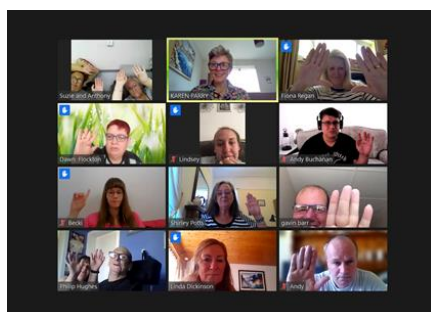


“People with lived experience have to be at the heart of this.”

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.

DNACPR



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.



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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

Organisations who have signed the letter are

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	Skills for People
Brighton and Hove Speak Out	Generate	Speakup Rotherham
BRIL	GraceEyre	Sunderland People First
BTM	Greater Manchester Disabled Peoples Panel	Support'ed Limited
Building Bridges Training	Imagine Act and Succeed	Talkback
Calderdale Self Advocacy Network	Inclusion East CIC	The Challenging Behaviour Foundation
Campaign 4 change	Inclusion Gloucestershire	The Surrey People's Group Active Prospects
Centre 404	Inclusion London	Together Matters
Centre for Welfare Reform	Keyring	Turning Point
CHAD	Kingston Mencap Carers Group	Under the Stars
Chair of BILD	L'Arche	Vonne
Changing our lives	Lewisham Speaking Up	Voyage Care
Choice Support	MacIntyre	Walls and Futures
Citizen Network	Mencap Wirral	Walshingham
Clasp Wokingham	My Life My Choice	
Cloverleaf	My Safe Home	
Community Catalysts	New Prospects	

People who have signed the letter are

Ian Penfold

Jo Hough

Katie Peacock

Mark Hamblin

Matt Howard

Melanie Rimmer

Patricia Charlesworth

Peter Loose

Rachel Wright

Ruth Clatworthy

Sara Kent

Shabaaz Mohammed

Sharon Wood

Sue Rzepczynski