK has a growing ageing population, it is vital that steps are taken soon to embed a new approach which minimises any ongoing misinformation and mismanagement regarding DNACPR processes in the future.

# Annex: overview of respondents

Respondents were asked, “In which specialty do you usually work (for example, Acute Medicine, Intensive Care Medicine, Palliative Medicine)?”.

Specialties with ten or more responses were grouped into the categories below.

89 respondents stated they worked across two specialties. These were grouped into four sub-categories: (1) **Intensive care medicine & Anaesthetics (dual specialty)**, (2) **Acute internal medicine & General (internal) medicine (dual specialty)**, (3) **General (internal) medicine & Geriatric medicine (dual specialty)**, (4) **Dual specialty (other)**.

The **Non-clinical/no specialty/unknown** specialty includes respondents from a range of backgrounds including nursing, ambulance services, and regulatory bodies.

**Figure 1: Breakdown of respondents by specialty**

| Specialty | Frequency | Percent |
|---|---|---|
| Acute internal medicine | 78 | 11% |
| Geriatric medicine | 70 | 10% |
| General practice | 65 | 9% |
| Palliative medicine | 65 | 9% |
| Intensive care medicine | 52 | 7% |
| Other specialties | 49 | 7% |
| Non-clinical/no specialty/unknown specialty | 47 | 7% |
| Emergency medicine | 46 | 7% |
| Dual specialty (other) | 44 | 6% |
| General (internal) medicine | 26 | 4% |
| Respiratory medicine | 24 | 3% |
| General surgery | 23 | 3% |
| Intensive care medicine & Anaesthetics (dual specialty) | 19 | 3% |
| Anaesthetics | 16 | 2% |
| Clinical oncology | 16 | 2% |
| Acute internal medicine & General (internal) medicine (dual specialty) | 14 | 2% |
| Paediatrics | 13 | 2% |
| General (internal) medicine & Geriatric medicine (dual specialty) | 12 | 2% |
| Haematology | 12 | 2% |
| Cardiology | 11 | 2% |
| Total | 702 | 100% |

**Figure 2: Breakdown of respondents by grade**

| Grade | Frequency | Percent |
|---|---|---|
| Consultant | 410 | 59% |
| Other | 116 | 17% |
| Doctor in training (higher specialty training) | 105 | 15% |
| Specialty and specialist (SAS) doctor | 26 | 4% |
| Doctor in training (post-foundation) | 23 | 3% |
| Doctor in training (foundation) | 18 | 3% |
| Total | 698 | 100% |

**Note: Non-responses are not included in the table above.**

**Figure 3: Breakdown of respondents by length of service**

| Length of service | Frequency | Percent |
|---|---|---|
| 3-5 years | 39 | 6% |
| 6-10 years | 89 | 13% |
| Less than 2 years | 18 | 3% |
| More than 10 years | 544 | 79% |
| Total | 690 | 100% |

**Note: Non-responses are not included in the table above.**

**Figure 4: Royal College membership**

| Membership organisation | Number of respondents |
|---|---|
| Royal College of Physicians | 299 |
| None | 83 |
| Dual membership | 59 |
| Royal College of General Practitioners | 59 |
| Royal College of Anaesthetists | 55 |
| Royal College of Emergency Medicine | 41 |
| Royal College of Surgeons of England | 31 |
| Royal College of Nursing | 18 |
| Royal College of Paediatrics and Child Health | 13 |
| Royal College of Radiologists | 9 |
| Unknown | 6 |
| Royal College of Psychiatrists | 5 |
| College of Paramedics | 4 |
| Royal College of Surgeons of Edinburgh | 4 |
| Royal College of Pathologists | 3 |
| Royal College of Physicians of Edinburgh | 3 |
| Faculty of Intensive Care Medicine | 2 |
| Other | 2 |
| Royal College of Obstetricians and Gynaecologists | 2 |
| Faculty of Public Health | 1 |

| | |
|---|---|
| Nursery and Midwifery Council | 1 |
| Royal College of Physicians of Ireland | 1 |
| Society for Acute Medicine | 1 |