

“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.



Black, Asian and Minority Ethnic people were less likely to know that a Do Not Resuscitate decision had existed for them.



These are shocking failures. 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.



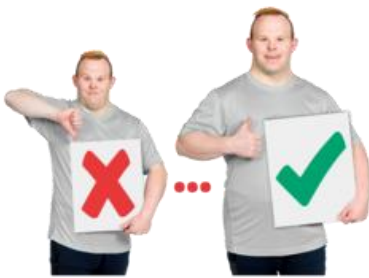
During Covid, decisions were made for people with a learning disability, older people and people with dementia without involving them and their families.



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

All these organisations have signed to support this letter

Ace Anglia	Connected Voice	NWTDT Pathways Associates
Active Prospects	Darlington Association On Disability	Oxfordshire Family Support Network
Advance UK	DIAL/Disability Peterborough	People First Dorset
Advonet	Dimensions	People First Keighley & Craven
Asian Peoples Disability Alliance	Disability Information Bureau	Positive support for you
Bemix	Disability Positive	Progress Group
BEST	Disability Rights UK	Seeability
Better Days	Encompass	Shaping our Lives
Books beyond words	Essex Carers Network	Shared Lives Plus
Border Links	Fairoak Housing	Silver Line Memories
Born at the Right Time	Liberation	Sheffield Voices
Brighton and Hove Speak Out	Generate	Skills for People
BRIL	GraceEyre	Speakup Rotherham
BTM	Greater Manchester Disabled Peoples Panel	Sunderland People First
Building Bridges Training	Imagine Act and Succeed	Support'ed Limited
Calderdale Self Advocacy Network	Inclusion East CIC	Talkback
Campaign 4 change	Inclusion Gloucestershire	The Challenging Behaviour Foundation
Centre 404	Inclusion London	The Surrey People's Group Active Prospects
Centre for Welfare Reform	Keyring	Together Matters
CHAD	Kingston Mencap Carers Group	Turning Point
Chair of BILD	L'Arche	Under the Stars
Changing our lives	Lewisham Speaking Up	Vonne
Choice Support	MacIntyre	Voyage Care
Citizen Network	Mencap Wirral	Walls and Futures
Clasp Wokingham	My Life My Choice	Walshingham
Cloverleaf	My Safe Home	
Community Catalysts	New Prospects	

All these people have signed to support this letter

Adam Butcher	Chris Hilliard	Helen Swift
Adam Jager	Chris Sterry	Ian Middleton
Ali Hayward	Christine	Ian Penfold
Alison Tupling	Christine-Koulla Burke	Ian Saliba-Curtis
Amy Telford	Claire Lee	Isabelle Garnett
Andrew Cowe	Claire Webster	Ivan Olbrechts
Andrew Fox	Clare Thompson	Jacqueline Hughes
Andrew Reece	Clive Parry	James O'Rourke
Andy Merker	Darren Lee	Jane Peters
Angela Black	David Barraclough	Jane Phipp-MacIntyre
Angela Crocker	Debra Harrison	Janice Mclaughlin
Anne Grange	Denise Bowles	Jill Short
Annie Smith	Derek Benn	Jo Harrison
Anusha Everson	Dr Alison M Clark	Jo Hough
Autumn Roesch-Marsh	Dr Joel Parker	Jo Varela
Barbara Booton	Dr Liz Ellis	Joanne McGeachin
Barbara Thompson	Dr Lucy Burke	Jodie Williams
Becki Parker	Elham Ahmed	Jude Gwynn
Beth Kyte	Elizabeth Harding	Judith Griffiths
Beverley Dawkins	Elmi Terjavjainena	Judith McGarty
Beverley Flute	Elyzabeth Hawkes	Karen Burrows
Carolyn Granthier	Emily Clixby	Karen Griffiths
Cate Macdonald	Fiona Duncan	Karen Jackson
Cathy Mellstrom	Heather Davison	Karen Parry
Charles Edwards	Helen Justice	Karen Tait
Chris Hatton	Helen Phoenix	Katherine Runswick-Cole

Kathryn Littlewood	Madeleine Johnson	Peter Bangs
Katie Peacock	Margaret Nicol	Peter Loose
Katrina Morrison	Marie Rhodes	Philipa Bragman
Kay Kirk	Mark Hamblin	Philippa Willitts
Kellie Woodley	Mary Bottomley	Rachael Munro-Fawcett
Kemi L	Matt Howard	Rachael West
Kerry Kilvington	Matthew Moon	Rachel Curtis
Kirsty Morgan	Matthew Prothero	Rachel Wright
Konnor Hoad	Melanie Holford	Rebecca Cole
Lara Bywater	Melanie Rimmer	Robert McLean
Laura	Melissa Peacock	Ros Cheetham
Lauran Doak	Melvyn & Jan John	Rose Matthews
Lauren Baynes	Michelle	Ruth Clatworthy
Layla Hughes	Mike O'Brien	S. Gibbons
Lee Bottomley	Mike Steel	Sally Hoban
Linda Dickinson	Moira McLoughlin	Sam Browning
Lindsey	Muniru Azeez	Samantha Clark
Lisa Clark	Neil Pattinson	Samantha Jamieson
Liz Croot	Nic Cook	Sandra A Marshall
Liz Howard	Nick Ball	Sara Kent
Lloyd Samuels	O. Popoola	Sara Ryan
Lorraine Temple	Pat Duffield	Sarah Fowler
Louise Fullerton	Pat Elsmie	Sarah Wilkinson
Lynda Armstrong	Patricia Charlesworth	Sarah Wyatt
Lynda Teagle	Patricia Hill	Scott Bartle
Lynsey Hunt	Patsy Corcoran	Shabaaz Mohammed

