COVID-19 AND DOWN SYNDROME
T2IRS SURVEY

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on behalf of the T2IRS COVID-19 Initiative
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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
COVID-19 and Down syndrome

The concern...

• 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)
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.
DATA SOURCES

• T2IRS 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?)
<table>
<thead>
<tr>
<th>MOST COMMON IN PATIENTS WITH AND WITHOUT DOWN SYNDROME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fever</td>
</tr>
<tr>
<td>Cough</td>
</tr>
<tr>
<td>Shortness of breath</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>MORRE COMMON IN PATIENTS WITH DOWN SYNDROME:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Altered consciousness or confusion</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>LESS COMMON IN PATIENTS WITH DOWN SYNDROME:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joint pain or muscle aches</td>
</tr>
<tr>
<td>Vomiting / nausea</td>
</tr>
</tbody>
</table>

*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 T2IRS 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?
<table>
<thead>
<tr>
<th>Risk factors</th>
<th>Potential risk factors</th>
<th>No evidence for increased risk</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (older than 40 years)</td>
<td>Gastroesophageal reflux</td>
<td>Living condition (residential care facility)</td>
</tr>
<tr>
<td>Obesity</td>
<td>Seizures/epilepsy (in children - hospitalization)</td>
<td>Level of intellectual disability</td>
</tr>
<tr>
<td>Alzheimer disease/dementia</td>
<td>Obstructive sleep apnea</td>
<td>Thyroid disorder</td>
</tr>
<tr>
<td>Male</td>
<td>Chronic lung disease (e.g., asthma, emphysema or COPD)</td>
<td>Behavioral/psychiatric condition (e.g., autism spectrum disorder)</td>
</tr>
<tr>
<td>Congenital heart defect (for hospitalization)</td>
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</tbody>
</table>
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)

<table>
<thead>
<tr>
<th>More Common in People with Down Syndrome</th>
<th>As Common as in Patients without Down Syndrome</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lung complications, including viral and bacterial pneumonia and acute respiratory syndrome</td>
<td>Heart complications</td>
</tr>
<tr>
<td></td>
<td>Kidney problems</td>
</tr>
<tr>
<td></td>
<td>Anemia</td>
</tr>
</tbody>
</table>

Comparison groups included those with Down syndrome (both from the UK and T2IRS 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.

Risk for death = 45%

- 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.

Deaths comparing patients with Down syndrome and the UK general population of similar age, gender and ethnicity:
• 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
• T2IRS recommends prioritising vaccination for people with Down syndrome

TAKE HOME MESSAGES
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.

T2IRS data are collected from different countries and different health care systems and may under-represent COVID-19 cases with Down syndrome.