# PATIENTS' ADVOCACY GROUPS IN ITALY: AN UPDATED PERSPECTIVE ON ACTIVITIES AND FUTURE DIRECTIONS

PT16

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## Introduction

The current healthcare system is evolving towards a dynamic and integrated model, where institutions, healthcare professionals, patients, and caregivers increasingly operate in synergy. This collaborative approach aims to promote prevention, enable early access to diagnosis, and ensure optimal and consistent care pathways across the entire territory.

In this evolving landscape, the role of Patient Advocacy Groups (PAGs) is becoming crucial, increasingly engaging in dialogue with institutions, helping to shape health policies that aim to improve care pathways and healthcare services.

This study updates previous research on the role of Italian PAGs, exploring how they have expanded their scope, diversified their initiatives, and reshaped strategic priorities in response to emerging healthcare challenges.

## Methods

In March 2025, a web-based survey investigating activities conducted over the past three years and gathering insights into future priorities was distributed to over 100 PAGs operating at the national level across various therapeutic areas.

PAGs' activities were grouped into 6 macro-areas:

1. Public awareness and education (e.g., disease information campaigns, trainings programs).
2. Activities for patients and caregivers (e.g., psychological support, home care, legal assistance).
3. Collaboration with hospitals and healthcare providers (e.g., co-design of care pathways, telemedicine).
4. Scientific activities (e.g., clinical trial design, scientific publications).
5. Social and institutional advocacy (e.g., engagement with policy-makers, contributions to health policy).
6. Fund raising (e.g., support for association activities, research).

## Results

115 PAGs participated, covering onco-hematology (28%), immunological diseases (10%), rare diseases (31%), infectiology (6%), and others (25%).

*Figure 1* shows activities carried out by PAGs per therapeutic area:

- There is an emphasis in information, education and disease awareness raising projects.
- Significant efforts were also reported in meeting patients' and caregivers' needs, including emotional assistance, free health screenings, and legal and financial aid, especially in onco-hematology and infectiology.
- In the scientific field, PAGs contribute to clinical studies and editorial projects.
- Crucial is also the role of institutional advocacy, aimed at making the healthcare system more responsive to patients' needs, and collaboration with hospitals to improve access to care and the quality of services provided.

The growing role of collaboration between PAGs and institutions at the national level is highlighted in *Figure 2*:

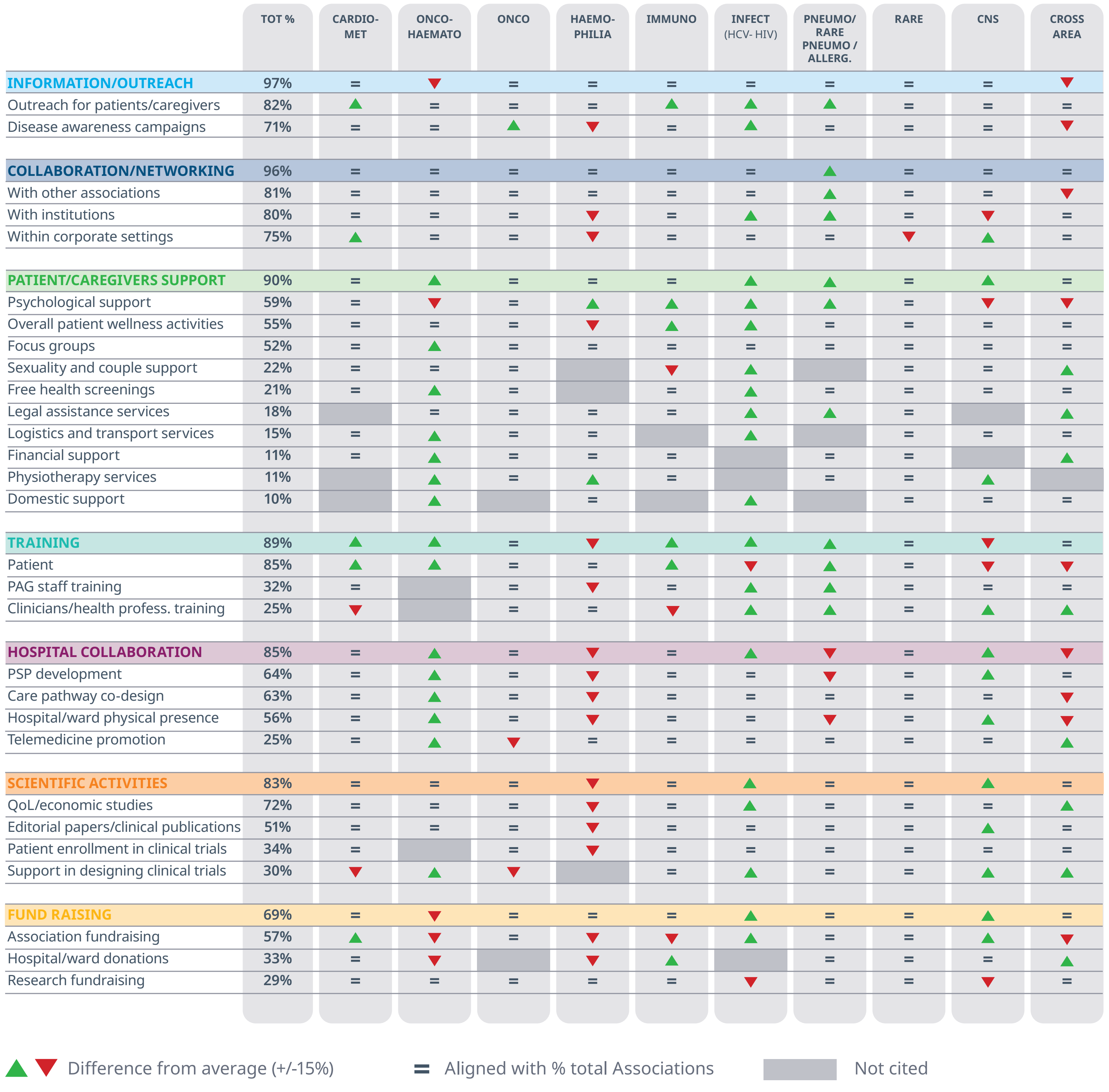
- Over 50% of PAGs take part in decision-making discussions with institutions, with 41% participating on a regular basis.
- Significant differences emerge across therapeutic areas, with notable emphasis observed in Immunology, Infectious Diseases, Central Nervous System (CNS), and Cross-Area domains.
- Overall, 59% of PAGs consider the impact of their participation on decision-making choices and policies to be very high.

In the near future, PAGs aim to further strengthen their advocacy and scientific role by focusing on service innovation, evidence-based communication, and targeted educational initiatives (*Figure 3*). Their long-term vision remains centered on standing alongside patients and generating valuable resources to improve both treatments and overall quality of life.

## Conclusions

**Italian PAGs are evolving from traditional support roles into proactive partners in healthcare innovation, research, and policymaking. Their expanding scope underscores the need for structured collaboration and institutional recognition to amplify the patient voice, foster system-wide integration, and promote equitable, patient-centered care.**

*Figure 1.* ***Current activities by therapeutic area***



| | TOT % | CARDIO-MET | ONCO-HAEMATO | ONCO | HAEMO-PHILIA | IMMUNO | INFECT (HCV- HIV) | PNEUMO/ RARE PNEUMO / ALLERG. | RARE | CNS | CROSS AREA |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **INFORMATION/OUTREACH** | 97% | = | ▼ | = | = | = | = | = | = | = | ▼ |
| Outreach for patients/caregivers | 82% | ▲ | = | = | = | ▲ | ▲ | ▲ | = | = | = |
| Disease awareness campaigns | 71% | = | = | ▲ | ▼ | = | ▲ | = | = | = | ▼ |
| **COLLABORATION/NETWORKING** | 96% | = | = | = | = | = | = | ▲ | = | = | = |
| With other associations | 81% | = | = | = | = | = | = | ▲ | = | = | ▼ |
| With institutions | 80% | = | = | = | ▼ | = | ▲ | ▲ | = | ▼ | = |
| Within corporate settings | 75% | ▲ | = | = | ▼ | = | = | = | ▼ | ▲ | = |
| **PATIENT/CAREGIVERS SUPPORT** | 90% | = | ▲ | = | = | = | ▲ | ▲ | = | ▲ | = |
| Psychological support | 59% | = | ▼ | = | ▲ | ▲ | ▲ | ▲ | = | ▼ | ▼ |
| Overall patient wellness activities | 55% | = | = | = | ▼ | ▲ | ▲ | = | = | = | = |
| Focus groups | 52% | = | ▲ | = | = | = | = | = | = | = | = |
| Sexuality and couple support | 22% | = | = | = | ▨ | ▼ | ▲ | ▨ | = | = | ▲ |
| Free health screenings | 21% | = | ▲ | = | ▨ | = | ▲ | = | = | = | = |
| Legal assistance services | 18% | ▨ | = | = | = | = | ▲ | ▲ | = | ▨ | ▲ |
| Logistics and transport services | 15% | = | ▲ | = | = | ▨ | ▲ | ▨ | = | = | = |
| Financial support | 11% | = | ▲ | = | = | = | ▨ | = | = | ▨ | ▲ |
| Physiotherapy services | 11% | ▨ | ▲ | = | ▲ | = | ▨ | = | = | ▲ | ▨ |
| Domestic support | 10% | ▨ | ▲ | ▨ | = | ▨ | ▲ | ▨ | = | = | = |
| **TRAINING** | 89% | ▲ | ▲ | = | ▼ | ▲ | ▲ | ▲ | = | ▼ | = |
| Patient | 85% | ▲ | ▲ | = | = | ▲ | ▼ | ▲ | = | ▼ | ▼ |
| PAG staff training | 32% | = | ▨ | = | ▼ | = | ▲ | ▲ | = | = | = |
| Clinicians/health profess. training | 25% | ▼ | ▨ | = | = | ▼ | ▲ | ▲ | = | ▲ | ▲ |
| **HOSPITAL COLLABORATION** | 85% | = | ▲ | = | ▼ | = | ▲ | ▼ | = | ▲ | ▼ |
| PSP development | 64% | = | ▲ | = | ▼ | = | = | ▼ | = | ▲ | = |
| Care pathway co-design | 63% | = | ▲ | = | ▼ | = | = | = | = | = | ▼ |
| Hospital/ward physical presence | 56% | = | ▲ | = | ▼ | = | = | ▼ | = | ▲ | ▼ |
| Telemedicine promotion | 25% | = | ▲ | ▼ | = | = | = | = | = | = | ▲ |
| **SCIENTIFIC ACTIVITIES** | 83% | = | = | = | ▼ | = | ▲ | = | = | ▲ | = |
| QoL/economic studies | 72% | = | = | = | ▼ | = | ▲ | = | = | = | ▲ |
| Editorial papers/clinical publications | 51% | = | = | = | ▼ | = | = | = | = | ▲ | = |
| Patient enrollment in clinical trials | 34% | = | ▨ | = | ▼ | = | = | = | = | = | = |
| Support in designing clinical trials | 30% | ▼ | ▲ | ▼ | ▨ | = | ▲ | = | = | ▲ | ▲ |
| **FUND RAISING** | 69% | = | ▼ | = | = | = | ▲ | = | = | ▲ | = |
| Association fundraising | 57% | ▲ | ▼ | = | ▼ | ▼ | ▲ | = | = | ▲ | ▼ |
| Hospital/ward donations | 33% | = | ▼ | ▨ | ▼ | ▲ | ▨ | = | = | = | ▲ |
| Research fundraising | 29% | = | = | = | = | = | ▼ | = | = | ▼ | = |

▲ ▼ Difference from average (+/-15%)   = Aligned with % total Associations   ▨ Not cited

*Figure 2.* ***Relationship with National institutions***

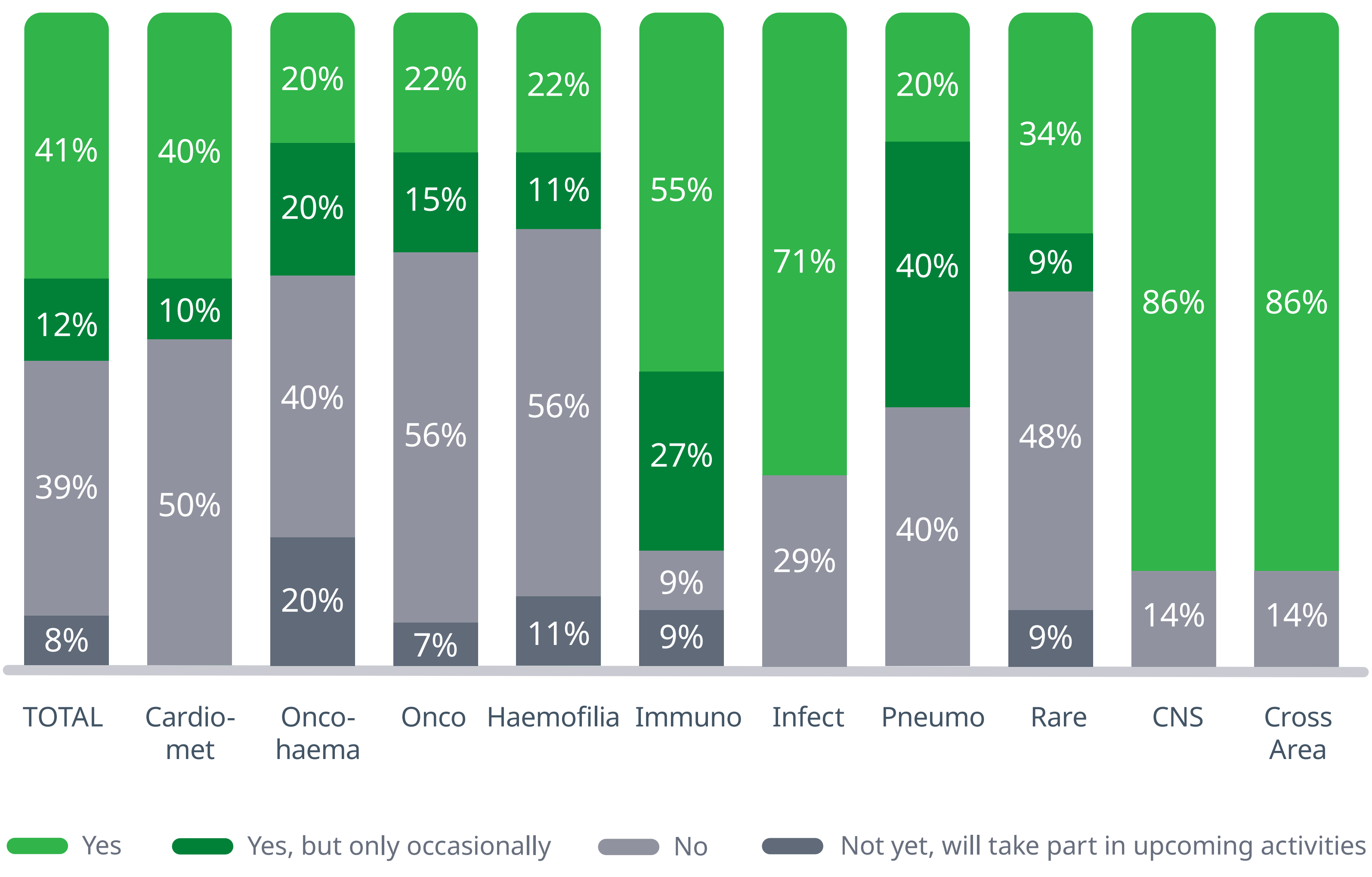
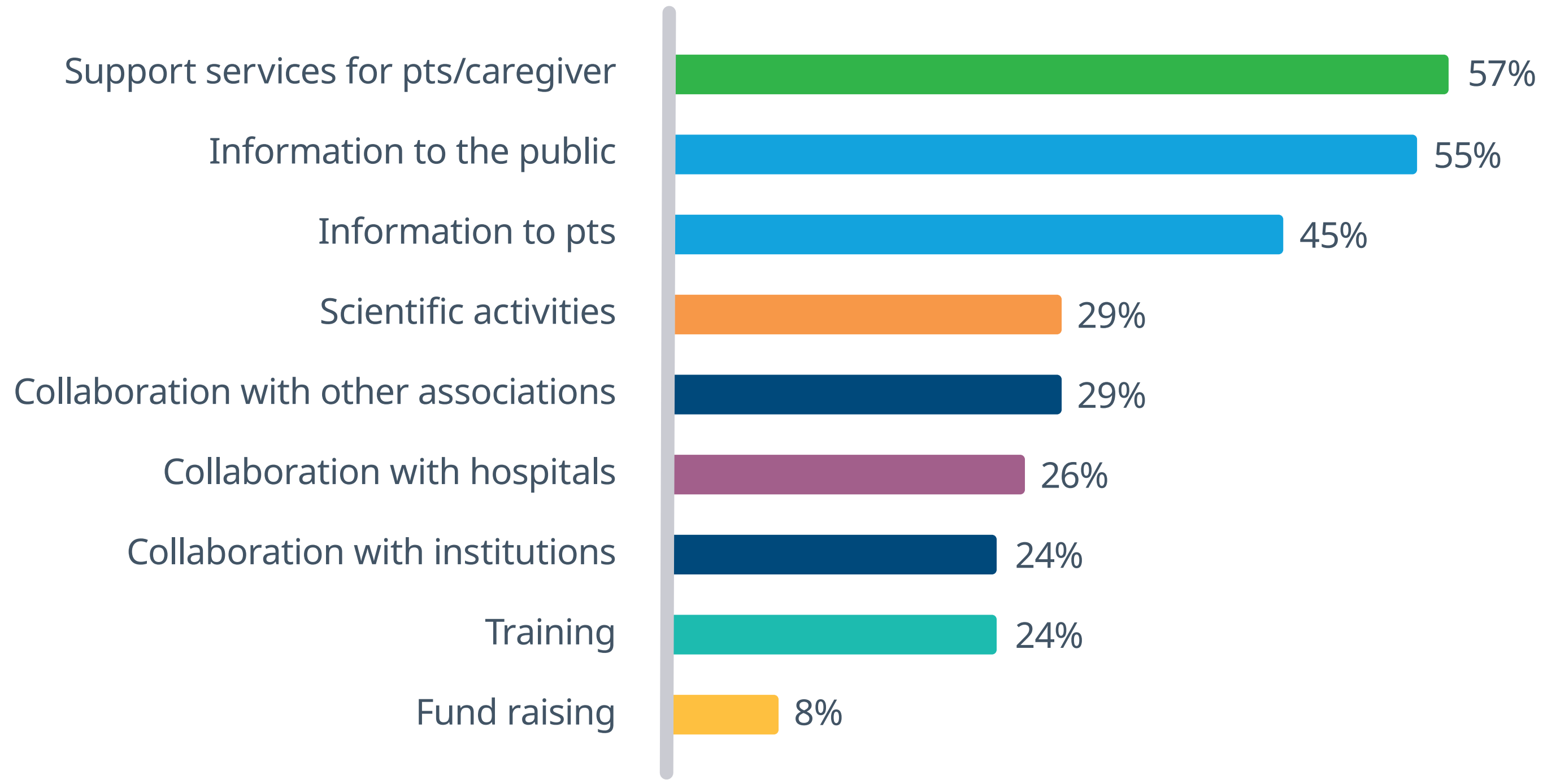


*Figure 3.* ***Expectations for the future***



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