Care Pathways Before and After Initial Diagnosis and Geographical Disparities Among Patients With Obstructive Hypertrophic Cardiomyopathy in France: A Retrospective Claims Analysis

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Introduction

Hypertrophic cardiomyopathy (HCM) is a commonly inherited cardiovascular disease defined by left ventricular hypertrophy that cannot be explained by an abnormal loading condition. This chronic, progressive myocardial disease occurs as obstructive or non-obstructive subtypes. It is the most frequent cause of sudden death in young people and can lead to disability (e.g., stroke, heart failure)[1,2]. In this context, understanding patients care pathway is crucial to optimize patient management.

Objectives

This study aimed :

- To describe the clinical management of incident patients with obstructive hypertrophic cardiomyopathy (oHCM) before and after their first HCM diagnosis during a hospitalization, at both national and regional levels.
- To describe modalities of the first HCM-related hospitalization (diagnosis, modalities of care).

Methods

Study design and data source

- This observational retrospective cohort study analyzed data from the French National Health insurance database (Système National des Données de Santé [SNDS])[3].
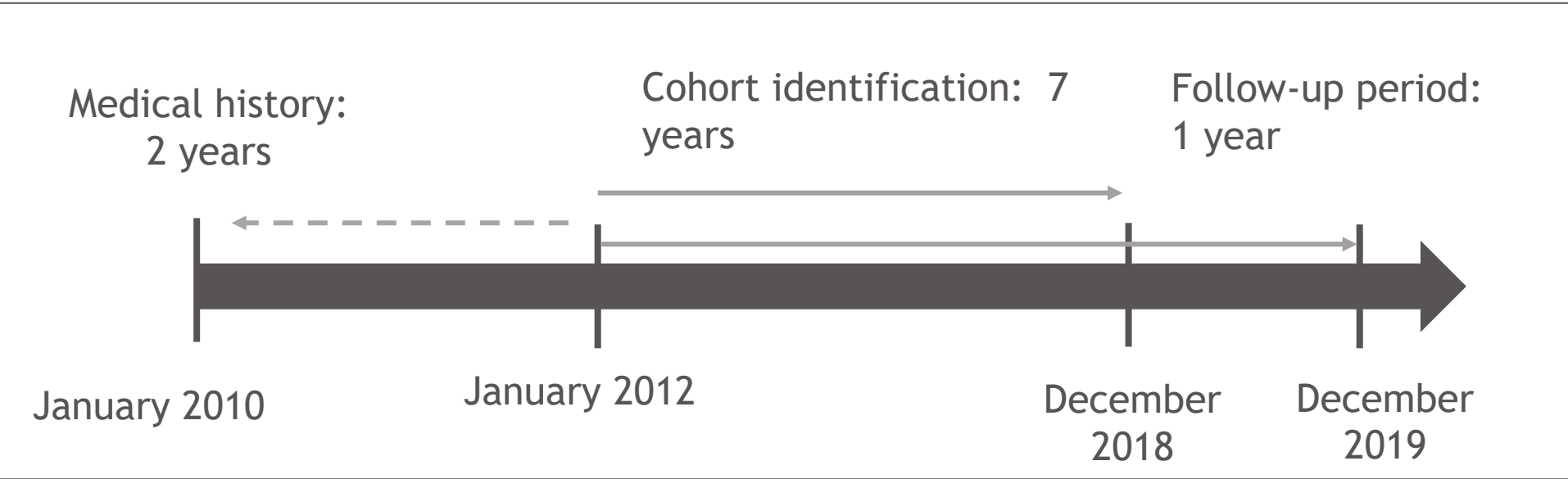
Study population

- All adult patients with at least a 12-month follow-up data available and a hospital stay related to obstructive HCM (International Classification of Diseases, 10th Revision [ICD-10] code I42.1), or at least one hospital stay with ICD-10 code I42.2 ('Other HCM') or I42.9 ('Cardiomyopathy, unspecified') and at least one code for SRT between January 1, 2012, and December 31, 2018, were identified.
- Patients without documented obstruction were categorized as non-obstructive HCM and not selected in this analysis.
- Patients without any record of HCM at hospital within the 2-year follow-back period were selected for this analysis and considered as incident.
- The index date was the date of the first HCM code during the study. Patients were followed up until the end of the study (December 31, 2019) or death, whichever occurred first (Fig. 1).

Statistical analyses

- Patient characteristics and hospital index stays were described using the following covariates: age, gender, NYHA classes, diagnosis codes, hospitalization in a reference center, admission in an emergency department. NYHA functional class is not available in the SNDS ; therefore, a proxy was calculated using an algorithm based on treatments and symptoms developed in collaboration with expert cardiologists[4].
- Consultations with primary care and hospital-based cardiologists were extracted and analyzed in a two-year period before the index date and during follow-up.
- Geographical disparities of care were assessed according to the 13 administrative regions of France.
- A subgroup analysis of index stays depending on the center type (Reference centers from the Cardiogen network of expertise in heritable cardiologic conditions, vs other centers).

Figure 1. Study design

Results

Patient selection and characteristics

- During the study period, among the 6,823 patients with an oHCM diagnosis, 4,571 patients were identified (Fig. 2) as incident on the study period. Most patients were male (54%) with a mean age at diagnosis of 66.1 years (+/- 16.57).
- Patients with oHCM may have been misclassified as non-obstructive HCM (nHCM) as screening for obstruction was not systematic at the time of the study ; literature has shown that up to 70% of patients with HCM exhibit obstructive physiology when assessed with appropriate techniques.[5]
- Patients at the index date were mainly distributed among NYHA classes II (31.5%) and III (60.1%).
- At index stay, 1/3 of patients were admitted after an admission in an emergency department.

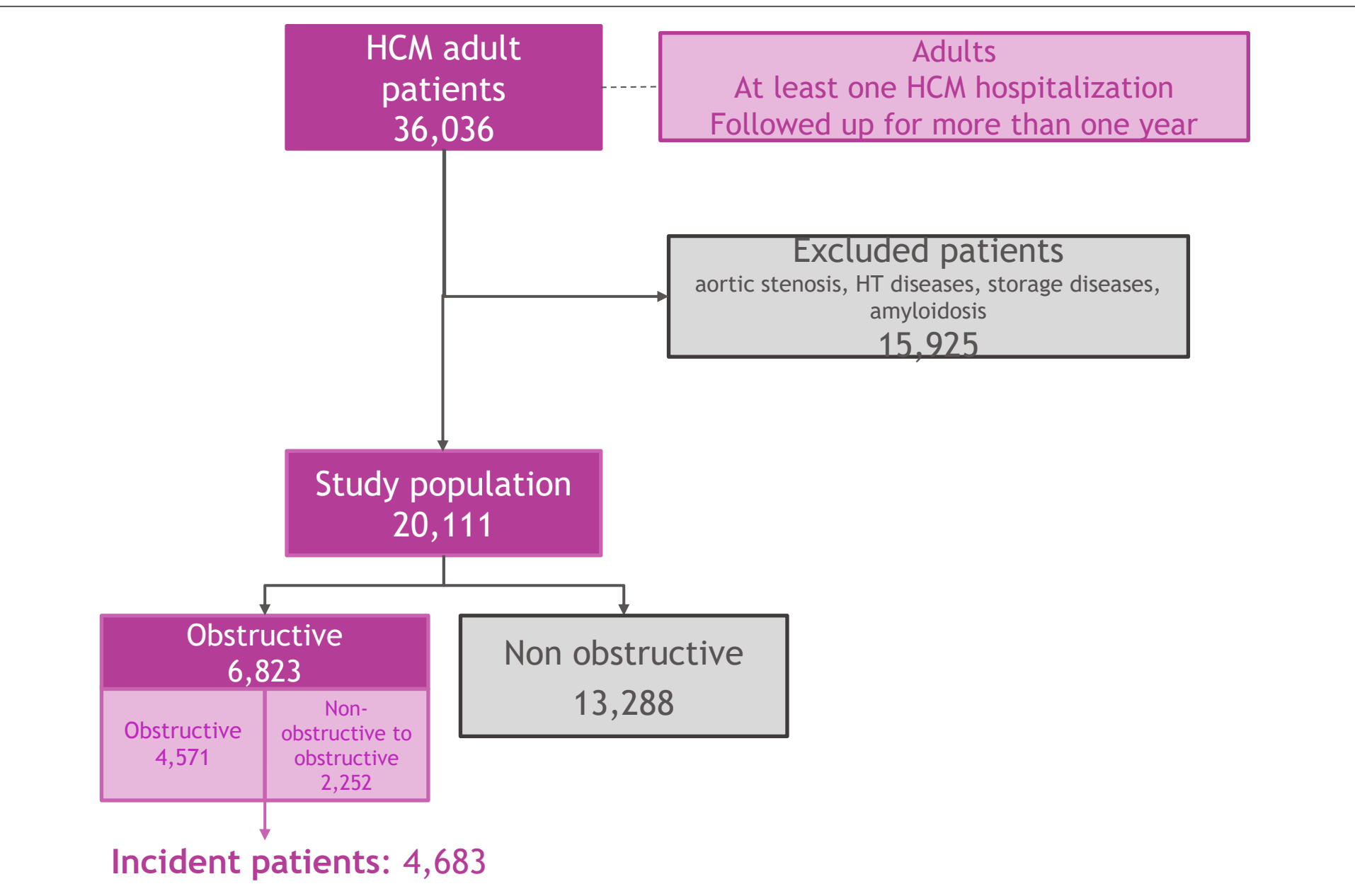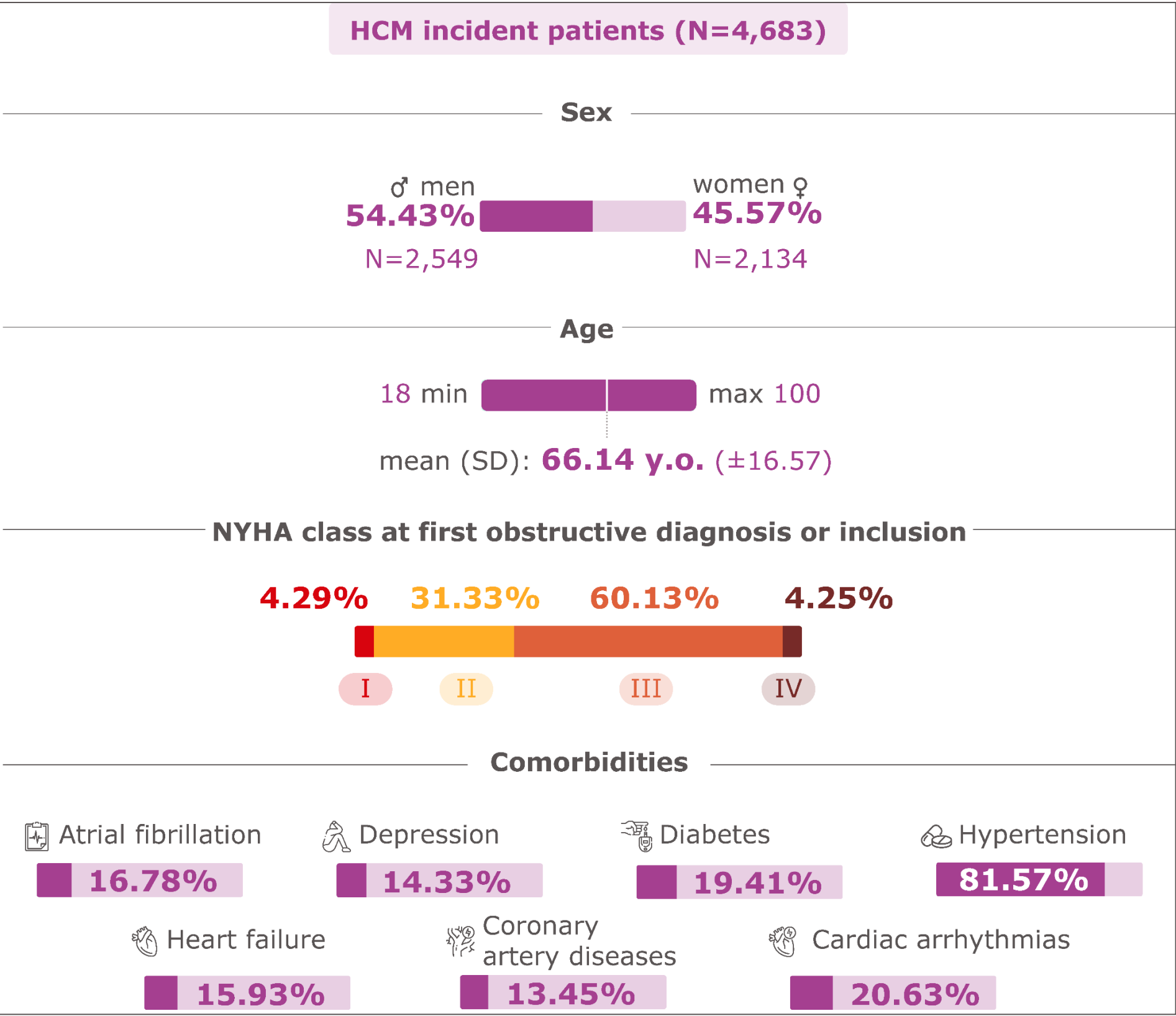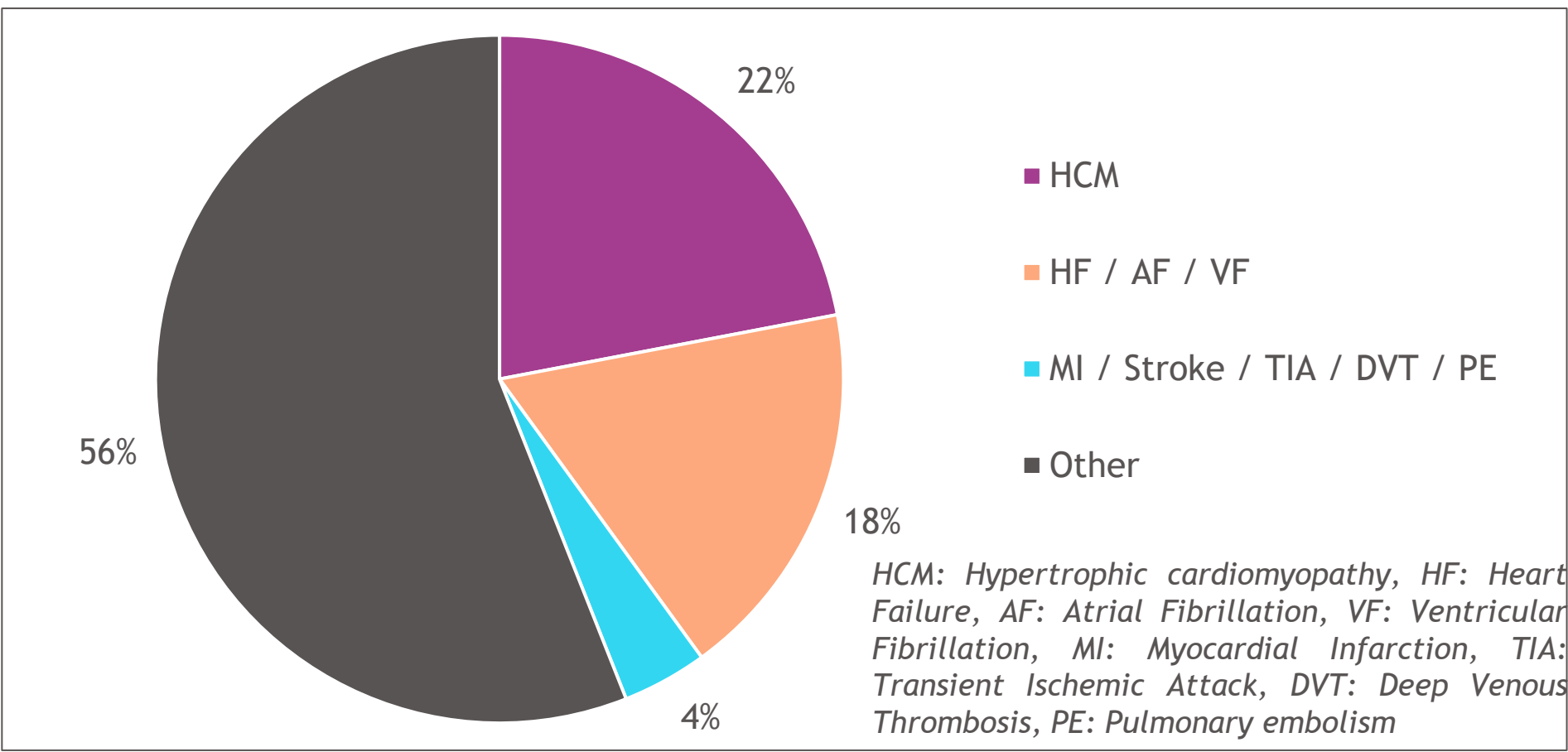### Figure 2. Patient flow chart

Figure 3. Baseline patient characteristics and comorbidities

Index date diagnoses

- Obstructive HCM was most often diagnosed during a hospital stay for another cause (i.e, as a related or significant associated diagnosis), often when the patient presented severe complications which could have been prevented by an earlier HCM diagnosis and care.

Figure 4. Principal diagnosis* at index date

HCM: Hypertrophic cardiomyopathy, HF: Heart Failure, AF: Atrial Fibrillation, VF: Ventricular Fibrillation, MI: Myocardial Infarction, TIA: Transient Ischemic Attack, DVT: Deep Venous Thrombosis, PE: Pulmonary embolism
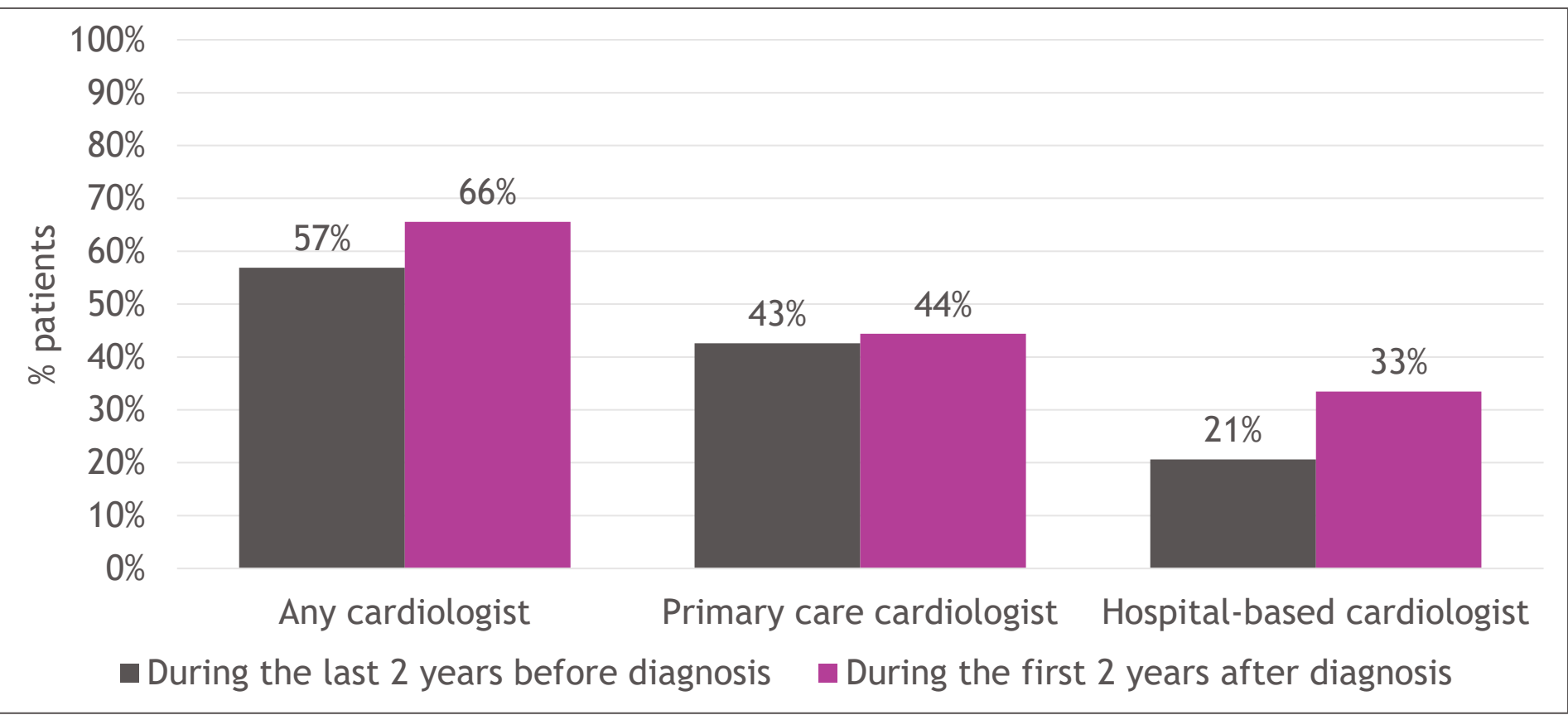
*Principal diagnosis: leading cause of hospitalization, Related Diagnosis (RD) give accuracy on patient management and Significant Associated Diagnosis (SAD) includes conditions coexisting with the principal diagnosis (complications, sequelae, comorbidities etc.)

Consultations and hospitalizations before and after oHCM diagnosis

- Cardiologist visits increased in the 2 years after diagnosis in comparison to the 2 years before, especially at hospital-based cardiologists.

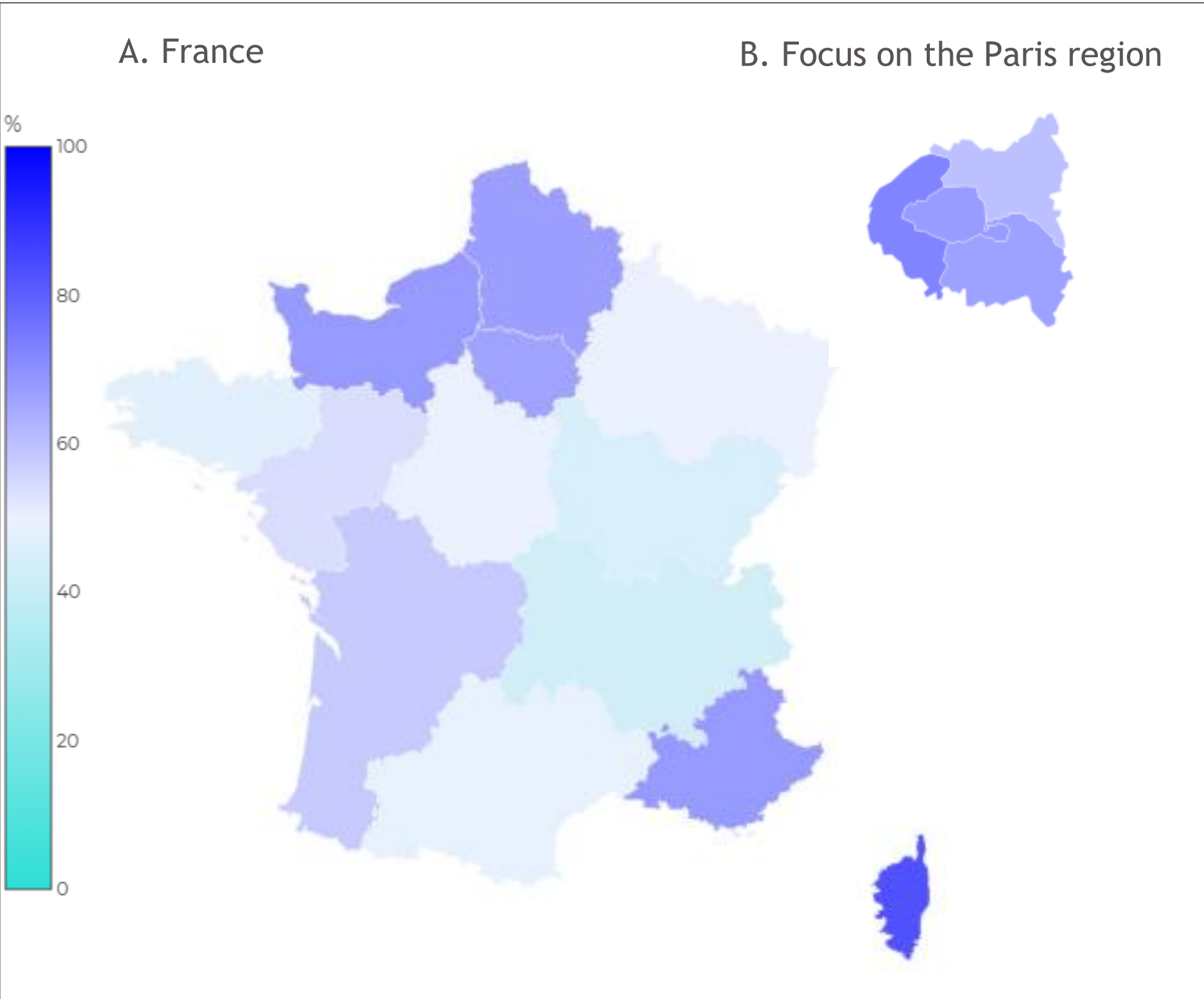### Figure 5. Cardiology consultations 2 years before and after index date

- During the last two years before the first diagnosis, 34% of patients had at least one hospitalization for cardio-vascular reason.

High regional disparities in consultations with cardiologist

- During the two years preceding the index date, 57% of patients had consulted a cardiologist in any setting, varying from 43% in Auvergne-Rhône-Alpes to 68% in Normandie and Provence-Alpes-Côte-d'Azur.

Figure 6. Percentage of patients with at least one private or hospital-based cardiologist visit in the 2 years period before index date

Patient profiles by site of initial diagnosis (Cardiogen expert centers vs other centers)

- 17.1% of patients had their first hospital-based HCM diagnosis made at a Cardiogen expert center.
- These patients were younger, slightly more frequently men and more frequently diagnosed at NYHA I and II compared to patients hospitalized in other centers.

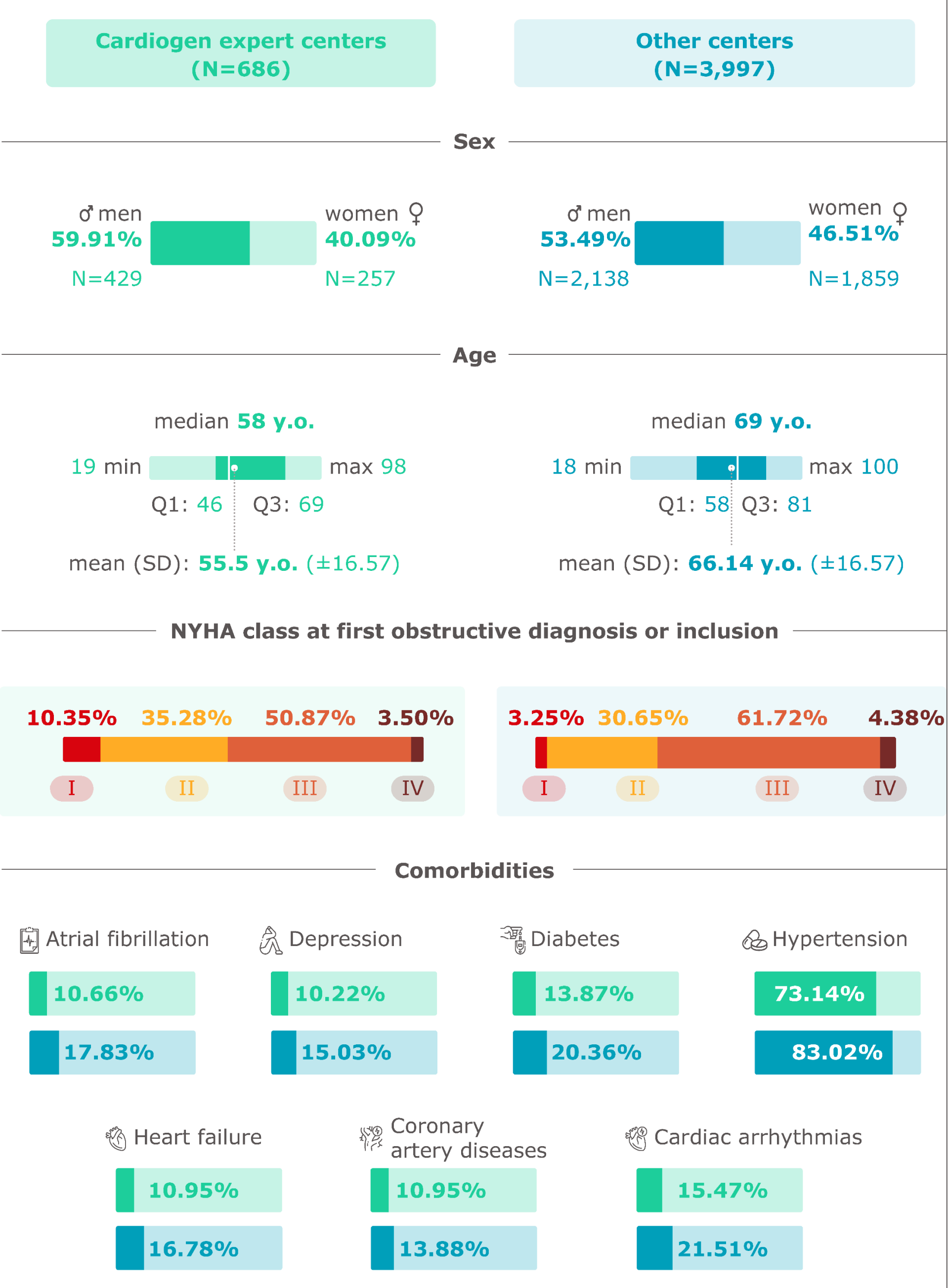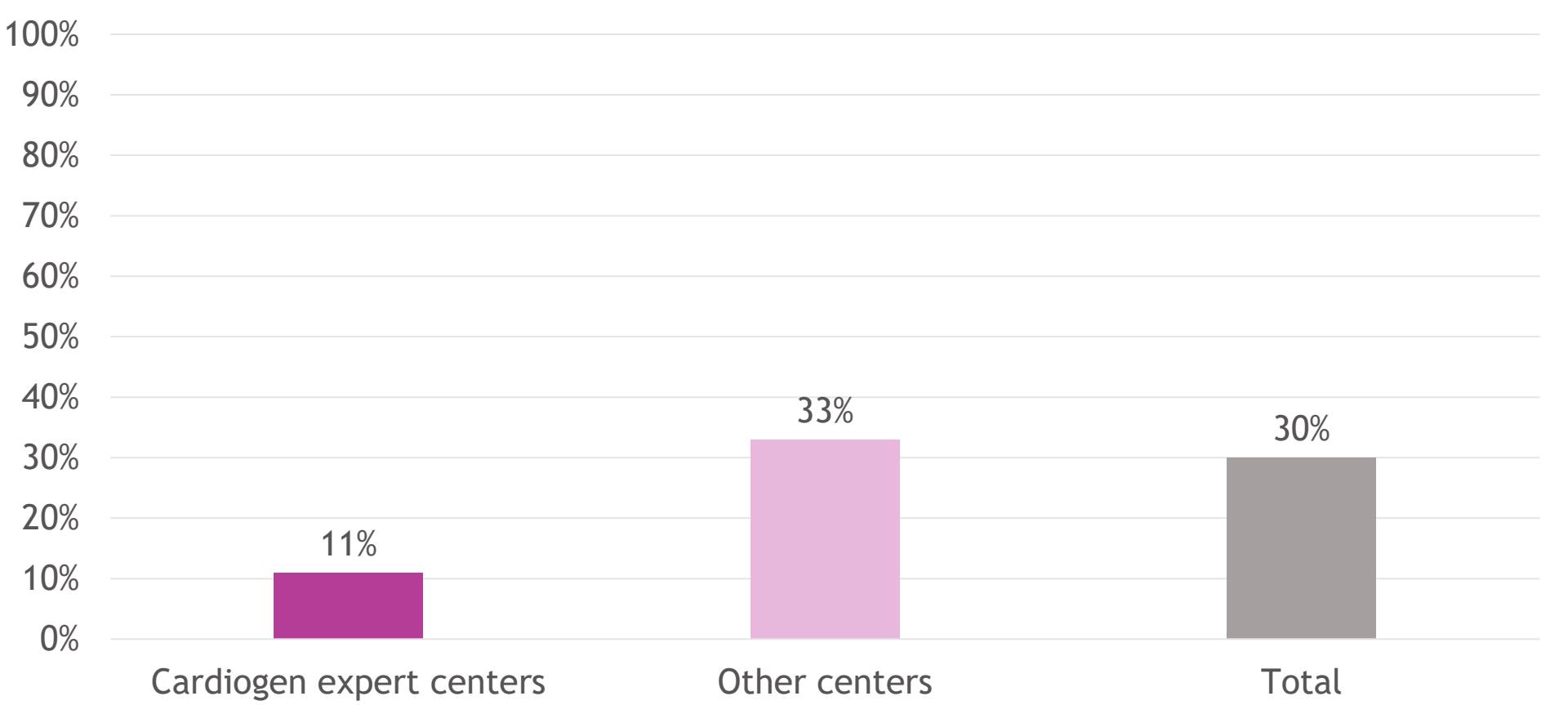### Figure 7. Baseline patient characteristics by hospital type

Table 1. Principal diagnosis at index date by hospital type

	Patients with HCM as Principal Diagnosis	Patients with HCM as Related or Associated Diagnosis	Patients with HCM as Related or Associated Diagnosis at index date	
			MI, Stroke, TIA, or DVT/PE as Principal Diagnosis	HF, AF or VF as Principal diagnosis
Cardiogen expert centers, N (%)	221 (32.2)	480 (70.0)	14 (2.04)	84 (12.24)
Other centers, N (%)	826 (20.67)	3,215 (80.44)	181 (4.53)	746 (18.66)

- One third of patients entered the hospital through the emergency department for the index stay.
- In Cardiogen expert centers, a higher proportion of patients had HCM as a principal diagnosis at index date (Table 1).
- Moreover, the patients whose first hospital-based HCM diagnosis was made at a Cardiogen expert center were less likely to come in through the emergency department (Fig. 9). This could be explained by the higher frequency of individual and familial screening in such centers.

Figure 9. Emergency admission for index stay, by hospital type

Conclusion

This is the first study describing oHCM patient diagnosis and management by regions in France. Nearly half of the patients were hospitalized with oHCM without previous regular cardiological monitoring, with high regional disparities. These results highlight a need for earlier detection and intervention.

References

1. Ommen SR, et al al. J Am Coll Cardiol 2020;76:e159-e240.
2. Elliott PM, et al. Eur Heart J 2014;35:2733-2779.
3. Tuppin P, et al. Rev Epidemiol Sante Publique 2017;65:S149-67.
4. Charron P, et al. Front Cardiovasc Med 2025 Jan 22:11:1458410.
5. Maron BJ, Ommen SR, Semsarian C, et al. J Am Coll Cardiol 2014;64:83-99.

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