

How did the French Rare disease network adapt to the first year of the covid-19 pandemic ?



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Context

France was amongst the most impacted countries by the coronavirus 19 outbreak in 2020. In order to limit the spread of the disease, the government took multiples decisions including two national lockdowns that year. We wanted to investigate how that complicated situation affected the care of rare diseases (RD) patients.

The French Rare Disease Registry is an ongoing initiative aiming to collect a minimal dataset on rare disease including care activities. It allows to study how the pandemic affected rare diseases patients care in expert network during the first year of the pandemic.

Objectives

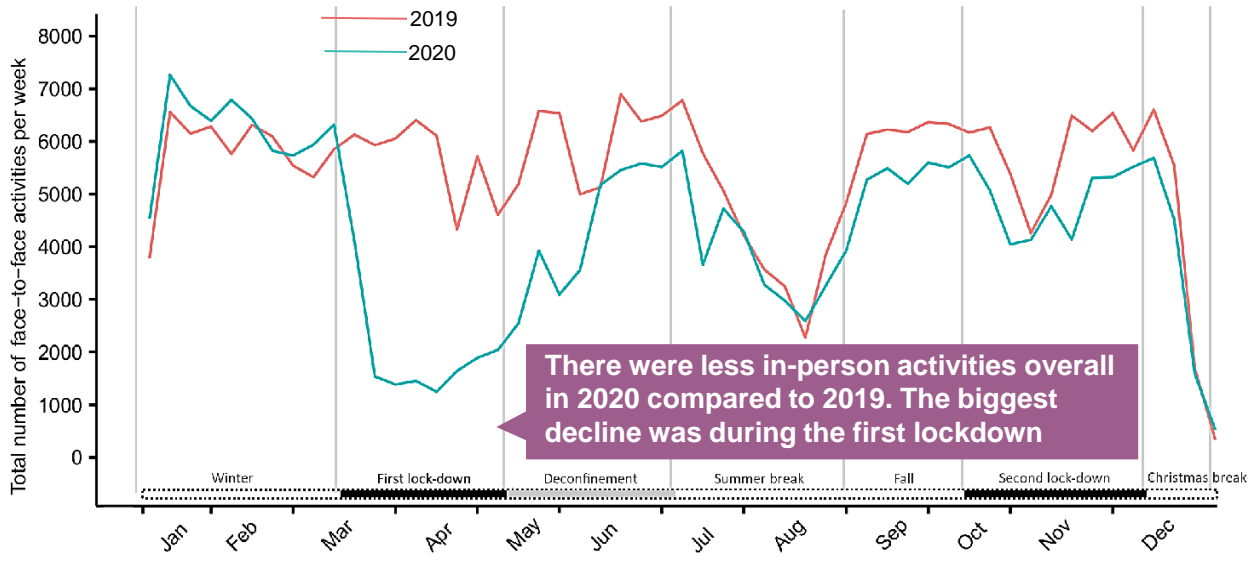
- How did RD patient overall care activities change between 2019 and 2020 ?
- How did the RD care network react to the lockdowns ?
- How were the different subpopulations of patients affected by the outbreak ?
- How did the pandemic affect the diagnosis process ?

Data Source

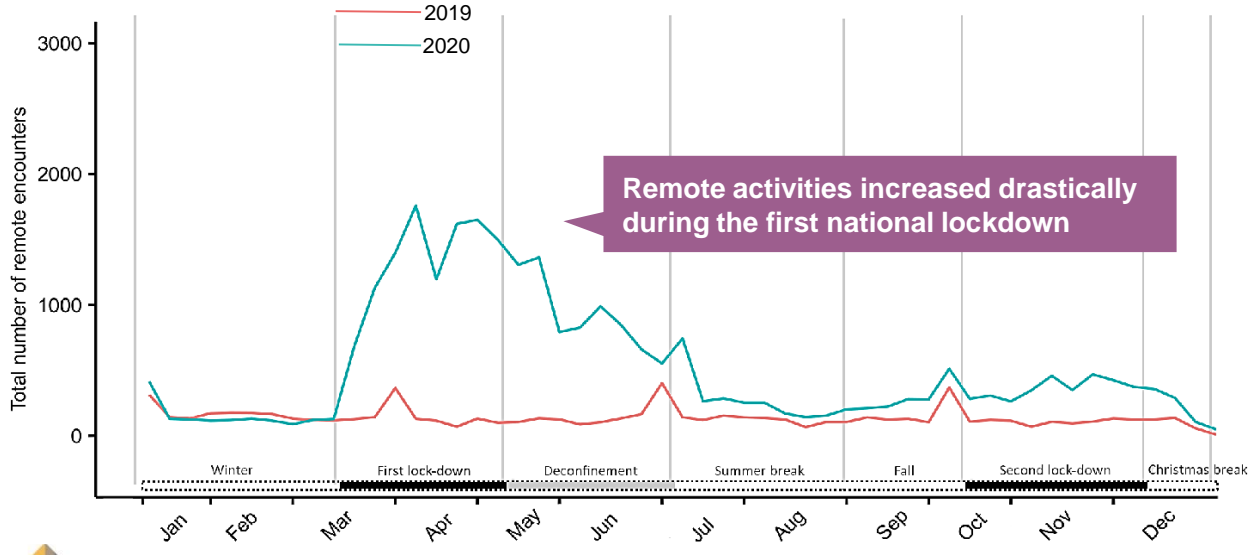
BNDMR Registry for RD expert network activity	
2170 expert sites in 98 hospitals	5600 different rare diseases
950,000 patients in the registry	



All in-person care activities



All telehealth consultations



- ⇒ All RD activities decreased by **13%** and care activity decreased by **45%** during the first lockdown with no catch up effect afterwards.
- ⇒ RD expert networks quickly adapted by adopting telehealth consultations during lockdowns but they returned to in-person consultations as soon as possible.
- ⇒ Overall **9%** decrease in the number of patients seen: **18%** decrease for adult patients and **5%** decrease for pediatric patients.
- ⇒ There was a **47%** decrease in the number of patients with a new confirmed diagnosis with the pandemic.