

# WHAT IS THE ANCA-ASSOCIATED VASCULITIS COMMUNITY DISCUSSING ONLINE? A SOCIAL MEDIA ANALYSIS FROM 5 EUROPEAN COUNTRIES

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## INTRODUCTION

ANCA-associated vasculitis (AAV) is a severe inflammatory condition with major impacts on patient reported outcomes and experience. This experience will be vary between patients and over time as the disease remits and relapses. Treatment choices and the impact, both positive and negative of specific drugs will be relevant.

It is important to understand patient unmet needs and appreciate their perspective on clinical trials, new developments and guideline recommendations.

There is little published evidence regarding patient reported experience in AAV – social media is an important platform to consider and examine since patients discuss their concerns spontaneously.

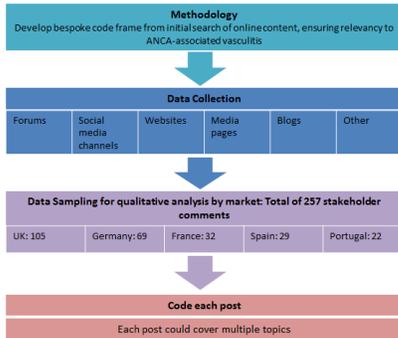
This study aimed to examine the scope and content of social media conversations about AAV in Europe in order to better understand challenges, unmet needs and patient experience.

## METHODS

**STUDY DESIGN.** The study collected data using the Radarly platform and a defined list of specific AAV terms – these search terms were translated into local language to allow cultural nuances to be captured. The period covered 01/10/2016 until 30/9/2018 and was conducted in UK, Germany, France, Spain and Portugal.

**INCLUSION & EXCLUSION CRITERIA.** All conversations were analysed and the source was determined – patient, healthcare professional or other individual.

**DATA COLLECTION AND ANALYSIS.** As well as an overall analysis a sub sample was taken to examine in more detail in order to perform qualitative analysis and categorise discussions into unmet needs and challenges, symptoms and treatments.



## RESULTS

Figure 1 – There was significant variation between countries on the amount, content and platforms for AAV discussions.

Online AAV discussion was most common in the UK driven by significant patient social media use. This translated to a high reach (users exposed to the post) – 1.57 million vs maximum of 255,000 in other countries

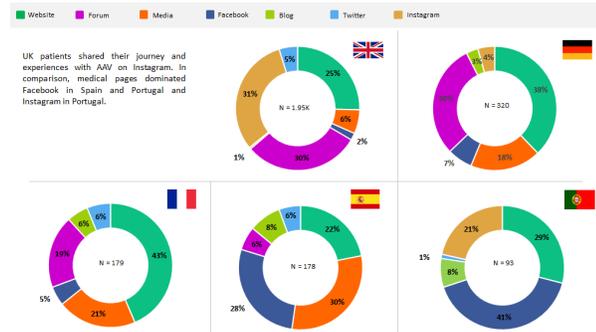


Figure 2 – A variety of individuals are using social media to discuss AAV – patients are more active in some countries

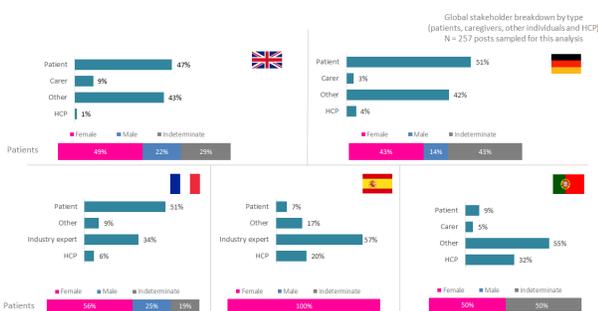
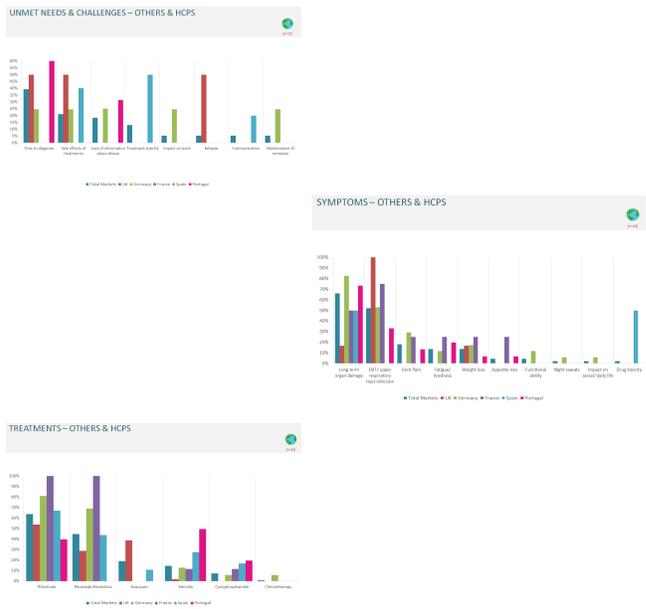


Figure 3 – Detailed qualitative analysis of patients social media discussions demonstrates their priorities revolve around impact of AAV on their life, delays to diagnosis, local symptoms and the impact of glucocorticoids



Results 4 – Health care professionals and other individuals were discussing different priorities on social media in terms of unmet needs, symptoms and treatments



## CONCLUSIONS

This study has demonstrated that the AAV community is active on social media in European countries.

There is significant variation in the volume, originator, platform and content between countries. In some countries eg UK, patients are very active on specific social media platforms sharing their experiences and looking to support each other.

The detailed analysis has demonstrated the areas of particular concern for patients and discussed most online;

**Unmet need and challenges** – time to diagnosis, impact on their life and need for more information

**Symptoms** – local specific symptoms to the patient

**Treatments** – the impact of glucocorticoids

Attention should be paid to patient experience and opinion through social media discussions when considering new therapy options in AAV.

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