

Prof. Wayne Martin, Director
Dr. Margot Kuylen, Senior Research Officer
Essex Autonomy Project
University of Essex
Wivenhoe Park, Colchester, CO4 3SQ

Rt. Hon. Harriet Harman, QC, MP, Chair
Parliamentary Joint Committee on Human Rights
Houses of Parliament
London, SW1A 0AA

2 November, 2021

Dear Ms Harman,

We write in response to the Call for Evidence from the Joint Committee on Human Rights concerning the topic: *Protecting Human Rights in Care Settings*.

About the Authors

Allow us first to introduce ourselves. Wayne Martin, PhD, is Professor of Philosophy at the University of Essex, where he also serves as an affiliated faculty member of the Essex Human Rights Centre and as the Director of the Essex Autonomy Project. Margot Kuylen, PhD, is Senior Research Officer at the Autonomy Project, where she led on a data-gathering exercise on the topic: *Ensuring Respect for Human Rights in Locked-Down Care Homes*.

About the Autonomy Project

Founded in 2010, the Autonomy Project is a multi-disciplinary research and public policy initiative that focuses on the ideal of self-determination (autonomy) in care contexts. Our research activities have been funded by major grants from the Arts and Humanities Research Council, UKRI and the Wellcome Trust. A principal focus of our activities is the challenge of protecting human rights in care settings. We publish extensively on this topic, provide research support to public bodies (including the Ministry of Justice), and conduct an ongoing programme of workforce training for frontline professionals, particularly in Local Authorities and NHS Trusts. Further information about the Autonomy Project can be found on our project website: <http://autonomy.essex.ac.uk>.

Funding and Ethics Approval

In what follows, we submit evidence that derives mainly from a recently completed research project on the topic of *Ensuring Respect for Human Rights in Locked-Down Care Homes*. The project was funded by a COVID 'Rapid-Response' grant from UKRI/AHRC (Grant number: AH/V012770/1); ethics approval was obtained from the University of Essex Humanities Research Ethics Sub-Committee.

Sources of Evidence

Much of the evidence presented herein is drawn from a data-gathering exercise that we conducted in the Spring and Summer of 2021 (i.e., approximately one year into the COVID pandemic). We conducted an online survey and follow-on focus groups focusing on care professionals who had worked in or with residential care facilities during the COVID pandemic. 262 care professionals took part in the online survey; 22 participated in the follow-on focus groups. Many of the participants belong to a group that we describe as ‘capacity professionals,’ meaning that they have specialist knowledge of and responsibility for applying the *Mental Capacity Act 2005* (MCA), particularly in care settings. Many also have specific professional role responsibilities with regard to ensuring human rights compliance in care settings.

In our data gathering exercise, we sought information about the experience of these professionals as regards (i) restrictive measures in care homes during the pandemic; (ii) use of guidance; (iii) residents’ access to care; (iv) the role of independent mental capacity advocates; and (v) practices regarding Do Not Attempt CPR decisions. Although our data-gathering exercise focused specifically on professionals’ experience working in and with care homes during the COVID pandemic, a number of our findings have broader relevance. A detailed report on the results of the online survey is available on our website.¹ Detailed reports on the results of the focus groups and pre-publication versions of research articles in which we analyse the results are available upon request.

In addition to the survey and focus group data, we also draw here on our experience in providing workforce training both before and during the pandemic. For the last ten years, the Autonomy Project has been providing human rights workforce training to frontline care professionals. At the onset of the COVID pandemic, we collaborated with the National Mental Capacity Forum (NMCF) to provide a series of online, rapid-response webinars directed at frontline professionals who play a role in applying the *Mental Capacity Act* (MCA) in care settings. As part of the registration process for these free national events, which attracted up to one thousand registrants, we posed a series of registration questions designed to elicit real-time information about the challenges faced by frontline professionals in applying the MCA during the pandemic. We used a similar pre-registration process in smaller workforce training activities that we conducted for care professionals applying the MCA during the pandemic in Local Authorities and NHS Trusts.

Key Findings Related the Committee’s Inquiry

In the two Appendices to this letter we provide a selection of data from our study, including both quantitative and qualitative findings. Rather than seeking to report comprehensively on the study, we confine our remarks here to two findings that are both novel and directly relevant to the Committee’s inquiry. These concern (i) safeguards to ensure that restrictive measures in care homes respect the liberty rights of residents, and (ii) practices regarding DNACPR decisions in care homes. The practices reported by participants in our study raise serious human rights concerns pertaining to (a) the right to life (Art 2 ECHR); (b) the right to liberty and security (Art 5 ECHR); and (c) the right to privacy and family life (Art 8 ECHR).

¹ https://autonomy.essex.ac.uk/wp-content/uploads/2021/10/Basic-Survey-Report_abridged_v2.1.pdf.

They also have bearing, in some cases, on the right to non-discrimination (Art 14 ECHR) and on the right to the highest attainable standard of health (Art 12 ICESCR; Art 25 UNCRPD).

Restrictive Measures and Failures of Art 5 Safeguards:

It has been observed that the COVID pandemic functioned to highlight significant structural weaknesses in the care system. One weakness identified in our study pertains to the system of safeguards intended to ensure that any deprivation of liberty in a care home setting is lawful and respectful of the human rights of residents. Our study points to significant structural obstacles to the smooth and effective operation of these safeguards. A particular cause for concern is our finding that *professionals with responsibility for applying the Deprivation of Liberty Safeguards (DoLS) were unclear about how to assess the lawfulness of restrictive measures, particularly where these were imposed primarily to protect others.*

It has long been recognised that care homes are sites where the liberty of residents is often restricted. During the pandemic, the nature, intensity and duration of restrictive measures changed, at times dramatically. For example, 18% of our participants reported that they were aware of residents being continuously confined alone in their bedrooms for periods in excess of four weeks, often with significant adverse effects on their health and well-being. This is just one, and a particularly extreme example of a whole range of restrictive measures that were imposed. These restrictions were different not only in degree but in kind from even the most stringent restrictions imposed on the general public.

A restriction of liberty does not in and of itself constitute a violation of a resident's right to liberty and security. But any deprivation of liberty must be necessary and proportionate to the risk of harm, and must be "in accordance with a procedure prescribed by law" (Art 5 ECHR). In England and Wales, the Deprivation of Liberty Safeguards (soon to be replaced by the Liberty Protection Safeguards) are the principal mechanism for ensuring that deprivations of liberty in care settings meet these human rights standards. But participants in our study reported that the pandemic strained these systems to breaking point. Professionals charged with ensuring respect for residents' Art 5 rights found themselves (i) unable to gain access to facilities whose residents they were tasked with protecting; (ii) reliant on remote cooperation from care home managers; (iii) struggling to apply the principle of proportionality where the stakes were so high; and (iv) unclear about how to apply the DoLS system in contexts where restrictive measures were introduced primarily in order to protect others rather than in the best interests of the individual whose liberty was restricted.

In sum, "One of our most troubling findings is that the very professionals tasked with protecting the rights of exceptionally vulnerable residents found themselves unclear about what principles to apply in determining whether a particular restrictive measure complies with legal and human rights standards."²

² Kuylen, M., et al., "COVID-19 and the Mental Capacity Act in Care Homes: Perspectives from Capacity Professionals"; *Health and Social Care in the Community*, under review.

DNACPR Decisions:

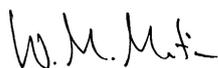
There has been widespread media coverage of Do Not Attempt Cardiopulmonary Resuscitation Decisions (DNACPRs) during the pandemic. In response, the Care Quality Commission (CQC) undertook a comprehensive review of DNACPR practices. Our findings complement those from the CQC, particularly in (i) documenting the unlawful practice of making 'blanket' DNACPR decisions for all residents of particular care homes or for residents in certain groups, and (ii) documenting the practice of making DNACPR decisions without consultation. But our findings also go beyond those of the CQC.

To date, discussion of DNACPR decisions has mainly concerned the practices in which such decisions are *made* and *recorded*. But we also asked participants in our study what they knew of the ways in which DNACPR decisions *informed subsequent decisions about the provision of care*. According to the UK Resuscitation Council, a DNACPR decision applies narrowly to the question as to whether to conduct cardiopulmonary resuscitation. *But a significant subset (17%) of our participants reported that DNACPR decisions, once recorded, were used to make other decisions as well.* For example, some residents were denied transfer to hospital, or were denied ward care, on the grounds that they had a DNACPR form in their files. In the words of one respondent: “[A DNACPR decision is] *about CPR, but also it’s about antibiotics, it’s about hospital treatment, it’s about fluid, it’s about anything that’s a sustaining treatment.*” Another respondent reported: “*Some staff see DNR as ‘do not care’, or ‘do not seek any medical treatment.’*”

The CQC report has called for new standards, guidance and training on the use of DNACPR decisions. We endorse this call, but we note that the CQC report says little about what such standards, guidance and training should consist in. We found evidence of widespread confusion among professionals about the meaning and legal status of DNACPR decisions. For example, 66% of respondents at a training event were of the view that DNACPR decisions are legally binding; they are not. And the overwhelming majority of registrants at an NMCF rapid response webinar reported that they had heard the terms DNACPR, DNAR and DNR used interchangeably, although the three concepts are by no means equivalent.

Inappropriate use of DNACPR decisions potentially impact upon a range of human rights of care home residents. In research articles analysing the empirical findings reported here, we make a series of policy recommendations about how the practices associated with DNACPR decisions might be improved. Details available upon request.

Sincerely



Wayne Martin, PhD (for Prof Martin and Dr Kuylen)

Appendix A: Data Excerpts Regarding Restrictive Measures

Appendix B: Data Excerpts Regarding DNACPR Decisions

Appendix A: Data Excerpts Regarding Restrictive Measures

- We asked participants which restrictions on visits (Figure 1) and movement (Figure 2) were implemented at any point in time during the pandemic, and which were still in place at the time of the survey (March 2021).

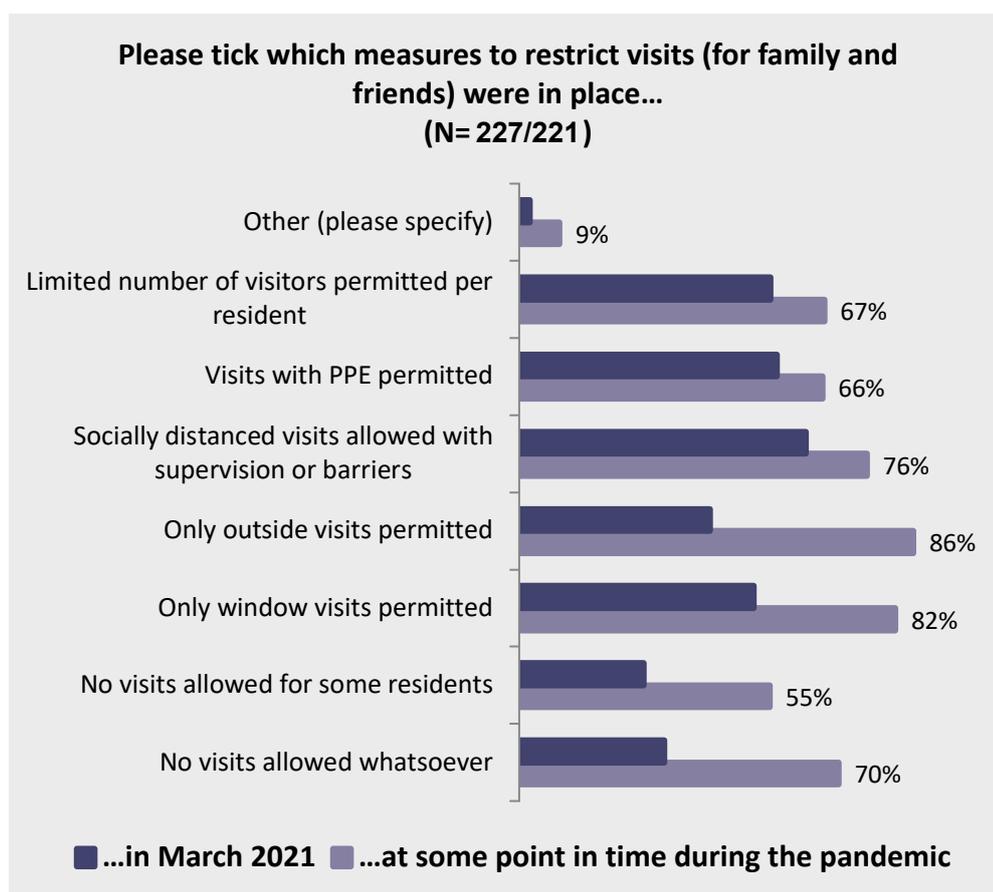


Figure 1

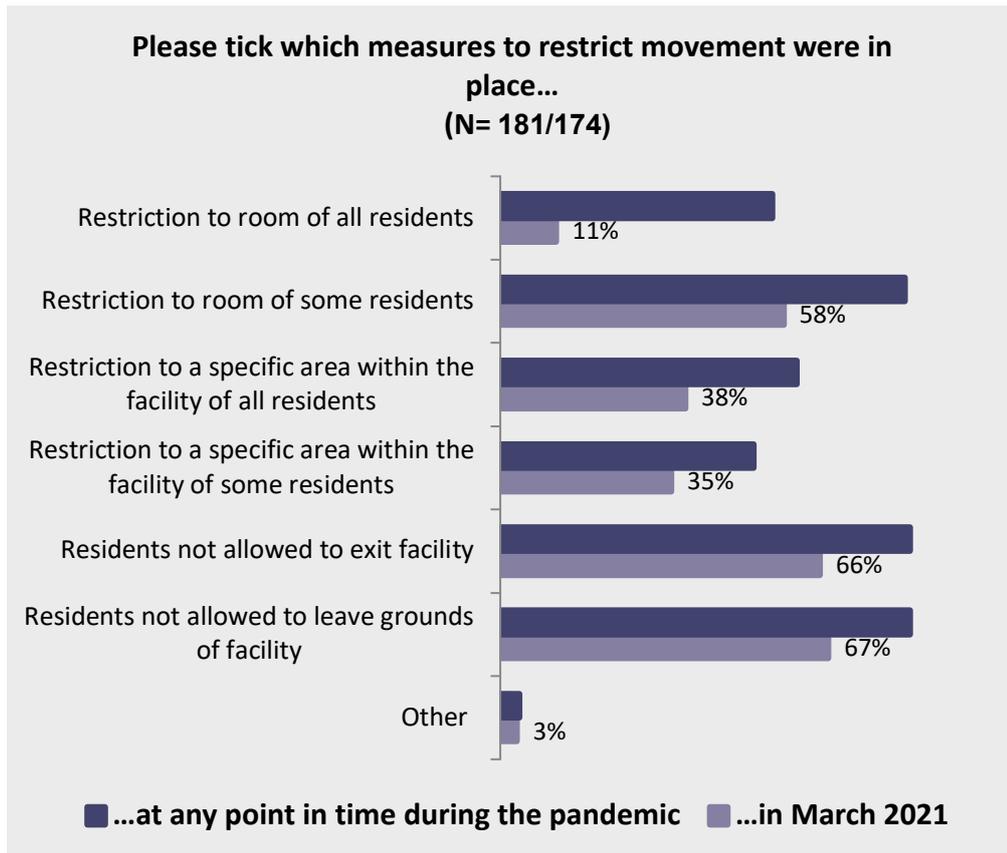


Figure 2

- Our survey showed that 18% of respondents reported on residents being restricted to their room for a duration of four weeks or more (Figure 3).

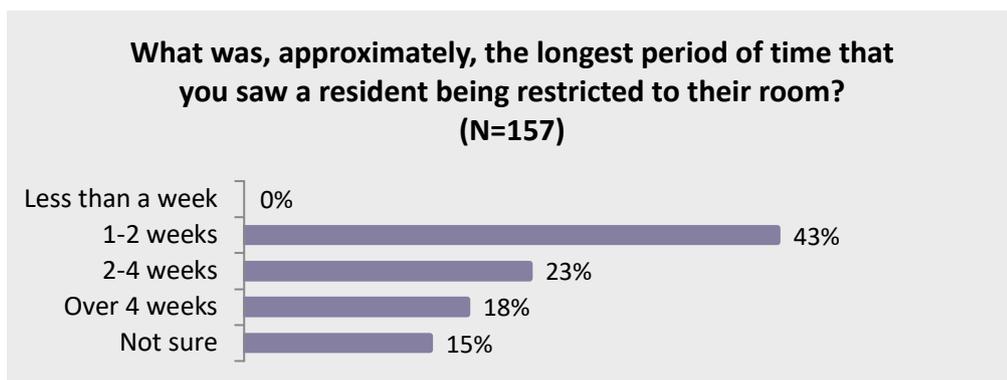


Figure 3

- When asked what was generally the most important consideration when restricting residents to their room, 70% of respondents said that this was to protect others (rather than the resident) (Figure 4).

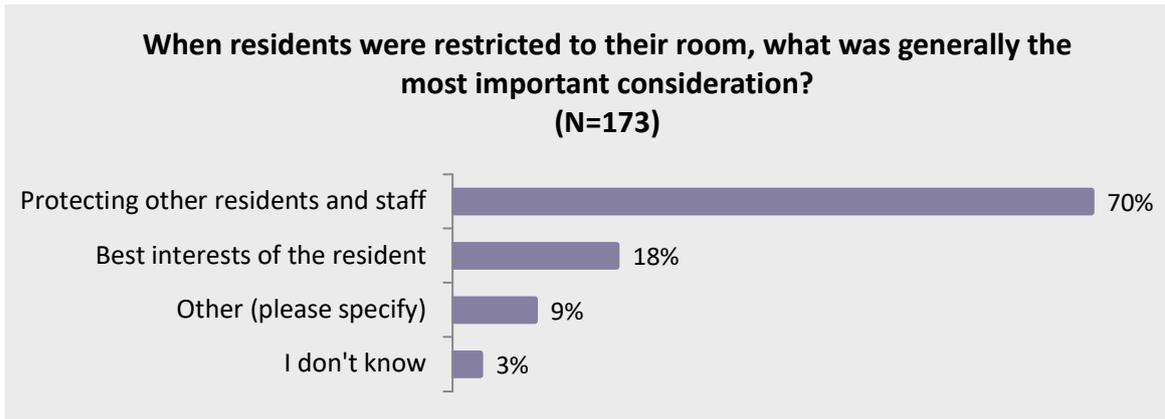


Figure 4

- Our survey found that it was unclear when the Deprivations of Liberty Safeguards (DoLS) system should be engaged during a pandemic. When residents with decision-making capacity were confined to their room, a new DoLS authorisation was rarely provided (Figure 5). When a new authorisation was not provided, this was usually because the legal basis for confinement was understood to be public health directives rather than the MCA (Figure 6).

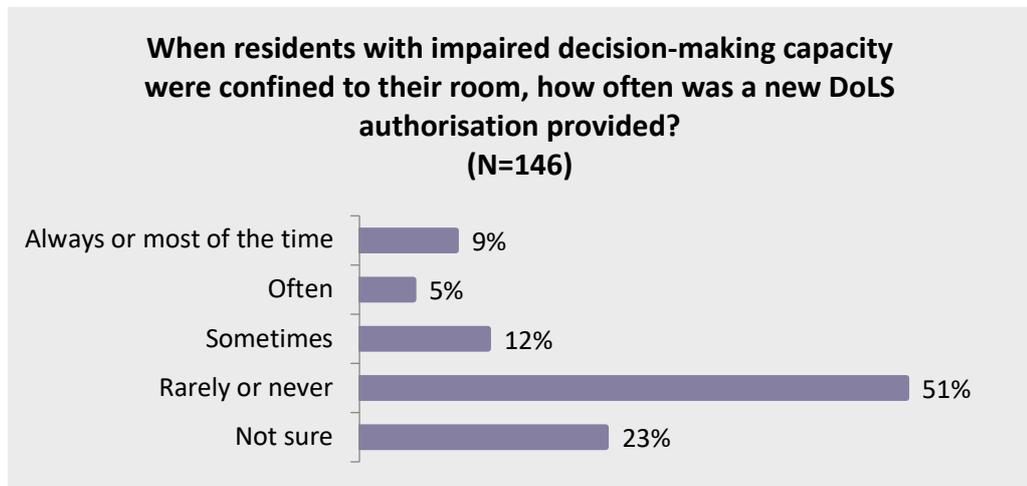


Figure 5

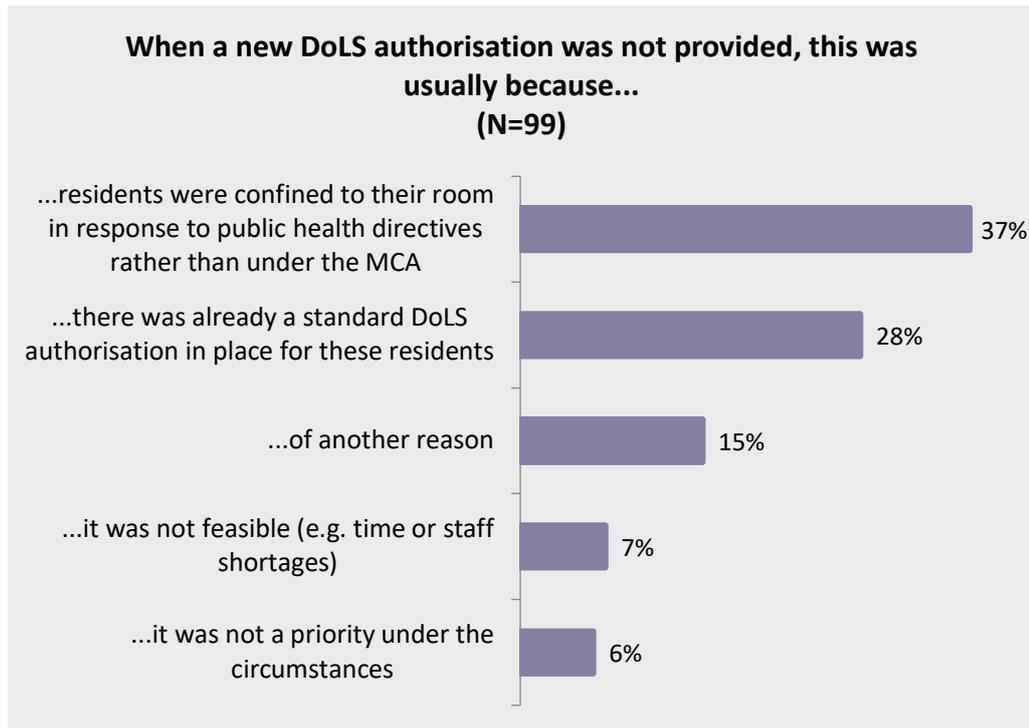


Figure 6

- Focus group participants further confirmed that new DoLS authorisations weren't requested when residents were confined to their room, and that this was mostly because these confinements were not intended to fall within the remit of the MCA:

No, definitely no increasing restrictions have actually been requested, and when you actually spoke to the care home they actually said, well, they didn't see it necessarily as an increase in the restrictions in place. – Social worker/BIA (Focus groups)

In relation to whether new assessments were requested - no they weren't. People either assumed it was a public health thing because it was about risk to others, or they just didn't think we need to apply for that. – BIA (Focus groups)

A key part of my role is: '...what's the legal framework for this, what are we relying on here for authority to do whatever it is we think we should do?', and I've been conscious of fudging that to the limits and beyond...we know we've got to restrict people's movements, because otherwise they'll get COVID or they'll give COVID to other people.....Trying to pick your way through the Mental Capacity Act and public health regulations and find a way of saying "for sure, okay, that's the justification for it"...there's a point beyond at which you're just... you're on your own. – DoLS Signatory/Team Manager (Focus groups)

- Respondents in both the survey and focus groups noted that some IMCAs were unable to access care homes even when they deemed it necessary:

I am very concerned about the inability to access people during the pandemic. Some homes have not answered the phones, have refused to accept visits and even when homes have passed on information it is hard to do advocacy without visiting or accessing records for yourself. I am very worried that bad practice may have developed in homes without outside scrutiny. – Advocate (Survey)

I am an advocate and I found that care homes have been very reluctant to accept visits even when I have deemed it as urgent and essential to the person I am supporting. Care homes in some instances have used Covid-19 as a way to restrict residents and not enhance their well-being. Care homes for the most part are still not allowing residents who are already restricted by 1-1 to leave the building for a walk in the park where transmission of Covid-19 is minimal. "We can't because of Covid" is a phrase I hear too often when asking for the minimum to improve P's quality of life. – Advocate (Survey)

Appendix B: Data Excerpts Regarding DNACPR Decisions

1. DNACPR Consultation

- 55% of survey respondents witnessed DNACPR orders being added without consultation with resident or family (Figure 7). This was most often because of a blanket decision (28%) or group decision (e.g. on basis of age or frailty, 25%) (Figure 8).

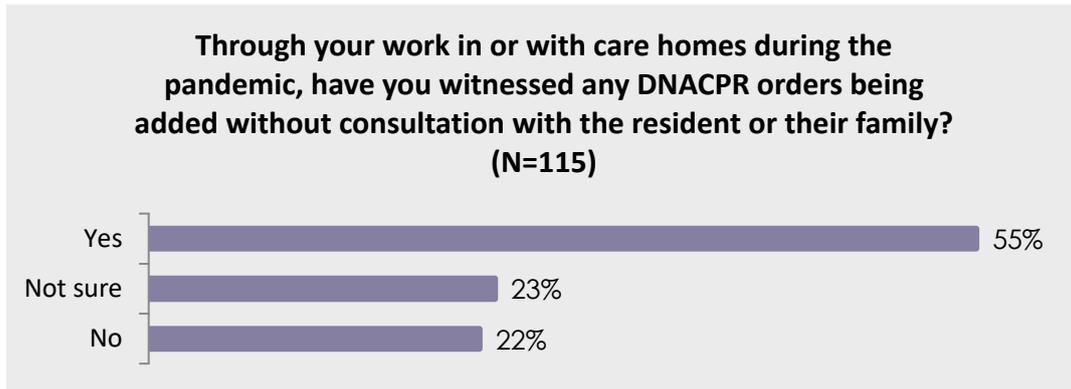


Figure 7

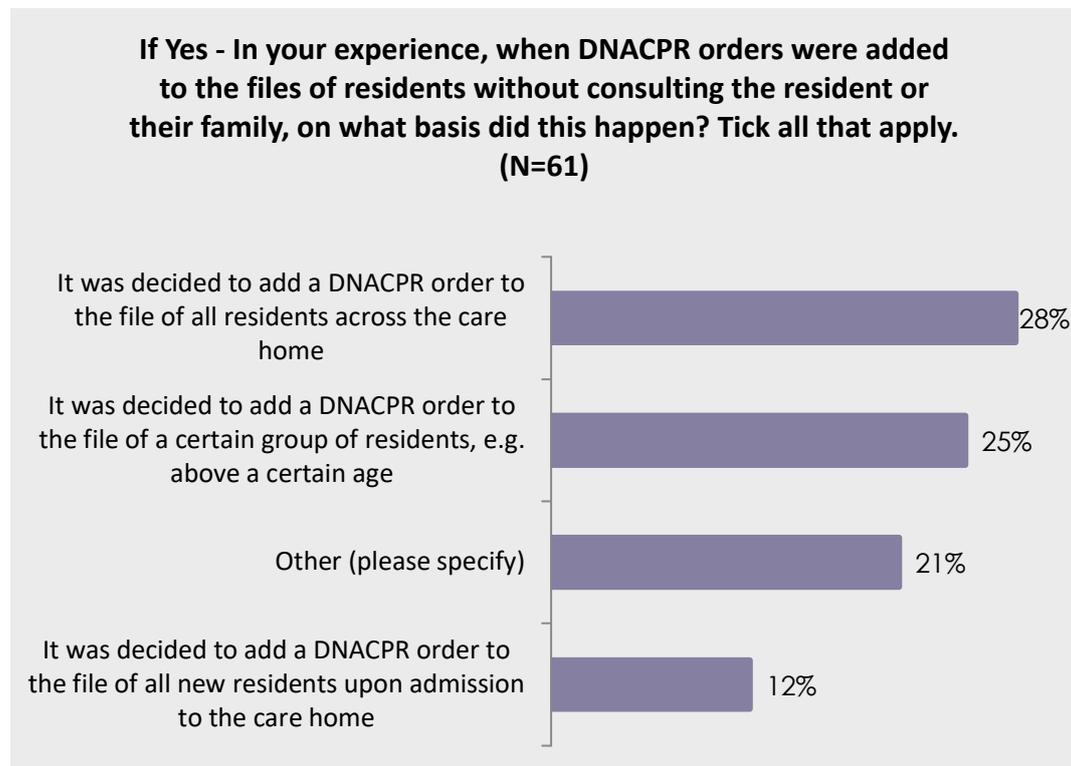


Figure 8

- This issue was also mentioned in the focus groups:

There was no consultations with family, no consultations with the person, and, in some instances, not even a consultation with the care home staff. They were just

returning with a piece of paper, that purple piece of paper that says, 'do not resuscitate this person.' – Advocacy Manager (Focus groups)

A lot of decisions get made and the person who they're about is never even informed of them. – Advocacy Manager (Focus groups)

2. Blanket DNACPR decisions

- Both in the survey (free text responses) and in the focus groups, participants reported the use of blanket DNACPR decisions:

There were serious issues with some GP practices seeking to impose blanket DNACPRs and not attending homes in person. This led to vulnerable people, particularly those living with learning disabilities, being severely disadvantaged in terms of their access to an acceptable standard of healthcare. I have had a number of clients die because of these inequities and hope there will be a thorough enquiry into how the social sector was (mis)treated during this period. – Advocate (Survey)

My overarching feeling is that it was age discrimination, pure and simple...If you're sending out blanket DNACPR forms it very much to me smacks of, well, to put it very bluntly, "these people are old, you know, if they're going to get COVID it's highly likely that if they do get it, that they will become seriously ill or even die. So let's reserve the hospital spaces for younger people who have got more chance of surviving. - Social worker/BIA (Focus groups)

3. Use of DNACPR decisions beyond CPR

- 17% of survey respondents had witnessed DNACPR orders influence medical decisions beyond CPR during the pandemic, mostly hospital/ICU admission (Figure 9).

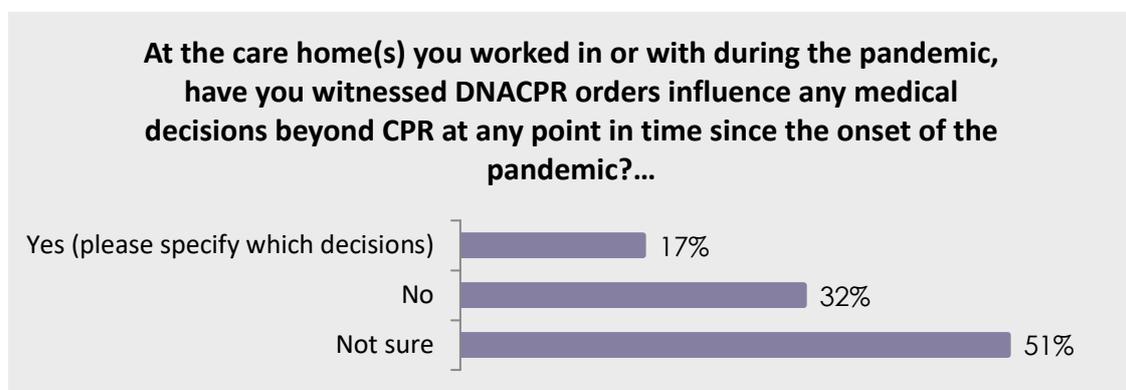


Figure 9

- Some participants told us about DNACPRs being used to deny access to other forms of treatment. In particular, several participants expressed the view that DNACPR orders informed decisions about transfer to hospital.

As a named GP for safeguarding I see residents who have choked to death and have not been resuscitated by care home staff as they didn't understand the difference between a respiratory arrest and a cardiac arrest. On the whole DNACPR's have not altered medical management. – Named GP for safeguarding adults (Survey)

There's a lot of talk about DNAR and DNR becoming mixed up with DNACPR, so the CPR bit actually gets lost somewhere...I think there's a difference in understanding between social care and health care staff, and I think it's also sometimes used as a way of managing end of life and whether people want to remain in the care home or be admitted to hospital. – Social worker/BIA (Focus groups)

With nursing homes, it was a bit like, "we will put an order on because, you know, they're not going to survive covid, it's not worth doing a hospital bed." – Social worker/BIA (Focus groups)

I do think that, from what I see, that the forms seem to go hand in hand with "whether to take this person to hospital or not". – Social worker at Care Home Support Team (Focus groups)