

Accurate representation of patients' opinions for decision-making: are online health communities good candidates?

Setti Rais¹, Lise Radoszycki², Paul Dourgnon¹, Lise Rochoaix¹, Michael Chekroun²
(1) Hospinnomics (Paris School of Economics and Assistance Publique – Hopitaux de Paris), France
(2) Carenity, France

Context and objectives

- ✓ The development of online patient communities worldwide has prompted questions about their ability to collect reliable information for a deeper understanding of patients' health experiences and unmet needs [1].
- ✓ The goal of this research is:
 - (1). To analyse the key socio-economic characteristics of patient communities' users,
 - (2). Examine their correspondence with national patients' demographics and
 - (3). Provide guidance on whether or not weighting schemes should be considered for patients' communities samples of users.

Methodology

CARENITY.COM PLATFORM

- ✓ CARENITY is an **international online patient community** devoted to people with chronic diseases. It exists since 2011, and allows patients and caregivers to share their experience as well as information, follow the course of their disease and contribute to medical research in various therapeutic areas, by generating real-world patients insights through online surveys.
- ✓ **CARENITY performs studies for private and public healthcare-related stakeholders:** healthcare professionals, scientists, patient advocacy groups and pharma companies.
- ✓ A **scientific committee** is also organized for any ethical or scientific issue.

METHODS

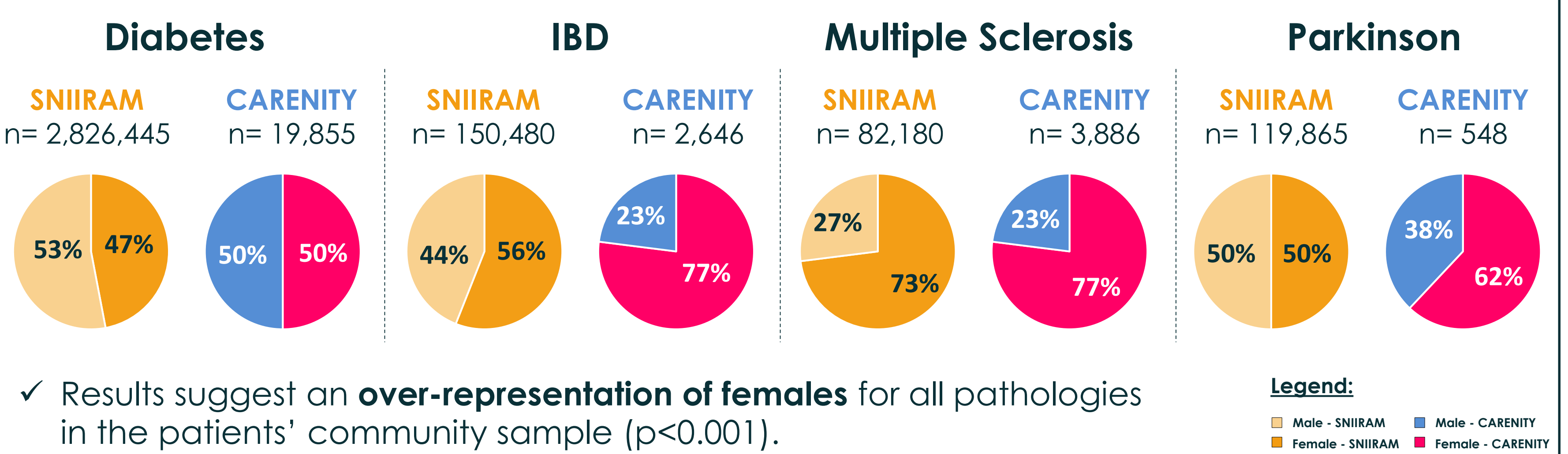
- ✓ A nationally representative sample of patients was extracted from the **French Health Insurance System (SNIIRAM)**, which compiles information about long-term illnesses' requests for exemption (ALD: affection longue durée)^[2].
- ✓ Patient-reported data from a patient platform (carenity.com) were collected and matched at disease-level with SNIIRAM sample for patients with: multiple sclerosis, Parkinson's disease, diabetes, and inflammatory bowel diseases.

	SNIIRAM	CARENITY
Diabetes	2,473,920	12,775
Inflammatory bowel diseases (IBD)	150,480	2,646
Multiple Sclerosis	82,180	3,886
Parkinson's disease	119,865	548

- ✓ A **bivariate descriptive statistics** was produced on the patient-reported data sample from Carenity (19,855 observations) and SNIIRAM sample (2,826,445 observations) for the following set of socio-demographic variables: gender, age distribution and residence area. Using **one-tailed** and **two-tailed** tests, we test for **equality of proportions** for those variables.

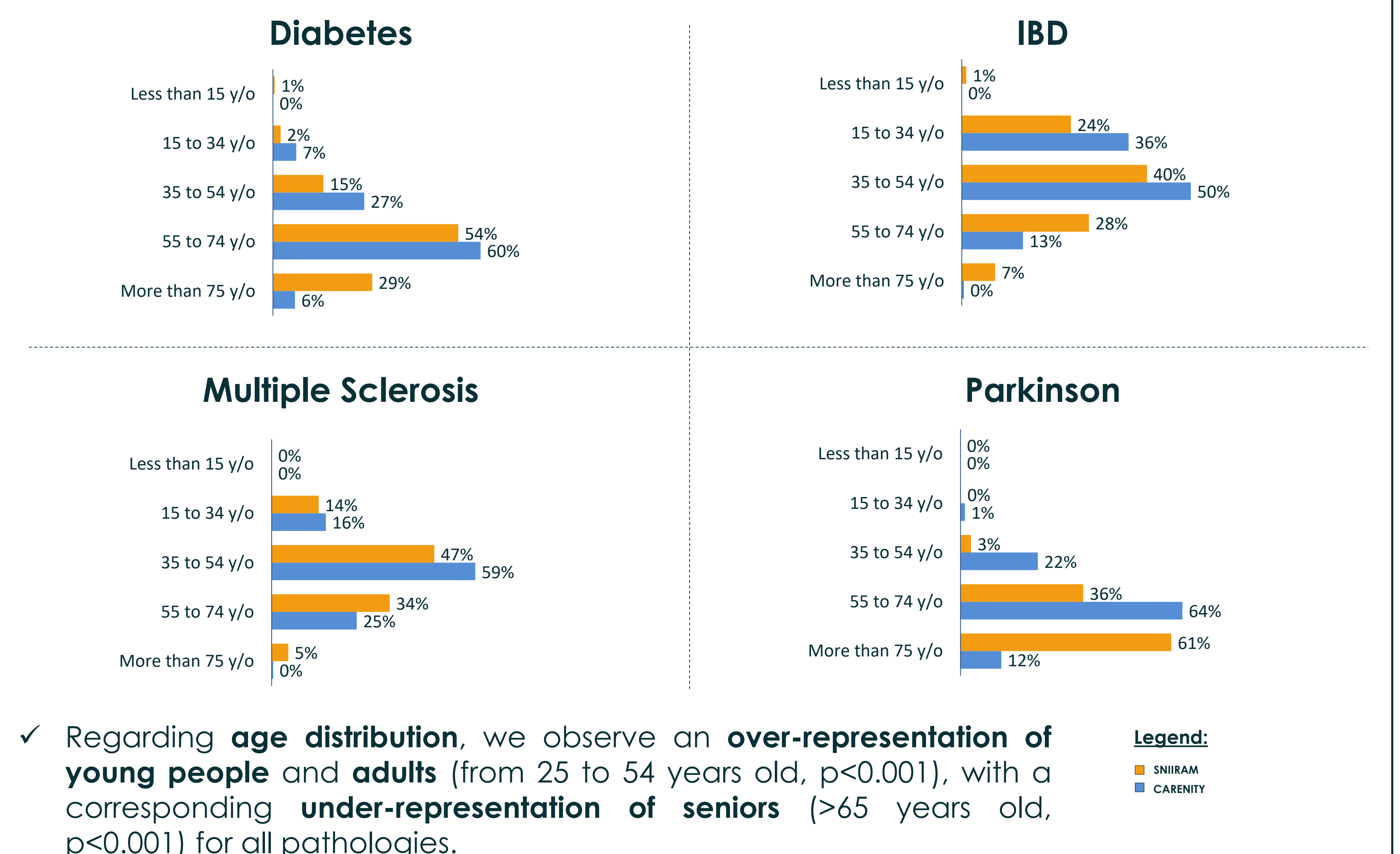
Results

COMPARISON SNIIRAM vs. CARENITY BY GENDER



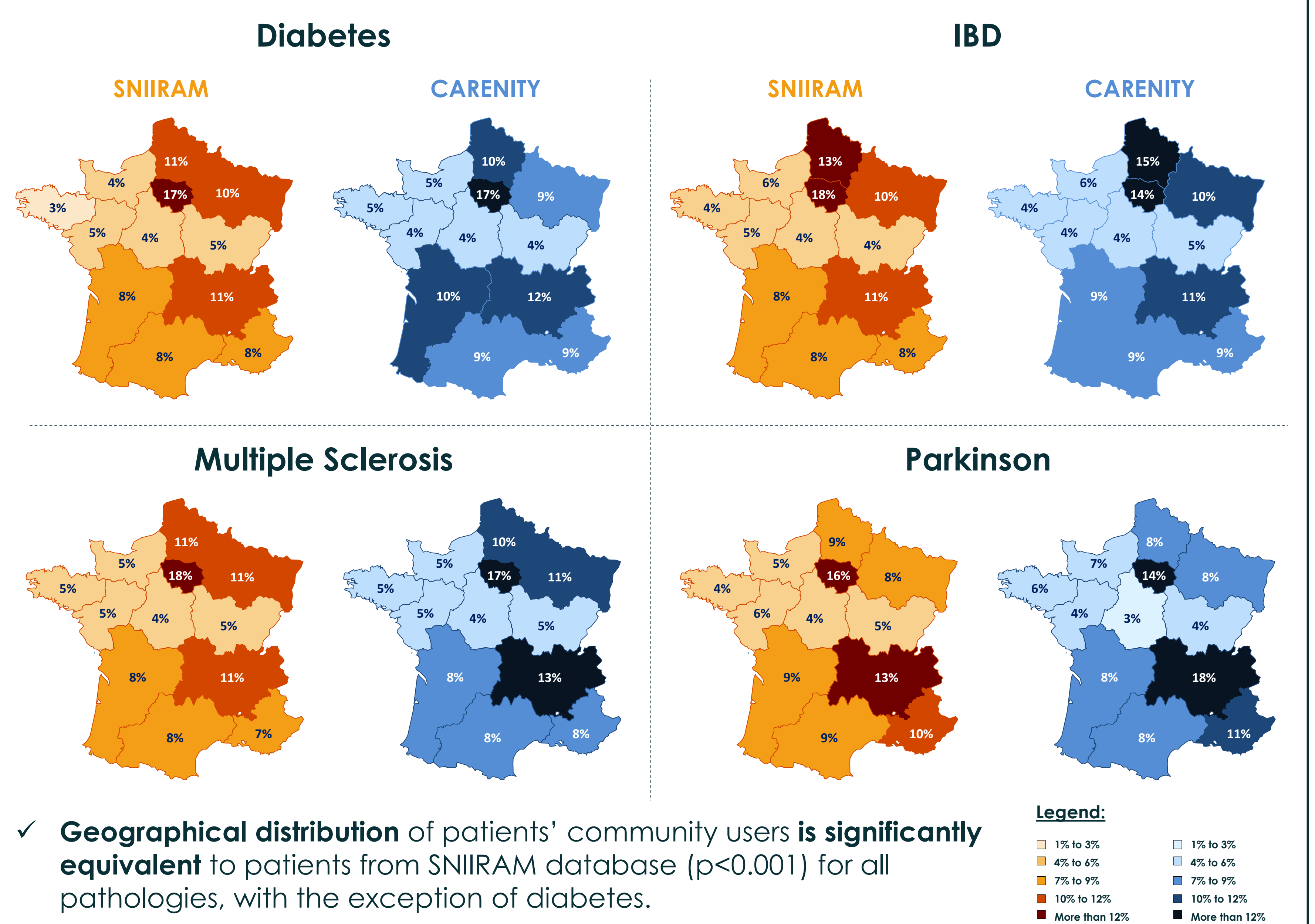
- ✓ Results suggest an **over-representation of females** for all pathologies in the patients' community sample ($p < 0.001$).

COMPARISON SNIIRAM vs. CARENITY BY AGE



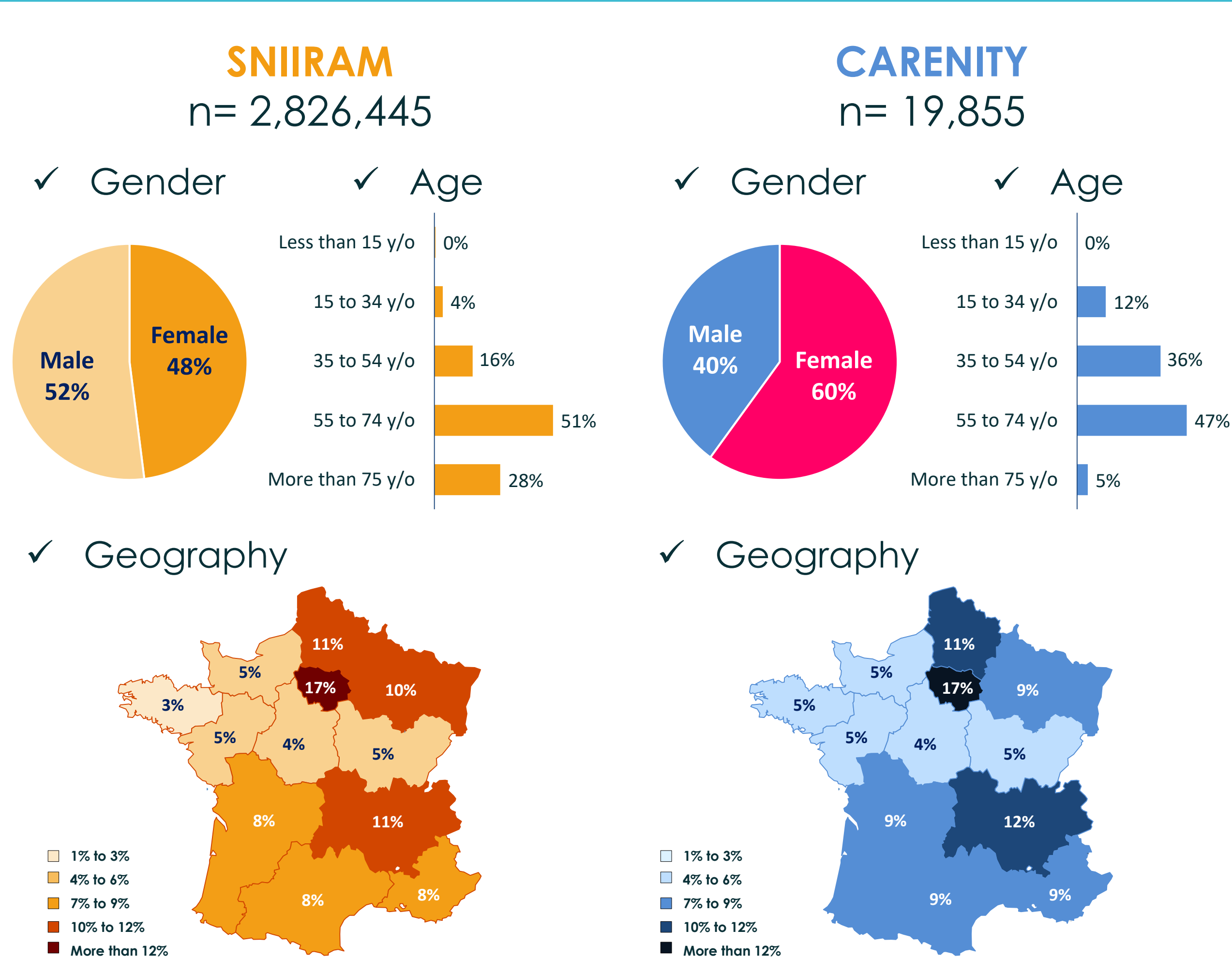
- ✓ Regarding **age distribution**, we observe an **over-representation of young people and adults** (from 25 to 54 years old, $p < 0.001$), with a corresponding **under-representation of seniors** (>65 years old, $p < 0.001$) for all pathologies.

COMPARISON SNIIRAM vs. CARENITY BY GEOGRAPHY



- ✓ **Geographical distribution** of patients' community users is **significantly equivalent** to patients from SNIIRAM database ($p < 0.001$) for all pathologies, with the exception of diabetes.

Patients' profile



Conclusions and perspectives

- ✓ Carenity communities, compared with SNIIRAM database, reflect the main characteristics of online users willing to share experiences related to their disease, with an over-representation of female patients, aged from 25 to 54 years old.
- ✓ This study captures sociodemographic comparability with a nationally representative sample in France but health-specific data may be considered in further work to determine the appropriate statistical methodology for patients' communities samples.

Health communities provide a new service for a swift collection and analysis of patient-reported outcomes in a real-world setting.