



**World Patients Alliance**

# Member Survey



# World Patients Alliance

**We are proud to include your organization as one of the 200 plus member organizations of the World Patients Alliance. To best serve your organization, and all our members, we asked members to take this brief survey to help us understand their organization's needs and opportunities for partnership.**



# Name of Organization

Bangladesh Women's Health Coalition

Action Contre le Cancer Infantile au Burkina

PinkDrive NPC

Hyper-Cent Care Africa

BELGIAN BRAIN COUNCIL

Egyptian Alzheimer Society

ASPA Cameroon

FEDERACION ESPAÑOLA DE CÁNCER DE MAMA

Chronic Pain Ireland

Tulasi Maya Memorial Cancer Relief Foundation

National Community of women living with HIV/AIDS in Uganda

Manica Youth Assembly (MAYA)

DiaLeb - National Diabetes Organization  
Respirando con Valor

Hepatitis Foundation of Ghana

Fundación Edificando Vidas

Arrhythmia Alliance

Zambian Cancer Society

THE PATIENT BENEVOLENT SOCIETY

National Rheumatoid Arthritis Society

Lymphoma Action

CRPS Bundesverband Deutschland e.V.

Welfare Hand Organization

American Chronic Pain Association

Global Chinese Breast Cancer Organizations Alliance

CANADIAN HEMOPHILIA SOCIETY

Alzheimer's Pakistan

Al Oun for Alzheimer's Patient Care Association



World Patients Alliance © 2021



# Year Established



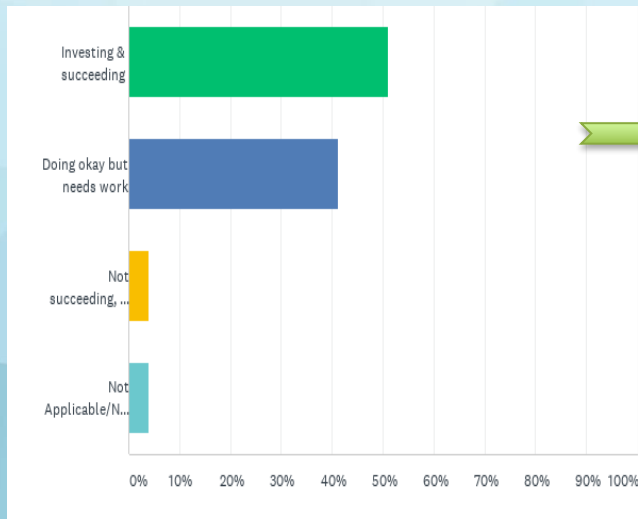


# Number of patients, caregivers, other stakeholders served





# Involvement & Success in ADVOCACY

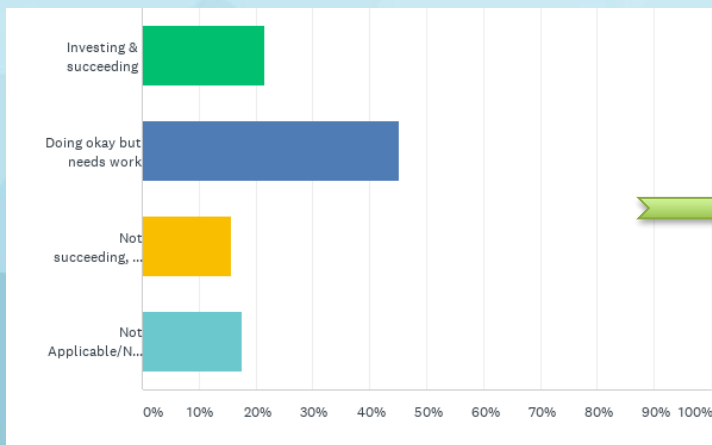


ANSWER CHOICES	RESPONSES	
Investing & succeeding	50.98%	26
Doing okay but needs work	41.18%	21
Not succeeding, but need to be	3.92%	2
Not Applicable/Not an area of focus for our organization	3.92%	2
TOTAL		51

Answered: 51   Skipped: 1



# Involvement & Success in RESEARCH



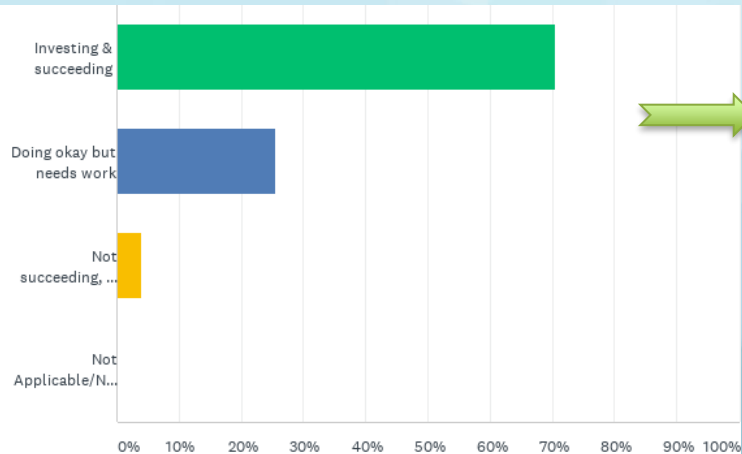
ANSWER CHOICES	RESPONSES	
Investing & succeeding	21.57%	11
Doing okay but needs work	45.10%	23
Not succeeding, but need to be	15.69%	8
Not Applicable/Not an area of focus for our organization	17.65%	9
TOTAL		51

Answered: 51   Skipped: 1





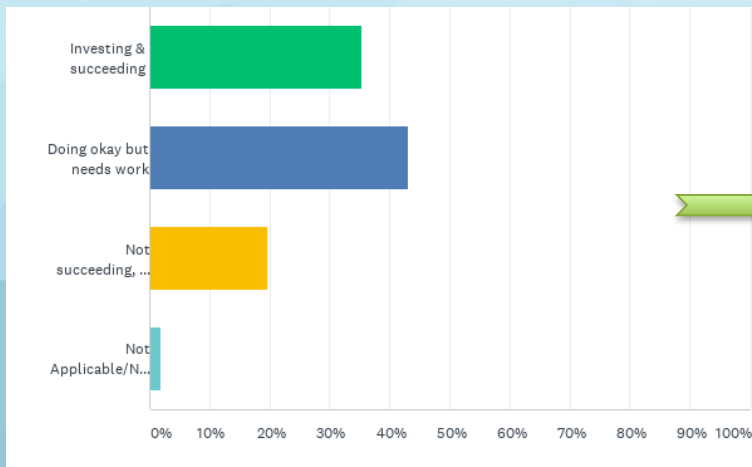
# Involvement & Success in AWARENESS



ANSWER CHOICES	RESPONSES	
Investing & succeeding	70.59%	36
Doing okay but needs work	25.49%	13
Not succeeding, but need to be	3.92%	2
Not Applicable/Not an area of focus for our organization	0.00%	0
TOTAL		51



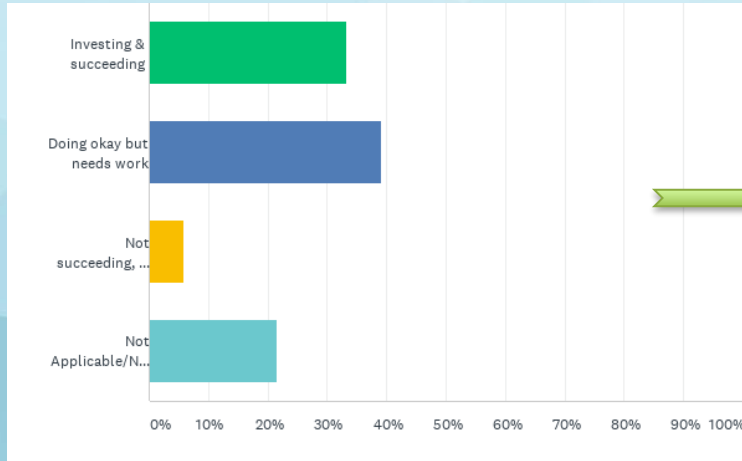
# Involvement & Success in FUNDRAISING



ANSWER CHOICES	RESPONSES	
Investing & succeeding	35.29%	18
Doing okay but needs work	43.14%	22
Not succeeding, but need to be	19.61%	10
Not Applicable/Not an area of focus for our organization	1.96%	1
TOTAL		51



# Organization's involvement and success in HEALTHCARE DELIVERY

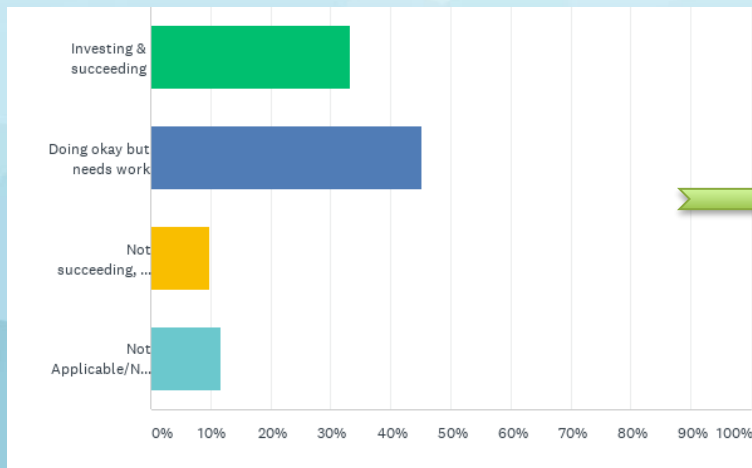


ANSWER CHOICES	RESPONSES	
Investing & succeeding	33.33%	17
Doing okay but needs work	39.22%	20
Not succeeding, but need to be	5.88%	3
Not Applicable/Not an area of focus for our organization	21.57%	11
TOTAL		51

Answered: 51   Skipped: 1



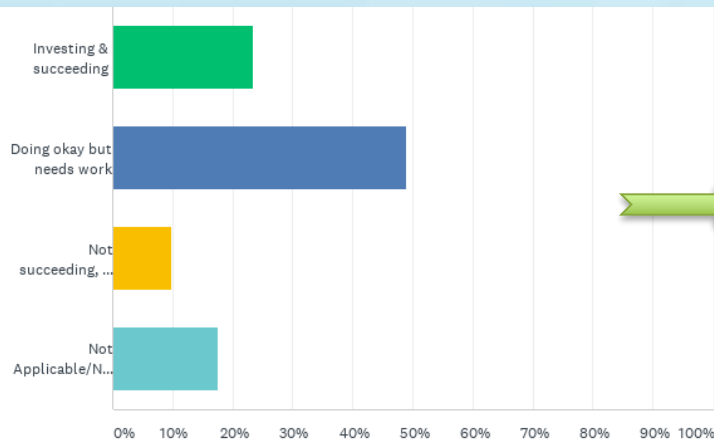
# Involvement & Success in OUTREACH SERVICES



ANSWER CHOICES	RESPONSES	
Investing & succeeding	33.33%	17
Doing okay but needs work	45.10%	23
Not succeeding, but need to be	9.80%	5
Not Applicable/Not an area of focus for our organization	11.76%	6
TOTAL		51



# Involvement & Success in ACCESS TO HEALTH CARE

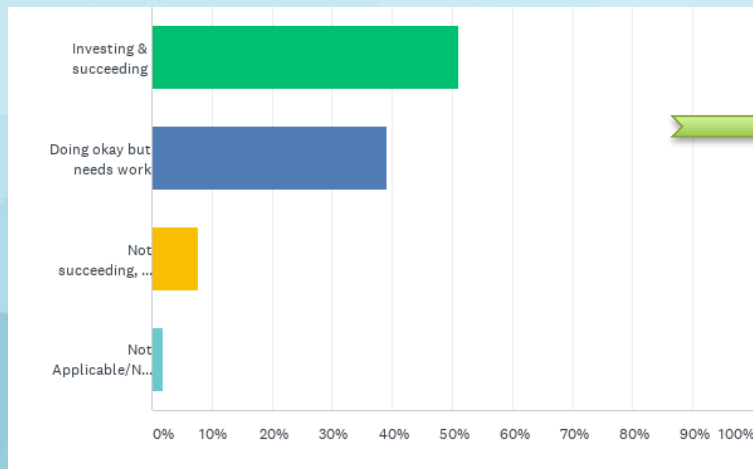


ANSWER CHOICES	RESPONSES	
Investing & succeeding	23.53%	12
Doing okay but needs work	49.02%	25
Not succeeding, but need to be	9.80%	5
Not Applicable/Not an area of focus for our organization	17.65%	9
TOTAL		51

Answered: 51   Skipped: 1



# Involvement & Success in INFORMATION to PATIENTS & FAMILIES

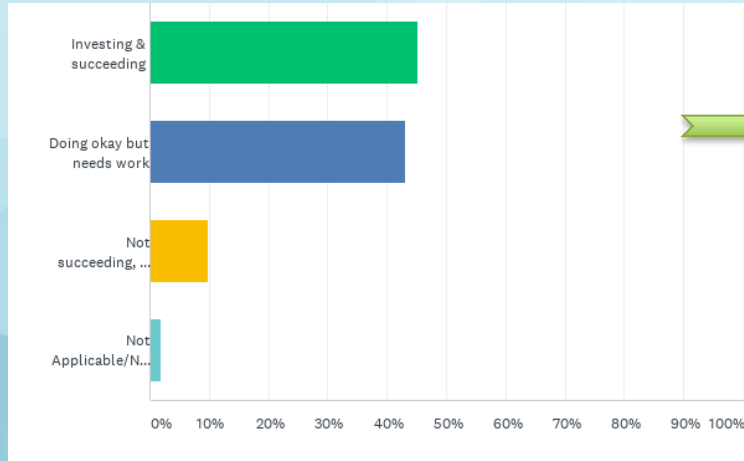


ANSWER CHOICES	RESPONSES	
Investing & succeeding	50.98%	26
Doing okay but needs work	39.22%	20
Not succeeding, but need to be	7.84%	4
Not Applicable/Not an area of focus for our organization	1.96%	1
TOTAL		51

Answered: 51   Skipped: 1



# Involvement & Success in EDUCATION of PATIENTS

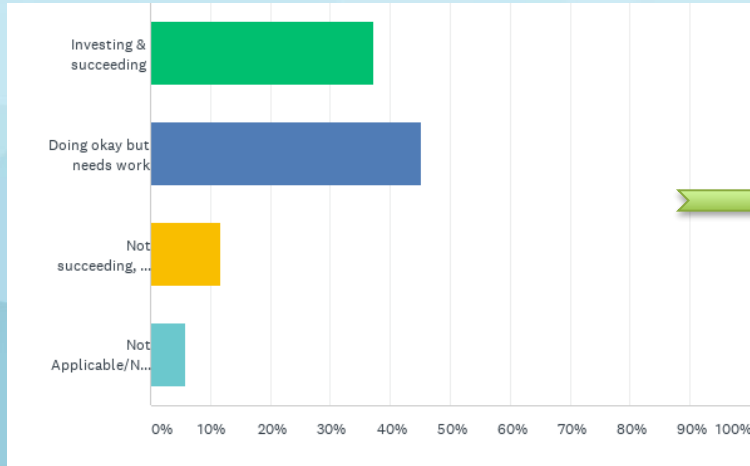


ANSWER CHOICES	RESPONSES	
Investing & succeeding	46.15%	24
Doing okay but needs work	42.31%	22
Not succeeding, but need to be	9.62%	5
Not Applicable/Not an area of focus for our organization	1.92%	1
TOTAL		52

Answered: 51   Skipped: 1



# Involvement & Success in EDUCATIONS of HEALTH CARE PROVIDERS



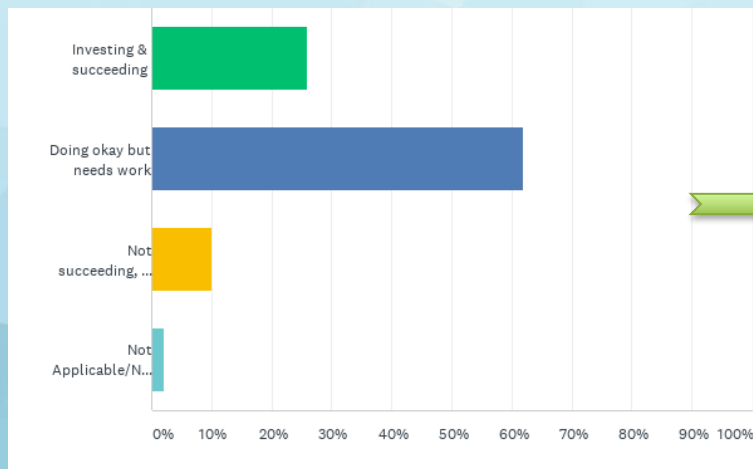
ANSWER CHOICES	RESPONSES	
Investing & succeeding	37.25%	19
Doing okay but needs work	45.10%	23
Not succeeding, but need to be	11.76%	6
Not Applicable/Not an area of focus for our organization	5.88%	3
TOTAL		51

Answered: 51 Skipped: 1





# Involvement & Success in CAPACITY BUILDING

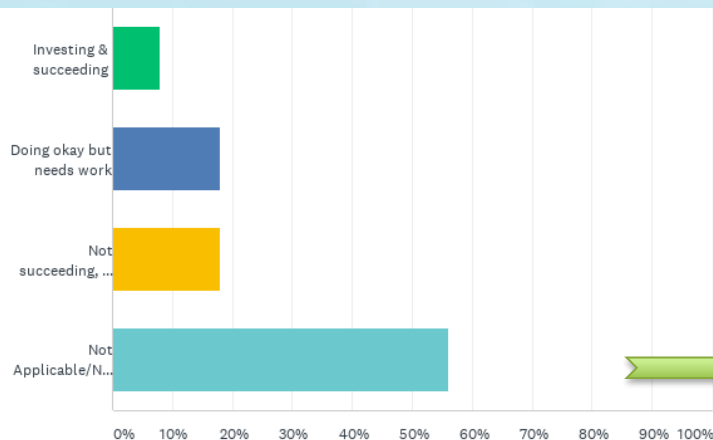


ANSWER CHOICES	RESPONSES	
Investing & succeeding	26.00%	13
Doing okay but needs work	62.00%	31
Not succeeding, but need to be	10.00%	5
Not Applicable/Not an area of focus for our organization	2.00%	1
TOTAL		50

Answered: 50   Skipped: 2



# Involvement & Success in BIOSIMILAR MEDICINES

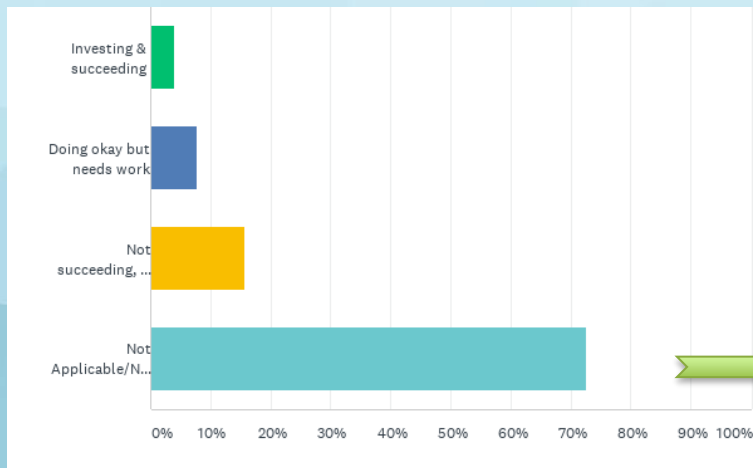


ANSWER CHOICES	RESPONSES	
Investing & succeeding	8.00%	4
Doing okay but needs work	18.00%	9
Not succeeding, but need to be	18.00%	9
Not Applicable/Not an area of focus for our organization	56.00%	28
TOTAL		50

Answered: 50   Skipped: 2



# Involvement & Success in FALSIFIED MEDICINES

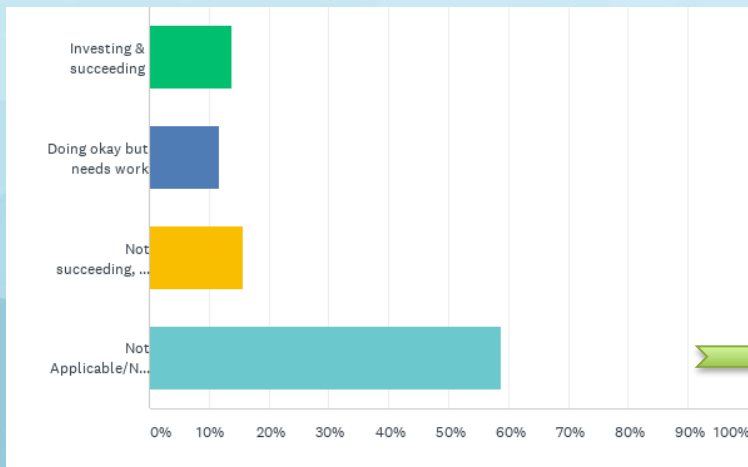


ANSWER CHOICES	RESPONSES	
Investing & succeeding	3.92%	2
Doing okay but needs work	7.84%	4
Not succeeding, but need to be	15.69%	8
Not Applicable/Not an area of focus for our organization	72.55%	37
TOTAL		51

Answered: 51   Skipped: 1



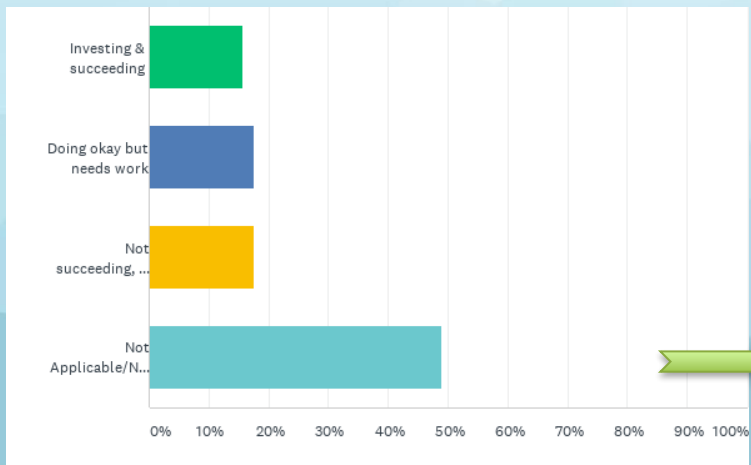
# Involvement & Success in CLINICAL TRIALS



ANSWER CHOICES	RESPONSES	
Investing & succeeding	13.73%	7
Doing okay but needs work	11.76%	6
Not succeeding, but need to be	15.69%	8
Not Applicable/Not an area of focus for our organization	58.82%	30
TOTAL		51



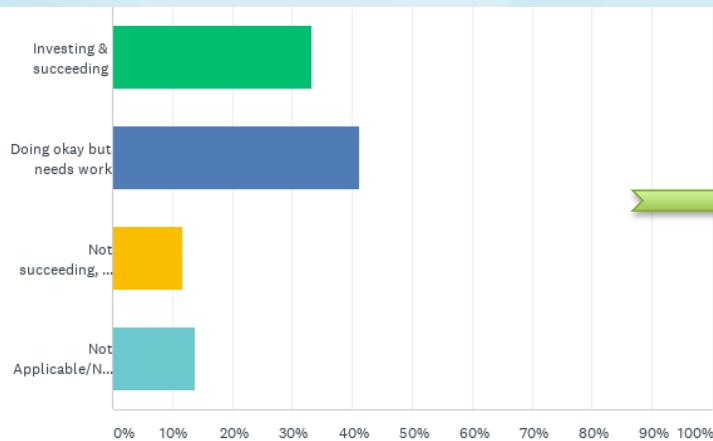
# Involvement & Success in RARE DISEASES



ANSWER CHOICES	RESPONSES	
Investing & succeeding	15.69%	8
Doing okay but needs work	17.65%	9
Not succeeding, but need to be	17.65%	9
Not Applicable/Not an area of focus for our organization	49.02%	25
TOTAL		51



# Involvement & Success in PATIENT SAFETY

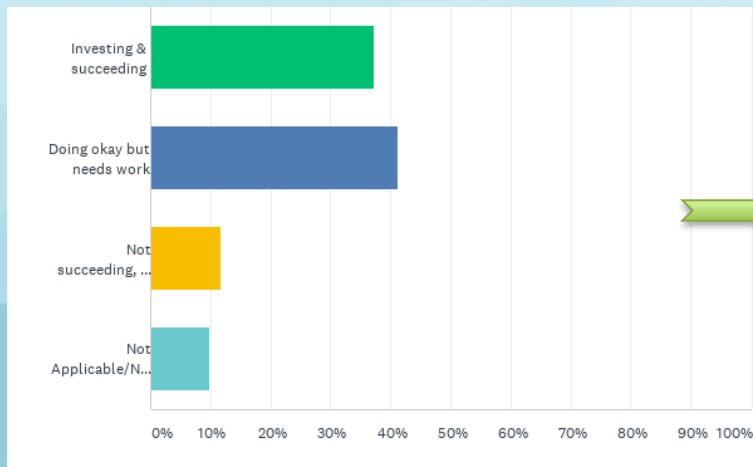


ANSWER CHOICES	RESPONSES	
Investing & succeeding	33.33%	17
Doing okay but needs work	41.18%	21
Not succeeding, but need to be	11.76%	6
Not Applicable/Not an area of focus for our organization	13.73%	7
TOTAL		51

Answered: 51   Skipped: 1



# Involvement & Success in PATIENT CENTERED HEALTHCARE

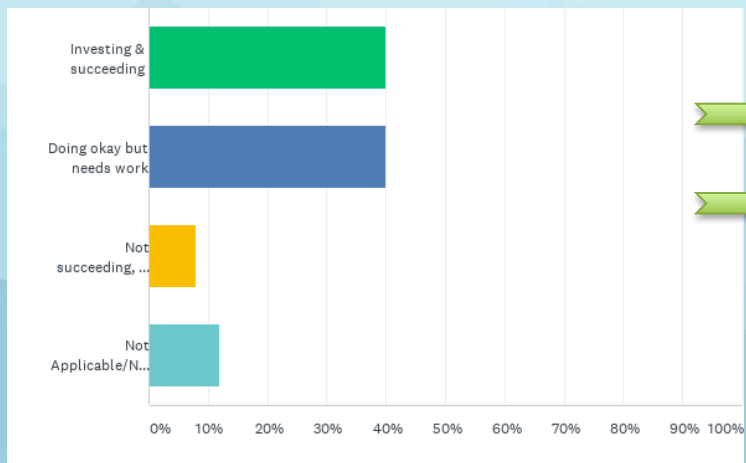


ANSWER CHOICES	RESPONSES	
Investing & succeeding	37.25%	19
Doing okay but needs work	41.18%	21
Not succeeding, but need to be	11.76%	6
Not Applicable/Not an area of focus for our organization	9.80%	5
TOTAL		51

Answered: 51    Skipped: 1



# Involvement & Success in COVID-19 SAFETY



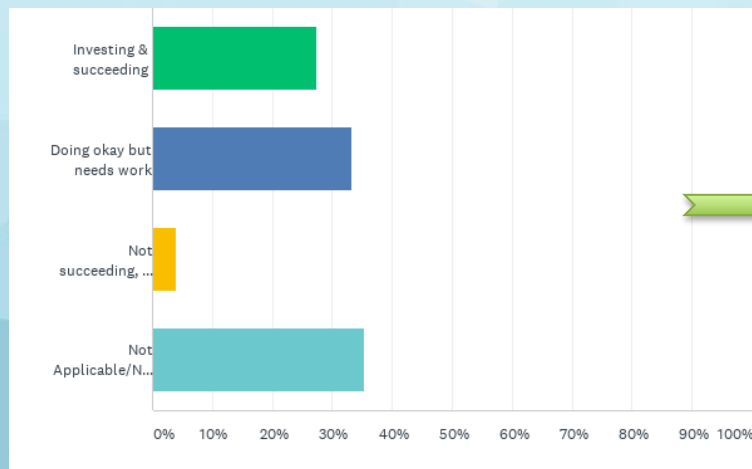
ANSWER CHOICES	RESPONSES	
Investing & succeeding	40.00%	20
Doing okay but needs work	40.00%	20
Not succeeding, but need to be	8.00%	4
Not Applicable/Not an area of focus for our organization	12.00%	6
TOTAL		50

Answered: 50   Skipped: 2





# Involvement & Success in NON-COMMUNICABLE DISEASES

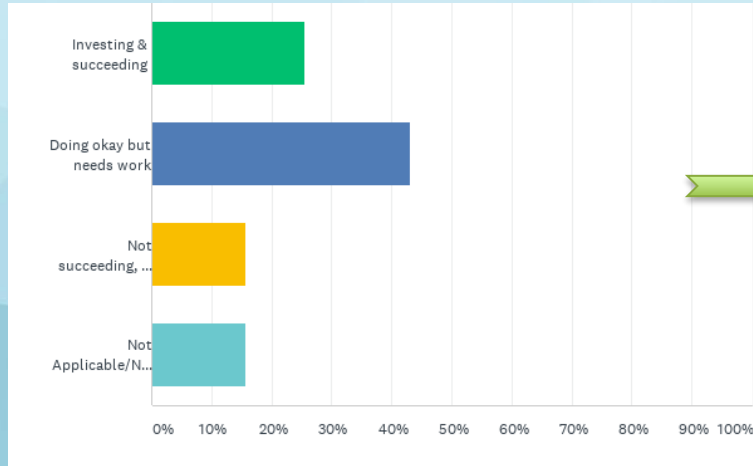


ANSWER CHOICES	RESPONSES	
Investing & succeeding	27.45%	14
Doing okay but needs work	33.33%	17
Not succeeding, but need to be	3.92%	2
Not Applicable/Not an area of focus for our organization	35.29%	18
TOTAL		51

Answered: 51    Skipped: 1



# Involvement & Success in SUSTAINABLE DEVELOPMENT GOALS

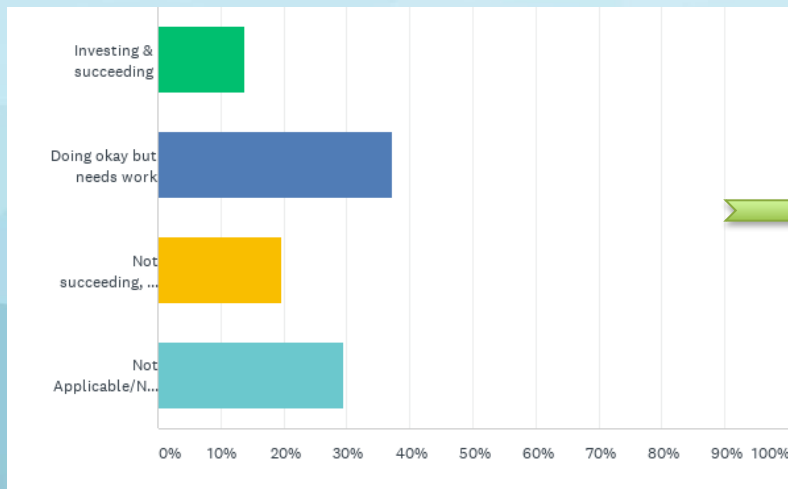


ANSWER CHOICES	RESPONSES	
Investing & succeeding	25.49%	13
Doing okay but needs work	43.14%	22
Not succeeding, but need to be	15.69%	8
Not Applicable/Not an area of focus for our organization	15.69%	8
TOTAL		51

Answered: 51   Skipped: 1



# Involvement & Success in UNIVERSAL HEALTH CARE

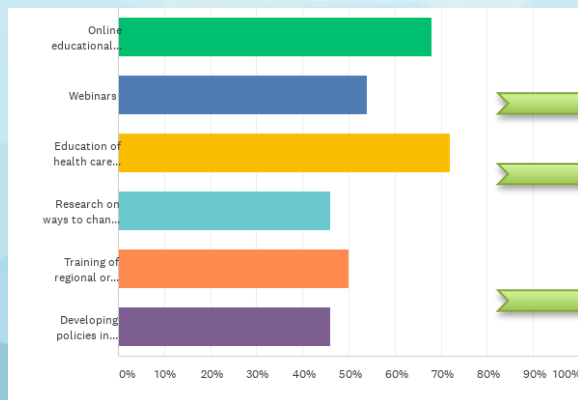


ANSWER CHOICES	RESPONSES	
Investing & succeeding	13.73%	7
Doing okay but needs work	37.25%	19
Not succeeding, but need to be	19.61%	10
Not Applicable/Not an area of focus for our organization	29.41%	15
TOTAL		51

Answered: 51   Skipped: 1



# How do you address disparities in health care access in your organization/country? (check all that apply)

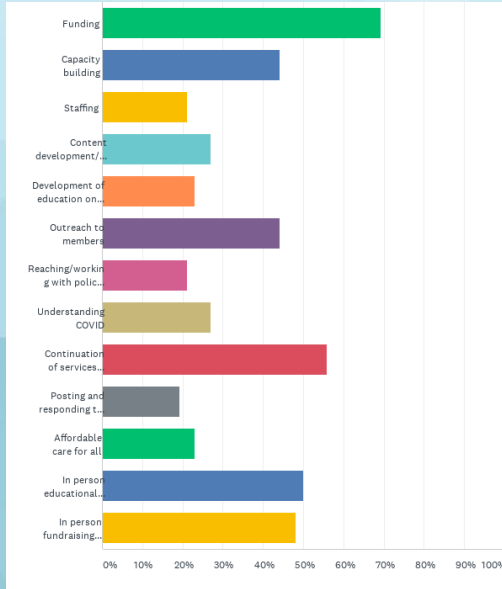


ANSWER CHOICES	RESPONSES	
Online educational materials	68.00%	34
Webinars	54.00%	27
Education of health care professionals about needs of underserved and diverse populations	72.00%	36
Research on ways to change policy on access to care for the underserved	46.00%	23
Training of regional or local leaders in your organization	50.00%	25
Developing policies in your organization to ensure diversity of reach	46.00%	23
Total Respondents: 50		

Answered: 50 Skipped: 2



# What was your organizations main struggle in 2020 because of COVID? (check all that apply)



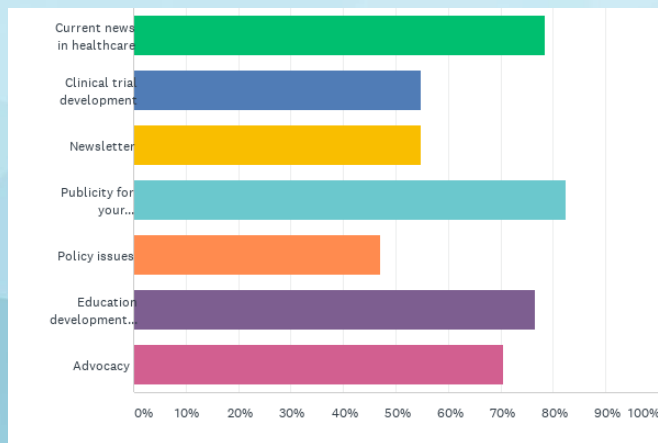
ANSWER CHOICES	RESPONSES	
Funding	69.23%	36
Capacity building	44.23%	23
Staffing	21.15%	11
Content development/education materials	26.92%	14
Development of education on issues important to membership	23.08%	12
Outreach to members	44.23%	23
Reaching/working with policy leaders	21.15%	11
Understanding COVID	26.92%	14
Continuation of services during COVID	55.77%	29
Posting and responding to social media	19.23%	10
Affordable care for all	23.08%	12
In person educational events	50.00%	26
In person fundraising events	48.08%	25
Total Respondents: 52		

Answered: 52 Skipped: 0



# What can World Patients Alliance (WPA) provide your organization to stay informed on global patient issues?

(check all that apply)

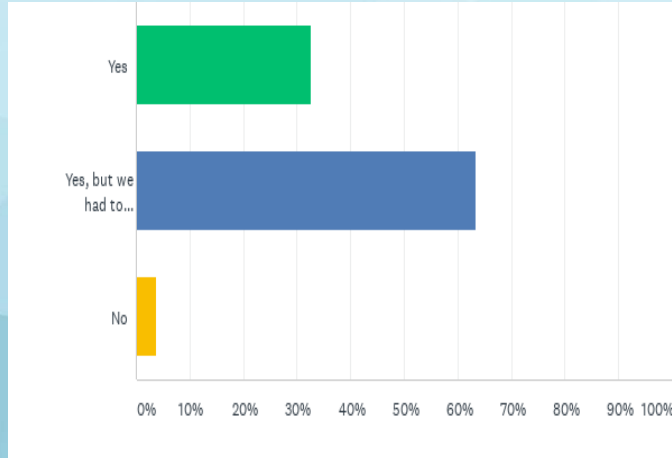


ANSWER CHOICES	RESPONSES	
Current news in healthcare	78.43%	40
Clinical trial development	54.90%	28
Newsletter	54.90%	28
Publicity for your organization	82.35%	42
Policy issues	47.06%	24
Education development (e.g. patient safety, falsified medicines, rare diseases)	76.47%	39
Advocacy	70.59%	36
Total Respondents: 51		

Answered: 51 Skipped: 1



# Have you been able to continue your services to the patients and community during the current COVID-19?

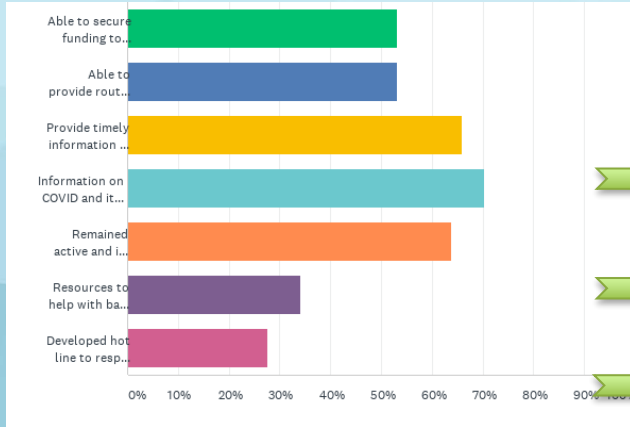


ANSWER CHOICES	RESPONSES	
Yes	32.69%	17
Yes, but we had to significantly change our structure to safely deliver services	63.46%	33
No	3.85%	2
TOTAL		52

Answered: 52 Skipped: 0



# If Yes, please provide brief information on the services and initiatives of your organization provided during the COVID -19 crisis. (check all that apply)



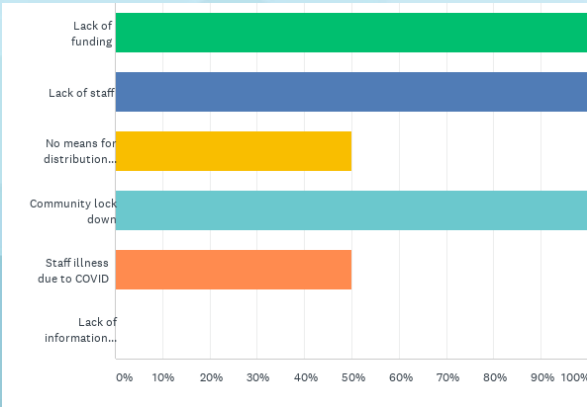
ANSWER CHOICES	RESPONSES	
Able to secure funding to carry out your mission	53.19%	25
Able to provide routine services to patients and families	53.19%	25
Provide timely information to members about what was happening in their community	65.96%	31
Information on COVID and its prevention	70.21%	33
Remained active and in contact with patients and communities through social media	63.83%	30
Resources to help with basic needs i.e. food, shelter, health care	34.04%	16
Developed hot line to respond to member concerns	27.66%	13
Total Respondents: 47		

Answered: 47 Skipped: 5





# If No, please provide brief information on the problems and hurdles that limited your ability to continue your services (check all that apply)

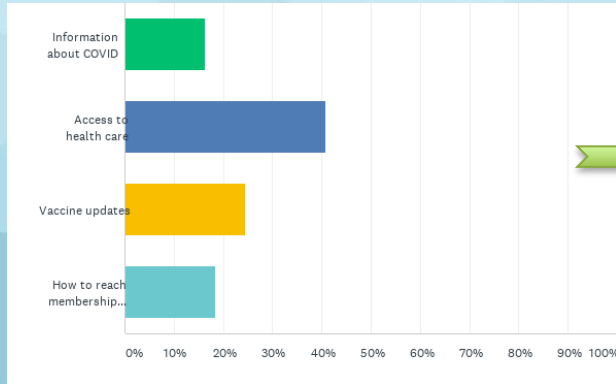


ANSWER CHOICES	RESPONSES	
Lack of funding	100.00%	2
Lack of staff	100.00%	2
No means for distribution of materials/education	50.00%	1
Community lock down	100.00%	2
Staff illness due to COVID	50.00%	1
Lack of information about COVID	0.00%	0
Total Respondents: 2		

Answered: 2 Skipped: 50



# When it comes to COVID -19, what is the greatest need for information you see for those that you serve?



ANSWER CHOICES	RESPONSES	
Information about COVID	16.33%	8
Access to health care	40.82%	20
Vaccine updates	24.49%	12
How to reach membership during lockdown	18.37%	9
TOTAL		49

Answered: 49 Skipped: 3