Question for written answer E-003791/2021
to the Commission
Rule 138
Piernicola Pedicini (Verts/ALE), **Ignazio Corrao** (Verts/ALE)

Subject: Global data collection on rare diseases

Rare diseases are often more common than we think. Huntington's disease, paroxysmal nocturnal hemoglobinuria and Duchenne muscular dystrophy are just three examples of the 7 000 different rare diseases that affect more than 400 million people globally today[1], including 30 million people across Europe[2].

Rare diseases present a multitude of challenges for individuals, their families and carers across the world, including long delays in diagnosis and persistent gaps in access to treatment and care. Better data collection is key to improving access to care for rare disease patients, by sharing knowledge, information and best practices. Collecting interoperable, aggregated data at a global level could lead to better diagnostics, better treatment and care for patients, and improved clinical trials.

Given that the challenges rare disease patients face are common worldwide, and given the important role of global cooperation on data collection in improving timely access to health services:

1. how will the Commission ensure that EU rare disease initiatives are more visible globally and have an impact beyond the EU;

2. how will the European Health Data Space contribute to improving global data collection and rare disease registries, in order to better inform healthcare strategies?

Supporter[3]

1 https://globalgenes.org/rare-facts/
2 https://www.thelancet.com/journals/landia/article/PIIS2213-8587(19)30006-3/fulltext#articleInformati
3 This question is supported by a Member other than the authors: Rosa D'Amato (Verts/ALE)