

“People with lived experience have to be at the heart of this.”

DNACPR



A letter to the Ministerial Oversight Group on Do Not Attempt Cardiopulmonary Resuscitation



We are the Stop People Dying Too Young group. We are a group of self advocates and family carers working in the North East on Leder – the learning from lives and death programme. We represent the interests of people with a learning disability, autistic people, and families.



We have joined together with groups representing older people and people with dementia, all speaking from lived experience.



Together we have a wealth of experience of working at a high level on a huge range of health and social care issues, as well as around people’s rights and having a voice.

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We are the experts on the reasons why some groups of people were discriminated against during Covid around how Do Not Resuscitate was used. We are at the heart of what is going on and it affects us directly.



For example, 82% of people with a learning disability who died of Covid had a Do Not Resuscitate decision, But only 69% of these Do Not Resuscitate decisions were done correctly.



This is a shocking failure. Unless we are present around the table poor practice like this will keep happening and will not be challenged strongly enough.



People with the relevant lived experience should have been involved in your work right from the start. We know where the problems are and have the ideas for the solutions.



Your Terms of Reference from May 2021 say you will work with other stakeholders, but this is very vague.



It is far from our vision of you including people with lived experience as equal partners in the work of the Ministerial Oversight Group.



We want to be involved in both acting on the Care Quality Commission recommendations and the decision making.



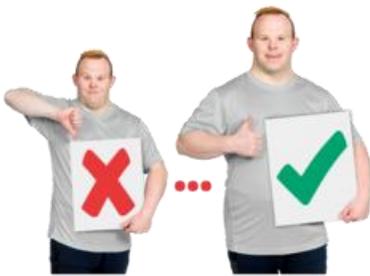
During Covid, decisions were made for people with a learning disability, older people and people with dementia without involving them and their families.



If your group is serious about making changes you have to start by listening to people's experiences.



It is not good enough to have a group set up without any representation of the people who are affected directly by this.



Your Terms of Reference say that membership of the group can be revised. We want you to change it to include people with lived experience.



For too long, people with lived experience who are most affected by health inequalities have had little or no influence.



The way your group has been set up seems like yet another example of this.



Unless we are involved as full group members, nothing will happen to make a big enough difference to our lives.



It is both common sense and the right thing to do to work closely with people with lived experience.



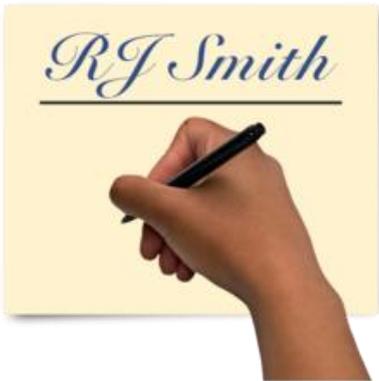
Otherwise things will continue to be done to people, rather than in partnership with them.



We are asking for real involvement, where you recognise the expertise we bring as being equal to your own professional experience.



We look forward to hearing back from you about how you intend to put people's lived experience at the very centre of this work.



Signed:

Stop People Dying Too Young Group



Inclusion North



Learning Disability England



British Institute of Human Rights



Difference North East