WOLFRAM SYNDROME UK

Wolfram syndrome UK

Wolfram community webinar

Short update on Covid, vaccines, and lockdown guidance

Welcome

- **Prof. Tim Barrett**
- Professor of Paediatric Endocrinology, AS Paediatric Clinical Lead,
  Birmingham Women's and Children's NHS Foundation Trust

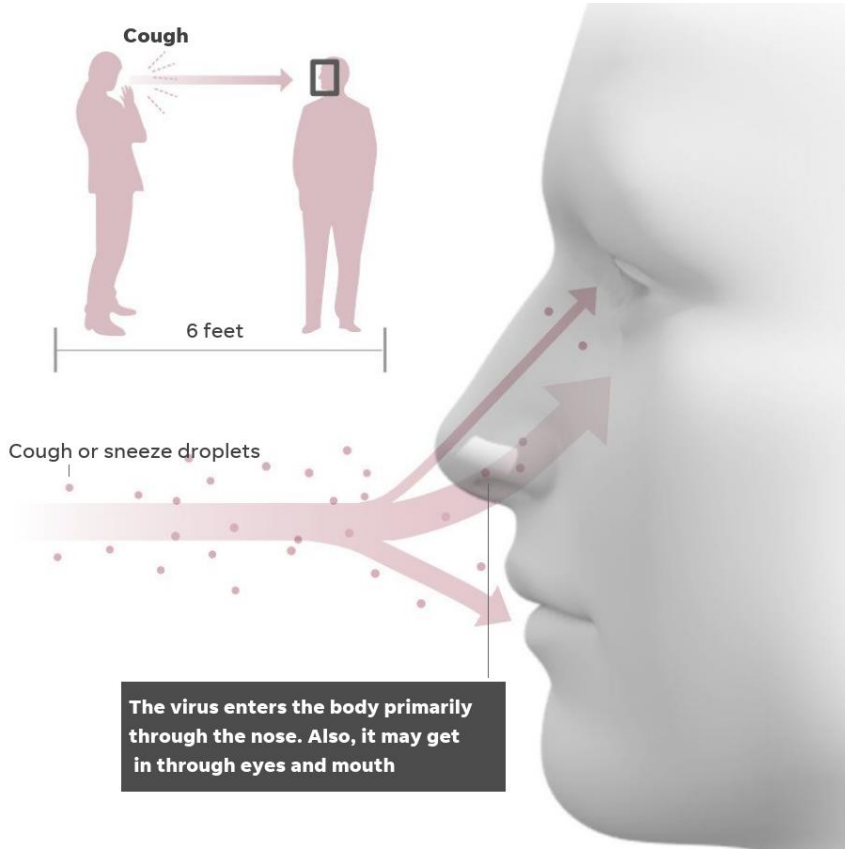
WSUK Team

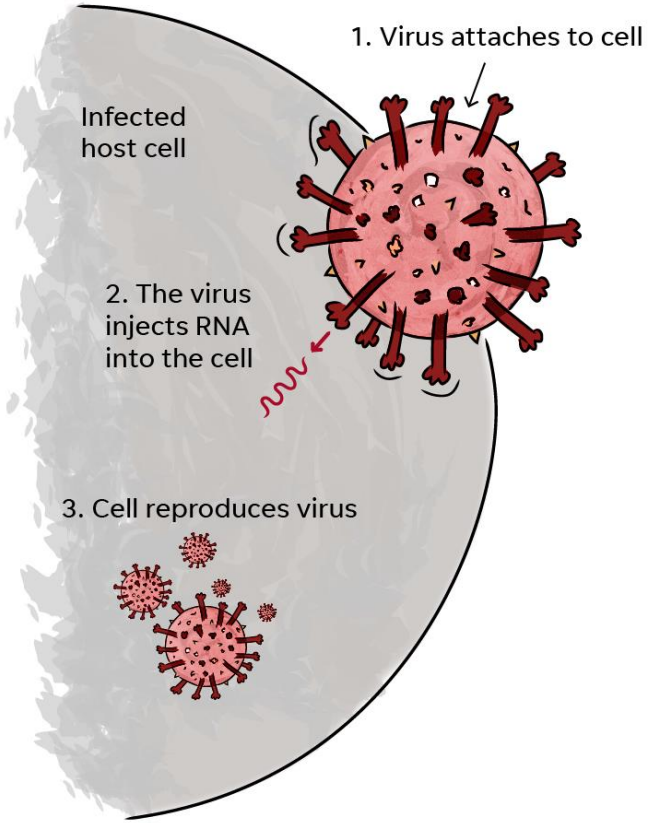
With thanks to colleagues in Alstrom Syndrome UK, Bardet Biedl Syndrome UK

Quick background to Covid-19 virus

Vast majority of infections transmitted via droplets

New variants make the virus particles better at attaching to nose and lung cells





Quick update on Covid-19 infections in children

Royal College of Paediatrics and Child Health evidence summaries www.rcpch.ac.uk

- There are far fewer children with Covid disease than adults (children make up about 20% of UK population but only 1-2% of people with Covid disease)
- Covid infection is milder in children than in adults. Most children develop mild or no symptoms. Less than 1 in every 100 children with Covid disease develop severe or life-threatening disease
- Children make a much better antibody response to the Coronavirus family of viruses (that includes the common cold and Covid-19) than adults.
- Deaths in children due to Covid-19 have been extremely rare: mortality 0.01-0.1% (1 in every 10,000 children with Covid disease to 1 in 1,000 children with Covid disease). This compares to at least 6 in every 100 children who have a rare disease

New Public Health England study Jan 14th 2021- relates to adults who have had a Covid infection

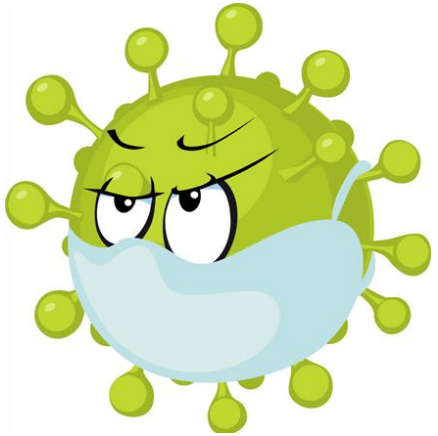
- SIREN study- been regularly testing tens of thousands of health care workers since June 2020 for new Covid-19 infections, and for antibodies which suggest past infections
- Between 18 June and 24 Nov, identified 44 possible reinfections out of 6614 participants who had tested positive for antibodies. Those reinfections were less severe than first time around.
- This suggests people who have had Covid, have over 80% protection from reinfection.
- However, some people who have had Covid, continue to carry the virus and can transmit it to others
- So if you have already had Covid, it is very unlikely you will have a severe infection if you get infected again; BUT you could still transmit it to others- so must carry on with HANDS FACE SPACE
- No information yet on how long Vaccine protection lasts

Government Guidance

People who are clinically extremely vulnerable and are being asked to shield:

These are:

- ❖ if they have received an organ transplant
- ❖ if they are on immunosuppressant medication
- ❖ if your child is undergoing cancer treatment
- ❖ those affected by severe asthma or chest infections
- ❖ those with severe disease such as severe kidney disease.



Government Guidance

If you are classed as extremely clinically vulnerable:

You must not leave, or be outside of your home except where necessary.

Shops and Pharmacies
Try to get someone to collect your shopping/medicines for you or use online services.
The **NHS Volunteer Service** may be able to help with this
https://nhsvolunteerresponders.org.uk/

Exercise
Only with your household (or support bubble), this should be limited to once per day, and you should not travel outside your local area.

Medical Assistance
It is important to seek medical assistance when needed to avoid injury, illness or risk of harm (including domestic abuse).

Government Guidance

Remember Hand. Face. Space

- Hands – wash your hands regularly and for at least 20 seconds.
- Face – wear a face covering in indoor settings where social distancing may be difficult, and where you will come into contact with people you do not normally meet.
- Space – stay 2 metres apart from people you do not live with where possible, or 1 metre with extra precautions in place (such as wearing face coverings).

Vitamin D

FREE 4-month supply of vitamin D supplements for all adults who are clinically extremely vulnerable to support general health.

During autumn and winter, everyone is advised to take vitamin D to keep their bones and muscles healthy and to support their general health.

This is particularly important if you've been indoors over the spring and summer as you may not have been getting enough vitamin D from sunlight.

Apply **https://www.nhs.uk/get-vitamin-d**

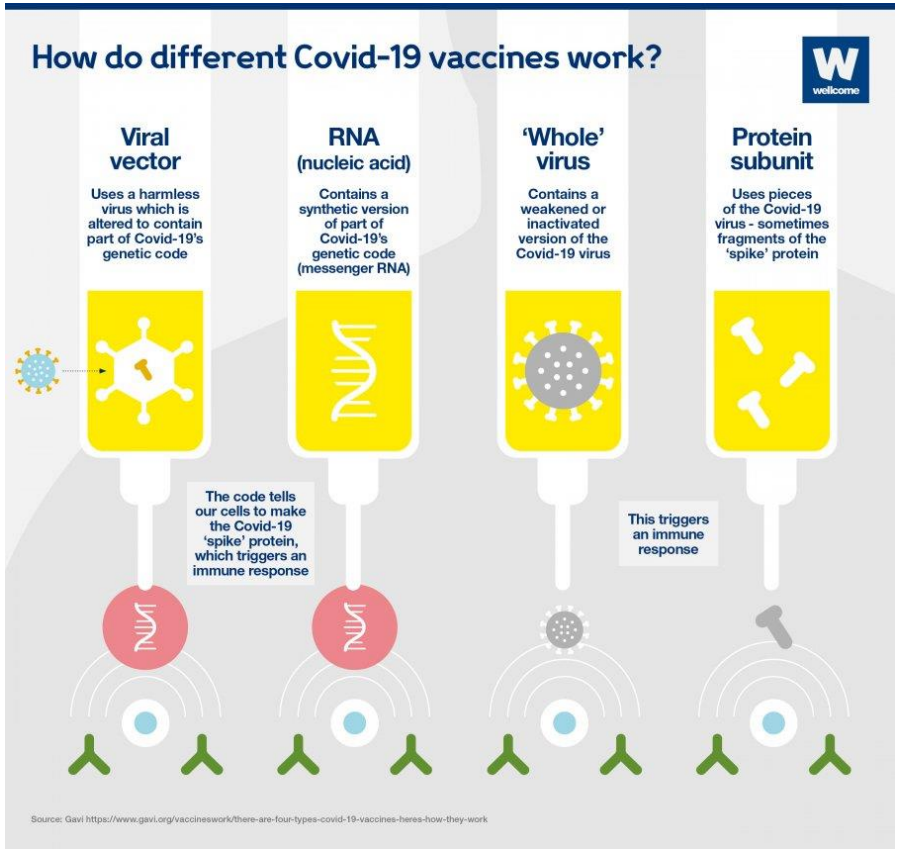
You need to apply before Sunday 21 February 2021.

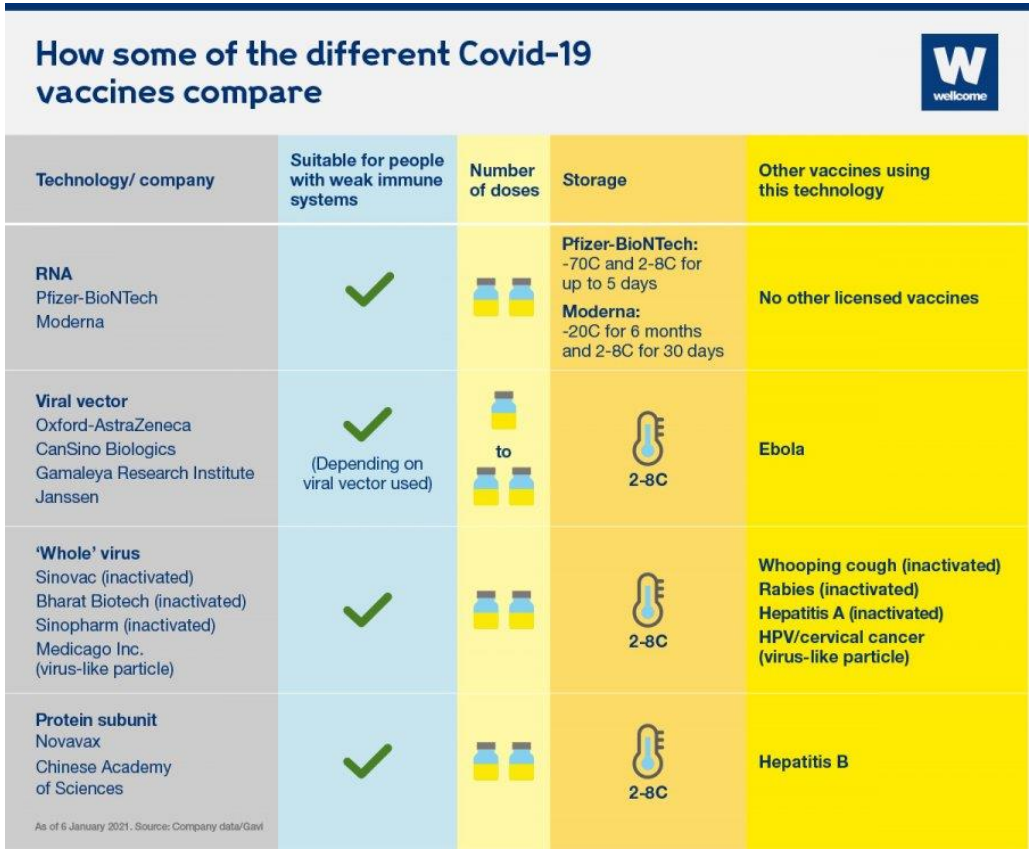
Further guidance on how to safely take vitamin D supplements will be provided during the opt in process

Quick background to vaccines

One dose provides about 90% protection after 3 weeks

The Pfizer and Astra Zeneca vaccines are predicted to protect from New Variant Covid viruses from Kent and South Africa





UK Government priority list for vaccines

- Residents in care homes for older adults and their carers
- 80-year-olds and over and frontline health and social care workers
- 75-year-olds and over
- 70-year-olds and over and clinically extremely vulnerable individuals
- 65-year-olds and over
- 16- to 64-year-olds with **serious underlying health conditions**
- 60-year-olds and over
- 55-year-olds and over
- 50-year-olds and over

Clinical risk groups aged 16yrs or over who should receive Covid vaccine

Chronic respiratory disease	Individuals with a severe lung condition, including those with asthma that requires continuous or repeated use of systemic steroids or with previous exacerbations requiring hospital admission, and chronic obstructive pulmonary disease (COPD) including chronic bronchitis and emphysema; bronchiectasis, cystic fibrosis, interstitial lung fibrosis, pneumoconiosis and bronchopulmonary dysplasia (BPD).
Chronic heart disease and vascular disease	Congenital heart disease, hypertension with cardiac complications, chronic heart failure, individuals requiring regular medication and/or follow-up for ischaemic heart disease. This includes individuals with atrial fibrillation, peripheral vascular disease or a history of venous thromboembolism.
Chronic kidney disease	Chronic kidney disease at stage 3, 4 or 5, chronic kidney failure, nephrotic syndrome, kidney transplantation.
Chronic liver disease	Cirrhosis, biliary atresia, chronic hepatitis.
Chronic neurological disease	Stroke, transient ischaemic attack (TIA). Conditions in which respiratory function may be compromised due to neurological disease (e.g. polio syndrome sufferers). This includes individuals with cerebral palsy, severe or profound learning disabilities, Down's Syndrome, multiple sclerosis, epilepsy, dementia, Parkinson's disease, motor neurone disease and related or similar conditions; or hereditary and degenerative disease of the nervous system or muscles; or severe neurological disability.
Diabetes mellitus	Any diabetes, including diet-controlled diabetes.

Clinical risk groups aged 16yrs or over who should receive Covid vaccine contd

Immunosuppression	Immunosuppression due to disease or treatment, including patients undergoing chemotherapy leading to immunosuppression, patients undergoing radical radiotherapy, solid organ transplant recipients, bone marrow or stem cell transplant recipients, HIV infection at all stages, multiple myeloma or genetic disorders affecting the immune system (e.g. IRAK-4, NEMO, complement disorder, SCID). Individuals who are receiving immunosuppressive or immunomodulating biological therapy including, but not limited to, anti-TNF, alemtuzumab, ofatumumab, rituximab, patients receiving protein kinase inhibitors or PARP inhibitors, and individuals treated with steroid sparing agents such as cyclophosphamide and mycophenolate mofetil. Individuals treated with or likely to be treated with systemic steroids for more than a month at a dose equivalent to prednisolone at 20mg or more per day for adults. Anyone with a history of haematological malignancy, including leukaemia, lymphoma, and myeloma and those with systemic lupus erythematosus and rheumatoid arthritis, and psoriasis who may require long term immunosuppressive treatments. Most of the more severely immunosuppressed individuals in this group should already be flagged as CEV. Individuals who are not yet on the CEV list but who are about to receive highly immunosuppressive interventions or those whose level of immunosuppression is about to increase may be therefore be offered vaccine alongside the CEV group, if therapy can be safely delayed or there is sufficient time (ideally two weeks) before therapy commences. Some immunosuppressed patients may have a suboptimal immunological response to the vaccine (see immunosuppression and HIV).

Clinical risk groups aged 16yrs or over who should receive Covid vaccine contd

Asplenia or dysfunction of the spleen	This also includes conditions that may lead to splenic dysfunction, such as homozygous sickle cell disease, thalassemia major and coeliac syndrome.
Morbid obesity	Adults with a Body Mass Index ≥40 kg/m².
Severe mental illness	Individuals with schizophrenia or bipolar disorder, or any mental illness that causes severe functional impairment.
Adult carers	Those who are in receipt of a carer's allowance, or those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill.
Younger adults in long-stay nursing and residential care settings	Many younger adults in residential care settings will be eligible for vaccination because they fall into one of the clinical risk groups above (for example learning disabilities). Given the likely high risk of exposure in these settings, where a high proportion of the population would be considered eligible, vaccination of the whole resident population is recommended. Younger residents in care homes for the elderly will be at high risk of exposure, and although they may be at lower risk of mortality than older residents should not be excluded from vaccination programmes (see priority 1 above). For consideration of children under 16 see below.

Covid vaccines and children

- Vaccine trials only just begun in children
- Children have a very low risk of severe illness or death from Covid compared to adults
- Limited data on risk factors in childhood
- Vaccination may be considered for children with severe neuro-disabilities who tend to get recurrent chest infections and who frequently spend time in specialized residential care settings
- This is outside the terms of MHRA approval so would be unlicensed use
- Recommendations on vaccinating children will be reviewed after initial roll-out.

Government Guidance

Keep up to date with the latest guidance on the individual Government websites:

England
https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19

Wales
https://gov.wales/guidance-shielding-and-protecting-people-defined-medical-grounds-extremely-vulnerable-coronavirus-0

Scotland
https://www.gov.scot/publications/covid-shielding/

Northern Ireland
https://www.nidirect.gov.uk/articles/guidance-shielding-extremely-vulnerable-people

Questions?

- What category do people with WS fall under ?
- Is the COVID-19 vaccine safe ?
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- If a person with WS is offered a vaccine for COVID should they go for it ?
- Does the COVID-19 vaccine have a lot of side effects such as swallowing issues, headaches after you have had it?
- Does diabetes increase the chance of getting COVID-19?