Overcoming Challenges in Establishing an Amyloidosis Center

Report of a virtual roundtable meeting on establishing and operating amyloidosis services in Europe

27 February 2025

1. INTRODUCTION

Amyloidosis is a complex and heterogenous disease that requires specialized expertise for accurate diagnosis and effective management. Specialized amyloidosis centers play a crucial role in providing multidisciplinary, standardized, and comprehensive care, offering access to advanced diagnostic tools, therapies, and clinical trials.[1,2]

In Europe, there is a significant need for more specialized amyloidosis centers to facilitate timely access to expert care. Patients with amyloidosis often face a complex and time-consuming diagnostic process, moving between different specialties and enduring long waiting times before receiving a diagnosis and appropriate treatment.[3–6] The rising awareness and diagnoses of amyloidosis have further increased the demand for expert centers.[7,8] Expanding the network of specialized centers across Europe is crucial to enhance patient outcomes. This virtual roundtable explored the key challenges involved in establishing and expanding amyloidosis centers in Europe and solutions to overcome these barriers.

2. MEETING ORGANIZATION

On 27 February 2025, a roundtable meeting was hosted by Professor Marianna Fontana (National Amyloidosis Center, UK) and moderated by Chris Elmitt (UK), bringing together experts from across Europe to discuss the challenges involved in establishing and running an amyloidosis center. Twelve amyloidosis specialists, with experience or an interest in setting up an amyloidosis service, participated in the meeting.

The group represented a range of specialties and geographic regions, with participants joining online from Italy, Portugal, Romania, Ireland, Denmark, the UK, Greece, and Switzerland. A breakdown of the participants' specialties is provided in **Table 1**.

Through open discussion and polling, the group identified region-specific barriers to establishing amyloidosis services and proposed solutions to address these challenges. Best practices for multidisciplinary collaboration and key obstacles in diagnosis and treatment were also explored.

Specialty	Number of participants
Cardiologist	6
Nephrologist	2
Haematologist	1
Specialist haematology nurse	1
Nephrologist	2
Hepatologist	1
Imaging specialist	1

Table 1. Breakdown of attendees by specialty

2.1 Meeting objectives

The aim of the roundtable meeting was to explore the challenges involved in establishing an amyloidosis service and discuss solutions to address them. After taking part in the roundtable, the learners should be able to:

1. Discuss region-specific challenges in amyloidosis center establishment and describe strategies to overcome them
2. Integrate specialized guidance from experts from established amyloidosis centers to have increased confidence in their mission to set up a center

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3. MEETING FINDINGS

3.1. Region-specific challenges in setting up an amyloidosis center

Session objective: Discuss the unique regional challenges that impact establishment and operation of amyloidosis centers in Europe and propose solutions to overcome these barriers.

This discussion on establishment and operation of amyloidosis centers highlighted key challenges faced by teams and services. Through audience polling (**Figure 1**) and expert insights, major barriers were identified, including lack of awareness among physicians, limited access to advanced diagnostic tools, the need for improved multidisciplinary collaboration, and funding constraints. Improving awareness, access to diagnostic tools, leveraging relationships with existing specialized centers, and enhancing training for specialists were emphasized as key steps towards improving patient outcomes.

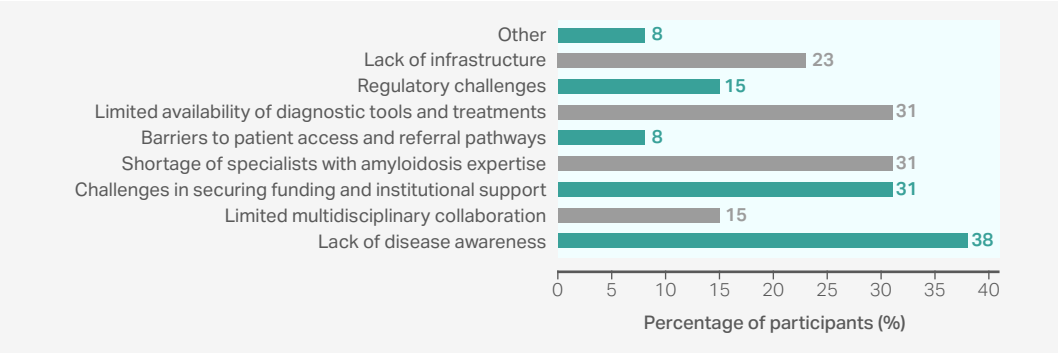

Figure 1. Most frequently identified challenges in establishing or running an amyloidosis service.

The following challenges were discussed by the group:

1. **Lack of disease awareness and delayed referrals**
   Many physicians have limited familiarity with amyloidosis, leading to missed referrals and delayed diagnoses. Patients often first present to other specialties, such as primary care. The group reiterated that this lack of awareness can result in missed opportunities for early intervention and referral, even in regions with established services:

   "The problem with the delayed diagnosis is that there's quite a bit of lack of awareness, I would say, before patients get referred to a specialist amyloidosis service. And that's not an issue that is restricted to us"

2. **Shortage of specialists with amyloidosis expertise**
   Attendees noted that there is a significant shortage of trained specialists, including pathologists, cardiologists, hematologists, and neurologists, with expertise in amyloidosis. This makes it difficult for centers to provide a comprehensive, multidisciplinary approach:

   "In our center, we struggle with neurologists, hematologists, and whatsoever, because our center is mostly a cardiovascular scientific institute"

3. **Limited access to advanced diagnostic tools**
   Multiple attendees highlighted their hospitals lack access to essential diagnostic tools like mass spectrometry and endomyocardial biopsy. This hinders the ability to make accurate and timely diagnoses:

   "We do not have access to endomyocardial biopsy, but also we do not have access to mass spectrometry"

4. **Challenges in reimbursement and accessing treatment**
   Regulatory and reimbursement challenges vary by country, making it difficult for patients in some regions to access treatment. Some insurance policies require frequent hospital visits to access medication, adding strain to already limited resources:

   "We have to see our patients once every month because the insurance pays for the TTR amyloidosis treatment only if the patient gets the medication from the hospital"

5. **Barriers to multidisciplinary collaboration**
   Specialists from different fields often struggle to communicate effectively or lack the proper processes and structures for successful multidisciplinary collaboration, with can lead to fragmented care:

   "We do not have a special dedicated clinic or consultation or time for these patients. So it's something in between and not an expert"

6. **Infrastructure and resource limitations**
   Some hospitals and clinics in Europe lack the dedicated space, equipment, and personnel needed to provide specialized care for amyloidosis patients:

   "Since the number of patients that get treatment is increasing, we struggle a bit to accommodate all these patients for the annual visits"

7. **Outdated perceptions of ATTR amyloidosis**
   In some regions, health authorities and regulatory bodies continue to view cardiac ATTR amyloidosis as a rare disease, which can create barriers to treatment access. Senior leaders within institutions can lack disease awareness and so are unaware of the advances made in its treatment, further contributing to its lack of prioritization:

   "One of the challenges that we have is a bit of lack of awareness, but also some pessimism maybe from the senior colleagues. I get faced with pessimistic opinions about, 'Is it even worth it doing the scintigraphy?'"

   "We have a very strict regulation about treatment for rare disease. And unfortunately, I personally think paradoxically, ATTR amyloidosis is still considered a rare disease"

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3.1.1. Overcoming challenges in establishing and running successful amyloidosis centers

The following solutions were identified from the discussion:

1. **Increasing local awareness and education:** Building local expertise will be key to delivering high-quality care and reducing the need for patients to travel long distances to receive it. One participant emphasized that "it is important to develop local expertise where you can provide comparable quality treatments, save the patients traveling", before explaining that "you need to know what you're doing, how to assess the patient for your treatment [plan], how to risk assess the patient, how to follow up, monitor response, discuss again feedback in the multidisciplinary team and ask advice from the specialized center of reference". Even where amyloidosis services have already been established, raising awareness and ensuring that different specialties can recognize red flags for amyloidosis will be essential for improving referrals to these services. Developing a local, dedicated workforce through targeted training and education will help ensure that healthcare services are prepared to identify, diagnose, and treat amyloidosis effectively.
2. **Expanding access to diagnostic tools:** Developing local diagnostic expertise is required to reduce the burden on reference centers, however, some services do not have access to advanced diagnostic tools (e.g., mass spectrometry, endomyocardial biopsy). While it may not be feasible to establish mass spectrometry and histology in every center, creating centralized testing hubs to support smaller, local centers could improve efficiency and diagnostic consistency. Collaborative services between institutions would further enhance access by allowing smaller centers to refer samples to specialized facilities for analysis. One participant highlighted the value of a centralized mass spectrometry service: "This is something that can actually be deferred to other centers and the new services could concentrate on developing some of the things that have to be on site, like imaging services."
3. **Improved multidisciplinary collaboration:** Amyloidosis is a complex condition that often presents with multisystem involvement, making a coordinated approach across specialties essential. Establishing multidisciplinary teams (MDTs), including cardiologists, hematologists, neurologists, nephrologists, and pathologists, will improve patient care and streamline referrals: "It is impossible to do it in any other way other than multidisciplinary… the more specialties you get in, the better the outcomes." Creating a formal structure for MDT working could enable specialists to manage cases collaboratively and determine the most effective approaches. This structured approach can improve the efficiency of managing patients by ensuring coordinated care.
4. **Collaboration with existing specialized centers:** Collaboration with established amyloidosis centers can be leveraged to create dedicated networks that link smaller services with larger, specialized centers, providing them with essential guidance and support through a 'hub-and-spoke' model. This approach could ensure that patients are managed appropriately at different levels of care. Complex cases can be referred to larger centers, while routine cases can be managed locally. By leveraging the expertise and resources of established centers, newer centers can enhance their capabilities and provide high-quality care. A UK-based expert emphasized: "One of the things that could help in that regard is for all specialists to know which one, which is their local, as it were, amyloid network or amyloid point, where at least they could present and say 'this could be amyloid[osis]. I have no other ways to make a definitive diagnosis. Can you help?' And then we could then ask for the expertise and the more specialized treatment and diagnostics that we could have access to at the amyloid center or a specialized center in each country." Such networks have been shown to be feasible in the UK,[9] and networks have also been formed in Italy and France.[10,11]
5. **Advocating for treatment access and resource allocation:** Advocating for improved reimbursement and updated treatment regulations is essential to enhance patient access to care. For cardiac ATTR amyloidosis, a shift in perception is needed among local authorities, policymakers, and healthcare administrators to recognize amyloidosis as a priority condition rather than a rare disease. This recognition is crucial to improving patient access to treatments within smaller, non-reference centers. Engaging senior hospital colleagues is also vital for securing institutional buy-in and ensuring the proper allocation of resources, with a participant from Denmark noting: "So it needs to be a shift in some of the more senior colleagues to look for the disease". Increasing awareness at this level will help drive support for better resource allocation and patient care.
6. **Enhancing training for specialists:** Encouraging more specialists to gain experience in amyloidosis through targeted training programs could help address the shortage of expertise. Attendees reiterated that training should not be limited to hematology and cardiology but should also involve neurologists, nephrologists, pathologists, and other relevant specialties. Hands-on training and mentoring opportunities within established centers and through international collaboration, could help specialists build confidence and expertise. One participant highlighted the value of fellowship programs: "I would have a huge benefit from a mentoring center from abroad because I struggle to establish a center right now in my hospital".

SESSION 1 SUMMARY

The challenges in establishing amyloidosis centers in Europe are complex and require a comprehensive strategy that includes **increasing physician awareness, expanding access to advanced diagnostics, strengthening multidisciplinary collaboration**, and **securing sustainable funding**. Leveraging relationships with established specialized centers and advocating for increased awareness and policy changes will be essential for acquiring the necessary resources for earlier diagnosis and improved patient outcomes.

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3.2. Best practices for diagnosis and management

Session objective: Explore barriers to best practices in amyloidosis diagnosis and treatment within new centers.

The session on diagnosis and management of amyloidosis highlighted several challenges, with the group mainly focusing on the diagnosis of cardiac ATTR amyloidosis. Key diagnostic challenges included a lack of awareness among healthcare providers, difficulties in establishing effective screening protocols, and limitations in diagnostic tools. Despite advancements in imaging techniques and treatment options, there remains a significant gap in recognition and early detection of the disease. Participants shared their perspectives on how awareness, diagnostic advances, and technology can play key roles in addressing these challenges during center establishment.

Lack of awareness and importance of suspicion in diagnosis:

One of the primary challenges discussed was the lack of awareness regarding cardiac amyloidosis, which hinders early diagnosis. Professor Marianna Fontana pointed out that "diagnosis is awareness, awareness, awareness. We don't suspect, and we're never going to get the right diagnosis". This was reiterated by several participants who emphasized the need for healthcare professionals to consider amyloidosis in their differential diagnoses, especially when red flags are present. However, an expert from Switzerland highlighted awareness has improved in this region following the approval of treatments for amyloidosis: "I think the game changer was the approval of [transthyretin stabilizer]". The increased recognition of cardiac amyloidosis as a condition that can be treated has led to more cardiologists being aware of the disease, with referrals for diagnostic imaging such as scintigraphy becoming more common. This insight highlights the importance of clinician knowledge and awareness of new and emerging amyloidosis therapies.

Challenges in establishing screening protocols:

Participants emphasized the challenge of establishing effective screening protocols within their institutions: "What we would like to have is a way of establishing a screening protocol that works for our hospital. And that's the main issue because these patients are lost". Without a standardized approach, potential cardiac amyloidosis cases may go undiagnosed, particularly when patients are referred to non-cardiology specialties. To address this, amyloidosis centers could develop structured screening pathways and foster multidisciplinary collaboration to ensure amyloidosis patients are identified and receive a diagnosis. Future research should focus on creating algorithms to determine which patients should be screened and at what stage in their clinical journey.

Role of diagnostic tools:

Lack of access to advanced diagnostics such as mass spectrometry and endomyocardial biopsy was identified as a key challenge in Session 1. In addition to this, attendees discussed other diagnostic modalities, with a particular focus on echocardiography and cardiac MRI. Professor Fontana emphasized the critical role of echocardiography in raising suspicion for amyloidosis: "Echocardiography has a really, really crucial role… it could be that the physician is aware of the red flags, and so once the echo is performed, then the suspicion is raised". However, challenges remain in effectively utilizing these tools. In Switzerland, cardiologists often prioritize perfusion imaging when evaluating patients with suspected heart disease. If perfusion abnormalities are not detected, further investigation for cardiac amyloidosis may be delayed, leading to missed or late diagnoses: "And then a couple of years later the patient ends up with a diagnosis of cardiac amyloidosis". Advanced cardiac MRI techniques, such as T1 mapping, can improve sensitivity for detecting amyloidosis earlier. However, as one participant noted, "not everybody has access to these methods," highlighting disparities in diagnostic capabilities between institutions.

Artificial intelligence (AI) and advancements in diagnostics:

Participants discussed the potential role of AI in improving early detection. Professor Fontana proposed this as a possible solution for detecting patients who should be screened for amyloidosis: "Many groups are working on trying to develop AI-based algorithms to flag the red flags", with a focus on echocardiography and medical records. This reflects an emerging trend of integrating AI into diagnostics to enhance the accuracy and speed of detecting cardiac amyloidosis.

SESSION 2 SUMMARY

The discussion focused on key challenges in diagnosing cardiac amyloidosis, including **low awareness** among healthcare providers, the **lack of standardized screening protocols**, and **limited access to advanced diagnostic tools**. Improving physician awareness and education, establishing structured screening pathways, and integrating AI-driven diagnostics were discussed as solutions that could enhance early detection and improve patient outcomes.

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3.3. Multidisciplinary collaboration for comprehensive care

Session objective: Discuss the critical role of a multidisciplinary team in delivering comprehensive care and best practices for team formation and communication.

This discussion centered around key challenges in multidisciplinary working, with a participant poll identifying ineffective communication among team members (55%), and time constraints and scheduling conflicts (55%), as the primary barriers to effective multidisciplinary collaboration (**Figure 2**). Participants explored key themes related to multidisciplinary collaboration, such as strategies to manage time constraints, enhance communication within MDTs, retain specialized staff, and the role of local, regional, and national networks in improving multidisciplinary collaboration.

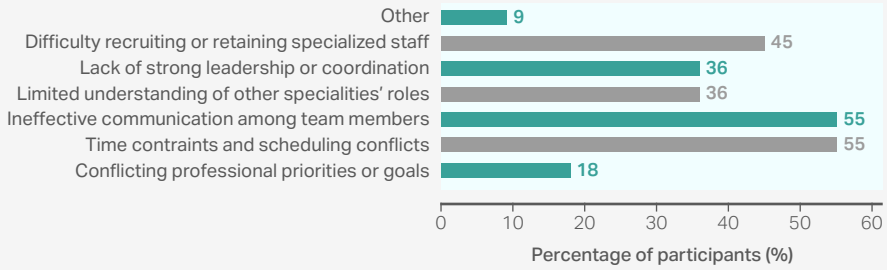

Figure 2. Most commonly identified barriers to effective collaboration in a multidisciplinary care team.

Effective collaboration and communication

- Effective MDTs rely on strong interdisciplinary collaboration, requiring input from multiple specialties, including cardiology, hematology, neurology, and pathology. Participants agreed that getting these disciplines to work together efficiently is key to delivering high-quality patient care: "I can't think of a way to have a proper amyloidosis service without actually having multiple specialties involved together". Attendees stated that acknowledging this should be the first step when setting up a service in any hospital.
- Motivated team members are essential for creating a functioning MDT. Teams that form organically, based on shared interest in amyloidosis, tend to function better according to one participant: "It's not going to be effective unless the people who are doing it are actually interested in it".
- Attendees highlighted the vital role that nurses play in amyloidosis MDTs, particularly in communicating treatment plans and decisions to patients. A UK-based expert stated: 'I think another important aspect to the MDT is also the input from not just the clinicians but also nurse specialists. They do play a major role in terms of communicating MDT outcomes to the patients". However, it was noted that logistical challenges can make it difficult for nurses to participate effectively within MDT meetings.
- Similarly, histopathologists play a crucial role in the care pathway. Attendees emphasized the importance of greater investment in training and stronger collaboration between clinicians and pathology services: "I think a very important partner is really the pathologist. I think they should have training, and we should have perhaps a network of pathologists".
- Multiple attendees highlighted the importance of having an MDT coordinator to address logistical challenges. One expert mentioned that "You have to have an effective MDT coordinator, otherwise it doesn't work". These coordinators play a crucial role not only in managing scheduling issues but also in streamlining multidisciplinary meetings by organizing and presenting clinical information. Additionally, they help guide MDT members to the appropriate contacts, facilitating referrals and improving management pathways.

Resource limitations and time constraints

- A major challenge in establishing an amyloidosis center is the shortage of specialists across multiple disciplines. Many centers struggle to have all necessary specialties available, which can impact patient care. A participant from Italy noted: "We are largely understaffed both in cardiovascular disease and in other specialties. So, it's very difficult to create a center where all the different specialties are available and also to establish trusted relationships".
- This issue extends to specialized nurses and histopathologists, who play a key role in diagnosis and patient management. A lack of trained personnel can lead to miscommunication and delays in treatment: "This understaffing is related also to nurses, for example. And in the end, it can lead to poor interaction or difficulty in understanding what is important from different specialties".
- The group identified time constraints and scheduling conflicts as significant barriers to running effective MDTs. Bringing multiple specialists together to discuss amyloidosis cases requires effective coordination, which is often difficult due to conflicting responsibilities. One expert from the UK stated: "The challenge is to try to get a number of specialists to sit together to talk about a patient, which is not straightforward at all".
- A proposed solution was assigning dedicated specialists for amyloidosis within each department. This ensures clear communication pathways and streamlines decision-making. One attendee suggested: "Each specialty appointed one person that is really taking care of the amyloid patients. So, whenever I have a problem as a cardiologist about the hematological question, I have one person to go and ask".

Retaining and attracting specialized staff

- Retention of staff in amyloidosis centers is a complex challenge influenced by local availability of expertise and institutional support. Attendees emphasized the importance of having a clear vision, strong leadership, and institutional backing to sustain and expand specialized services.

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- One key factor in retention is ensuring that team members feel they are contributing to meaningful patient care. A shared vision and enthusiasm among staff were highlighted as key for building and growing a new center: "Whoever joins the team needs to join a bit of a dream, of creating something new that wasn't there before and is going to help patients". Support from hospital management is also crucial for sustaining a new center. Attendees stressed that a successful service requires institutional buy-in: "There needs to be support from hospital managers and a vision for the changes that could be associated with a new service".
- Finally, leadership plays a large role in retention and staff motivation. Having a dedicated leader to guide and inspire the team is important: "There needs to be one person with a vision who guides the rest of the team". However, effective leadership is not just about direction and must also foster an inclusive and respectful working environment. One expert highlighted how this approach could improve retention and attract expertise: "If you're inclusive and appreciative of each other's expertise, you attract more interest and you attract people in the team, you attract expertise and also you build the service, at least on a local level".

Leveraging center networks to improve access to multidisciplinary care

- While national amyloidosis centers remain essential, attendees reiterated the importance of developing local expertise to ensure equitable access to multidisciplinary care. One expert mentioned that "it is very important to start developing expertise locally because it is not possible for every patient to be treated in the centers of reference. It is important to develop local expertise where you can provide comparable quality treatments, save the patients traveling. And it is not rocket science." By strengthening local networks, hospitals can deliver high-quality multidisciplinary care for patients closer to their home, ensuring that patients receive timely and accessible care without the burden of extensive travel.
- A structured network also improves multidisciplinary coordination by ensuring that clinicians know who to contact for specific needs. "From my point of view, one of the things I can do is help streamline that patient journey, so I know who to contact according to what the patient is struggling with at that time and who to go to for that expertise", noted a UK-based nurse.
- Beyond local networks, smaller centers can collaborate with established national centers to form regional or national networks, to optimize resources and ensure that patients receive the appropriate level of care. In Italy, efforts have been made to develop regional networks, allowing smaller centers to work closely with larger, more specialized centers: "One of the keys is a wise use of resources and also a strong network which we have been trying to build in different regions of Italy where there is one center[...] to which we can refer patients who require biopsy and require a specific assessment from a hematology point of view". This tiered approach to patient management ensures that complex cases are referred without delay, while local centers manage patients within their local multidisciplinary teams: "We should be realistic in trying to understand which kind of patient can be managed in a smaller center and which patients should be referred to a larger center without delay".
- Attendees also discussed the importance of national and international collaborations for enabling knowledge-sharing, standardization of care, and multidisciplinary networking. A UK-based expert highlighted: "It is important to have interaction talks or go and visit other hospitals to give a talk and present the service awareness, increase awareness [at] local level and perhaps meet once a year for a national conference, as we used to do in London with the UK Amyloid Network".
- Some participants expressed interest in international mentoring and networking to help bridge knowledge gaps in developing centers: "I would have a high benefit or a huge benefit from a mentoring center from abroad Romania, because I struggle to establish a center right now in my hospital. We have very little experience. Is it possible to have a pan-European connection or mentoring between centers with more experience?"

SESSION 3 SUMMARY

Effective MDTs rely on strong interdisciplinary communication and collaboration. Establishing formalized procedures for multidisciplinary working, providing training, and appointing multidisciplinary coordinators could help teams within centers work together more effectively.

Strong leadership, a shared vision, and an inclusive environment were identified as key facilitators for promoting effective collaboration and attracting a specialist workforce dedicated to amyloidosis.

Additionally, services could leverage networks at multiple levels to enhance access to specialized multidisciplinary care, improve efficiency, gain mentorship opportunities, and achieve better patient outcomes.

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CONCLUSIONS

This roundtable highlighted the complex challenges involved in establishing and operating amyloidosis centers in Europe and identified solutions to improve patient outcomes. Strengthening multidisciplinary collaboration, increasing access to diagnostics and treatment, enhancing regional and national networks, and securing sustainable resources and support will be critical for improving early diagnosis and care (**Figure 3**).

To build on the insights from this roundtable meeting clinicians, MDTs, hospital leaders, policymakers, and authorities could work together to implement the solutions proposed by the group:

Calls to action

- Regardless of center size or stage of development, a functioning MDT is essential for delivering comprehensive amyloidosis care. Teams seeking to establish or expand services can strengthen multidisciplinary collaboration by creating formal MDT structures, providing multidisciplinary training, and appointing strong leadership and dedicated MDT coordinators.
- Developing local expertise will be key to successfully establishing amyloidosis centers. Investing in training for specialists across multiple disciplines will build local capability and help create a dedicated amyloidosis workforce. Expanding diagnostic capacity will be crucial for improving access to care, with structured screening protocols and the use of technology representing tools that could be explored to facilitate this.
- While access to advanced diagnostic tools remains a challenge, collaboration with centralized hubs could support smaller centers by providing access to specialized tools (e.g., mass spectrometry) and expertise. Strengthening regional and national networks through a 'hub-and-spoke' model could enable new centers to work alongside established services, ensuring high-quality care and facilitating knowledge-sharing. In regions without existing centers, international collaborations and mentoring opportunities could be considered.
- Advocacy and raising awareness at multiple levels will be essential for establishing and supporting amyloidosis centers. Regulatory and policy changes are required to improve access to treatment in some regions, whilst awareness among senior hospital leaders will be key for increased institutional support. Those looking to establish or expand services should focus on raising awareness of amyloidosis across healthcare settings to encourage progress and improve patient outcomes.

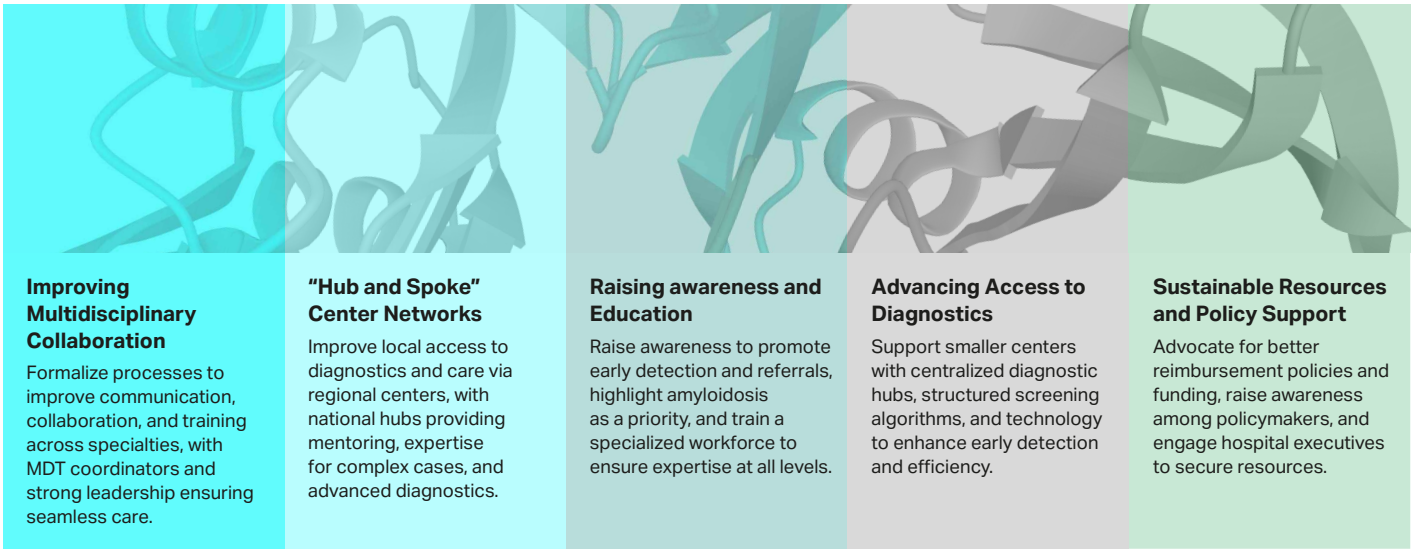

Figure 3. Enhancing Amyloidosis Care Through Collaboration and Network Expansion

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