# Patient Community Matters: EPIS community perspective

EPIS 2021 Webinar #3, 11th November 2021[1]

What the **EPIS community does around heath data matters.** Webinar #3 aimed to identify ways in which patient organisations **can empower patients around health data** through registries, surveys and other data collection methods.

## Top tips for patient advocacy groups to take action around health data*

**Patient Registries:** Registries are a great way to explore the natural history of a disease and to increase access to medications by providing strong evidence to health technology assessments (HTAs).

**Crowd-sourcing:** Many initiatives require money, time and energy – but leveraging community members' skills, such as for translation, can save on costly outgoings.

**FAIR data:** Ensuring that all data produced is FAIR (findable, accessible, interoperable, reusable) allows 'data visiting'[2], a form of open science where the patient is the co-pilot of their own health data and help researchers identify better solutions to ultimately benefit patients.

**Surveys:** Collecting data points from across all aspects of patients' lives provides a complete picture of what it means to live with a certain disease, information that can be leveraged to inform conversations with scientists, policymakers, patients and the general public.
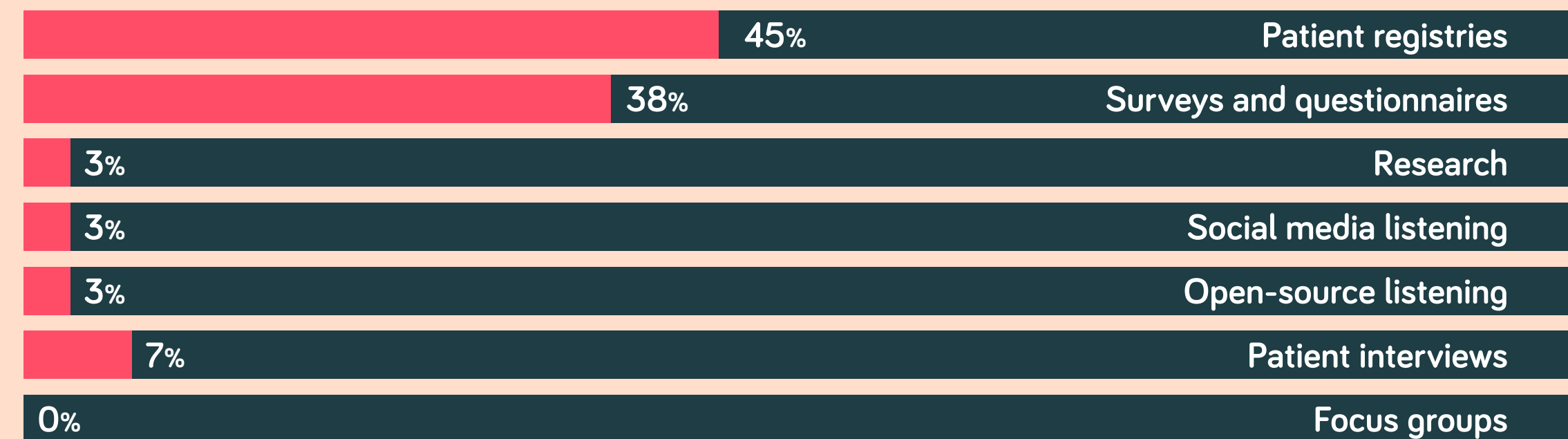
> *We have used the data by having a new 'Delay to Diagnosis' project to **help policymakers** to understand how important it is for people with axSpA to receive an **early diagnosis and early treatment.***

**Andri Phoka,**
Axial Spondyloarthritis International Federation (ASIF), Cyprus

## How are data best collected by the patient community?

| Method | Percentage |
|---|---|
| Patient registries | 45% |
| Surveys and questionnaires | 38% |
| Research | 3% |
| Social media listening | 3% |
| Open-source listening | 3% |
| Patient interviews | 7% |
| Focus groups | 0% |

From an interactive poll, **patient registries, surveys and questionnaires** were viewed as the best methods for patient organisations to collect health-related data from patients in Europe today.

> *We visited many patient groups and patients to explain to them about the importance of clinical studies and obtaining data to be able to prove to the regulators and HTAs that the drug could work. **People understood that without their participation there was no way that the project would succeed.***

**Nicolas Sireau,**
AKU Society, United Kingdom

> *It is a **steep learning curve,** but once you have done it once, **you can build on what you have learnt from previous projects to improve.** Patient organisations must think about what we can contribute that no one else can...*

**Bettina Ryll,**
Melanoma Patient Network Europe, Sweden

> *There is a role for **umbrella organisations** to educate their member organisations on what is the actual goal of data collection. You need to make the patients aware of the **value of their data while also protecting them.***

**Suzie-Ann Bakker,**
World Duchenne Organization, Netherlands