

Describing the diagnostic journeys of transthyretin amyloid cardiomyopathy patients in the United States: a real-world survey

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INTRODUCTION

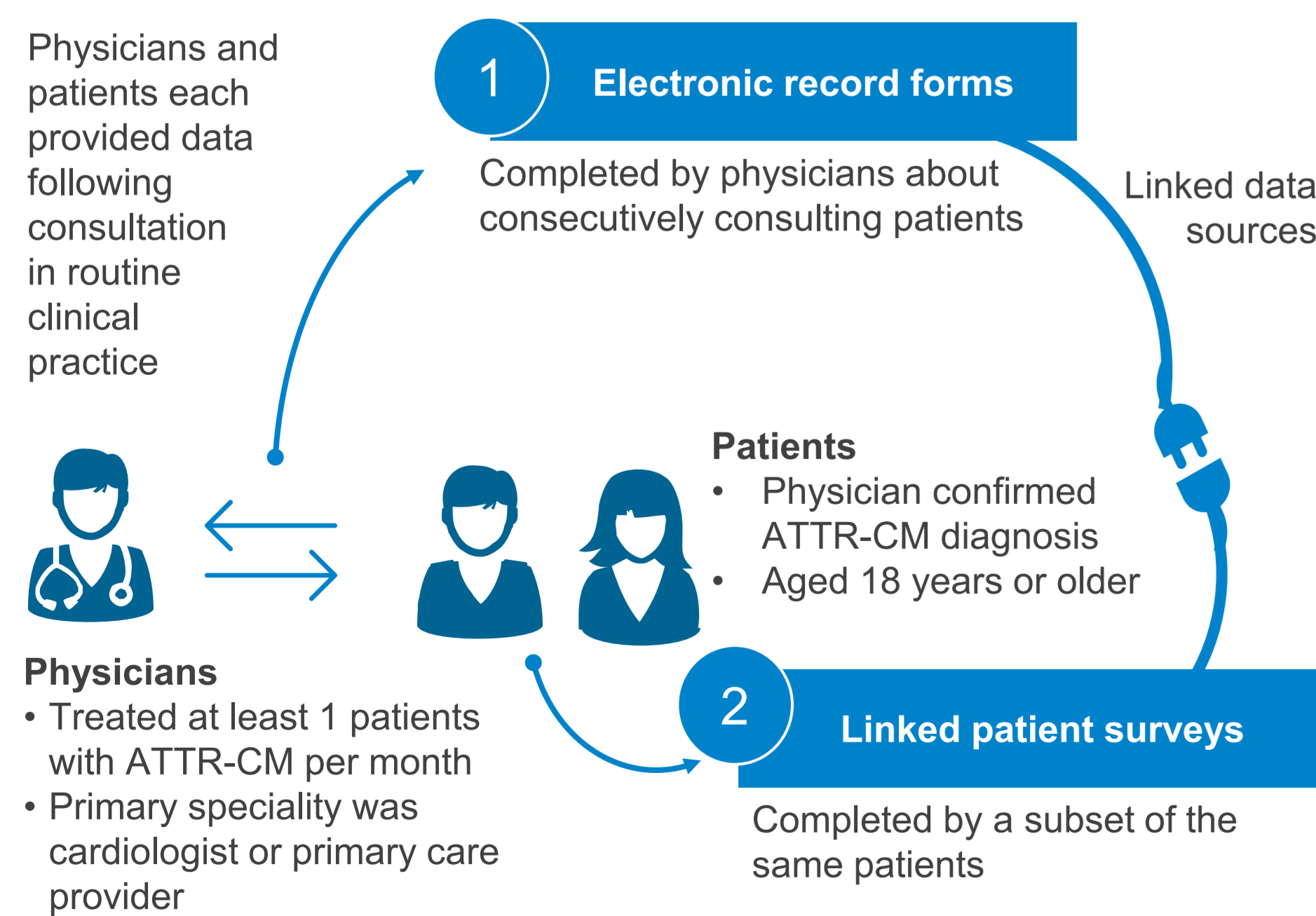
- While diagnostic times for ATTR-CM have improved in clinical practice, additional efforts are needed to enhance the patient experience, as the condition is often initially overlooked, leading to difficulties and delays in diagnosis reported by the patients¹.
- Transthyretin amyloid cardiomyopathy (ATTR-CM) is a rare and challenging form of heart failure (HF) to diagnose².
- Early recognition and diagnosis is crucial for optimizing treatment outcomes³.

OBJECTIVE

To describe referral pathways, diagnostic delays, and diagnostic testing for ATTR-CM patients in the United States (US).

METHODS

- Descriptive analyses of secondary data from the Adelphi Real World ATTR Disease Specific Programme™, a cross-sectional survey of ATTR treating physicians and their consulting patients, conducted in the US from August 2024 to February 2025.
- The DSP methodology has been published and validated⁴⁻⁷.
- Physicians provided information on patient demographics, healthcare professional involvement, diagnostic tests, diagnostic timelines, and prior diagnoses.
- Patients reported on diagnostic challenges encountered.



In total, 33 physicians provided data for 256 patients with ATTR-CM

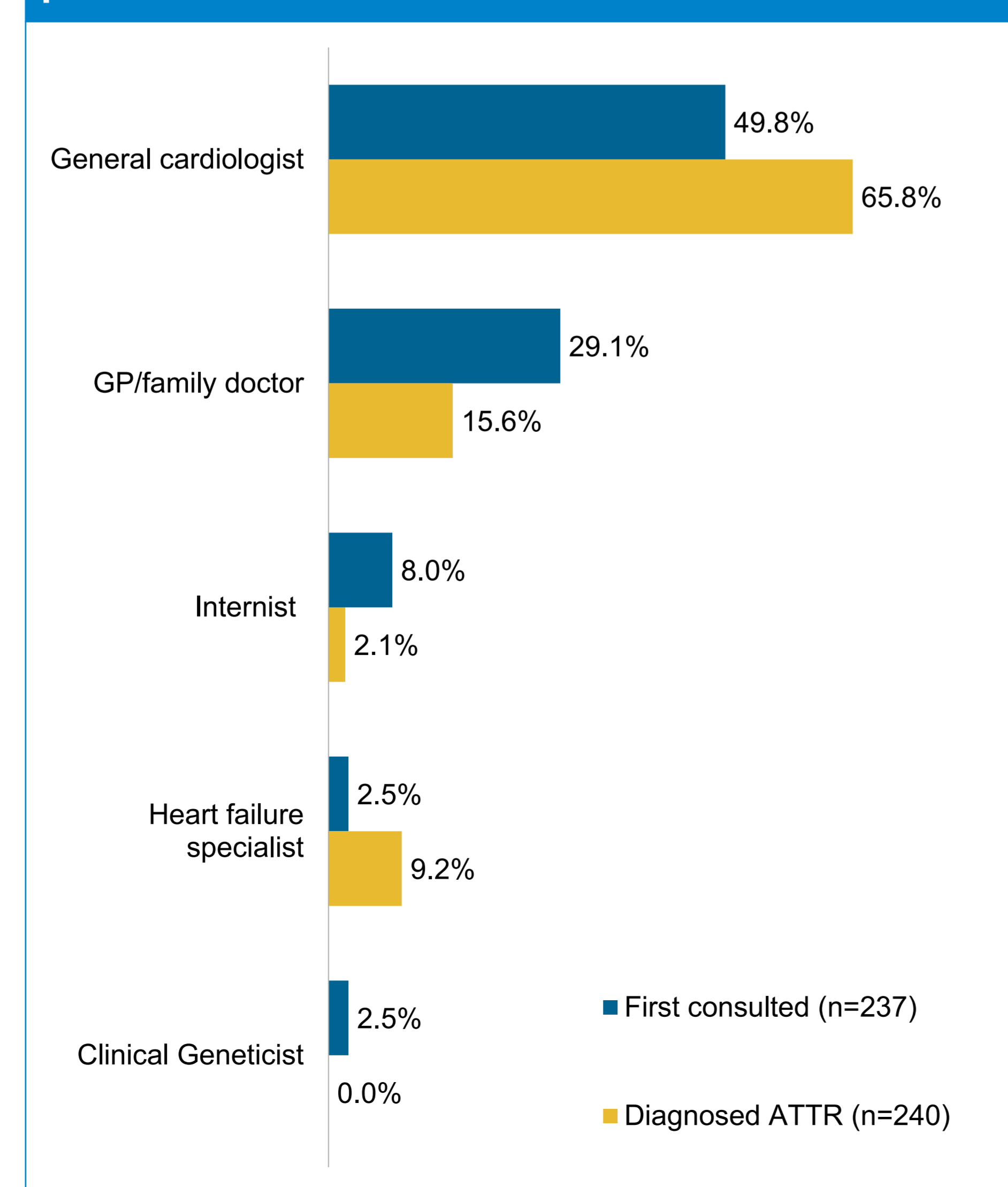
RESULTS

- Data from 33 physicians covering 256 patients were analyzed, with 58 patients self-reporting. Patient demographics are reported in Table 1.

	US (n=256)
Patient age (years); mean (SD)	63.9 (13.2)
Gender, male; n (%)	156 (60.9%)
Ethnicity, White; n (%)	143 (55.9%)
Mixed cardiomyopathy-neuropathy phenotype; n (%)	52 (20.3%)
NYHA class at time of survey; n (%)	
I	56 (21.9%)
II	139 (54.3%)
III	51 (19.9%)
IV	10 (3.9%)
Time in days since diagnosis; median (IQR) days	493.0 (306.3-814.3)

- General cardiologists most frequently conducted the first consultation (49.8%) and diagnosed two thirds of patients (Figure 1).
- The top 5 most frequently reported diagnostic assessments are presented in Figure 2.

Figure 1: Healthcare professionals that conducted the first consultation and ATTR diagnosis, % of patients



- Median (IQR) duration from ATTR symptom onset to first consultation and median (IQR) from first consultation to ATTR diagnosis are presented in Figure 3.

Figure 2: Top 5 most frequently reported diagnostic tests, % of patients (n=234)

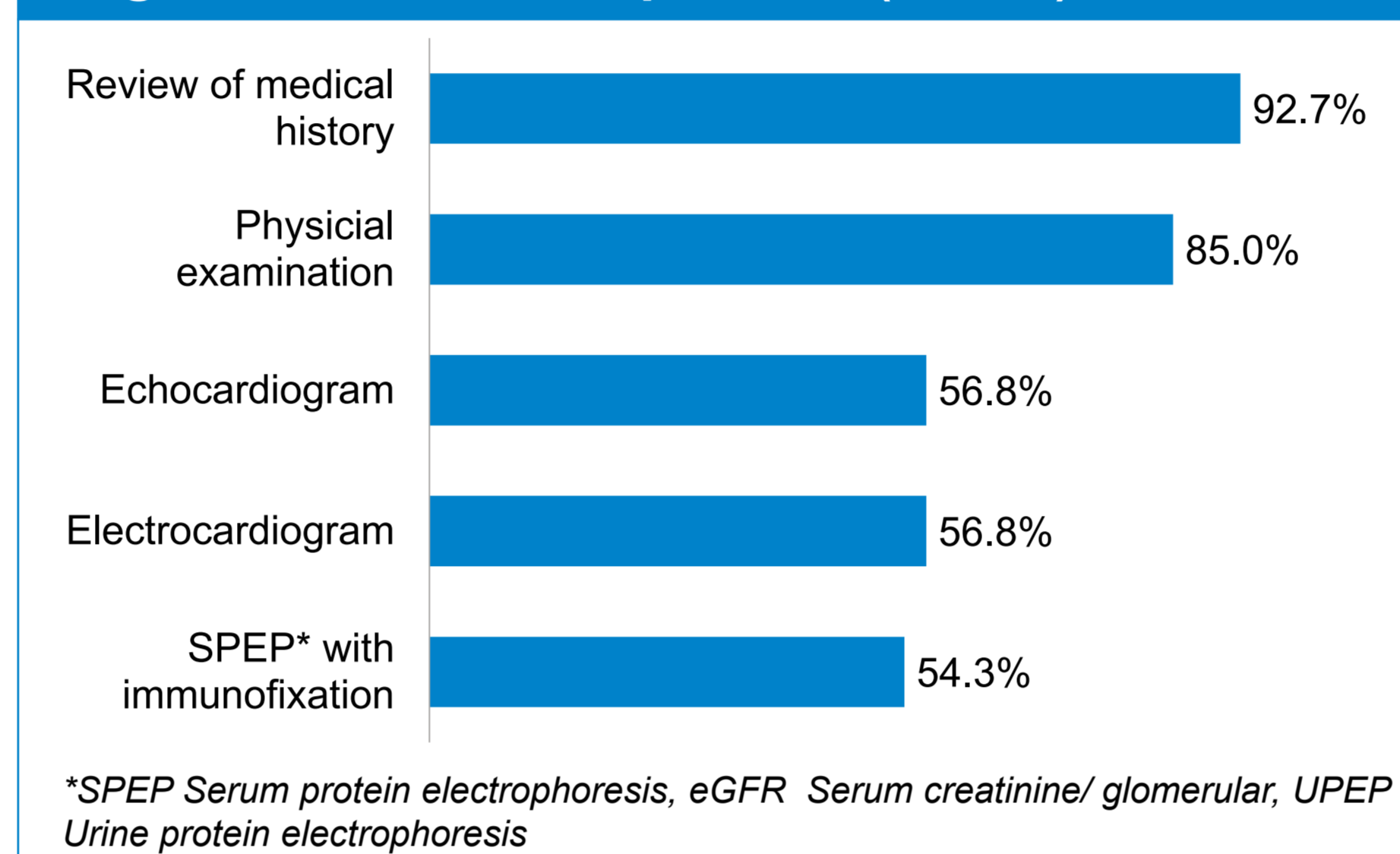
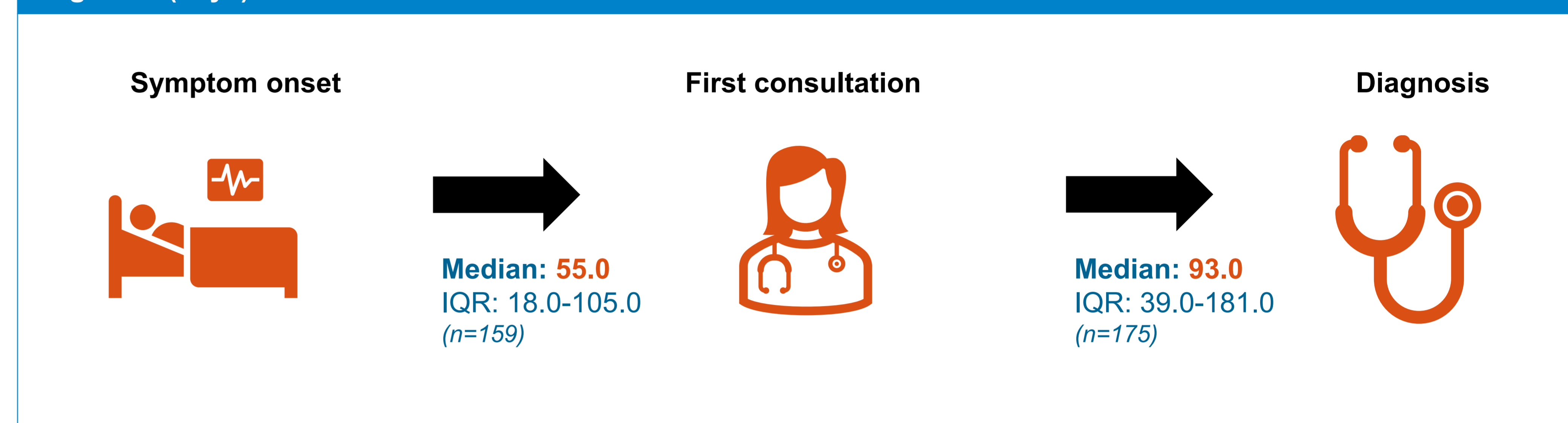
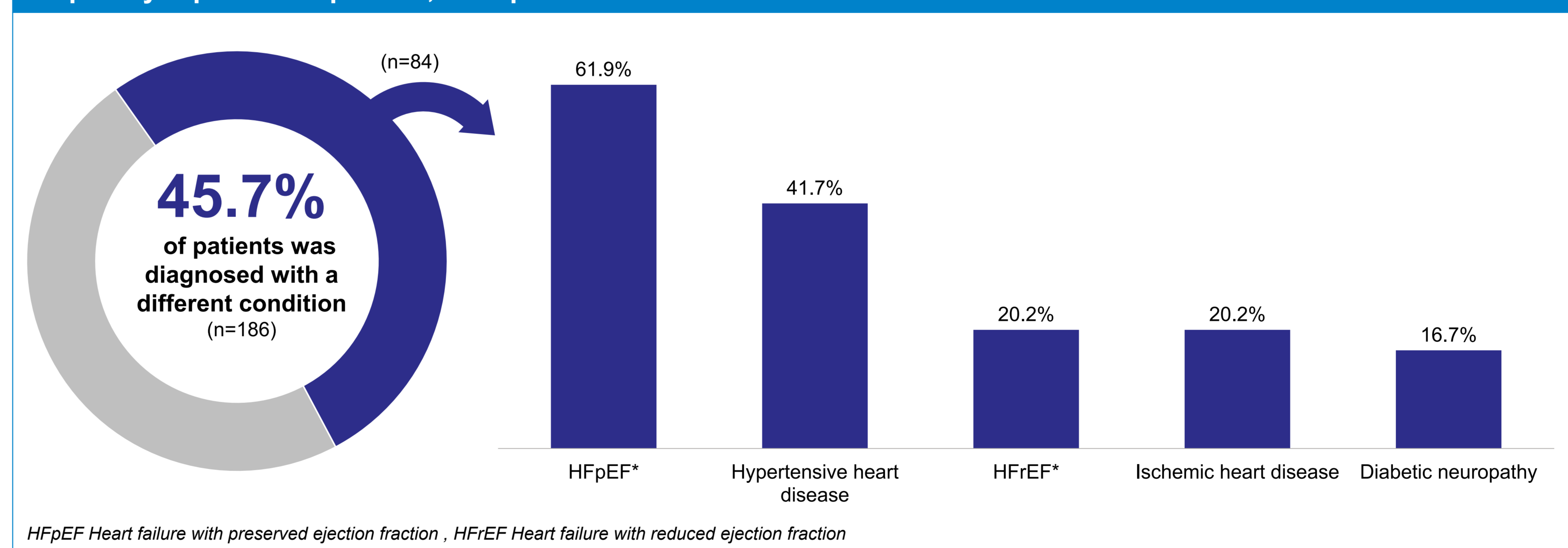


Figure 3: Duration from ATTR symptom onset to first consultation, and duration from first consultation to ATTR-CM diagnosis (days)



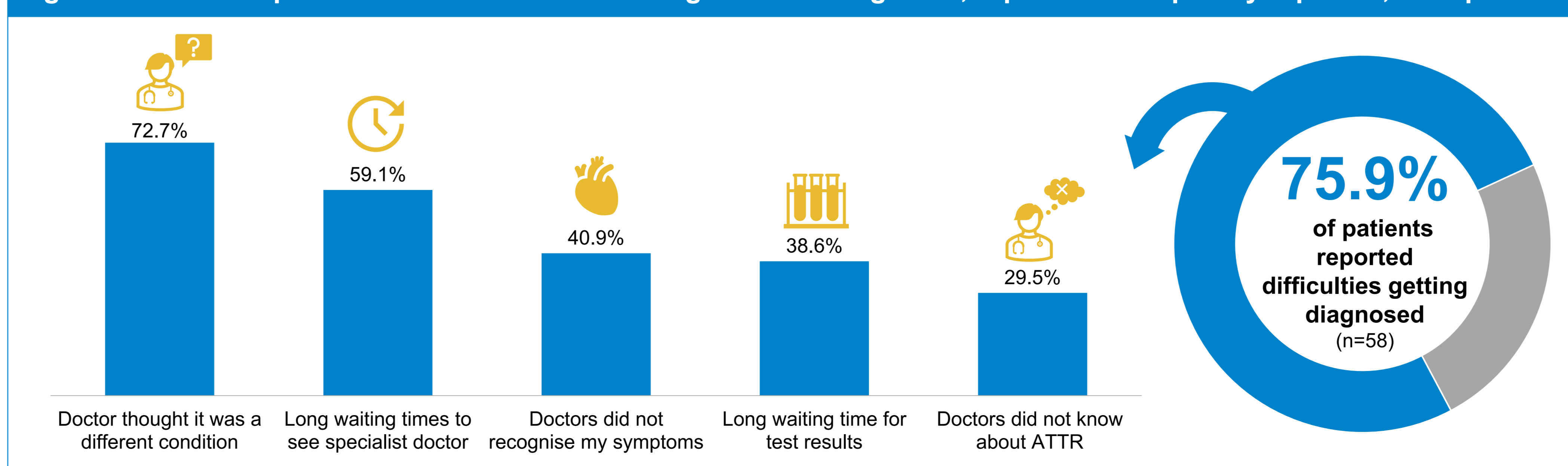
- Overall, 45.7% of patients were initially diagnosed with a different condition based on their ATTR symptoms (Figure 4). Prior diagnoses are presented in Figure 4.

Figure 4: Physician-reported prior diagnoses based on symptoms that were later attributed to ATTR-CM; top 5 most frequently reported responses, % of patients



- Most patients (75.9%) reported difficulties getting diagnosed; the most frequently reported issues are shown in Figure 5.

Figure 5: Patient-reported difficulties with receiving an ATTR diagnosis; top 5 most frequently reported, % of patients



CONCLUSIONS

- While a cardiologist was often the first specialist seen by patients, diagnostic approaches are inconsistent.
- Nearly half of the patients receive alternative initial diagnoses.
- Findings suggest that ATTR-CM remains underrecognized in clinical settings, contributing to prolonged diagnostic timelines and delayed intervention for patients.

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DISCLOSURES

- This study used data from the Adelphi Real world ATTR DSP, an independently conducted survey. The DSP is a wholly owned Adelphi Real World product. Pfizer were one of multiple subscribers to the DSP, and funded the analysis described here.
- JW, JGW, AB and KS are employees of Adelphi Real world.
- SMC, CB, AW, JC, PFB, MI are employees of Pfizer Inc and hold stocks/shares

LIMITATIONS

Participants from the DSP do not constitute a true random sample, as participation was influenced by willingness to complete the record forms.