

# IDENTIFYING THE MAIN SYMPTOMS OF LONG COVID BY COMPARING REAL-WORLD MEDICAL DATA AND SOCIAL MEDIA CONTENT

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Poster presentation and discussion

## BACKGROUND

The COVID-19 outbreak is declared a pandemic in March 2020

- Long COVID infection, characterised by persisting symptoms, emerges
- Patients describe the illness and would like it to be recognised and understood
- Most studies are based on patients hospitalised [ 1 ] with severe COVID
- GPs remain patients' main medical correspondents, irrespective of how serious their initial infection was [ 2 ]

## OBJECTIVES

- To widely examine the main symptoms of Long COVID, as described by patients themselves
- To compare two sources of real-world data obtained either when patients received medical care or when they posted public testimonials on social media

## MATERIALS AND METHOD

### Data from social media

Posts on French-speaking social networks between January 2020 and August 2021  
 Collected using Brandwatch® and MedDRA

### Type of study

Retrospective observational

### Data from medical consultations

Long COVID symptoms and diagnoses where the patient has no other pathology [3] available in the THIN® France database, 6 months after acute infection  
 Collected between March 2020 and March 2022

## RESULTS

The automated language processing algorithm filtered messages detailing actual medical experiences, creating an analysis corpus of 5,364 users (6,484 messages). And 73,338 patients suffering from Long Covid within six months of their acute infection were identified in THIN®

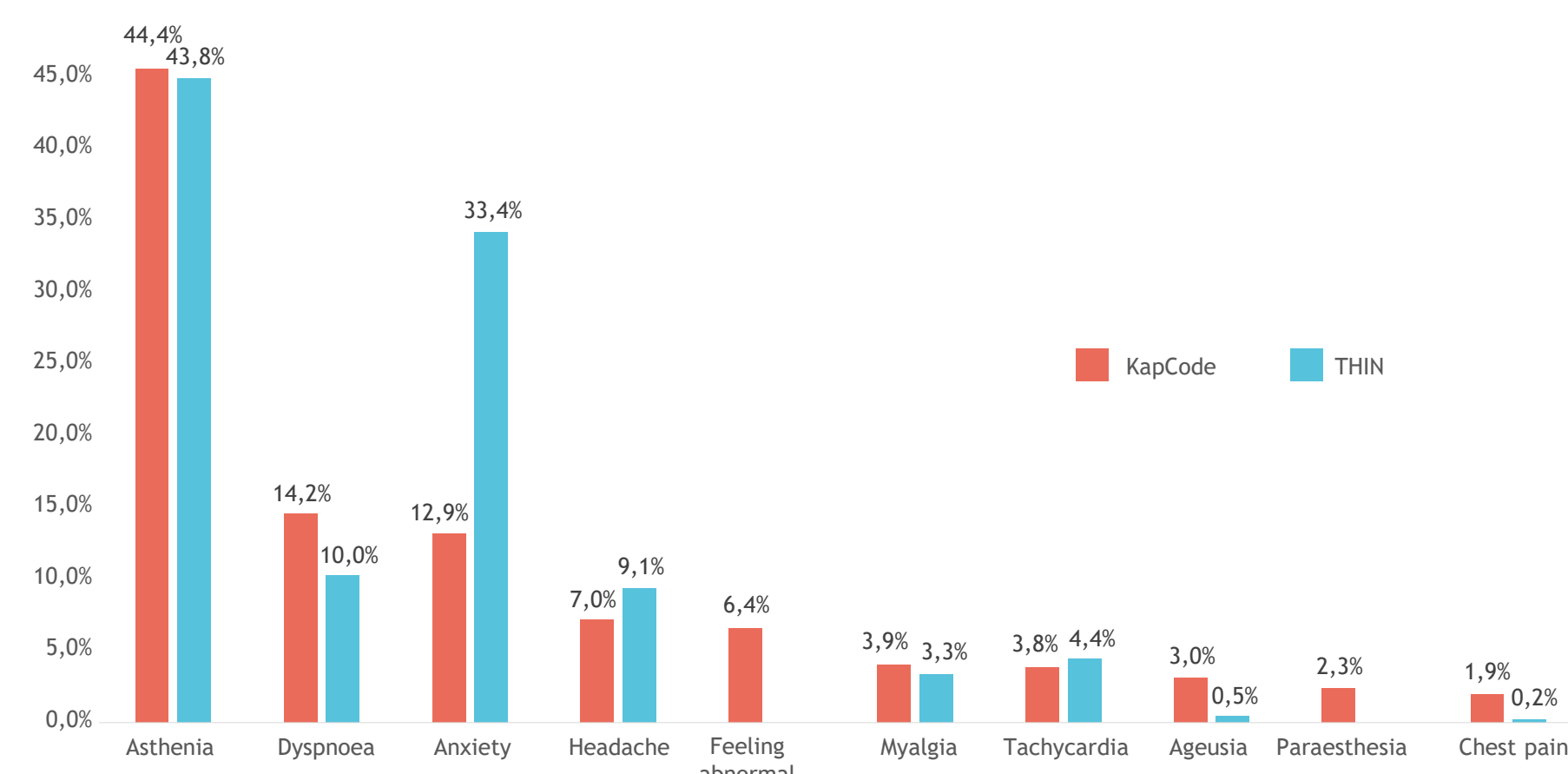


Figure 1. Symptoms associated with Long COVID: social media content compared with medical consultation content

- Top 3 of most frequent symptoms in both Long COVID populations are the same: asthenia, dyspnoea and anxiety (figure 1)
- In social media, we can observe (figure 2):
  - In 35.3% of patients, asthenia is combined with dyspnoea
  - In 22.5% of patients, asthenia is combined with anxiety
  - In 17.3% of patients, asthenia is combined with headache

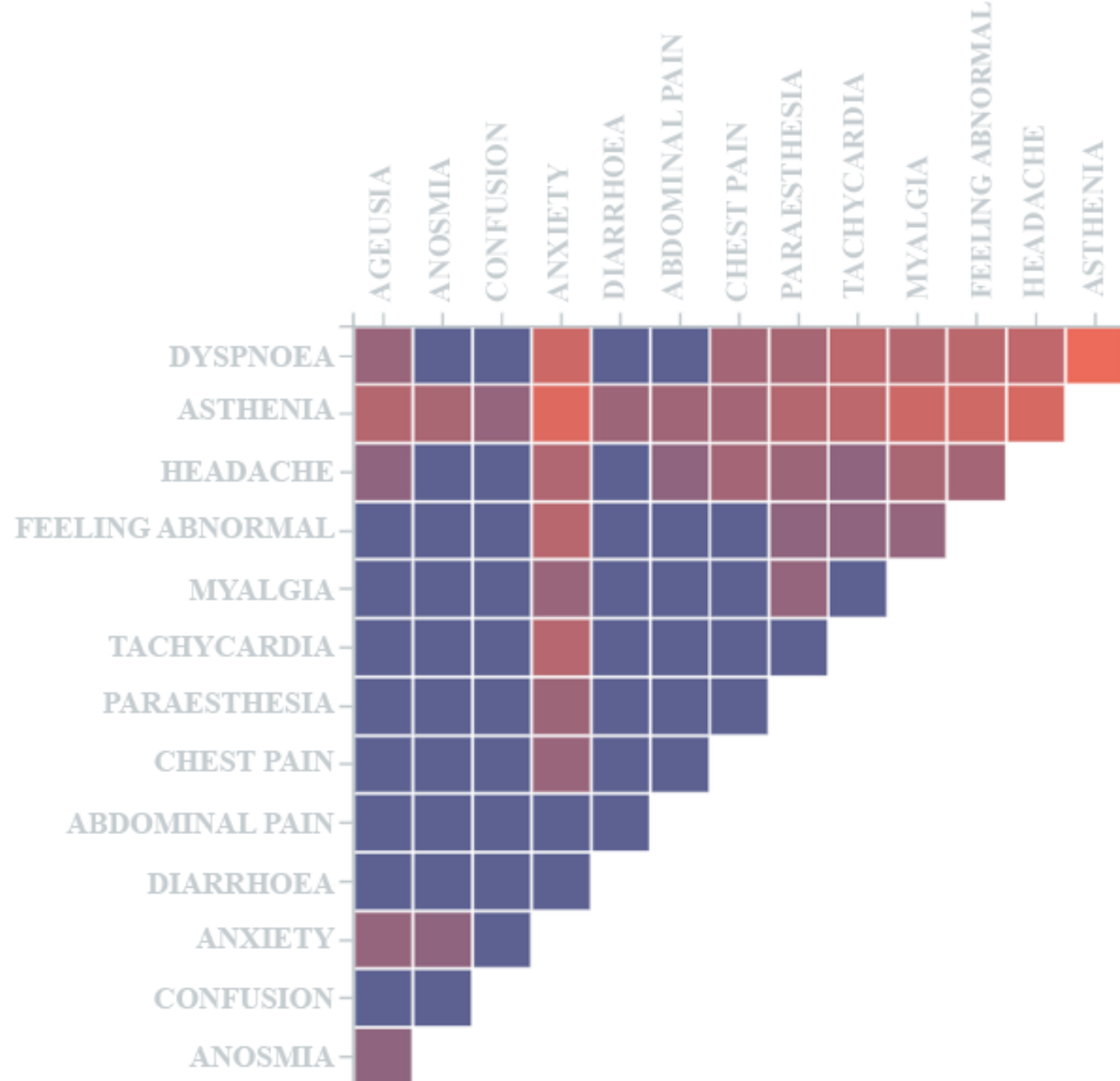


Figure 2. Co-occurrence of concomitant symptoms in social media

Figure 3. Co-occurrence of concomitant symptoms in THIN®

- In consultations information, we observe (figure 3):
- In 20.1% of patients, abdominal pain is combined with diarrhoea
  - In 17.1 % of patients, asthenia is combined with anxiety
  - In 9.9 % of patients, asthenia is combined with dyspnoea

“@ApresJ20 Brain fog is worse on day 141, but is this a relapse? I’ve been taking vials of vitamin b12 for a few days, but this morning the top of my skull aches and the fatigue has also got worse”

“I was diagnosed on April 7. The symptoms started before then. Today I am still stiff and aching and very tired. I have a lump in my throat and I feel breathless after the slightest effort. I feel like I’m choking 24/7. I’m fed up with paracetamol #ApresJ20”

“D458 - March 01, 2020 / June 1, 2021, 15 months of Long COVID. Thanks to treatment, all symptoms reduced, except fatigue. With 2 naps a day, I’m bearing up #ApresJ20”

We used automatic clustering to identify 3 different patient groups, based on the symptom combinations (figure 4).

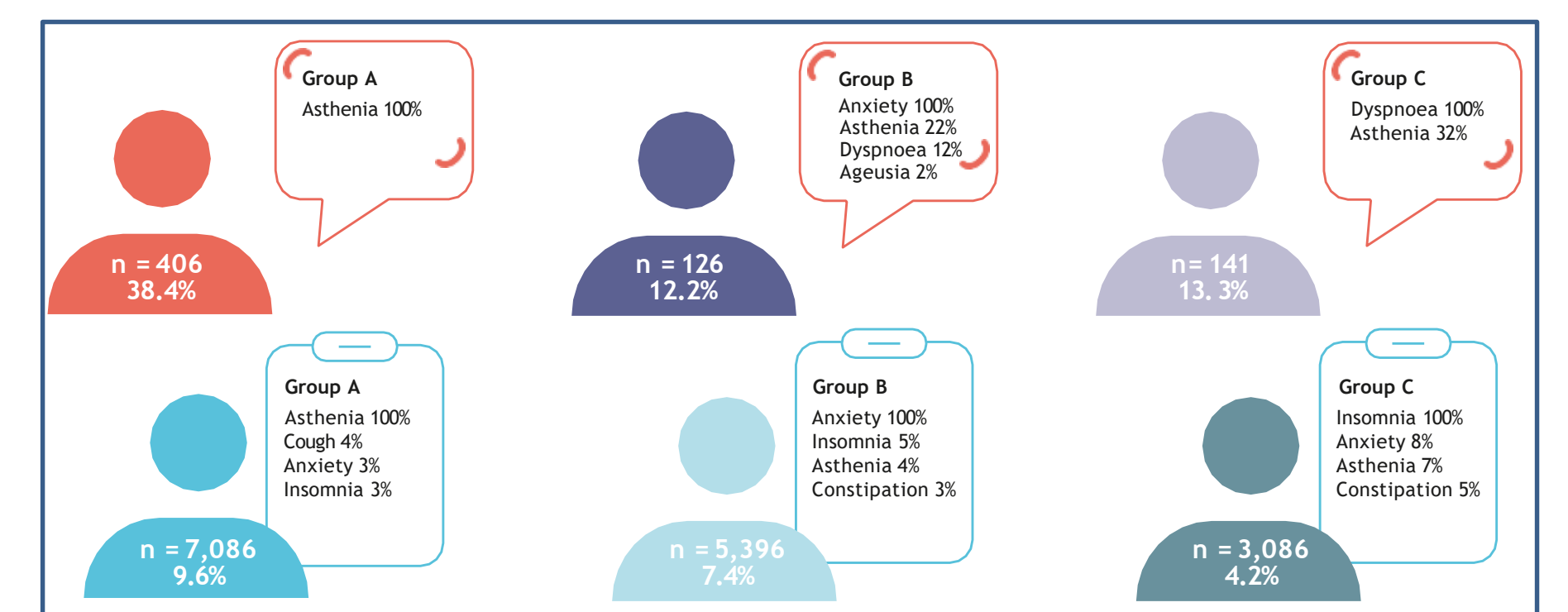
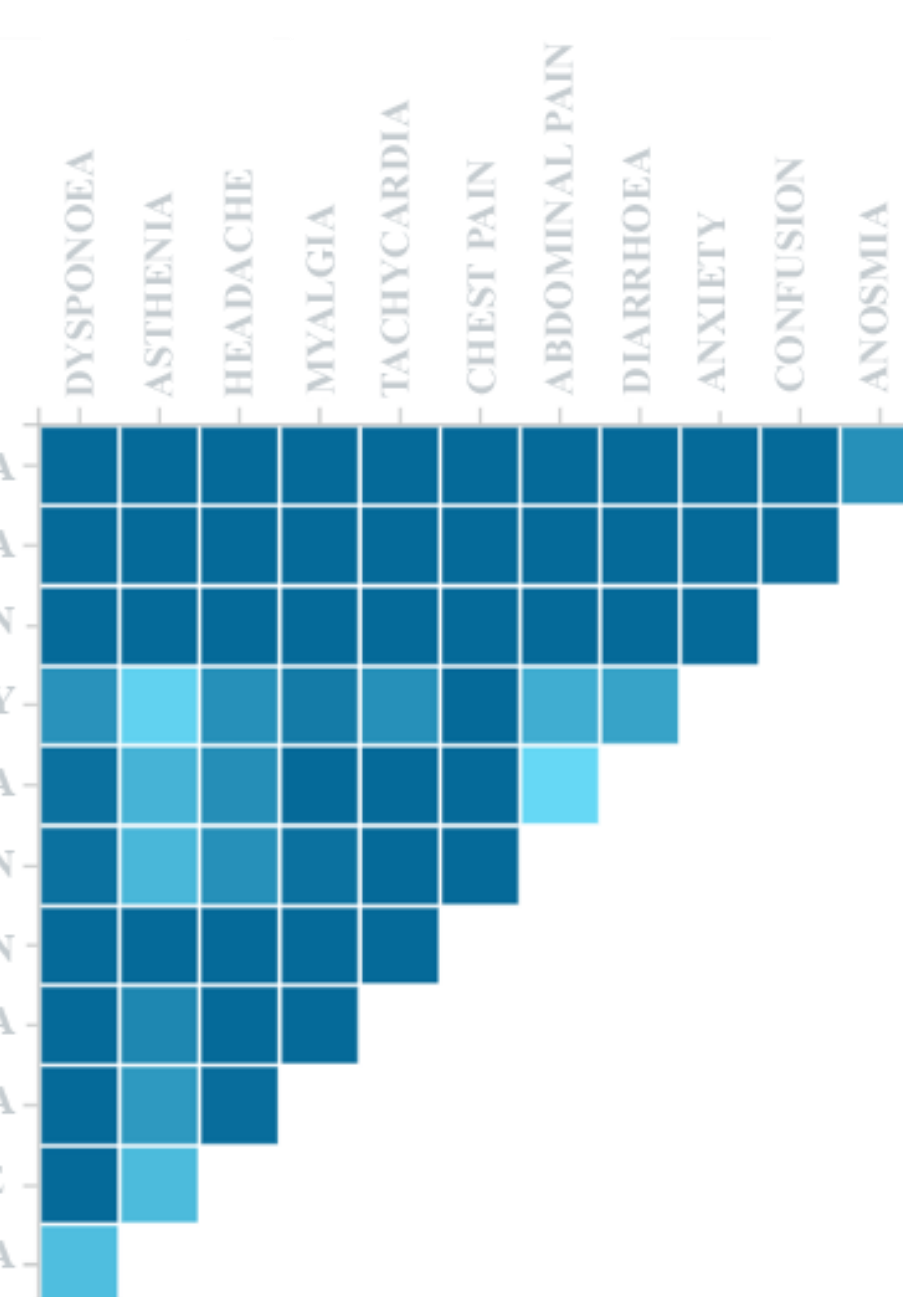


Figure 4. Patient groups according to the symptoms observed

- In Social media, we observe (figure 5):
- 6 17 posts (1 6 1 patients) refer to “persistence” of symptoms
  - Posts are grouped together per individual
  - Temporal evolution, assessed every quarter, based on their own testimonials, using language rules (REGEX)
  - Half the contributors said they still had symptoms more than 6 months on, and 16.1% more than a year later

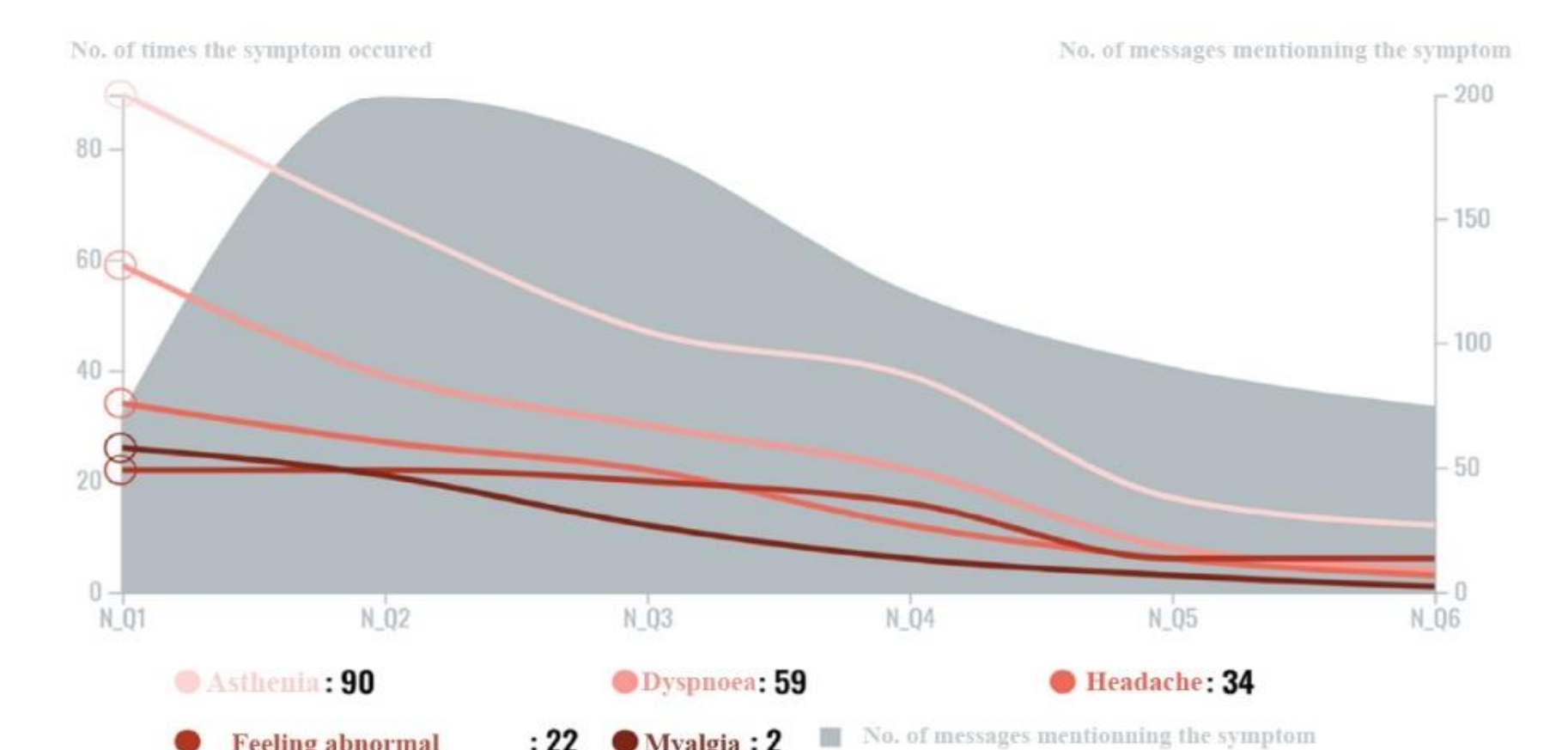


Figure 5. Symptom persistence and temporal evolution

GP consultation data: Asthenia (14.2%), anxiety (13.7%) and dyspnoea (2.7%) are always among the symptoms mentioned by patients after the date Long COVID was diagnosed (figure 6).

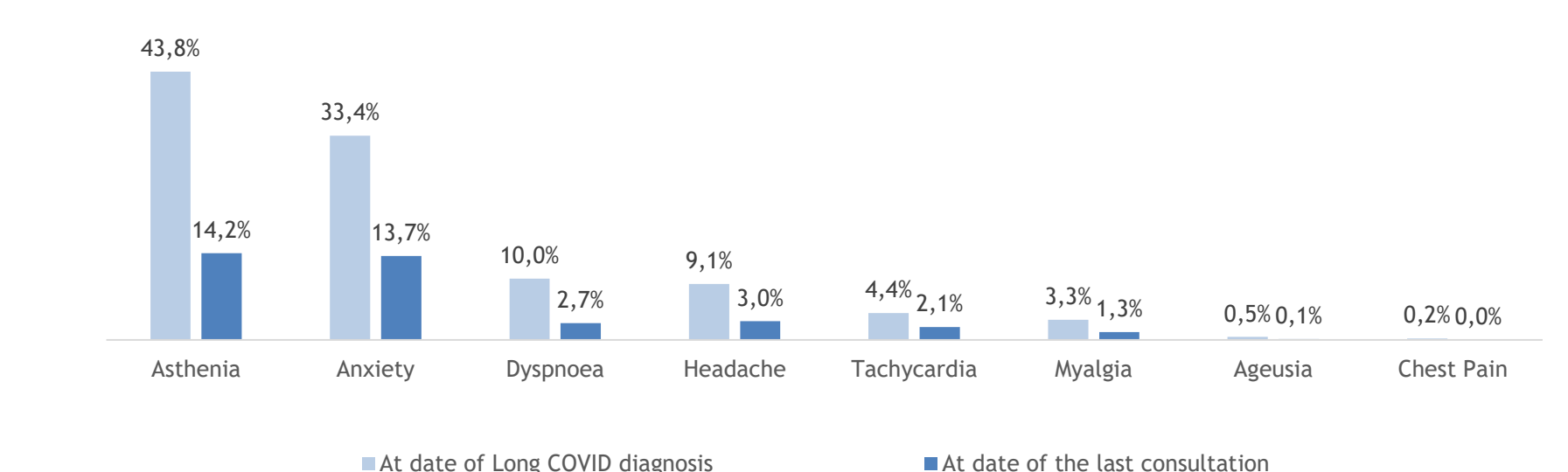


Figure 6. Long covid symptoms persistence

## DISCUSSION & CONCLUSION

Comparing two sources of real-world data to identify symptoms of Long COVID proved highly relevant since the signs found in both sources concurred. Patients have played a crucial role in defining their own symptoms and illness. Thanks to them, the medical community and health institutions have a better description. This has improved their ability to recognise and diagnose the illness. The anxiety we identified in both data sources is a consequence of the illness and is prompted by the severity of the symptoms and the difficulty patients encounter in obtaining care. The data collected from GP consultations confirms the symptoms mentioned early on by patients in social media posts. The public authorities must factor in real-world data sources to improve the care provided for people with Long COVID. The limitations of this study concern the different temporal windows for the proactive analysis of social media data and retrospective analysis of GP consultation data. This could explain why we were not able, or hardly able, to identify some patient profiles (digestive, cardiac, neurological, vascular or cognitive disorders) as specified by the #ApresJ20 patient group. A comprehensive approach that includes participatory research protocols, accounts for the fact that Long COVID is a multi-systemic, fluctuating illness, and factors in the patients' own experience-based knowledge, would definitely help guide public health policies. Long COVID is a new and complex illness, and we should take a multidisciplinary, collaborative approach to understand it better and improve patient care.

<sup>1</sup>Walker AJ, MacKenna B, Inglesby P, Tomlinson L, Rentsch CT, Curtis HJ, Morton CE, Morley J, Mehrkar A, Bacon S, Hickman G, Bates C, Croker R, Evans D, Ward T, Cockburn J, Davy S, Bhaskaran K, Schultze A, Williamson EJ, Hulme WJ, McDonald HI, Mathur R, Eggo RM, Wing K, Wong AY, Forbes H, Tazare J, Parry J, Hester F, Harper S, O'Hanlon S, Eavis A, Jarvis R, Avramov D, Griffiths P, Fowles A, Parkes N, Douglas IJ, Evans SJ; (The OpenSAFELY Collaborative). Clinical coding of long COVID in English primary care: a federated analysis of 58 million patient records in situ using OpenSAFELY. Br J Gen Pract. 2021 Oct 28;71(712):e806-e814. doi: 10.3399/bjgp.2021.0301. PMID: 34340970; PMCID: PMC8340730.

<sup>2</sup>L'affection post-COVID-19 (aussi appelée COVID long) en France. Results of the "Affection post-COVID" (post-COVID illness, also called Long COVID) survey, March 22 - April 8 2022. Saint-Maurice : Santé publique France, 5 p. Publishing Director : Pr Geneviève Chêne. Legal deposit: July 21, 2022.

<sup>3</sup>Haute Autorité de Santé. Symptômes prolongés suite à une COVID-19 de l'adulte - Diagnostic et prise en charge. Saint-Denis La Plaine: HAS (French national authority for health (HAS)). Prolonged symptoms after COVID-19 infection in adults - diagnosis and care.

