



Summary report and recommendations on engaging with small patient advocacy groups

Background

Genetic Alliance UK has developed a toolkit to help Genomics England engage with small patient advocacy groups in a way that is proportionate to the time they can contribute and helps them to gather and share the views of their community as easily as possible.

Our definition of the size of these organisations is based on Genetic Alliance UK's experience of working with over 200 member charities and support groups. Three out of ten Genetic Alliance UK members are micro charities or support groups with income under £10,000 each year which tend to be volunteer-led. A further five out of ten alliance members are small charities or support groups with income under £250,000 each year which tend to have a small number of staff members.

The toolkit is based on the views of small and micro charities about how much time they have to contribute to Genomics England's work and the easiest ways for them to gather and share their community's views.

Why does listening to small patient advocacy groups matter?

Small patient advocacy groups are frequently set up by family members of people with a particular rare or genetic condition who are passionate about helping others in the same situation, and they often juggle running the organisation alongside paid work and caring responsibilities. Both volunteers and staff in smaller patient advocacy groups tend to focus on providing information and peer-to-peer support as well as fundraising to sustain their vital work. They may have limited capacity and limited experience of contributing the views of people living with the condition to the work of government bodies and research projects.

However, it is vital to hear from small patient advocacy groups. This is because for many rare and ultra-rare conditions there is:

- A poor understanding of the natural history of the condition.
- Limited evidence from published literature about what it is like to live with the condition, how it is diagnosed and managed, and how it impacts on quality of life for both the person living with the condition and their wider family.
- A small number of health professionals (if any) who have any experience of the condition. Even for health professionals with expertise, they may only see patients for an annual check-up. This means that they have a clinical understanding of the condition, which provides a different type of evidence to the 24/7 lived experience of people who have the condition.
- Limited clinical trial data relating to new treatments. Where there is clinical trial data it tends to focus on small patient populations across multiple international clinical trial sites. Most small patient advocacy groups will be in contact with far more people living with a particular condition in the UK than have taken part in a clinical trial.

This means that there is a practical need to engage with small patient advocacy groups to learn from the lived experience of people living with rare and genetic conditions.

However, it is incredibly important to do this in a way that is proportionate and does not put too much pressure onto already over-stretched small patient advocacy groups.

There can be a huge cost and burden to engaging with government bodies on top of providing day-to-day support for individuals, families and the wider community.

This is particularly challenging for micro and small charities set up by parents of a child with a rare condition to help other families in similar situations, as they are connected professionally, personally and emotionally to their work. They are passionately committed to supporting their community and doing this well is more than just a job to them.

How did we approach this challenge?

We started this project by completing desk research to review the current landscape for engaging with small patient advocacy groups. We sought to share learning from the approaches taken by the following organisations who regularly seek the views of rare and genetic condition charities and support groups:

- National Institute for Health and Care Excellence (NICE)
- Scottish Medicines Consortium (SMC)
- Health Technology Wales (HTW)
- Human Fertilisation and Embryology Authority (HFEA)

We focused on HTW rather than the Welsh Health Specialised Services Committee (WHSSC) as HTW's approach has been highly recommended by the smaller patient advocacy groups that we work with in Wales. We planned to include the Medicines and Healthcare Products Regulatory Agency (MHRA) in this analysis, but we did not do so since the MHRA are currently reviewing their approach to engaging patient groups in their work with a view to improving it.

Based on the learning from desk research we developed draft recommendations for engaging small and micro charities. These recommendations were tested and refined in conversation with small and micro Genetic Alliance UK members, and through a short survey to understand the preferences of a broader group of small and micro charities.

What does this summary report include?

This summary report sets out our recommendations on engaging with small patient advocacy groups.

Recommendations on engaging with small patient advocacy groups

- Only ask a small or micro advocacy group to share the views of their community if you are clear how it will influence the work you are doing: there are lots of competing calls on their time so you need to avoid ‘engagement for engagement’s sake’.
- Be mindful of the size of small and micro advocacy groups supporting people affected by genetic and rare conditions when establishing processes for listening to lived experience. Make sure any practical (burden of the ask) and ethical (duty of care) considerations are identified and addressed before approaching these groups for their views.
- Consider how you will support small and micro advocacy groups that are invited to contribute to your work. If you will regularly be seeking their views you may wish to consider establishing:
 - A patient and public involvement staff team with expertise in patient and public involvement and engagement to support them day-to-day
 - An expert patient and public involvement advisory committee to advise you on the right approach on a project-by-project basis.
- Approach small and micro advocacy groups/patient advocacy groups early in the life cycle of projects so that they can plan work schedules accordingly and have optimum impact on the project.
- Use accessible language in all materials developed for working with advocacy groups and the communities they support.

- Tailor your approach to engaging **advocacy group representatives** for each project through tried-and-tested techniques used by academic researchers and pharmaceutical companies. These could include the following approaches (in order of preference), with support materials co-created with the relevant group:
 - Online surveys (short)
 - Focus groups
 - Expert advisory groups
 - Video interview
 - Online survey (long)
 - Telephone interview
 - Paper-based surveys (short or long)

- Tailor your approach to engaging **people with lived experience** of rare conditions and family carers for each project through tried-and-tested techniques used by academic researchers and pharmaceutical companies. These could include the following approaches (in order of preference), with support materials co-created with the relevant community:
 - Online surveys (short)
 - Focus groups
 - Video interview
 - Telephone interview
 - Expert advisory groups
 - Online survey (long)
 - Paper-based surveys (short or long)

- If you are inviting small and micro patient advocacy groups to contribute the views of their community at a large meeting, plan carefully to ensure they can contribute fully. This is particularly important for meetings with a range of stakeholders including clinicians and academics where technical jargon and scientific language is used. Approaches (in order of preference) could include:
 - Provide meeting materials, with technical terms explained, ahead of the meeting.

- o Inviting their input at key points on the agenda.
 - o Using an audience participation tool such as Slido or Mentimeter to encourage contributions from people who may not feel comfortable speaking at a large meeting.
 - o Designating a senior member of staff attending the meeting to highlight and explain in accessible terms any technical jargon and scientific language that is being used.
 - o Setting aside time at the start of the meeting to ask for patient group input and set the right tone.
- When seeking views on a particularly technical issue or against a very tight deadline, consider if it is more appropriate to seek views through an umbrella organisation or existing network who are already familiar with your approach.
 - Demonstrate that you value the time and expertise of advocacy groups by (in order of preference):
 - o Paying for their services at a standard hourly rate for smaller projects.
 - o Signing a standard contract with the charity to agree the scope and scale of their input and reimburse them for larger projects.
 - o Providing public acknowledgement and recognition for their contribution to your work to boost their reputation, generate further opportunities for networking, and support their future applications for grants and funding.
 - Recognise that it may be more challenging to demonstrate that you value the time and experience of people with lived experience of rare conditions and family carers. This is because some people are unable to accept reimbursement that could impact on their benefit or tax thresholds. Pharmaceutical companies and academic researchers often offer a £50 voucher for a high street store or a donation to a charity of their choice as payment. You may wish to consider if there is a similar way to thank people with lived experience of rare conditions and family carers who share their views with you by building this into your contract with the relevant advocacy group or an appropriate research partner.

Report produced by Genetic Alliance UK and funded by Genomics England.

Genetic Alliance UK

Postal address:

3rd Floor
86-90 Paul Street
London EC2A 4NE

Registered address:

The Clock Tower
5 Farleigh Court
Old Weston Road
Flax Bourton
Bristol BS48 1UR

Registered charity numbers: 1114195 and SC039299

Registered company number: 05772999

0300 124 0441

contactus@geneticalliance.org.uk