



Building your Membership



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The value of members

When individuals join your organisation by becoming a member, the person becomes 'formally' affiliated to your organisation. Membership can take different forms and will depend on what you decide it will involve.

Being a member gives people a sense of belonging to a community. It can also help them to get support, find out more about axSpA and access helpful, reliable information.

Having members allows you to build a base of loyal supporters. As your organisation expands over time, your members will be an important source of support to draw on for fundraising, to raise awareness about axSpA and for operational tasks, if you choose to involve them at an administrative level.

Benefits of growing your membership

Growing your membership can be challenging, and often takes time.

The top two reasons to increase your membership are:

- Having a large membership makes your association robust and gives you more credibility with the stakeholders you plan to work with
- Larger organisations can have an advantage when requesting funding.

The key to growing your membership is raising awareness of your group and being clear about the benefits. Tell the world what you do, and people with an interest will want to join and support you.

Tell people about your organisation

Producing digital and print materials, such as a leaflet or poster, can be a great way to share information about your organisation.

What should be included in a leaflet?

Keep it short and simple! Information in leaflets should be limited to the key points that you want to share including:

- Your organisation's name and logo
- A short description of what axSpA is
- A brief description of what your group does.
For example, *'We provide educational and community support, and a voice for people living with axSpA'*
- Contact information, website address, social media channels and phone numbers, if relevant
- Benefits of being member – and how to become one
- Images – limiting the written information gives more space for images and allows you to create a more attractive design. Generally, people are more likely to read a document that looks appealing.

The basics of finding members

Getting started

- Set up social media channels for your organisation. Facebook, Twitter and Instagram can be effective tools for increasing awareness. Post interesting things about your organisation regularly and ask your friends/followers to share your posts. This will help increase your visibility and reach, but it will take time.
- Reach out to other patient organisations, such as local arthritis associations, who might be willing to share information about your group with their members and stakeholders.
- Search for axSpA pages on Facebook or Instagram; there may be an 'informal' community already in your region.

Healthcare providers

A logical place to find members is through healthcare providers such as rheumatologists, physiotherapists or general practitioners.

- Healthcare providers can help to connect patients and caregivers to your organisation, so let them know you exist! You can start by sending an introductory email. It may be helpful to start with your own doctors and ask for referrals to other healthcare providers who treat people with axSpA.
- When you get to know healthcare providers, you can ask them to tell their axSpA patients about your organisation.
- Often, healthcare providers are looking for additional resources to provide to patients. Let them know if you have leaflets for patients and caregivers or a poster that they can display in their waiting room.
- Reach out to the national organisations or professional groups that represent different medical specialties to ask them if they would be willing to distribute information to the healthcare providers in their network.



Growing your membership

Websites

Keep your website updated with news about your organisation and relevant interest stories. This allows prospective members to keep up to date with the work of the organisation and demonstrates the value of joining.

Other patient support groups that work in areas related to axSpA, as well as hospital and clinic websites, may welcome the opportunity to advertise and promote your organisation, which can help to attract prospective members. You can offer to reciprocate by hosting their information on your group's website.

Newsletters and healthcare publications

Find out about newsletters that are sent out to patients and caregivers. Also identify relevant healthcare journals. You can contact the editor to ask if you can advertise your organisation in their newsletter or you might offer to write an article. Often editors are looking for content, so take the opportunity to pitch a short piece that describes axSpA, or a story that spotlights one of your members.

If you already have members, they can help

- Ask current members the reason they decided to join. You will learn about what attracted them to your organisation. You can use their reasons to help attract new members.
- Your current members may also be willing to help distribute information about your organisation.
 - You can supply them with leaflets that they can bring to their appointments and leave with their doctors or at local pharmacies.
 - Ask them to share your organisation's social media information on their own channels.
- They can also share their personal experiences (face to face or on social media) about why they decided to get involved and the benefits of being part of your organisation.

Determine the needs of your members

It is important to understand the needs of your members. This will ensure you are meeting their expectations and providing a meaningful experience. It also means people are more likely to be longer-term members and recommend joining the organisation to others.

Ask your members what they want from your organisation via email, a survey (Google forms is a good free option) or through social media.

Some things your members may want:

Education and Information

This could be learning more about the clinical elements of the disease, how different treatments work or about the latest research or opportunities to take part in research.

Support

This could include support groups, exercise classes or developing a private group on Facebook or WhatsApp where members can ask others about their experiences and support each other.

Resources

People might want resources on which exercises to do, about what treatment options are available or guides on how to prepare for and what to ask at a rheumatologist appointment.

Events

Members value the opportunity to meet others and participate in virtual and in-person events.

Member database management

- Create a member database; this may be required to officially register as a patient organisation.
- In the database, you can include the member's name, phone number and email address, plus anything else that is useful to your organisation. Not every member will be a person living with axSpA, so record what type of member they are. You might also have:
 - Family members or caregivers of an axSpA patient
 - Healthcare providers (rheumatologist, physiotherapist etc.)
 - Sponsors, funders or others with an interest in the organisation
- Having a member database will be important, particularly as your organisation grows. The database will help you communicate with your members about all kinds of things, from specific projects to your newsletter.
- It is important to check your local privacy laws regarding your database, as you may be storing personal information.



Membership section on your website

On your website, include a 'Join us' or 'Become a member' section.

- Outline the benefits of becoming a member, including how members will have access to support, information, resources and the opportunity to participate in meetings or events
- Consider having one or two testimonials from existing members about how being a member has benefitted them
- Include all information necessary about membership, for example whether there is a fee to pay and how to join
- Make sure this section is easy to use.

About membership fees

Some organisations choose to collect an annual fee from their members.

Advantages

- Membership fees provide a predictable and ongoing funding base
- Members might feel more personally connected to the organisation.

Disadvantages

- Managing membership fees requires administrative work
- Some members may be volunteers and feel they give enough already
- Losing prospective members who cannot afford to pay
- Some may be put off joining if they don't see the advantage of paying a fee
- Member expectations in return for their membership fee might be unrealistic.







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