

ADDING DOWN'S SYNDROME TO THE CLINICALLY EXTREMELY VULNERABLE CONDITIONS LIST

Frequently Asked Questions

- **What has been decided?**

A decision has been made to include all adults who have Down's syndrome in the group of people who are considered to be clinically extremely vulnerable. This is the group who were previously advised to shield.

- **What does clinically extremely vulnerable mean?**

A person who is clinically extremely vulnerable has the highest risk of a more serious outcome if they catch COVID-19. It means they need to take extra care compared to other people, to avoid getting COVID-19.

- **What is the clinically extremely vulnerable conditions list?**

Early in the pandemic, the government made a decision to try to protect those individuals thought to be at greatest risk of severe COVID-19 outcomes.

A list was put together using advice from the UK Chief Medical Officers on which medical conditions meant people faced the highest risk. This list is updated as we learn more about COVID-19 and who is most affected.

- **Why has this been decided now? What has changed?**

We now have more information to show who is most at risk of becoming very unwell or dying from COVID-19, than we did at the start of the pandemic. This is based on what actually happened to people with COVID-19 in the UK between January and June.

We now have information that adults who have Down's syndrome are at a higher risk of severe outcomes from COVID-19. As with all groups, the older you are the higher your risk of becoming seriously unwell.

- **How do you know that people with Down's Syndrome are at high risk?**

Researchers have developed a tool that estimates a person's risk of being admitted to hospital and of dying from COVID-19 based on information about the person such as their age, gender, ethnic group or whether they have long standing illnesses.

The tool considers a wide range of features that research shows could mean a person was at greater risk. It includes whether a person had Down's syndrome -

The tool shows that most adults who have Down's syndrome are at a greater risk.

- **What information was used in this tool?**

We have looked at the information in medical records from 1,205 GP practices, which included over 8 million adults. This information records a wide range of information about people and the health services that they use. We removed all the patient identifiable information (like name, address, date of birth) from them first to protect people's privacy.

These records were then matched against other data like positive COVID-19 test results and information about people who went to hospital or who died so that we could see which health conditions had the highest risks of more serious outcomes.

- **How was this data analysed?**

We looked at other factors in this data, such as whether they had existing conditions, to see if they increased the risk of a person becoming seriously unwell or dying from COVID-19. The tool showed that even when we take account of other factors, people who have Down's syndrome would have a higher risk of becoming more seriously ill or dying from COVID-19.

- **Who decided to add people with Down's Syndrome to the clinically extremely vulnerable group?**

In September, the UK Chief Medical Officers (CMOs) reviewed the new information which showed that most adults with Down's Syndrome were at a higher risk amongst the population. Therefore, the UK CMOs decided that people who have Down's syndrome should be added to the clinically extremely vulnerable group.

- **Does it apply to everyone who has a Learning Disability?**

No. We are only adding people who have Down's syndrome to the clinically extremely vulnerable group.

We don't think that a learning disability (except where a person also has Down's syndrome) by itself is a significant risk factor however, many people with a learning disability are more likely to have other health conditions (such as diabetes) that could put them at risk of becoming very unwell or dying from COVID-19. As we learn more about COVID-19 we will keep the list of conditions in the clinically extremely vulnerable group under review.

- **Where can I find out more about the tool and research that used to make this decision?**

The research "Living risk prediction algorithm (QCOVID) for risk of hospital admission and mortality from Coronavirus-19 in adults: national derivation and validation cohort study" has been published in the British Medical Journal. You can find it here:

<https://www.bmj.com/content/371/bmj.m3731>

- **Why is this different to the findings of the other research which shows that older adults face the highest risk?**

It is likely to be the case that older people who have Down's syndrome face the highest risks. However, the tool showed that compared to other people of the same age and sex, adults who have Down's syndrome are more at risk.

- **Why is this for adults only?**

As our knowledge of COVID-19 has grown, we now know that very few children are at highest risk of severe illness due to the virus, even those with other health conditions. Using the information on COVID-19 and outcomes for people who have had it, we haven't found evidence that children who have Down's syndrome are at higher risk than other children.

- **Where can I find out more?**

There is information about what to do if you are in clinically extremely vulnerable group on the government's website: <https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19>