

The impact of dedicated FAIRification stewardship guiding European Reference Networks towards making rare disease resources FAIR

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1 Introduction

The FAIRification stewards team was established in July 2020 with the goal of helping **European Reference Networks (ERNs)** apply the FAIR principles (Findability, Accessibility, Interoperability and Reusability) to their patient registries.

In this analysis, we study the progress of ERNs in making their registries FAIR with the support of the **FAIRification Stewards team**.

2 Method

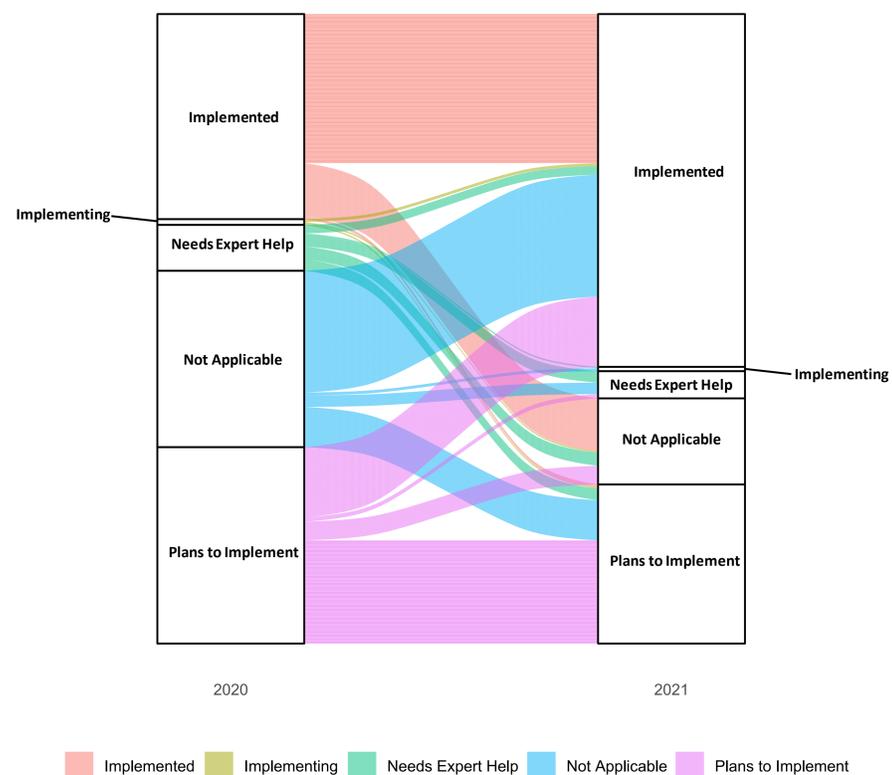
- The FAIRification stewards team created an inventory with 94 tools, addressing different phases of the Data FAIRification process (e.g. Modelling data, Data collection, Accessing and Querying data).
- In **2020**, the inventory was sent via email to all 24 ERNs. The responses to this survey were used to collect information on the current FAIR standards and identify ERNs' urgent needs.
- After one year of activities, the same inventory was sent to ERNs in **2021** to examine the FAIR implementation progression, evaluate the impact of the FAIRification Stewards support and develop future efforts.

3 Results

Fig 1. ERNs' Response distribution regarding FAIR implementation tools across 2020 and 2021 per FAIRification phase



Fig 2. ERNs response Progression between 2020 and 2021



The results indicate an **increase** in the number of tools implemented across different phases of FAIRification;

- Most significant increases were observed in the phases of **Modelling**, Data **Accessibility**, and **Registering** the registry in the European Rare Disease Registry Platform;
- Plans to Implement indicated a decreasing trend for all phases, but **Data Query** and **Accessibility**;

Most of the newly implemented tools were previously classified as **"Not applicable"** followed by **"Plans to Implement"**;

4 Conclusions

The Joint approach between FAIRification stewards and ERNs appears to have resulted in more FAIR tools being implemented, specifically for the **modelling** phase.

The majority of newly implemented tools regarded tools not previously known by the ERNs, further highlighting the FAIRification Stewards' support role.

Future work should focus in improving other phases of data FAIRification, namely **data query**.