

Burden of Patient Journey in the Management of Alpha-1 Antitrypsin Deficiency in Spain

Martínez Sesmero JM¹, Cabeza Barrera J², Quintero P³, Campins L⁴, Roch M⁵, Zamora D¹, Montoro JB⁵

¹Hospital Clínico San Carlos – Madrid (Spain); ²Hospital Universitario San Cecilio – Andalucía (Spain); ³Hospital Virgen del Rocío – Andalucía (Spain); ⁴Hospital de Mataró, Consorci Sanitari del Maresme – Barcelona (Spain); ⁵Hospital Universitario de la Vall d’Hebrón – Barcelona (Spain)

INTRODUCTION

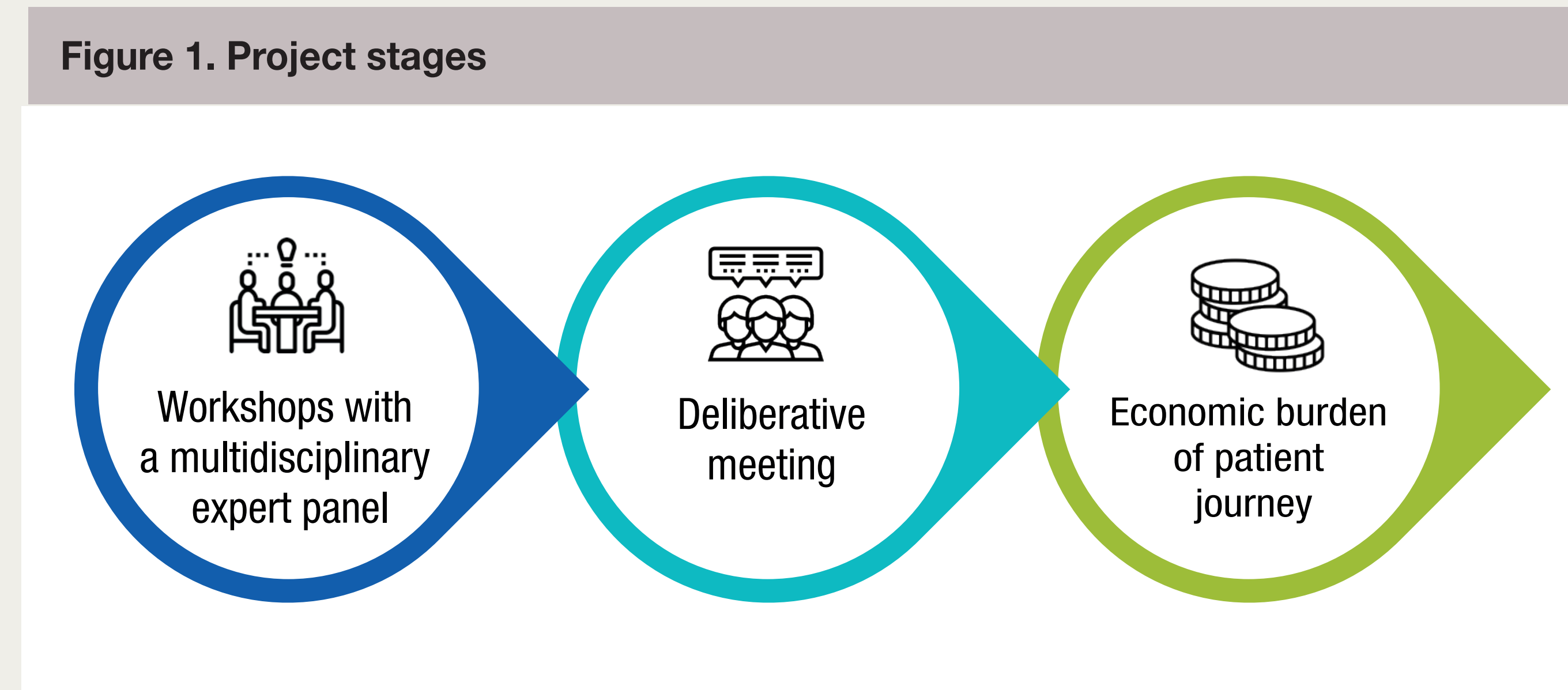
- Alpha-1 antitrypsin deficiency (AATD) is a rare genetic disorder affecting an estimated 3.4 million individuals worldwide¹ and is characterised by a reduced serum concentration of alpha-1 antitrypsin and/or the identification of a defective genotype².
- As a progressive lung disease, it is important that the patient takes an active role in the management of their disease. For this, there are patient-reported experience measures (PREMs) that capture a person’s perceptions of their experience while receiving care. Within PREMs, the most used technique is the patient journey, a cross-cutting process used to focus and improve healthcare processes around patient care by analyzing the patient’s experience during their illness³.

OBJECTIVE

The aim of this study was to define the patient journey in the treatment of AATD in the day hospital, from the perspective of healthcare professionals in Spain, and to estimate the economic burden that this process implies for the healthcare system.

METHODS

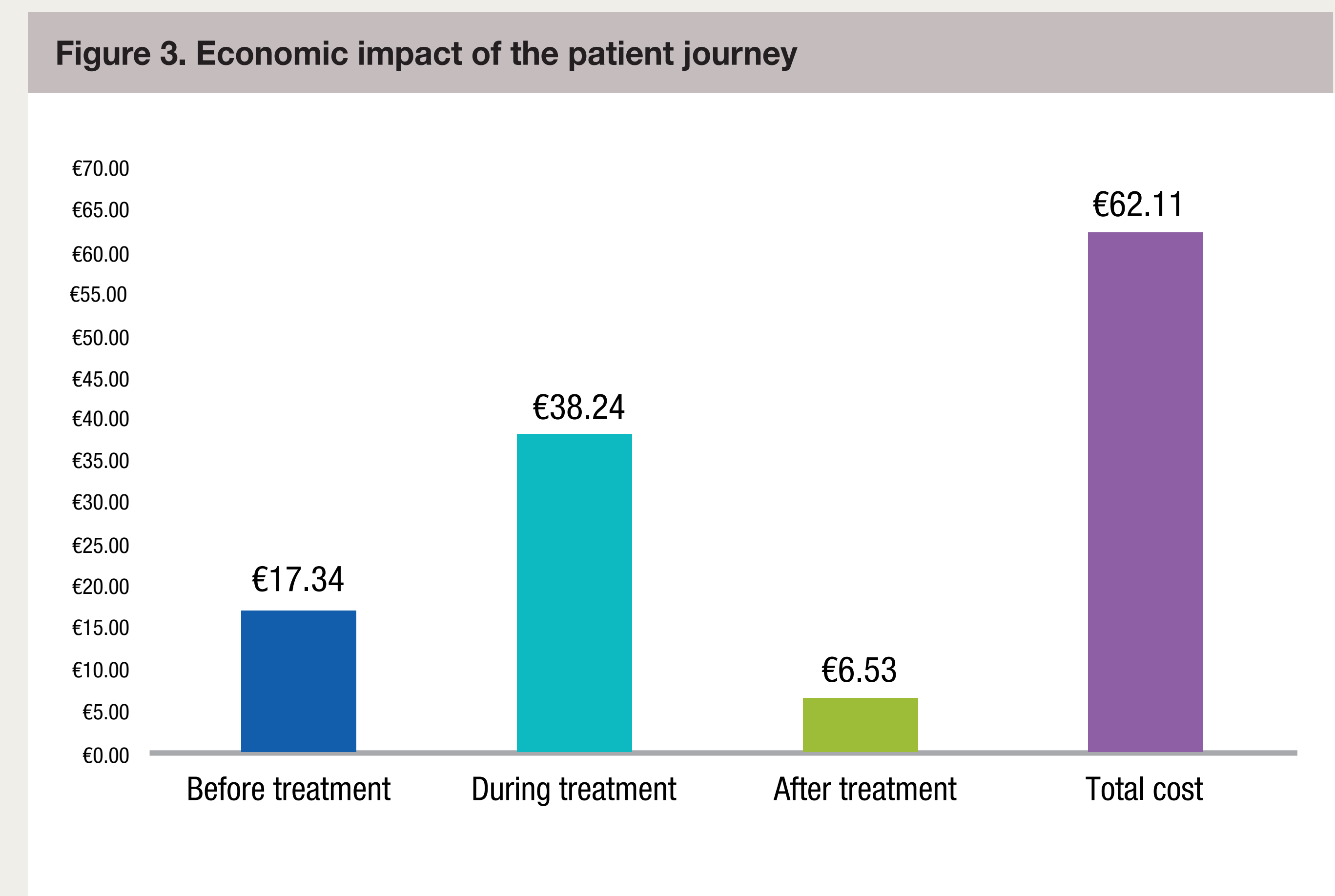
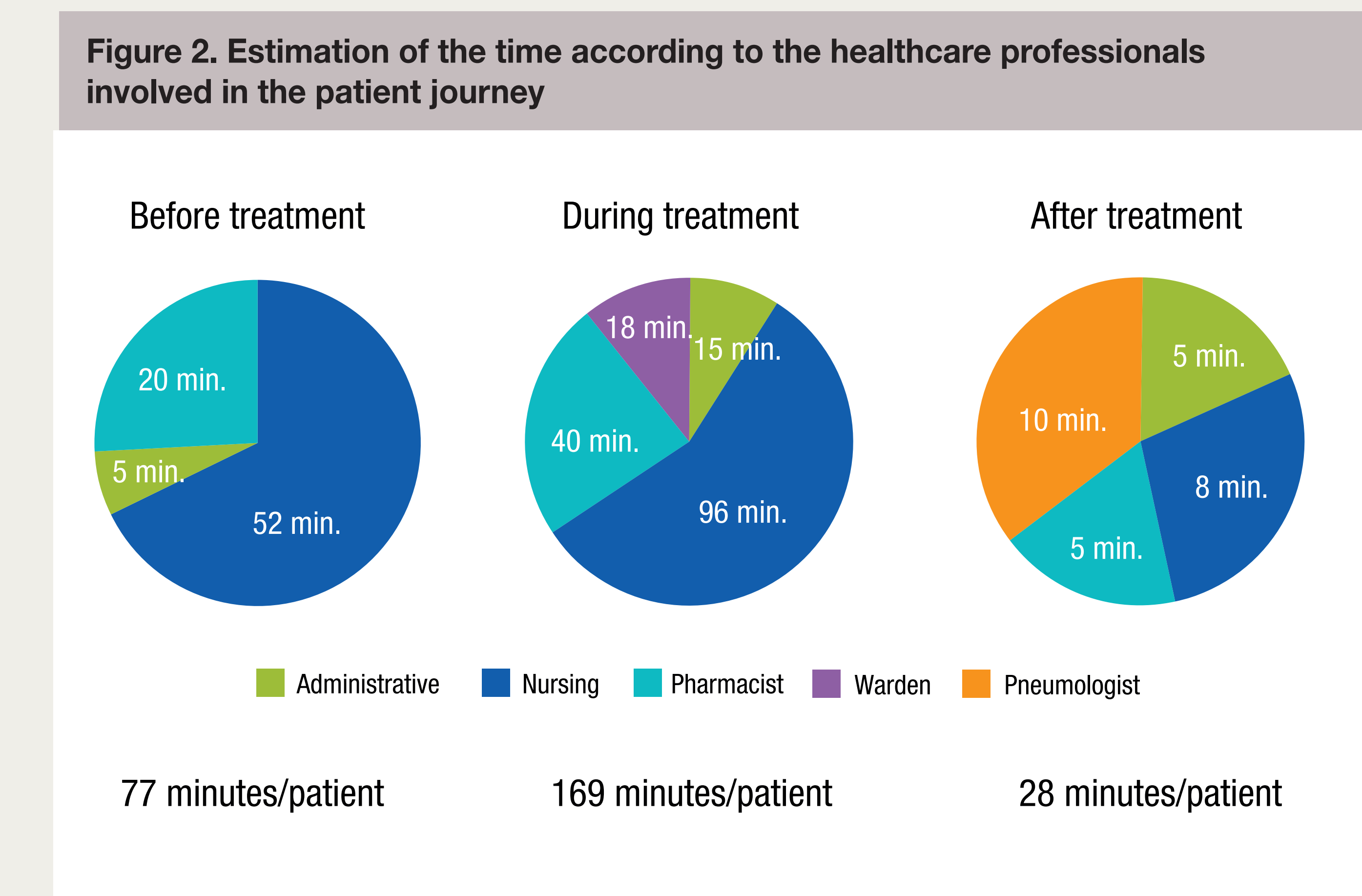
- A qualitative study was carried out in 3 different stages (Figure 1):



- Three workshops were carried out with a multidisciplinary expert panel (8 pneumologists, 8 pharmacist and 5 nurses) to collect the actions, time and healthcare professional involved in the patient journey.
- Subsequently, a consensus meeting was held to validate and agree on the actions and timings as well as the representativeness of the patient journey in Spanish clinical practice.
- Finally, the economic burden associated with the process was quantified. For it, we considered the time spent by each specialist in the different phases and the costs of the professionals per minute, which were obtained from the salaries published in the Spanish official bulletins (administrative, €0.16; warden, €0.13; nursing, €0.22; pharmacist, €0.27 and pneumologist, €0.27)⁴⁻¹⁵.

RESULTS

- The starting point of the patient journey is established at the time the patient arrives at the day hospital and the end point, once the patient leaves the day hospital immediately after receiving treatment. Three phases were identified: 1) before treatment; 2) during treatment; and 3) after treatment.
- An average time was estimated at 77 minutes/patient, 169 minutes/patient, and 28 minutes/patient for phase 1, 2 and 3, respectively (Figure 2).
- In phase 1, the estimated average cost per patient was €0.81 for administration staff, €11.09 for nursing and €5.44 for pharmacy.
- During the phase 2, cost per patient was estimated at €1.98, €20.56, €10.89, and €4.81 for the warden, nursing, pharmacy and pneumology, respectively.
- In the phase 3, an average cost per patient was estimated at €0.81 for administration staff, €1.61 for nursing, €1.36 for pharmacy, and €2.75 for pneumology.
- The total cost of the entire process was €62.11 per patient (Figure 3).



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CONCLUSIONS

Use of the patient journey can help clinicians to understand the experiences their patients go through helping them to develop patient-centred treatment.

In this case, the patient journey related to the treatment of AATD is widely conditioned by the long time required to prepare and administrate the drug. Reducing this time should be a priority to healthcare professionals to reduce the burden of care on the healthcare system.