



## **T21RS statement on “shielding” or confinement of individuals with Down syndrome during the COVID-19 pandemic**

The chief medical officers of the U.K. have recently decided to add individuals with Down syndrome over 18 years of age to their “extremely vulnerable list” for COVID-19, which entails recommending their shielding\*. Although the guidance is advisory in nature, this decision may affect the physical and mental health of people with Down syndrome. This decision may also unreasonably restrict opportunities for these individuals to participate in occupational, work and other activities, which could potentially impact on their socio-family environment.

This decision does not take into account the data recently reported in the international study promoted by the Trisomy 21 Research Society (T21RS)\*\*. This work is the largest of its kind and investigated more than 1,000 cases of people with Down syndrome from around the world who had contracted COVID-19 between April and October 2020. The collected cases were reported by families and by clinical professionals, thus representing the best available information on people's living conditions, pre-existing conditions and course of the disease.

The results of the study\*\*\* indicate that people with Down syndrome are a very heterogeneous group, whose risk factors for severe outcomes due to COVID-19 (hospitalization and death) are similar to those of the general population: age, diabetes, obesity, dementia, and male sex, with the addition of severe or untreated congenital heart defects as a potential risk factor for hospitalization in people with Down syndrome. It is critical to point out, however, that while in the general population the risk for poor outcomes of COVID-19 increases around 60 years, in people with Down syndrome it becomes more pronounced after age 40 and is increased in these older individuals compared to the general population of similar age.

Based on the results of this international study, we are reluctant to consider younger adults under 40 years of age and children with Down syndrome as an “extremely vulnerable group”, except for those individuals who have significant coexisting health concerns. With the data available to us, we do not consider the generalized confinement of the entire population of adults with Down syndrome to be sufficiently justified. The risk needs to be balanced against the potential negative consequences of confinement or shielding on the mental and physical health, and access to education (particularly for young people aged 17 – 25). Individuals with Down syndrome contribute to society in many ways, and the potential economic impact of work opportunity deprivation is also a concern for many adults.

Similar to current guidance for those in the general population, it is critical to emphasize the need for necessary precautions to reduce the spreading of infection, such as frequent and thorough hand-washing, social distancing, use face masks or face shields, and ensuring that immunisations and health checks are up to date.

\*<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/>

\*\* <https://www.medrxiv.org/content/10.1101/2020.11.03.20225359v1/>

\*\*\* <https://www.t21rs.org/results-from-covid-19-and-down-syndrome-survey/>

**On behalf of T21RS COVID-19 initiative and stakeholders:**

Down Syndrome Affiliates in Action (DSAIA), Down Syndrome Medical Interest Group-USA (DSMIG-USA), GiGi's Playhouse, Jerome Lejeune Foundation, LuMind IDSC Foundation, The Matthew Foundation, National Down Syndrome Society (NDSS), the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), Global Down Syndrome Foundation (USA), Down Syndrome Association (UK), Down syndrome medical interest groups (DSMIG UK and DSMIG USA), Down's syndrome research foundation (DSRF-UK), Down Syndrome International (DSi), Down Syndrome Education (DSE international), Trisomie21-France, Down España, National Down Syndrome Congress (NDSC), Down Madrid, Fundació Catalana Síndrome de Down (Spain), CoordDown (Italy), Associazione Italiana Persone Down (AIPD; Italy), AFRT (France), Fundación Iberoamericana Down 21 (Spain), FIADOWN (Latin America), Federação Brasileira das Associações de Síndrome de Down (Brazil) and the European Down Syndrome Association (EDSA).