Report

WPA Members Survey 2024

Annual Membership Survey 2024

**Assessing Needs and Gap Areas of Patient Advocacy Organization Members**

WPA conducts an annual survey of our member organizations. The results of

this survey inform us how to best serve our members. We are pleased to

share the findings of this year's survey with you:
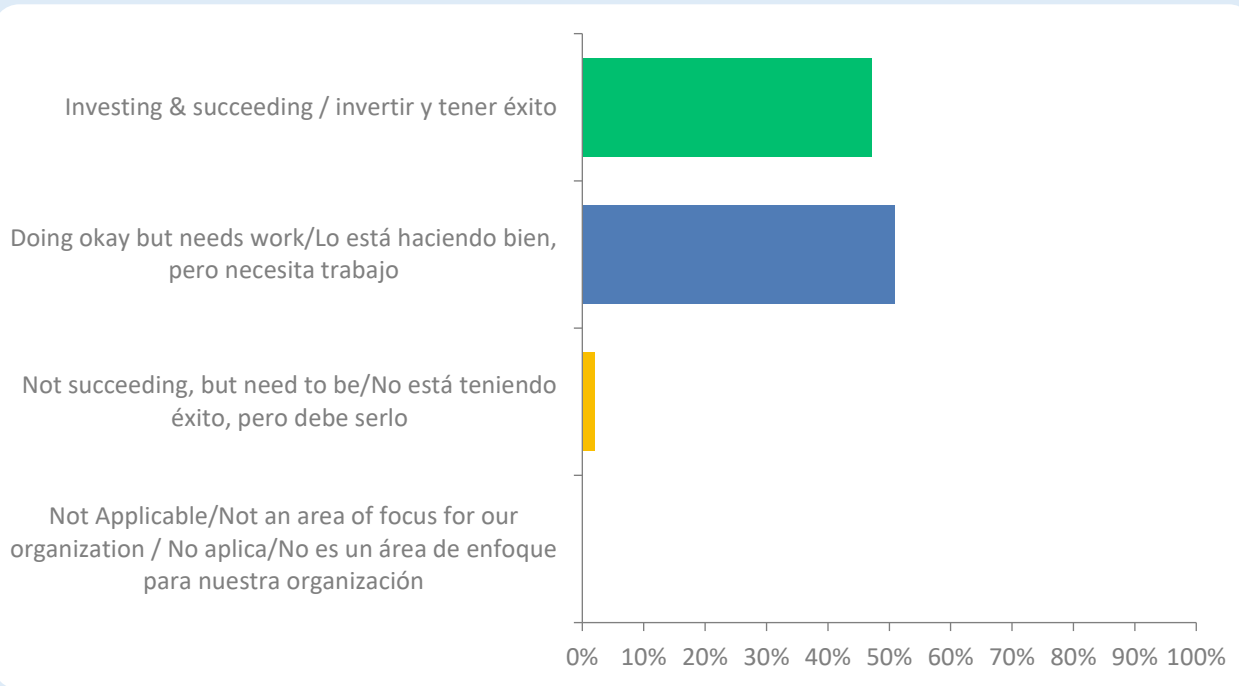
World Patients Alliance

Advocacy

(Is advocacy a priority/focus area for your organization? How well are you doing in this area?)
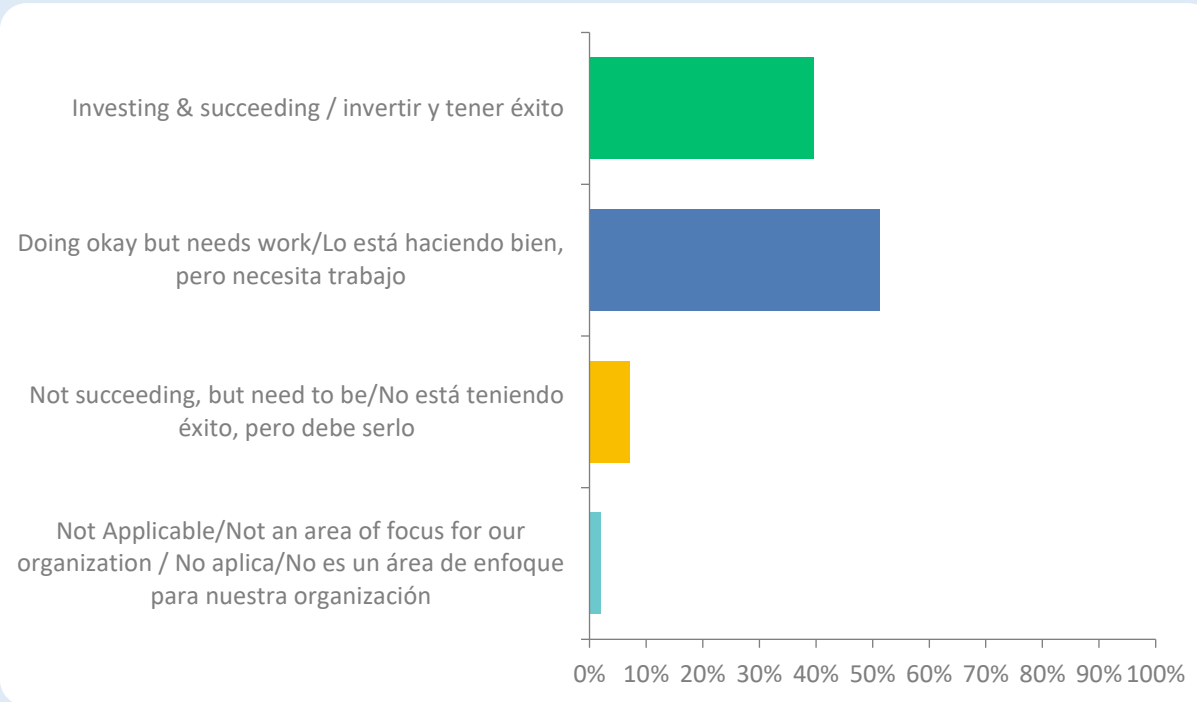
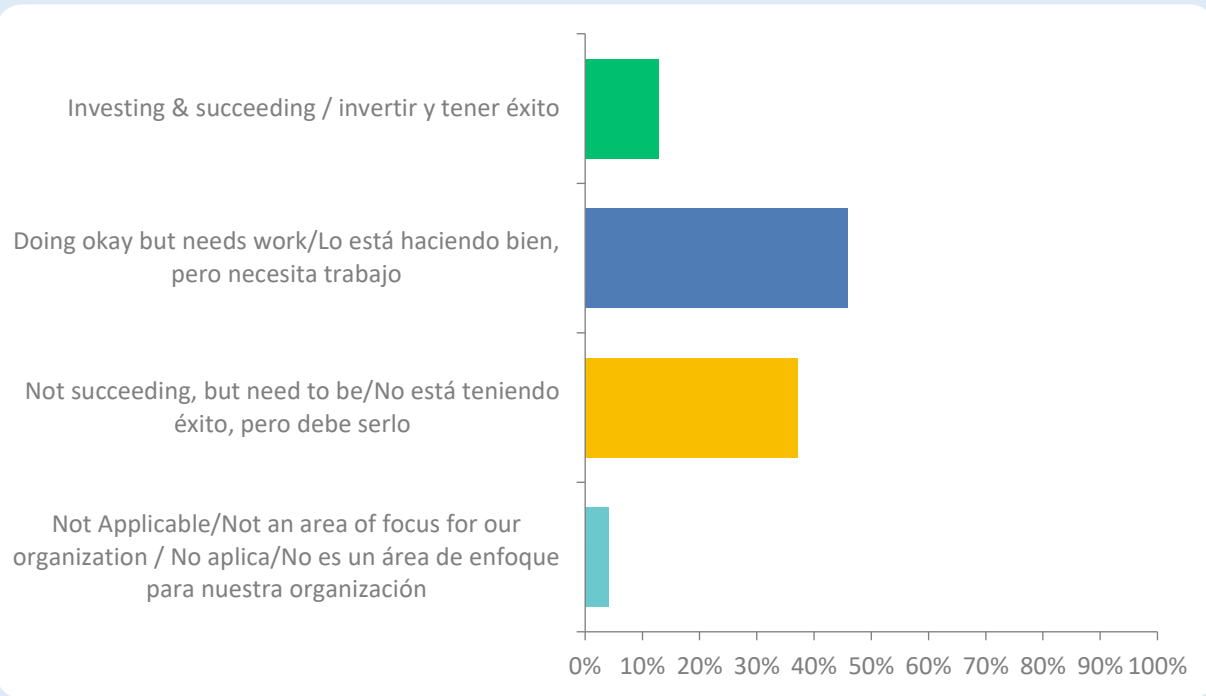| ANSWER CHOICES	RESPONSES
Investing & succeeding	39.58%
Doing okay but needs work	51.25%
Not succeeding, but need to be	7.08%
Not Applicable/Not an area of focus for our organization	2.08%

World Patients Alliance

Awareness

(Is awareness a priority/focus area for your organization? How well are you doing in this area?)

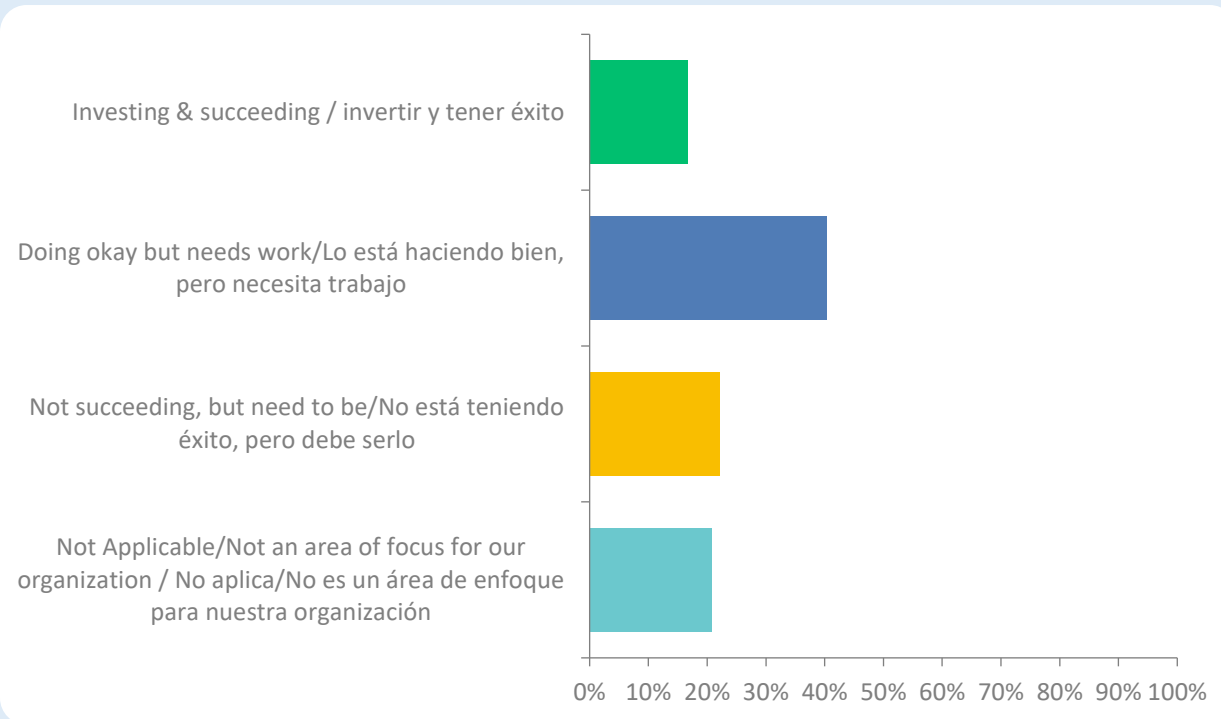| ANSWER CHOICES	RESPONSES
Investing & succeeding	47.08%
Doing okay but needs work	50.83%
Not succeeding, but need to be	2.08%
Not Applicable/Not an area of focus for our organization	0%

Chart categories:
- Investing & succeeding / invertir y tener éxito
- Doing okay but needs work/Lo está haciendo bien, pero necesita trabajo
- Not succeeding, but need to be/No está teniendo éxito, pero debe serlo
- Not Applicable/Not an area of focus for our organization / No aplica/No es un área de enfoque para nuestra organización

World Patients Alliance

Fundraising

(Is fundraising a priority/focus area for your organization? How well are you doing in this area?)

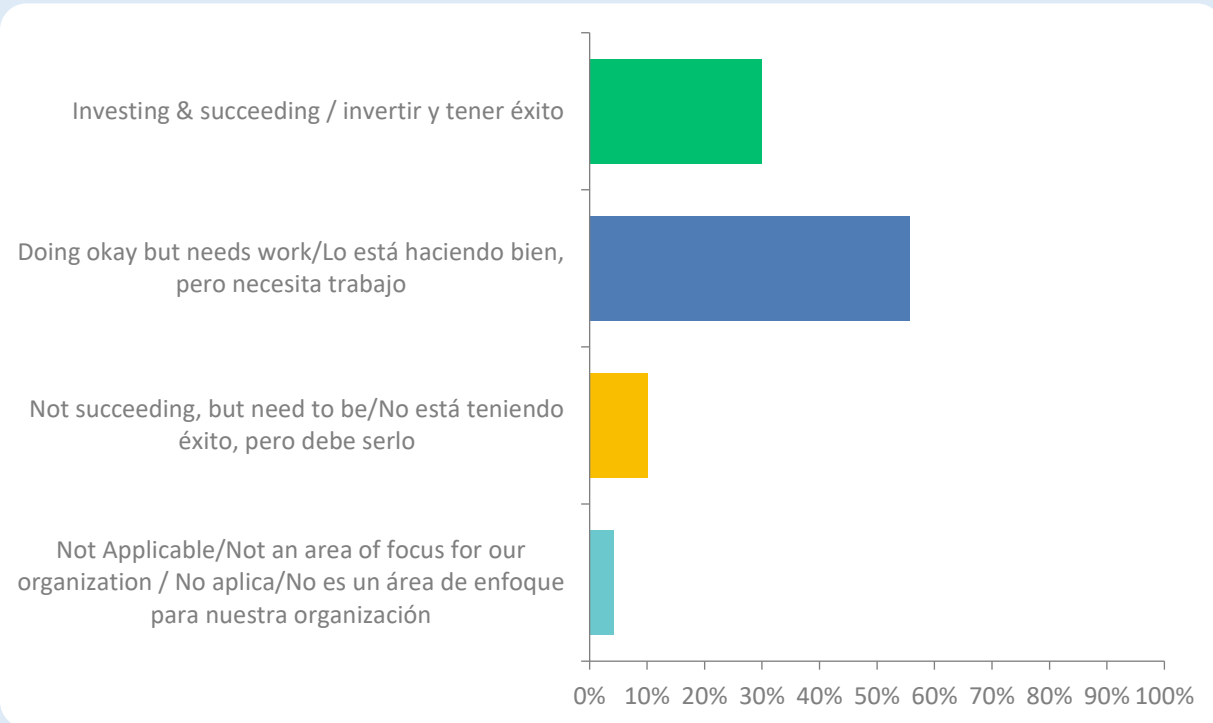| ANSWER CHOICES	RESPONSES
Investing & succeeding	12.81%
Doing okay but needs work	45.87%
Not succeeding, but need to be	37.19%
Not Applicable/Not an area of focus for our organization	4.13%

World Patients Alliance

Research

(Is research a priority/focus area for your organization? How well are you doing in this area?)

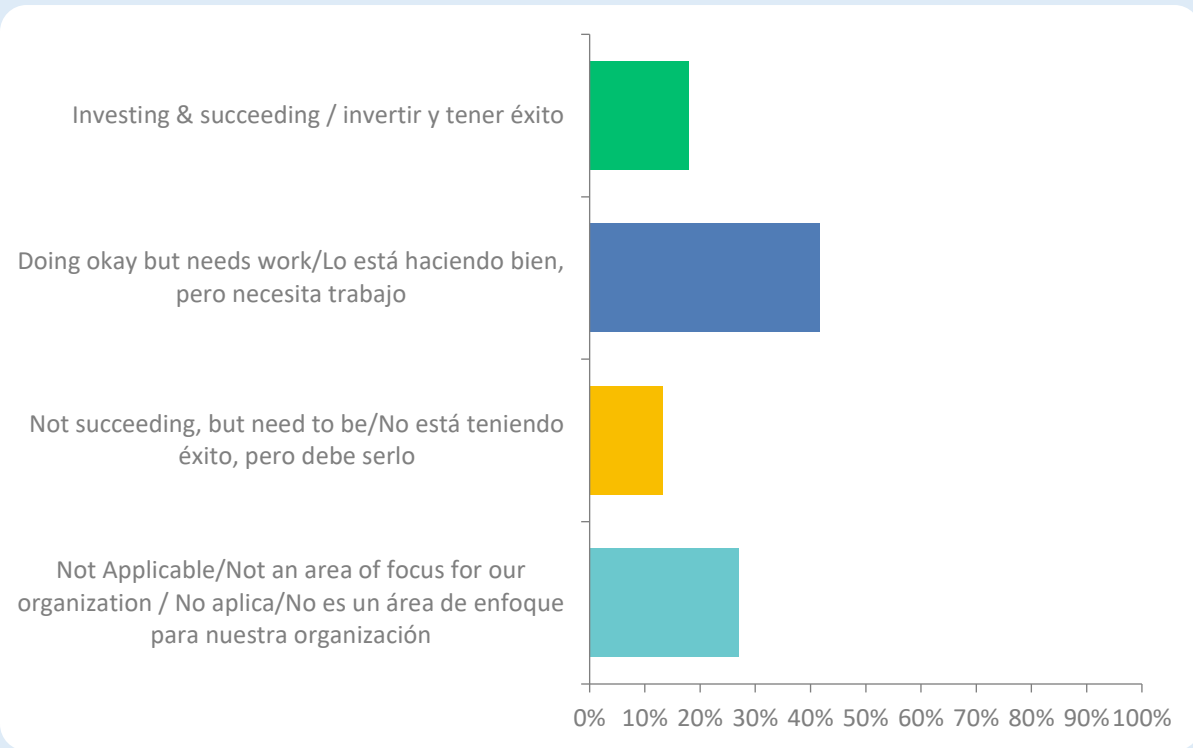| ANSWER CHOICES	RESPONSES
Investing & succeeding	16.57%
Doing okay but needs work	41.44%
Not succeeding, but need to be	19.34%
Not Applicable/Not an area of focus for our organization	22.65%

World Patients Alliance

Access to Health Care

(Is your organization working on/promoting access to healthcare? How well are you doing in this area?)

ANSWER CHOICES	RESPONSES
Investing & succeeding	29.96%
Doing okay but needs work	55.70%
Not succeeding, but need to be	10.13%
Not Applicable/Not an area of focus for our organization	4.22%

World Patients Alliance

Healthcare Delivery

(Is your organization involved in healthcare delivery? How well are you doing in this area?)

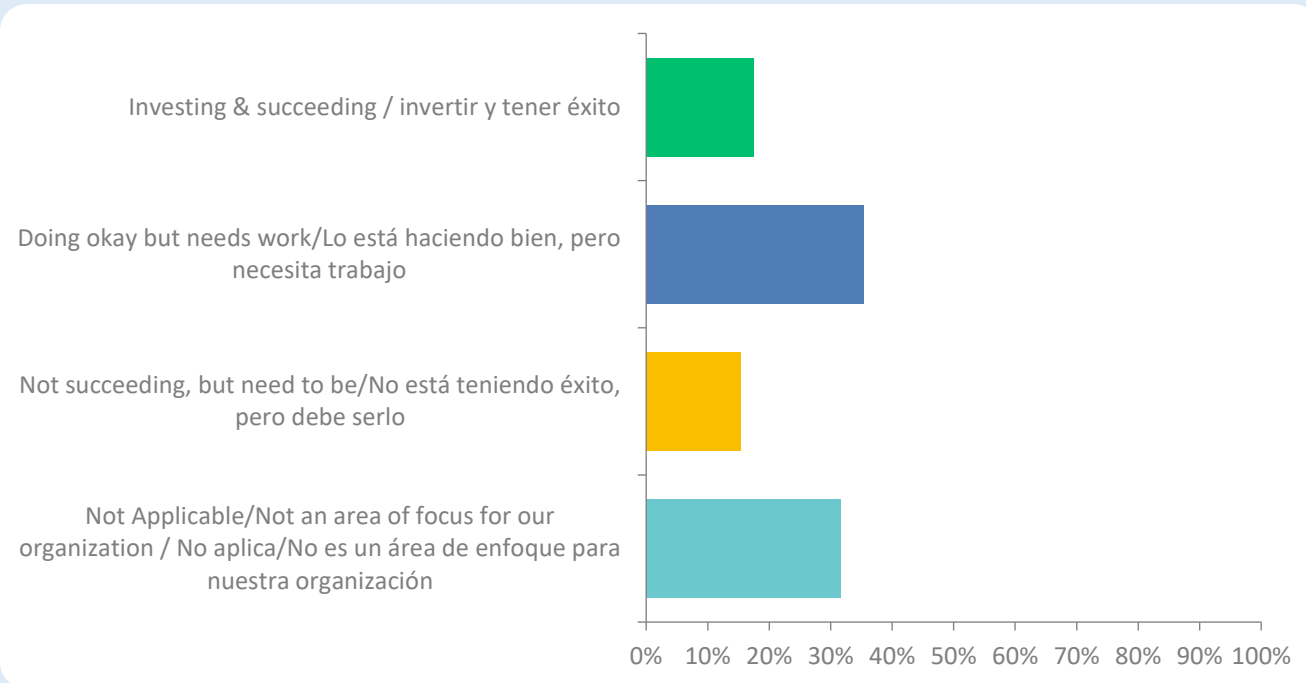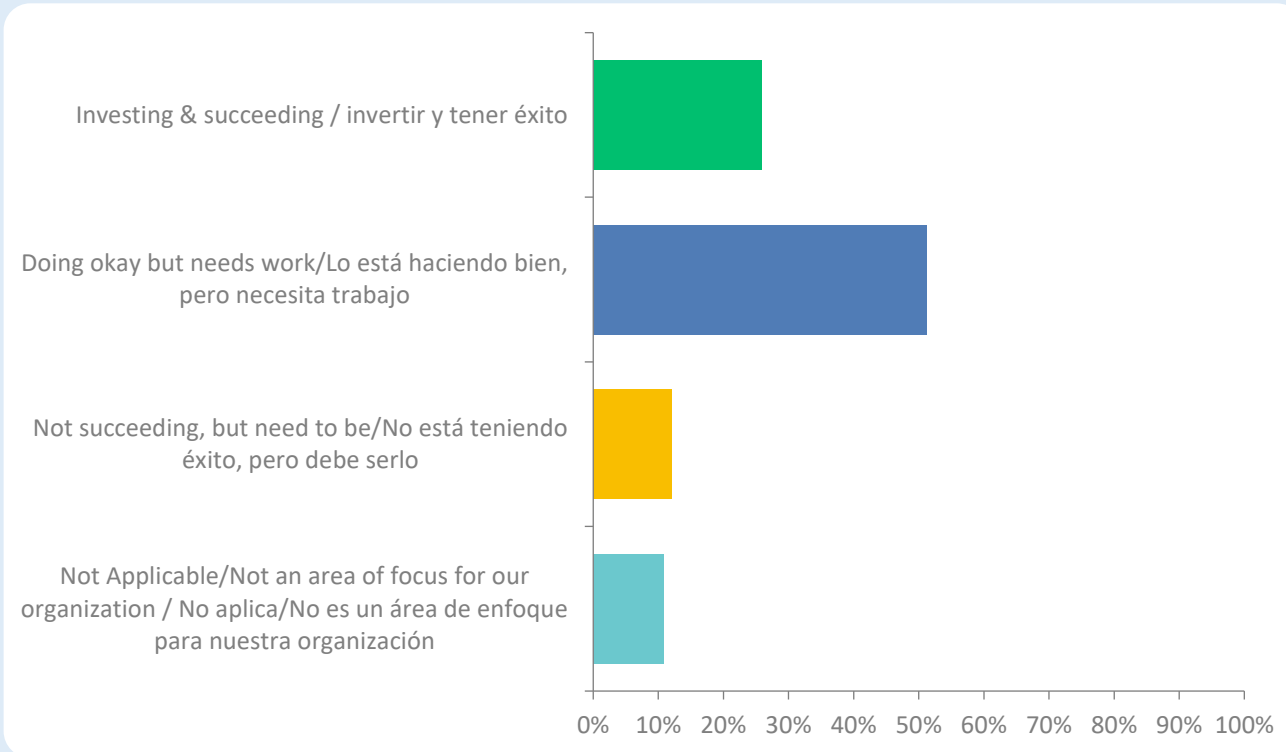| ANSWER CHOICES	RESPONSES
Investing & succeeding	17.92%
Doing okay but needs work	41.67%
Not succeeding, but need to be	13.33%
Not Applicable/Not an area of focus for our organization	27.08%

World Patients Alliance

Medication Safety

(Is Medication Safety a priority/focus area for your organization? How well are you doing in this area?)

ANSWER CHOICES	RESPONSES
Investing & succeeding	17.50%
Doing okay but needs work	35.42%
Not succeeding, but need to be	15.42%
Not Applicable/Not an area of focus for our organization	31.67%

World Patients Alliance

Patient safety

(Is Patient safety a priority/focus area for your organization? How well are you doing in this area?)

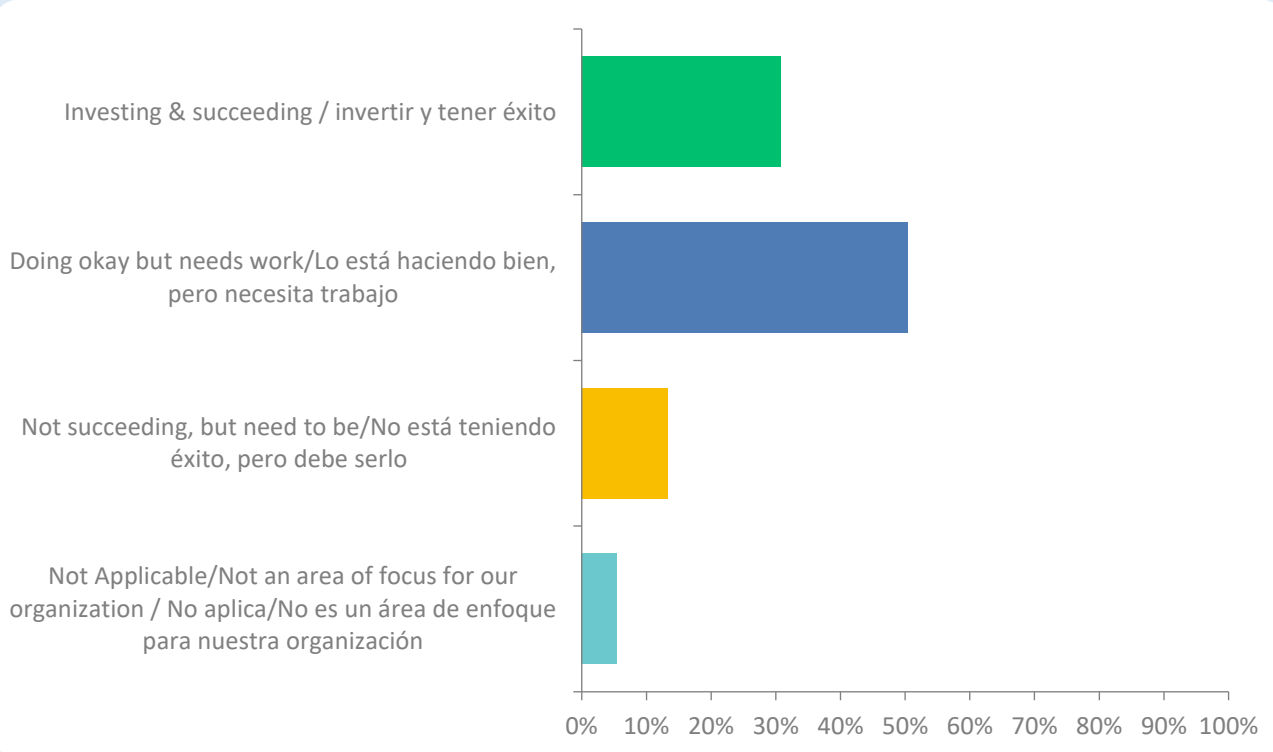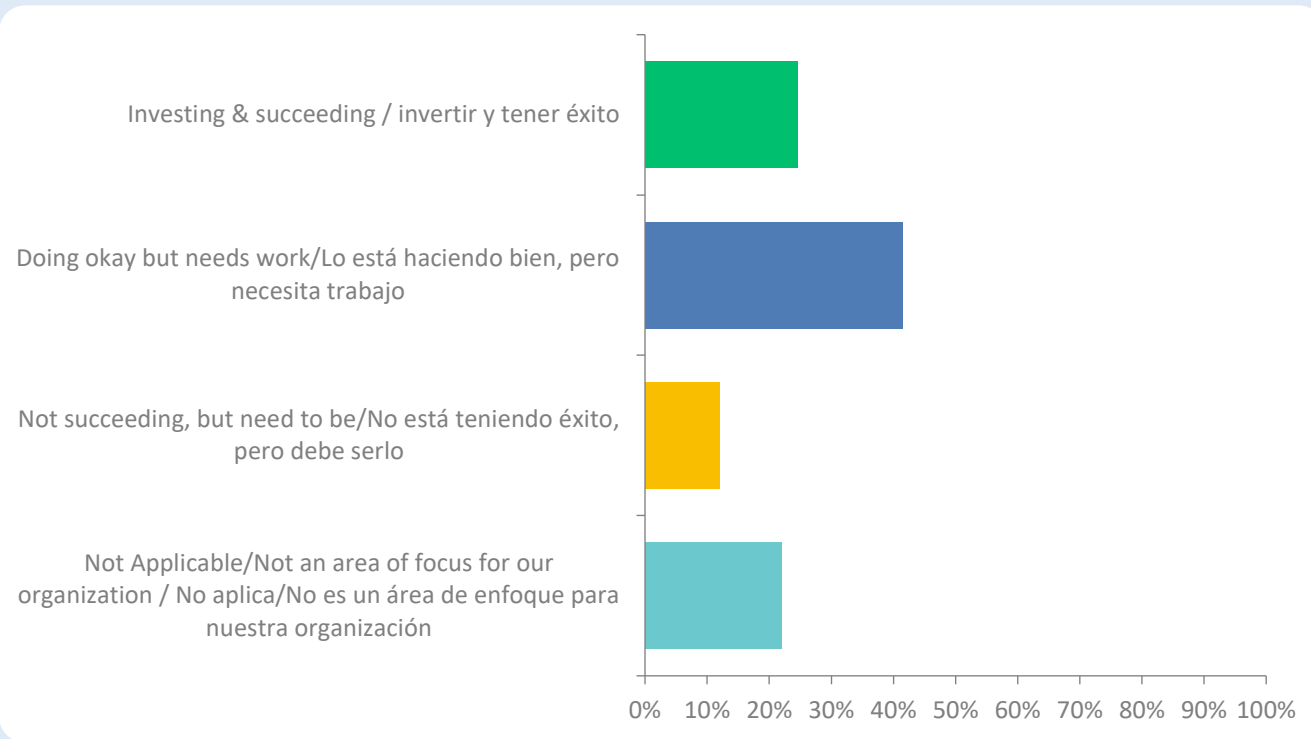| ANSWER CHOICES	RESPONSES
Investing & succeeding	25.83%
Doing okay but needs work	51.25%
Not succeeding, but need to be	12.08%
Not Applicable/Not an area of focus for our organization	10.83%

World Patients Alliance

Patient-Centered Healthcare

(Is Patient-centered healthcare a priority/focus area for your organization? How well are you doing in this area?)

ANSWER CHOICES	RESPONSES
Investing & succeeding	30.83%
Doing okay but needs work	50.42%
Not succeeding, but need to be	13.33%
Not Applicable/Not an area of focus for our organization	5.42%

World Patients Alliance

Non-Communicable Diseases

(Is Non-communicable diseases a priority/focus area for your organization? How well are you doing in this area?)

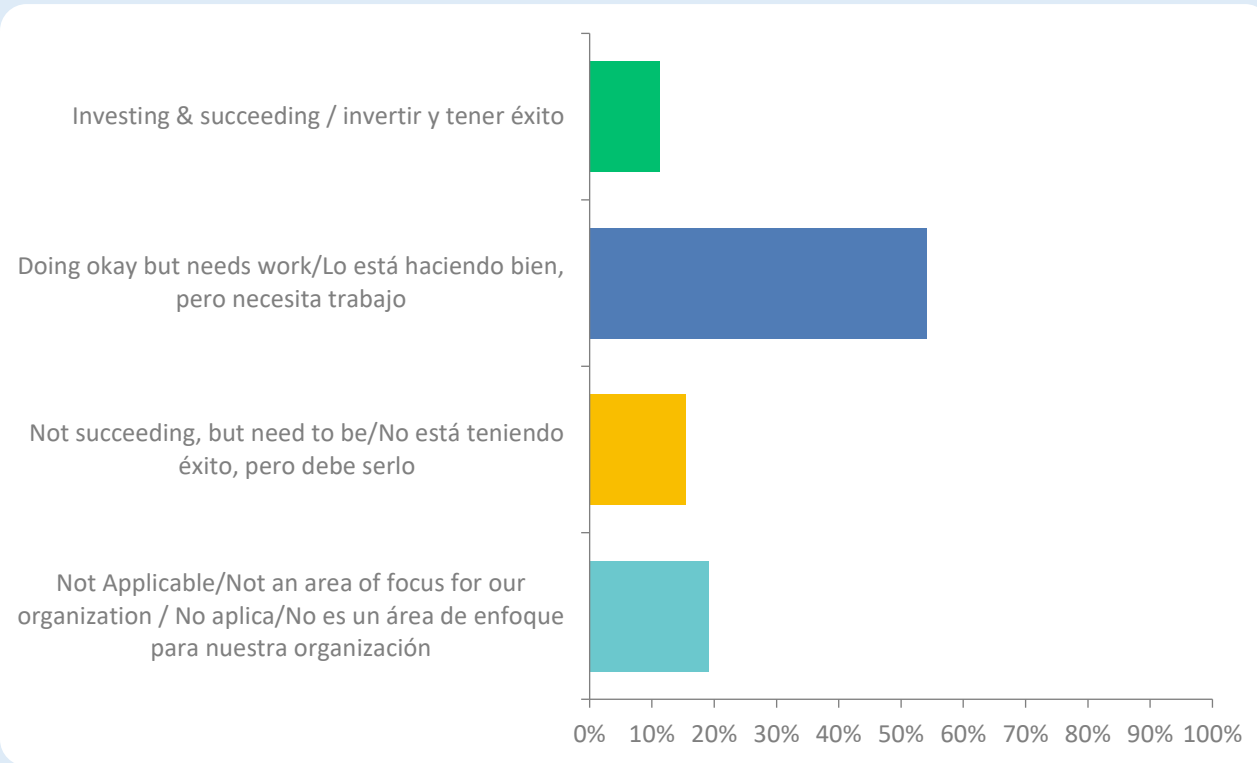| ANSWER CHOICES	RESPONSES
Investing & succeeding	24.48%
Doing okay but needs work	41.49%
Not succeeding, but need to be	12.03%
Not Applicable/Not an area of focus for our organization	21.99%

World Patients Alliance

Universal Health Care

(Is Universal health care a priority/focus area for your organization? How well are you doing in this area?)

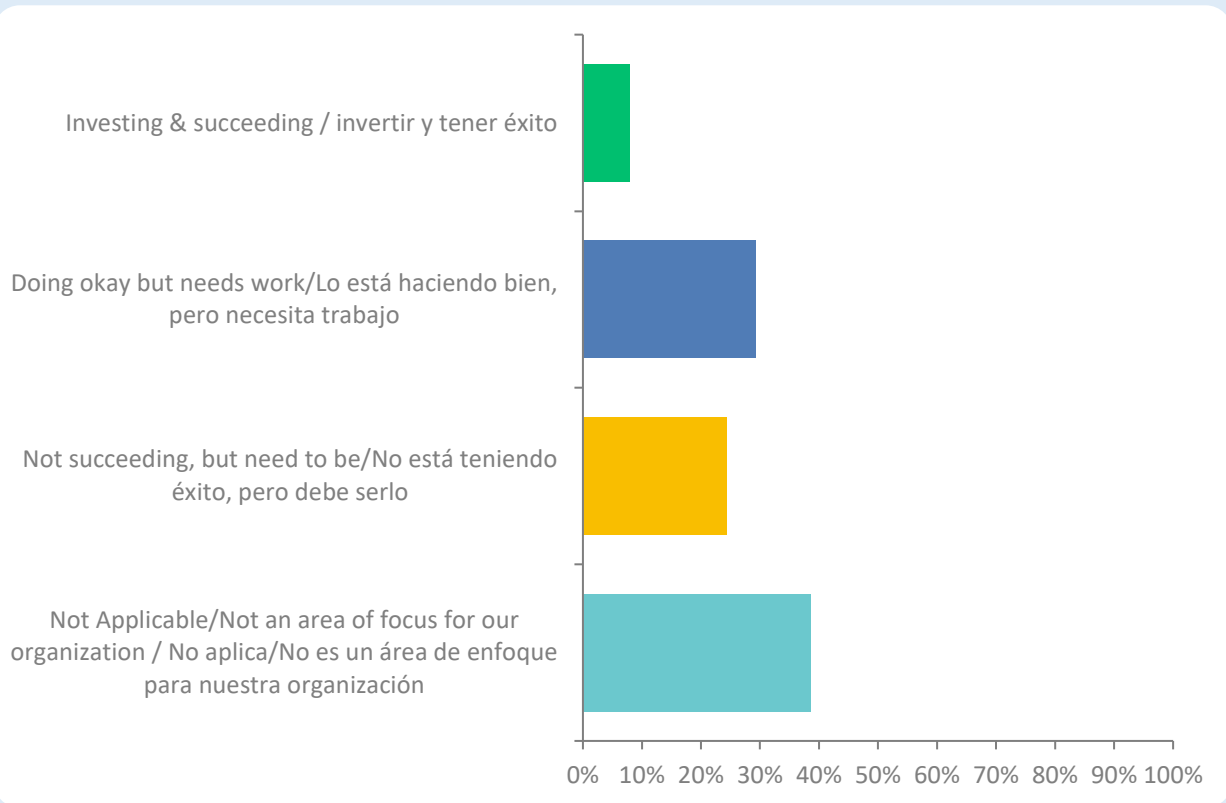| ANSWER CHOICES	RESPONSES
Investing & succeeding	11.25%
Doing okay but needs work	54.17%
Not succeeding, but need to be	15.42%
Not Applicable/Not an area of focus for our organization	19.17%

World Patients Alliance

Clinical Trials

(Is patient involvement in Clinical trials a priority/focus area for your organization? How well are you doing in this area?)

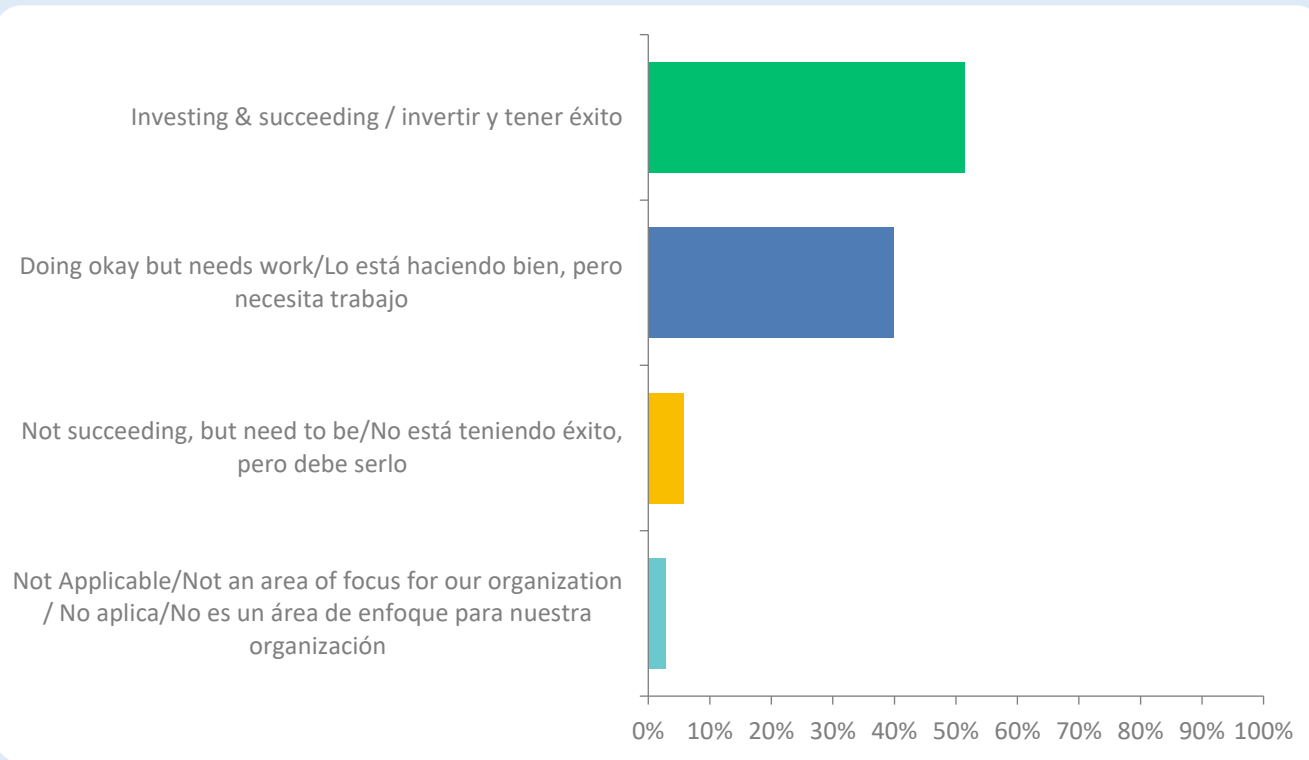| ANSWER CHOICES	RESPONSES
Investing & succeeding	7.95%
Doing okay but needs work	29.29%
Not succeeding, but need to be	24.27%
Not Applicable/Not an area of focus for our organization	38.49%

World Patients Alliance

Information to Patients and Families
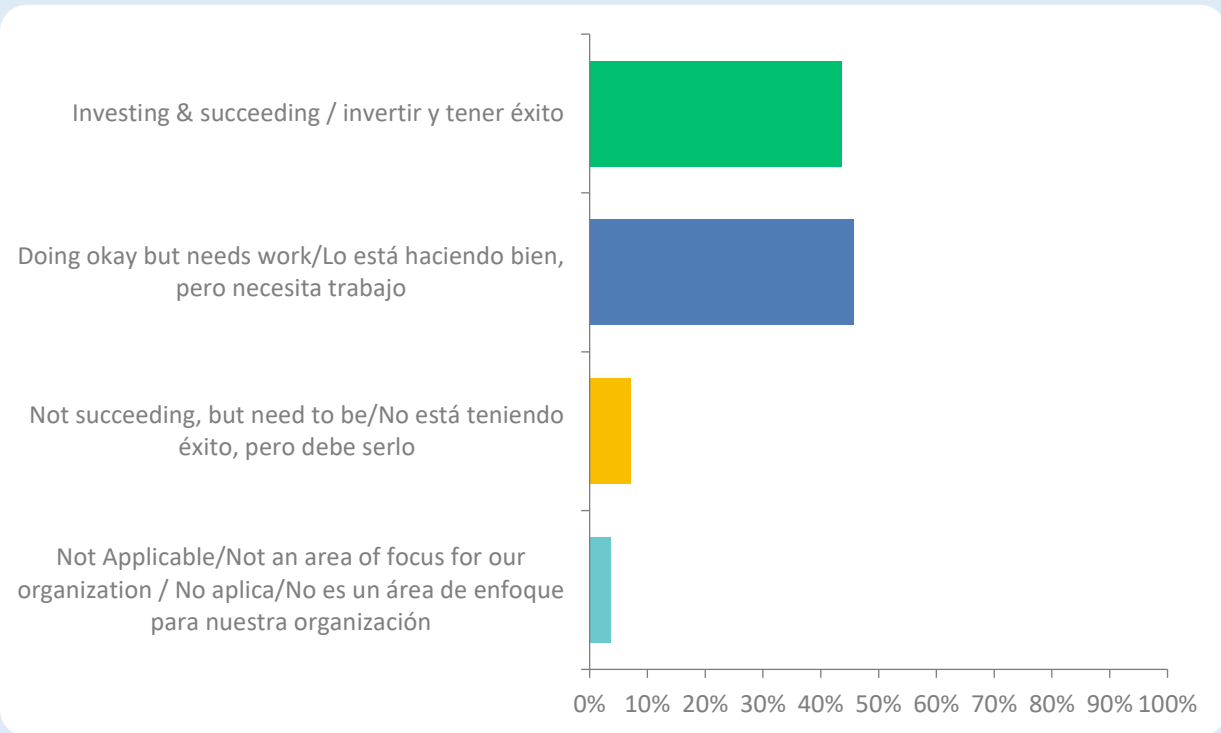
(Is providing information to patients and families a priority/focus area for your organization? How well are you doing in this area?)

ANSWER CHOICES	RESPONSES
Investing & succeeding	51.45%
Doing okay but needs work	39.83%
Not succeeding, but need to be	5.81%
Not Applicable/Not an area of focus for our organization	2.90%

World Patients Alliance

Education/Capacity Building of Patients

(Is education /capacity building/health literacy of patients & families a priority/focus area for your organization?

ANSWER CHOICES	RESPONSES
Investing & succeeding	43.57%
Doing okay but needs work	45.64%
Not succeeding, but need to be	7.05%
Not Applicable/Not an area of focus for our organization	3.73%

World Patients Alliance

Education/Capacity Building of Healthcare Providers

(Is education /capacity building of healthcare providers a priority/focus area for your organization? How well are you doing in this area?)
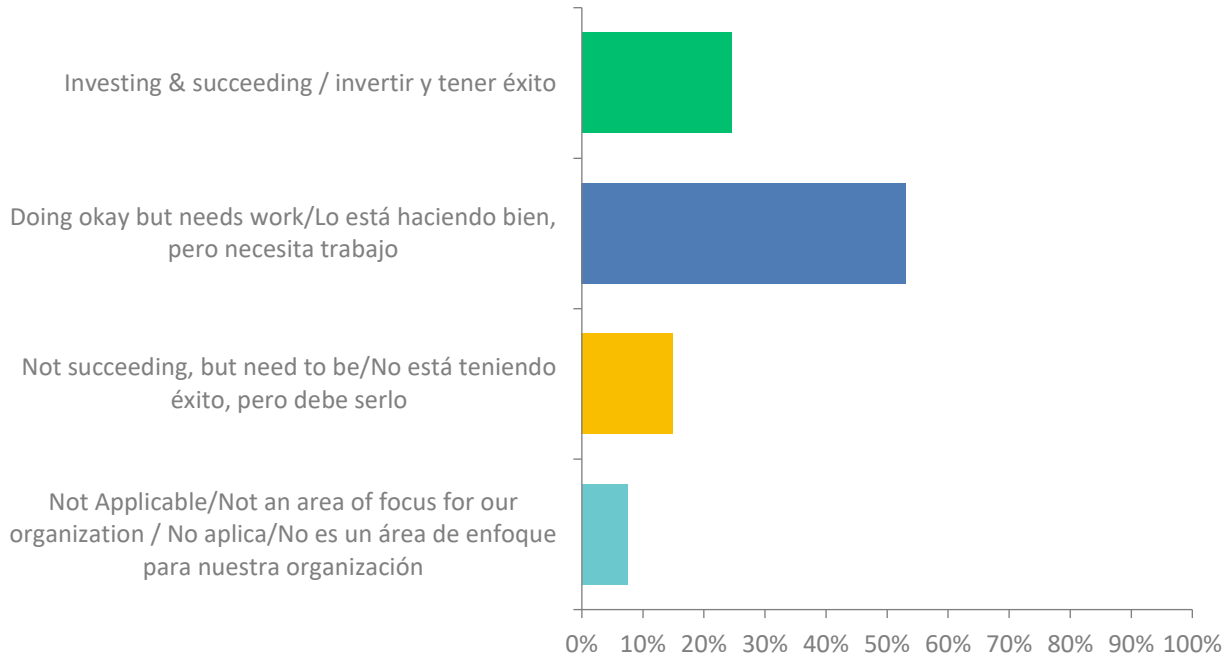
ANSWER CHOICES	RESPONSES
Investing & succeeding	24.48%
Doing okay but needs work	53.11%
Not succeeding, but need to be	14.94%
Not Applicable/Not an area of focus for our organization	7.47%

World Patients Alliance

Education/ Capacity Building of Your Organization

(Is education /capacity building within your organization is a priority/focus area for you? How well are you doing in this area?)
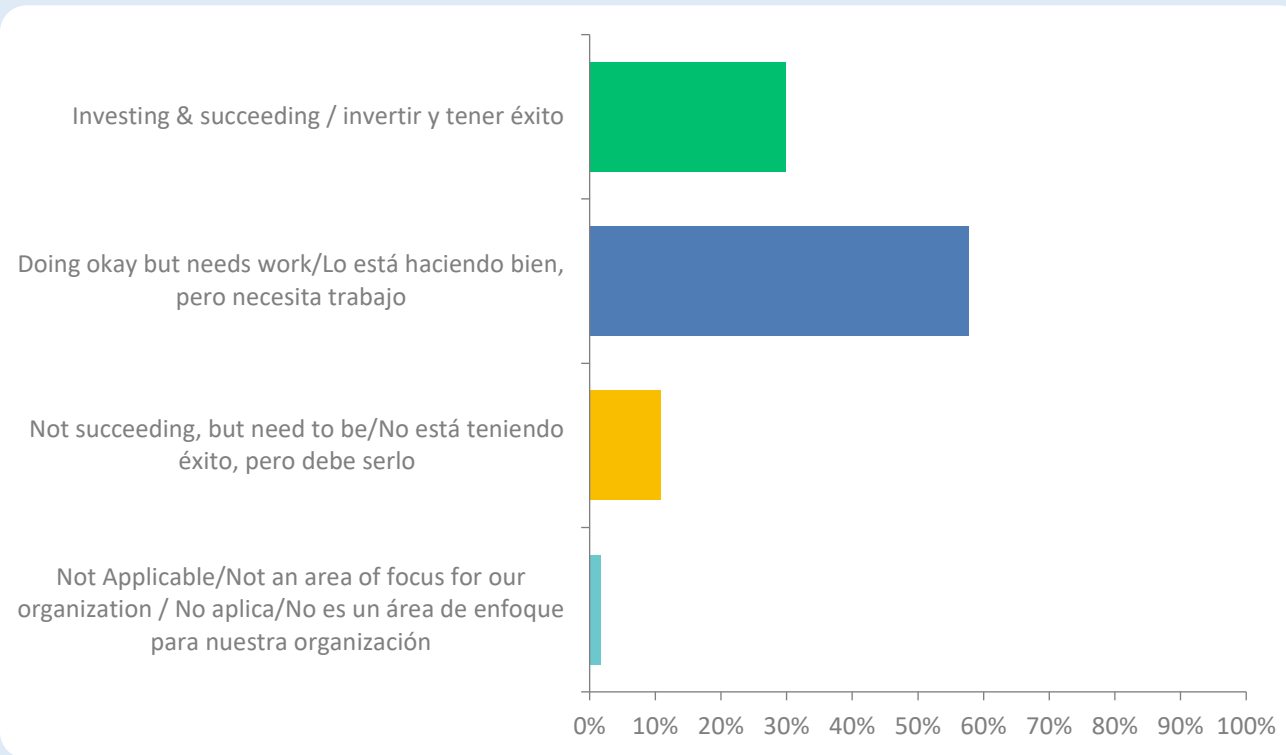
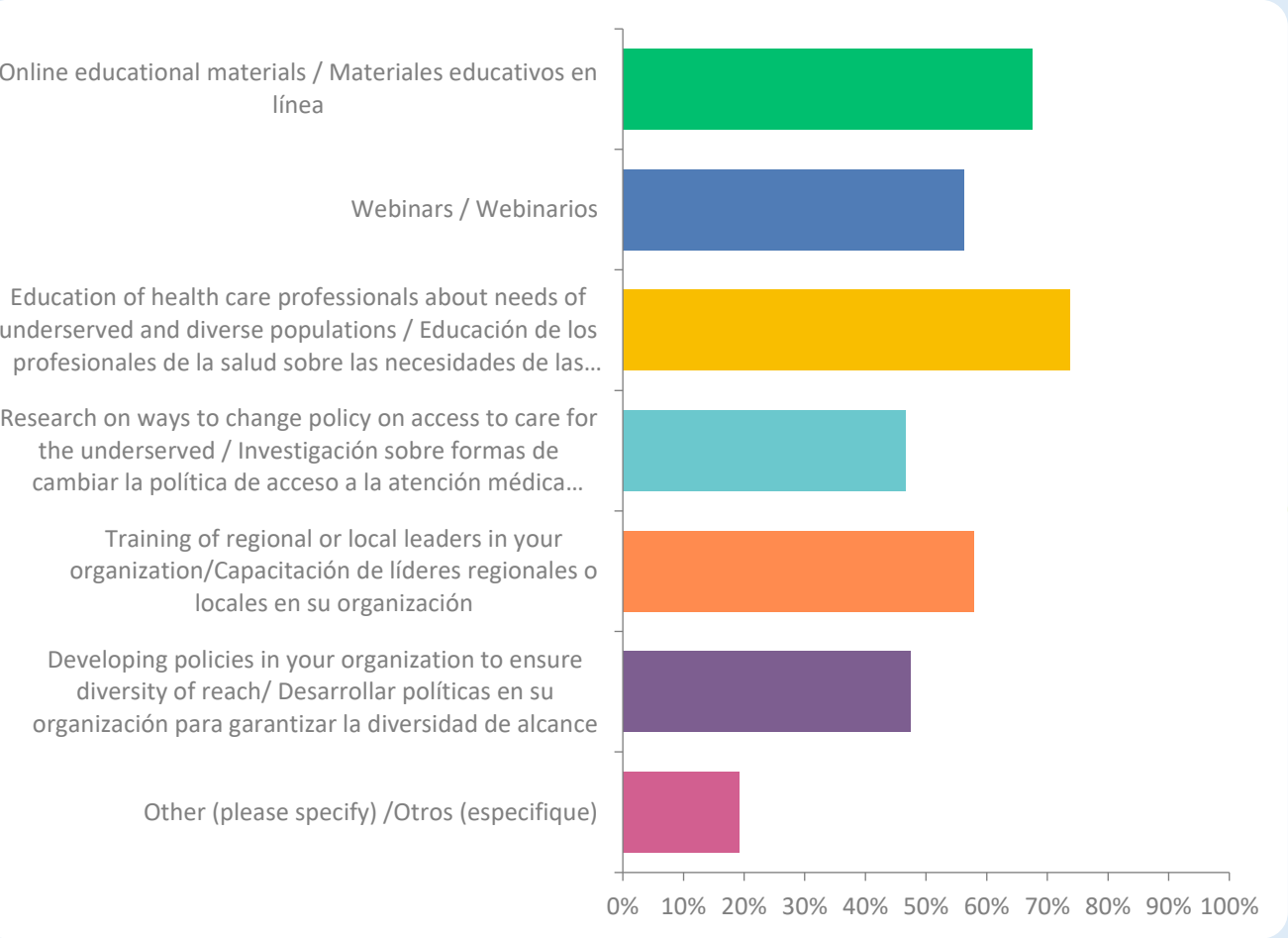| ANSWER CHOICES	RESPONSES
Investing & succeeding	29.88%
Doing okay but needs work	57.68%
Not succeeding, but need to be	10.79%
Not Applicable/Not an area of focus for our organization	1.66%

World Patients Alliance

How Does Your Organization Tackles Unequal Access to Healthcare or How Do You Address Disparities in Healthcare Access

ANSWER CHOICES	RESPONSES
Online educational materials	67.50%
Webinars	56.25%
Education of health care professionals about needs of underserved and diverse populations	73.75%
Research on ways to change policy on access to care for the underserved	46.67%
Training of regional or local leaders in your organization	57.92%
Developing policies in your organization to ensure diversity of reach	47.50%
Other (please specify)	19.17%

Bar chart labels:
- Online educational materials / Materiales educativos en línea
- Webinars / Webinarios
- Education of health care professionals about needs of underserved and diverse populations / Educación de los profesionales de la salud sobre las necesidades de las…
- Research on ways to change policy on access to care for the underserved / Investigación sobre formas de cambiar la política de acceso a la atención médica…
- Training of regional or local leaders in your organization/Capacitación de líderes regionales o locales en su organización
- Developing policies in your organization to ensure diversity of reach/ Desarrollar políticas en su organización para garantizar la diversidad de alcance
- Other (please specify) /Otros (especifique)

Others: Lobbying at the national level, Mobile clinic - outreach to hard-to-reach populations (due to stigma or geographically), Preventative diagnostic tools online to assess the risk, Working with authorities to exterminate the taenia-cysticerci that is a real problem in the poor. sex education to teens, Training other healthcare workers, joint actions with other organizations, Engagements, and Collaboration, Influencing public policies, Organization of awareness groups, Patient Advocacy Training, seminars, information days, workshops, roundtables, Working with pharmaceutical companies to fund patient support and affordability programs

What were Your organization's Main Struggle in 2023? Kindly prioritize each of the following issues, with 01 being the biggest struggle and 05 no struggle.
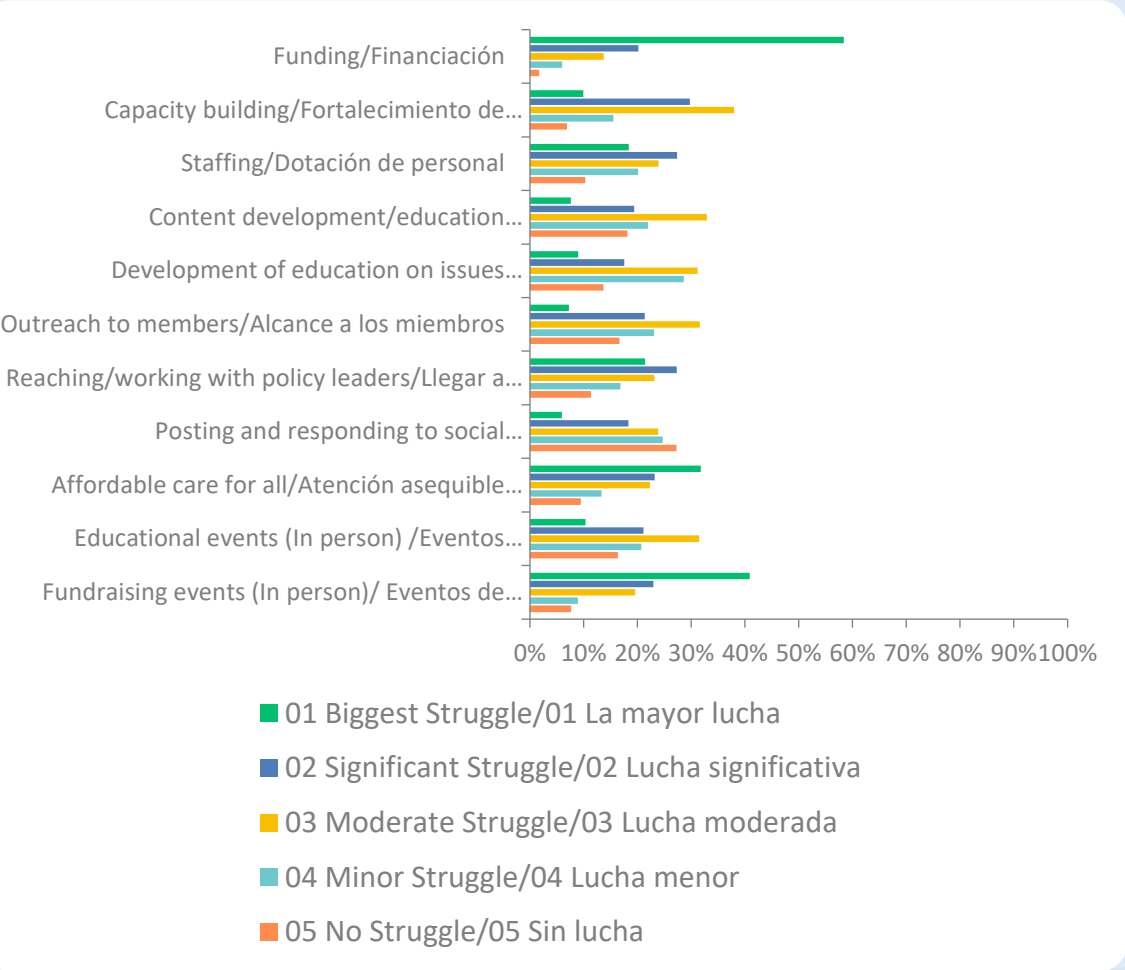
|	01 BIGGEST STRUGGLE	02 SIGNIFICANT STRUGGLE	03 MODERATE STRUGGLE	04 MINOR STRUGGLE	05 NO STRUGGLE/
Funding	58.37%	20.17%	13.73%	6.01%	1.72%
Capacity building	9.91%	29.74%	37.93%	15.52%	6.90%
Staffing	18.38%	27.35%	23.93%	20.09%	10.26%
Content development	7.59%	19.41%	32.91%	21.94%	18.14%
Development of education on issues important to membership	8.97%	17.52%	31.20%	28.63%	13.68%
Outreach to members	7.26%	21.37%	31.62%	23.08%	16.67%
Reaching/working with policy leaders	21.43%	27.31%	23.11%	16.81%	11.34%
Posting and responding to social media	5.96%	18.30%	23.83%	24.68%	27.23%
Affordable care for all	31.76%	23.18%	22.32%	13.30%	9.44%
Educational events (In person)	10.34%	21.12%	31.47%	20.69%	16.38%
Fundraising events (In person)	40.85%	22.98%	19.57%	8.94%	7.66%

Would You Like WPA To Develop Educational Material (e.g. toolkits) on Any of the Given Topics
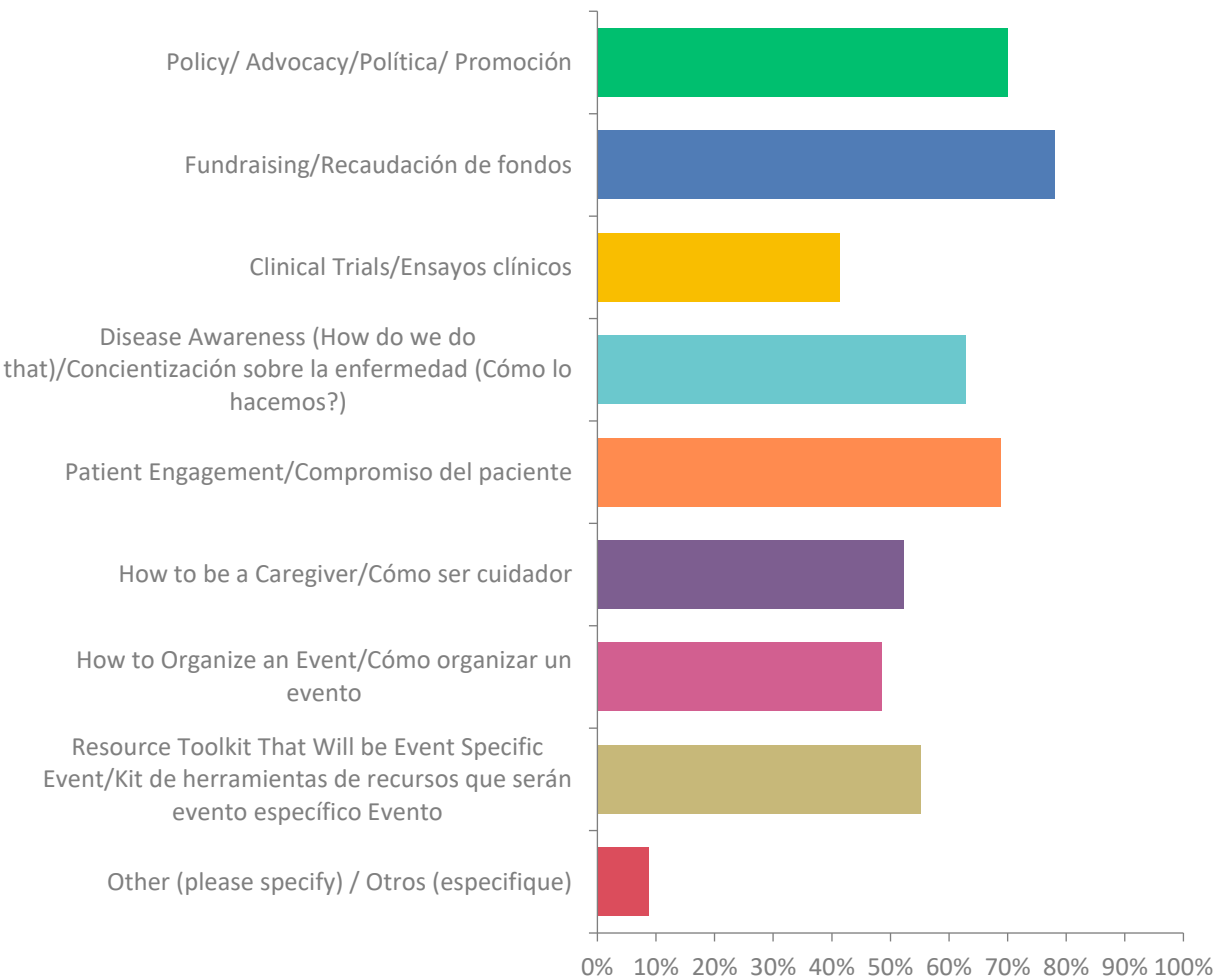
ANSWER CHOICES	RESPONSES
Policy/ Advocacy	70.04%
Fundraising	78.06%
Clinical Trials	41.35%
Disease Awareness (How do we do that)	62.87%
Patient Engagement	68.78%
How to be a Caregiver	52.32%
How to Organize an Event	48.52%
Resource Toolkit That Will be Event Specific Event	55.27%
Other (please specify)	8.86%

Others: Treatment literacy materials, Survivorship Care/support, How to build a network, AI, Digital Health Literacy, Advocacy, navigation and expert patient program, How to claim your human rights, Importance of accredited facilities, Toolkit for patient engagement

Please Indicate if You Would Like WPA to Assist in Any of the Following Areas:
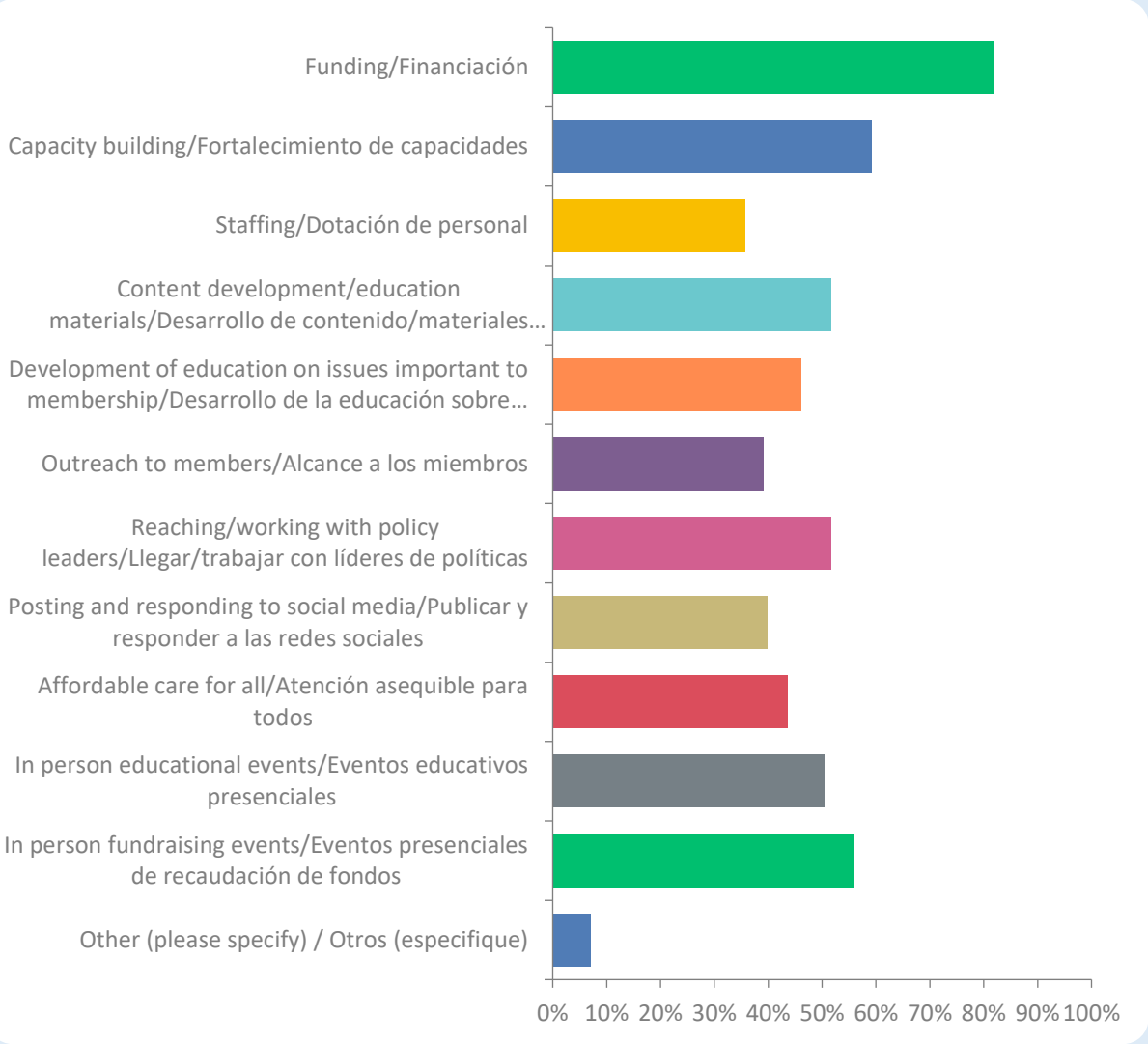
ANSWER CHOICES	RESPONSES
Funding	81.93%
Capacity building	59.24%
Staffing	35.71%
Content development/education materials	51.68%
Development of education on issues important to membership	46.22%
Outreach to members	39.08%
Reaching/working with policy leaders	51.68%
Posting and responding to social media	39.92%
Affordable care for all	43.70%
In person educational events	50.42%
In person fundraising events	55.88%
Other (please specify)	7.14%

Other: Exchange learning visits among members, Building the network, use of the Portuguese language, Building the network, Educational Events For Political Actors And Science Professionals In Person, Connecting to other healthcare and life science stakeholders.

What Can World Patients Alliance (WPA) Provide Your Organization to Stay Informed on Global Patient Issues?
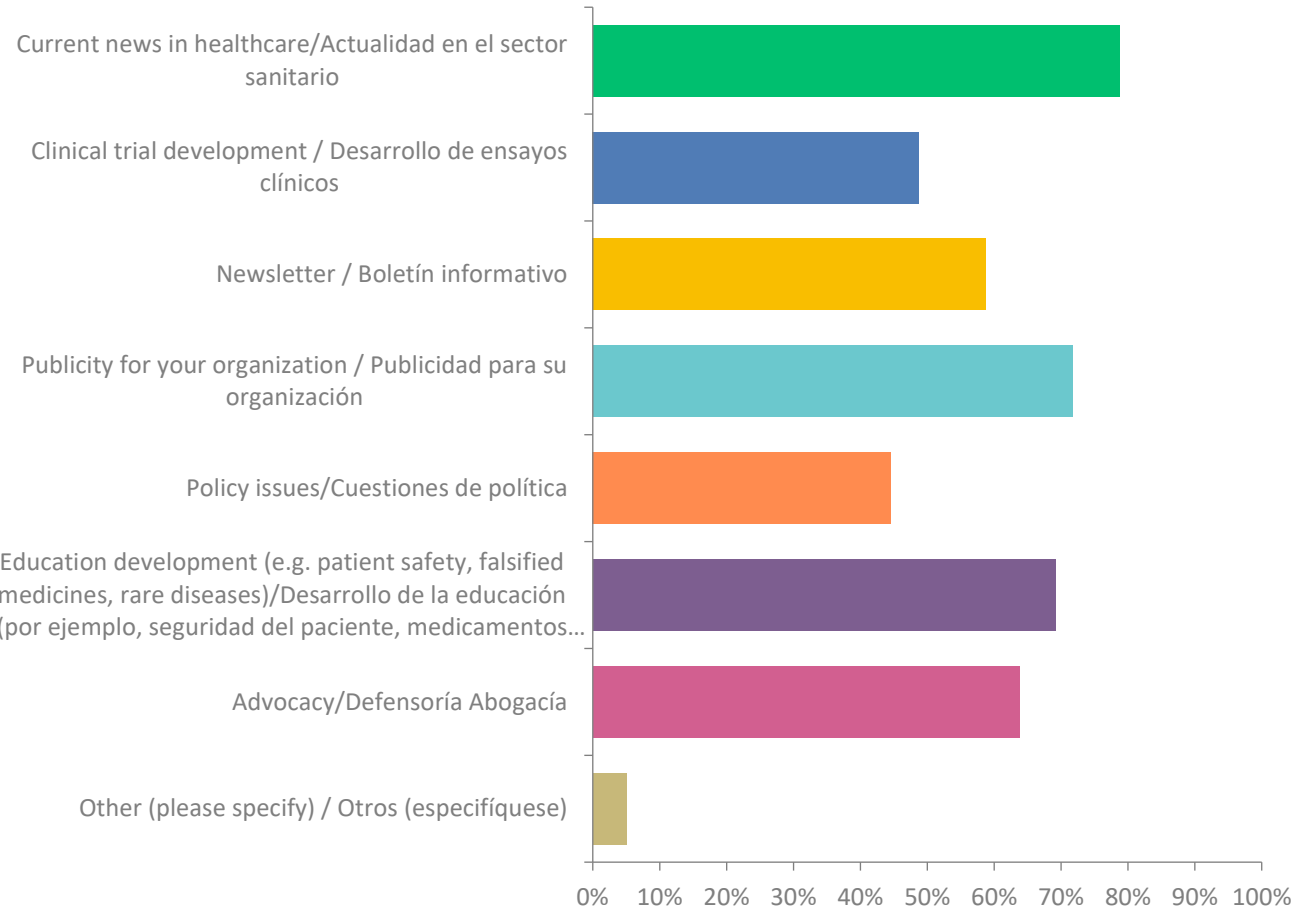
ANSWER CHOICES	RESPONSES
Current news in healthcare	78.75%
Clinical trial development	48.75%
Newsletter	58.75%
Publicity for your organization	71.67%
Policy issues	44.58%
Education development (e.g. patient safety, falsified medicines, rare diseases)	69.17%
Advocacy	63.75%
Other (please specify)	5.00%

Others: GSD IV outreach, Human rights in/and HIV care. Current news should include recent and effective HIV treatment regimens, Scholarship to in-person events, Running patient support and access to treatment programs, Grants

What topics would you prefer to be included during the upcoming 2nd World Patients Conference scheduled for October 19-20, 2024, in Cape Town?
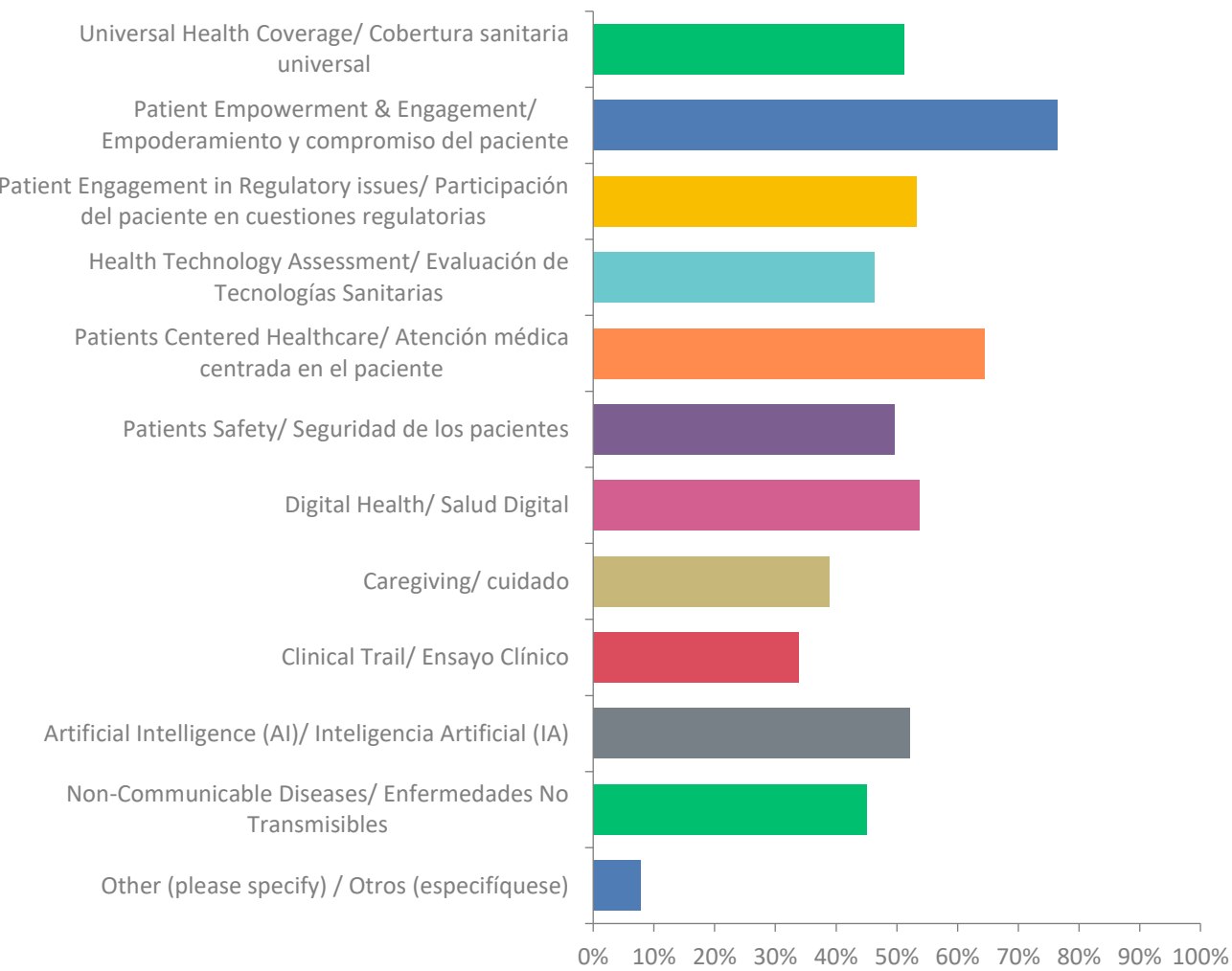
ANSWER CHOICES	RESPONSES
Universal Health Coverage	51.24%
Patient Empowerment & Engagement	76.45%
Patient Engagement in Regulatory issues	53.31%
Health Technology Assessment	46.28%
Patients Centered Healthcare	64.46%
Patients Safety	49.59%
Digital Health	53.72%
Caregiving	38.84%
Clinical Trail	33.88%
Artificial Intelligence (AI)	52.07%
Non-Communicable Diseases	45.04%
Other (please specify)	7.85%

Others: Patient - Healthcare worker relationship, non-stigmatizing language, A closer look into HIV care in the next 10-20 years, cancer care specific topic within the NCD, Mental Health, prevention - new ways or how to prevent illnesses and doctor-to-doctor communication, Pain management