



Essex Autonomy Project

Human Rights in Care Homes: A Survey-Based Study

Study Report (Abridged)

6 July 2021

Version 2

<http://autonomy.essex.ac.uk/covid-19>

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Background

This document summarises the most significant findings from an anonymous online survey held by the Essex Autonomy Project in the context of an AHRC-funded research project, “Human Rights in Care Homes”, which investigated the impact of the Covid-19 pandemic on care home residents in England and Wales. The survey was aimed at care professionals who worked in or with care homes during the pandemic, and was disseminated using the existing networks of the research team. The survey was open from March 3rd until April 2nd, 2021. A total of 266 survey responses was collected.

Note that not all questions were answered by all respondents. This because some follow-up questions only displayed to participants who selected a certain answer, and because respondents were free to skip questions. The total number of respondents is displayed for every question in this report.

Where free-text responses contained obvious typos, these have been corrected.

This report follows the structure of the survey, which consisted in five sections, each addressing a different theme: (1) restrictive measures, (2) use and usefulness of guidance, (3) access to care, (4) use and usefulness of Independent Mental Capacity Advocates (IMCAs), (5) the use of DNACPR orders during the pandemic.

This research study was funded by the Arts and Humanities Research Council; Grant Number AH/V012770/1: Ensuring Respect for Human Rights in Locked-Down Care Homes.

The study was granted ethical approval by the Humanities Sub-Committee at the University of Essex; Application number ETH2021-1210.

Sample characteristics and variables

In which region do you work?

England	93%
Wales	5%
Other	1%

If England: In which area of England do you work?

South East	21%
Yorkshire and the Humber	16%
London	15%
North West	11%
South West	11%
East of England	9%
West Midlands	8%
East Midlands	5%
North East	4%
Prefer not to say	1%

Which role(s) do you have? Tick all that apply.

Social worker	22%
Other	20%
Best Interests Assessor (BIA)	20%
Advocate (e.g. IMCA or RPR)	18%
Facility Management Team member (e.g. Care Home Manager or Director)	10%
Care Home Nurse/Carer	6%
Primary Care Clinical lead for a care home (e.g. named GP)	2%
Paramedic	1%

Since the onset of the pandemic in March 2020, have you...

...worked mainly with care homes from the outside (remotely, e.g. conducting remote DoLS authorisations)	69%
...worked mainly within care homes (physically present)	26%
My professional role has not involved working within or with care homes during the pandemic	5%

Since the onset of the pandemic in March 2020, have you...

...worked mainly in or with one care home	18%
... worked in or with several care homes	83%

If in or with one care home: How many residents live at this care home?

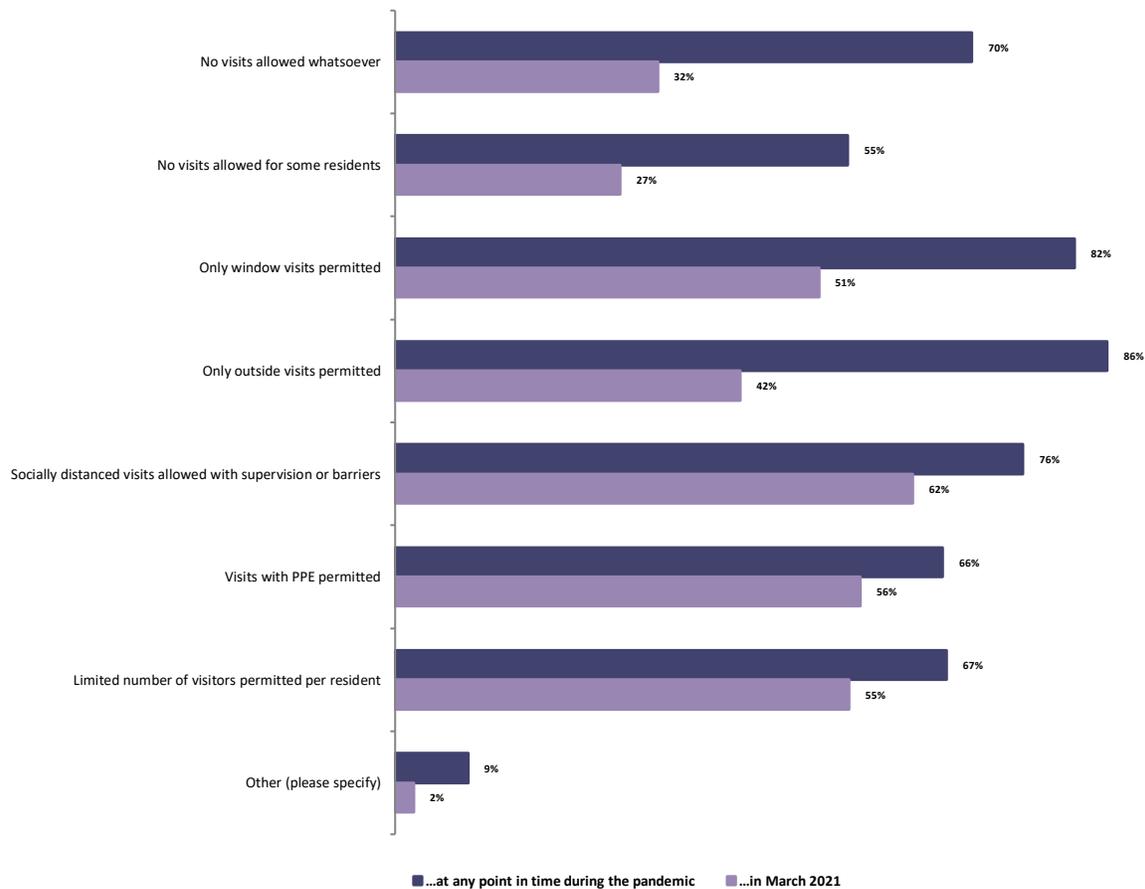
	1-10 residents	19%
	11-50 residents	48%
	51-100 residents	21%
	100+ residents	5%
	Not sure	7%

A. Restrictive measures

A.1 Restrictions on visits

Please tick which measures to restrict visits were in place...

N=277



- Other (please specify)

N=24

Selected responses:

visits outside the care home entirely in the community

varied between homes but in general, no visits

Visits only for palliating patients, if they were in the right unit. This meant that someone dying who did not have a private room did not have a visitor, someone who did could.

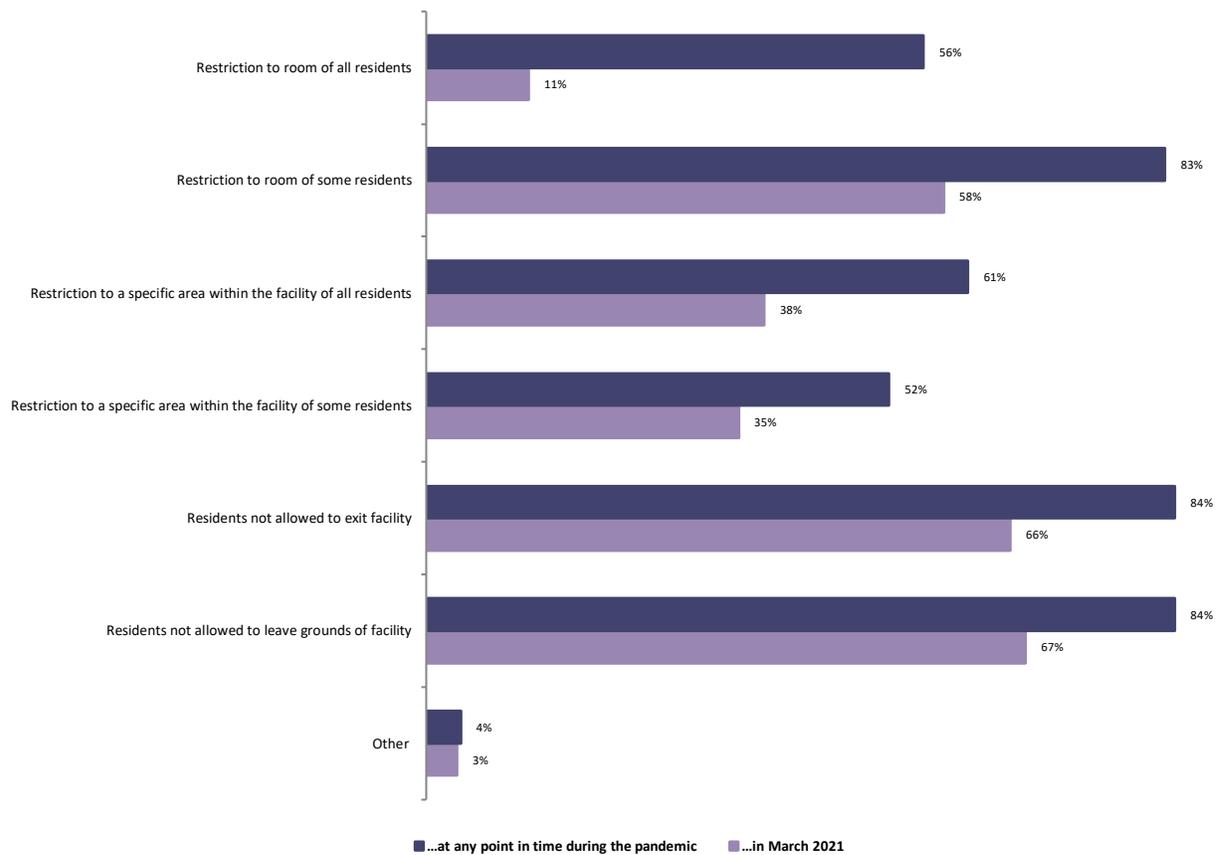
Time limits on visits

No visits allowed for most residents exceptions made for those on end of life care

A.2 Restrictions on movement

Please tick which measures to restrict movement were in place...

N=181



Restrictions in place at any point in time during pandemic - Other (please specify)

N=6

Selected responses:

Residents continue to be supervised on calls and video chats whether this is necessary or not impeding instructions and free conversation with legal team

Only if there is an outbreak

Restrictions still in place in March 2021- Other (please specify)

N=7

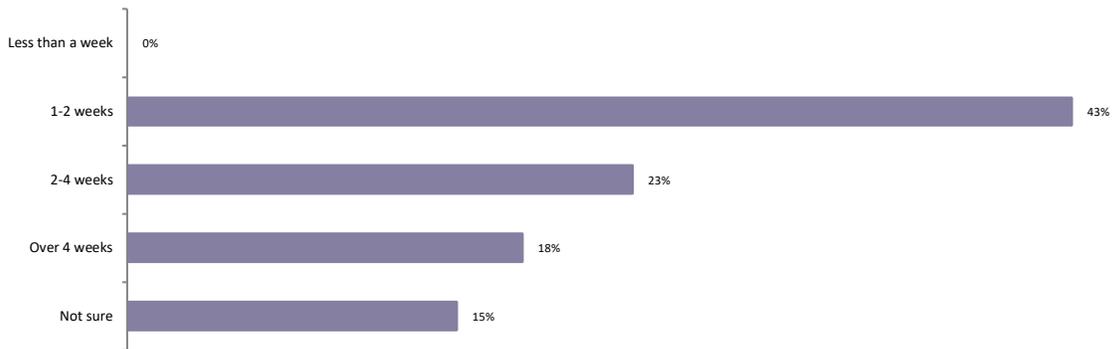
Selected responses:

when in video meetings residents not able to speak without a staff member being present despite being capable of navigating technology

Residents could exit the facility, but if they did, they could not return. This clearly meant that they couldn't leave, but they weren't locked in actually

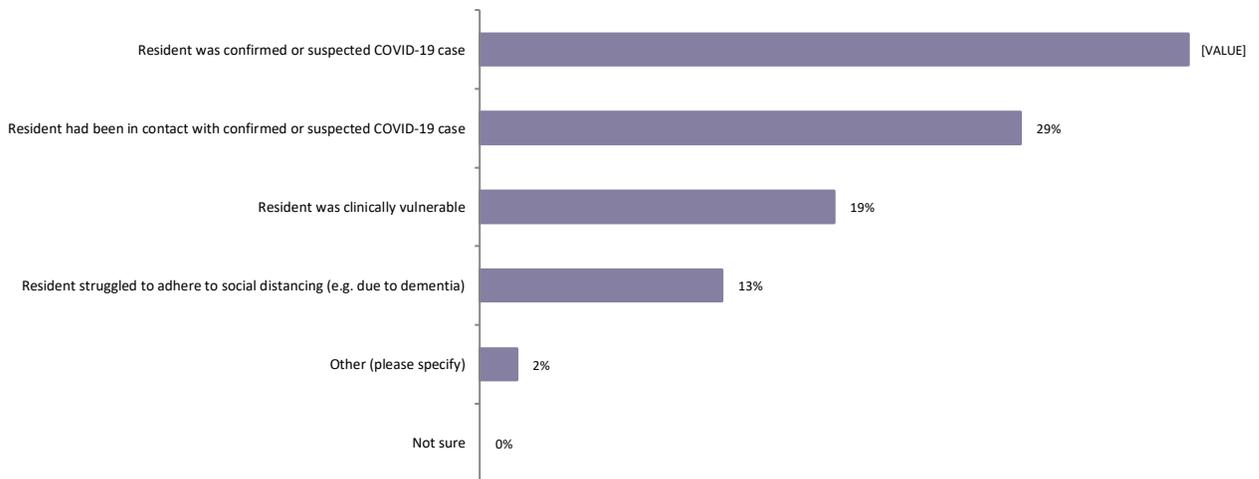
What was, approximately, the longest period of time that you saw a resident being restricted to their room?

N=157



In your experience, on what basis were residents confined to their room? Tick all that apply.

N=56



- Other (please specify)

N=3

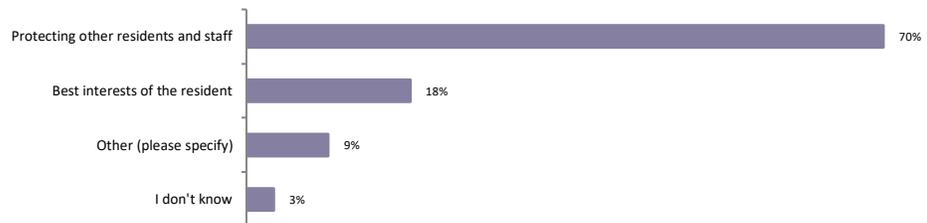
Selected responses:

If there was an "outbreak" within the home

Residents had regular hospital visits/appointments or stays

When residents were restricted to their room, what was generally the most important consideration?

N=173



- Other (please specify)

N=14

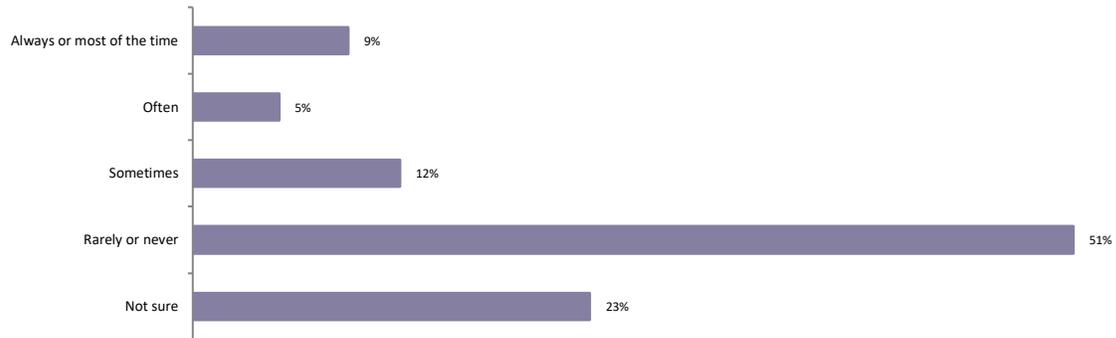
Selected responses:

could have been for either of the first two reasons - a mix of both of these reasons and either one could have been the main reason at any given time - if the individual was C-19 positive then the first reason, if there was an outbreak in force then would have been reason two for the resident

Both protecting the resident and other residents and staff.

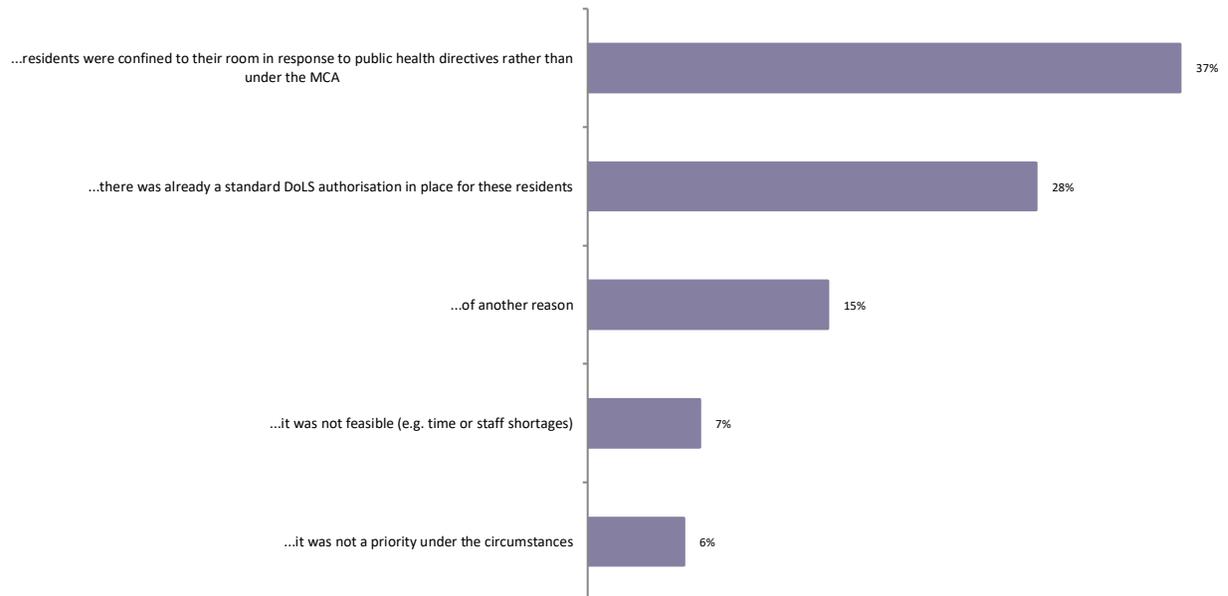
When residents with impaired decision-making capacity were confined to their room, how often was a new DoLS (Deprivation of Liberty Safeguards) authorisation provided?

N=146



When a new DoLS authorisation was not provided, this was usually because...

N=99



- ...of another reason (please explain)

N=15

Selected responses:

lack of understanding of needing to do this

The local Authority advised a new Dols would not need to be done.

MA did not apply

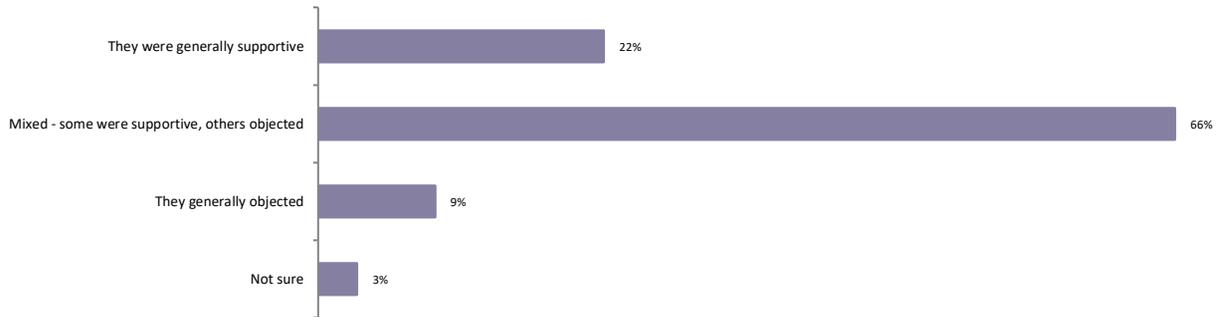
I would say all of the above might be applied and there was no firmly identified reason

I think it was a combination of: some residents already had a DoLS application, it was seen as a health directive, it was not prioritised and not feasible due to time or staff shortages. The bottom line is, residents' rights were overlooked for external factors.

A.3 Impact of restrictions

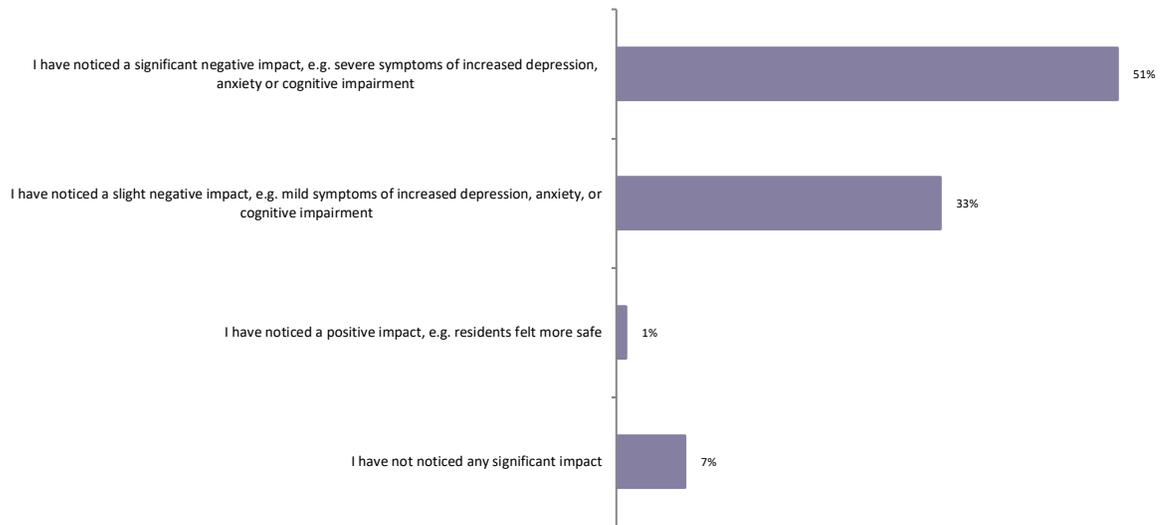
In your experience, how have residents and/or family members of residents generally responded to these restrictions (on visits and/or movement)?

N=174



In your experience, what has been the general impact of these restrictions (on visits and/or movement) on residents?

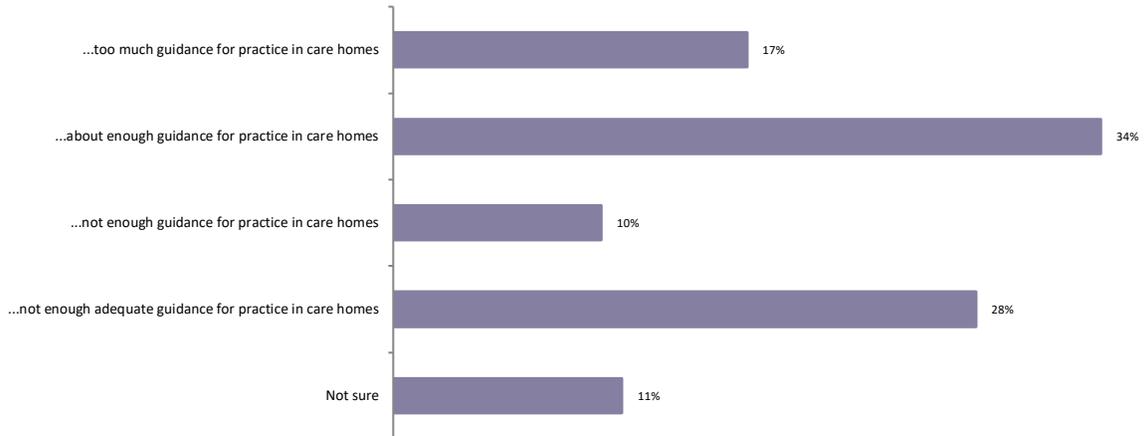
N=174



B. Guidance

At the current stage of the pandemic (January 2021-now), do you think there is....

N=218



What would you like to see more guidance on?

N=16

Selected responses:

risk v rights of residents

The visiting policies vary significantly between care homes, I feel more guidance should be available on this

The guidance has not been specific enough so have assessed residents in care home that have interpreted in a wide-ranging response. The concern I had was for residents that had harsher restrictions the vague guidance could still be used to cover this so was hard to enforce conditions of a DOLS.

Rights of people during pandemic, guidance on decisions made on behalf of people lacking capacity during a pandemic

Really clear and concise guidance in particular for those who have been deemed to lack capacity for all care homes in relation to accessing the community and allowing visitors.

More clear guidance on opening homes to visits from family members and from professionals

For all care homes to be implementing guidance at the same time. Care homes are working on different timescales, so some have been able to facilitate pod visits others are expecting a 91 year old husband to stand outside the window to visit his wife.

DoLS authorisation. Often care homes are not aware of what this is.

In your opinion, how could guidance be made more adequate?

N=52

Selected responses:

not enough attention has been made to care providers having to adhere to human rights act. [...]

Without assumption of understanding of capacity - many care home staff don't understand the legal structure well.

The guidance is just that, it is only guidance and homes are choosing how to implement it across the home, and whether to implement it. This means that some homes will allow visitors in people's rooms, some won't even allow garden visits.

The guidance has been for older people and residential care. It has not considered the needs of younger people, those in MH units, those in supported living and for some people they are often living far away from family and friends.

The guidance fails to consider how safe trips out could be managed. Staff come and go but residents are being expected to stay put and have only limited contact with family.

Stopping placing care managers, who have ADL and business management training, and have a huge conflict of interest- in absolute charge of visiting. Require them to facilitate safer visiting, not say 'care homes are best placed to decide " Make the damage to mental and cognitive health as important as keeping the virus out. Tell care homes how. Enforce staff PPE wearing & proper hand hygiene.

Most homes still appear to be enforcing a blanket policy - need to be clear that restrictions have HRA elements that need authorising

Many homes are taking the guidance as law and not considering individuals best interests. There should be an obligation to weigh the risks and benefits for each individual and their family circumstances and make homes provide solid reasons not to allow visits rather than family having to prove why visits would be beneficial and outlawing of blanket bans.

Letters given to the NOK of all residents. Letters given to residents, explaining the restrictions - in an easy to read / understand format. Central government contact number / named individual for queries

Just some clarity given. Each home seems to interpret the guidance differently.

It was too easy to be misinterpreted allowed for so many providers to make so many different decisions re contact without any worry of consequence.

It could be more personalised to enable more creative interventions whilst still aiming for individual and community low risks.

I think the guidelines should have been more practical and taken into consideration the vast difference in capacity and abilities within the care home

Guidance should be specific and should cover all homes irrespective of status - private/public

Guidance for care homes does not appear to correspond or work very well with the guidance provided for the general public and for NHS institutions. For example, care home guidance says that anyone moving into a care home has to have a covid test no more than 48 hours old. The hospital guidance is not to re-test anyone less than 90 days after their first positive covid test. So there are problems when people who have had covid, but less than 90 days ago, have to be discharged to care homes. There is also the 'double isolation'. A covid positive patient has to self-isolate in hospital for 14 days prior to their discharge to a care home. Then they have to isolate again for 14 days on arrival at the care home, because that is the care home general guidance.

Easier to accessible, in one place with accessible and Easy Read versions co-produced with Disabled people

Clear guidance for visitors which include their rights and rights of residents.

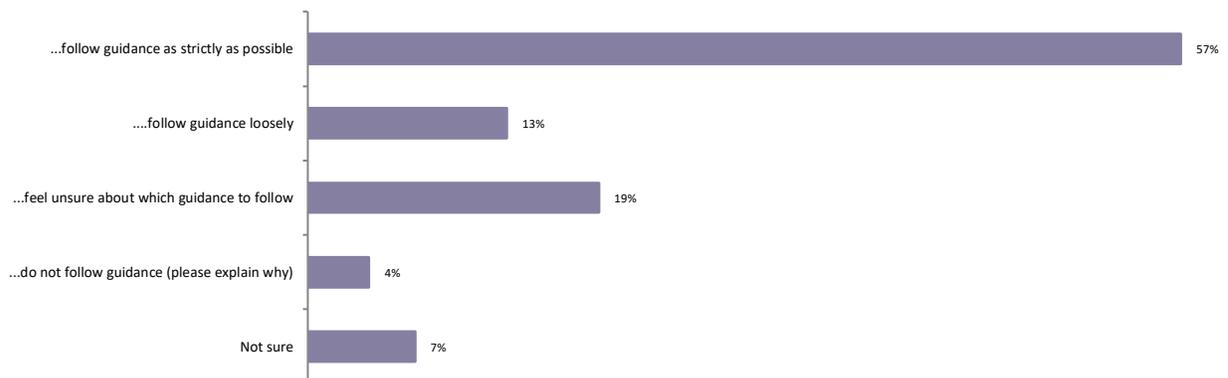
Clarity of information. Clearer channels of communication for advice and support.

*By correctly advising care homes that there has never been a ban on indoor visits, that it is severely harming to deprive people of their support systems and families and to prevent them from accessing recreating outdoors. That care homes should be advised to examine what separates their infection control procedures from those that the average member of the public is now very practised at and why *exactly* homes are operating blanket bans on visits against CQC advice.*

A short official video to explain all procedures to follow for staff and one for potential visitors, a simple appropriate one also for residents who are receptive

In your experience, at the current stage of the pandemic (January–March 2021), care home staff generally...

N=216



---do not follow guidance (please explain why)

N=8

Selected responses:

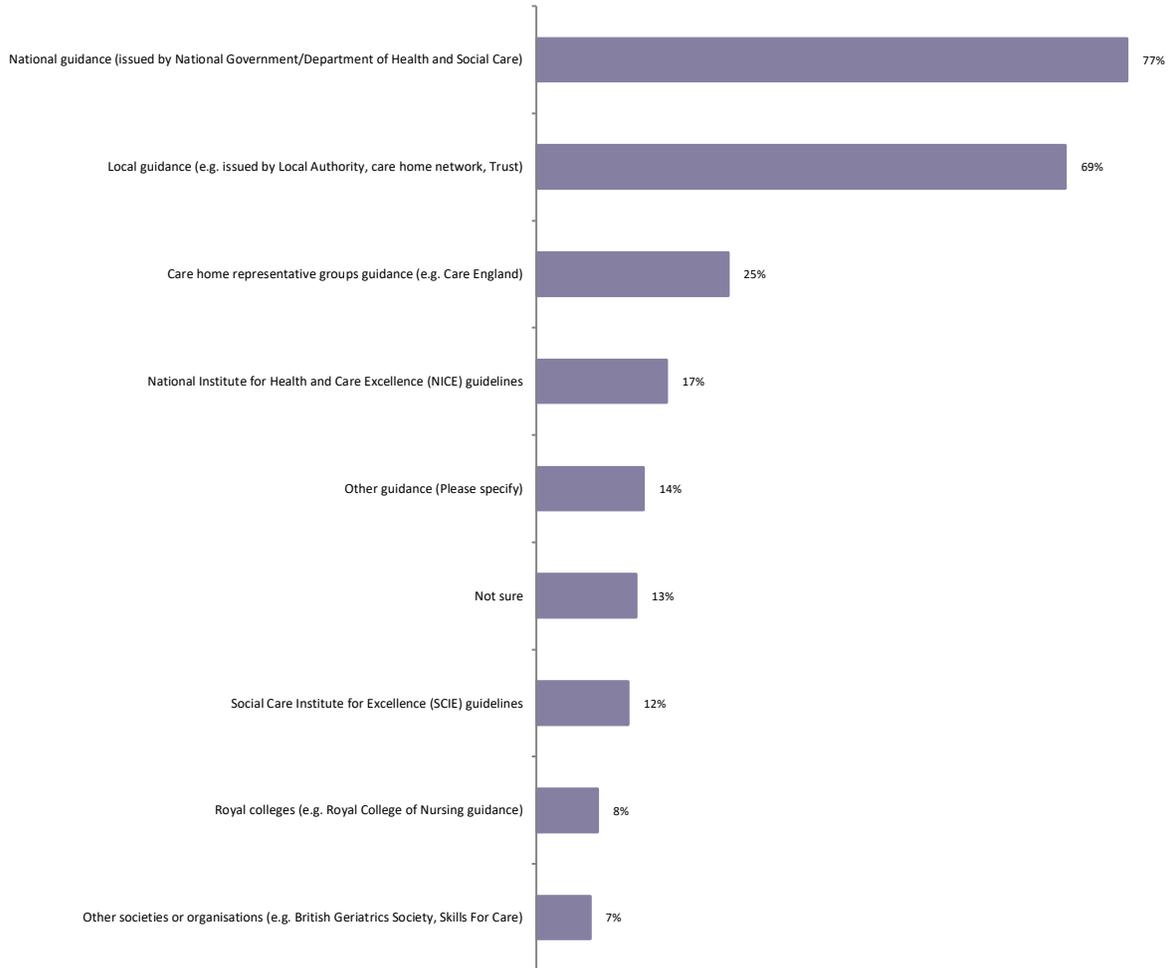
All applying guidance differently. Care homes making own visiting policy still keeping family out

The managers I have spoken to are on their knees, especially with vaccinations. They mainly don't have time to consider this and are worried about the consequences of getting it wrong and having an outbreak of covid.

This is variable, dependent on each individual home. Some are very strict and others in practice do not appear to be as careful. However I have not completed face to face visits so this is purely from discussion with colleagues.

In your experience, which guidance has been relied upon by care homes since the onset of the pandemic? Tick all that apply.

N=212



- Other guidance (Please specify)

N=29

Selected responses:

Guidance comes from the management company running the care home.

Public health England guidance

local policy and procedure.

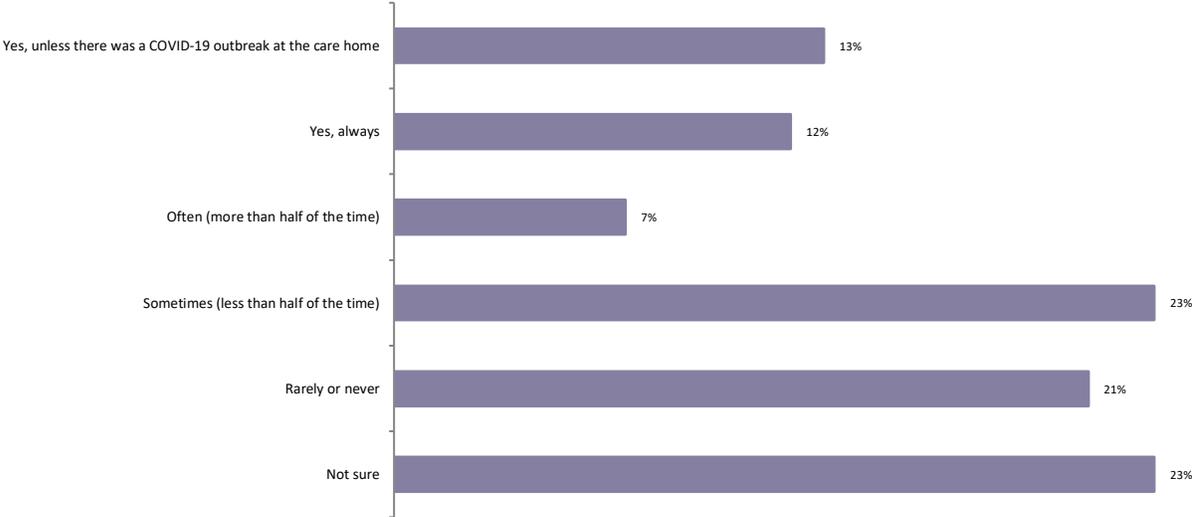
Home's own policies or organisational policies seem to dominate practice.

C. Access to care

C.1 Access to in-person care

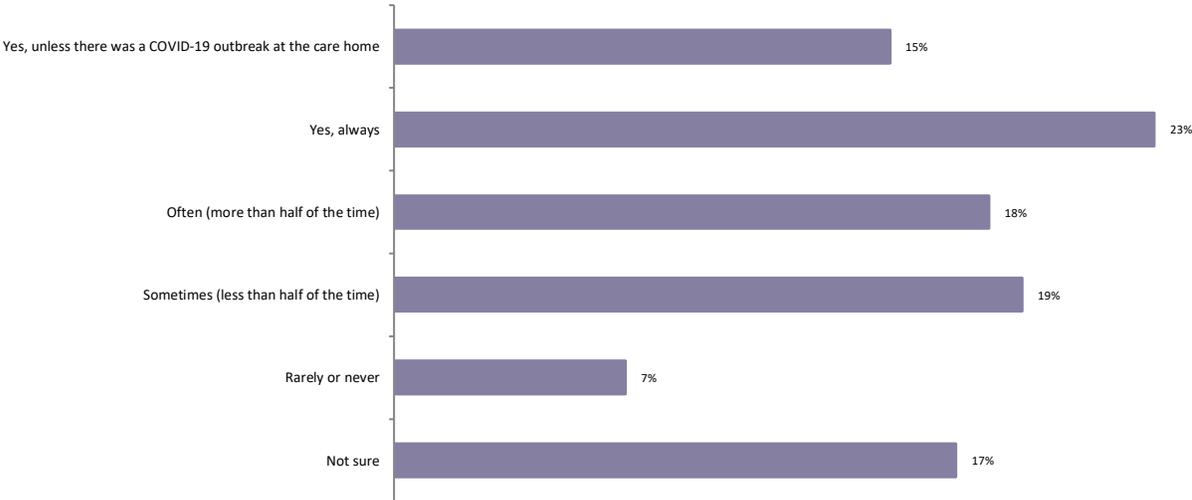
At the care home(s) you worked in or with during the pandemic, have residents been able to access in-person GP care when this was needed?

N=216



At the care home(s) you worked in or with during the pandemic, have residents been able to access other types of in-person health care when this was needed?

N=216



C.2 Access to hospital

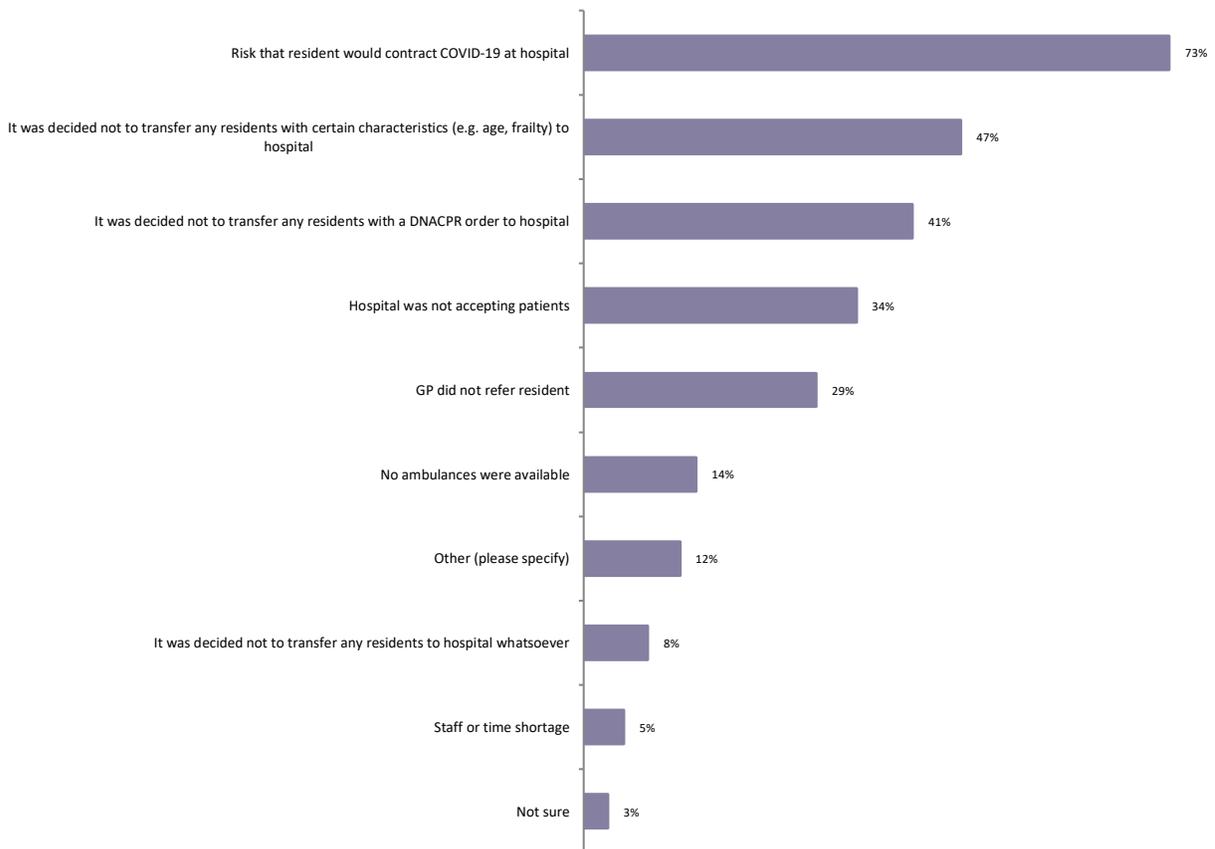
At the care home(s) you worked in or with during the pandemic, were any residents not transferred to hospital who would have been transferred to hospital under normal circumstances?

N=211



In your experience, when residents were not transferred to hospital who would have been transferred under normal circumstances, on what basis did this happen? Tick all that apply.

N=59



- Other (please specify)

N=7

Selected responses:

Ambulance crew encouraged resident to remain in home

At the beginning of the pandemic there was no testing of residents, and they were admitted into hospital if they were unwell, if they were found to be Covid positive they were discharged back to the care homes for symptom management, and the hospital were discharging Covid positive patients into care homes, to free up bed capacity in hospital

Resident did not want to go. Serious concerns about capacity. Safeguarding team deemed resident had capacity without ever visiting

DNACPR remotely done not for hospital transfer without proper consultation with patient, family, carers or other professionals.

In the above - it was not a direction from the Trust, rather than a decision that residents with DNACPRs wouldn't be transferred to hospital.

When it was decided not to transfer any residents with certain characteristics to hospital (who would have been transferred under normal circumstances), on the basis of which characteristics did this happen? Tick all that apply.

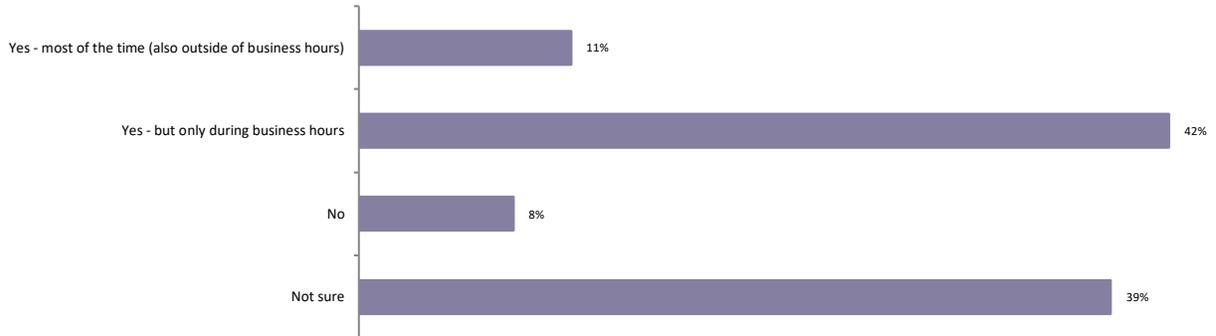
N=28



D. IMCAs

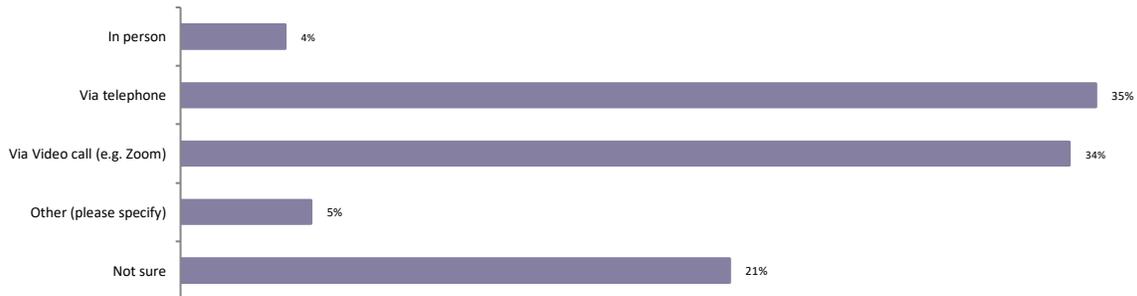
We also have a few questions about the role of IMCAs (Independent Mental Capacity Advocates) during the pandemic. In your experience, were care homes generally able to access an IMCA when one was needed during the pandemic?

N=206



In your experience, what was the most common mode of access for IMCAs at care homes during the pandemic?

N=206



- Other (please specify)

N=10

Selected responses:

Email

they were not used

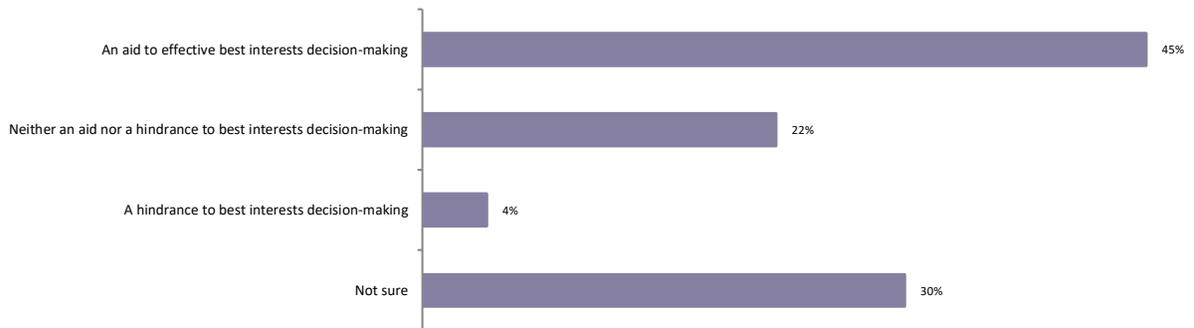
IMCAs have not be available

I have completed most visits remotely via telephone or video calls. However, in some cases I have been allowed to visit in person following a robust risk assessment.

Visiting pods

In your experience, the involvement of IMCAs during the pandemic has generally been:

N=202



- An aid to effective best interests decision-making (Please explain why)

N=62

Selected responses:

To stop doctors from 'dishing out' do not resuscitate for older patients

IMCA eligible issues have still been present regardless of the pandemic and therefore the statutory duty has still applied. Peoples' rights have been impacted by the pandemic and therefore IMCAs role has been vital as a safeguard

The MCA Code of Practice has not changed since the pandemic started and there remains an expectation that the Code of Practice should be adhered to. Overall, referrals are coming in as we would expect. However, there appears to be a trend emerging in which people discharged on the Covid pathway from hospital are still in a care home without a best interest decision having been made up to 9 months after the discharge. These have then become highlighted during the DoLS assessment process.

At least hopefully. In what was a pressured environment during the pandemic and an IMCA could offer advice and guidance particularly in discussions with family and in resolving conflicts between the various guidance notes issued to care homes. Although not strictly the role of the IMCA an outside voice was often useful

As always, the input from an IMCA is useful as it provides additional information generally

Identified concerns and raised them with our authority, particularly where blanket restrictions were made on visiting, testing and self-isolation.

IMCAs have been the eyes and ears in the care home where potentially others (family etc) have been refused access. They have reported concerns both individually and policy based. Having someone independent to the provider accessing the home is crucial

It gives an independent voice to raise questions about whether restrictions are reasonable & proportionate. However, the care homes that request an IMCA tend to be the ones that would consider these issues carefully anyway.

Ensuring the patients voice has been heard. I have found they have been less busy and therefore quicker to get into BI meetings to help ensure the individuals wishes are listened to.

- A hindrance to best interests decision-making (Please explain why)

N=8

Selected responses:

Haven't really been available enough to warrant a comment

Not used

Access to advocates is limited to criteria, often there are delays, they need lots of information from social workers, always (in my experience) copy the social work report, sometimes without meeting the individual.

demands for form filling to often and in large amounts

The IMCA's were being very aggressive and not adhering to their remit in the MCA. They were particularly aggressive about DNACPR decisions even when they were done completely in line with national guidance. At times it felt they belonged to a militant band interested only in their agenda and not that of the individual they were supposed to be representing

People with dementia find video link very hard. One video link session is not relationship-led advocacy

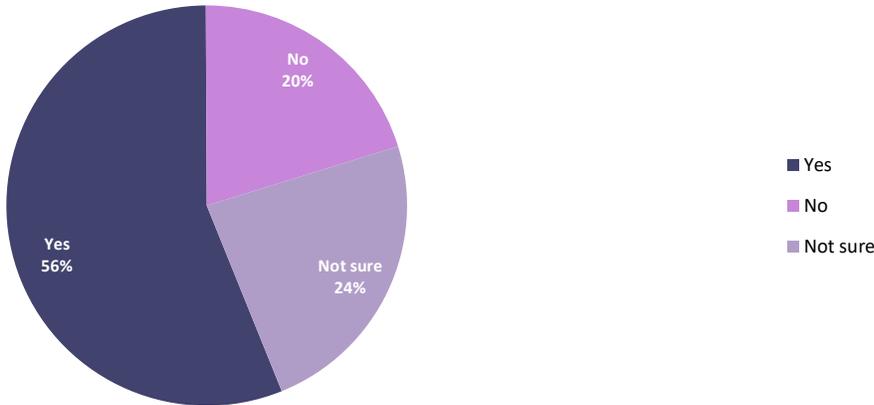
Accessing IMCAs was increasingly difficult once lockdown began. When they were involved, they generally acted as though there was no pandemic. There was concrete and unrealistic thinking at times which didn't account for the severity of the context.

E. DNACPR orders

E.1 Process of adding DNACPR orders

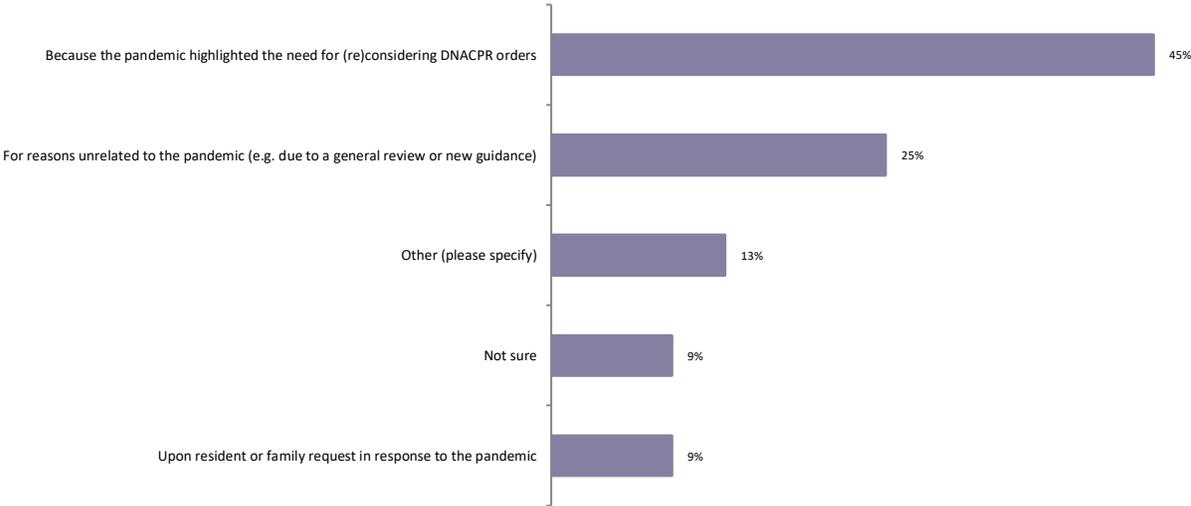
At the care home(s) you worked in or with during the pandemic, were new DNACPR orders added to the files of residents?

N=207



Why were DNACPR orders added to the files of residents? Tick all that apply.

N=116



- Other (please specify)

N=22

Selected responses:

following hospital admissions

Issued due to general decline and increased frailty

At times during the start of the pandemic homes were contacted and blanket DNACPR orders were asked to be put in files.

GP pressure

End of life statement

CCG instructed 1 home to put blanket DNARs in place

My view is that they were added to files to limit hospital admissions where they though / assumed admission would not be beneficial.

Reasons are unclear and vary in most cases. There was certainly a trend by which some GPs were trying to add these. For residents where IMCA became involved these were picked up and addressed using the appropriate best interest process. I worry for those that did not have an IMCA, whether an updated ReSPECT and/or DNACPR has been added without any consultation and purely driven by the pandemic and the possibility that resident may get Covid19 at some point. That said, it has been incredibly difficult for everyone working under the restrictions faced in the past 12 months with numerous pieces of guidance coming through, often confusing, and the need to balance day-to-day care, as usual for all residents.

Mostly that DNACPR's/ReSPECT had not been considered prior to the pandemic. Ascertaining wishes and feelings was very important before a patient were to get covid so that if necessary clinical decisions could be made swiftly in line with less emotional circumstances. This forward planning also aids the care home staff who at times felt really unsupported.

Blanket DNACPRs and due to believing hospitals would be overrun

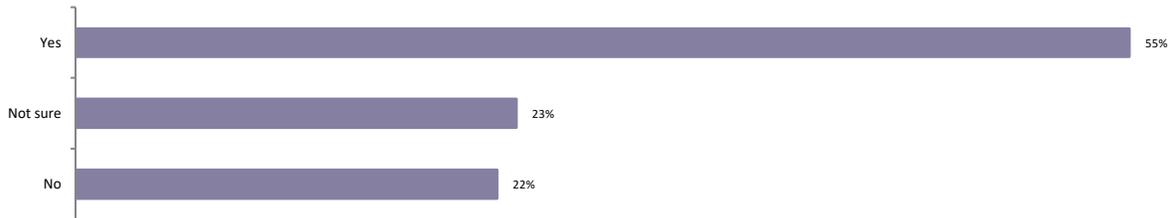
because of the care home considering it would be unlikely that the individual would attend hospital. this was challenged and when they did contract COVID they were taken to hospital with minimal difficulty and have now recovered.

As a panic response - often involving 'whole home' DNACPR orders being put in place.

Inappropriately, because the person had a learning disability.

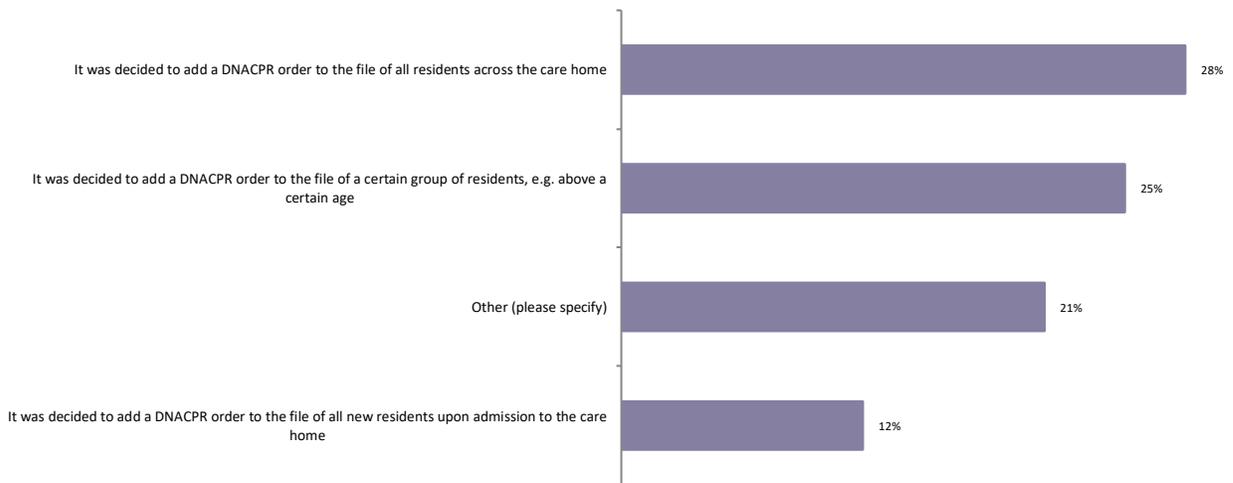
Through your work in or with care homes during the pandemic, have you witnessed any DNACPR orders being added without consultation with the resident or their family?

N=115



If Yes - In your experience, when DNACPR orders were added to the files of residents without consulting the resident or their family, on what basis did this happen? Tick all that apply.

N=61



- Other (please specify)

N=16

Selected responses:

individual conversations about care needs and review were done without family present due to restrictions so orders were only discussed post implementation.

added in response to COVID-19

When DNACPR orders were added to the files of residents, this is seen as a medical decision by a clinician.

Reasons have varied from my involvement in cases. At times the DoLS assessment process picked these up and an IMCA referral was subsequently made. At others, care home managers have made contact for this to be revisited and reviewed appropriately.

In emergency circumstances

I went into many care homes during the pandemic. The vast majority of DNACPRs were done completely in compliance with all local and national guidance. There were some pockets of bad practice. These were highlighted to our service and amended appropriately

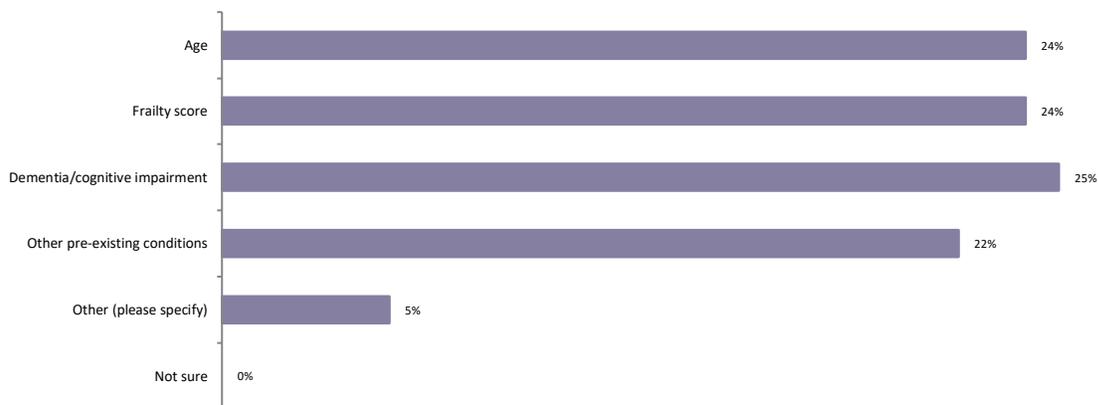
Frailty nurse was asked by GP to assess all residents and took a blanket approach

As part of considerations about admissions to hospital during the pandemic

Added in hospital and left on file

When DNACPR orders were added to the files of a certain group of residents, on the basis of which characteristics did this happen? Tick all that apply.

N=19



- Other (please specify)

N=3

Selected responses:

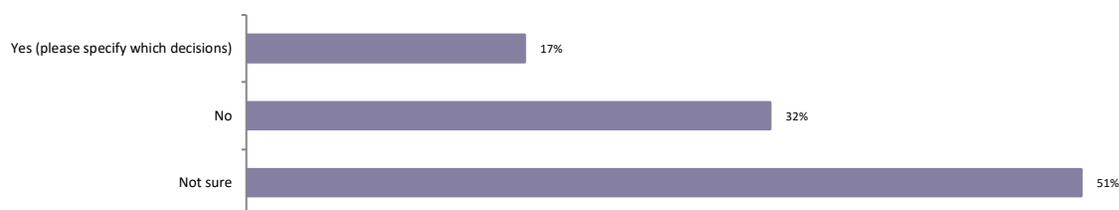
Learning disability / autism with additional health needs

Respiratory diseases, other significant physical health problems

E.2 Use of DNACPR orders

At the care home(s) you worked in or with during the pandemic, have you witnessed DNACPR orders influence any medical decisions beyond CPR at any point in time since the onset of the pandemic?

N=203



- Yes (please specify which decisions)

N=27

Selected responses:

Ambulance decision to transfer factored in the DNACPR and advanced care plans

When people tested positive for COVID GP were asking homes to complete DNACPR on treatment decisions and hospitalisation

To prevent hospital admission.

This has been a deciding factor in hospital admittance

Some staff see DNR as "do not care", or "do not seek any medical treatment". Some GPs think this too.

I had one relative who told me his story about DNACPR being used to prevent hospital admission for medical treatment - he insisted she went to hospital and the ambulance eventually took her

Confusion about the remit of the order.

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

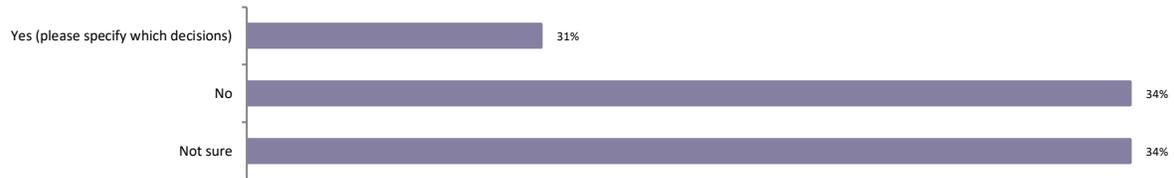
Admission to hospital/ treatment for COVID

Admission to ICU. The giving of intravenous anti-biotics

Admission and treatment escalation As part of best interest decision

At the care home(s) you worked in or with during the pandemic, are you aware of DNACPR orders influencing medical decisions beyond CPR at this point in time (March 2021)?

N=35



- Yes (please specify which decisions)

N=9

Selected responses:

unable to answer as not present during decision making

admission to ICU and giving intravenous antibiotics

To withdraw all medication, to allow nil by mouth and not consider hospital admission for dehydration

Person at risk to access hospital because of Covid -19

Admission to hospital.

F. Any other comments

Is there anything else you want to tell us about your experiences working in or with care homes during the pandemic?

N=89

Selected free-text comments are organised by respondents' primary role.

F.1 Advocates

There is insufficient funding for there to be enough resources to enable remote engagement with care homes to work sufficiently for people like advocates – Advocate

The early stages of the pandemic in particular were very difficult for everyone, but 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

Some consultants have made DNACPR based on their perception of quality of life. Failure of adequate risk assessments generally in attempting to maintain a degree of access to community, lack of foresight into how these lack of access could affect physical health weight gain etc. but also psychological in terms of distress, anxiety which in turn can lead to medication changes and PRN being used. – Advocate

I feel very strongly that residents in care homes have not been treated the same as other citizens. It seems to have been thought acceptable that some care home residents have not been out for exercise during the entire pandemic-a whole year! This would be deemed unacceptable for anyone in the community. Not all care home residents are frail. Some are physically fit and accustomed to going out into the community. I understand that care homes have been very scared of allowing the coronavirus to enter their establishments but I do feel that it is inhumane to restrict a person's liberty to such an extent that they are confined to a building or part of a building for such an extended period. – Advocate

I do not believe advocacy providers have also struck the right balance between protecting the rights of those in care homes (right to life vs right to liberty, right to family) and I would have liked to have seen advocacy services being far more active in confronting decisions about advocates not being able to get into care homes (and other settings) to support clients, whether that came from care homes themselves or indeed advocacy providers themselves. I hope there is some honest reflection about this. Advocacy via Zoom or telephone for people in care homes must not become the norm as it simply doesn't work. – Advocate

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

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

Generally the response to advocacy from care homes has been adequate but knowledge from staff (including managers) of the Mental Capacity Act and DoLS is often low. The pandemic has shown how a lot of homes' access to high speed internet required for video calling is low, even in London, and often the connection dips. Care homes should have better access to high speed internet in order to adhere to residents' Article 8 rights. I get the sense that for some care homes that have an opaque culture, the pandemic has allowed them to 'double down' on this culture and use it as an excuse to provide inadequate information about the care they provide and what is in residents' best interest. However, care homes with transparent culture have been receptive to remote advocacy. - Advocate

Communication with care homes has been very difficult at times, especially when visits could not occur as this would increase the amount of telephone/video calls to the home and the work load of staff. However, I have found that the majority of care homes I work with have facilitated contact with residents as far as possible and have recognised the importance of family/advocate contact through the pandemic. I have found that some homes have reviewed family visits on a case by case basis and have allowed visits for some residents to aid their mental state. – Advocate

As an advocate, the major concern that has been raised for us is that care homes have not understood capacity well - how to carry out an assessment properly, have not been referring for IMCAs, that capacity is decision-specific, and have not understood that family cannot give consent for medical decisions without an LPA for health and welfare in place, or that a restriction to a room is not covered by a previous DoLS authorisation. There have also been many delays with DoLS authorisations. There have also been many difficulties getting in touch with care homes who tell us they are too busy to talk to us or that they cannot arrange for us to speak to the individuals we advocate for. – Advocate

As an advocate I have seen so many decisions made due to "risk assessments" or "covid guidance" and no use of the MCA. I have had a number of care homes telling me that there were easements to the MCA, when there never were. I have had care homes tell me they were shielding residents who did not have a shielding letter. Many care homes I have seen have not used the guidance for RPR visits in particular, as an RPR I have been told by care homes that my role is not classed as essential visit despite this guidance. I have seen care homes block visits from family members who are RPRs but allow visits from paid RPRs for other residents, purely on the basis of the RPR being family and giving no consideration to the RPR's legal role and obligations. I have had difficulties getting records to review. There is also a lot of focus on care homes but from my care act work I think a lot of these problems are mirrored in supported living too. – Advocate

F.2 BIAs

Yes - although there has been a mostly negative impact on care home residents as a result of restrictions on visiting and outings, some residents have responded well to these changes, indicating that their environments may have been too busy and overstimulating beforehand and their days are now much more predictable. In some cases I have seen anxiety and 'challenging behaviour' decrease as a result. – BIA

Varied approach on allowing visitors and at times with no clear explanation. – BIA

The care homes were at the coal face of this pandemic from the very start and were ill prepared for the measures asked of them. The restrictions have given the care homes a lot of power, which again they were ill prepared for. The balance needs to be redressed. – BIA

Some residents were placed into care homes as a short term plan upon discharge from hospital under 'Covid-19 funding'; still there after 6 months+ even when their needs improved, without follow up from the social work team or the care home notifying relevant professionals of change in needs. – BIA

Some of the care homes I have worked with have been exemplary in facilitating the continued contact between their residents and their families.- BIA

Some colleagues have noticed that some clients have responded positively to the limits on access to the outside world. eg. it was the professionals expectations that the client went out to various groups x times a week and it was not really a person centred decision, so some clients are preferring to not attend their 'day centres'. – BIA

Practice in different care homes varied according to age group and vulnerability of residents and whether COVID was present within the care home. A couple of care homes for older people were very risk averse to their residents going out for a walk or in their wheelchair in the summer. Some care homes are now opening up and I have had my first physical visit in a year to a care home for older people - they did a swab and 10 minutes later I was found to be negative and allowed into see my resident in their bedroom, I wore a mask. – BIA

It has been exhausting, frustrating and it has felt as though we have taken a lot of steps backwards. Away from my professional opinion, I would like to tell you about my lovely 90 year old neighbour, who struggled through the pandemic, but I saw her every day for a chat at her door and I did her shopping. As time went on and her world shrank, her friends were all shielding, she couldn't go out without people telling her to go home because she was old, she started to become delusional some of the time, usually late in the afternoon, but she was always OK until about 3.00. She told me that she was getting married and she withdrew large amounts of cash from the bank to prepare for the wedding. On another day she decided to call a taxi so that she could go and stay in a hotel because she was so sick of being stuck in her bungalow. She was eventually taken to A&E when her nephew reported this to the GP. She saw a psychiatrist who moved her on the same day to a care home (contracted by the NHS to deal with hospital rapid discharges). I know she was distressed about this and she gave the manager hell, as she told me herself that my neighbour was strongly objecting to the deprivation. She was isolated in a bedroom for 2 weeks. No TV, none of her things as she hadn't expected to go there and when I asked the care home if I could see her, I was told they had put an

urgent DOL in place and she could not leave her room for two weeks. I told them that as well as being her neighbour I was a BIA and this wasn't right because she had capacity - the delusions were intermittent. Also if you said to her, "Do you remember you were married to X, but sadly he died a few years ago." She would generally continue with the same story for a while and then eventually say, "Oh yes. I remember now." She trusted me and she could be persuaded to go back to her home if you gave her a bit of time and didn't tell her what to do. She knew where she was living and she knew all about care and treatment and was starting to think it might be an idea to have more help at home. She could definitely weigh up and communicate a decision. The care home manager admitted she was distressed and wanted to go home and didn't stop telling them that. Two weeks later I had arranged to see her the minute she was allowed out of the bedroom at a window visit. To be honest I just wanted to put her in my car and bring her back home although I didn't want to be arrested for kidnapping her. I did intend having a conversation with her about the DOL that day and trying to get her back home if that is what she still wanted. I was just leaving to see her when I had a phone call to tell me that she had died. She had a heart attack, but to me she was another victim of Covid-19. Sorry, I know this has moved away from my professional knowledge, but this is not just about care home residents but how they were used during the pandemic as a dumping ground with such appalling consequences. – BIA

I have found it sometimes easy to remote work but this has been dependant on either meeting residents of the care home previously or knowing and visiting the home and good working relationships with professionals. Other times it has been difficult to get through on the phone or when appointments made this has not been passed on so has resulted in time delays re-arranging. – BIA

Everyday practice has improved since last March. Care homes are now aware of having to risk assess everybody individually re restricting movements. There are few who continue with blanket decisions regarding access to the community and this is being addressed by the local authority. My thoughts are that when families can visit it may be very difficult for them to accept the decline and deterioration of their loved ones. I believe the families will need a lot of emotional support. – BIA

At present it is my impression that care homes are interpreting the current guidance differently. For example I have been told that a care home group has "decided" to continue with "pod" and outside visiting rather than allow in person in care home visits – BIA

was from when the positive result was received. – Facility Management Team member

F.3 Social Workers

both on a personal and professional note: it is good to see the guidance change on families being able to visit those deemed end of life care. As a family we could not visit a close relative in April 2020 at a care home, who was dying. Sadly we could not hold their hand or be there for them in their final moments, when they only lived 10min away from us. A member of the nursing staff at the care home sat with her to comfort her through her final hours. We have some comfort that she did not die on her own, however like many families this has had a massive impact on us. – Social worker

While I can appreciate the stress of working in a care home over the past 12 months and the desperate need to keep Covid out of the homes, I believe that the balance of restriction has often been too heavily weighted in favour of restricting movement and contacts. With some honourable

exceptions, too often a blanket approach has been taken by homes, rather than looking at each individual resident's needs before balancing the community's needs against them. I think the level of restriction has too often been too high. – social worker (also BIA) My issue has been that every company running care homes worked to their own set of policies existing outside of governmental or health guidelines. This meant that whilst some supported residents being seen by family for window visits or via plexiglass, others closed themselves off completely and were not even able to provide video calls for residents which detrimentally affected their mental health and wellbeing and that of their family members. – Social worker

I observed lack of guidance to care home staff and manager until the guidance for visits was issued with regard to visits starting on March 8th 2021. Prior to this, the guidance and the messages on the media (Official Covid-19 briefings) failed to send clear messages about what was allowed and not allowed in care homes in terms of visits (admission protocol for new residents, when to test residents, when do residents need to isolate after visiting the hospital: eg A&E visits, outpatient appointments, can visitation pods be used during lockdown, etc). The new Guidance on care home visiting (8th March) clarified several of these areas, but in many care homes, the damage was done by limiting peoples' rights indefinitely for a prolonged period of time. This seem to also change the dynamic of some care homes, which are now reluctant to allow visitors or promote activities in the communal areas. – Social worker

All care home residents had decision making ability removed from them re weighing up risk for themselves re contact. They were treated differently to the rest of the public. – Social worker

F.4 Facility Management Team Members

We having been using Telemedicine for triage, advice and next step. We have weekly GP rounds with video calls. – Facility Management Team member

Some homes coped really well, others really struggled. Issues re PPE, having enough staff, especially nursing staff. Trying to keep to the line about visitors was difficult, families wanted other families not to visit their family members, but it was ok for them to visit their family members. Difficult for people placed out of area for the local authority to support as not the host authority. I know several care homes across the country where I had allocated cases that struggled to get food deliveries at the start of the pandemic. I have been told by several homes that I was the only care manager that contacted the homes to check how my allocated cases were, some boroughs did not check on their out of borough placements for months. – Care Manager

PHE and our local IC team have been invaluable, keeping in touch during and post outbreak. Giving clarification at the end of the phone at times on conflicting advise. eg: when LFD tests were first introduced, some guidelines was not to test within 90 days following a positive result, however local guidance said this only applied to PCR tests. They also gave clarification on what was considered to be day 1 of isolation depending on when symptoms were first notice, to when test was taken if no symptoms, to NHS app saying it – Facility Management Team Member

F.5 Other roles

[...] Advice from Mencap was to lock everyone into their bedrooms irrespective of the distress caused. When pushed they said to lock staff in with the residents. But at all costs to keep people in their bedrooms. For 28 days. – Role unspecified

With respect to in house GP or health workers, my experience is the contact didn't stop but that most if not all of these visits were virtual. Most families I've spoken to chose to not visit either due to their own health or because they found the window visits / safeguards more distressing & confusing for the person. Family would say 'they don't know if I've been so rather than distress them I'm waiting until it's safe to visit'. Most care homes when I asked if the person was affected (by PPE, lack of visitors, lack of overall people in the home) would say no. I'd conclude with the fact most if not all of us have been restricted in seeing our loved ones, care homes seem different because the person is more vulnerable and more reliant on visitors than the general public - and this is of course an important issue. I never envisioned this would have happened a year ago, it seemed impossible because of human rights. But the health of other professionals & family factors in to how much people wish to go into care homes. For me what covid is shown is there isn't necessarily a correct answer with regards how homes should operate but rather shines a light on the fact that high numbers of strangers living with each other isn't necessarily the way forward. The overall environment has been a massive factor because the fact is, a home does have to make sure covid doesn't spread and existing public health guidance tells all of society to keep a distance and see as little people as possible. I'd genuinely wish for this to be the shift in how many vulnerable adults live in a care home, it's a cruise ship on land, just like prisons, the environment needs to change in the future not care home policy as such. –Court of Protection visitor

With all the issues of DNACPR's a proper audit of this would be useful, as most of this is anecdotal evidence only with a few small exceptions. This needs to be kept in perspective. Good clinicians feel beleaguered by it. Also I was astonished at the fact that IMCAs have no recognised training regulation or registration- this needs rectifying. – Named GP for safeguarding adults

We had residents not admitted to hospital who had covid because they 'wouldn't be eligible for a ventilator' paramedics commented 'why did you call us for this person, we can't take him in' and referred to the frailty score. This was probably the saddest moment of the pandemic for me – Care Home Nurse/Carer

Individuals with a learning disability within care home environments have been significantly impacted. As a community team we have seen increasing frustrations from individuals around lack of services, challenging behaviours as a result of boredom and breaches of freedoms and quality of life. Increase in self harming behaviours in residential patients. – Primary Care Liaison LD

I'm disgusted by staff's attitude towards families. Nearly every care home I know of has had a COVID-19 outbreak caused by care staff. These homes won't open to families because of the risk of covid being brought in by them! Staff have already done this themselves! I'm appalled by the total disregard for human rights. No resident was asked if they wanted to be isolated and imprisoned. No families were asked, either. No new DoLS. Just an assumption that residents belong to the care home, and staff can do what they want because they've decided to. I'm astounded at the number of care home staff who were non compliant with PPE & hand hygiene (mainly masks on chins, under noses or No masks), who remained adamant that families were the only risk, & staff needed keeping safe from them! Managers ignoring their staff wearing masks improperly. Managers referring to NHS staff (families) as too high risk to visit. The absence of GPs in far too many homes. Patients

referred for elective surgery, yet the GP hadn't seen the patient in months, & never for that condition. Care home managers deciding that mental health isn't essential, so refusing access to patients by mental health teams. Care Home staff requesting antipsychotics for distressed people, having not recognised the person misses their daily visitor. Lack of health oversight- GPs, DNs not going into care homes in many cases. No CQC. No quality team. Care staff acting as health care professionals without knowledge or qualifications. A resident put back to bed after a fall without any medical assessment. They'd had a stroke, resulting in significant behavioural changes and lack of recognition of having had a stroke. No medical care. Lack of communication with families, even despite government instructions to keep them updated. Poor documentation. – Nurse educator and supporter of people with dementia

I have seen residents in care homes deteriorate, particularly where residents have dementia. being in an already unfamiliar environment not having access to familiar family members and visitors has had a detrimental impact on their presentation. Many do not understand virtual visits and struggle to engage so this cannot and should not be seen as an alternative or replacement for face to face visits. Further, the use of PPE has made visits to residents who have mental health issues difficult - their response to face masks in particular was difficult as they struggled to understand and misunderstandings have arisen which has put pressure on professional relationships with clients. – Legal role

I have found it incredible how GP's and health care professionals have just turned their backs on frail and sick clients because they didn't want to put themselves at risk by entering a care home. People have been left without essential medications or care teams have had to beg to be taught how to assist people with medications to ensure they got them. Some clients who are still living now - one year on - would have died unnecessarily during the past year - and their deaths would have - wrongly - been chalked up to covid. – Operations and Compliance Manager

Care homes need to be advised they must allow family members to assist their relatives putting in place the relevant mitigating factors and that mental health is not just a category, two words but the most critical factor in human existence and without duty of care to this very real suffering is happening leading to devastating outcomes – Role unspecified

Care home staff have been incredible. Many above and beyond. The majority of homes/staff have taken advantage of IPCT and RESTORE2 training available to them. The response to support and advice has been positive and gratefully received. Training has provided an opportunity for staff to communicate how they have been affected by the pandemic and the toil it has taken on them is tangible. Often this has been the only support provided and no structured supervision or talking therapy has been offered through any channels. They feel overlooked, broken and mentally and physically exhausted. – Community Care Home Support Team

At the commencement of the pandemic homes were adversely affected by infected patients arriving from hospital. I am sure that this influenced subsequent behaviours which have always tended to the most restrictive interpretation of the guidance. Care homes have been very restrictive of visits to care homes and away from care homes even though the staff come and go freely. The physical safety has completely overridden the emotional benefits of physical visits. Video visits are often baffling for residents. Staff also tend to give less privacy - sitting in to provide support, e.g with the technology. – Barrister

Huge confusion about law vs guidance, following 'Guidance' to restrict visiting, self isolating people etc and not using Principles of the MCA. Increase in Section 21a appeals from paid RPRs due to objection, a few due to self isolation being implemented. Some care homes incredibly stressed trying to following PH guidance and adhere to DoLS/ less restrictive practices. – Team Manager

A big concern is how many assessments (Care Act assessments and reviews, DOLS assessments, fresh assessments for Court of Protection proceedings) are still being carried out remotely even when care homes started allowing visits. I have spoken to care home staff who say that they offered a social worker / s 12 doctor / some other type of professional an in-person visit but the professional declined and carried out their work by phone or video, even when they had been made aware this was not ideal for the resident. I understand that lots of professionals may have their own concerns about going into a care home, but I worry that the default still seems to be a remote assessment, regardless of the impact this has on the resident or the work produced. – Community Care Solicitor

Most care homes have done their best to promote their residents' best interests during the pandemic. Some have been very creative in providing opportunities for families and professionals to visit. Others have been more risk-averse. On the whole residents' families have accepted the restrictions but have been distressed and worried by them. Some families are very concerned about not being able to see family members in person - contact via phone or screen doesn't always work. In my local authority there has been a lot of support for care homes from adult social care and public health right from the start. This has helped to build good working relationships and problem-solving.- MCA/DoLS team manager

There were often inconsistencies between different care providers about their policy of letting members of the community learning disability team in to carry out clinical assessments and interventions. Some homes required rapid flow tests on their site before entry into residential areas, which was time consuming and sometimes delayed care to other patients and service users. Our trust risk assessment also stated that if any care home staff members were off isolating awaiting a COVID test result, we were to delay our visit until the result was returned, or for 14 days, unless we deemed it urgent enough to process with a higher level of PPE. I guess this means that there will be differences in different people's approach to assessing that risk and what can be deemed 'urgent enough'. One of the biggest impacts on people's liberty and decisions about their care and support during this pandemic, has been access to day opportunities. For some people, this isn't just about their social interaction and behaviour/ mood, but it has led to deterioration in their physical health as a result of not having access to therapies and equipment necessary to maintain their mobility e.g. hydro and walking frames too large for their house/living space. This has led to reduced function and mobility, increase in pressure ulcers and chest infections. – Speech and language therapist