



INTRODUCTION

Join the
European
Patient Registry



COVID-19

OBJECTIVES

To develop a patient-led, longitudinal survey to identify the potential risk-factors associated with COVID-19

To assess outcomes in those patients.

METHOD

The COVID-19 European Patient Registry (EPR) was developed by parents of children and young people (CYP) representing ENCA, with involvement from individuals and organisations across Europe. The EPR is available in 13 languages. Data was captured through the web-based online survey tools. Each participant is sent a short follow-up survey, weekly, asking about exposure, preventative steps, symptoms, diagnosis and outcomes. The initial and follow-up surveys generate the longitudinal registry

RESULTS

As of 23 August 2020-3,600 adults and 629 children included in the EPR. 50 adults (1.4%) and 6 children (1.0%) have been infected.

Only 5 adults (9.8%) were hospitalized.

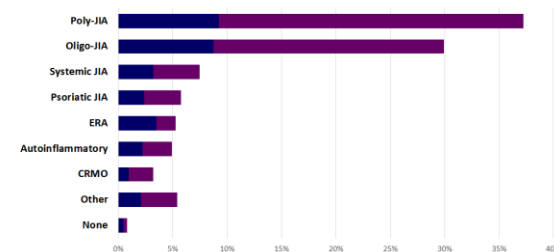
Participants report high levels of **worry**, averaging over 6 (scale 0-10).

The level of worry was associated with behaviours that affect an individual's personal level of risk of exposure to the coronavirus.



629 children

- Median age 15.5 years
- All but one were aged 13+
- Two boys, five girls.
- Diagnosis group:
- Oligo JIA 2
- Poly JIA 1
- Systemic JIA 1
- Psoriatic JIA 1
- ERA1
- Auto inflammatory 1



CONCLUSIONS

The COVID-19 EPR provides an opportunity to develop an understanding of how COVID-19 infection affects rheumatology patients. The ongoing pandemic is a stressful and worrying. It is important to keep follow-up appointments in place, even virtually, to give an opportunity to discuss concerns and disease activity. The updated data is freely available from www.jarproject.org/covid.