COVID-19 AND DOWN SYNDROME
T21RS SURVEY

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on behalf of the T21RS COVID-19 Initiative
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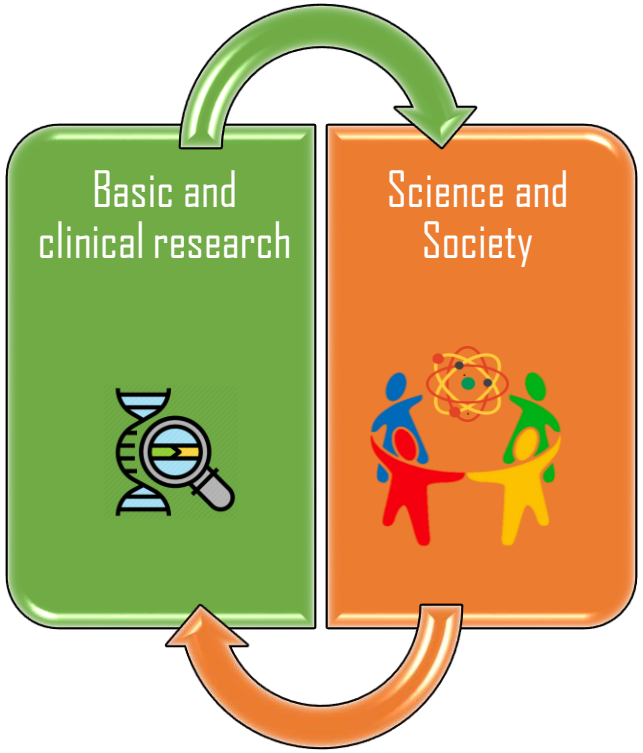
Covid-19 Initiative Trisomy 21 Research Society

Trisomy 21 Research Society

The first international non-profit scientific organization founded to promote basic and applied research on Down syndrome, stimulate translational research and apply new scientific knowledge to improve the quality of life for people with Down Syndrome.



Become a member:
https://www.t21rs.org/membership-terms-conditions/
Website:
http://www.t21rs.org/
Twitter:
https://twitter.com/t21rs

The concern…

COVID-19 and Down syndrome

- People with Down syndrome may have additional health issues (e.g. diabetes, obesity) shown to increase the risk for more severe COVID-19
- Viral infections and pneumonia are an important health concern for people with Down syndrome
- People with Down syndrome may have unusual immune systems that could put them at higher risk for infections such as COVID-19

Hospitalizations rate in DS

- Greater risk of admission to a hospital due to infections
- Prolonged stay at the hospital
- May require intensive support (respiratory tract infections)

The T21RS COVID-19 initiative

https://www.t21rs.org/covid-19/

T21RS COVID-19 Actions

Trisomy 21 research society (T21RS) recommendations to protect individuals with Down syndrome against COVID-19

COVID-19 and Down Syndrome on-line survey

T21RS statement on "shielding" or confinement of individuals with Down syndrome during the COVID-19 pandemic

T21RS Statement with regards to vaccinations for people with Down syndrome during the COVID-19 pandemic

T21RS COVID-19 Activities

Local and International webinars
Six publications ongoing (two reviews, three original papers, one meta-analysis, one Lancet Neurology correspondence)

T21RS COVID SURVEY WORKGROUP

- Stefania Bargagna, *Fondazione Stella Maris, Italy*
- Nicole Baumer, *Harvard University and DSMIG representative, USA*
- Angelo Carfì, *Fondazione Policlinico Universitario A.Gemelli, Italy*
- Maria Carmona Iragui, *Hospital de la Santa Creu i Sant Pau and Centro Médico Barcelona Down de la Fundación Catalana Síndrome de Down (FCSD) and Co-Chair T21RS Science and Society Committee, Spain*
- Brian Chicoine, *Advocate Medical Group Adult Down Syndrome Center, USA*
- Alberto Costa, *Case Western Reserve University and Chair T21RS Clinical committee, USA*
- Mara Dierssen, *Center for Genomic Regulation and T21RS Past-President, Spain*
- Jesus Florez, *Fundación Iberoamericana DOWN 21, Spain*
- Anke Huels, *Emory University (Environmental health and epidemiology), USA*
- Monica Lakhanpaul, *University College London and DSMIG-UK representative, UK*
- Coral Manso, *Down España, Spain*
- Miguel-Angel Mayer, *Hospital del Mar. Instituto de Investigaciones Médicas (GRIB, IPSN), Spain*
- Andrew Nowalk, *University of Pittsburgh (Infectious diseases), USA*
- Maria del Carmen Ortega, *Hospital 12 de Octubre, Spain*
- Anne Sophie Rebillat, *Lejeune Institute and Co-Chair T21RS Science and Society Committee, France*
- Diego Ruiz de Asúa, *Hospital Universitario de la Princesa, Madrid, Spain*
- Guissy Sgandurra, *Fondazione Stella Maris, Italy*
- Stephanie Sherman, *Emory University and Co-Chair T21RS Clinical committee, USA*
- Andre Strydom, *King's College London and T21RS president, UK*
- Rafael de la Torre, *Consorci MAR Parc de Salut de Barcelona, Instituto de Investigaciones Médicas IMIM, Spain*
- Diletta Valentini, *Ospedale Pediatrico Bambino Gesu, Italy*

The T21RS COVID-19 survey

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We also obtained data from a national survey of COVID-19 in hospitals in the UK, identified everyone with Down syndrome who have been admitted and compared them to people from the general population to determine if people with Down syndrome do worse than expected

MORE DETAIL ABOUT WHAT WE DID

DATA SOURCES

- **T21RS survey of people with Down syndrome and COVID-19**

  - 801 cases (461 clinician and 340 family surveys)
  - 422 hospitalized cases
  - 60% of the 801 cases have recovered; 14% have died

- **UK survey of people hospitalized for COVID-19**

  - 100 people with Down syndrome
  - 58,916 people without Down syndrome

Symptoms of COVID-19 in people with Down syndrome

- Similar to general population:

- fever

- cough
- shortness of breath

- Nasal symptoms (runny nose) are common, especially in children

- Shortness of breath is associated with hospital admission

Are symptoms different in people with Down syndrome compared to other people (from the general population?

COVID-19 SYMPTOMS IN HOSPITALIZED PATIENTS

MOST COMMON IN PATIENTS WITH AND WITHOUT DOWN SYNDROME

Fever

Cough

Shortness of breath

MORE COMMON IN PATIENTS WITH DOWN SYNDROME:

Altered consciousness or confusion

LESS COMMON IN PATIENTS WITH DOWN SYNDROME:

Joint pain or muscle aches

Vomiting / nausea

*Note: Some symptoms may be more difficult to recognize in people with Down syndrome due to the need for self-report (e.g. pain or nausea) Comparison groups included those with Down syndrome (both from the UK and T21RS surveys) to those without Down syndrome (UK controls) of similar age, gender and ethnicity

What existing health conditions may increase risk for poor outcome of COVID-19 in people with Down syndrome?

Risk factors for severe outcome of disease among COVID-19 patients with Down syndrome

Risk factors

- Age (older than 40 years)
- Obesity
- Alzheimer disease/dementia
- Male
- Congenital heart defect (for hospitalization)

Potential risk factors

- Gastroesophageal reflux
- Seizures/epilepsy (in children - hospitalization)
- Obstructive sleep apnea
- Chronic lung disease (e.g., asthma, emphysema or COPD)

No evidence for increased risk

- Living condition (residential care facility)
- Level of intellectual disability
- Thyroid disorder
- Behavioral/psychiatric condition (e.g., autism spectrum disorder)

What happens when people with Down syndrome are admitted to hospital with COVID-19?

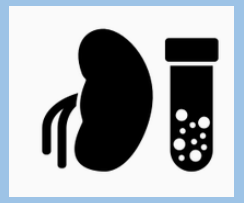
MEDICAL PROBLEMS DUE TO COVID-19 (IN PEOPLE ADMITTED TO HOSPITAL)

MORE COMMON IN PEOPLE WITH DOWN SYNDROME

Lung complications, including viral and bacterial pneumonia and acute respiratory syndrome

AS COMMON AS IN PATIENTS WITHOUT DOWN SYNDROME

Heart complications

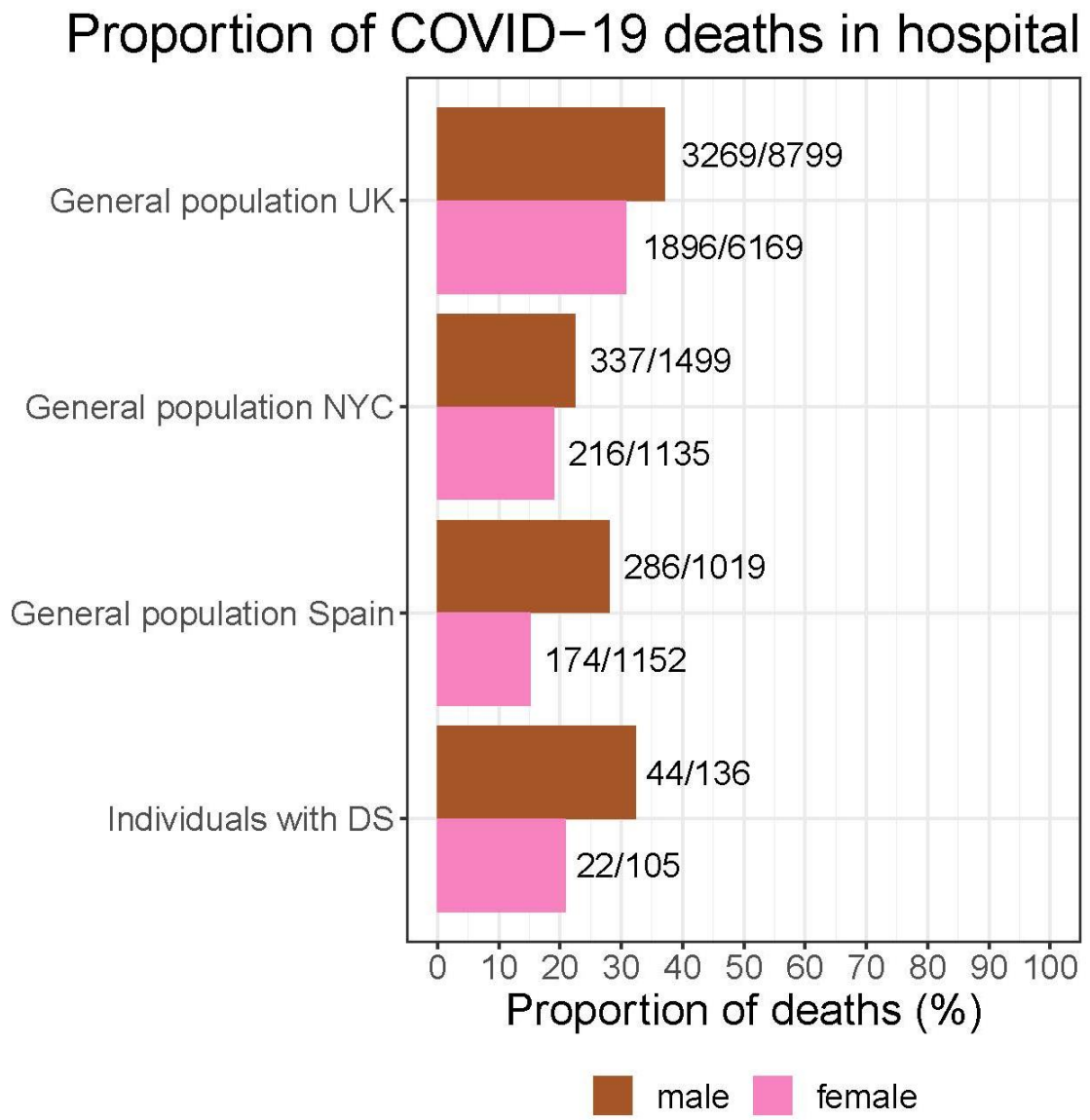


Kidney problems

Anemia

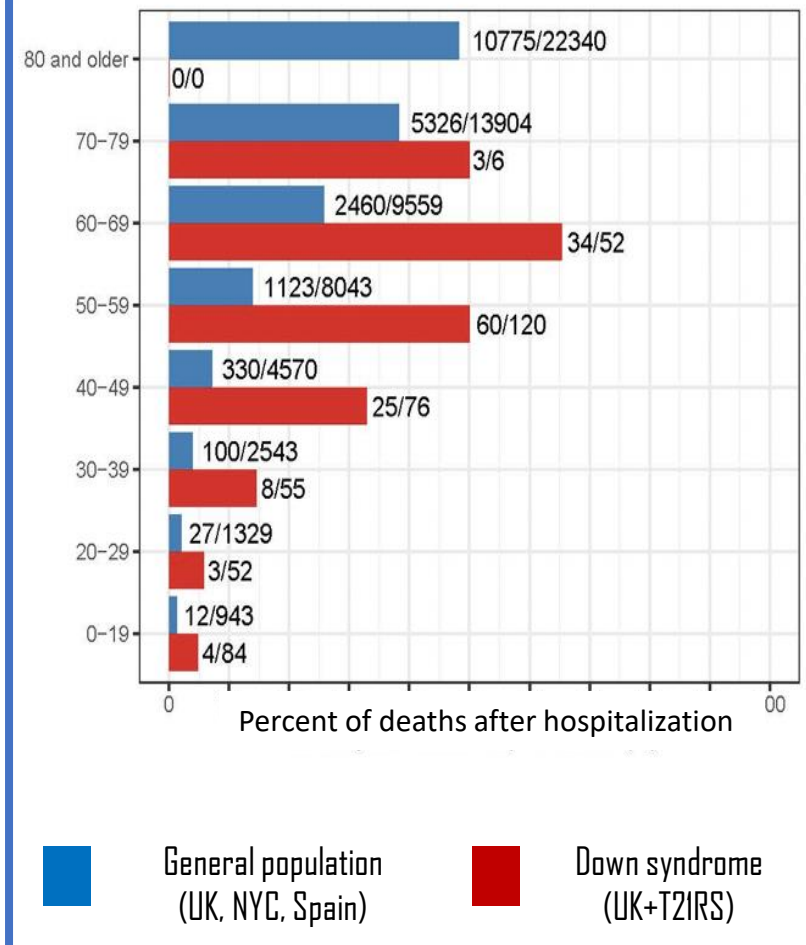
Comparison groups included those with Down syndrome (both from the UK and T21RS surveys) to those without Down syndrome (UK controls) of similar age, gender and ethnicity

Are people with Down syndrome more at risk of dying of COVID-19?

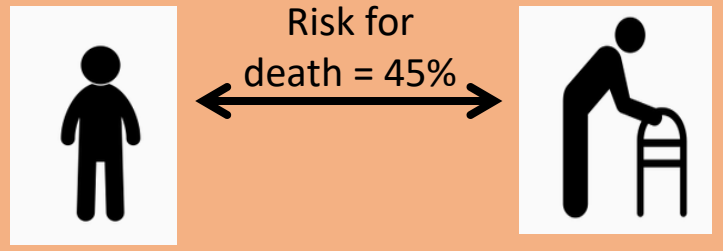


COVID-19 RELATED DEATHS AMONG HOSPITALIZED PATIENTS

Risk of death among hospitalized patients with Down syndrome is increased by age 40

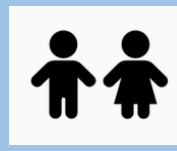


The risk for death for patients with Down syndrome age 40 and older is similar to patients in the general population who are age 80 and older



Deaths comparing patients with Down syndrome and the UK general population of similar age, gender and ethnicity

	With Down syndrome		Without Down syndrome
	T21RS survey	UK survey	UK survey
Younger (<age 40)	6%	12%	3%
Older (≥age 40)	43%	49%	17%



- Few children with Down syndrome died with COVID-19
- More data are needed to determine risk factors for severe outcomes of COVID-19 in children.

TAKE HOME MESSAGES

- Look out for the same symptoms (fever, cough and shortness of breath)
- Increasing shortness of breath and change in consciousness or confusion may be a sign of worse illness
- Among hospitalized patients with COVID-19, lung complications are more frequent in patients with Down syndrome
- Comparing people of the same age, gender and ethnicity, adults with Down syndrome 40 years and older have a greater risk of death compared with patients without Down syndrome
- Only a few children with Down syndrome have died of COVID-19
    - They were living in countries with limited health care provision, and had additional health needs
    - This suggests that both children with and without Down syndrome do not often get severely sick from the virus
- T21RS recommends prioritising vaccination for people with Down syndrome

What we could not do

- We are not able to say whether people with Down syndrome are more likely to catch the virus (SARS-COV-2) that causes COVID-19
  - Some scientists think they may be more vulnerable, but this is not clear
  - Some people may have higher risk of exposure because of where they live
  - But many people have been very good at keeping themselves safe
- We are also not able to say how many people are asymptomatic (without symptoms) when they are infected with the virus
- We do not yet know how to best treat people with COVID-19

STUDY LIMITATIONS

The current life expectancy for people with Down syndrome is 60 years old. Most COVID-related deaths in the general population occur in people greater than 80 years old. This makes it difficult to compare the overall risk of COVID-19 related death in people with and without Down syndrome.

More data are needed to understand risk for severe outcomes among children and adolescents. We cannot generalize our findings on older adults to this age group.

There may be unknown factors that affect the rate or reason for hospitalization differently for people with or without Down syndrome".

Only patients with COVID-19 are included, so questions about the risk of infection cannot be answered.

T21RS data are collected from different countries and different health care systems and may under-represent COVID-19 cases with Down syndrome.