



Engagement strategy guide for amyloidosis centers

1. Introduction

This guide provides you with a structured approach to help you engage effectively with national organizations, medical societies, patient advocacy groups, and other key stakeholders as you establish or enhance an amyloidosis center. By using this guide, you will be able to build partnerships that support disease awareness, earlier diagnosis, improved care pathways, and better patient outcomes.

Why does strategic engagement matter?

Strategic engagement can help you to:

- Increase the visibility and credibility of your amyloidosis service
- Establish a clear and accessible referral point for suspected or confirmed cases
- Support the implementation of coordinator roles to streamline patient pathways
- Access educational resources, guidelines, and research opportunities
- Collaborate on awareness and outreach initiatives
- Strengthen referral networks and multidisciplinary collaboration
- Build trust with patient communities

2. Understanding the engagement landscape

Multiple stakeholders can support the development of amyloidosis services. Each group offers different opportunities for collaboration.

Stakeholder type	Examples	Potential value
Local care providers	Primary care, community specialists, local clinics and hospital departments	Awareness, early recognition, referral pathways, data on local burden
National clinical societies	Hematology, cardiology, nephrology, neurology, pathology societies	Continuing medical education, endorsement, dissemination, guideline development
Rare disease alliances	National rare disease organizations, umbrella patient groups	Policy influence, public awareness, patient representation,
Patient advocacy groups	Amyloidosis patient associations, caregiver networks	Public awareness, lived experience insights, storytelling, patient data, campaign support
Research networks	National amyloidosis registries, academic consortia	Data access, research collaboration, clinical trials
Government or policy bodies	National health services, rare disease coordinators	Funding, service designation, quality frameworks, system-level change
Hospital leadership	Executive leadership, operational directors, medical/clinical directors	Strategic endorsement, funding and resource allocation, protected MDT time, approval of service models, governance oversight

3. Preparing for engagement

Before initiating contact, ensure that your service is aligned on goals and needs, and on who will be responsible for outreach and engagement. The following steps are suggested. You can fill in the boxes to select the most suitable objectives to guide your engagement strategy.

1 Define your objectives

Be clear about what you want to achieve. For example, you could:

- Raise awareness of your service
- Improve diagnostic pathways
- Secure national recognition or designation
- Collaborate on patient education
- Build referral networks
- Join a registry or research initiative
- Influence policy or funding

2 Be clear on what your service can offer

Engagement should be mutually beneficial. Consider what your service can offer, such as:

- Access to multidisciplinary care for patients in [region/country]
- Clinical expertise to contribute to national guidelines
- Capacity to participate in research or registries
- Willingness to codevelop educational materials
- Commitment to sharing data across services

3 Gather relevant evidence

Prepare materials that strengthen your case, for example:

- An overview of your service
- A summary of local burden data
- Diagnostic and care pathway maps
- Service gaps and proposed solutions
- Examples of patient experiences or unmet needs

4 Consider establishing an engagement team

You may wish to establish a dedicated engagement team to promote outreach with external stakeholders. This will depend on resources, but could include:

- Named clinical lead
- Administrative support (for scheduling, documentation, and communications)

4. Step-by-step outreach strategy

STEP 1: Research the organization

Before making contact, understand the organization, including:

- Their mission, priorities, and current initiatives
- Any existing work in rare diseases or amyloidosis
- Key decision-makers or contacts

STEP 2: Preparing for outreach

Before outreach, clearly define what contacting the target organization aims to achieve. Examples of possible collaborative opportunities include:

- Joint educational materials or webinars
- Contribution to clinical guidelines or consensus statements
- Participation in awareness campaigns
- Referral pathway collaboration
- Involvement in policy roundtables/meetings
- Insights on the local burden of amyloidosis

Before initiating contact with the organization, determine what value you can bring as an amyloidosis service or team. You can determine this by asking questions like:

- Why should this organization partner with us?
- What expertise can we contribute?
- What mutual value can we create?

You should also prepare any relevant materials that will support your outreach. Useful documents to have ready include:

- A 1-page summary of your service
- A 1-page summary of the local burden and relevant data
- Proposed areas for collaboration (3–5 bullets)
- Contact details and biography of the lead clinician

You may wish to refer to the **local burden data collection framework** and **customizable awareness deck** to aid you when collecting local data and deciding how to present this to stakeholders.

STEP 3: Making initial contact

You can use the following tips during your initial outreach:

- Use email as the first point of contact
- Request a short introductory meeting (≈30 minutes)
- Tailor your message to the audience. For example, when engaging with patient advocacy groups, tailor your messaging to demonstrate the potential impact that the collaboration could have on patients and their families
- Refer to the templates section for example emails that can be used for outreach

During the first exploratory meeting, focus on:

- Identifying shared organizational goals
- Listening to stakeholder priorities
- Identifying quick wins for collaboration
- Understanding collaboration processes
- Aligning on next steps

STEP 4: Formalize next steps

Agree on an action plan based on the outcome of the first meeting. This can include:

- Drafting a shared work plan
- Agreeing roles and timelines
- Scheduling follow-up meetings
- Establishing formal contracts and service agreements (when appropriate/required)

5. Tips for engagement: Dos and Don'ts

DO	DON'T
Bring data and patient perspectives	Approach without a clear objective
Tailor your message to the stakeholder	Focus only on funding requests
Highlight patient impact	Overload communication with clinical or technical detail
Prepare 2 or 3 clear collaboration asks	Overcomplicate agreements
Offer mutual value	Exclude patient and care partner voices
Follow up with clear next steps	Fail to maintain communication after initial contact

6. Maintaining relationships and sustainability

Building partnerships requires ongoing engagement. After connecting with potential partners, it is important to maintain momentum. Consistency and repeated, meaningful interactions will be key to building relationships. Ways to maintain contact and consistency include:

- Scheduling regular check-ins (e.g., quarterly)
- Conducting annual partnership reviews
- Defining and tracking shared key performance indicators (e.g., referral rates, time to diagnosis)
- Collaborating on joint initiatives or advocacy statements

7. Summary and next steps

Engaging national organizations and advocacy groups is a critical step in building an effective amyloidosis center. By using this guide, you can develop targeted, strategic partnerships that support better patient outcomes. The templates on the following pages can be used to reach out to these organizations and groups and start building key partnerships.

Next steps:

- Identify one organization to approach in the next month
- Outline priorities, and clarify your objective and what your service can offer
- Initiate contact using the outreach templates
- Reassess and refine engagement strategies regularly

Email template: Initial outreach to a national society

Subject: Collaboration opportunity: Strengthening amyloidosis care in [region/country]

Dear [Name/Title],

I hope you are well.

My name is [Your Name], and I am a [Your Role] at [Institution/Service Name]. I am writing to introduce our amyloidosis service and to explore potential opportunities to collaborate with [Organization Name].

We are working to [briefly state your goal, e.g., improve early diagnosis, strengthen referral pathways, establish a specialized amyloidosis center] in [region/country]. As part of this work, we are keen to engage with [Organization Name] given your leadership in [relevant area, e.g., clinical education, guideline development, professional engagement].

We believe there may be opportunities to collaborate in areas such as:

- [e.g., developing educational activities or continuing medical education initiatives]
- [e.g., contributing to clinical guidelines or consensus statements]
- [e.g., improving referral pathways and multidisciplinary care]

We would welcome the opportunity to arrange a short introductory meeting (approximately 30 minutes) to explore potential areas of alignment.

Please let me know if you would be interested in collaborating with us and I look forward to hearing from you.

Kind regards,

[Your Name]

[Title/Role]

[Institution]

[Email]

[Phone (optional)]

Email template: Outreach to a patient advocacy group

Subject: Exploring collaboration to improve amyloidosis care and patient experience

Dear [Name/Organization],

I hope you are well.

My name is [Your Name], and I am a [Your Role] at [Institution/Service Name]. I am reaching out to introduce our work in amyloidosis and to explore opportunities to collaborate with [Organization Name].

We are focusing on improving [e.g., early diagnosis, patient pathways, access to specialist care] for people living with amyloidosis in [region/country]. We recognize the critical role that patient organizations play in representing lived experience and supporting patients and their families.

We would value the opportunity to work together in areas such as:

- Raising awareness of amyloidosis among patients and healthcare professionals
- Understanding patient experiences and unmet needs
- Codeveloping patient education resources
- Supporting advocacy efforts to improve care

We would greatly appreciate the opportunity to arrange a short introductory discussion (approximately 30 minutes) to learn more about your priorities and explore how we might collaborate.

Please let me know if this would be of interest.

Kind regards,

[Your Name]

[Title/Role]

[Institution]

[Email]

[Phone (optional)]

Tip: You can convert these email templates into a word document to edit and personalize them.

Partnership planning template

Organization details

- Organization name:
- Contact person(s):
- Date of meeting:

Shared priorities and goals

What are the key areas of alignment?

-
-
-

Identified collaboration opportunities

-
-
-

Agreed actions

Action	Responsible person	Timeline

Resources or support required

-
-
-

Follow-up plan

- Next meeting date:
- Key milestones: