

# Expanding Horizons in Patient Advocacy

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**A common perception of what patient organisations are...**



**...and how they operate...**





## This is today's reality of patient advocacy



Provide  
**patient support**



Shape  
**health & regulatory  
policy**



Support and shape  
**research**



## Patient advocacy operates on 3 “horizontal” and 3 “vertical” levels



### Patient support

Inform, support, navigate



### Health policy

Influence health policy,  
patient care



### Research

Contribute in partnership with  
clinicians, networks and industry

|                            |  |
|----------------------------|--|
| <b>Local/<br/>national</b> | <b>Information and support, national policy, awareness, campaigning, access (reimbursement)</b><br>Largest and (locally) most influential organisations operate within the national level.                           |
| <b>European</b>            | <b>EU policy / frameworks / systems, research collaboration, access (systems, inequalities), evidence generation, inequalities</b><br>Strengthen, share, disseminate, amplify work of national member organisations. |
| <b>Global</b>              | <b>Some European-based organisations are Europe-resident global coalitions</b><br>or members of global umbrellas or alliances  |

# Precedents in changing medicine through activism



## Patient activism from 1968



# The European example



Substantial obstacles in EU

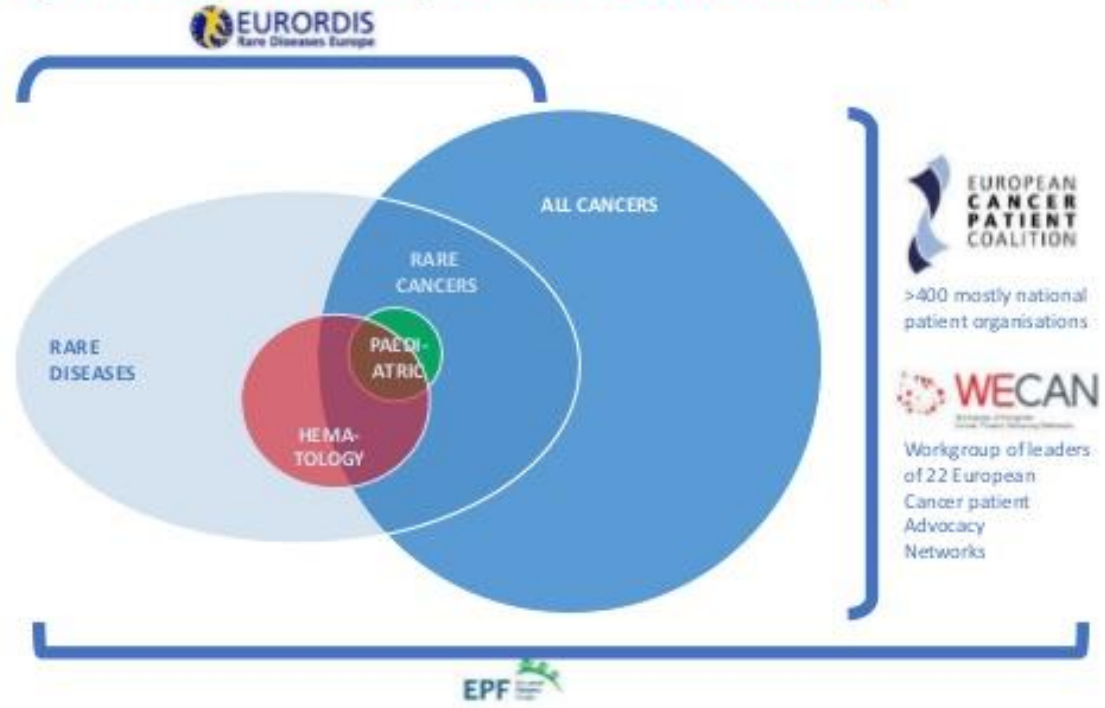
## Average Languages Spoken By EU Members



- 24 languages + 60 minority languages
- 512 M population
- >27 different health care systems



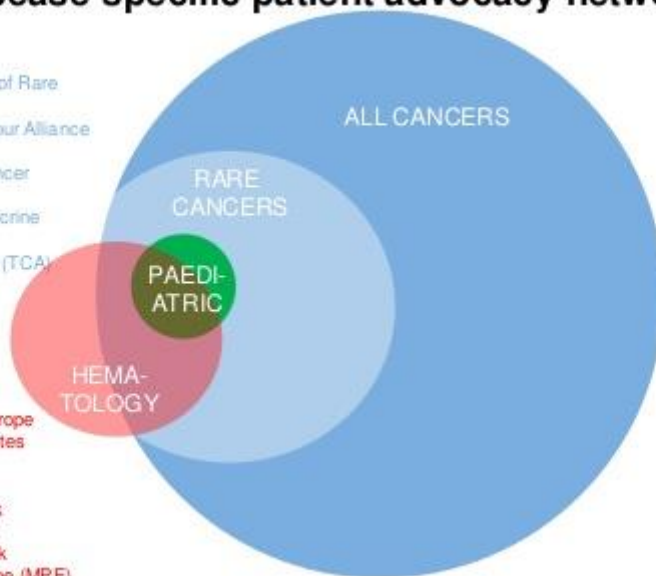
# European patient advocacy community (cancer, rare diseases, chronic diseases)



## European disease-specific patient advocacy networks

### RARE CANCERS:

- European Organisation of Rare Diseases (EURODIS)
- International Brain Tumour Alliance (IBTA)
- International Kidney Cancer Coalition (IKCC)
- International Neuroendocrine Cancer Alliance (INCA)
- Thyroid Cancer Alliance (TCA)
- Sarcoma Patient Advocates European Network (SPAEN)
- Chordoma Foundation
- European Morbus Waldenström Network
- Lymphoma Coalition Europe
- Acute Leukemia Advocates Network
- MDS Alliance
- CML Advocates Network
- CLL Advocates Network
- MPN Advocates Network
- Myeloma Patients Europe (MPE)
- Childhood Cancer International (CCI)



### COMMON CANCERS:

- European Men Health Forum (EMHF)
- European Network of Gynaecological Cancer Advocacy Groups (ENGAGE)
- Europa Colon
- Europa Donna
- Europa Uomo
- Lung Cancer Europe (LuCE)
- Melanoma Patients Network Europe (MPNE)
- Pancreatic Cancer Europe Network



## Key activities of the umbrella organisations

- **Developing patient information** – most provide at least some basic disease information, but some more than others. Often this is a domain/specialism of the national organisations working in their field.
- **Sharing best practices/facilitating networking** – all do this.
- **Provide a knowledge base/sharing educational and research resources** – most do this in varying degrees.
- **Advocacy resources/toolkits** – most do this.
- **Involvement in research/regulatory projects, guideline/clinical practice development** – some do this more than others.
- **Global/regional surveys** – most carry out some form of patient experience research.
- **Healthcare professional education programmes** – a small number provide such learning.
- **Awareness raising/public campaigns** – most/all involved in this area of work.

# Global Kidney Cancer Summit



Meeting of patient advocacy affiliate groups

Simultaneous local professional meeting through professional societies, with overlapping sessions

Exposing HCPs to advocates



# Evidence-based advocacy



**Data, not just  
opinions:**

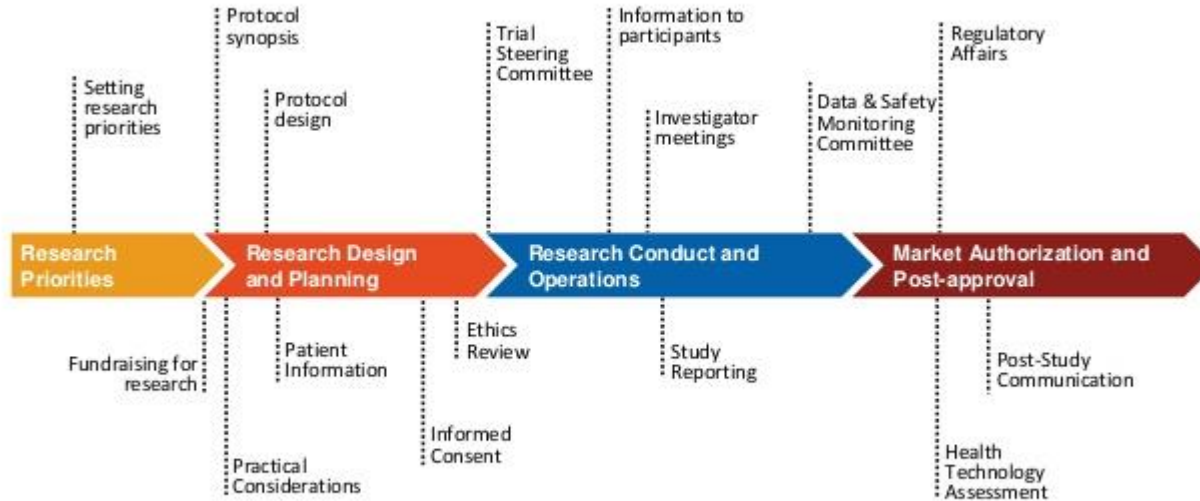
**Evidence-based  
advocacy**



# Expectations for representation



## Patient involvement in clinical trials in practice



# Expert advocates: how to grow them



## Expert patients for patient involvement in R&D: European Patients' Academy

- 14-month expert training course for patient advocates on medicines R&D , 98 graduates from 58 disease areas
- 500.000 individual users of EUPATI Toolbox on eupati.eu



1. Discovery of Medicines
2. Pre-clinical Development
3. Clinical Development
4. Clinical Trials
5. Regulatory Affairs, Drug Safety, Pharmacovigilance
6. Health Technology Assessment

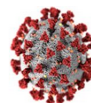




- Informal workgroup and “think tank” of leaders of 20 pan-European cancer patient umbrella organisations, initiated in 2015
- Share workload for meetings, coordinate our representation in committees
- Form a “think tank” to develop ideas on how to cross bridges between advocacy
- Share resources and concepts on joint patient-driven evidence
  
- First activities:
  - Reasonable Agreements on interaction of patients advocates with industry
  - Fair Market Value project
  - Coordinated approach to education of advocates
  - Positioning towards Stakeholder Engagement
  - Coordination of contribution to research in cancer advocacy

## COVID-19 AND CANCER

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pandemic.

The COVID-19 epidemic is of concern to many cancer patients. Many of the European cancer patient organisations are providing information about COVID-19 and specific recommendations to their patient community. See the [COVID-19 Resources of WECAN members](#)

See also our [Virtual Meeting Resource Center](#) how to set up virtual meetings, conferences and AGMs during the



# More Patient Advocacy in Europe



ESMO > For patients

## ESMO PATIENT ADVOCACY TRACK

VIRTUAL 2020 ESMO congress



SCIENCE: 19-21 SEPTEMBER 2020  
EDUCATION: 16-18 OCTOBER 2020

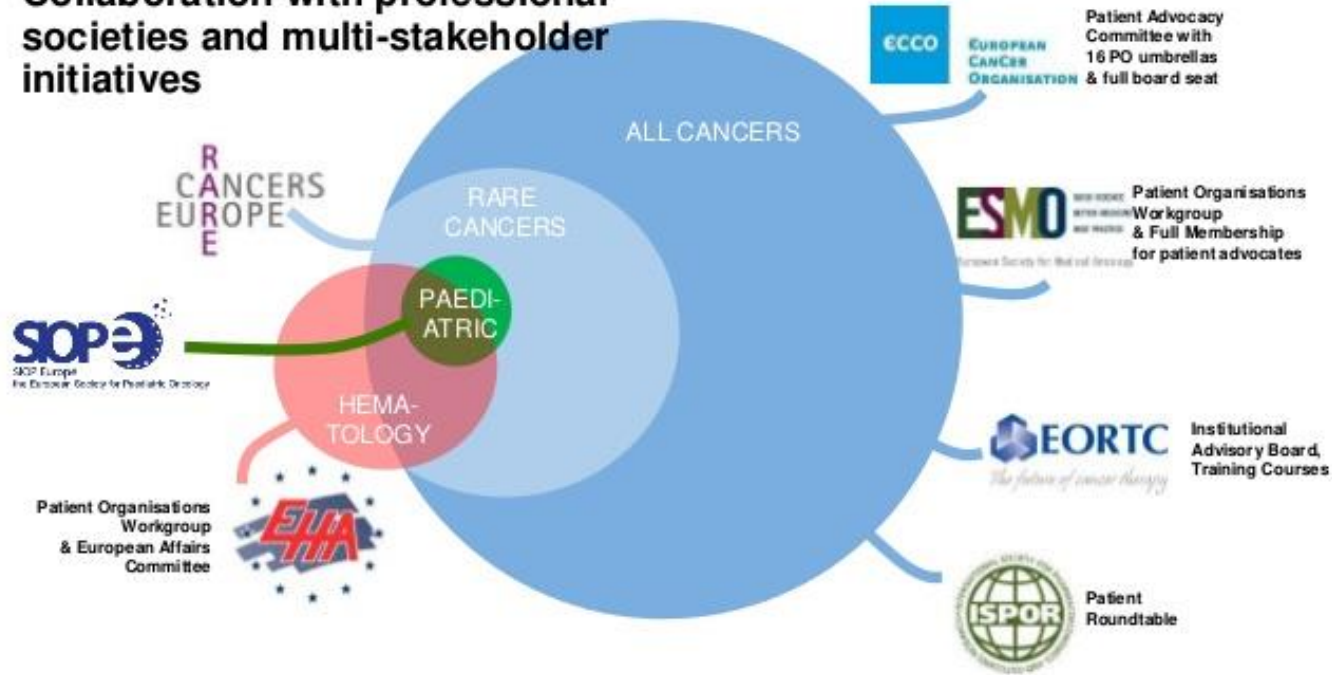
**Patient advocacy allows ESMO to support and promote equal access to optimal cancer treatment and care**

Rare Cancers Europe > Events

## RCE-ESMO-ESO TRAINING COURSE FOR RARE CANCER PATIENT ADVOCATES 2021 ONLINE TRAINING



## Collaboration with professional societies and multi-stakeholder initiatives



## Involvement in public private partnerships and industry initiatives

- Innovative Medicines Initiative
  - EUPATI (Coordination)
  - Big Data: HARMONY, (BIG4)
  - GetReal
  - PARADIGM
  - IMI Strategic Governance Group Oncology
  
- EFPIA Patient Think Tank
  
- Patient involvement in Investigator Meetings, Trial Protocol Review, Data Safety Monitoring Boards





# COVID-19: Impact on Cancer Patient Organisations Worldwide in 2020



A joint initiative by



>750 organisations  
>14 million cancer patients

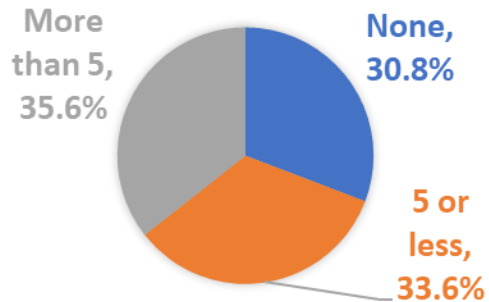


# Survey of 157 organisations



## Pre-COVID-19

### PAID STAFF DECEMBER 2019

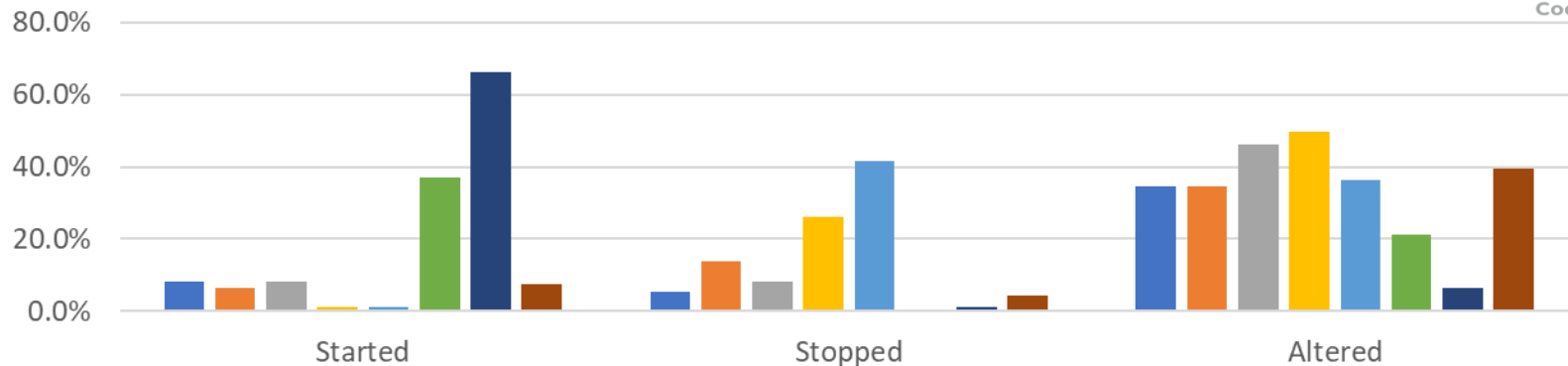


Average number of volunteers per organisation: **369**

## December 2020

- For those organisations with staff, average numbers of full-time equivalent staff fell from 21.2 to 17.4 – a drop of **17.9%**
- The average number of volunteers per organisation fell from 369 to 107 – a drop of **70%**
- The majority are either fully or mainly home-based since the beginning of the pandemic
- 2 organisations have had to close permanently and 13 have had to pause services temporarily due to local restrictions

# Changes to services

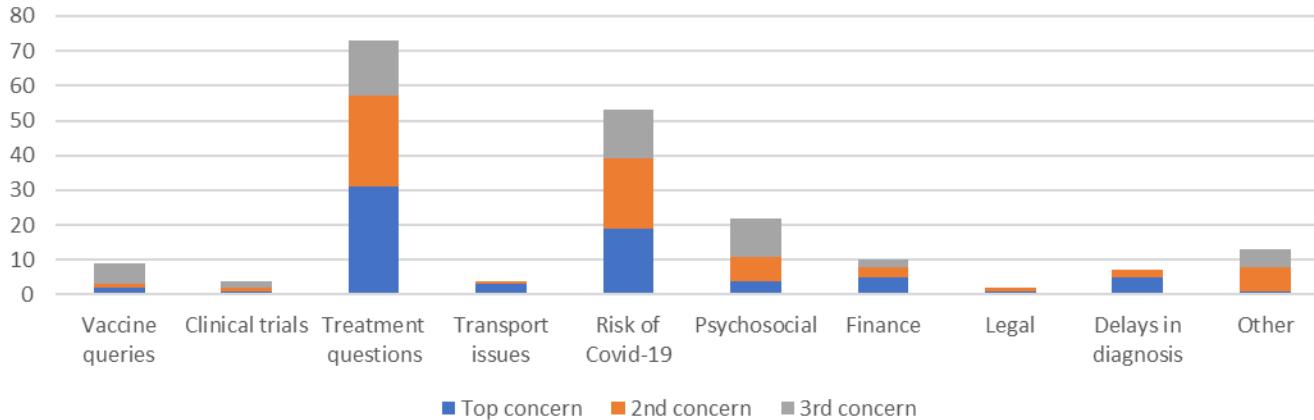


- Symptom awareness
- Health professional education
- Patient/caregiver education
- Annual meeting for patients/health professionals
- Face to face support services
- Online support services
- COVID-19 information for patients
- Influencing/lobbying

# Helplines and emails



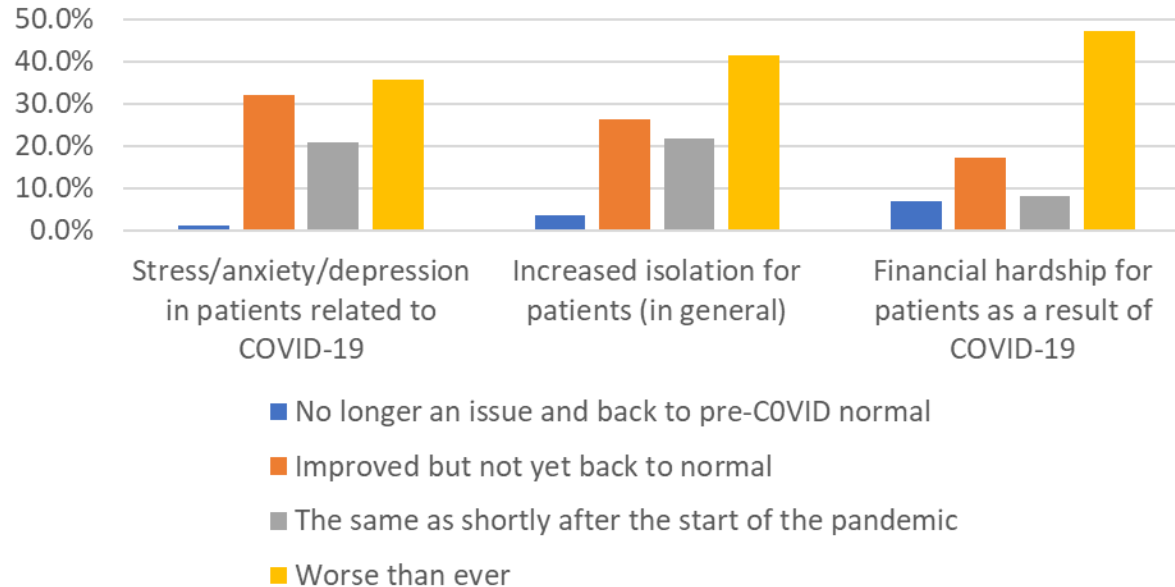
Most common queries raised (n=65)



Overall 8 in 10 run a helpline or take email enquiries.

Of these, 56.4% saw an increase in calls – with the average increase of 46%

# Impact on patients



# Can Patient Organisations weather the funding storm?

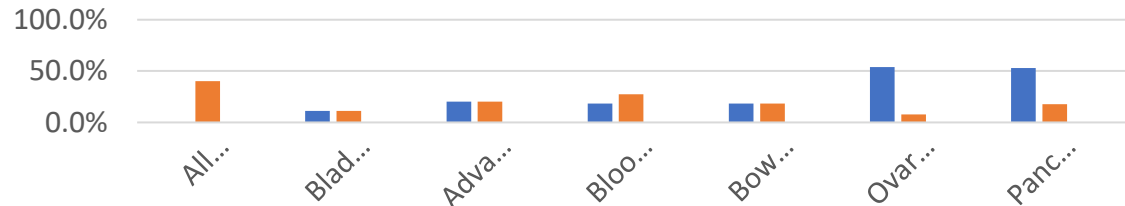


## Predictions

- 79% of those who raise funds were predicting a fall in income over the year
- Average expected fall was 46%
- Just 5% did not expect their funds to fall

## Actual financial impact over 2020

- 67.4% experienced falls in income, with an average fall of 48%
- 21 organisations from 18 mixed countries experienced falls of more than 50%. Ovarian and pancreatic groups seem to have been hit hardest.

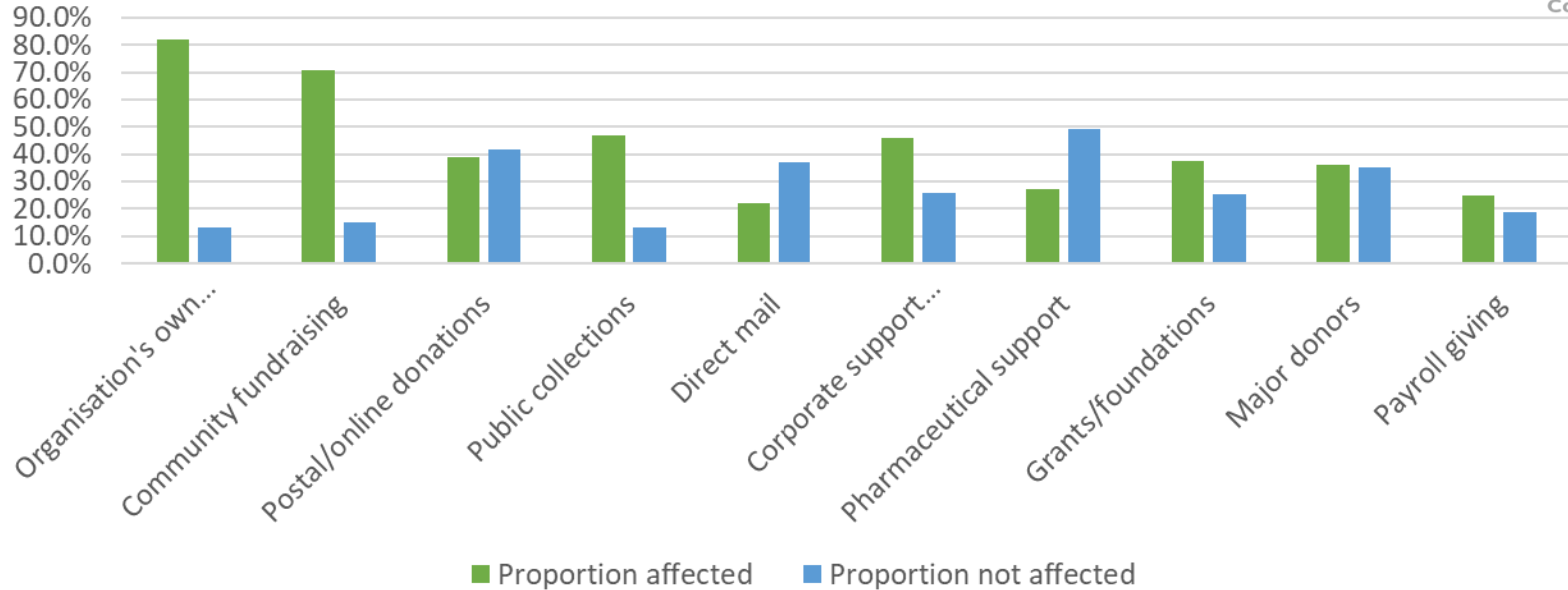


■ Proportion of organisations with falls in income of more than 50%, by cancer type

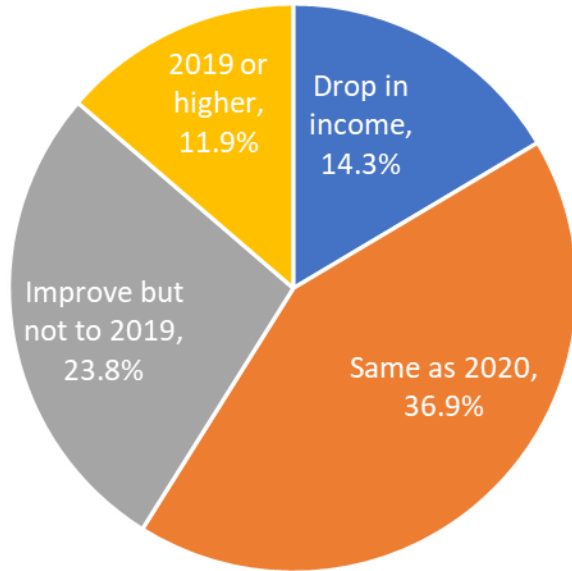
■ Proportion of organisations with no falls in income, by cancer type



# All types of fundraising affected



# Income predictions for 2021



One in ten say their viability is currently threatened

A further third say their future viability is uncertain

# Our message to you all



Cancer care cannot and will not wait for COVID-19 to pass, if it ever will. You provide essential services, filling important gaps left by health services.

You are not alone. We will champion your cause. Ask for funds. Network and collaborate as much as you can. Try to take the positives forward.

You cannot look after others if you do not look after yourselves.