

# Cancer Care during COVID-19: Data from 157 Patient Organisations

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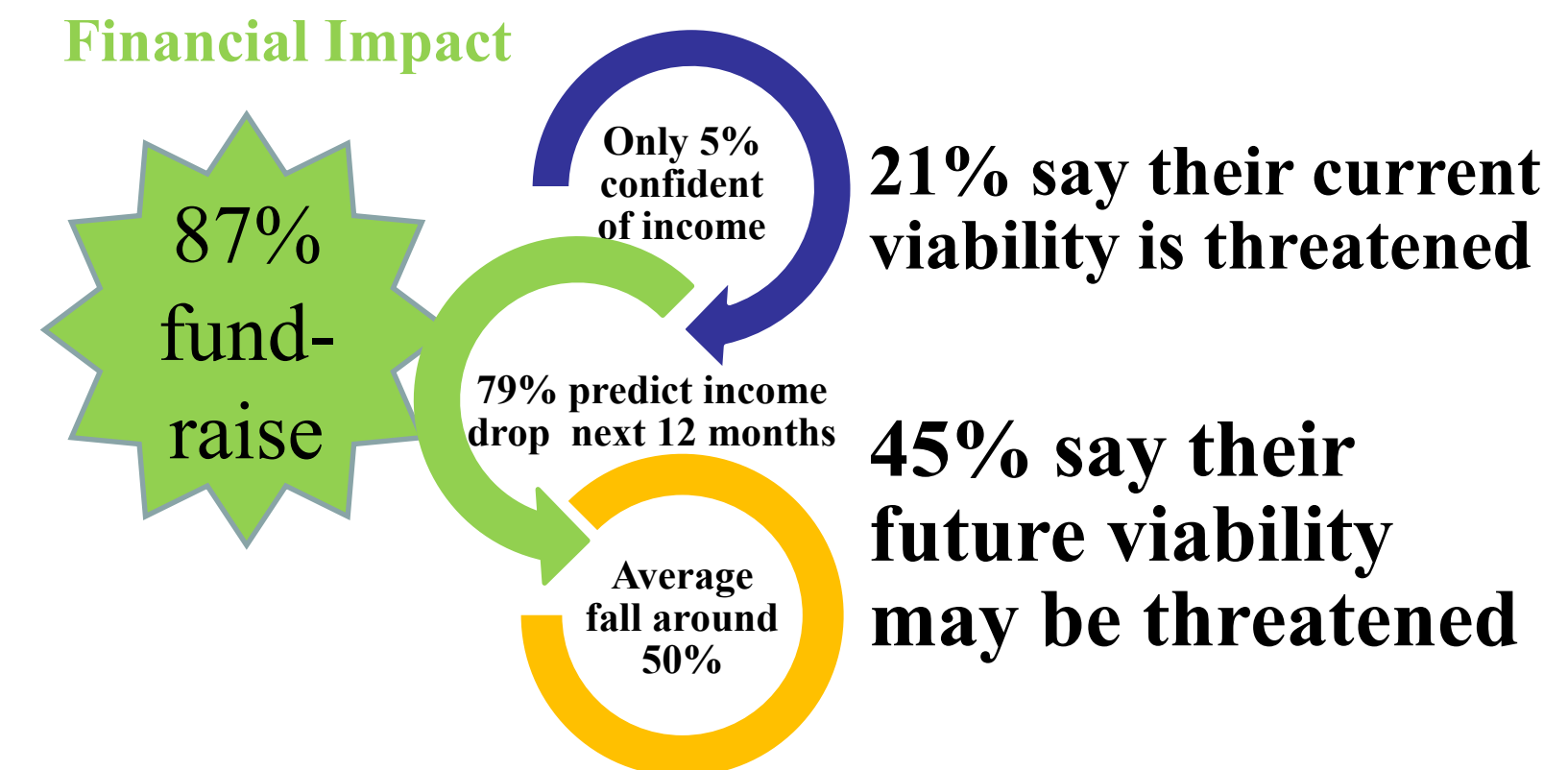
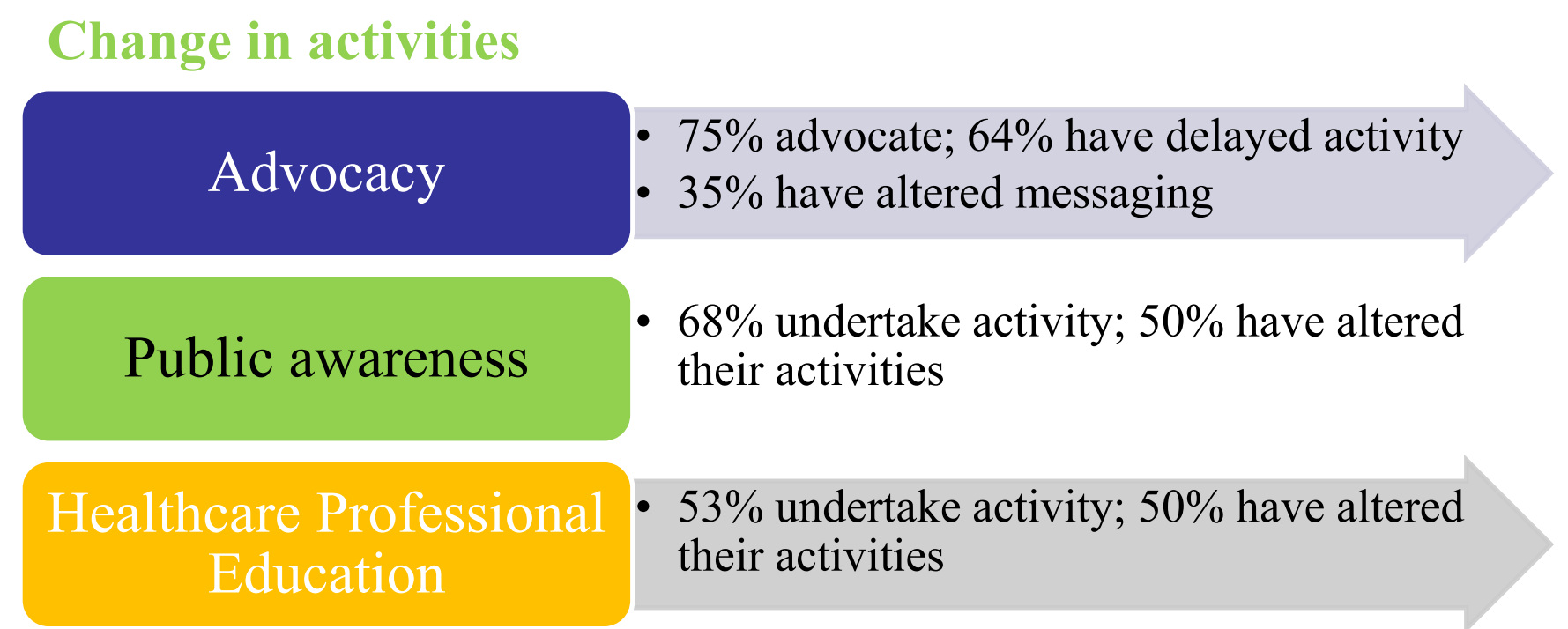
## Abstract

**Background:** Representatives from 8 global cancer coalitions/alliances, representing 650 cancer patient groups and the interests of over 14 million patients have come together during the pandemic to review and evaluate the patient-perspective impact. Cancer services have faced challenges as a result of COVID-19, including suspension of screening and diagnostic services; delays in diagnosis leading to higher mortality rates; cancellation/deferral of life-saving treatments; changes in treatment regimens and suspension of vital research. For organisations that provide support to cancer patients, declining income, the need to reduce staff and move to virtual working practices has put extra strain while demand for support due to the pandemic has increased. Methods: 5 coalitions surveyed their member organisations. A number of coalitions consulted their members by individual surveys or consultations.

**Results:** A survey of 157 organisations representing advanced breast, bladder, lymphoma, ovarian and pancreatic cancer patient groups from 56 countries found that 57% experienced an average increase of 44% in patient calls and emails. 45% reported that their future viability may be under threat because of the impact of COVID-19 on income. Examples of good practice were reported where healthcare systems have acted to protect patients and cancer services. These include the introduction of COVID-free centres, separation of cancer patients from those who may have COVID-19, and the introduction of virtual and telemedicine services. Organisations have also introduced new ways of working including virtual psychological support services and app-based support groups. These best practices should form part of a global plan of action for future health crisis.

**Conclusions:** Collaboration between patient advocacy organisations, governments and health services is needed to ensure the ground lost to the COVID-19 pandemic is regained. Action is required to restore cancer services safely and effectively without delay. Additional resources for organisations that support cancer patients are required to ensure that they continue to provide vital services. Finally, a global plan of action for cancer is required to meet the challenges of any future health crisis.

## RESULTS

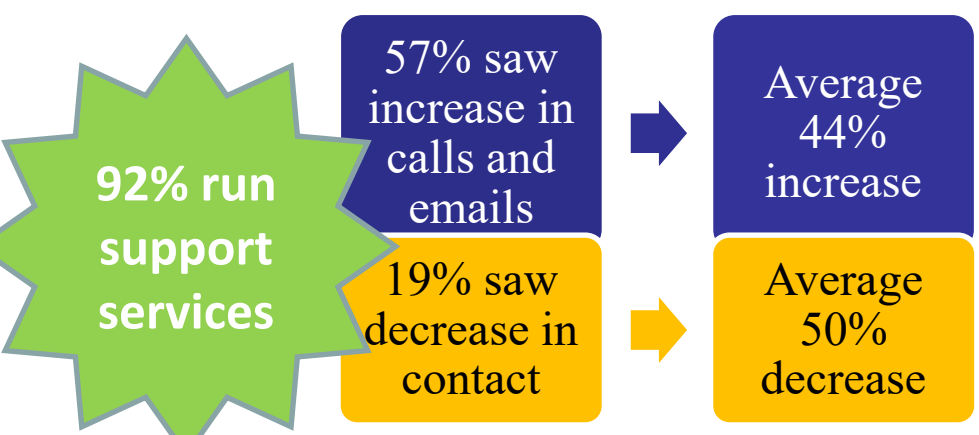


## RESULTS

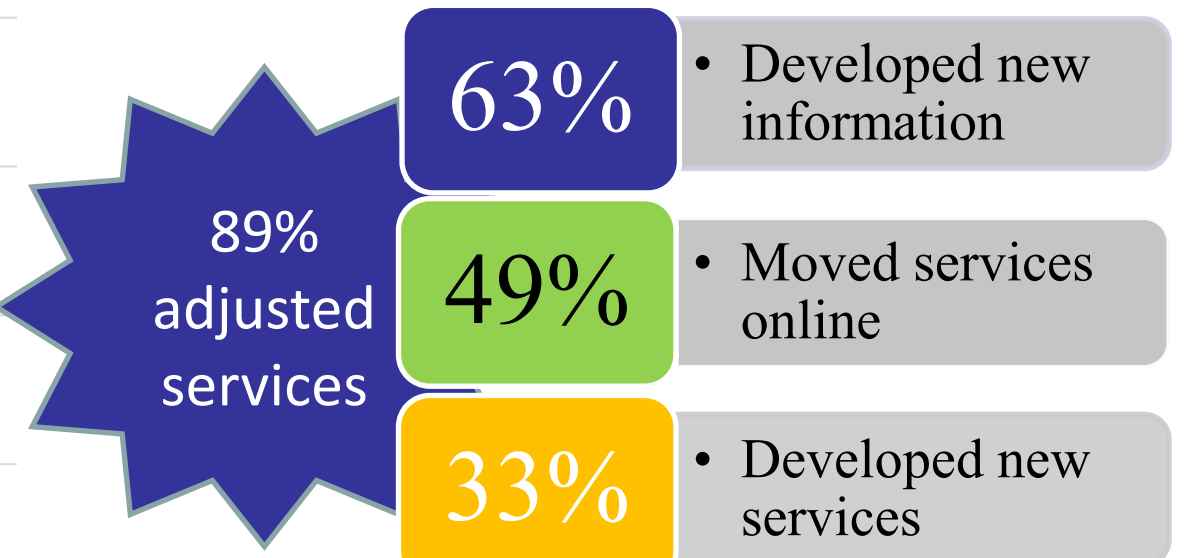
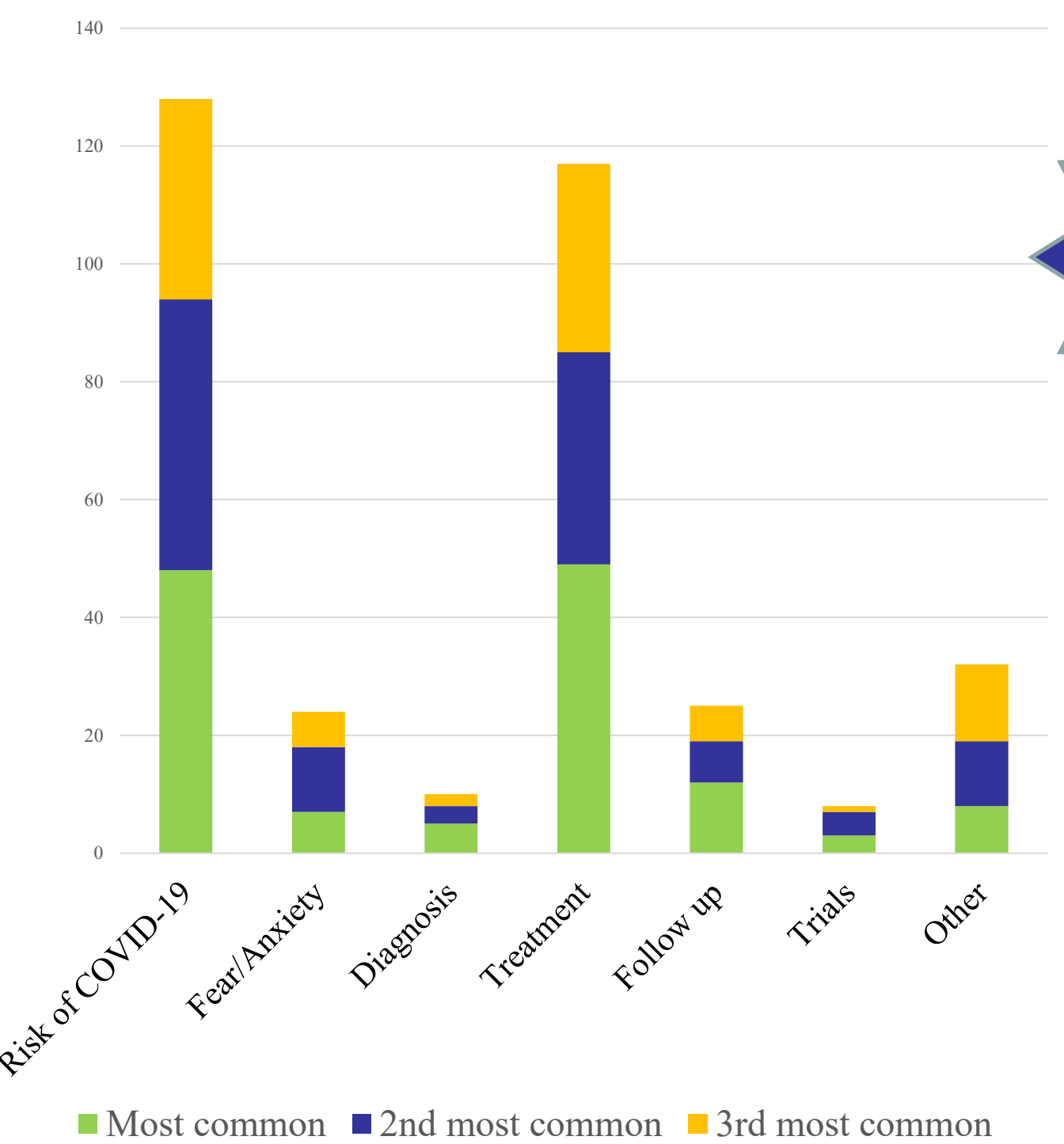
### Organisations (n=157)

- 40% no paid staff
- 24% > 5 FTE staff
- 17,500 volunteers
- Total >350,000 cancer patients

### COVID-19 Impact

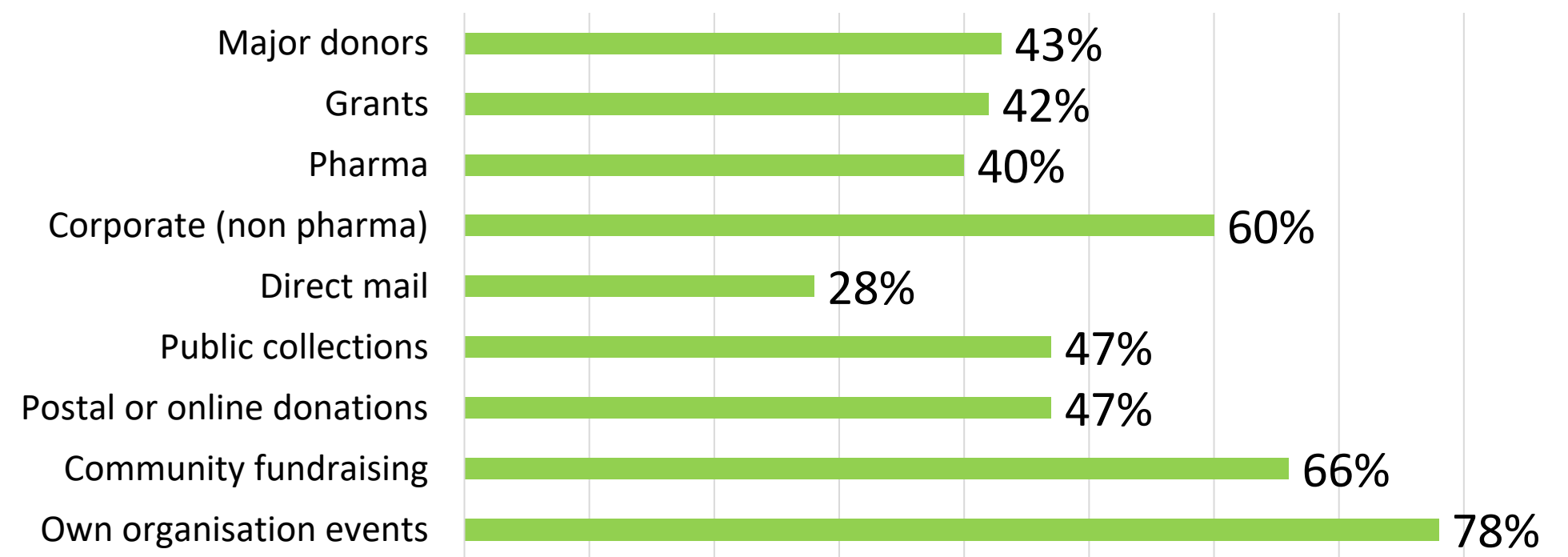


69% had COVID calls or emails



- Webinars
- Ask the expert
- WhatsApp support groups
- Materials distribution
- One-to-one online psychosocial support
- Choir
- Increased frequency of activity
- Increased reach – people in hospital or isolated
- Less travelling for patients

### Organisation income has decreased significantly



- Every type of fundraising affected
- 60% are trying to find new ways of fundraising
- 65% concerned for fundraising and philanthropy after the pandemic is over
- 55% already cutting costs
- 1/3 have had to spend more on technology and equipment for home workers and new services
- Some seeking mentoring, partnerships



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## CONCLUSIONS

- The survey identified several unmet patient needs during the COVID-19 pandemic. Substantial need for psychosocial support and information from patient organisations has increased by approximately 50%, while organisation services have had to adjust their activities and to provide evidence-based information.
- This global survey of 157 patient organisations serves as real-world evidence as a benchmark for longitudinal data collection.
- Despite increased demand for patient organisation services, income has dropped, organisations have had to lay off staff, and >45% of the organisations bear financial burden threatening their viability.