



Top tips for engaging with small and micro patient advocacy groups

Genetic Alliance UK has developed advice on engaging 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. We define small charities as those with income under £250,000 that have a small number of staff members, and micro charities or support groups as those with income under £10,000 which tend to be volunteer-led.

These top tips are based on the views of small and micro charities about how much time they have to contribute to the work of national bodies and the easiest ways for them to gather and share their community's views.

‘Only ask us to seek and share the views of our community (people with lived experience of a genetic or rare condition and family carers) if you are clear how it will influence the work you are doing. There are lots of competing calls on our time so please avoid “engagement for engagement’s sake”’

‘Be mindful of the size of patient 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 us for our views.’

‘Consider how you will support patient groups that are invited to contribute to your work. If you will regularly be seeking our views you may wish to set up:

- A patient and public involvement staff team with expertise in patient and public involvement and engagement to support us 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 patient groups early in the life cycle of projects so that we can plan our work schedules accordingly and maximise our impact on the project.’

‘Use accessible language in all materials developed for working with patient groups and the communities we serve.’

‘Tailor your approach to engaging **patient 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 us:

- Online surveys (short)
- Focus groups
- Expert advisory groups
- Video interview
- Online survey (long)
- Telephone interview
- Paper-based surveys (short or long)’

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'If you are inviting patient groups to contribute the views of our community at a large meeting, plan carefully to ensure we 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.
- Inviting our input at key points on the agenda
- 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.
- 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.
- 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 patient group representatives by (in order of preference):

- Paying for our services at a standard hourly rate for smaller projects.
- Signing a standard contract with us to agree the scope and scale of our input and reimburse us for larger projects.
- Providing public acknowledgement and recognition for our contribution to your work to boost our reputation, generate further opportunities for networking, and support our future applications for grants and funding.'

‘Recognise that it may be more challenging to demonstrate that you value the time and experience of our community (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.’

These top tips have been produced by Genetic Alliance UK, based on the findings from a [report and recommendations on engaging with small patient advocacy groups](#) funded by Genomics England.

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