An Easy Read report about a Zoom meeting held on 5 June 2020 with families shielding from coronavirus



June 5





NHS England and NHS Improvement

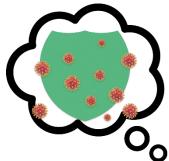


Introduction

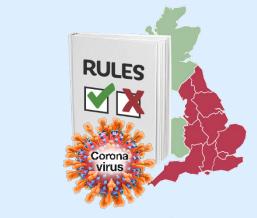
NHS England and NHS Improvement



NHS England and NHS
Improvement worked with
an organisation called
Bringing Us Together



to find out what families felt about having to **shield** during **lockdown**.



Lockdown is when everyone in the UK follows rules about **coronavirus**.



Shielding guidelines help to protect very vulnerable people who could get very ill if they catch **coronavirus**.



They spoke to a group of **twenty-four people**





on 5 June 2020.



All comments made at the meeting were private.



Most of the group were family members **shielding** others in their family.



They had to stay at home to protect vulnerable members of their family from **coronavirus**.



Some of the group were vulnerable people so had to **shield** themselves.



Everyone said that they found shielding was very difficult during lockdown.



The group was asked:

- What was most difficult?
- What worked well?
- What would you like to happen in the future?



This **Easy Read report** tells you what the group talked about on Zoom.



We have been forgotten

7



Seven family members said: "We have been forgotten."



The group talked about this issue the most.



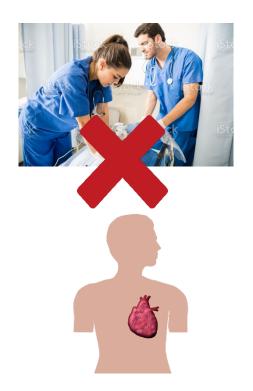
"When I watch the government meetings on the TV no-one talks about us."



"Are other families worried?"



"We are getting less protection and we have to do our own thing."



We feel scared that our loved ones will not be resuscitated.

Resuscitation is when someone tries to make your heart start again if it stops.



People said they do not trust the **government**.



People told us about the National Institute for Health and Care Excellence or NICE.



NICE is part of the Department of Health. It checks medication and gives medical advice.



NICE made a link between someone being **frail** and catching **coronavirus**.



Someone is **frail** when they are weak or unwell.



When the families heard this, they were scared that their loved ones could get very ill from **coronavirus**.



And that they would not be **resuscitated** and die.



One of the group members said:

"It was not about protecting people it was about deciding who would die."



The messages and the language was not clear



People in the group said:

 advice about shielding changed too many times



 information was not easy to understand



we do not like the word vulnerable





 shielding families were missed out of all the important information.



"The government said we could go out."

But when I asked my GP he said: "**Do not** go out."



"Social services do more to support people with a learning disability than anyone else."



"They do important work like the **NHS**, but **social services** is not thought of in the same way."



"My daughter did not understand the **shielding** letter. She was very upset that night after she read it."



We are family



People understood:

 that they had to protect some family members



 other family members found **shielding** difficult because they could not go out



"I came home from university to support my family. But what do I do next?



There is no information for young people."



"My daughter cannot go back to school because someone in her family is **shielding**.



This means she cannot see her friends."



Our wellbeing and mental health

This is what people said about their **mental health** and **wellbeing**.



"I am a parent of a young adult with serious health problems.



Is it more important to be safe at home or go out where it is less safe?"



"I am depressed and very angry. But do not know what to do with my anger."



Should we stay safe or take risks?



Families said it was difficult to take risks **and** have a good quality of life.



"My son may only live for another **3 years**. It would be awful if he could not enjoy the rest of his life."



"My daughter is very ill and the longer we shield her the more difficult it gets and she gets more lonely."



"When she gets paid support after a long break, she may not get on with her support worker like she used to."



No-one asked us about ending lockdown



Families said there was a plan for the rest of the country, but they felt left out of this plan.



"There was no warning. Shielding families were just told that lockdown was ending."



"No one talked to us first. We were just told we could **go out**.



And others could have barbecues."



Getting the right support

For many families getting the right **support** was difficult.



Lockdown made it even more difficult.



"It was very difficult to get support for my **disabled child**."



"I was told I could not go **shopping** during quiet times as this was for **NHS** workers and carers.



My ID was not enough, so I got **no support**."



Getting healthcare

Families found it difficult to get **healthcare**



and they were worried about the health of their family members that were **shielding**.



"My daughter has serious **cerebal palsy**.

Her hips are very painful as she is not getting support."



"My son needs a lot of support when he is out.



If he had to go to hospital, I'm worried he would be given **too much medication** so that they could cope."



We worry about the future



Lots of people were very worried about what life will be like after **coronavirus**.



"Their life is all about **going** out every day.

Will we still be able to go out and keep them safe and healthy?"



"It was difficult to get support for him until he was **18 years old**.



"We would like him to **live independently**. Right now we cannot do anything to get a house for him.



What will his **future** look like?"



What has been good?



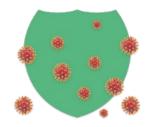
The families we spoke to had some **good things** to say about **shielding**.



"We had an **online health check with a GP**. It was very good. They asked a lot of useful questions.



After the **health check** we went out for the first time and got a **blood test** at a surgery for shielding patients."



"The children's hospice was very good. We felt **safe** there as they knew why we were **shielding**.



"School is now open for **1 day** a week.



It was great to see **how happy he was** when he saw
people he knows. The school
should have opened much
sooner."



What next?





Two **reports** were sent to:



Department of Health & Social Care

 Department of Health and Social Care



 Ministry of Housing, Communities and Local Government



The reports helped to change **Government guidance** that came out



at the end of June.

160



So far **over one hundred and sixty people** have taken part in the groups:



younger people



• Black And Minority Ethnic people



Minority ethnic groups are people from different cultures.



 people with high support needs who are shielding



 people with a learning disability and autistic people



• parents, carers and families



people with health problems.



People from the groups said: "I think if the public understood **shielding** they might behave differently."



"People should find out more about **shielding** and respect people who are **shielding**."



"We are all the same, if we are **shielding** or not.



When people do not social distance it makes a big difference to people who are **shielding**."



Thank you to everyone who took part in the groups set up by the organisation called **Bringing Us Together**.

Contact details?