



Learning Disability England

Do Not Resuscitate Notices and People with Learning Disabilities

January - April 2020 during Covid 19

Findings from our Survey

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May 2020

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Findings from our Survey

What this is about

This report is about Do Not Resuscitate decisions.

Do not resuscitate means a doctor deciding, before it happens, that a person should not be given treatment when they might be dying.

We call this DNAR in this report.



We are worried that this might happen too much to people with learning disabilities, so we tried to find out how much it is happening.



Learning Disability England did a survey to find out more about how decisions are being made.



The survey showed that in a lot of places DNR decisions are happening in good ways.



There are some decisions being made in the wrong ways that break the law or do not respect people's rights.



Learning Disability England will work with members to help everyone look out for these and stand up for people's rights.



About Do Not Resuscitate decisions

These are sometimes called DNR or DNAR or DNACPR.



Resuscitate is the word used when someone's heart is started again by doctors.

It is sometimes called CPR.

CPR is different for everyone.



Sometimes the DNAR decision might include not using a ventilator to help you to breathe.



A ventilator gives you oxygen. This keeps you alive if you are too ill to breathe properly for yourself.



You can find out more about DNARs in these easy read leaflets from [East Kent NHS trust](#) or [Knowsley NHS Trust](#).



A Do Not Resuscitate (DNAR) Notice means someone decides they do not want doctors to try to start their heart again if it stops.



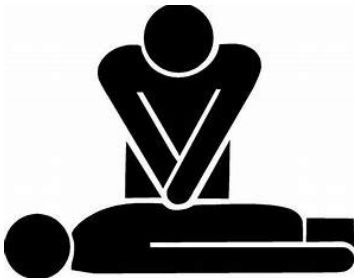
We don't want people to be afraid of these decisions.



We think it is important everyone talks about it with their family and the people they trust.



Each person or people who know them well should decide if they want to be put on a ventilator if they need it.

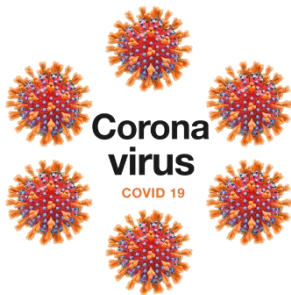


They should decide if they want CPR to try to start their heart if it stops.



This decision is put on someone's hospital notes so doctors know.

The law says this decision is always made with each person and their family whenever possible.



What is happening about DNR decisions

Learning Disability England had heard about DNR decisions being made by doctors without talking to the person, their family or the people who support them.

Some people said more decisions not to treat people were being made because of Coronavirus.

We asked members if they had seen more or different DNR decisions.



= 88

What we found out

88 organisations filled in the survey.



They told us about DNR decisions during coronavirus for the people they support.

Most organisations who replied said that they have not seen different decisions on DNAR in 2020 for the people they support.

But some organisations said DNAR decisions had been made on groups of people.

Some DNAR decisions had been made without a person or their supporters being involved.

Organisations had been able to help people get bad DNAR decisions changed.



What we can all do next

We do not want people to be afraid of having discussions about their Health Action Plans, advance care planning and DNAR during coronavirus.

DNAR Notices are right for some people. And they are wrong for some people.

Talk about what you want. You should make the choice that is right for you.

We will help people share information and ideas to stop bad DNR decisions happening.

Everyone can look out for bad DNAR decisions happening and be ready to stop them.

Summary of Key Findings

- DNARs being incorrectly used is not universal or inevitable.
- The majority of support providers who replied to the survey have not seen an increase in poor practice since Covid 19 started.
- DNAR Notices are, in themselves, not wrong. We do not want people to be afraid of having discussions about advance care planning and DNAR, or of making the choice that is right for them.
- Some people with learning disabilities have been supported to make an informed decision about treatment or DNAR themselves or with those that care for them.
- There is evidence there **are** still some blanket applications being applied to groups of people or added to individual's medical notes without their consent in April 2020 after the guidance was clarified.
- We think everyone needs to be looking out for this happening to them or people they support – we must all be vigilant.
- Learning Disability England is working with some members on resources that can support people to challenge poor processes or unlawful use of DNARs.

#WeMustAllBeVigilant

Introduction and Background to Survey

In March 2020, Learning Disability England began to hear anecdotal stories about an increase in Do Not Attempt Resuscitation (DNAR) Notices being imposed on individuals with a Learning Disability without their consent or a Best Interest process being followed.

Disabled people and their allies were alarmed at the original NICE guidance issued in March on adult critical care and the inclusion of the Clinical Frailty Scale. NICE clarified that the scale should not be used with people under 65 years old or adults with learning disabilities, and the guidance was updated following challenges from organisations.

There was considerable public comment and lobbying including from over 70 disabled people's organisations and allies in late March to write an [Open Letter supporting a Statement about the rights of disabled people during Covid 19](#).

The Medical Director and Chief Nurse at NHS England [wrote to all NHS organisations on 7th April](#) reiterating that all DNAR decisions must be made on an individual basis in consultation with the person.

Their letter reinforced the Care Quality Commission, the Royal College of General Practitioners, the British Medical Association and the Care Providers Association's [joint statement on advance care planning](#).

They said: *"it is unacceptable for advance care plans, with or without DNAR form completion, to be applied to groups of people of any description"*.

Alongside this, the Chair of the United Nations Committee on the Rights of Persons with Disabilities and the Special Envoy of the United Nations Secretary-General on Disability and Accessibility, issued a [Joint Statement: Persons with Disabilities and COVID-19](#).

However, despite this well publicised NHS response and attendant guidance, Learning Disability England continued to get informal reports about the imposition of DNAR without consultation and where the individual with a learning disability had no other underlying health condition.

Any decision made purely because someone has a learning disability, or based on medical professionals' assumptions about their quality of life, is potentially unlawful. It could be in breach of the Equality Act by providing the person who has a learning disability with a worse service than other patients. In addition, it could be argued that the person's rights have been denied under article 2 of the Human Rights Act: The right to life, and also the right to freedom from inhuman or degrading treatment (article 3).

Medical professionals are not obliged to attempt CPR against their clinical judgement, but they must take into account their patient's wishes and any non-medical issues that are relevant to the patient's decision and explain their decision to the patient and/or family if appropriate.

If there is doubt or disagreement, the General Medical Council (GMC) advises that "a second opinion should be [sought] from a senior clinician with experience of the patient's condition but who is not directly involved in the patient's care. It should be based on an examination of the patient by the clinician".

In order to understand the extent to which non-compliance with the guidance on DNAR continues to be an issue, we decided to survey our member organisations who provide a range of different types of support to individuals with a learning disability.

These member organisations range from user led or small local organisations to complex national organisations. Across the membership they work with people with learning disabilities in a range of ways: support to live at home, residential care, advocacy, arts development or training for example.

We conducted this 'snapshot' survey between 27 and 30 April 2020, specifically concerning DNAR practices and timeframes relating to the people they support. We also asked for anonymised examples and stories to evidence their response.

At the same time, we also asked individual members if they wanted to share their experiences.

This report details the responses we received to this 'snapshot' survey.

What we asked

Learning Disability England conducted a survey of our organisational members from 27-30 April 2020 concerning DNAR practices relating to the people they support.

We received 88 responses to our survey of organisational members.

Firstly (Q1.), organisations were asked if they were aware of any change in DNAR notices in relation to the people they supported since the start of 2020.

Next (Q2.), organisations were asked if they thought that, since the start of 2020, the number of DNAR notices was higher, similar or lower in the following circumstances:

- Where the person (or their representative and family) have made an informed choice on having a DNAR notice in place
- Where there was a blanket application made by someone else without the person or their representative's knowledge or involvement
- Where a notice came to light attached to the person's medical record but you are not aware they or their representatives knew about it
- Other circumstances

In addition to the organisational survey, we also asked individual members if they wanted to share their experiences.

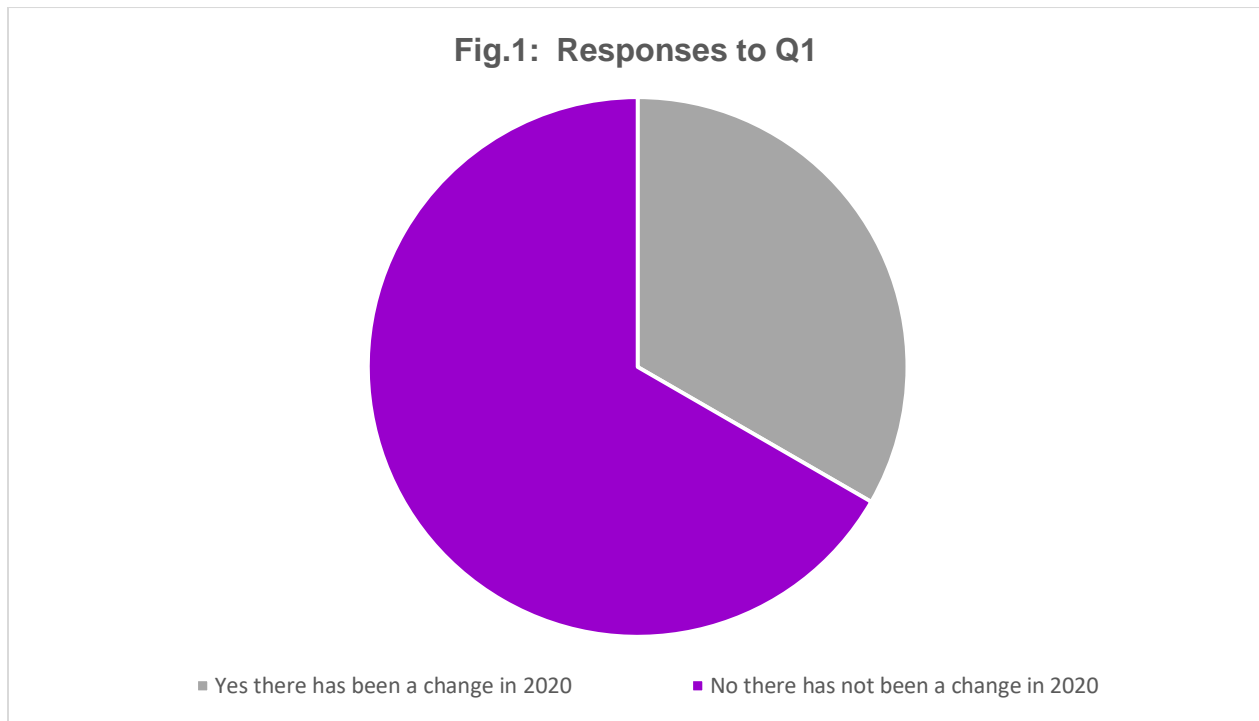
Two family members contacted us with their experiences.

Key Findings

The responses we received to the two questions were as follows:

Q1. One-third of responding organisations (29 organisations; 33%) said they were aware of changes in DNAR notices since the start of 2020.

Two-thirds of responding organisations (58 organisations; 67%) said that they were not aware of any changes.



“We have not had any communication in this regard. We have had conversations with some service users and their families in order to update their end of life care plan - it has so far not involved a DNAR. No medical professional has been in touch in this regard. We have been asked to complete grab sheets, so hospitals are prepared when a service user is admitted - something we all welcome.”

Q2. Informed choice on having a DNAR notice in place:

Of the 68 organisations providing information about Informed Choice DNARs, almost three-quarters (50 organisations; 74%) said that numbers of these were similar since the start of 2020.

Of the rest, more organisations (11 organisations; 16%) said that Informed Choice DNARs had increased since the start of 2020 compared to organisations saying that Informed Choice DNARs had decreased since the start of 2020 (7 organisations; 10%).

“We became aware of the guidance from NICE and from NHS Chiefs, specifically around not using the Clinical Frailty Scale or DNACPR on people with learning disabilities, Down's Syndrome and autism. We didn't trust that that information would reach the frontline paramedics/first responders so attached a very assertive letter to everyone's hospital passports, with an injunction to staff to ensure they drew healthcare staff's attention to it. So we have acted preventatively.

What I would say is that the issue is about blanket DNR but it is also about adverse triage: decisions not to take people to hospital, decisions not to escalate treatment which are equally if not more worrying for the people we support.”

Q2 Blanket Applications:

64 organisations provided information about Blanket Application DNARs, with half of them (32 organisations; 50%) saying that numbers of these were similar since the start of 2020.

Over a quarter of responding organisations (18 organisations; 28%) said that Blanket Application DNARs had increased since the start of 2020.

Around one in six organisations (11 organisations; 17%) said that Blanket Application DNARs had decreased since the start of 2020.

“People who would usually be admitted to hospital told that they would not receive ICU support or ventilation. These were people with no underlying health conditions.”

Q2. DNAR Notice came to light in Medical Records:

63 organisations provided information about DNARs being attached to people’s medical records apparently without consultation with the person or their representatives.

Most responding organisations (38 organisations; 60%) said that numbers of these were similar since the start of 2020.

Almost a quarter of organisations (16 organisations; 22%) said that DNARs found in medical records had increased since the start of 2020.

Around one in six organisations (11 organisations; 17%) said that these DNARs had decreased since the start of 2020.

“A DNAR was put in place for a gentleman on admission to A&E by the consultant attending him. On questioning the reason for this and confirming that no best interest decision making process had been followed (family, support staff and care manager were not involved) the DNAR was rescinded by a doctor on ward where he was subsequently admitted.”

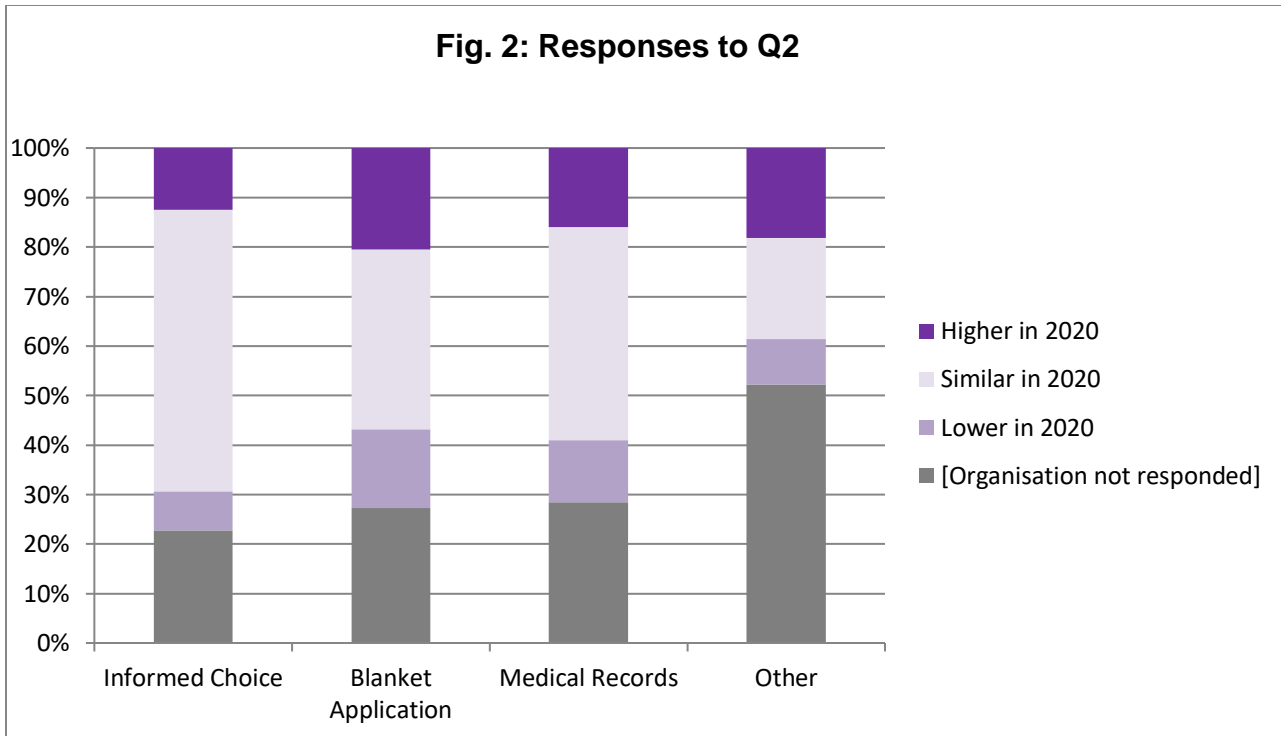
Q2. Other circumstances:

42 organisations provided information on the use of DNARs in other circumstances.

Less than half of responding organisations said that DNARs in other circumstances were occurring at a similar level since the start of 2020 (18 organisations; 43%).

Over a third said that DNARs in other circumstances had increased since the start of 2020 (16 organisations; 38%), and almost one in five (8 organisations; 19%) said that DNARs in other organisations had decreased since the start of 2020.

“Individual lacking capacity but paid carers being told in place until after decision made but in one case the family were informed but did not fully appreciate its meaning - in two of the three cases this was challenged and later removed as the individual had not been diagnosed and recovered with no long term effects.”



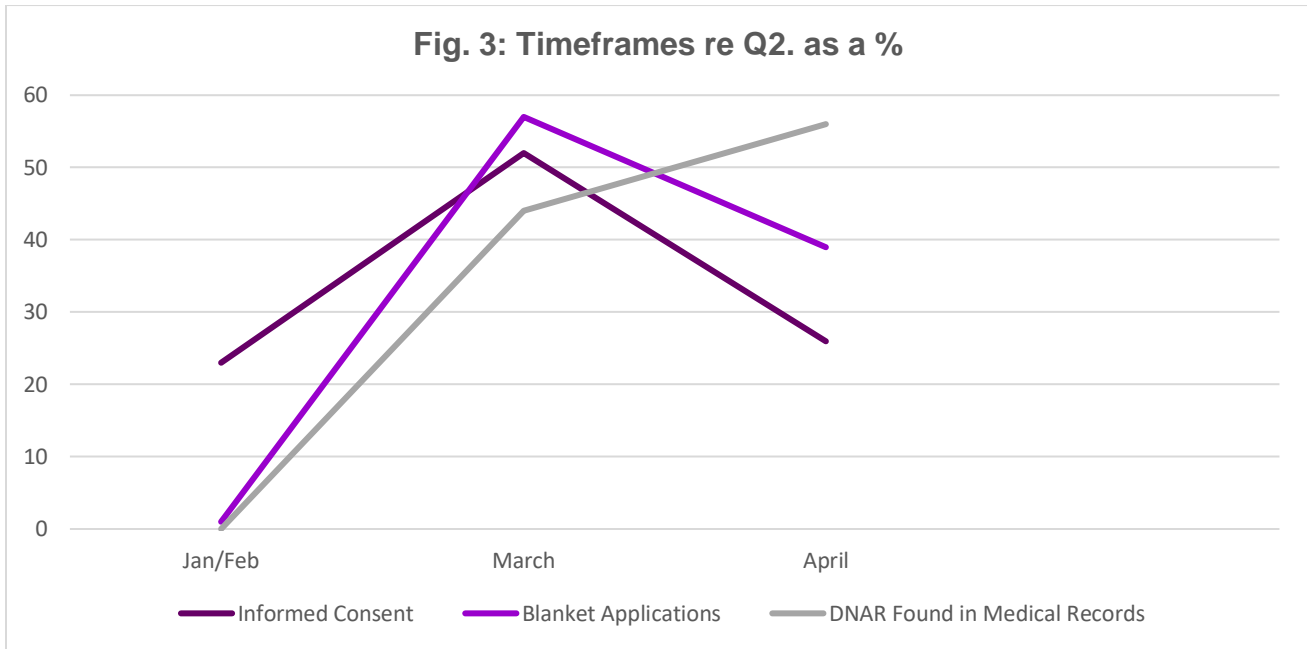
As part of question 2, we also asked organisations **when** they had seen any changes. The results were as follows:

For DNARs involving informed consent, just over half of the organisations responding to this question said that changes had happened in March (16 organisations; 52%), with fewer in January-February (7 organisations; 23%) or April (8 organisations; 26%).

For DNARs involving blanket applications, most organisations responding to this question said that these changes had happened in March (13 organisations; 57%), with one organisation reporting this in January-February (1 organisation; 4%) and almost two-fifths of organisations reporting this happening in April (39%).

For DNARs found in medical records apparently happening without consultation, no organisations responding to the question reported this happening in January-February, almost half of organisations reported this happening in March (8 organisations; 44%) and most organisations reported this happening in April (10 organisations; 56%).

Fig. 3: Timeframes re Q2. as a %



Conclusion

Not surprisingly, given the threat from the virus, more attention is being paid to DNARs.

We are clear that DNAR Notices are, in themselves, not wrong. We do not want people to be afraid of having discussions about advance care planning and DNAR, or of making the choice that is right for them.

However, despite clear guidance that placing Do Not Attempt Resuscitation Notices (DNARs) on an individual's notes without consent is wrong, Learning Disability England's survey of our member organisations indicates that since the start of the Coronavirus crisis there has been some increased use of DNAR notices in the notes of people with learning disabilities without consultation with the person concerned, or the people who care about them.

The picture is nuanced, and it should be noted that our survey found that approximately two thirds of respondents did not report an increase in DNARs.

However, there are clear indications of the continued potentially illegal use of DNARs since the start of the Coronavirus crisis in March in a number of cases and scenarios. In addition, there are circumstances reported to us where medical staff have made a clinical decision whilst an individual was critically ill without reference to the individual, their advocate, family or wider circle of support.

Despite the [letter from senior NHS leaders to all NHS organisations](#) reiterating clearly that blanket use of DNARs are unacceptable and [the statements from the Royal Colleges, regulator and sector bodies reiterating this](#), 13 member organisations reported that they had seen an increase in blanket DNARs in March and April.

8 organisations had seen DNARs placed in people's records without consultation in March, and despite the publicity and clear guidance, 10 reported this happening in April.

As a direct result of the survey findings, Learning Disability England is now working with some members on additional resources that can support people to challenge poor processes or unlawful use of DNARs.

“We have seen an increase in people being admitted to hospital and DNACPR being used without consulting the person or their carers, or sometimes where the only person consulted is a relative who has minimal contact with the person and therefore does not know them well.

This has happened before corona virus and has continued - we have seen more people come home from hospital with DNACPR in place without our knowledge or evidence of a best interest process.

The respect process has been beneficial in having these conversations and supporting people to make plans for future care.”

The message is clear: that every individual with a learning disability, their family and loved ones and the organisations that support them should remain vigilant, have conversations about the individual’s wishes and preferences around treatment and DNAR, ensure these wishes are clearly documented. Any attempt to impose a DNAR without proper consultation and where necessary, a Best Interest process being followed, should be challenged.

#WeMustAllBeVigilant

Professor Chris Hatton supported the survey and analysis. Thank you to him for sharing his expertise and giving time and knowledge.

With thanks to everyone who contributed to the survey and the findings in this report.

Appendix:

Full Record of All Comments

Below is a complete list of comment from responding organisations.

Comments potentially leading to the identification of an individual have been removed.

“The conversations have been seen in the press but this has not occurred in my division.”

“Blanket applications initiated by GP's but soon dispelled with discussion when they realised it was inappropriate.”

“We have not been made aware that any of our members have been sent anything regarding DNAR. Many are currently with their family so we may just not have been told.”

“Blanket re-assessment from GP practice of all LD patients. Use of frailty scales to justify DNAR in a case of two people with LD but no significant underlying health issues.”

“We have seen an increase in people being admitted to hospital and DNACPR being used without consulting the person or their carers, or sometimes where the only person consulted is a relative who has minimal contact with the person and therefore does not know them well.

This has happened before corona virus and has continued - we have seen more people come home from hospital with DNACPR in place without our knowledge or evidence of a best interest process. The respect process has been beneficial

in having these conversations and supporting people to make plans for future care.”

“Specifically since the beginning of the Covid 19 pandemic. The Issues appear to have centred around the people we support who have or who are likely to soon have a diagnosis of cancer. There has been a decision made and communicated by phone by a GP to halt diagnostic testing and an assumption of a positive diagnosis has been made and in only one example an explanation given by letter of why this person could not have surgery and then a DNAR has been proposed and Palliative care team input has been offered, even when it has already been in place.

When managers have pushed back , NoK contact details have been asked for and then we have received calls informing us by families indicating a certain pressure being brought to bear and 'medical opinion' being used as the reason why the DNAR has been put in place.

Where we or families have pushed back the DNAR has been removed or changed with alarming speed. Which begs the question how robust it was in the first place if it can be removed so quickly.

We have seen a DNAR notice that was produced from 2018 with the words 'severe learning disabilities' written on it as one of the reasons, one was 'frailty' the other was illegible. it was noted by one manger that the conversation was centred on the likelihood of the individual surviving Covid 19 and then the DNAR which came through cited Cancer.”

“Non-blanket DNARs that have been made by acute hospital staff without involvement of the patient, their families/advocates or their usual care team/circle of support/CLDT.”

“Our client base is Mental Health and Learning disability. We are unaware of any one having a DNR notice as are our Service users.”

“Individual lacking capacity but paid carers being told in place until after decision made, but in one case the family were informed but did not fully appreciate its meaning - in two of the three cases this was challenged and later removed as the individual had not been diagnosed and recovered with no long term effects.”

“Where the DNAR don't meet the Equalities Act e.g. providing learning disabilities as a reason for the decision.”

“A support worker was asked whether a DNAR notice should be put on a person's records, without consultation/MCA test/Best Interests discussions with other professionals. Worrying trend of bypassing individuals without following correct processes.”

“GP's are asking provider services for TEP's and provider services are coming to CTPLD for guidance. Guidance given is that people with a learning disability should receive the same consideration for treatment of Covid-19 as everyone else. TEP's are being completed with guidance for reasonable adjustments to be made.”

“Discussions held with NOK and decisions made, without following a best interest pathway.”

“I have heard that one practice did all of one home, however this wasn't something I was directly involved with I just heard it via a third party.”

“We've been asked to contribute to more TEP plans but haven't seen any increase in DNAR.”

“Higher number of DNARs being used due to COVID situation - sometimes being inappropriately applied.”

“Documenting Learning Disability as a reason not to resus.”

“No DNAR has been put on our clients.”

“I have no awareness of any changes made to any DNAR notices for service users that my team supports.”

“None received and no changes.”

“I have no awareness that anyone has had a blanket or individual DNAR put in place. As a team we have discussed that if we did find out about this I would be prepared to challenge it and support the person’s rights and choices.”

“We are not aware of any changes.”

“We wrote to the individuals’ doctors to inform that the individuals did not have a DNAR in place and we would not be making that decision for them.”

“I cannot comment as any issues with DNAR's have not yet been raised with me as an issue among the patients’ placements I commission.”

“The tenants of 2 flats were sent a blanket letter from their GP to advise that due to Covid -19 all tenants would need to be put on a DNAR, they are all adults with learning disabilities with no need to have DNAR's in place.”

“We have not had any communication in this regard. We have had conversations with some service users and their families in order to update their end of life care plan- it has so far not involved a DNAR. No medical professional has been in touch in this regard. We have been asked to complete grab sheets, so hospitals are prepared when a service user is admitted - something we all welcome.”

“No changes noticed to service users' records (to date).”

“Had a couple at the start of lockdown but none since.”

“Still seeing DNACPR in place without the appropriate people being involved. Not Using MCA OR IBM.”

“A DNAR was put in place for a gentleman on admission to A&E by the consultant attending him. On questioning the reason for this and confirming that no best interest decision making process had been followed (family, support staff and care manager were not involved) the DNAR was rescinded by a doctor on ward where he was subsequently admitted.”

“We have not received any notices or contact from GPs in relation to DNAR's as an organisation since the start of 2020.”

“This hasn't happened at all for any of the people [organisation] supports.”

“Pandemic - Communication between NHS and Care services has deteriorated , DNAR attached to discharge, communication re this with family members not clear, they did not know what they were agreeing to.”

“We have Four PMLD people we support. NO blanket DNR/DNAR or any such thing been spoken about at this time. We do support one person that already has a DNR in place. No changes to the three others residing here. No admittances to Hospital or call outs for any illnesses at this time, so this may change.”

“I think our view is that this has always happened it is just under the spotlight now through coronavirus. We know through ‘Leder’ that the lives of people with a learning disability are not valued as much as others so in a pandemic this DNACPR issue was inevitable.

Hopefully now it is irrefutable. It’s not about whether learning disability is cited on the DNACPR, although that is unforgivable, it is about learning disability being part of a value judgment when a DNACPR decision is made.”

“No impression gained.”

“People who would usually be admitted to hospital told that they would not receive ICU support or ventilation. These were people with no underlying health conditions.”

“We have not seen or noticed any changes so far.”

“Template conversation opening letters used by some health teams have led to a perception of a blanket policy but the intent of the letter was to commence a dialogue about wishes and views should illness become sudden and severe.”

“We became aware of the guidance from NICE and from NHS Chiefs, specifically around not using the Clinical Frailty Scale or DNACPR on people with learning disabilities, Down's Syndrome and autism.

We didn't trust that that information would reach the frontline paramedics/first responders so attached a very assertive letter to everyone's hospital passports, with an injunction to staff to ensure they drew healthcare staff's attention to it. So we have acted preventatively.

What I would say is that the issue is about blanket DNR but it is also about adverse triage: decisions not to take people to hospital, decisions not to escalate treatment which are equally if not more worrying for the people we support.”