

# Survey Overview



## Process

- This was a collaborative project between the Fabry International Network (FIN) and Amicus Therapeutics
- Amicus funded the survey
- FIN is an umbrella patient advocacy organisation that represents over 62 patient organisations from 54 countries around the world
- Invitations to participate were sent via email by FIN
- 30 FIN member organisations responded to the survey via a Survey Monkey link
- Respondents were allowed to select more than one answer for some of the questions

## Objectives

- Gather feedback and insights from FIN membership on their current challenges
- Understand how engaged they feel their communities are
- Identify what communication ideas and activities would support them in the future

## Strong Agreement That In-Person Is Best for Engagement

Survey responders were asked:  
What would you like to take away following the leadership roundtable sessions?

Total respondents: 30



- 37% Capacity building opportunities
- 47% Social media campaigns
- 50% New educational resources
- 53% Awareness day activities
- 60% Virtual networking opportunities to meet other participants/families and have informal discussions
- 83% In-person networking/opportunities to meet other participants/families and have informal discussions

## Biggest Challenges Facing the Fabry Community

Total respondents: 30

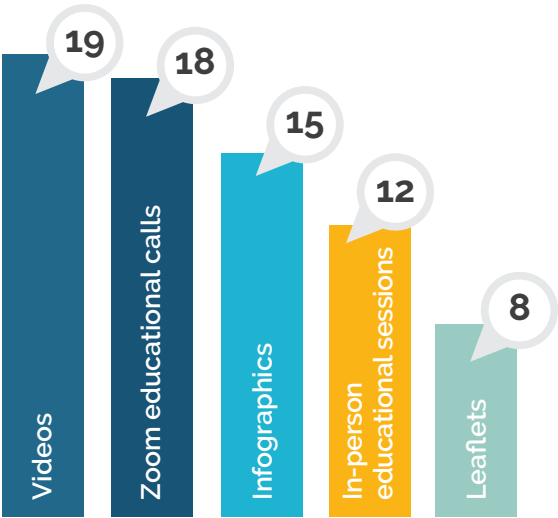
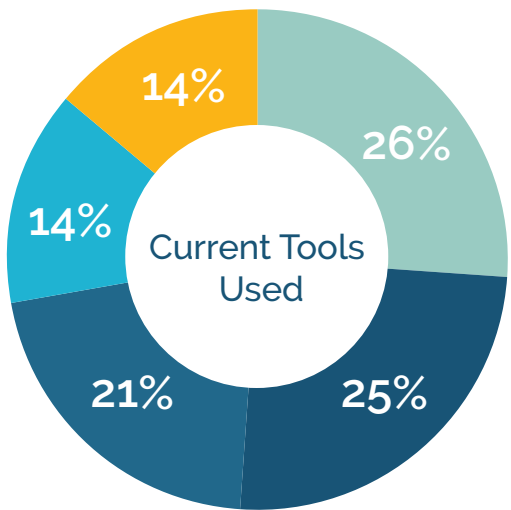
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| 27% <sup>8</sup> General on-going COVID-19 pandemic issues around vaccination | 47% <sup>14</sup> General on-going COVID-19 pandemic issues around accessing timely diagnosis                               |
| 33% <sup>10</sup> Supporting patients utilising virtual appointments          | 50% <sup>15</sup> General on-going COVID-19 pandemic issues around understanding COVID-19 risk to Fabry patients            |
| 40% <sup>12</sup> Accessing appropriate resources/education                   | 53% <sup>16</sup> Supporting Fabry patients to manage their day-to-day symptoms with their healthcare teams                 |
| 43% <sup>13</sup> Supporting patients in accessing their healthcare teams     | 57% <sup>17</sup> Supporting newly diagnosed Fabry patients and those who feel they may have Fabry but can't get diagnosed. |

## Need for Additional Educational Videos and Zoom Calls

Total respondents: 29

Survey responders were asked:  
What new tools would you be interested in using for education?

- Leaflets
- Zoom educational calls
- Videos
- Infographics
- In-person educational sessions



Interest in New Tools

## Preferred Channels of Communication Is Mixed

Total respondents: 30

- 70% Social media channels (21)
- 67% In-person meetings (20)
- 57% Closed social media groups (17)
- 54% Virtual meetings (16)
- 54% Website (16)
- 40% Newsletter (print or email) (12)
- 37% Email (11)

## Over ½ (23/30) of Respondents Are Engaged with Their Local Fabry Organisation



## Overwhelming Support to Participate in FIN Roundtable Meetings

Total respondents: 26

- 93% of respondents were interested in participating in FIN roundtable meetings
- 65% strongly support meeting at in-person/hybrid FIN Expert Meeting
- 54% strongly support hosting bi-annual Zoom meetings
- 65% of respondents are interested in an action plan with local and regional ideas for customisation

## FIN Survey Country Participation

