



World Patients Alliance

Member Survey 2023

Report



Name of Organization

- Global Liver Institute
- Ukrainian Hemophilia Association
- National Kidney Foundation of Malaysia
- Alzheimer Society of Bangladesh
- Zambian Cancer Society
- SAID NGO
- LUGEI FOUNDATION UGANDA
- DementiaSA
- Patient Voice Partners
- Alzheimer's Pakistan
- Hyper-Cent Care Africa
- International Alliance of Dermatology Patient Organizations (GlobalSkin)
- Epilepsy Warriors Foundation
- Asociación de Talasemia Argentina
- Anasovi
- Stroke Support India
- ESPERANTRA
- AAA Associaton - Association of patients with allergies, asthma and atopic dermatitis
- Women's Coalition Against Cancer - (WOCACA)
- FINCOPP
- Fundación de Apoyo a Enfermos con Trastornos Hipofisarios FAETH
- Jahandad Society For Community Development
- Hepatitis Foundation of Ghana
- Association Guatemalteca Heroes De Esperanza
- Arrhythmia Alliance
- ESTONIAN Inflammatory Bowel Disease Association



Country

Tunisia
Kenya
Colombia
Mozambique
United States
España
MALI
Pakistan
Brazil
Zambia
México
Canada
Portugal
United Kingdom
Croatia
Philippines
Cameroon
Lebanon
Belgium
Germany
Slovenia
Ireland
Ghana
Jordan
Россия
Nigeria
South Africa
MALTA
Bangladesh
Egypt
Nepal



Year Established

1964

1978

1980

1969

2000

2006

2018

2015

2008

2009

1996

2016

1994

1991

2012

1985

2004

2020

2022

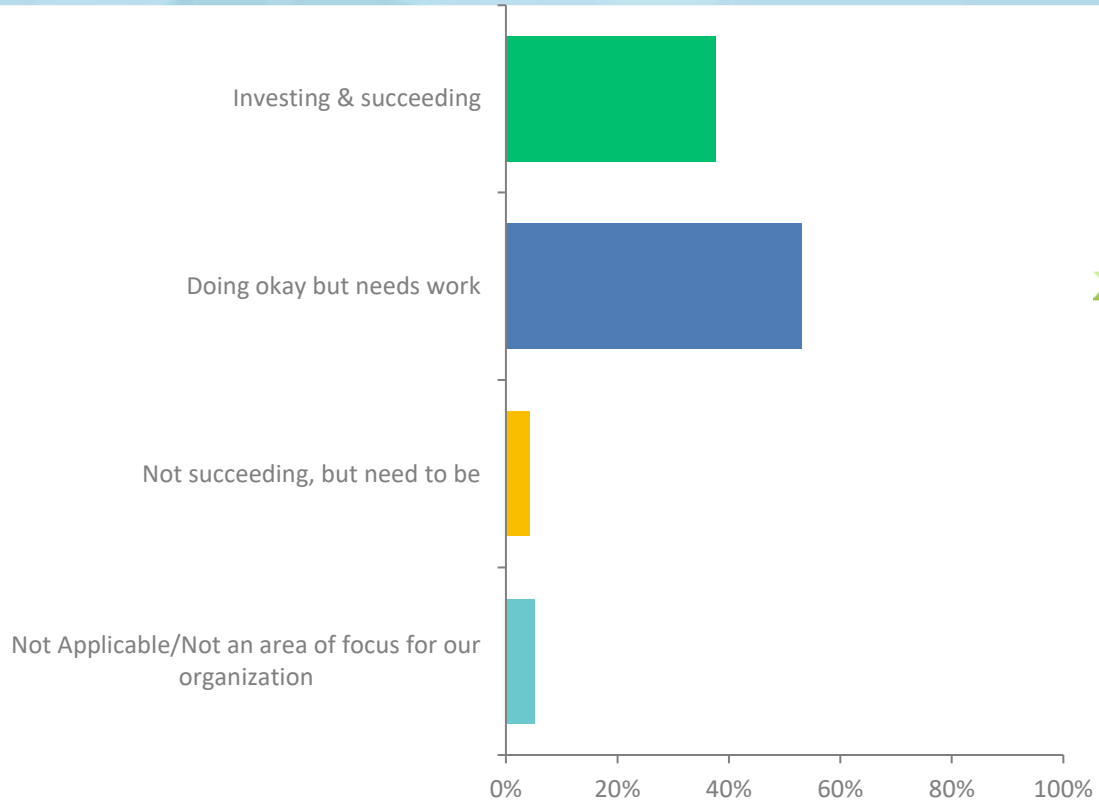


Number of patients, caregivers, other stakeholders served





Involvement & Success in ADVOCACY



ANSWER CHOICES

RESPONSES

Investing & succeeding

37.61%

Doing okay but needs work

52.99%

Not succeeding, but need to be

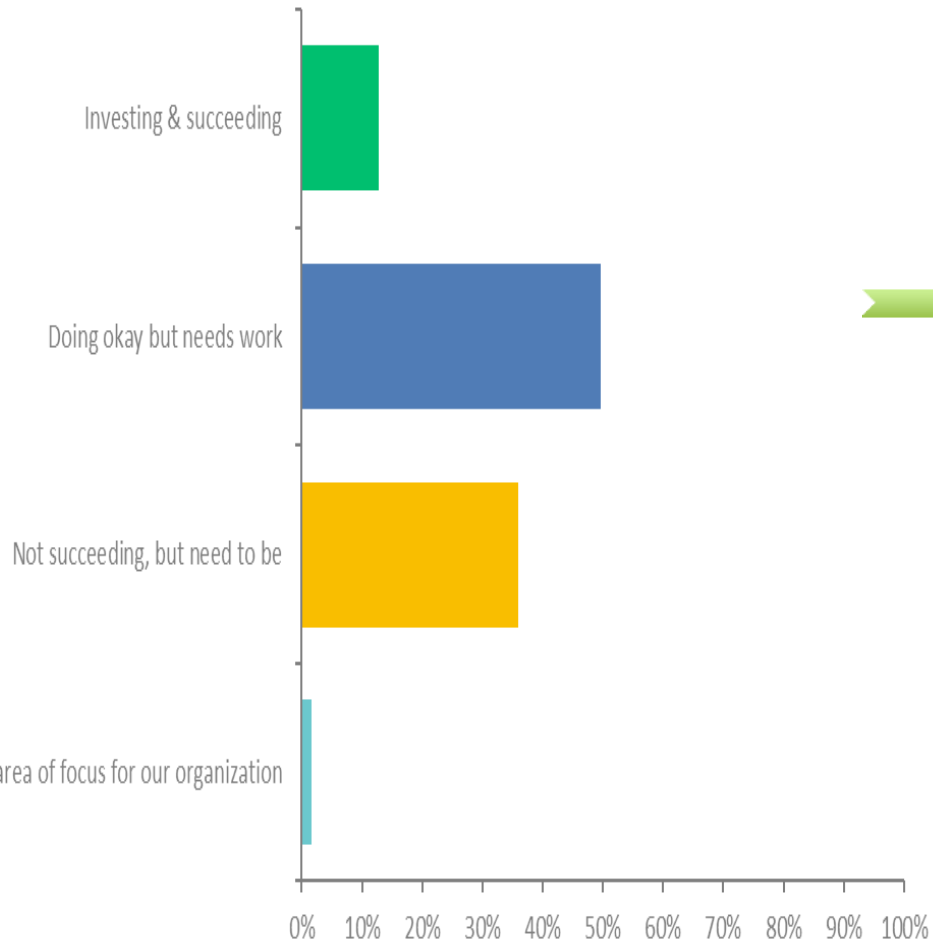
4.27%

Not Applicable/Not an area of
focus for our organization

5.13%



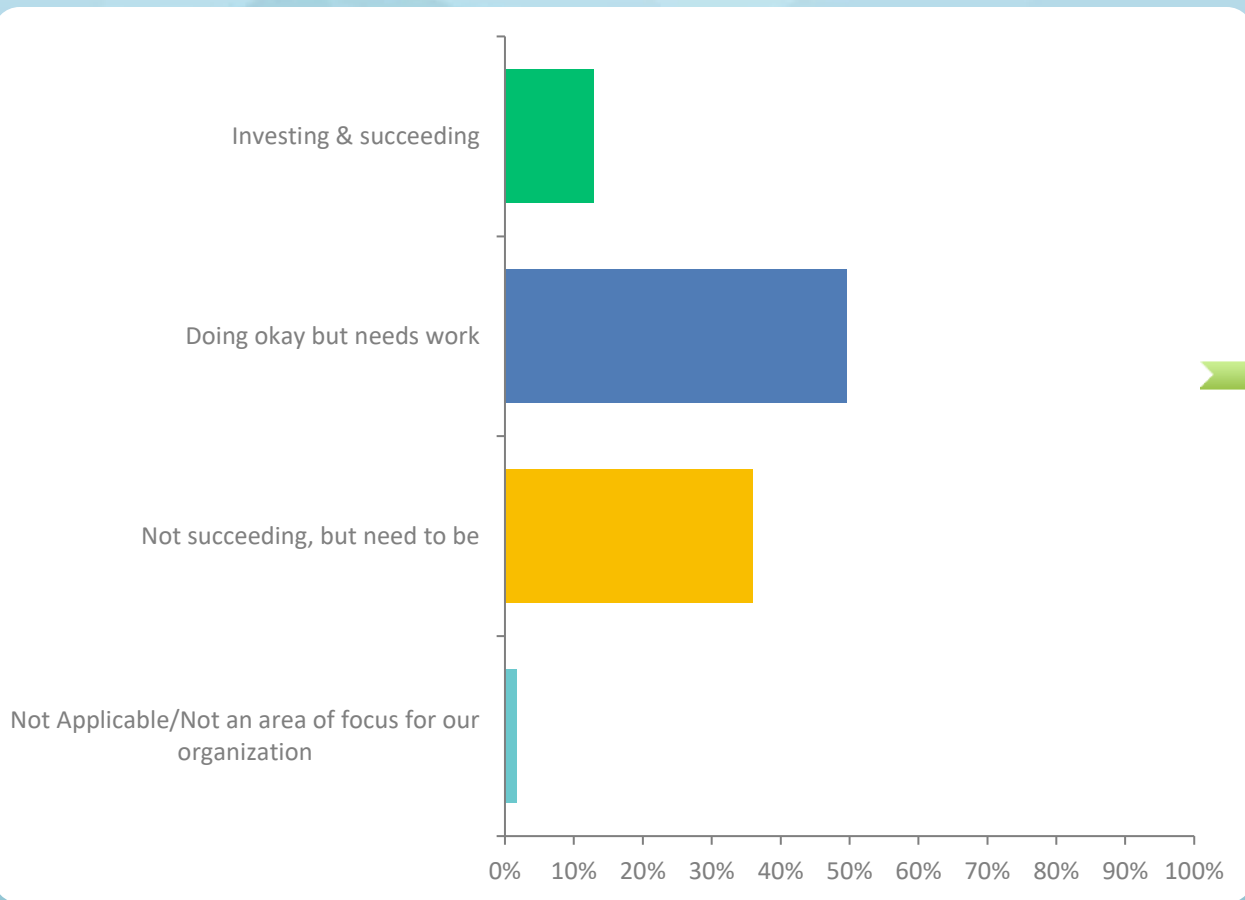
Involvement & Success in AWARENESS



ANSWER CHOICES	RESPONSES
Investing & succeeding	46.15%
Doing okay but needs work	50.43%
Not succeeding, but need to be	3.42%
Not Applicable/Not an area of focus for our organization	0%



Involvement & Success in FUNDRAISING/ /working with funders



ANSWER CHOICES

RESPONSES

Investing & succeeding

12.82%

Doing okay but needs work

49.57%

Not succeeding, but need to be

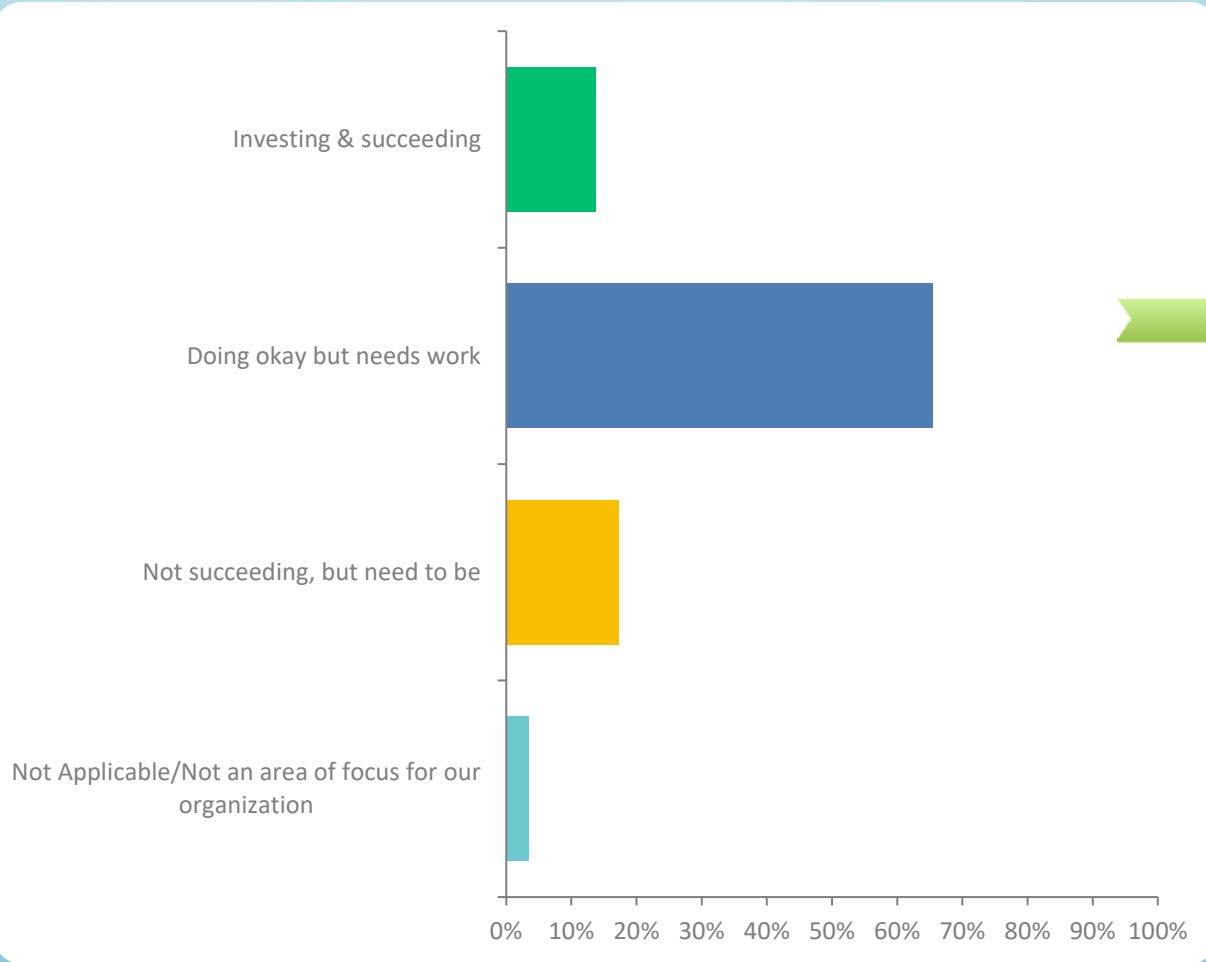
35.90%

Not Applicable/Not an area
of focus for our
organization

1.71%



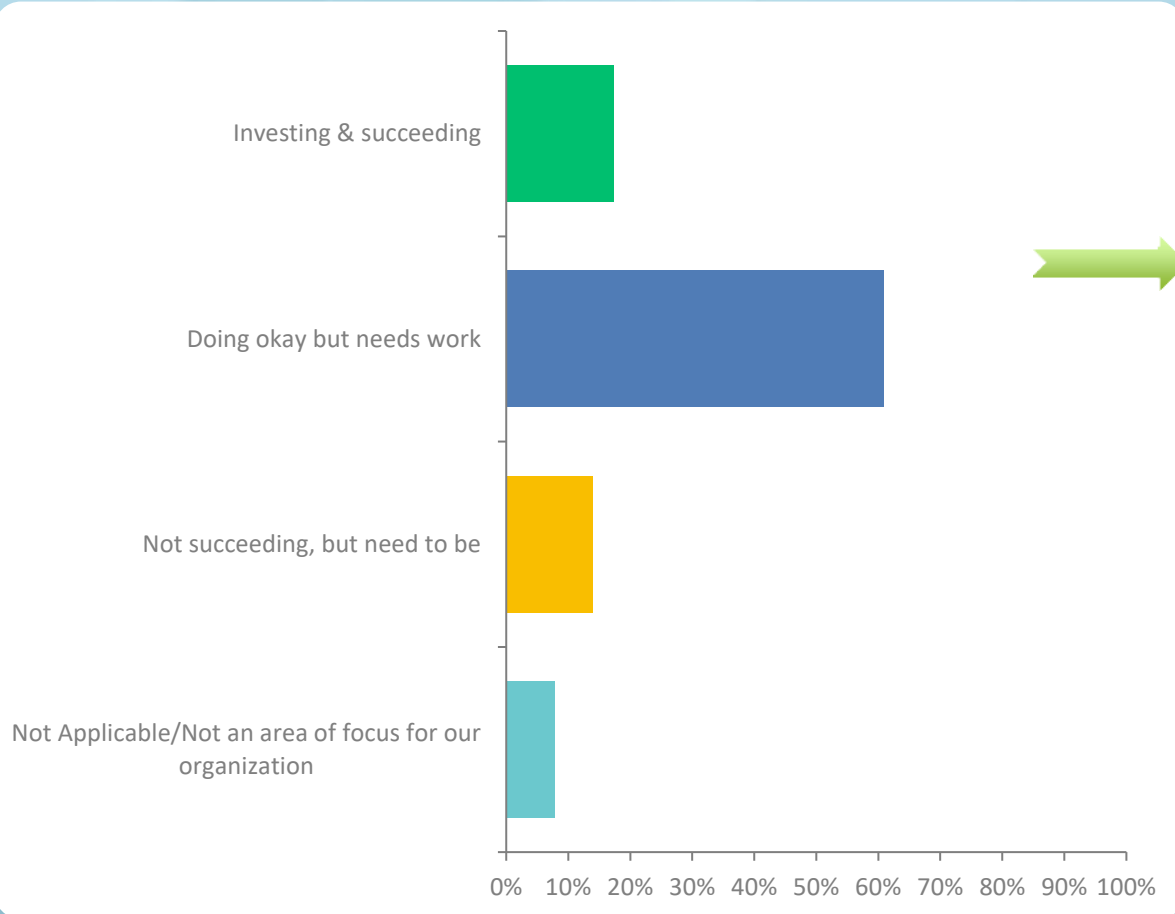
Organization's involvement and success in CAPACITY BUILDING FOR YOUR ORGANIZATION



ANSWER CHOICES	RESPONSES
Investing & succeeding	13.79%
Doing okay but needs work	65.52%
Not succeeding, but need to be	17.24%
Not Applicable/Not an area of focus for our organization	3.45%



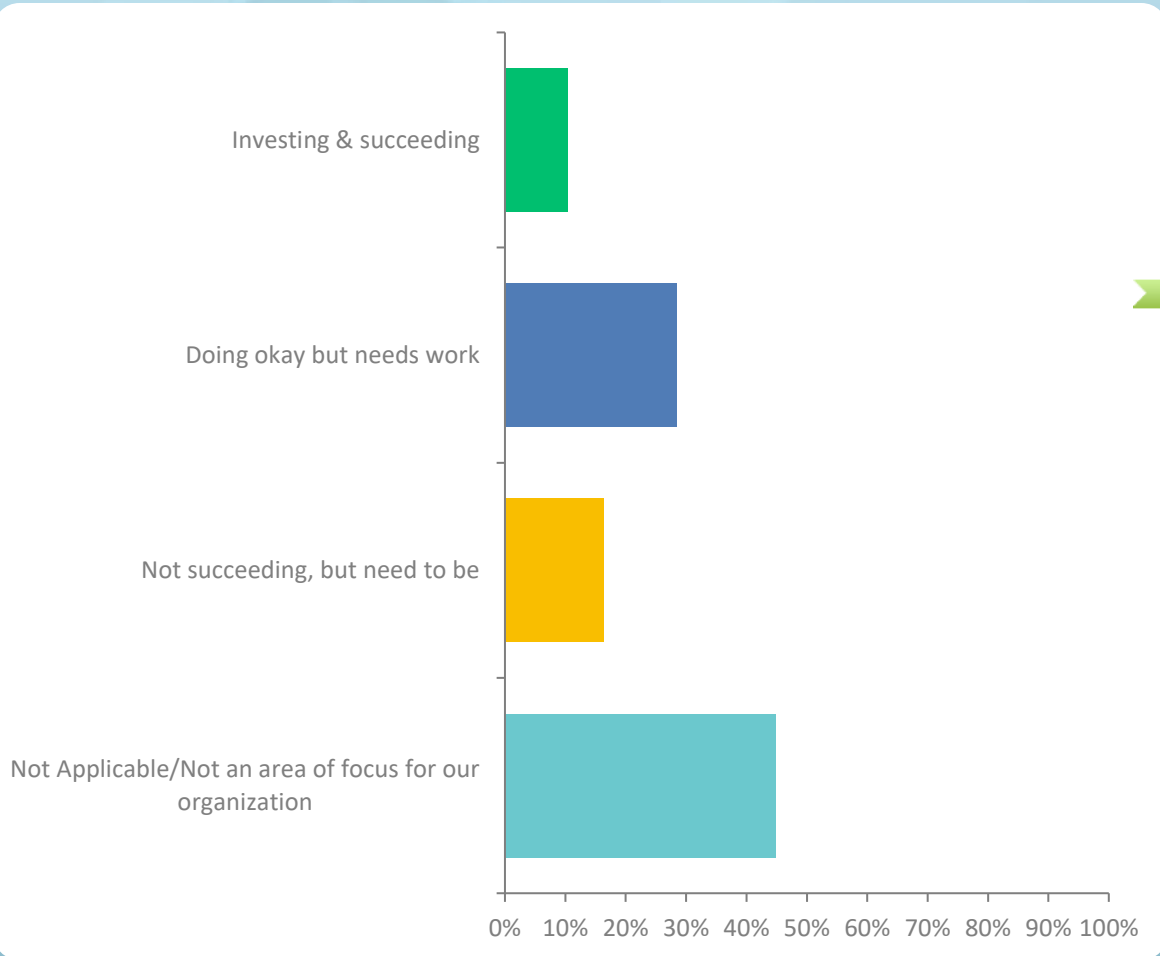
Involvement & Success in ACCESS TO HEALTH CARE



ANSWER CHOICES	RESPONSES
Investing & succeeding	13.79%
Doing okay but needs work	65.52%
Not succeeding, but need to be	17.24%
Not Applicable/Not an area of focus for our organization	3.45%



Involvement & Success in HEALTHCARE DELIVERY (e.g. running a treatment center)

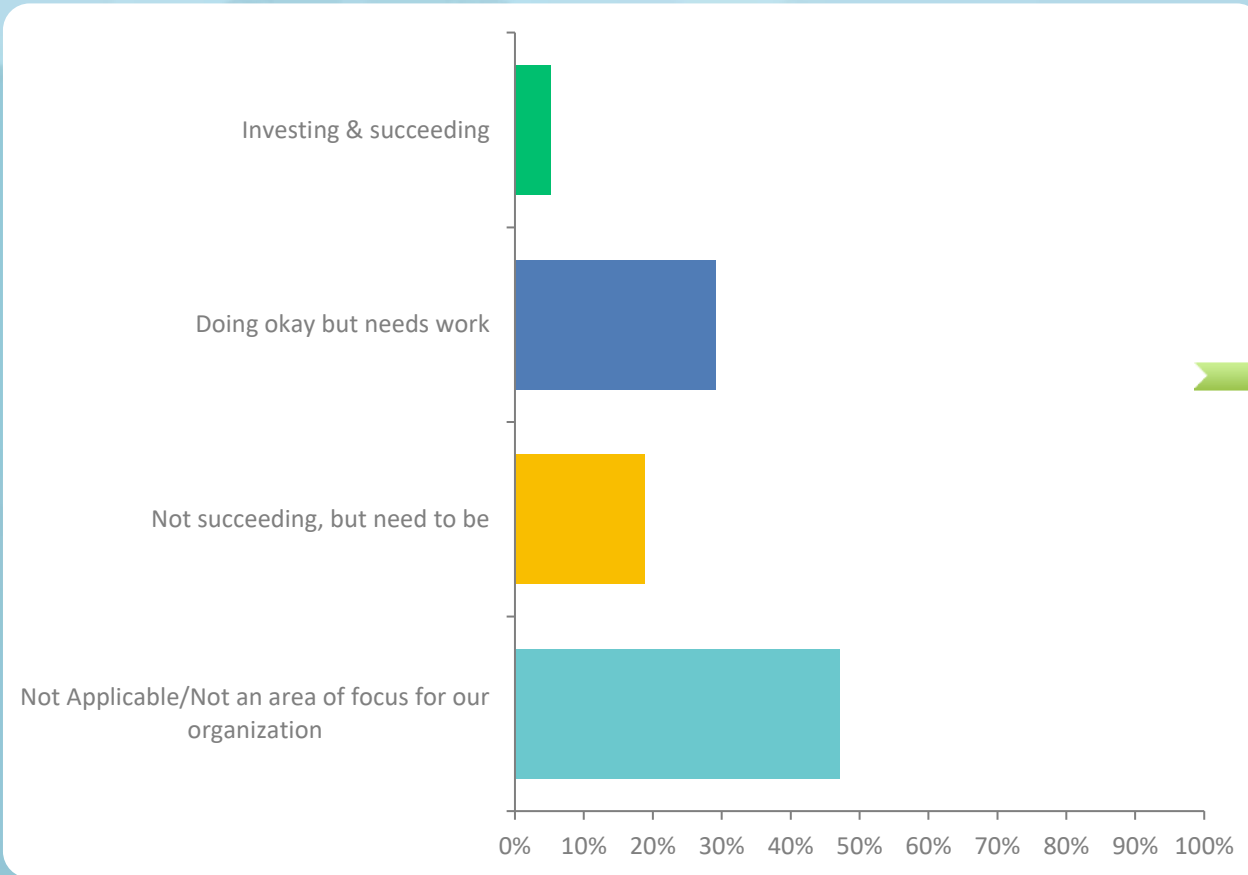


ANSWER CHOICES	RESPONSES
Investing & succeeding	10.34%
Doing okay but needs work	28.45%
Not succeeding, but need to be	16.38%
Not Applicable/Not an area of focus for our organization	44.83%



Involvement & Success in

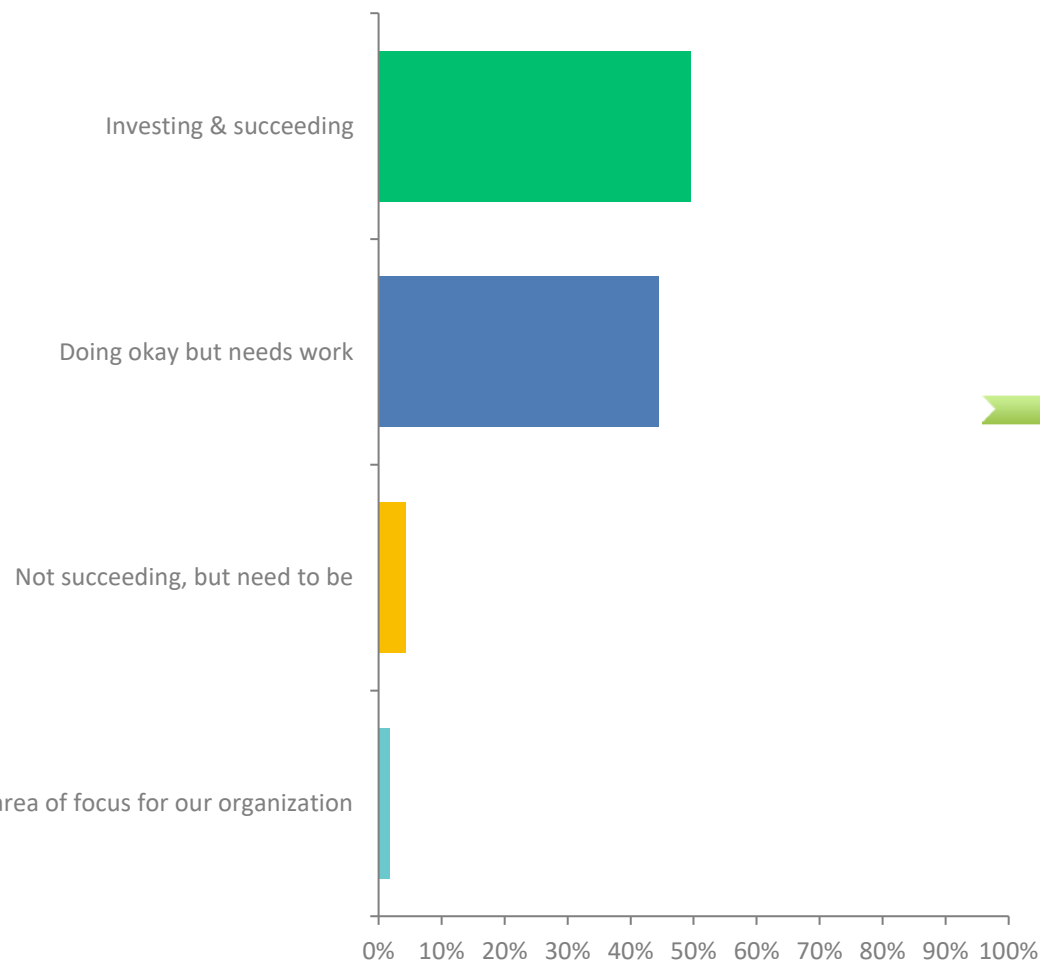
OUTREACH SERVICES (e.g. providing home-based patient care services)



ANSWER CHOICES	RESPONSES
Investing & succeeding	5.13%
Doing okay but needs work	29.06%
Not succeeding, but need to be	18.80%
Not Applicable/Not an area of focus for our organization	47.01%



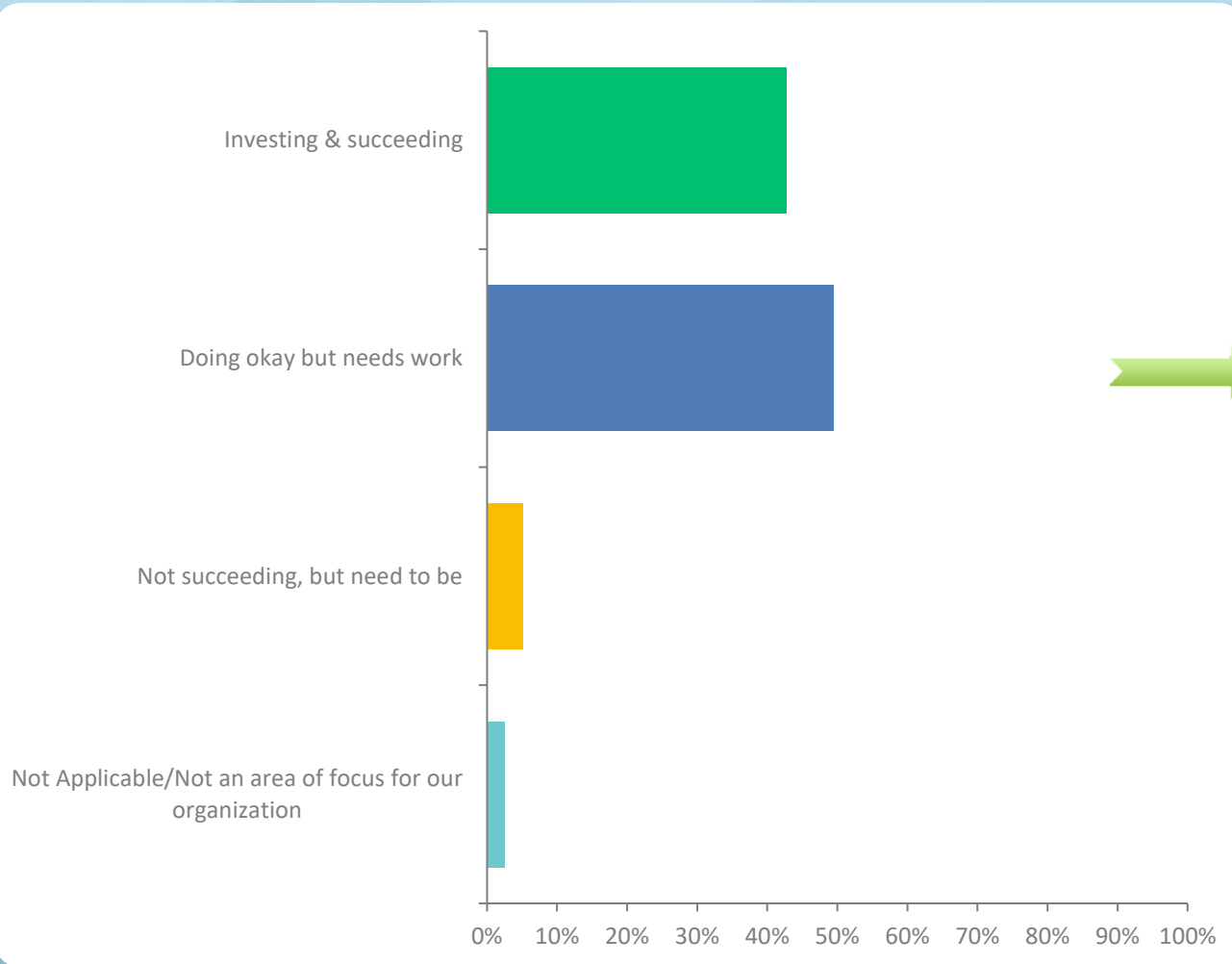
Involvement & Success in INFORMATION TO PATIENTS AND FAMILIES



ANSWER CHOICES	RESPONSES
Investing & succeeding	49.57%
Doing okay but needs work	44.44%
Not succeeding, but need to be	4.27%
Not Applicable/Not an area of focus for our organization	1.71%



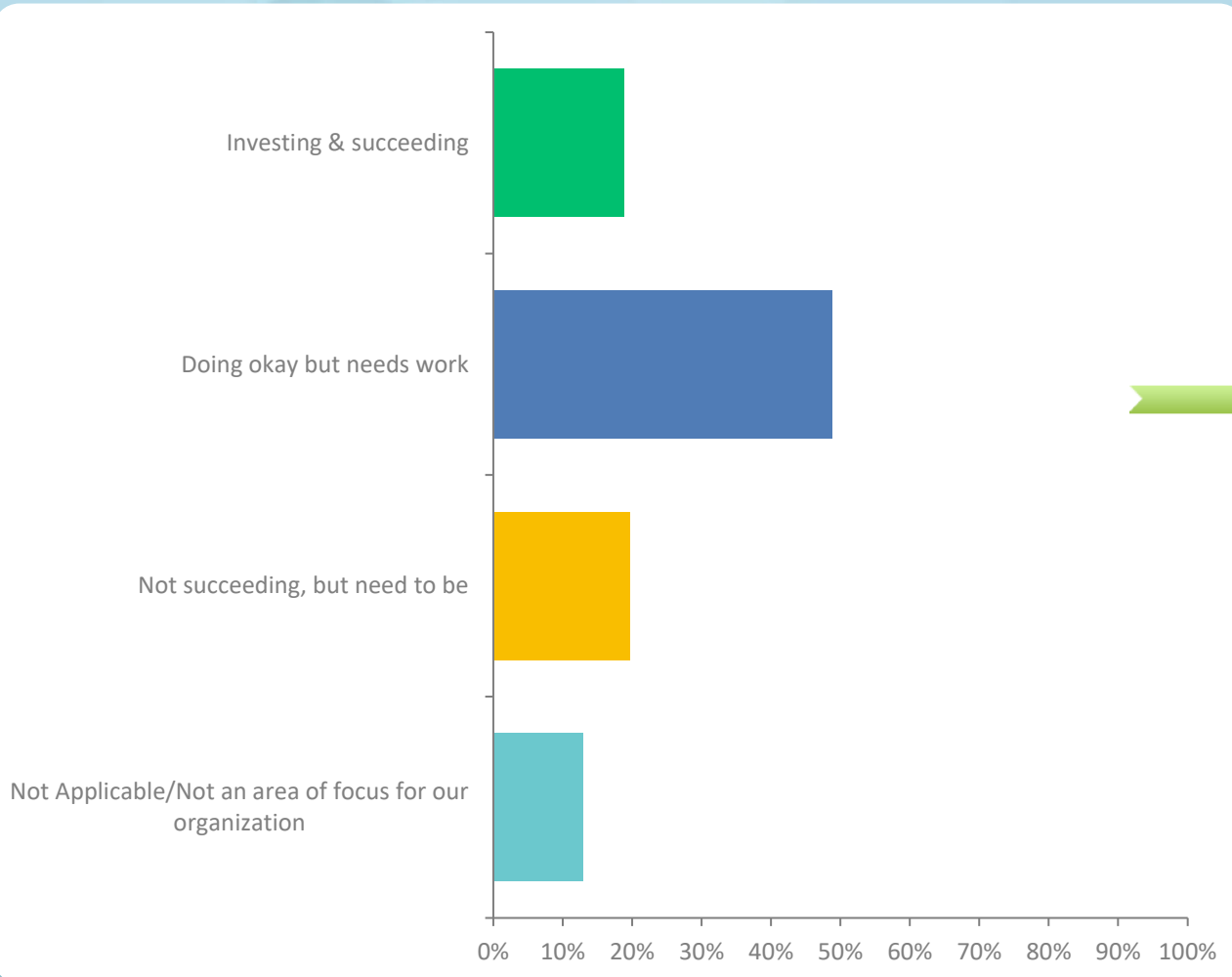
Involvement & Success in EDUCATION OF PATIENTS



ANSWER CHOICES	RESPONSES
Investing & succeeding	42.74%
Doing okay but needs work	49.57%
Not succeeding, but need to be	5.13%
Not Applicable/Not an area of focus for our organization	2.56%



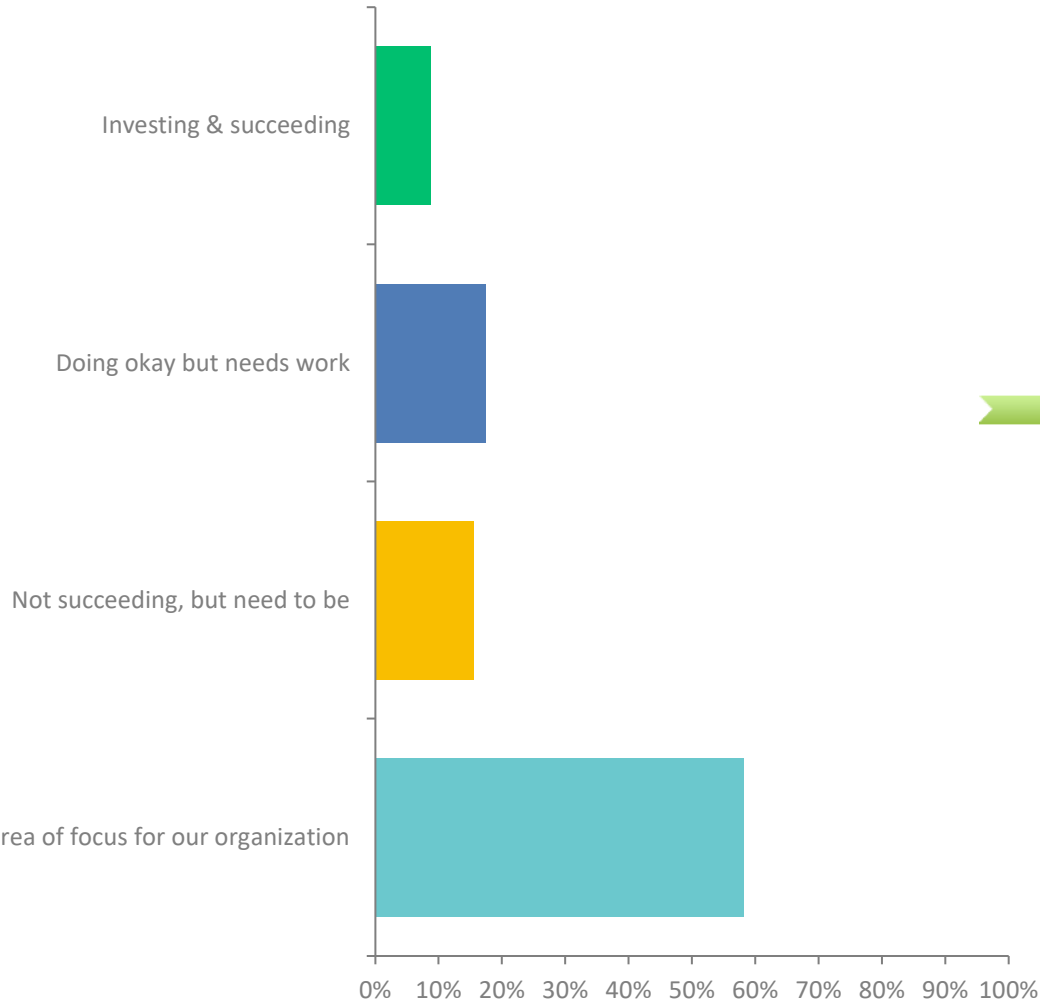
Involvement & Success in EDUCATION OF HEALTH CARE PROVIDERS



ANSWER CHOICES	RESPONSES
Investing & succeeding	18.80%
Doing okay but needs work	48.72%
Not succeeding, but need to be	19.66%
Not Applicable/Not an area of focus for our organization	12.82%



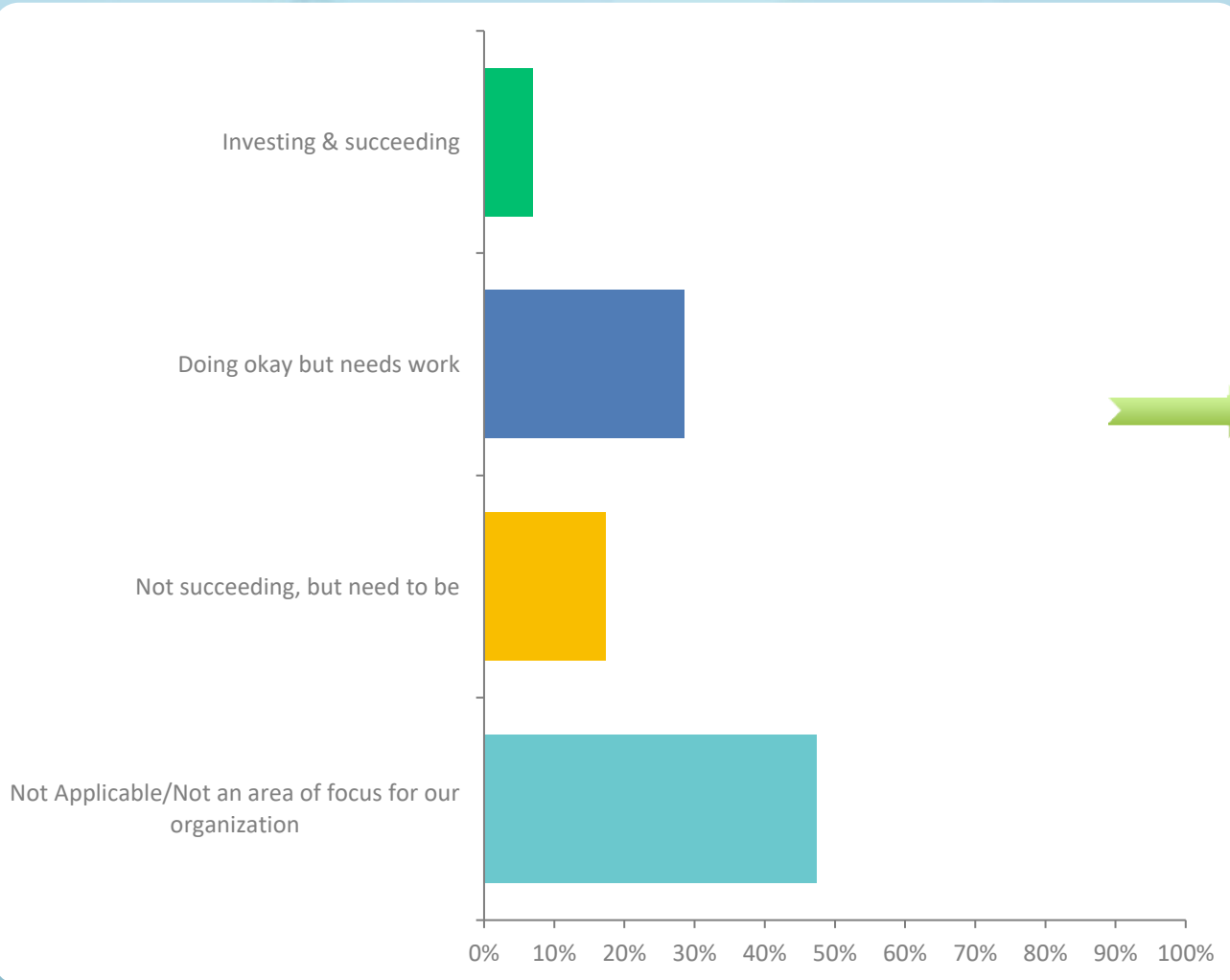
Involvement & Success in CLINICAL TRIALS



ANSWER CHOICES	RESPONSES
Investing & succeeding	8.70%
Doing okay but needs work	17.39%
Not succeeding, but need to be	15.65%
Not Applicable/Not an area of focus for our organization	58.26%



Involvement & Success in RARE DISEASES



ANSWER CHOICES

RESPONSES

Investing & succeeding

6.90%

Doing okay but needs work

28.45%

Not succeeding, but need to be

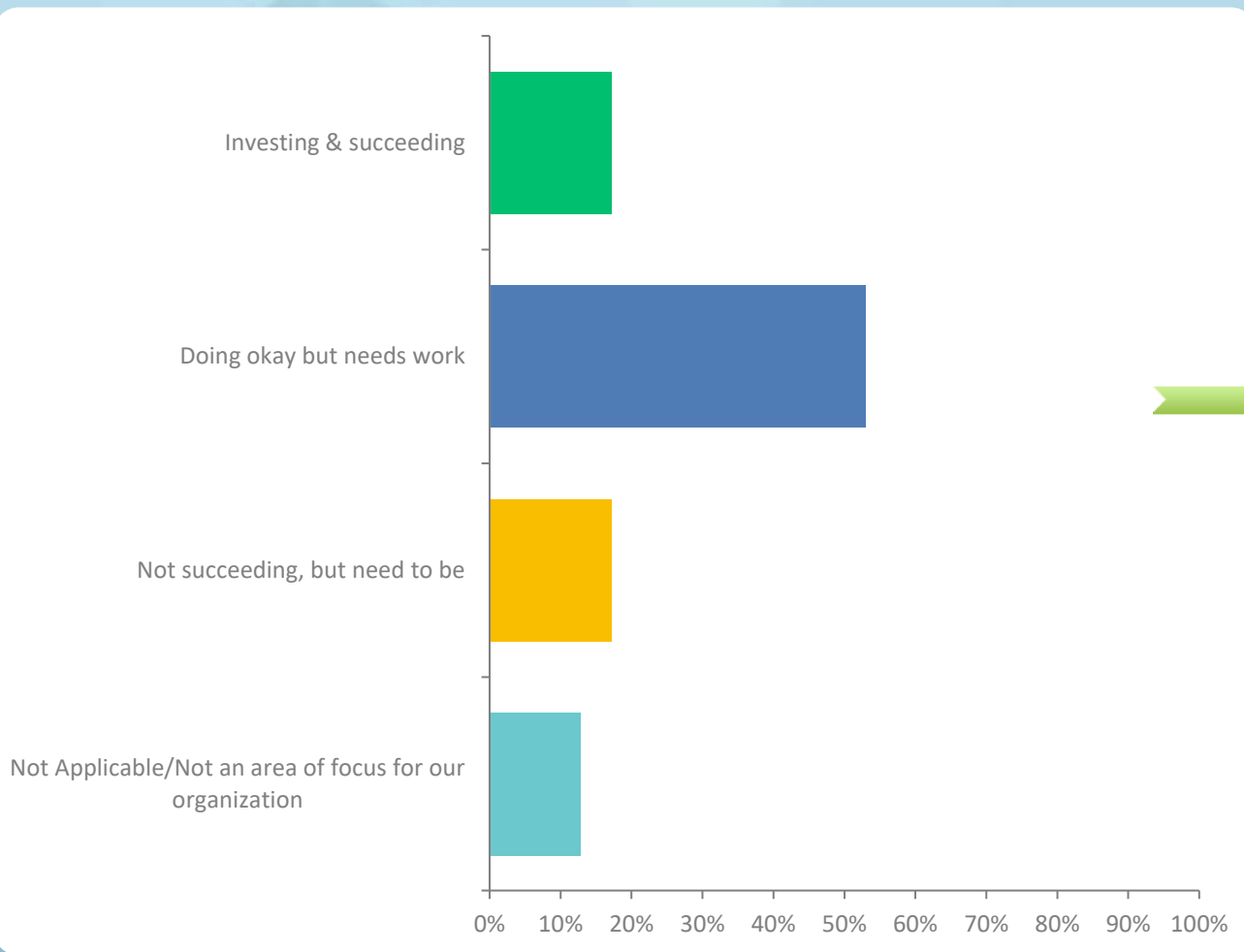
17.24%

Not Applicable/Not an area of
focus for our organization

47.41%



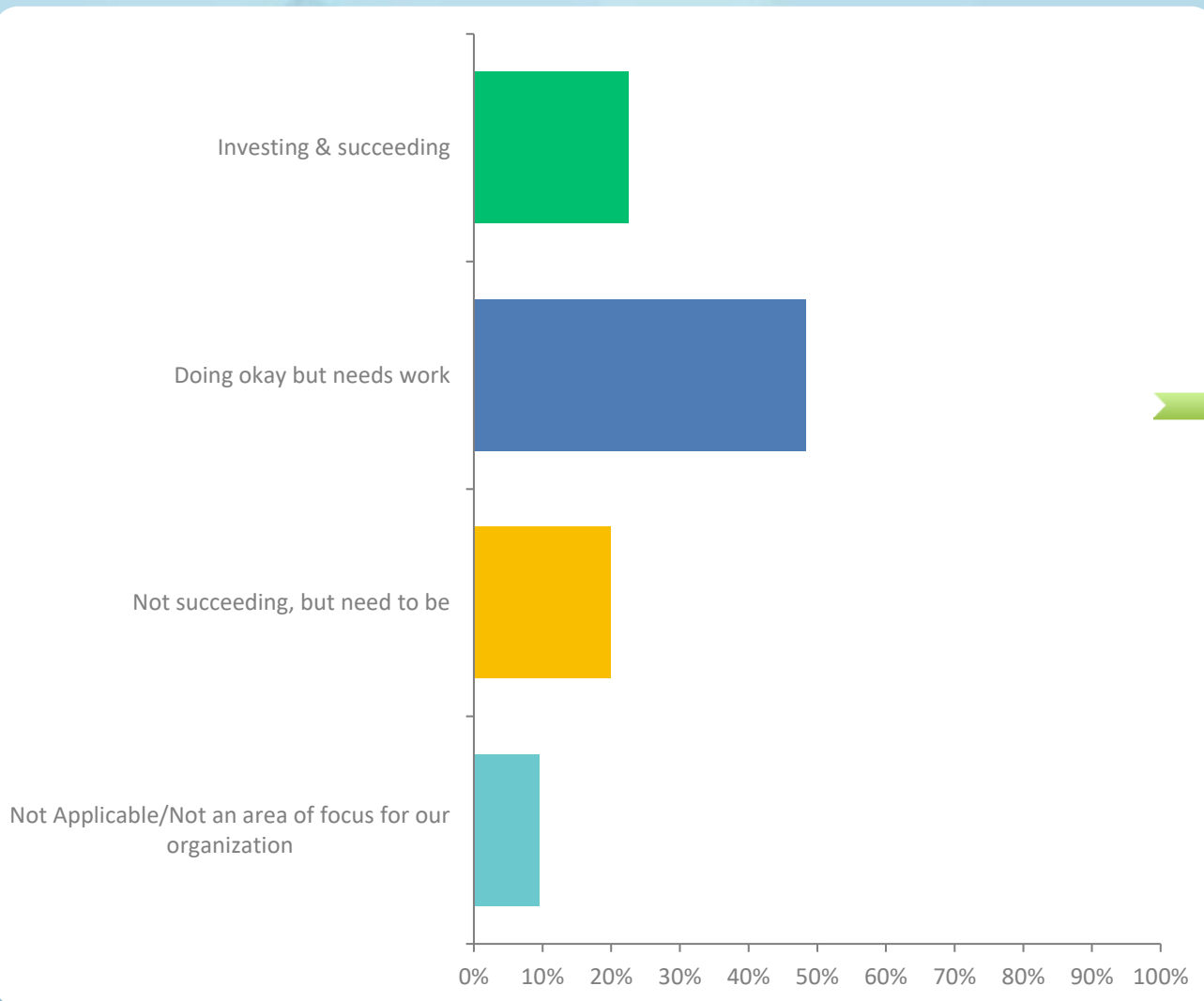
Involvement & Success in PATIENT SAFETY



ANSWER CHOICES	RESPONSES
Investing & succeeding	17.09%
Doing okay but needs work	52.99%
Not succeeding, but need to be	17.09%
Not Applicable/Not an area of focus for our organization	12.82%



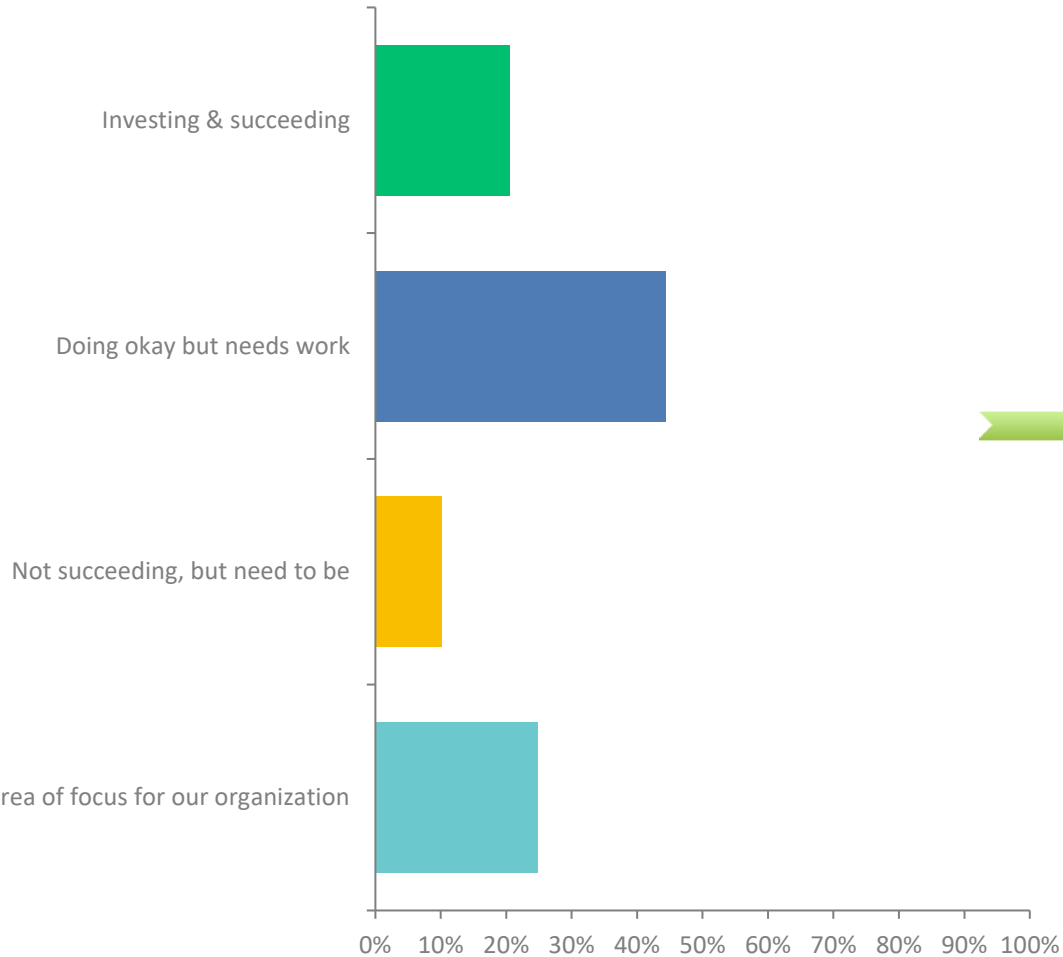
Involvement & Success in PATIENT CENTERED HEALTHCARE



ANSWER CHOICES	RESPONSES
Investing & succeeding	22.41%
Doing okay but needs work	48.28%
Not succeeding, but need to be	19.83%
Not Applicable/Not an area of focus for our organization	9.48%



Involvement & Success in NON-COMMUNICABLE DISEASES



ANSWER CHOICES

RESPONSES

Investing & succeeding

20.51%

Doing okay but needs work

44.44%

Not succeeding, but need to be

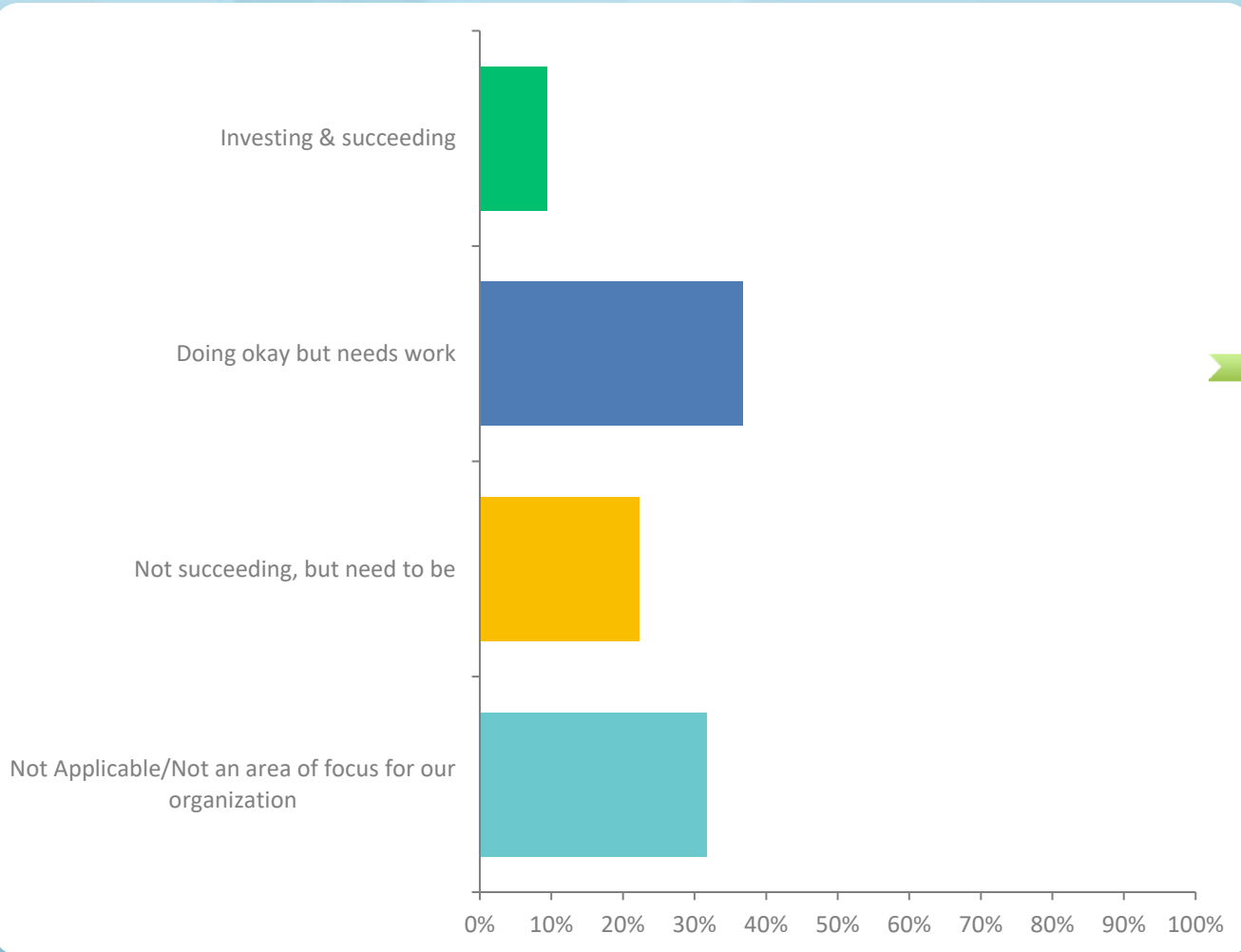
10.26%

Not Applicable/Not an area of focus for our organization

24.79%



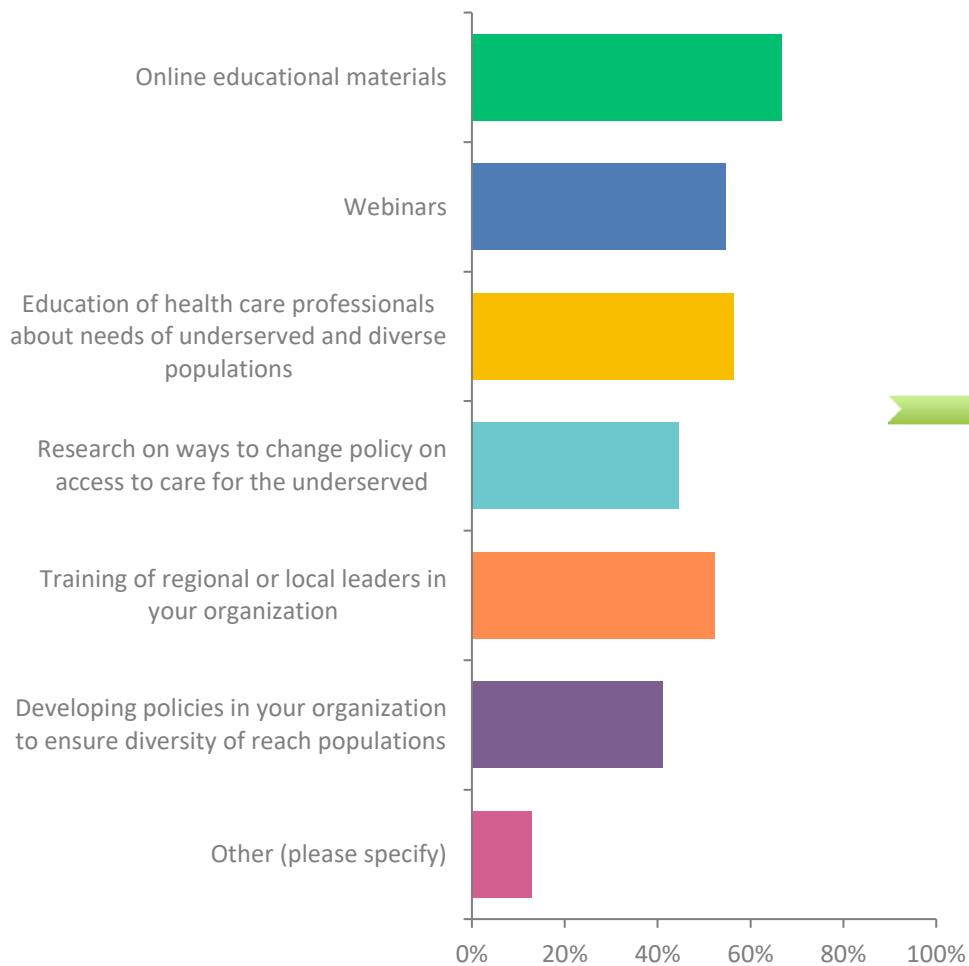
Involvement & Success in HEALTH TECHNOLOGY ASSESSMENT



ANSWER CHOICES	RESPONSES
Investing & succeeding	9.40%
Doing okay but needs work	36.75%
Not succeeding, but need to be	22.22%
Not Applicable/Not an area of focus for our organization	31.62%



How do you address disparities in health care access in your organization/country?



ANSWER CHOICES

RESPONSES

Online educational materials

66.67%

Webinars

54.70%

Education of health care professionals about needs of underserved and diverse populations

56.41%

Research on ways to change policy on access to care for the underserved

44.44%

Training of regional or local leaders in your organization

52.14%

Developing policies in your organization to ensure diversity of reach populations

41.03%

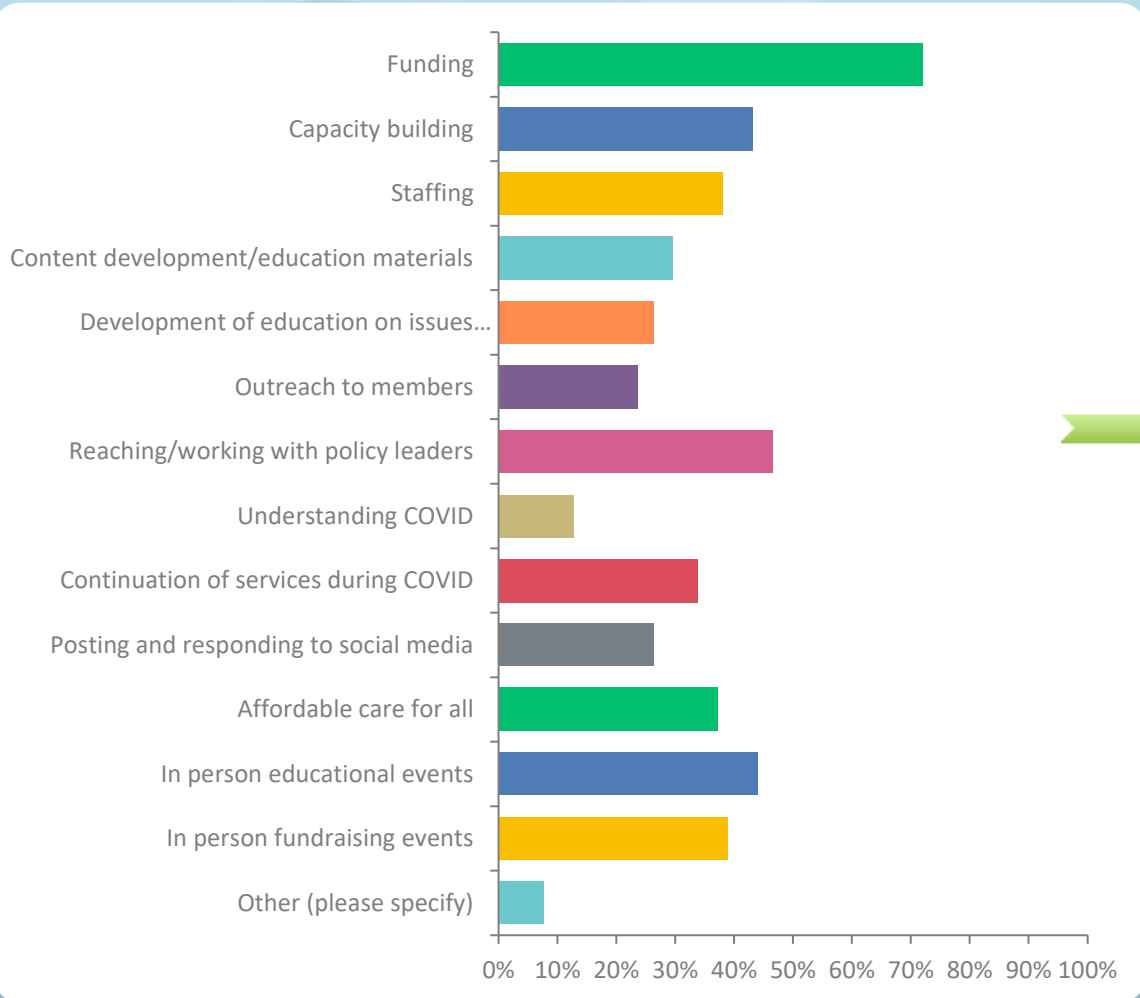
Other (please specify)

12.82%



What was your organizations main struggle in 2022?

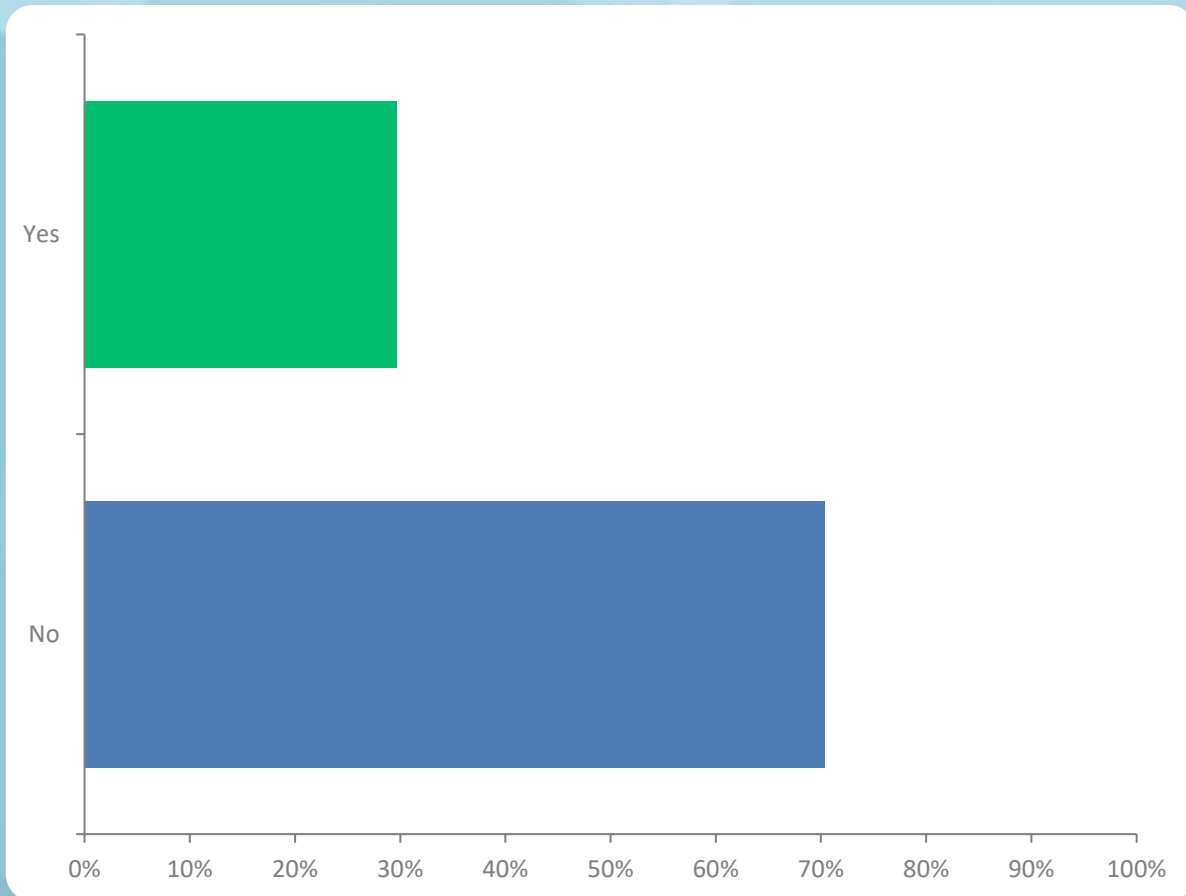
(check all that apply)



ANSWER CHOICES	RESPONSES
Funding	72.03%
Capacity building	43.22%
Staffing	38.14%
Content development/education materials	29.66%
Development of education on issues important to membership	26.27%
Outreach to members	23.73%
Reaching/working with policy leaders	46.61%
Understanding COVID	12.71%
Continuation of services during COVID	33.90%
Posting and responding to social media	26.27%
Affordable care for all	37.29%
In person educational events	44.07%
In person fundraising events	38.98%
Other (please specify)	7.63%



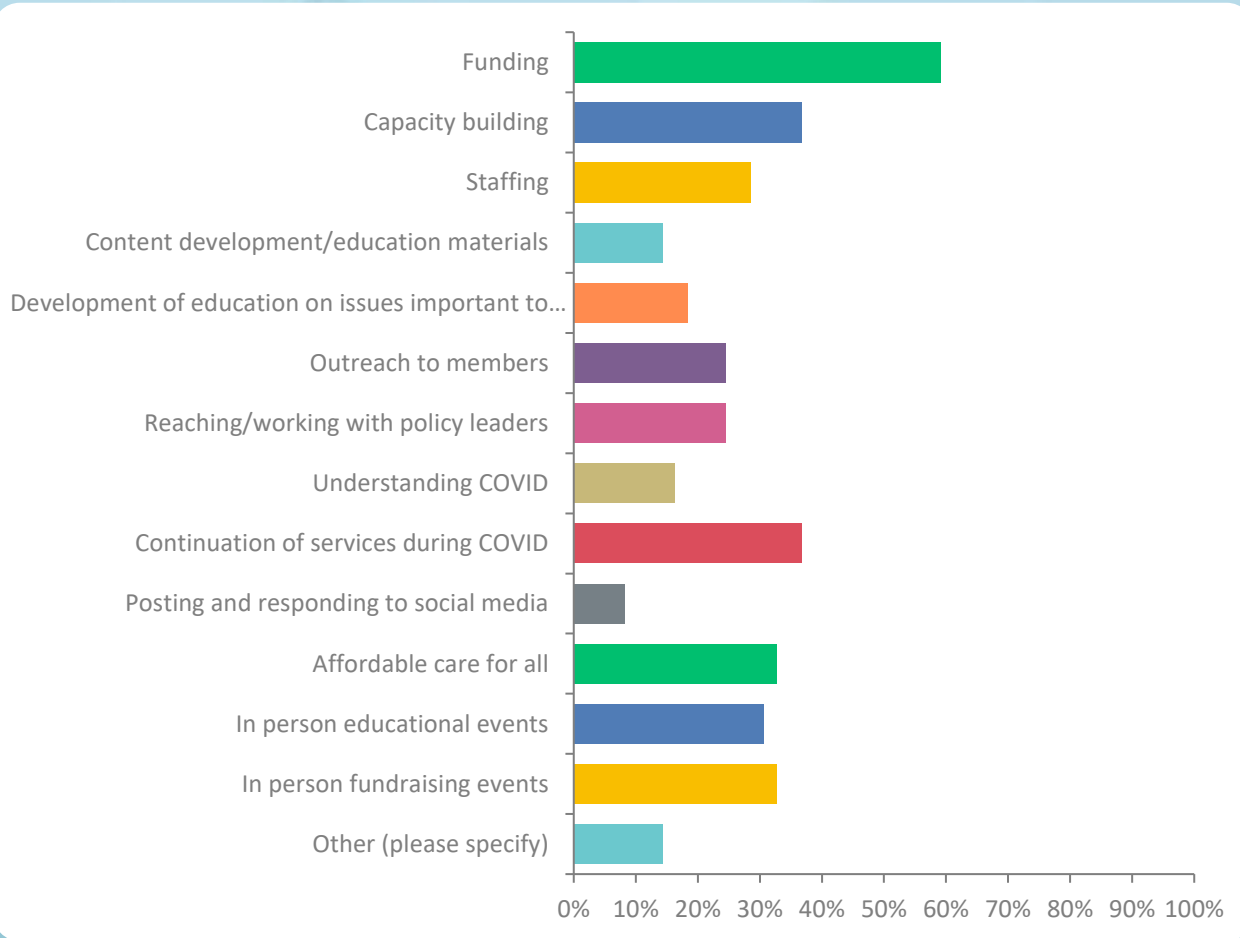
IS COVID STILL A PROBLEM FOR YOUR ORGANIZATION AND PATIENTS?



ANSWER CHOICES	RESPONSES
Yes	29.66%
No	70.34%



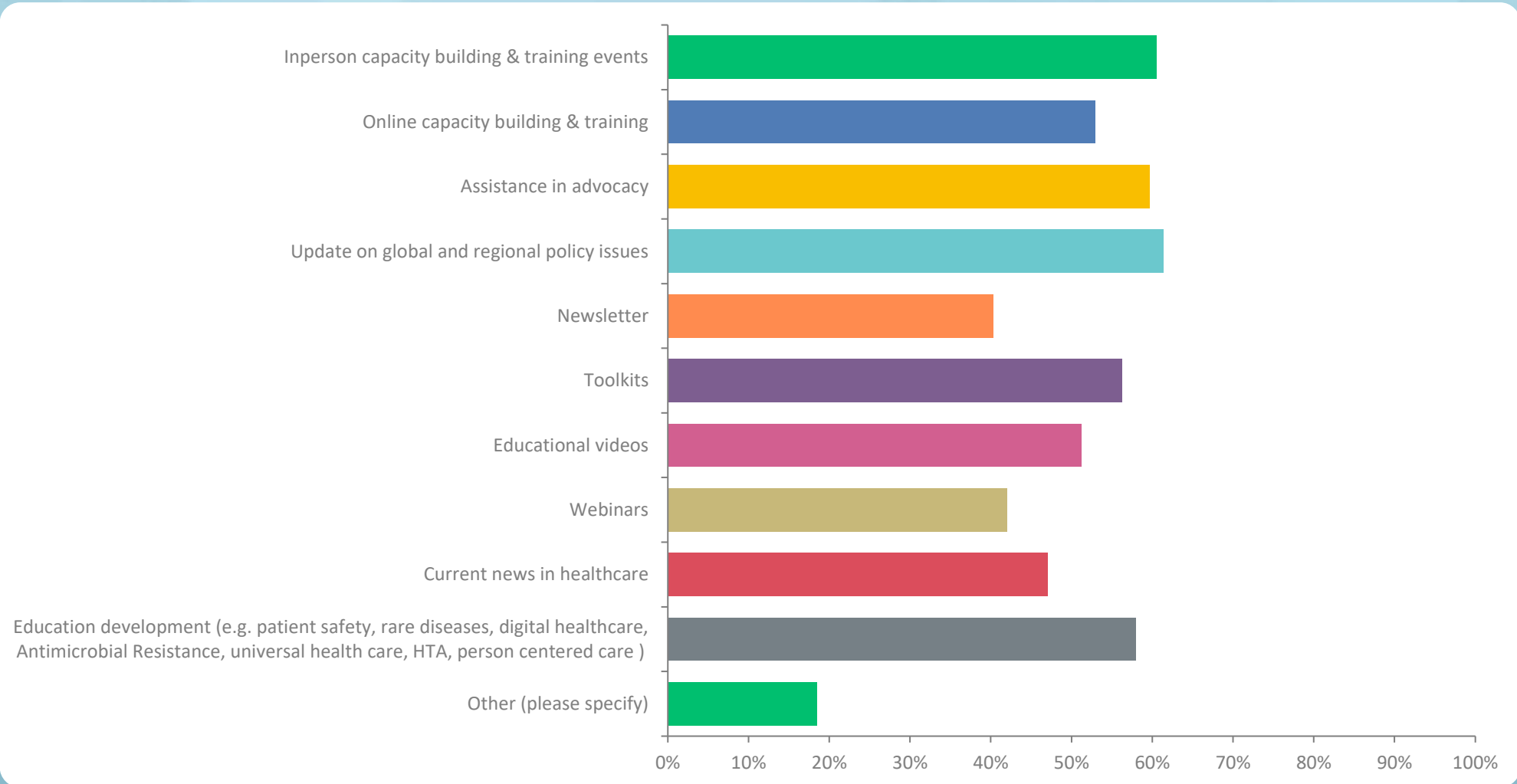
IF YES, GIVE REASONS (check all that apply)



ANSWER CHOICES	RESPONSES
Funding	59.18%
Capacity building	36.73%
Staffing	28.57%
Content development/education materials	14.29%
Development of education on issues important to membership	18.37%
Outreach to members	24.49%
Reaching/working with policy leaders	24.49%
Understanding COVID	16.33%
Continuation of services during COVID	36.73%
Posting and responding to social media	8.16%
Affordable care for all	32.65%
In person educational events	30.61%
In person fundraising events	32.65%
Other (please specify)	14.29%



What can World Patients Alliance (WPA) provide your organization to stay informed and serve your communities and patients better? (Check all that apply)





What can World Patients Alliance (WPA) provide your organization to stay informed and serve your communities and patients better? (Check all that apply)

ANSWER CHOICES	RESPONSES
Inperson capacity building & training events	60.50%
Online capacity building & training	52.94%
Assistance in advocacy	59.66%
Update on global and regional policy issues	61.34%
Newsletter	40.34%
Toolkits	56.30%
Educational videos	51.26%
Webinars	42.02%
Current news in healthcare	47.06%
Education development (e.g. patient safety, rare diseases, digital healthcare, Antimicrobial Resistance, universal health care, HTA, person centered care)	57.98%
Other (please specify)	18.49%



THANK YOU