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Unmet needs and challenges in the diagnosis and management of antiphospholipid syndrome: a qualitative stakeholder study within the ReCONNET framework

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ABSTRACT

Objective Antiphospholipid syndrome (APS) is a rare autoimmune condition characterised by thrombosis and/or pregnancy morbidity in the presence of antiphospholipid antibodies. Despite the publication of updated American College of Rheumatology (ACR)/European Alliance of Associations for Rheumatology (EULAR) classification criteria in 2023, persistent diagnostic and therapeutic challenges remain. This qualitative study, conducted within the European Reference Network for Connective Tissue and Musculoskeletal Diseases, ReCONNET, aimed to map stakeholder-identified gaps in APS care across Europe to inform subsequent quantitative prioritisation.

Methods Between February and April 2025, we conducted 16 semistructured interviews with purposively sampled stakeholders (clinicians across different specialties—rheumatologists, haematologists, obstetricians, neurologists, general practitioners, paediatricians, researchers and translational scientists, health systems and policy professionals, laboratory medicine experts, pharmaceutical trialists, patient and research nurses, medical students and trainees). Transcripts were thematically analysed and categorised into three domains: clinical, systemic and educational/research-related unmet needs.

Results Over 85% of stakeholders cited delayed diagnosis as a major barrier. Eleven participants highlighted limitations of the current classification criteria in capturing all the clinical settings of APS. 75% (12 out of 16) identified lack of access to multidisciplinary teams as a barrier to optimal care. Nine respondents reported that warfarin remains the mainstay of therapy despite challenges in adherence and monitoring. Twelve stakeholders emphasised the need for integration across national or European APS registries and insufficient integration in rare disease policy frameworks. Gaps in undergraduate and postgraduate education were universally reported, with 100% of educational stakeholders noting minimal curricular exposure to APS.

Conclusion APS remains underdiagnosed, inconsistently managed and inadequately represented in both policy and education. This study identifies quantifiable stakeholder-perceived gaps that will inform the design of Europe-wide standardised, multidisciplinary strategies to improve APS care and research infrastructure within the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases and similar networks.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Antiphospholipid syndrome (APS) causes thrombosis and pregnancy morbidity, but diagnosis is often delayed, treatments have changed little in decades, and care remains fragmented.

WHAT THIS STUDY ADDS

⇒ This study highlights stakeholder-perceived gaps in APS care, including diagnostic delays, reliance on warfarin, lack of multidisciplinary services, limited education and poor policy integration.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Findings support the need for pragmatic diagnostic tools, multidisciplinary models, better education and registry-driven policies, with networks like the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases well placed to drive these changes.

INTRODUCTION

Antiphospholipid syndrome (APS) is a systemic autoimmune disorder defined by the presence of antiphospholipid antibodies in association with arterial and/or venous thrombosis and pregnancy morbidity. Although originally described in the context of SLE, APS is now recognised as a distinct clinical entity that can occur independently or in overlap with other autoimmune diseases. APS affects a diverse patient population and can present across a spectrum of specialties, including

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rheumatology, haematology, obstetrics, neurology and cardiology.[1 2]

Despite recent efforts to standardise the identification of patients with APS, most notably the 2023 American College of Rheumatology (ACR)/European Alliance of Associations for Rheumatology (EULAR) classification criteria,[3] substantial gaps remain in timely diagnosis, optimal treatment and coordinated care. Many patients continue to be diagnosed late or misclassified, particularly those with non-thrombotic manifestations or isolated serological findings.[4] Existing treatments, such as vitamin K antagonists (VKAs), have changed little in decades, and clinical practice remains highly variable across settings.[2]

The complexity of APS management, combined with limited clinical trial data and fragmented healthcare systems, has created an environment where both patients and professionals experience significant unmet needs. These challenges span clinical, educational, research and health policy domains.

Addressing these multifaceted gaps requires coordinated, transdisciplinary approaches. Within the framework of ERN ReCONNET, the European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases, this study aimed to explore unmet needs in APS through the perspectives of key stakeholders involved in its diagnosis, management, research and policy-making, providing a structured approach following the unmet needs identified in the first years of ERN ReCONNET.[5]

Using semistructured qualitative interviews conducted with clinicians, researchers, policy experts and patients from across Europe, we sought to map the lived and professional challenges in APS care and identify cross-cutting themes to inform future research agendas, educational efforts and policy initiatives.

METHODS

Study design and setting

We conducted a qualitative study using semistructured interviews to explore unmet needs in the diagnosis, management and research of APS. The study was developed within the framework of ERN ReCONNET.

Participant selection and recruitment

A purposive sampling strategy was used to recruit a diverse group of stakeholders involved in APS care across Europe with clinical experience or conditions directly relevant to the study focus, ensuring the inclusion of diverse, information-rich perspectives essential for in-depth qualitative analysis. Semistructured interviews were chosen for their ability to elicit in-depth personal and professional experiences across diverse stakeholder roles. This qualitative approach is particularly well suited to exploring rare and complex conditions such as APS, as it allows for the identification of emergent themes not predefined by existing literature or frameworks. Interviews facilitated a deeper understanding of participants' lived realities, enabling the researchers to probe context-specific challenges, uncover overlooked nuances and adapt the discussion dynamically to issues raised spontaneously by the interviewees.

Sixteen participants (Belgium (2), Denmark (2), France (1), Italy (3), Portugal (1), Romania (1), Spain (2), Sweden (1), Germany (1), The Netherlands (2)) were selected to represent a broad range of perspectives and representatives from each of the following medical specialties: rheumatology, haematology, obstetrics, neurology, internal medicine, paediatrics, laboratory medicine. Also, one researcher and translational scientist, health systems and policy professionals, one pharmaceutical trialist, one patient and research nurse, one medical student, and one trainee (online supplemental table 1) were included. Participants were recruited through professional networks affiliated with ReCONNET, academic centres, and APS-focused advocacy or clinical groups.

Data collection

Semistructured interviews were conducted between February and April 2025. The semistructured interview guide was developed collaboratively by the study investigators, drawing on prior ReCONNET work on unmet needs in rare and complex autoimmune diseases. Core domains were predefined to ensure coverage of[1] clinical and diagnostic challenges,[2] systemic and policy-level issues, and[3] educational and research priorities. Within each domain, open-ended questions were formulated to elicit personal and professional experiences, while allowing flexibility for participants to raise additional topics. Examples of guiding questions included: 'Can you describe a recent clinical scenario where diagnosing APS was particularly challenging?', 'What barriers do you encounter when coordinating care for APS patients?' and 'What changes in education or research would have the greatest impact on APS care?'. For each stakeholder category (eg, clinicians, researchers, policy experts and patients), the guide was adapted with context-specific prompts while maintaining comparability across interviews. Interviews typically lasted 30–45 min and were conducted either in person or via secure videoconferencing. All interviews were transcribed verbatim and de-identified.

Each stakeholder category in this study was represented by one participant, as detailed in online supplemental table 1. As such, the qualitative design was intended to capture a broad range of perspectives rather than to quantify the prevalence of specific views. Thematic convergence and divergence were assessed descriptively, but no formal quantitative comparison between categories was performed.

Data analysis

Transcripts were analysed using thematic analysis, following an inductive approach. Coding was carried out by a researcher, using NVivo. Codes were then reviewed collaboratively to generate themes and subthemes, which

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Table 1 Proposal of actionable ERN ReCONNET activity to address identified unmet needs in the field of APS

Domain	Unmet need	Proposed ERN ReCONNET action
Clinical and diagnostic	Delayed or missed diagnosis	Develop and disseminate pragmatic algorithms and red flags for APS (eg,stroke in the young, thrombosis in atypical sites, multiple pregnancy loss)
	Limited utility of current classification criteria in real-world practice	Host consensus workshops to develop diagnostic aids and case vignettes for non-specialist settings
	Lack of individualised treatment strategies	Promote multicentre observational studies and registries to inform risk stratification and treatment response profiling
Systemic and policy-level	Fragmented, siloed care	Pilot multidisciplinary APS clinics and implement virtual case conferences within ERN centres
	Absence of harmonised data infrastructure	Support the integration of existing national APS registries into a federated, GDPR-compliant European data ERN platform
Educational and research	Minimal APS exposure in medical education	Co-develop curriculum modules and e-learning materials on APS for undergraduate and postgraduate levels
	Insufficient translational research and trial readiness	Facilitate joint calls for pilot translational projects and rare autoimmune disease trial platforms within the ERN community
	Underutilisation of patient and nursing perspectives	Include research nurses and patient partners in ERN-led studies and guideline development processes

APS, antiphospholipid syndrome; ERN ReCONNET, European Reference Network on Rare and Complex Connective Tissue and Musculoskeletal Diseases.

were grouped into three broad domains: clinical unmet needs, system-level challenges, and gaps in education and research. Discrepancies in interpretation were resolved through discussion and consensus. Illustrative quotations were selected to represent key themes and stakeholder perspectives, while identifying details removed to preserve anonymity.

RESULTS

Overview of themes

Analysis of the 16 interviews revealed a complex landscape of unmet needs in APS that transcended clinical disciplines and healthcare systems. Despite diverse stakeholder roles, several cross-cutting concerns emerged, particularly around delayed diagnosis, fragmented care and lack of individualised treatment strategies. Main messages are summarised in table 1.

Clinical and diagnostic challenges

Delayed and missed diagnoses

Participants across specialties, including primary care providers, neurologists and patients, emphasised that APS is frequently diagnosed late, often after irreversible complications such as thrombosis or pregnancy loss. Non-thrombotic manifestations and the absence of a concomitant systemic autoimmune disease contribute to diagnostic uncertainty.

> When a young person presents with stroke or TIA, APS isn't always on our radar. We need prompts for when to suspect it. —Neurologist

Limitations of the current diagnostic criteria

Although it is acknowledged that classification criteria are not diagnostic, in clinical practice they may still be used as guidance. In fact, several clinicians noted that while the 2023 ACR/EULAR classification criteria are useful for research, they remain restrictive for real-world diagnosis. Patients with suggestive clinical features but laboratory profiles not meeting the classification criteria (eg, low titres, isolated IgM, doubtful LA positivity) may risk being left without a definitive diagnosis.

> We should be vigilant not to miss patients who don't fit the criteria. —Rheumatologist

Lack of individualised treatment

Haematologists and obstetricians highlighted the difficulty in tailoring therapy, particularly in refractory cases. Antithrombotic management is still largely reliant on VKAs, with limited evidence to guide newer agents or risk-stratification strategies.

> Warfarin is all we have. DOACs are convenient, but not recommended. We need better options and better trials. —Haematologist

Systemic and policy-level gaps

Fragmentation of care

Care for patients with APS is frequently siloed, with little coordination across disciplines such as rheumatology, haematology, obstetrics and neurology. This

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fragmentation contributes to diagnostic delay and inconsistent management.

> We need multidisciplinary clinics. APS doesn't respect specialty boundaries. —xpert rheumatologist

Inadequate policy recognition

Public health and regulatory experts noted that APS is often overlooked in both thrombosis strategies and rare disease frameworks, falling into a policy 'blind spot'. This impedes funding, trial infrastructure and equity of access.

> APS is too rare for funders and too complex for pharma. We need better recognition and incentives. —Policy advisor

Need for data infrastructure

Stakeholders emphasised the lack of public health registries and data linkage systems to assess burden, track outcomes or support research. Without robust epidemiological data, advocacy and planning efforts remain constrained.

> We don't know the real population burden because there is no true integration across available registries. —Public health expert

Educational and research needs

Medical education gaps

Students and early career clinicians reported limited exposure to APS in medical curricula and training rotations. This lack of familiarity contributes to under-recognition and referral delays.

> We had one lecture on antiphospholipid antibodies — nothing about APS complexity. —Medical student

Limited research capacity and translational models

Researchers pointed to the need for mechanistic studies and better in vitro/in vivo models to understand APS heterogeneity. Trialists noted that APS presents unique methodological challenges due to small sample sizes, variable endpoints and poor infrastructure for rare autoimmune disease trials.

> We struggle with trial design and recruitment. Endpoints aren't standardized, and inclusion criteria are debated. —Pharmaceutical clinical trialist

Underused nursing and patient insights

Research nurses highlighted their often-overlooked role in understanding patient experiences, especially around quality of life, treatment burden and adherence.

> Patients share things with us they don't tell the doctors — fatigue, anxiety, real-world complexity. —Research nurse

DISCUSSION

This qualitative study identified wide-ranging and interconnected unmet needs in the diagnosis and management of APS, as perceived by diverse stakeholders across Europe. Conducted within the framework of the ERN ReCONNET network, our findings reveal that despite increasing awareness and evolving classification criteria, APS continues to pose diagnostic, therapeutic and systemic challenges. These challenges extend beyond any single specialty or care setting, underscoring the need for coordinated, multidisciplinary strategies.

The consistent theme of diagnostic delay, described by both patients and clinicians, confirms previous findings that APS remains under-recognised in clinical practice, particularly in primary care and non-rheumatological specialties.[4] Contributing factors include limited awareness of non-thrombotic manifestations, restricted access to antibody testing and variability in test interpretation. These barriers suggest the need for pragmatic diagnostic algorithms, especially in the context of pregnancy loss, young stroke or unexplained thrombosis. Also, it is important to distinguish between the inherent scope of classification criteria and limitations arising from laboratory testing. The concern with isolated IgM positivity, which does not fulfil the serological criteria according to the 2023 ACR/EULAR framework, exemplifies the gap between clinical suspicion and classification eligibility. Likewise, variability in LA detection remains a persistent challenge in APS diagnostics. Broader use of Taipan/Ecarin-based assays has been proposed as a means to improve accuracy and reproducibility and could help reduce misclassification attributable to laboratory factors rather than to the criteria themselves.

Participants also mentioned the inadequacy of current treatment paradigms. From this perspective, some considerations are worth noting. While several stakeholders highlighted challenges related to warfarin monitoring and adherence,[1] it is important to recognise that, in properly anticoagulated patients, recurrence rates of thrombosis can be as low as ~3% in large international cohorts such as AntiPhospholipid Syndrome Alliance For Clinical Trials and InternatiOnal Networking (APS ACTION).[2 6 7] Current guidelines consistently recommend VKAs such as warfarin[5] as the most effective treatment for high-risk APS, and available evidence indicates that direct oral anticoagulants (DOACs) are associated with increased thrombotic risk in this population.[5] The low cost and proven efficacy of VKAs remain important advantages, and strategies to optimise their use, including structured patient education, adherence support and regular follow-up, are critical to achieving optimal outcomes.

Besides, in addition to thrombotic and obstetric complications, certain APS manifestations, including microthrombosis and haematological involvement (eg, thrombocytopenia, haemolytic anaemia),[2] remain under-recognised in clinical practice and are often undertreated. These features may significantly contribute to disease burden and, in some cases, to irreversible organ damage.

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Their pathophysiology is incompletely understood, and they are not adequately represented in most clinical trials or guidelines. Targeted research to elucidate the underlying mechanisms and evaluate specific treatment strategies is urgently needed. Addressing these manifestations requires not only improved awareness among clinicians but also the integration of these outcomes into future APS studies and registries.

Stakeholders identified a striking lack of care integration, with patients often navigating siloed services across haematology, obstetrics, rheumatology and neurology. This fragmentation delays diagnosis, complicates follow-up and undermines trust in the healthcare system. Multidisciplinary APS clinics, where feasible, may help address these gaps and support individualised care planning.

At the policy level, APS appears to fall between the cracks: too rare to be prioritised in mainstream thrombosis guidelines, yet not consistently recognised within rare disease frameworks. Regulatory and funding disincentives further hinder innovation in trial design and therapy development. The absence of integration across national and international APS registries also limits efforts to estimate disease burden, monitor outcomes and conduct large-scale studies.

Our findings underscore substantial educational gaps at all levels of training. From medical students to general practitioners and trainees, stakeholders reported minimal formal exposure to APS. This lack of knowledge translates into missed diagnostic opportunities and inappropriate referrals. Updated curricula, case-based learning tools and interdisciplinary continuing education programmes are urgently needed.

From a research perspective, stakeholders emphasised the need for improved pathophysiological models to address the heterogeneity of APS manifestations. Integration of omics technologies, systems biology approaches and well-characterised biobanks could accelerate progress. However, small patient populations and heterogenous trial endpoints continue to pose methodological challenges. Greater collaboration across European rare disease networks, including ERN ReCONNET, or globally, like the existing effort coordinated by APS-ACTION, may help overcome these limitations.

This study's strength lies in its inclusion of a wide array of stakeholders, capturing both lived experience and systemic insight. The qualitative approach enabled deep exploration of nuanced perspectives that are often lost in survey-based research. However, limitations include the modest sample size and potential selection bias. Although participants represented a range of European contexts, results may not be generalisable to all health systems. Additionally, while thematic saturation was reached, we did not formally validate findings through member checking or triangulation. Similarly, future studies will explore whether differences exist across stakeholder groups. In particular, we are planning a Europe-wide survey among ERN ReCONNET experts and affiliated networks to quantify the frequency of each identified theme and to investigate potential variations in priorities and perceptions between specialties. Finally, a further limitation of this study is that we did not formally account for differences in healthcare systems, diagnostic pathways or treatment protocols across participating European countries.

CONCLUSION

APS remains a paradigmatic challenge in rare autoimmune disease care: straddling specialties, eluding early diagnosis and resisting therapeutic individualisation. Despite advancements in classification criteria and emerging research efforts, significant gaps persist in clinical recognition, treatment options, care coordination and health system integration.

This qualitative study, conducted within the framework of ERN ReCONNET, reveals that stakeholders across the APS spectrum, patients, clinicians, researchers and policy experts, share overlapping concerns. Delayed diagnosis, fragmented services, limited treatment innovation and educational deficits emerged as cross-cutting unmet needs. Importantly, many of these challenges are systemic and addressable through targeted reforms in guideline development, medical education, registry infrastructure and rare disease policy frameworks.

The findings underscore the need for transdisciplinary collaboration and stakeholder-informed strategies to improve APS care. As a next step, we propose the development of a Europe-wide survey to quantify and prioritise unmet needs identified in this study. Such data will be essential to guide future clinical trials, educational interventions and policy initiatives aimed at improving outcomes for individuals living with APS.

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Contributors SS conceptualised the study and led the coordination of data collection and analysis. SS and DM reviewed the interviews and initial thematic coding. RT, MM, AT and MGT contributed to the interpretation of the findings and critical revision of the manuscript. SA ensured patient and stakeholder perspectives were integrated. SS, SA, MGT and RC drafted the initial version of the manuscript. DM, RT and MM critically reviewed the results and contributed to the revision of the manuscript. All authors contributed to writing and approved the final manuscript. SS serves as the guarantor. During the preparation of this manuscript, we used ChatGPT (OpenAI, San Francisco, USA) to support minor editing tasks, including correction of typographical errors and improvement of grammar and language clarity. The authors reviewed and approved all AI-assisted modifications, and take full responsibility for the content and accuracy of the manuscript.

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