



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

EMA Human Scientific Committees' Working Parties with Patients' and Consumers' Organisations (PCWP) and Healthcare Professionals' Organisations (HCPWP)

Joint Meeting: Workshop on Social Media - 19 Sep 2016

## **2. Medicines communication using social media – how do we get it right?**

Findings from the PCWP/HCPWP  
Topic Group on Social Media

Professor Donald RJ Singer  
On behalf of the Group

@EACPT  
@HealthMed

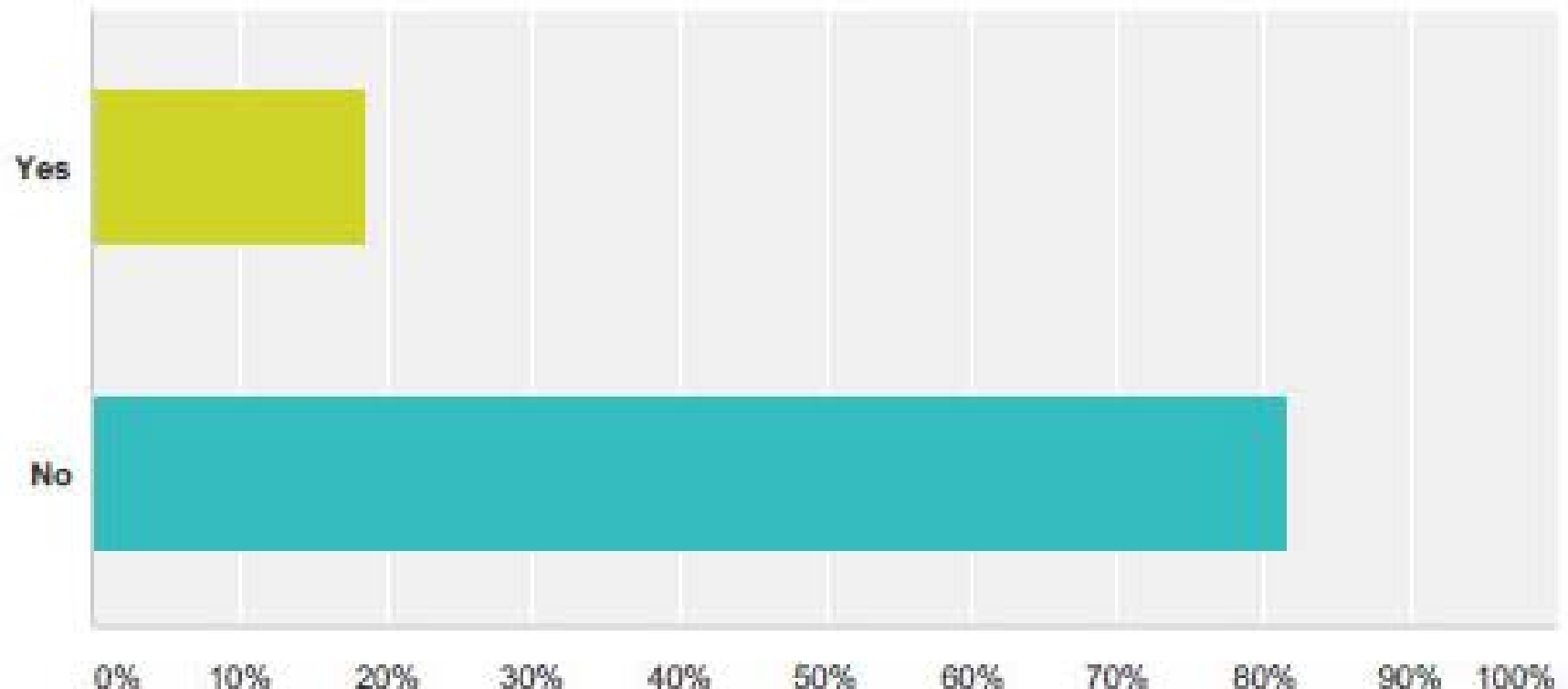


# 2015 EMA survey on use of social media

- Aim: map current practices and expectations in relation to the use of social media
- Sent to all 65 EMA eligible organisations
- Forward to relevant person in organisation
- One response/organisation
- 28 of 65 replies
  - 11 patients/carers; 12 HCP; 4 consumers)

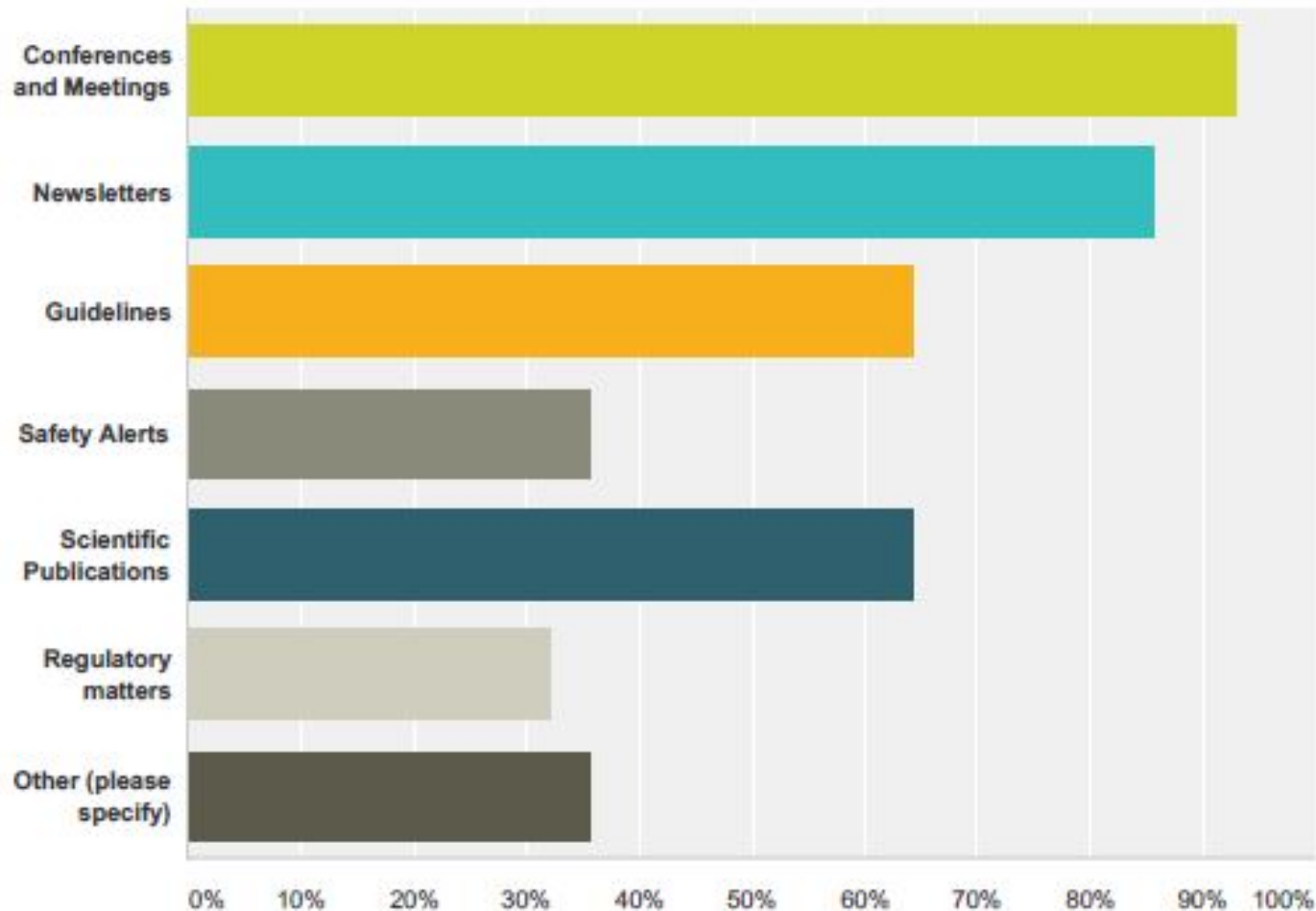
## Q4 Does your organisation have a formal social media communications strategy?

Answered: 27 Skipped: 1



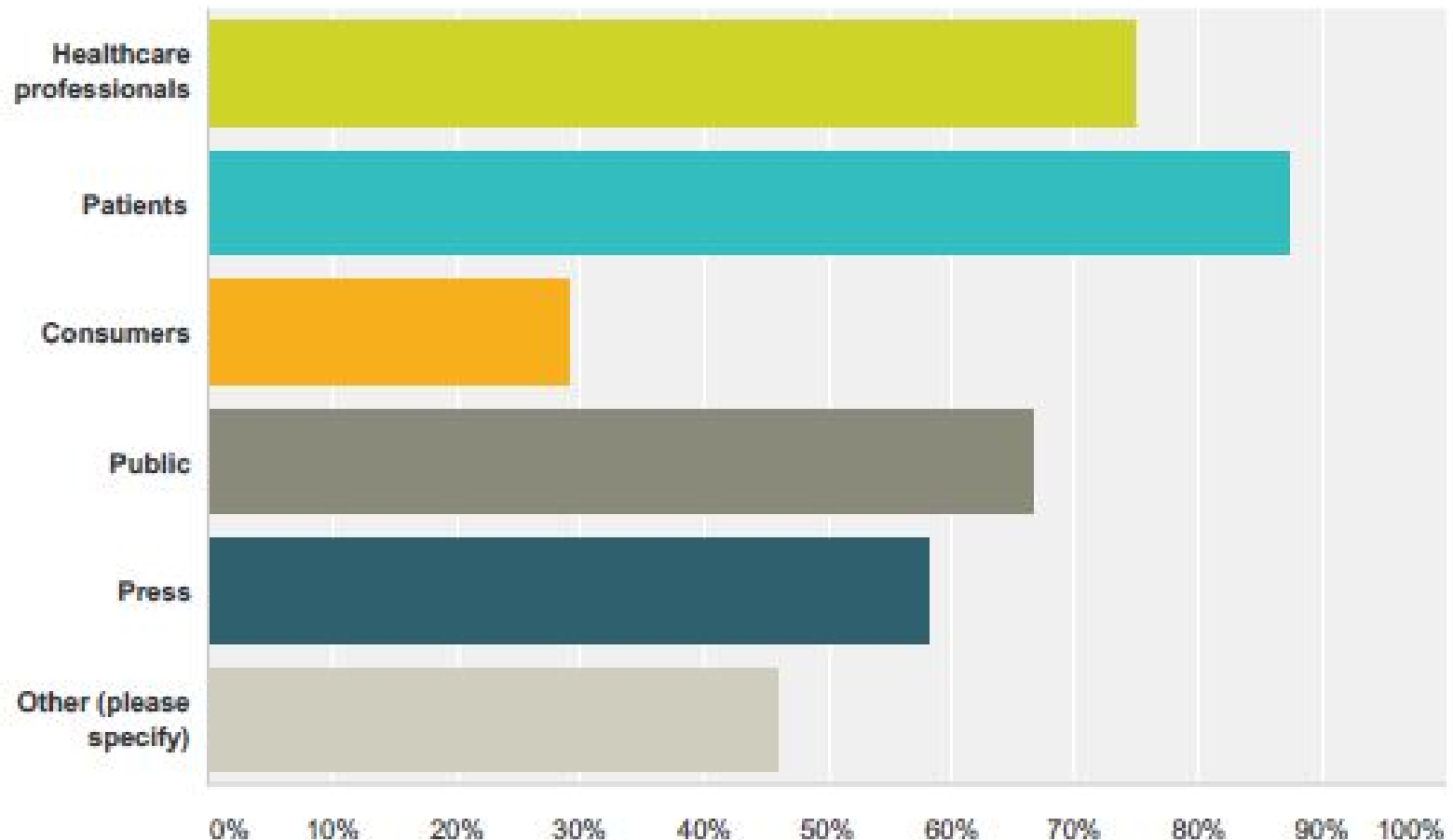
**Q5 Would you or do you currently use social media to communicate on the categories below? (please select all that apply)**

Answered: 28 Skipped: 0



**Q6 Who is your organisation targeting by communication through social media?  
(please select all that apply)**

Answered: 24 Skipped: 4



# 2016 SWOT survey re Social Media

- Survey of
  - stakeholder sectors (including representatives of PCWP and HCPWP)
  - other key target groups/organisations
- Members of Topic Group to conduct pilot SWOT analysis
- Survey of 65 PCWP and HCPWP member organisations over summer of 2016
- A – Active users of social media (28)
- B – Not actively using social media (3)

# Organisations actively using Social Media

- AGE Platform Europe
- ALGEA Research Project
- Alzheimer Europe
- Associação Portuguesa de Doentes da Próstata
- Caritas Malta Epilepsy Association
- EACPT
- EAN
- ECPC-European Cancer Patient Coalition
- EFCNI
- EULAR
- European Association of Hospital Pharmacists
- European Association of Urology
- European Cancer Patient Coalition
- European Federation of Allergy and Airways Diseases Patients' Associations
- European Federation of Neurological Associations
- European Forum for Primary Care
- European Heart Network
- European Parkinson's Disease Association
- European Patients' Forum
- European Society of Endocrinology
- Fabry International Network
- FAKS - foreningen af kroniske Smertepatienter (Eng, The Danish Association of chronic pain patients)
- Health Care Without Harm Europe
- Herpes Viruses Association
- IDF Europe
- Liga Reumatológica Galega
- Norwegian Prostate Cancer Association
- Svenska Distriktsläkarföreningen

# Strengths for your organisation

## Direct, fast contact with target audience

Allow users to express their thoughts about activities of the organization

Immediate contact among members and organization

Online participation in activities of members

Contribute our expertise

Reach new people interested in our activities

Health is social

Making conversations public on political issues (Twitter) at the same level than anything else

Provide quick information involving limited resources

All apply if someone is responsible and has time allocated each day as part of their role to engage with the social media challenges

Find participants from the general community to participate in one of ours' ongoing research projects

## No strengths

informal exchange with individuals from network as those are often online

## Strong tool to mobilize like-minded

stakeholders and to target high level institutes with clear messages

Promoting activities

Immediate access to large hospital pharmacy audience and stakeholders with interest in hospital pharmacy.

Fast conduit for news relevant to hospital pharmacy.



# Weaknesses for the organisation (n=12)

People may get frustrated by messages which are not relevant

Social media in healthcare need a specific set of skills and professionalism, not easily available

Need of dedicated resources to achieve results

So much noise in big patient events, publicity, need to pay to be referred... monitoring is very superficial and will not yield meaningful insights (or at least not sufficient data to progress certain actions)

Again, as before, allowing someone to have the time to devote to the social media is a challenge with limited staffing

Target visitors are not touched. Too much generic and hard to maintain

As the information flow needs to be high it's difficult ensure the opinions of the administrators on social media are in tune with the ethics and opinions of the organisation.

It requires a deep knowledge of who is who, of the sector in general, and continuous sector news update. This means investment in human resources. If specific results are sought then, better do it professionally

Followers are found easier for national/ regional than supranational organisations

Likes don't means action

Not all professionals use social media. The focus on brevity of messaging can compromise nuance (e.g. journal articles).

# Opportunities for the organisation (n=10)

None/Almost none

Connect to our members, supporters, sponsors

Share our interests and learn about those of our members

Establish online personal contacts with individual members

As many people living with chronic pain have a difficult time transporting themselves and our organization don't have the resources to be present all over the country, social media presents they opportunity for us to reach and communicate with this patient group. Post news the moment they happen, use it a lot for live tweeting from events to spread the word, awareness and information (education of public)

A way for people with a functional loss to be part of some sort of social network. As many pain patients lose their functional abilities they also lose their social network, as their surroundings often have a hard time understanding their pain and respecting their functional loss. Becoming part of a social network with people who understands you and where are you can share experiences and knowledge is therefore important for many patients quality-of-life.

Connecting with individual hospital pharmacists across a wide number of countries, including beyond the borders of the EU and Europe. Connecting with hospital pharmacist and pharmacist associations in other parts of the globe.

Receiving feedback on advocacy activities.

# Threats/challenges for organisation (n=9)

- Repetition of messages
- Privacy of messages
- Constant need of ethical and professional character of posts to avoid abuse
- **Public harassment from lobbies**
- To do it efficiently **you need an insightful person** to handle your accounts.
- Risk to become superficial and to look more for likes than for content
- Identity theft
- **Reputational risk from adverse communication incidents** e.g. misinterpretation

## Facebook

- When using social media such as Facebook, important to differentiate between Facebook page and Facebook group.
- On our official Facebook page we have control of approving the post from users. However, in our group the users can freely express their opinions. Nevertheless, we have the ability to discard posts if we feel they are inappropriate.
- **Very time-consuming** need to read all posts + identify the inappropriate.

# Case studies – 1 - process

1. Social media from start considered integral part of event
2. Obtained twitter/FB handles & addresses of blogs/sites and speakers/chairs
3. Informed all participants about dedicated hashtag of event and invited them to share their thoughts/comments using #
4. Posted well in advance of the event using the dedicated #
5. Registered event #
6. Answered/acknowledged all participants in online discussion via #
7. Included social media feeds into event webpage
8. Wrote/quoted social media comments in event's report
9. Published results of event including comments on social media
10. Continued online contacts with users of event's # after its end

# Case studies – 2 – One Day

- Recently, as part of our Under the Umbrella campaign to raise awareness of brain disorders, we asked people to take a photo under an umbrella and share on social media to mark World Brain Day - July 22nd.
- This was a huge success. The campaign is running for one year - from March 2016 to March 2017.
- However, we learned that by focusing our limited resources on one day - we had more success.
- We also saw that by combining the social media work with offline events and an established awareness campaign/day - then the engagement is higher.
- We also saw that unless you put in work beforehand, then it won't take off. You can't just expect people to engage on the day, unless they are informed in advance via social media or other channels. We will replicate this approach in future, rather than a prolonged online campaign. It is also worth recognising that although users are spread across various social media channels, the use of the hashtag means that all content can be more easily aggregated and shared.

# Case study – 3 - Lobbying

- Attending several WHO or EU meetings from a distance being **able to influence the average opinion** in such meetings with no big costs and low HR impact.
- By using Twitter in such a case we could also mobilize our members and even connect meetings at different locations in Europe around one specific topic/opinion.
- Unique opportunity which **enhances impact of lobby** actions of rather small networks like ours, not supported by the industry financial sponsoring.
- Provides **a bit more fair level playground** where in the past it was completely impossible to counteract industry lobby as their presence in Brussels or London is overwhelming.

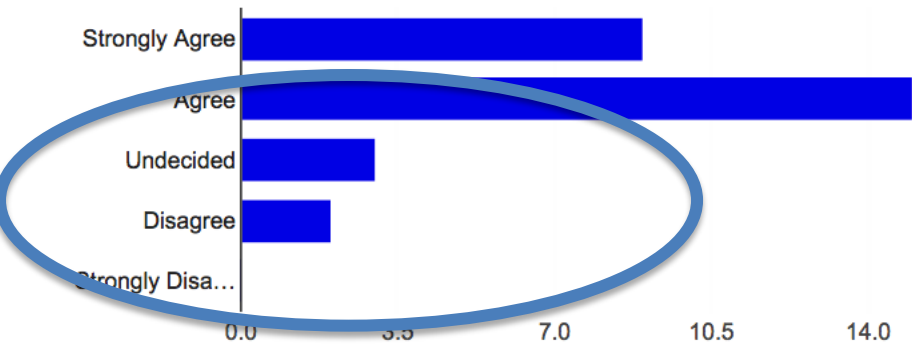
# What could have gone better?

- We should be able to use better the opportunity to engage with members and stakeholders via webinars etc. Needs investment of time and energy. Made us clear that **we need to invest in a younger generation** within our network to keep pace with the fast ongoing developments.
- Directed a social media campaign around Diabetes Week in UK but with all content delivered by the association. **This did not engage with our audiences at all as it was seen as being 'preachy' and 'we know best'. Subsequent campaigns relied on online community to provide content and direction - sharing their own stories etc - and these have been much better received**

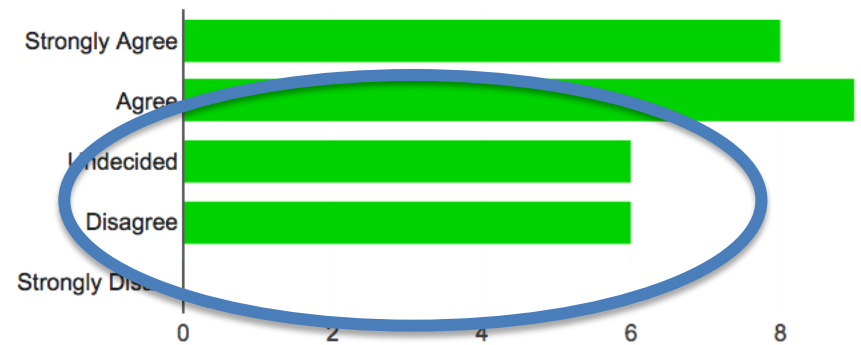
# Strengths of social media



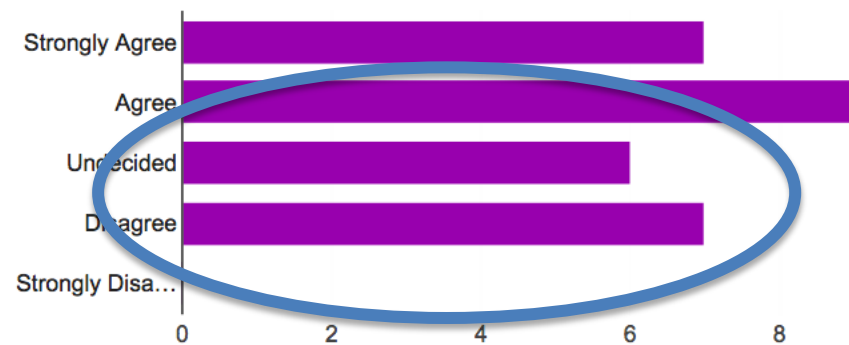
Let people take part in live events/workshops  
they would otherwise be unable to access



General

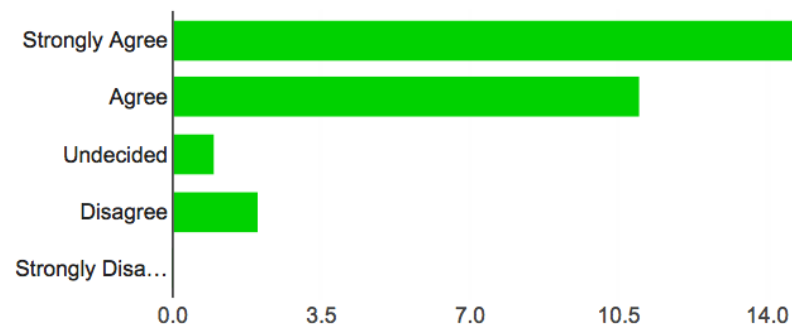


Organisation

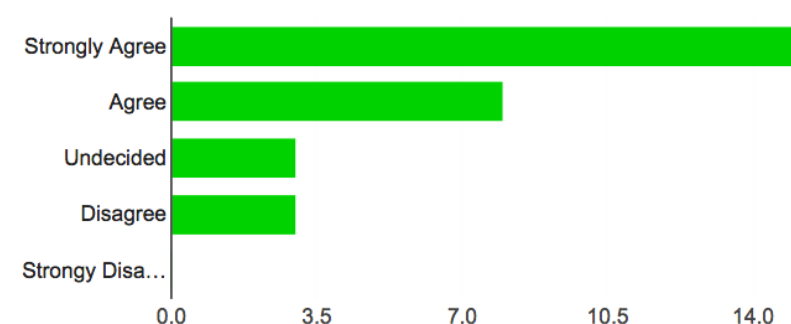


Let people watch live events/workshops they  
would otherwise be unable to access

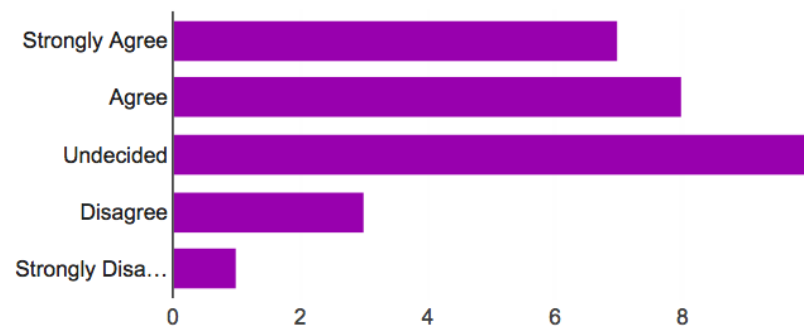
**Instant connection to live events/happenings [1a. What are**



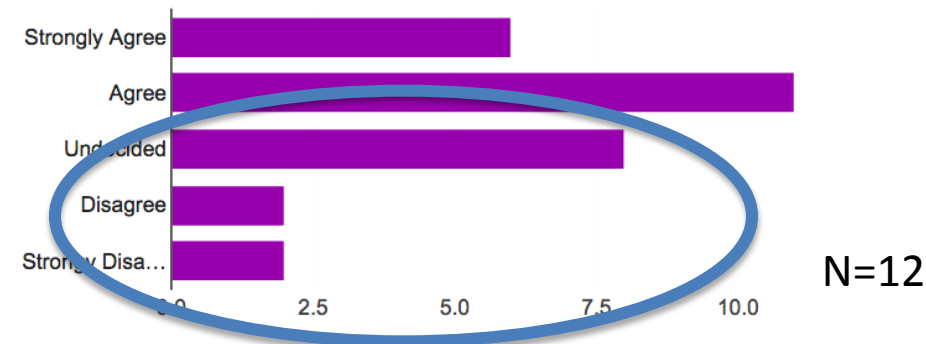
**Instant connection to live events/happenings [2a. What are t**



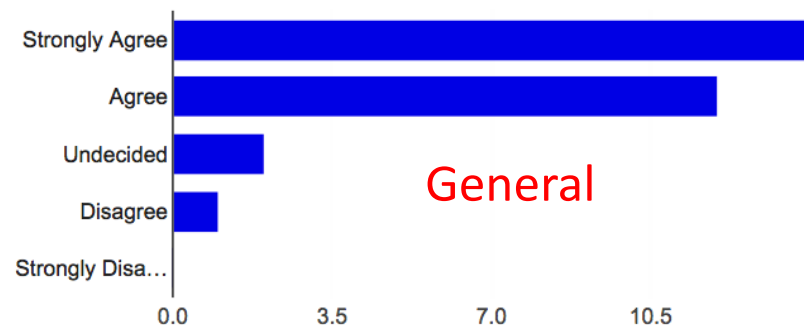
**Monitoring success of campaigns [1a. What are the strengt**



**Monitoring success of campaigns [2a. What are the strength**

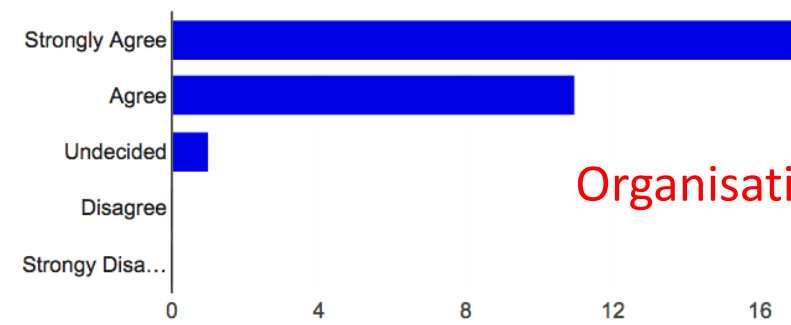


**Promoting activities [1a. What are the strengths of social m**



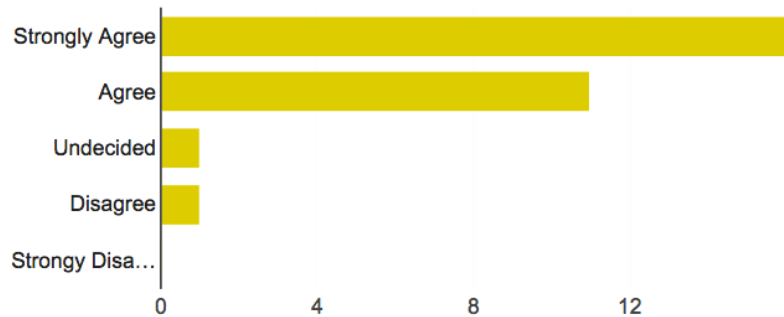
General

**Promoting activities [2a. What are the strengths of social med**

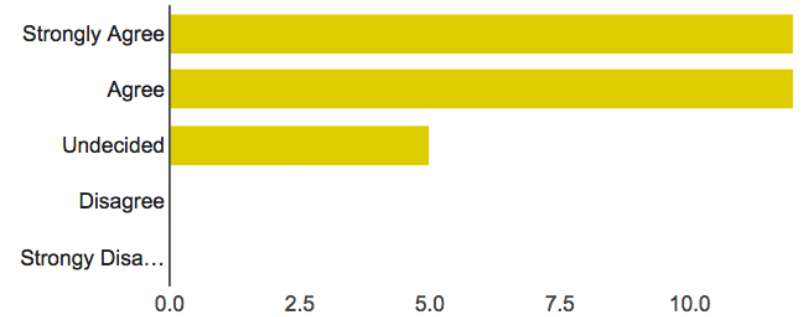


Organisation

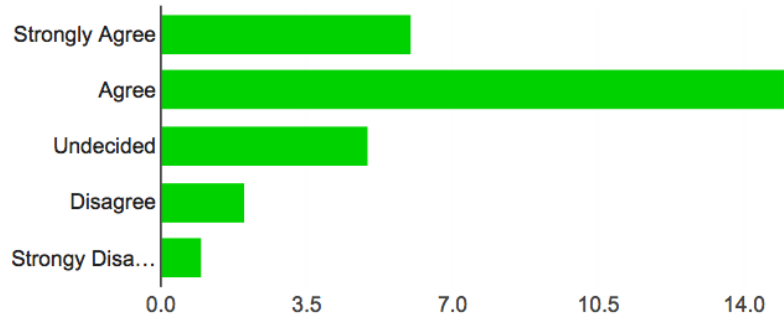
**Quick flow of information [2a. What are the strengths of so**



**Bigger audience [2a. What are the strengths of social media a**



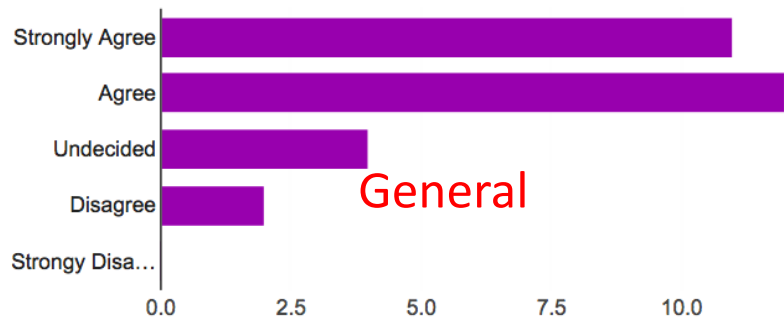
**Raising awareness faced by people living with specific hea**



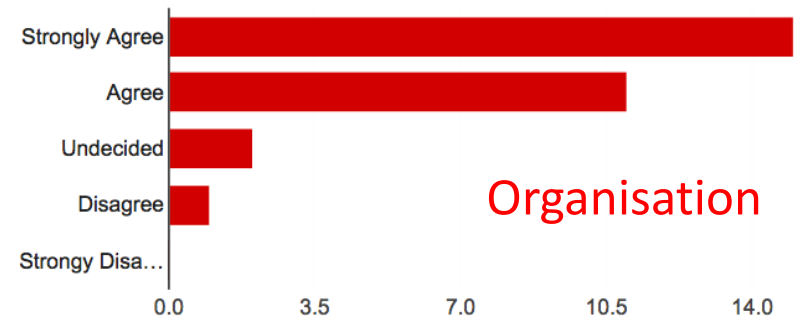
**Tool for organising a Health Awareness Day [2a. What are t**



**Sharing of points of view [2a. What are the strengths of soc**

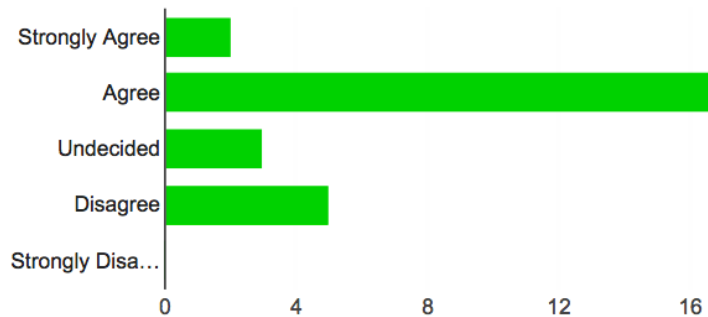


**Promoting involvement of organisation in specific projects**

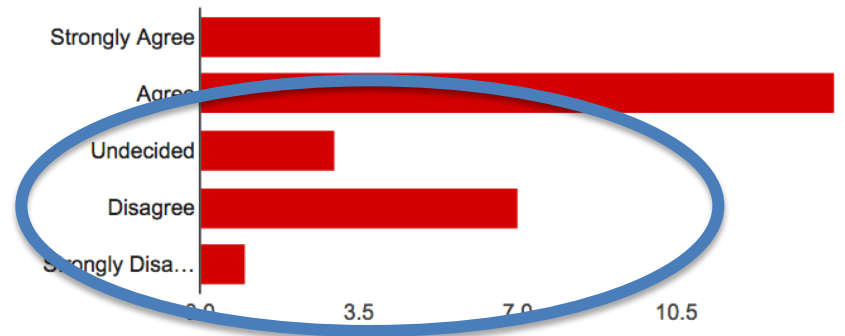


# Weaknesses of social media

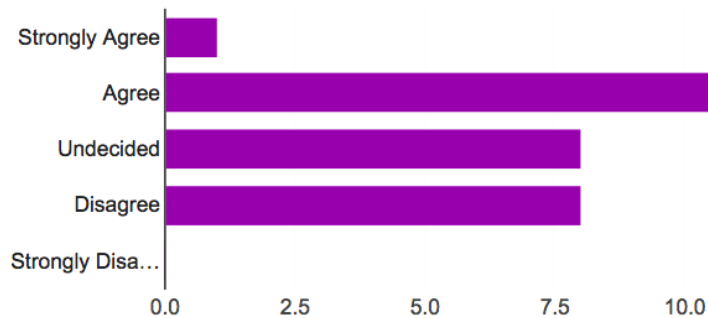
**Limited depth of messaging [3a. What are the weaknesses**



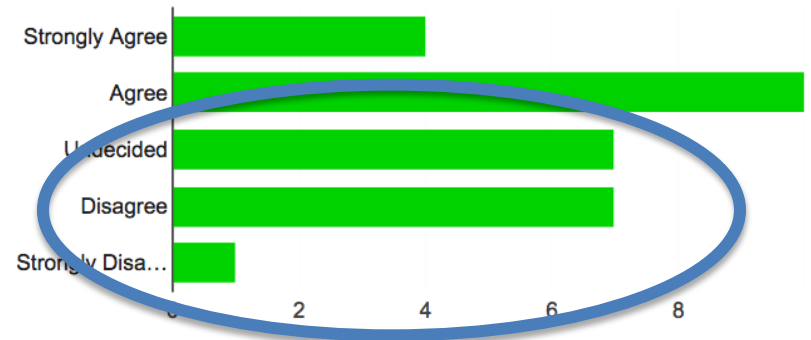
**Limited depth of messaging [4a. What are the weaknesses o**



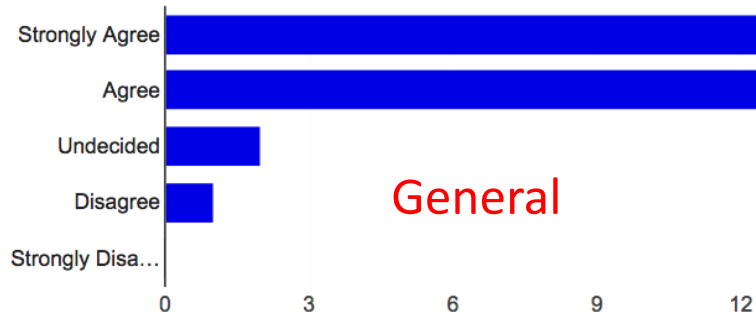
**Low response rate [3a. What are the weaknesses of social**



**Low response rate [4a. What are the weaknesses of socia**

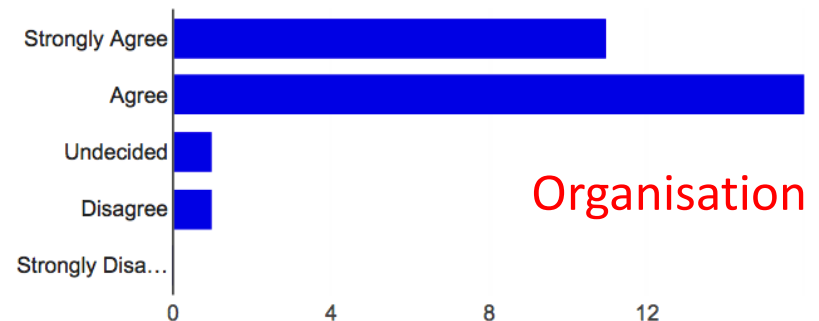


**Need to keep posting new content to keep channels effect**



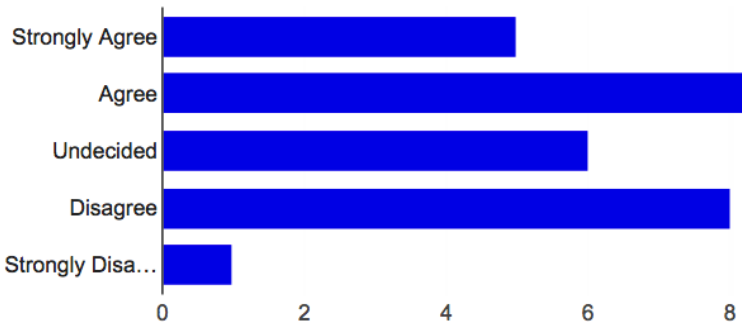
General

**Need to keep posting new content to keep channels effective [**

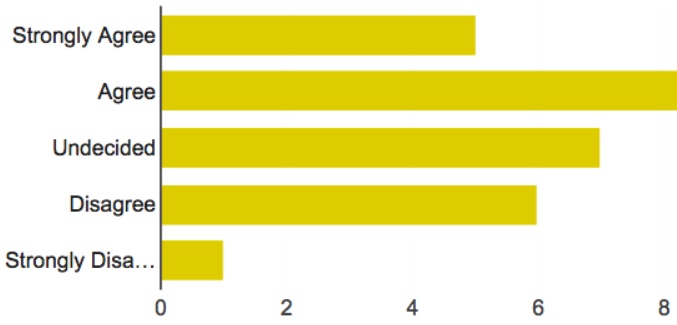


Organisation

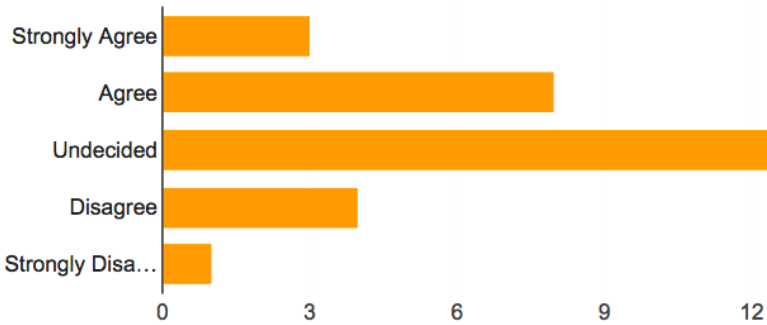
**Cost of international organisation using multiple languages [4a. What are the weaknesses of internationalisation?]**



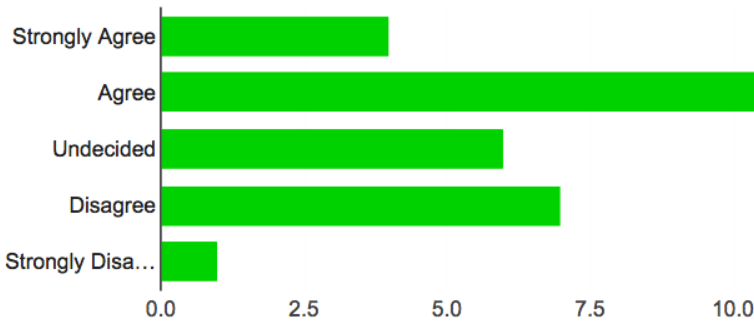
**Different educational attainment of target audiences [4a. What are the weaknesses of internationalisation?]**



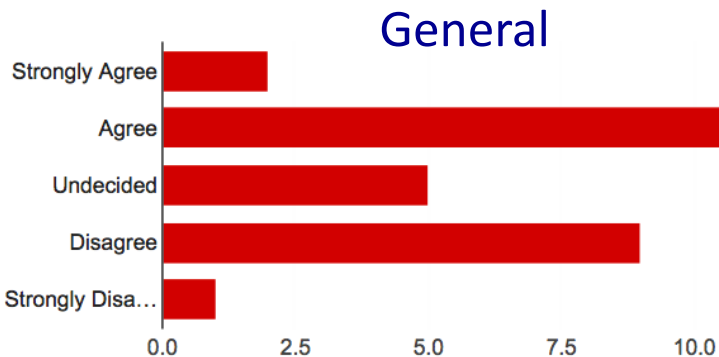
**Current low uptake of livestream events [4a. What are the weaknesses of internationalisation?]**



**Different level of IT development of target countries [4a. What are the weaknesses of internationalisation?]**

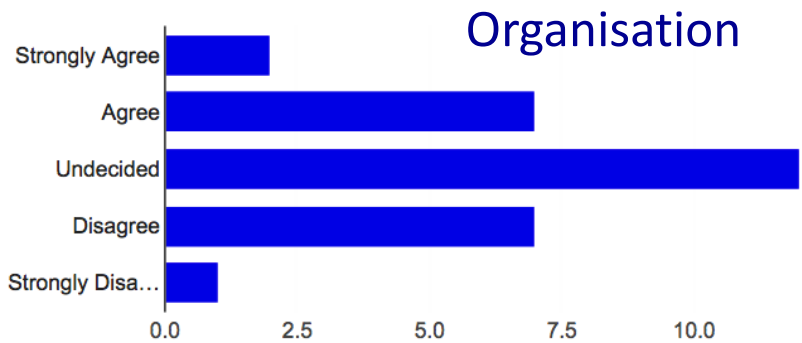


**Differences in cultural background of audience [4a. What are the weaknesses of internationalisation?]**



General

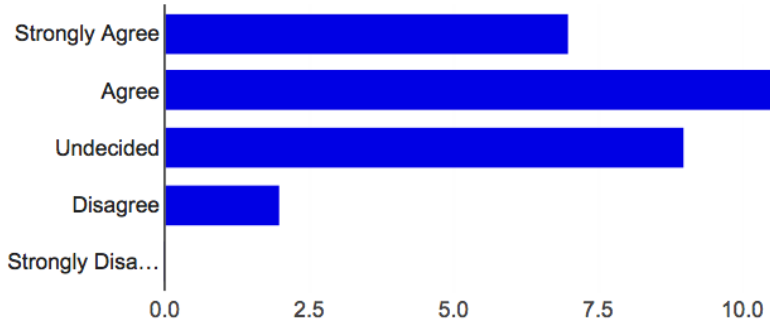
**High cost of livestream events [4a. What are the weaknesses of internationalisation?]**



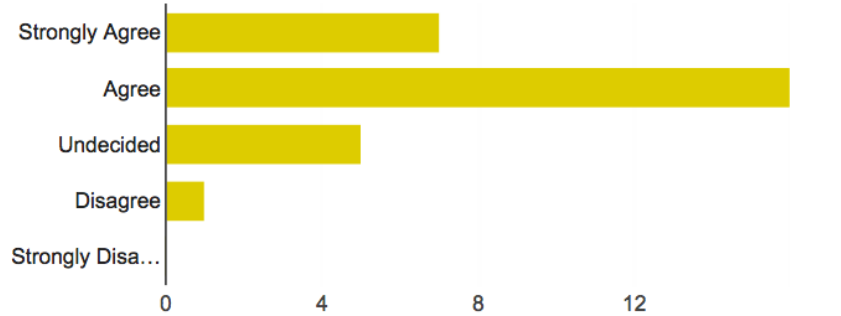
Organisation

Opportunities from social media

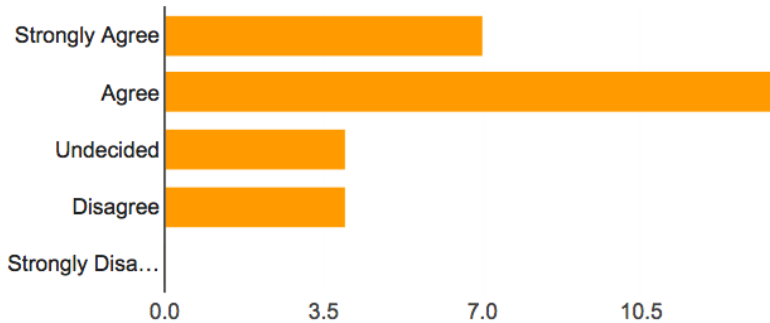
Connecting to isolated patients [5a. What are the opportuni



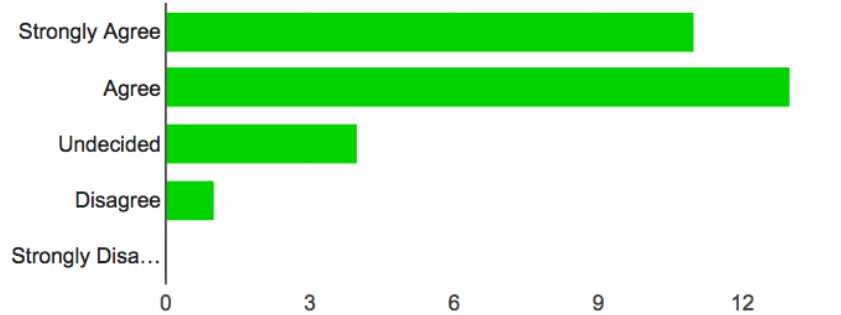
Feeling connected to organisations [5a. What are the oppor



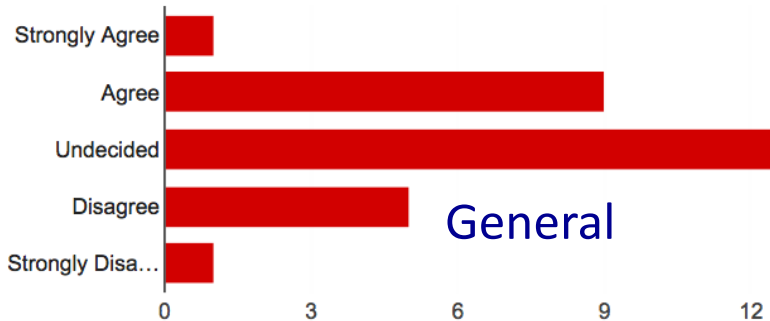
Connecting to people otherwise difficult to contact [5a. Wh



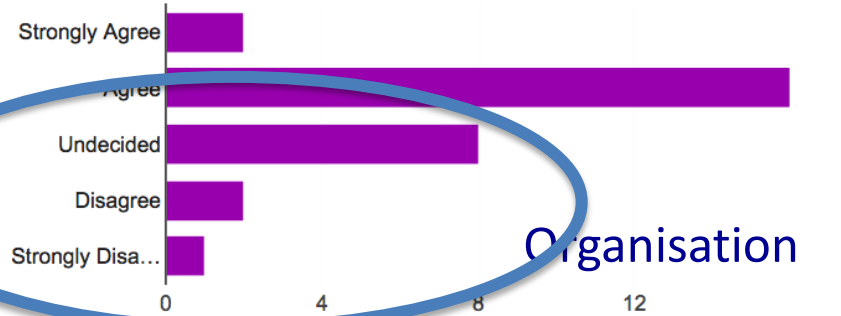
Feeling connected to people [5a. What are the opportunities



Connecting to undiagnosed patients [5a. What are the oppi



Help patient groups follow best practice [5a. What are the o]



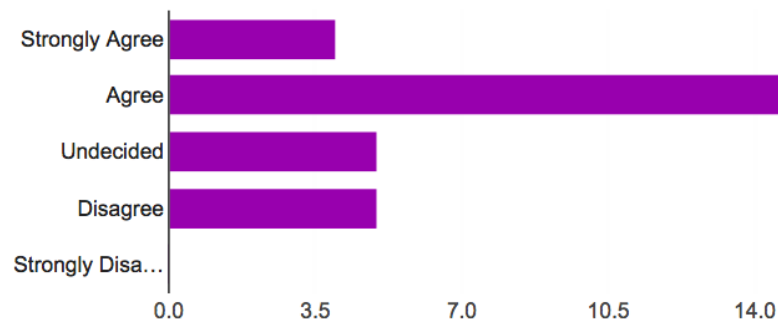
General

Organisation

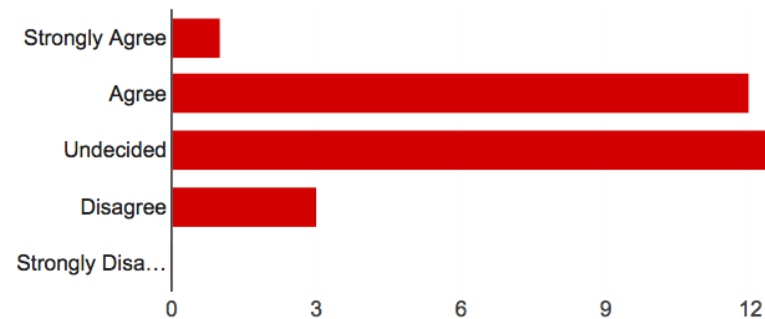


# Opportunities for social media in your organisation

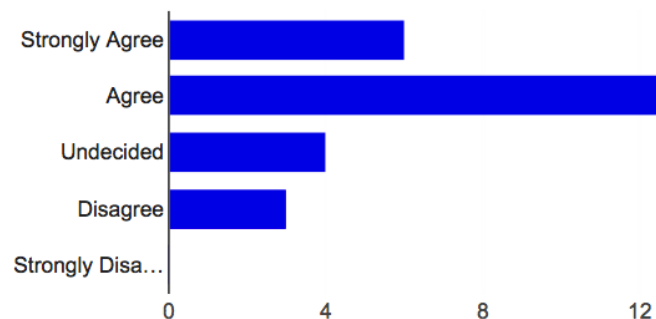
**Facilitating training for members [6a. What are the opportu**



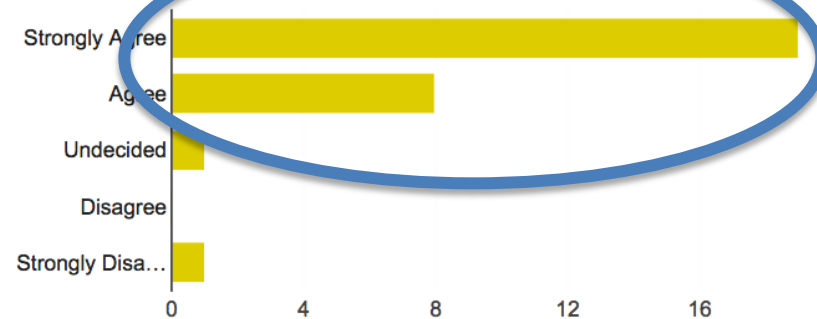
**Help patient groups follow best practice [6a. What are the c**



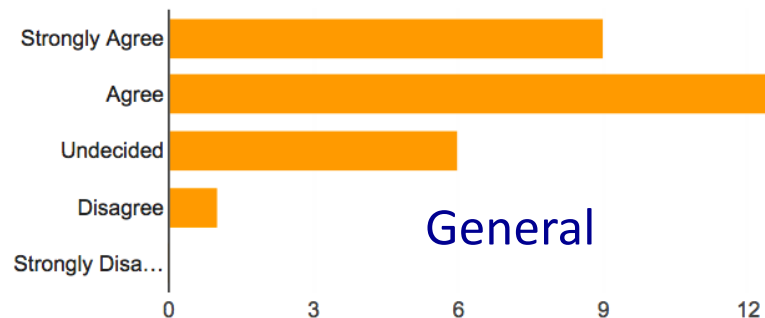
**Feeling connected to organisations [6a. What are the oppor**



**Increasing visibility of the organisation [6a. What are the op**

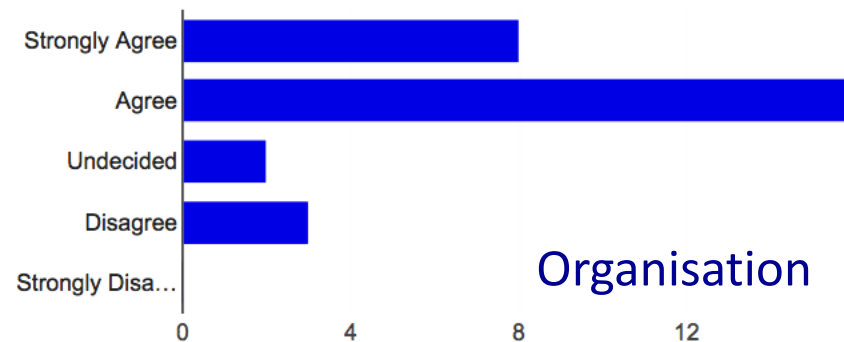


**Feeling connected to people [6a. What are the opportunities**



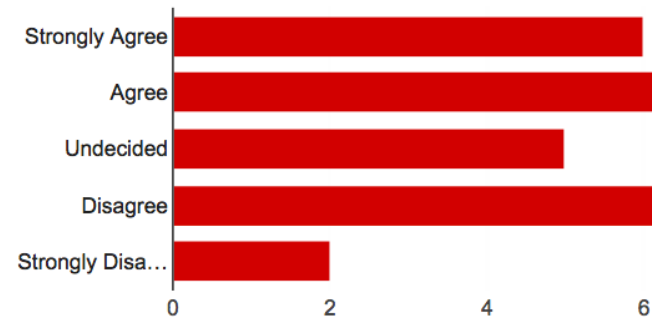
General

**Show relevance to current members [6a. What are the oppo**

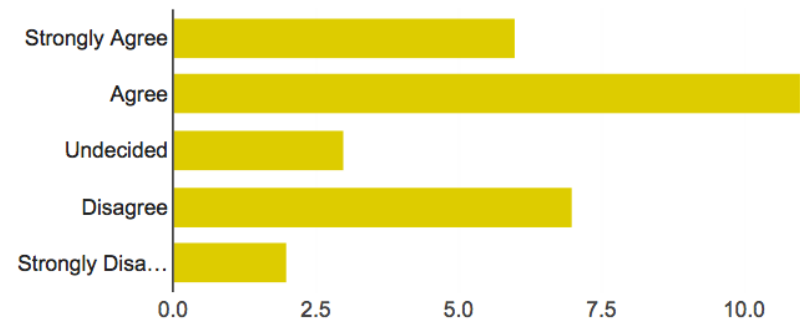


Organisation

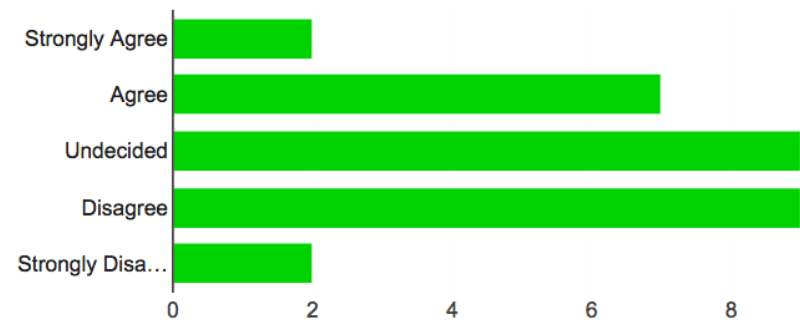
### Connecting to isolated patients [6a. What are the opportu



### Connecting to people otherwise difficult to contact [6a. W

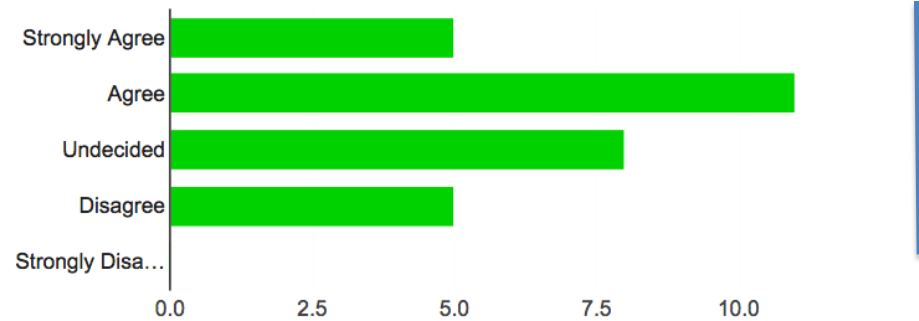


### Connecting to undiagnosed patients [6a. What are the op

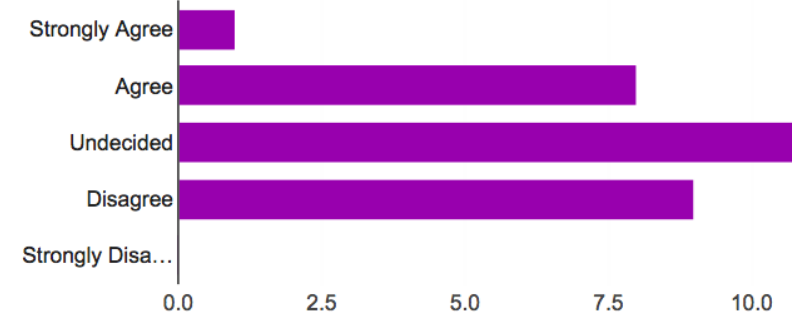


Threats/challenges from social  
media

**Loss of control of messages [7a. What are the threats/chall**



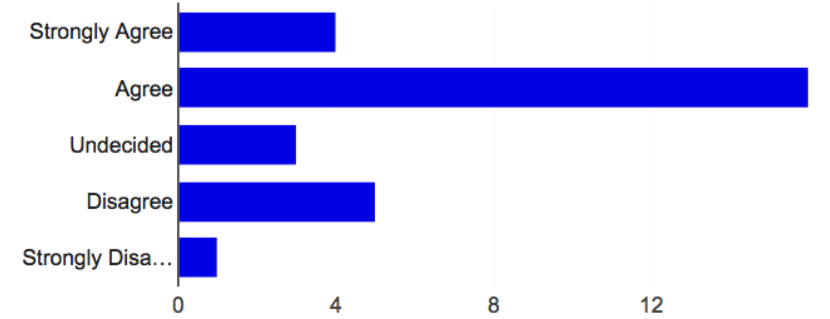
**Loss of control of messages [8a. What are the threats/cha**



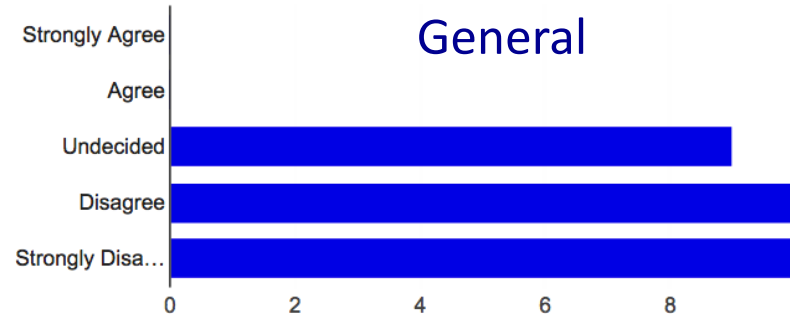
**Misinterpretation of messages [7a. What are the threats/ch**



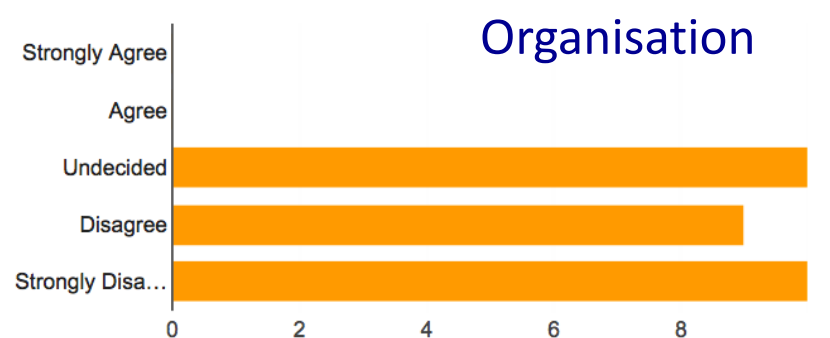
**Misinterpretation of messages [8a. What are the threats/cf**



**None [7a. What are the threats/challenges when using soci**

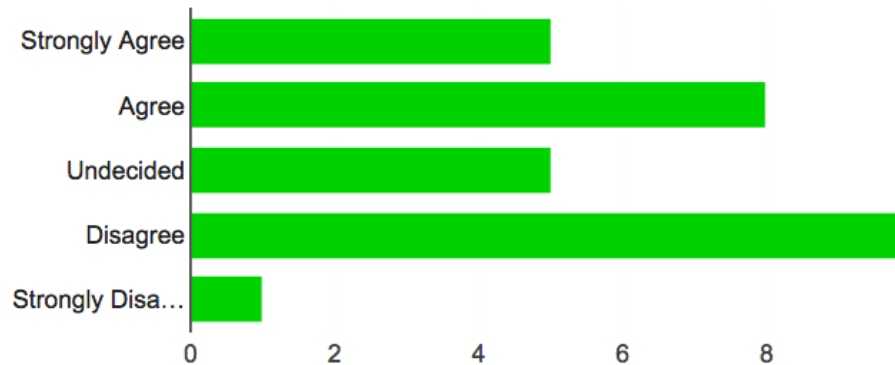


**None [8a. What are the threats/challenges for social media as**

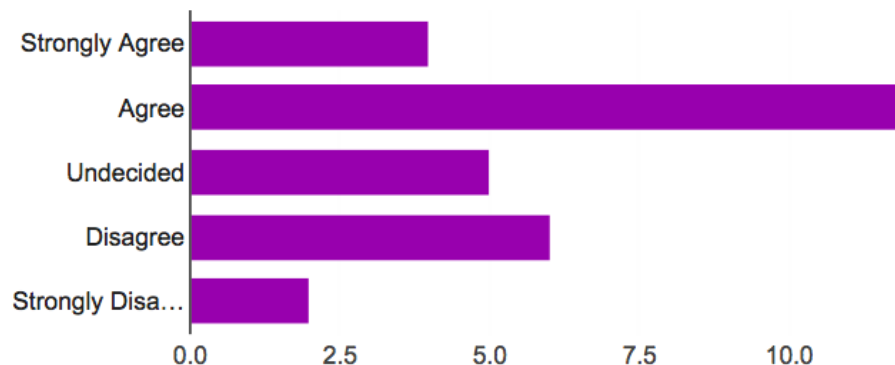


# Threats – uncertainty re costs for the organisation

## IT hardware/software costs



## Staff costs



# Organisations not actively using Social Media

Myeloma Euronet Romania

European Academy of Paediatrics

European Working Group on Gaucher Disease

# Replies

- **Strengths** — Customer support — Effective communication
- **Large number of weaknesses noted**
  - Different level of IT development of target countries
  - Information overload
  - Could become a deadly tool when used with mal-intentions in mind
  - Hard to stand out/Very competitive/Return on investment low
  - Likes don't mean people act on communication message
  - Limited depth of messaging
  - Need to keep posting new content to keep channels effective
  - Difficult and not interesting for older patients
- **Opportunities** — Easy access to information
- **Threats** — Mishandling by evil-intended people



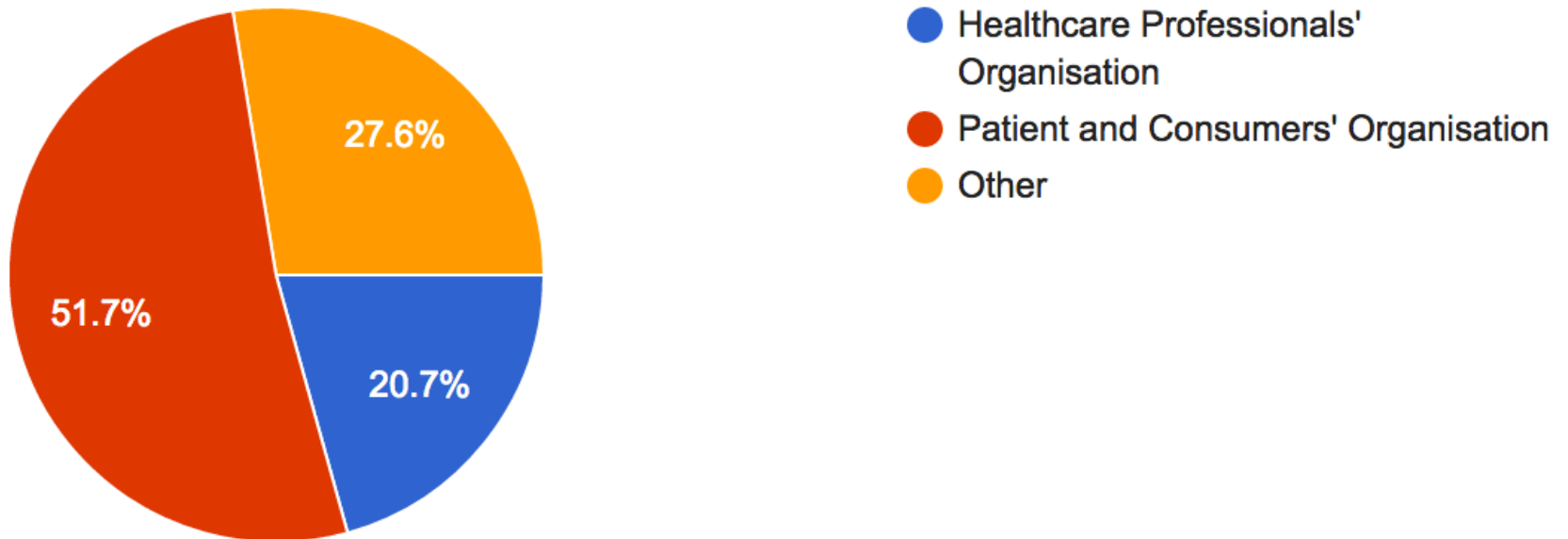
# Conclusions: major areas of uncertainty for up to ¼ organisations re social media

- Ease of use?
- Monitoring campaign success?
- Helping to organise a health awareness day?
- Connecting to patients with specific health issues?
- IT in target countries
- Privacy risk?
- Hard to stand out?
- Low response rate?
- Depth of messaging?
- Popularity?
- Return on investment?
- Letting people take part in live events?
- Peer group activity in social media?

# Appendices

- Comments re social media in general
- Summary figures

# Organisations active in social media (28 responses)



# Strengths in general

## Direct, fast contact with target audience

Using social media in healthcare not a trend, it's the right thing to do in the interests of patients

Help people and patients reach other people and patients when, where, how they want to receive health and other interests related messages

Improves availability and flow of content  
increase satisfaction and trust in messages received

Connect with friends, family, colleagues, other patients out there

Help HCPs share difficult cases and ask for advice from peers

Build collaborative relationships with people you know or not

A fast means to spread messages - specific connections using #

People, no matter who they are, at a click  
Many people are connected and **more likely to read a short informative message than a letter of email.**

It is also then so much easier to share with their contacts/followers.

All of the above apply but for it to be effective, there needs to be someone with ongoing responsibility, tasked with creating social media content, making connections, monitoring updates, etc.

Inform interest for various research project in chronic pain

## Almost none

Characters limitation helps writing only the gist, analytics simple and more sophisticated allow to learn a lot about contacts

Strong tool to mobilize like- minded stakeholders and to target high level institutes with clear messages

## Cost effective

Targeted sharing of information and two way dialogue

# General weaknesses (n=10)

People frustrated by messages which are not relevant

To achieve results investment in expert human resources is needed

When used in a professional setting **goals should be set and measured, the latter not easy for all users**

One may easily consider quantity as quality

Social media, may lead to forget social rules prevail in both online and offline behaviour

Need to post frequently may lead to repetitions, copying and other such practices that frequent readers will soon find out

**Difficult to grasp what is important**

To do this effectively, some expertise will be helpful.

**Difficult to assess direct impact**

The need to input on a regular basis

**Too much generic, confused use**, out of control  
In order to reach your goals you need to learn a lot and understand analytics; each social media platform needs its own strategy and has its own rules.

For efficient use and results you have to invest time and energy, **it is not a game.**

**Likes don't mean action**

Over 55-60 years old do not use social media so no easy to reach them with this tool.

Content overload occasionally at the expense of quality. Engagement in 'dry' topics often difficult to establish.

**Social media emphasises brevity which occasionally comes at the cost of nuance.**

Users are split over different platforms and use by professionals is not universal.

# Opportunities in general (n=9)

Disseminate content that target audience would hardly reach

Educate audience

Possibility to connect with politicians, other high level persons and organizations that it would be difficult offline

Online mobilisation and awareness when campaigning and **collateral opportunities to place your asks**

Our organisation has no patient database, and limited patient contact.

instant publication of up and coming events

Spread the word and get information and awareness out (**education of public**)

Feeling connected to people **Attaining an audience for a topic area that would not otherwise be feasible** (e.g. costs of print, subscription involved with other forms of media).

opportunity for 2-way dialogue e.g. hear opinions of individual patients and healthcare professionals.

# Threats/challenges in general (n=8)

- **Misinterpretation** of messages
- Use of online presence vs. employability/other interests
- Needs **constant control of posts** re privacy + ethical issues
- It is a mess
- Loss of privacy a real concern, as well as getting addicted
- **becoming superficial**: looking for likes more than content
- Identity theft
- **Oversimplification** of complex issues/conditions
- Misinterpretation from focus on brevity/  
**difficult to convey nuance.**

# Comments re case studies

- We have a private/secret Facebook page for members to chat. Nothing more sophisticated. There is a public Facebook page which people can view/like but **we do not permit others to post** because of spam/adverts
- **Nothing went well. Our targeted patients (over 55 years old) almost do not use Social Media.**
- Quite often we receive enquiries from university students who are looking for specific subgroups of pain patients. We use our Facebook group to facilitate the contact between the students and our users.
- The posts we consistently have high level of interactions from are the ones from the EPDA's **PD info section of the website.**
- Promoting an event on social media, **it was well prepared** from posting post dated tweets, to getting speakers twitter handles and engaging with them, before-during-after the event, announcing early the event hashtag, etc.
- Awareness-raising and information-sharing on symptoms or disease
- When we promoted informational campaigns on Facebook and twitter we had a extremely good response in how many people turned up.
- **Patient Empowerment Campaign: 2.2 million impressions on social media**



# Comments re Case Studies - ctd

- Use of a video on Twitter raised issue of people with diabetes being fined for not having a prescription exemption certificate. The message was directed at then Health Minister in the UK and, having tried more conventional methods of challenging this before without success, with the number of retweets (and the embarrassment caused) the **decision was overturned within 2 weeks.**
- Adding photos, tagging people and researching # before using them, helped us getting our message across.
- Our Annual Conferences attract 500-600 participants physically attending the event. Thanks to live tweeting, possible to **get instant feedback** from audience on content, **generate discussions with people not attending** and informing non-attending people about key presentations
- **"love your heart" twitter campaign reaching an estimated 800 000 people**
- Strong communication reach achieved on Facebook, Twitter and LinkedIn, strong inputs received to EAHP surveys as a result of social media, **enhanced understanding and awareness of EAHP advocacy messages** amongst target stakeholder audiences.

## Case Studies: What could have gone better?

- We took photos of delegates/attendees under the umbrella events and posted them across our social media channels.
- While people happy to be photographed and for us to share their photos, **they weren't hugely proactive** in posting the photographs to their own personal social media profiles and so provide a channel for reaching the general public.
- As a pan-European organisation, reaching down to the general public is challenging and **our members are key** in helping to do so. We can't do it alone.

# What could have gone better?

- 1. Organization of pre-, during- and post-event activity should be as carefully planned as all other elements of an event
- 2. If not sufficient human resources available, need provision to ask volunteers to join SM team: **requires detailed briefing and supervision of volunteers**
- 3. Planning and post-dating some tweets, posts with use of tools helps face pressure during the event day
- 4. **Acknowledge and thank participants** to your event's #, social media is social!
- 5. Online publicity of your event in social media is as important as your all other tasks.  
**Don't leave to last moment.**

# What could have gone better?

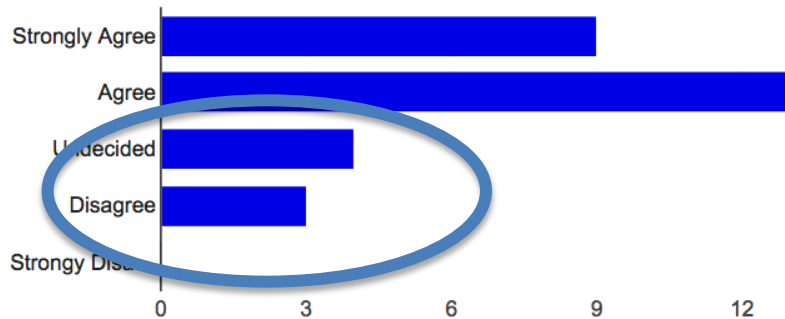
- We had an exhibition with pictures and stories of people living with chronic pain to gain awareness of our telephone helpline for chronic pain patients.
- We paid for Facebook advertisement to target a specific audience prone to participating - in a specific region near the exhibition.
- A waste of money as **no people responded** to the advertisement.

# What could have gone better?

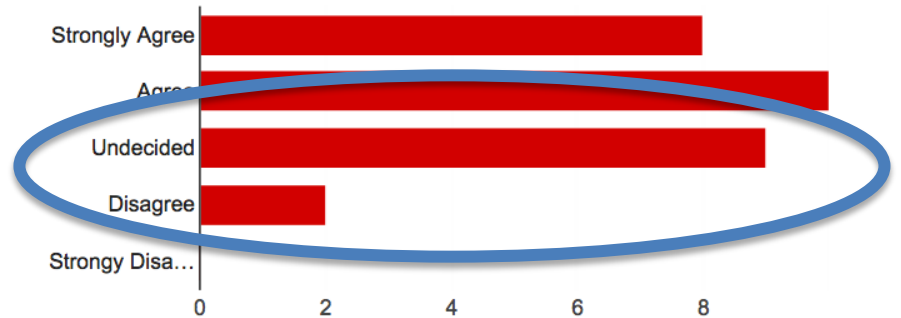
- Posts encouraging fundraising and donations consistently have a low level of interactions.
- If preparation not done before event, live tweeting not enough.
- Constant learning by doing and looking for "up to date" platforms
- Could have promoted earlier + done reminders with a count down.
- Uptake by local members
- Increase amount of engagement with followers.
- Our Facebook and LinkedIn accounts remain largely under used.
- We need to be careful with the links we use
- Remaining ambition to improve communication reach AND engagement.

# Strengths for the Organisation

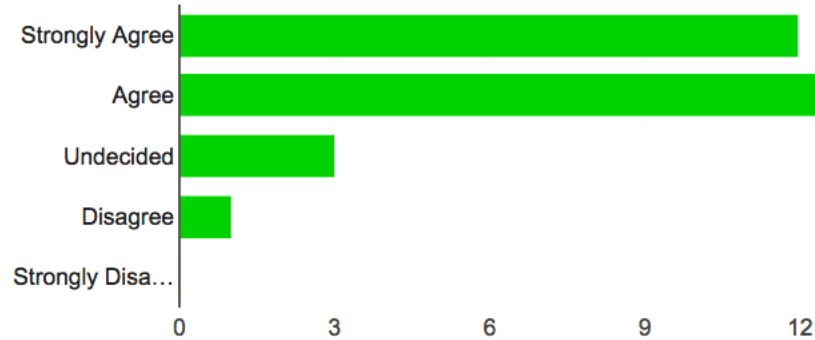
**Allows users to follow professional interests [2a. What are the strengths for the organisation?]**



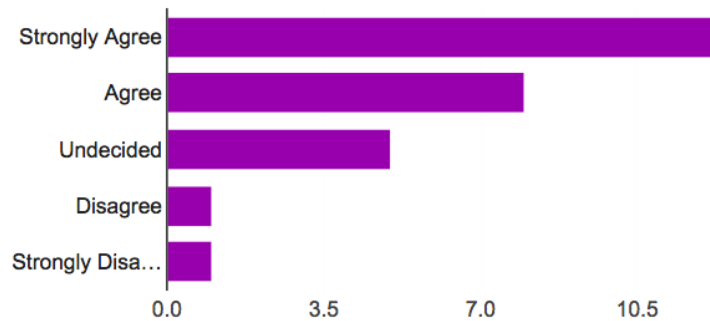
**Better insights into needs of audience [2a. What are the strengths for the organisation?]**



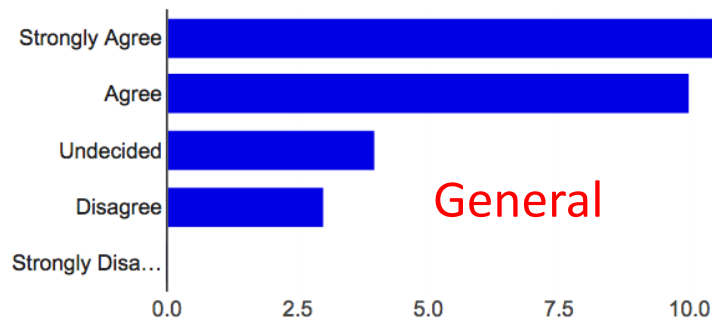
**Building relationship with target audience [1a. What are th**



**Cost-effective [1a. What are the strengths of social media in g**

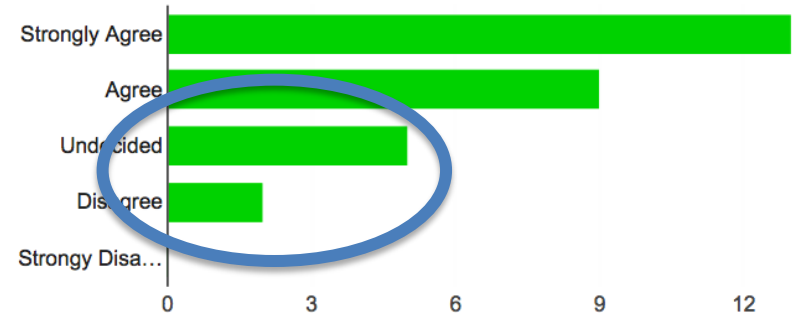


**Direct contact with target audience [1a. What are the strength**

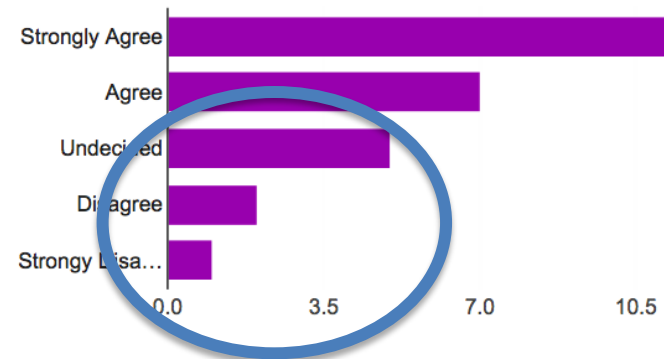


General

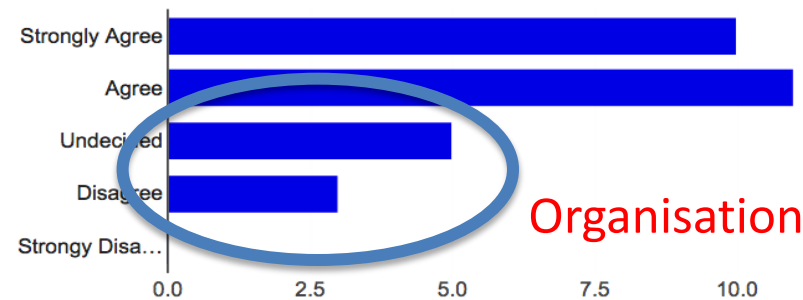
**Building relationship with target audience [2a. What are the st**



**Cost-effective [2a. What are the strengths of social media as u**

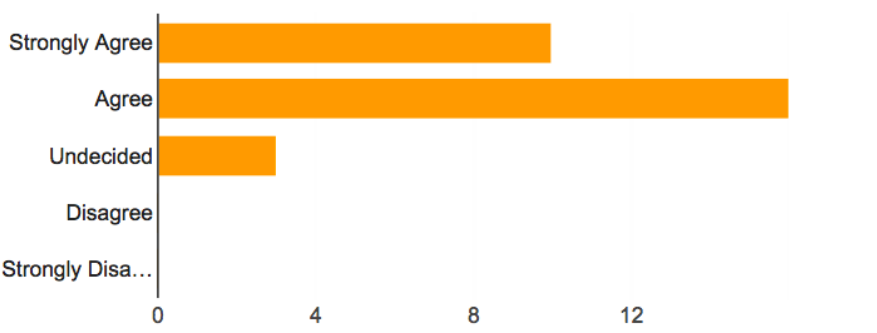


**Direct contact with target audience [2a. What are the stre**

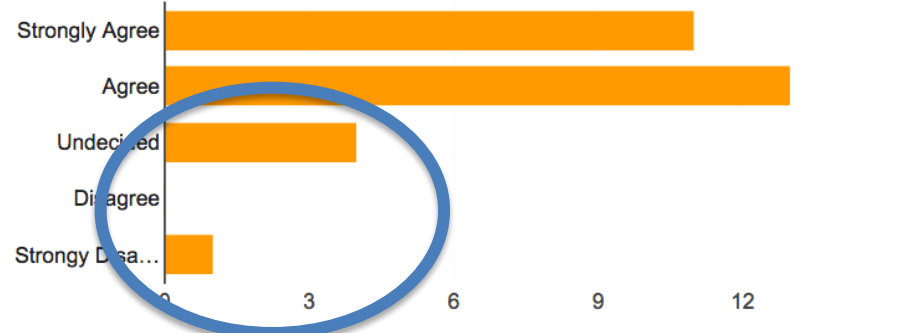


Organisation

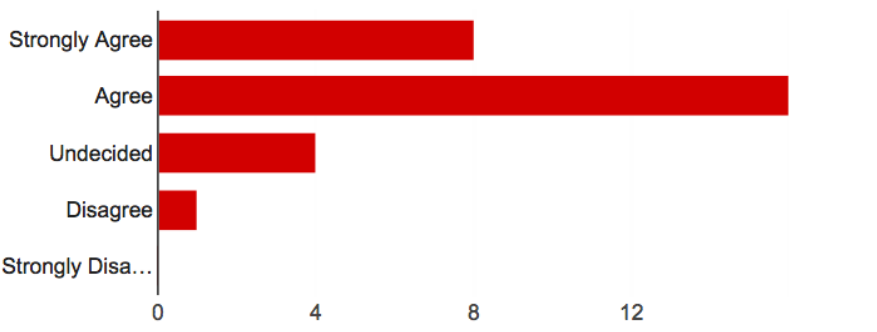
Easy to use [1a. What are the strengths of social media in ger



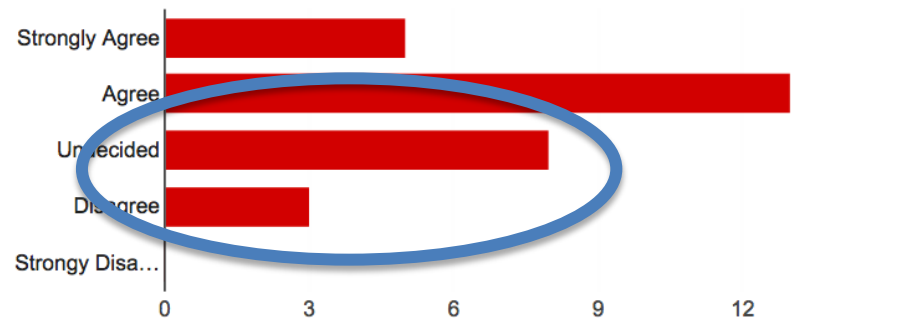
Easy to use [2a. What are the strengths of social media as u:



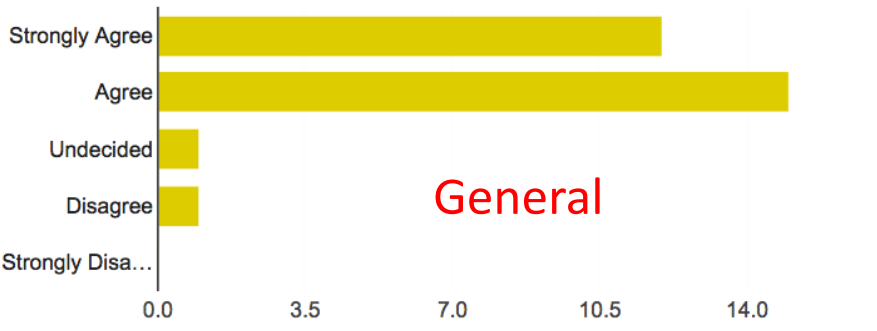
Insight into interests of others [1a. What are the strengths of :



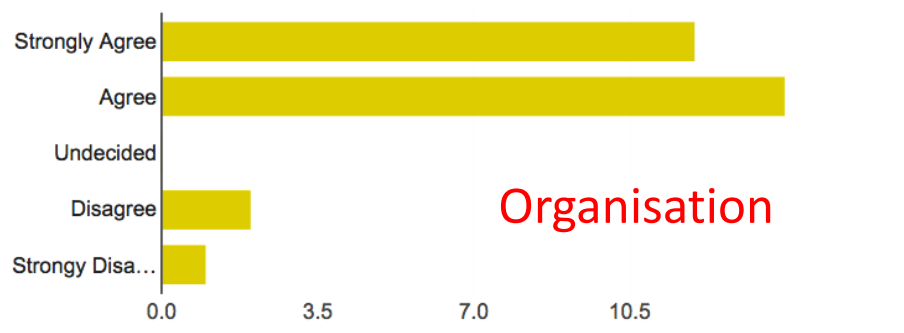
Insight into interests of others [2a. What are the strengths of



Informal way to provide information [1a. What are the strengt

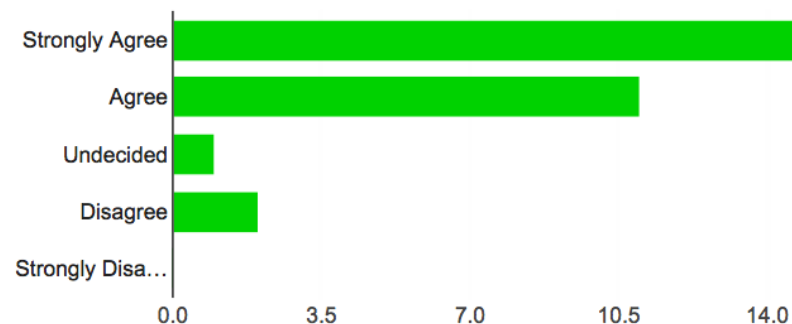


Informal way to provide information [2a. What are the streng

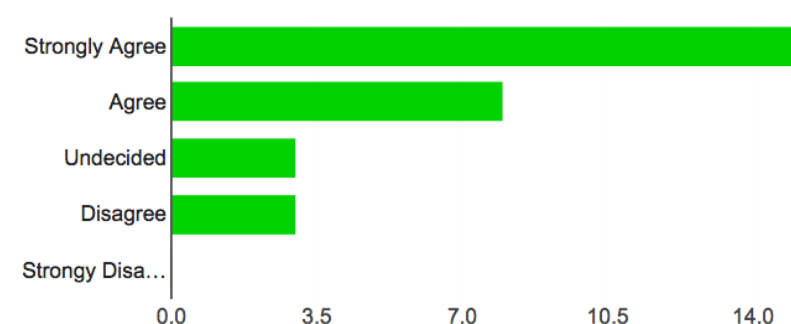




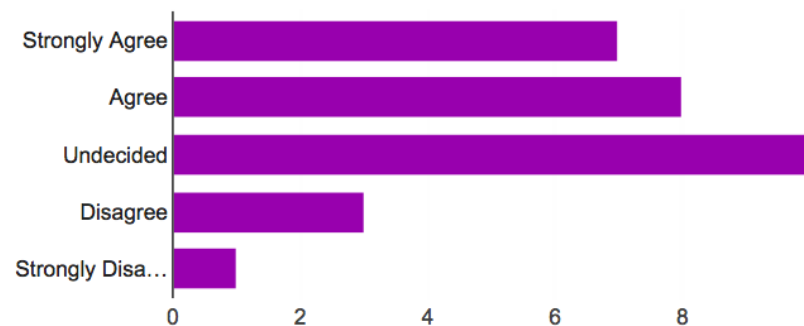
**Instant connection to live events/happenings [1a. What are**



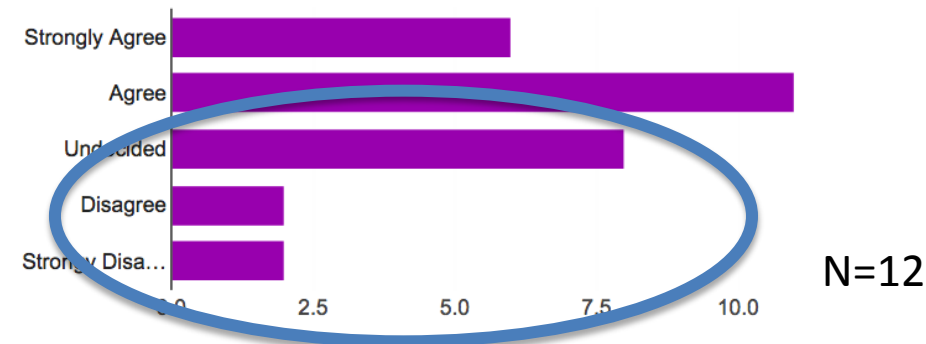
**Instant connection to live events/happenings [2a. What are t**



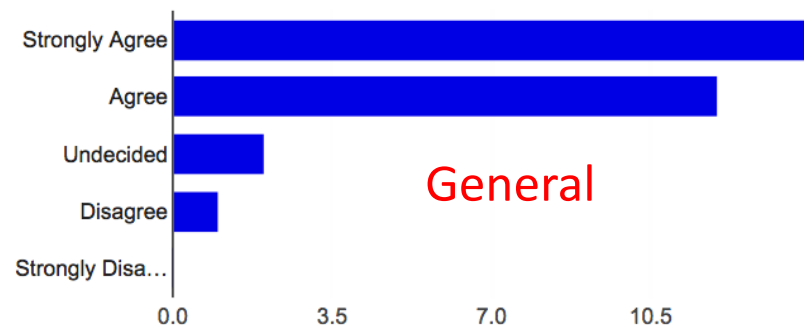
**Monitoring success of campaigns [1a. What are the strengt**



**Monitoring success of campaigns [2a. What are the strength**

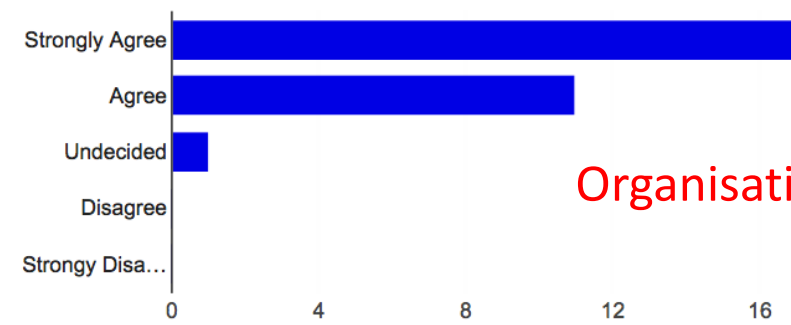


**Promoting activities [1a. What are the strengths of social m**



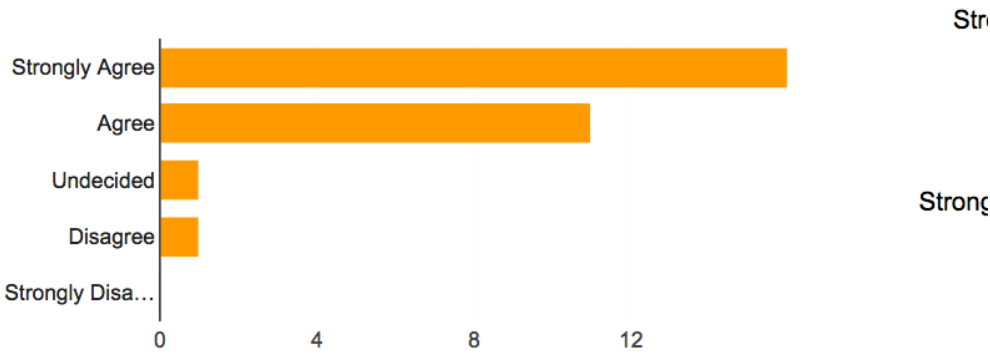
General

**Promoting activities [2a. What are the strengths of social med**

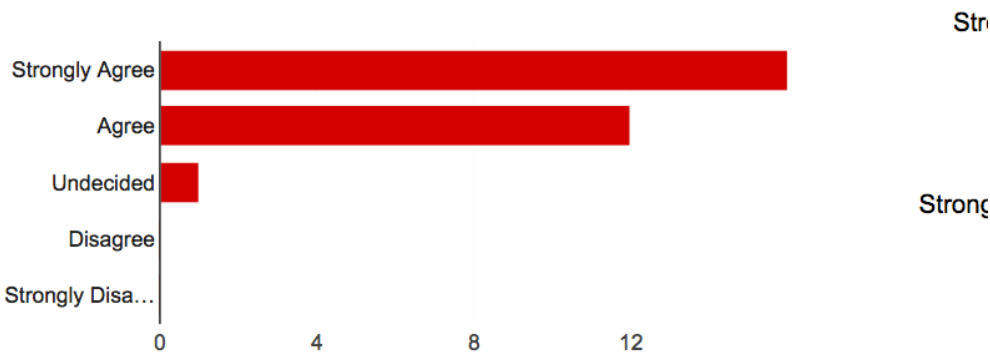


Organisation

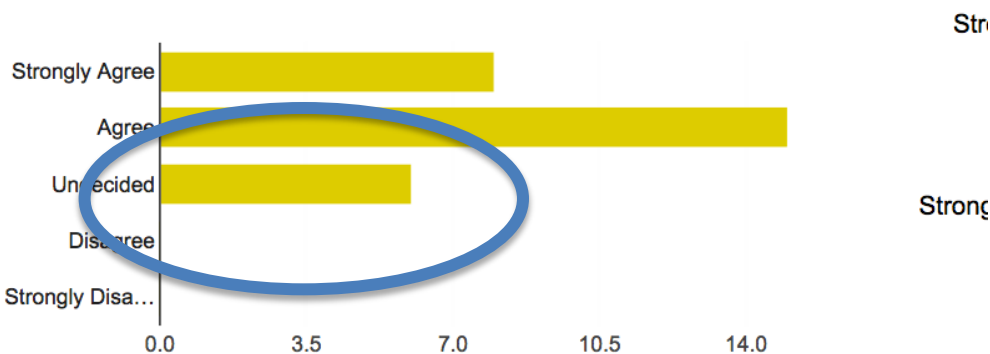
Promoting new website content [1a. What are the strengths of social media]



Quick flow of information [1a. What are the strengths of social media]



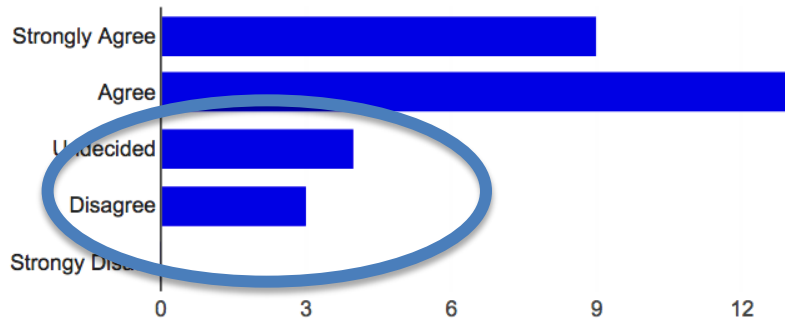
Raising awareness faced by people living with specific health issues



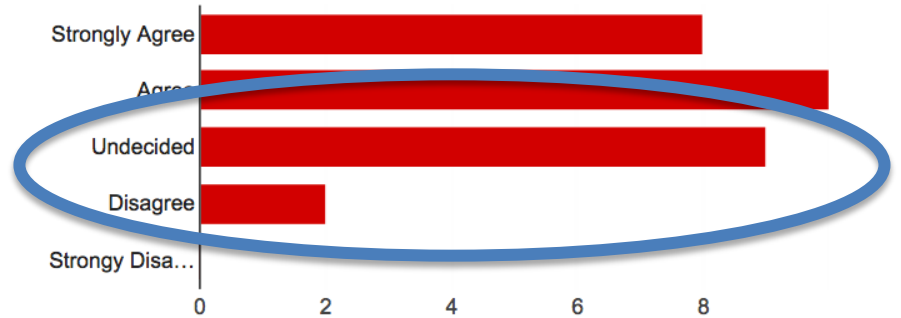
Strength of social media for your  
organisation

# Strengths for the Organisation

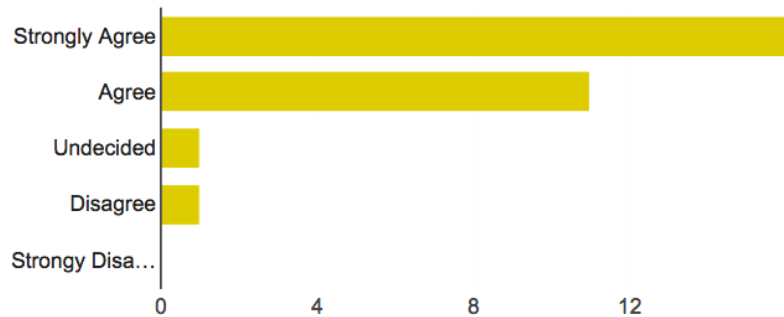
**Allows users to follow professional interests [2a. What are the strengths for the organisation?]**



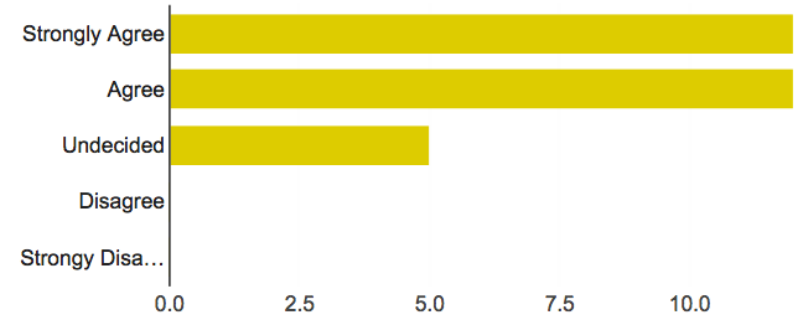
**Better insights into needs of audience [2a. What are the strengths for the organisation?]**



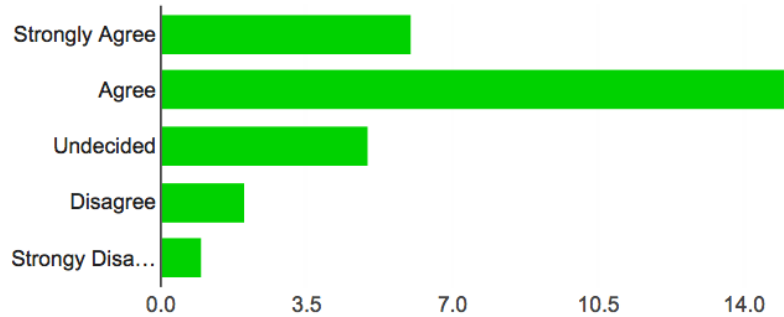
**Quick flow of information [2a. What are the strengths of so**



**Bigger audience [2a. What are the strengths of social media a**



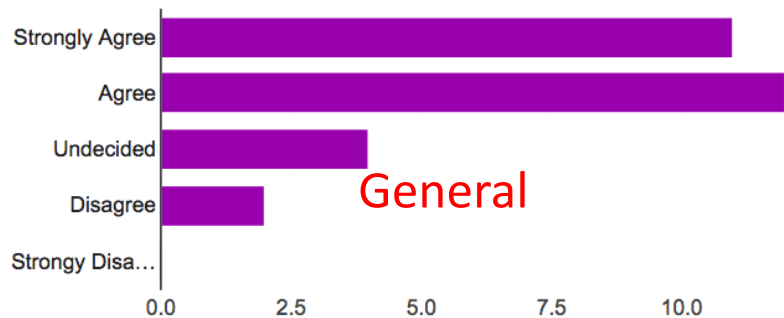
**Raising awareness faced by people living with specific hea**



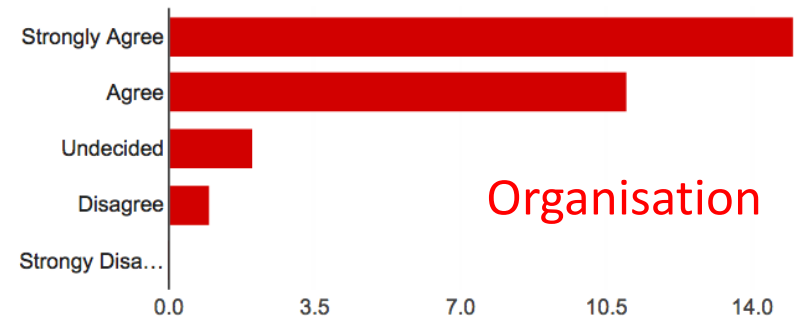
**Tool for organising a Health Awareness Day [2a. What are t**



**Sharing of points of view [2a. What are the strengths of soc**

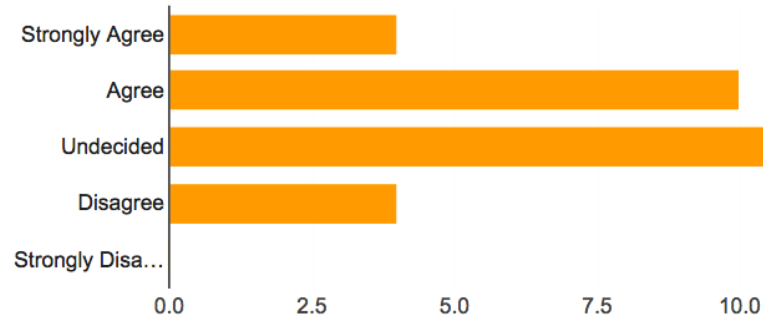


**Promoting involvement of organisation in specific projects**

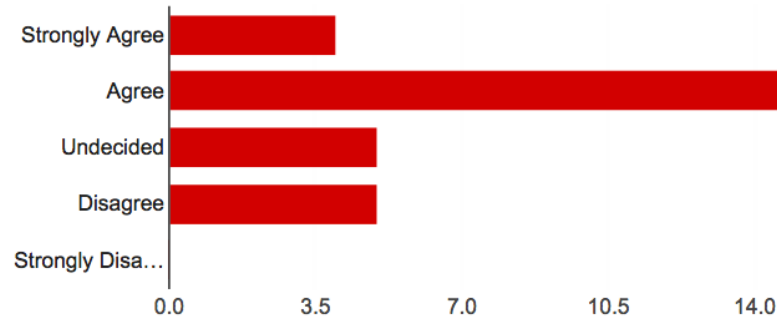


# Weaknesses of social media in general

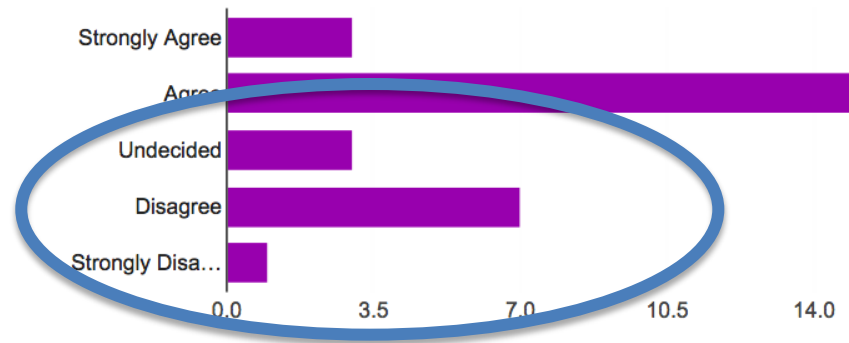
### Different level of IT development of target countries [3a. W



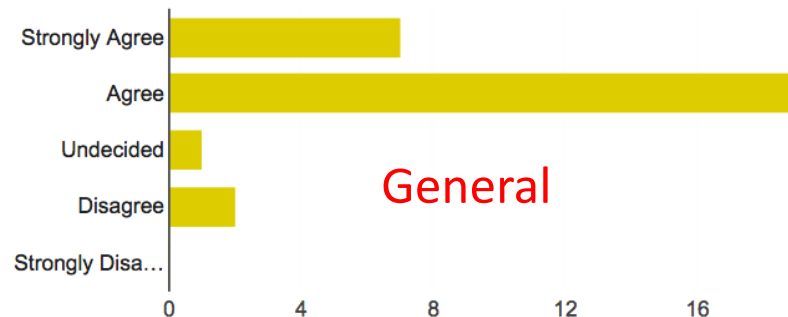
### Hard to stand out/be noticed on social media [3a. What are



### Hard to stand out/be noticed on social media [4a. What are

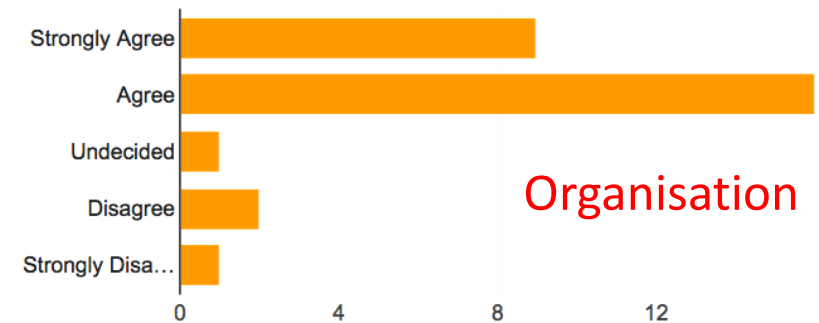


### Likes don't mean people act on communication message [



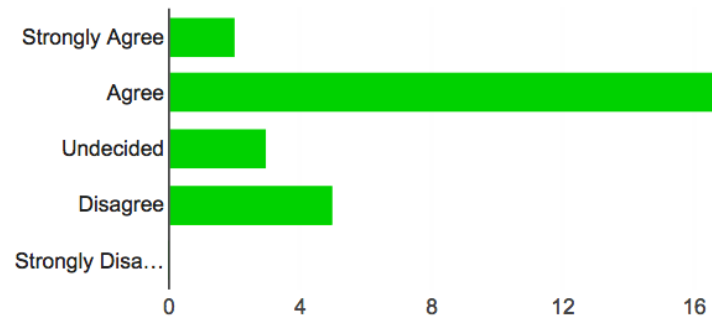
General

### Likes don't mean people act on communication message [4:

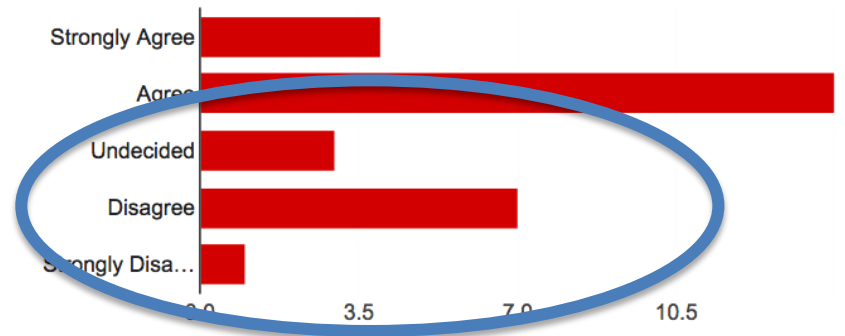


Organisation

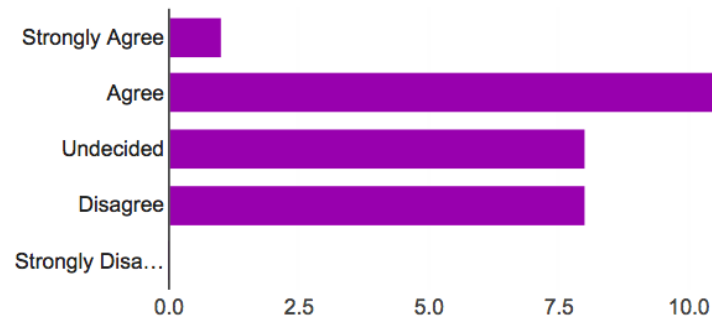
**Limited depth of messaging [3a. What are the weaknesses**



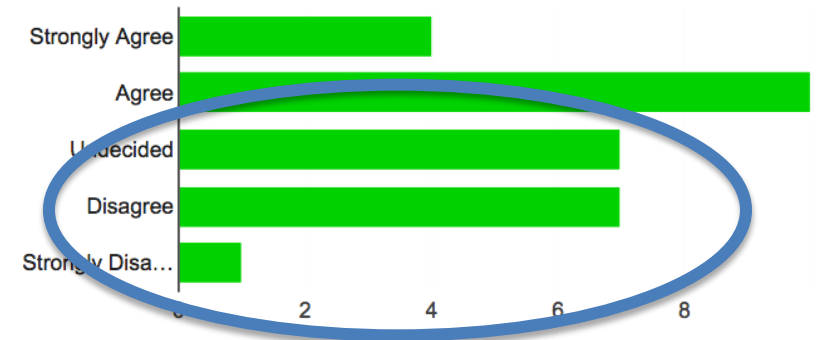
**Limited depth of messaging [4a. What are the weaknesses o**



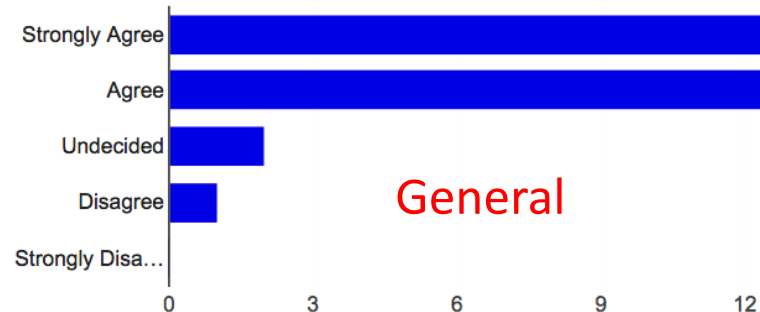
**Low response rate [3a. What are the weaknesses of social**



**Low response rate [4a. What are the weaknesses of socia**



**Need to keep posting new content to keep channels effect**



General

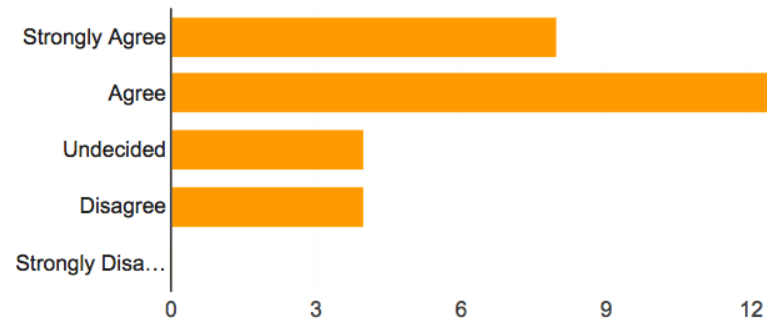
**Need to keep posting new content to keep channels effective [**



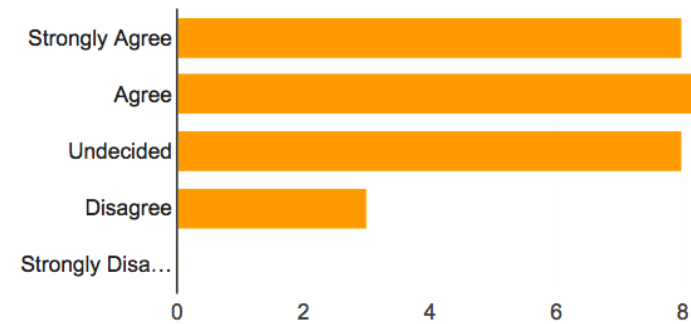
Organisation



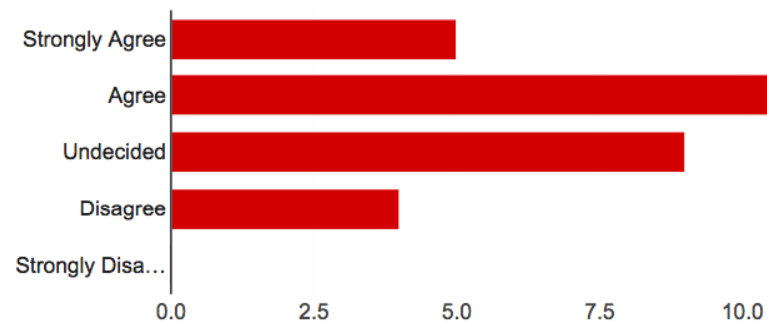
**People are spread over many social media platforms [3a. What are the weaknesses of social media?]**



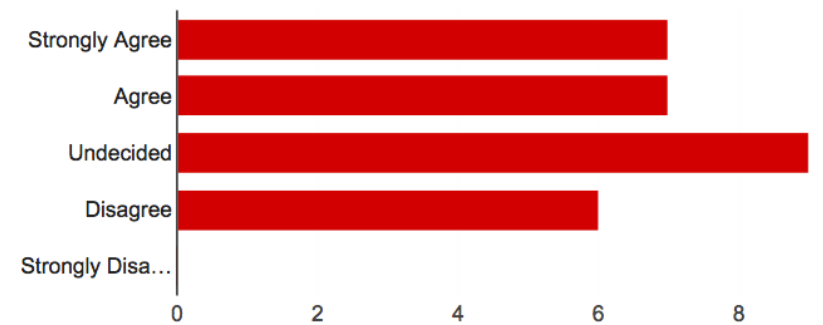
**People are spread over many social media platforms [4a. What are the weaknesses of social media?]**



**Popularity overestimated [3a. What are the weaknesses of social media?]**



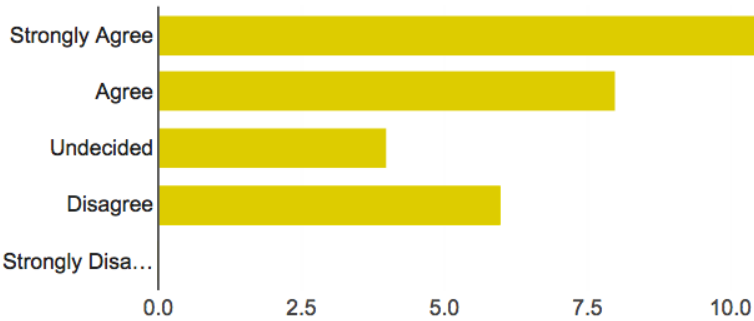
**Popularity overestimated [4a. What are the weaknesses of social media?]**



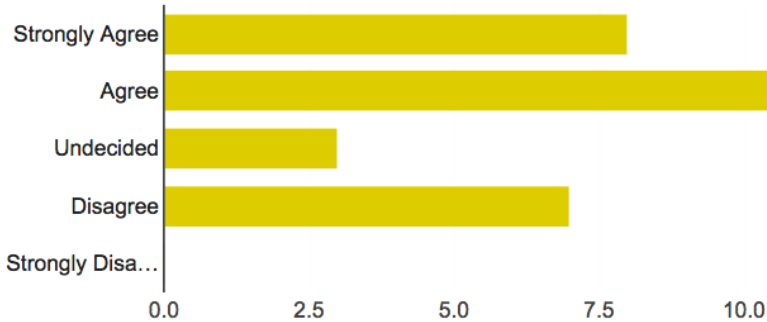
General

Organisation

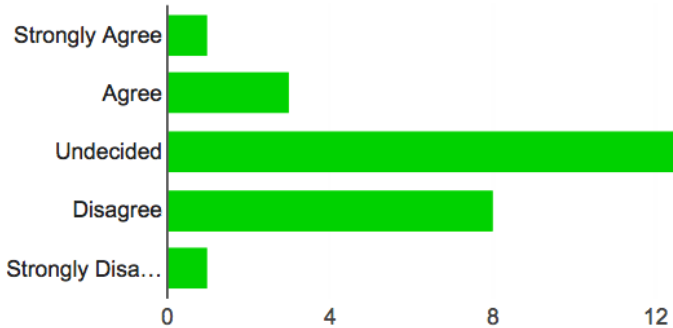
Resources needed to be effective over all social media plat



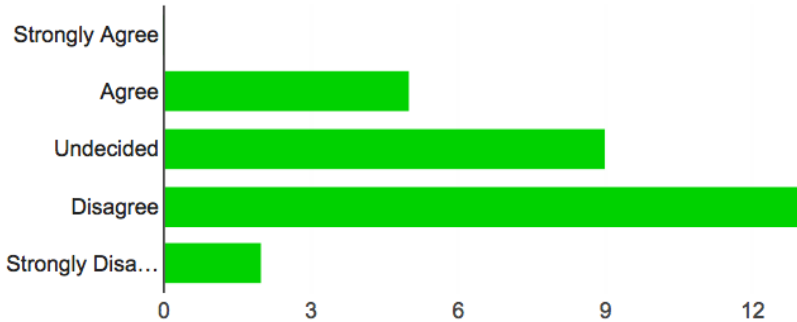
Resources needed to be effective over all social media plat



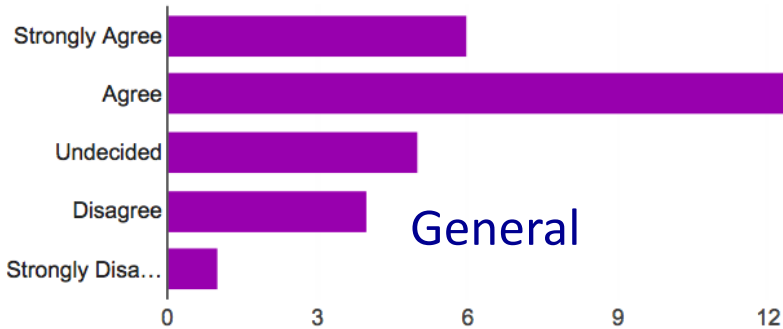
Return on investment low [3a. What are the weaknesses of



Return on investment low [4a. What are the weaknesses of

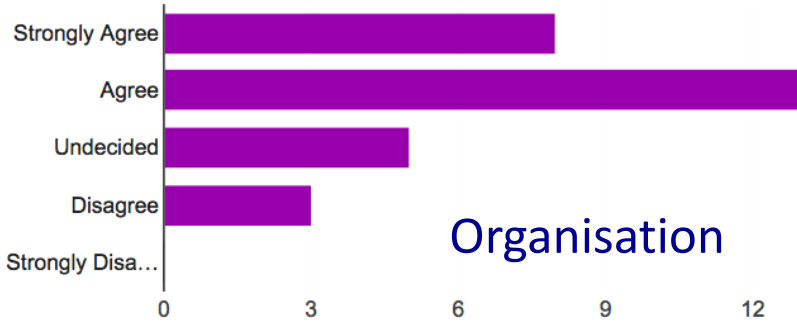


Very competitive [3a. What are the weaknesses of social m



General

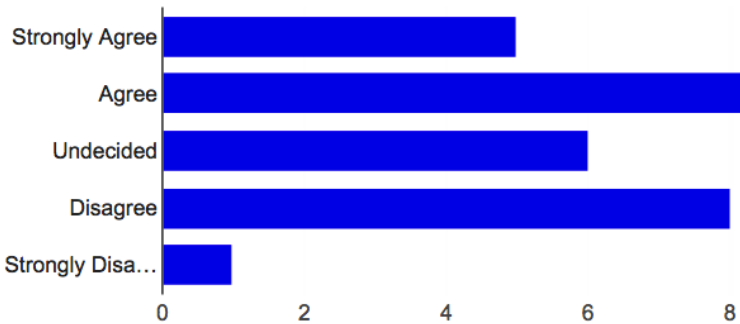
Very competitive [4a. What are the weaknesses of social m



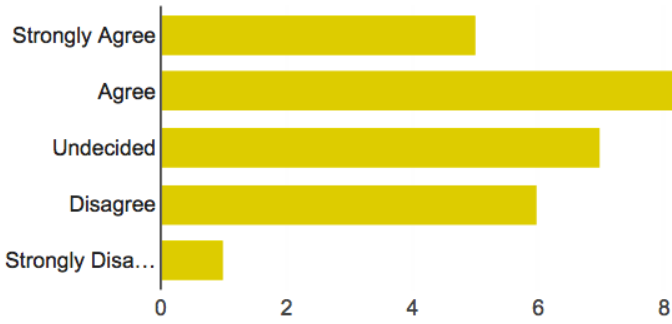
Organisation

# Weaknesses of social media for your organisation

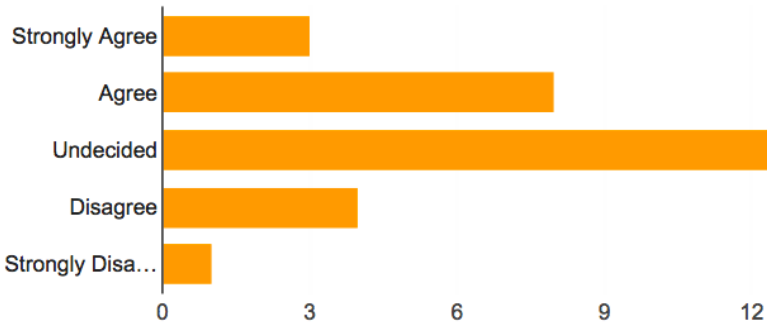
**Cost of international organisation using multiple languages [4a. What are the weaknesses of internationalisation?]**



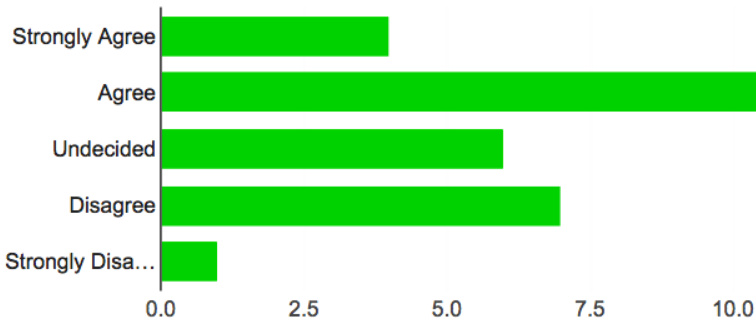
**Different educational attainment of target audiences [4a. What are the weaknesses of internationalisation?]**



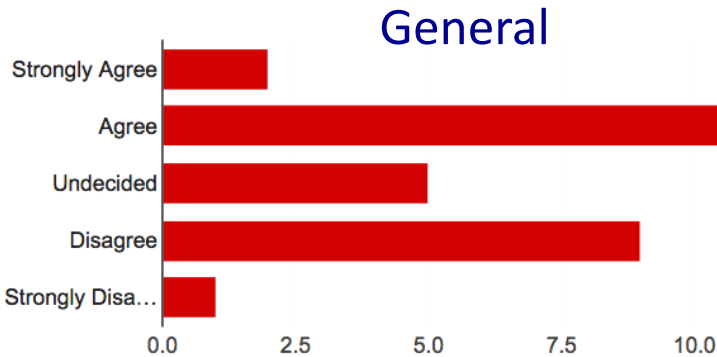
**Current low uptake of livestream events [4a. What are the weaknesses of internationalisation?]**



**Different level of IT development of target countries [4a. What are the weaknesses of internationalisation?]**

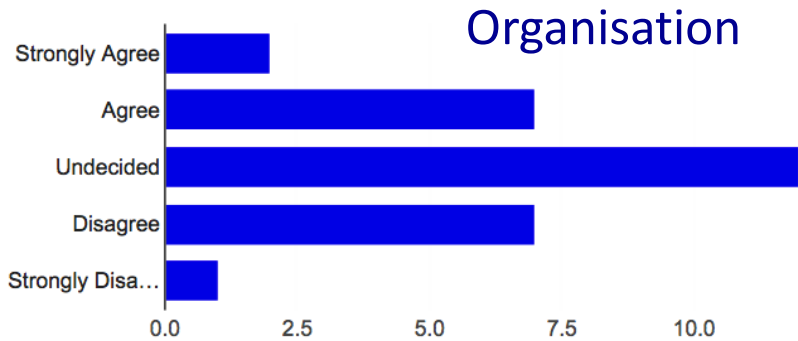


**Differences in cultural background of audience [4a. What are the weaknesses of internationalisation?]**



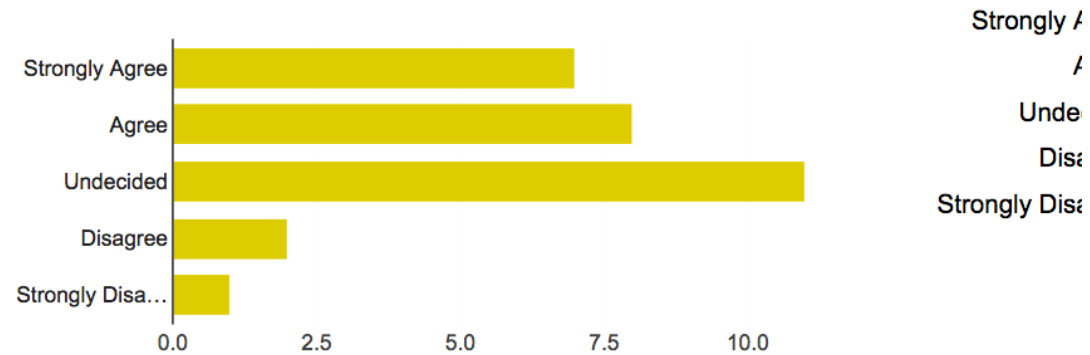
General

**High cost of livestream events [4a. What are the weaknesses of internationalisation?]**

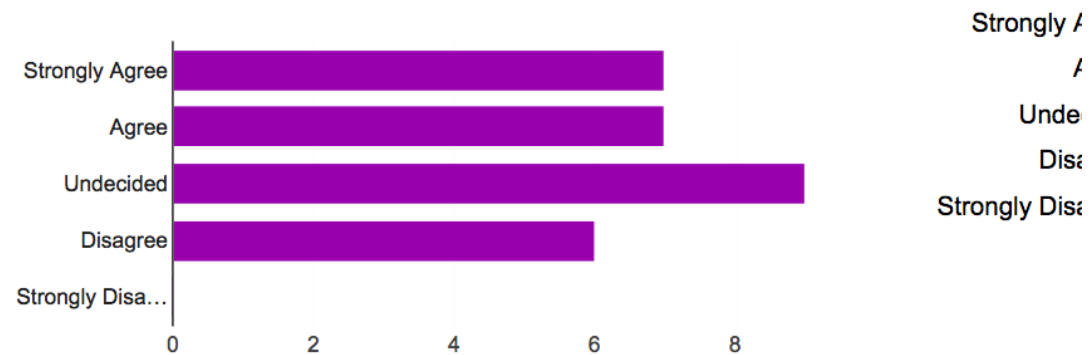


Organisation

### Low maturity of social media use among many peer group organisations [4]

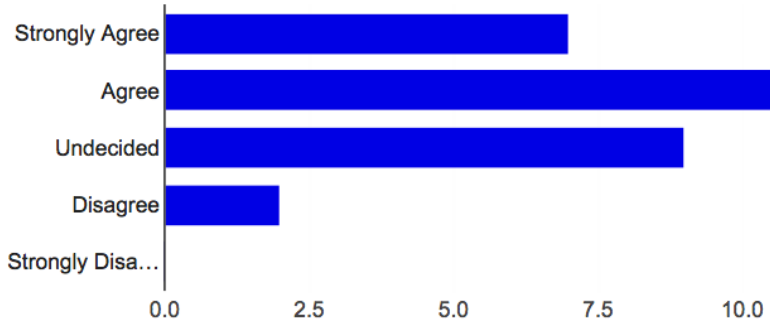


### Low use of reciprocal amplification of social media messages by peer group

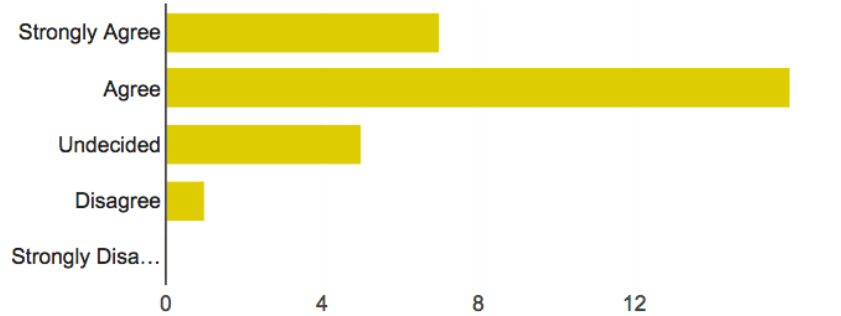


Opportunities for social media  
in general

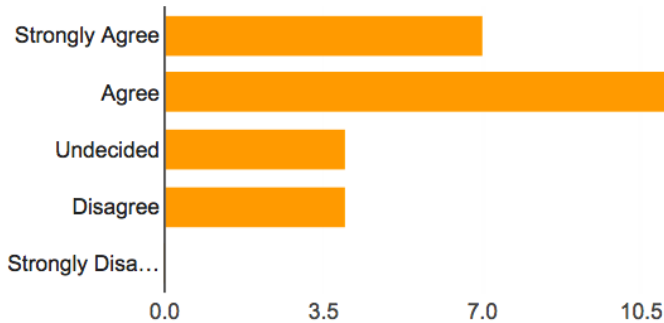
Connecting to isolated patients [5a. What are the opportuni



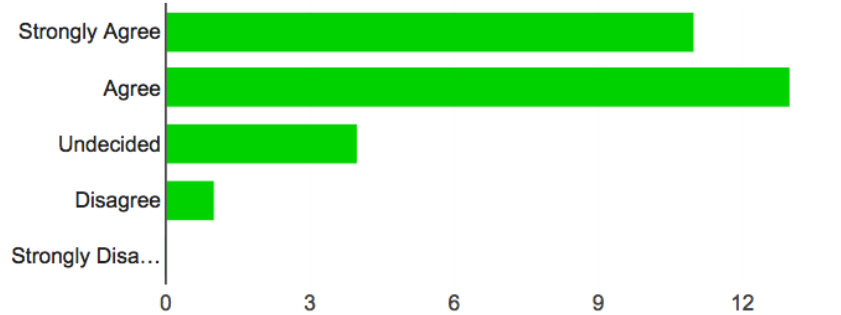
Feeling connected to organisations [5a. What are the oppor



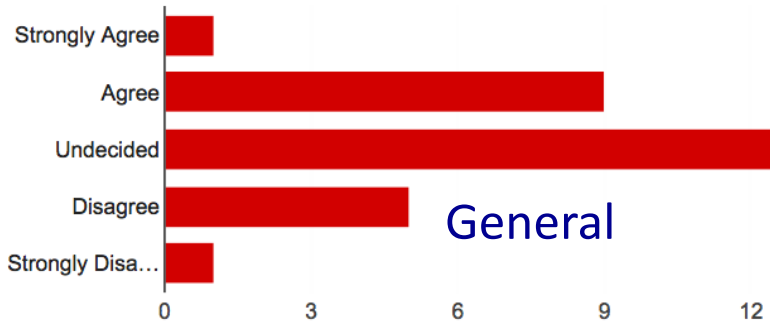
Connecting to people otherwise difficult to contact [5a. Wh



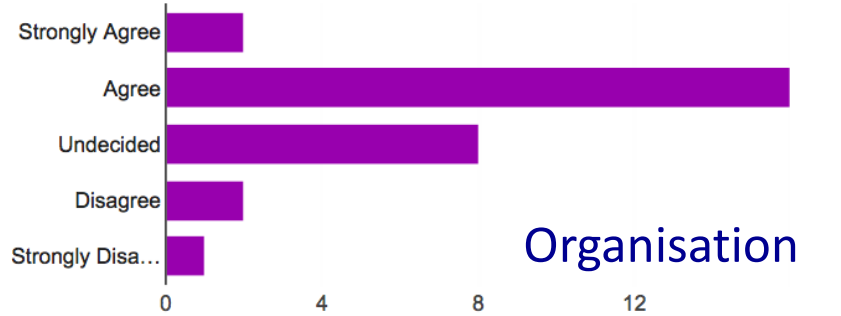
Feeling connected to people [5a. What are the opportunities



Connecting to undiagnosed patients [5a. What are the oppi



Help patient groups follow best practice [5a. What are the o]



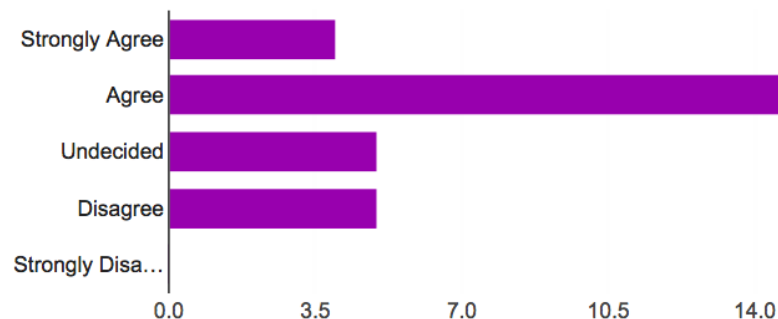
General

Organisation

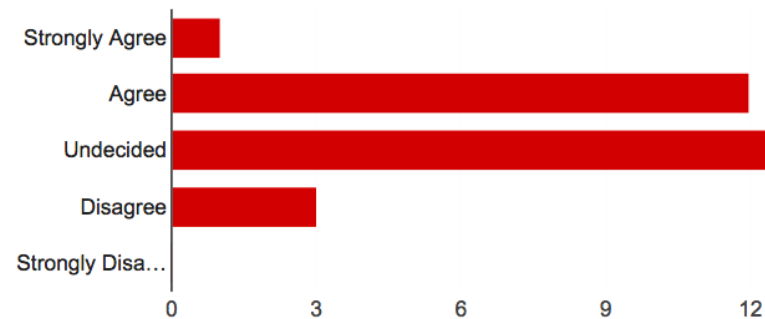
# Opportunities for social media in your organisation



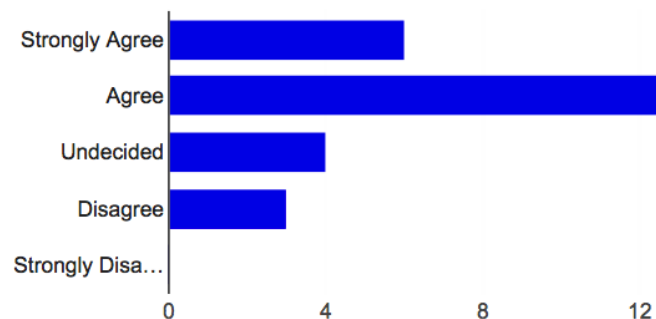
**Facilitating training for members [6a. What are the opportu**



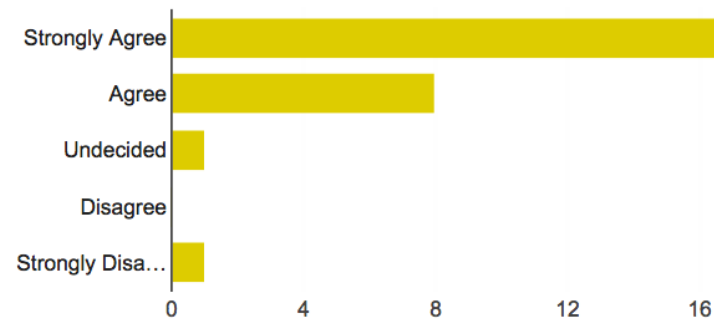
**Help patient groups follow best practice [6a. What are the c**



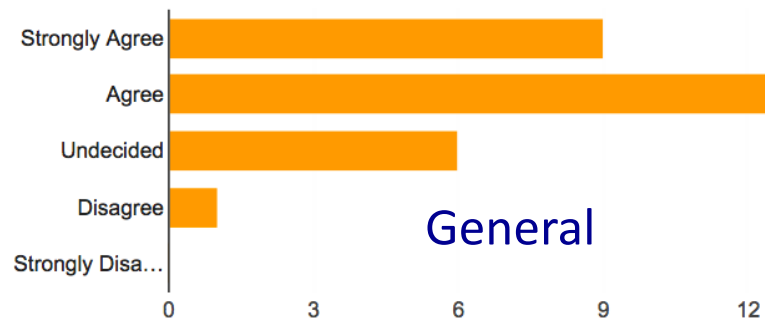
**Feeling connected to organisations [6a. What are the oppor**



**Increasing visibilty of the organisation [6a. What are the op**

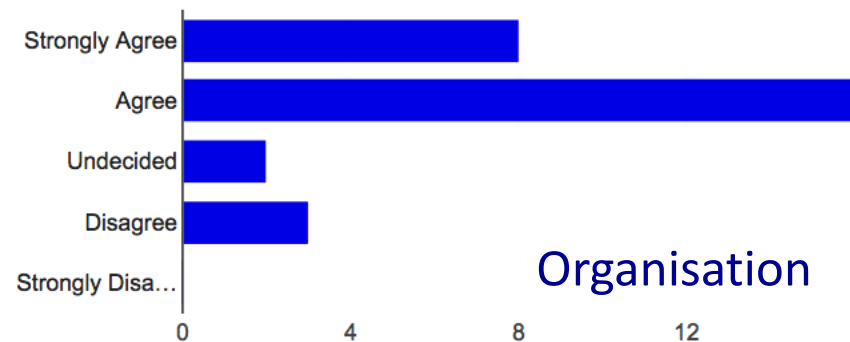


**Feeling connected to people [6a. What are the opportunities**



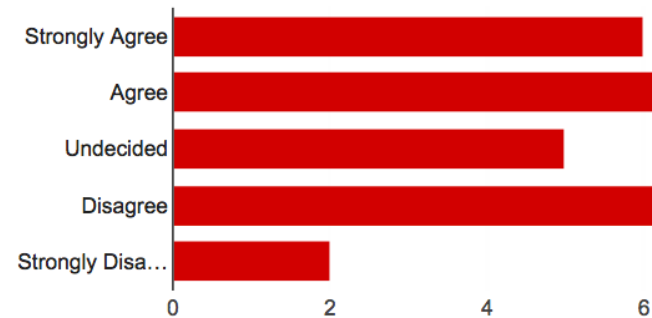
General

**Show relevance to current members [6a. What are the oppo**

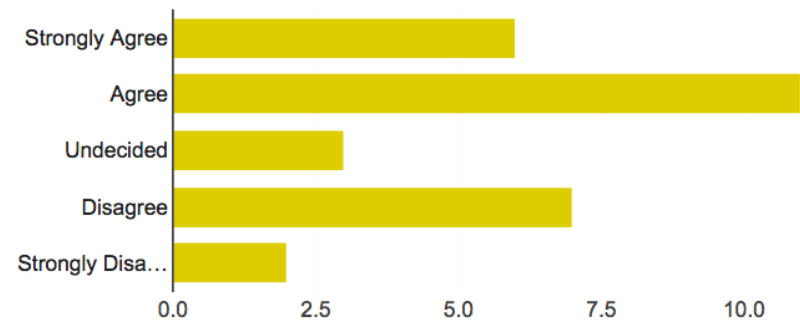


Organisation

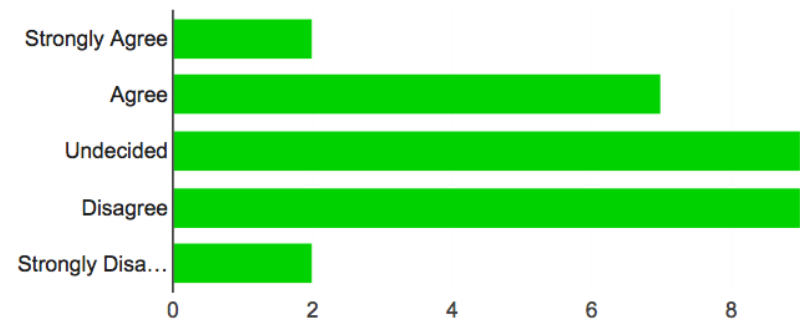
### Connecting to isolated patients [6a. What are the opportu



### Connecting to people otherwise difficult to contact [6a. W

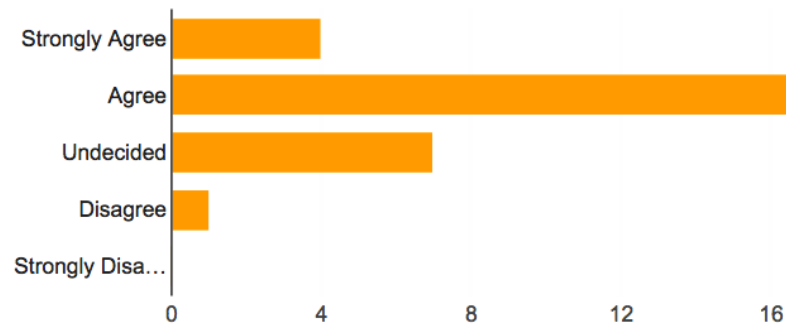


### Connecting to undiagnosed patients [6a. What are the op

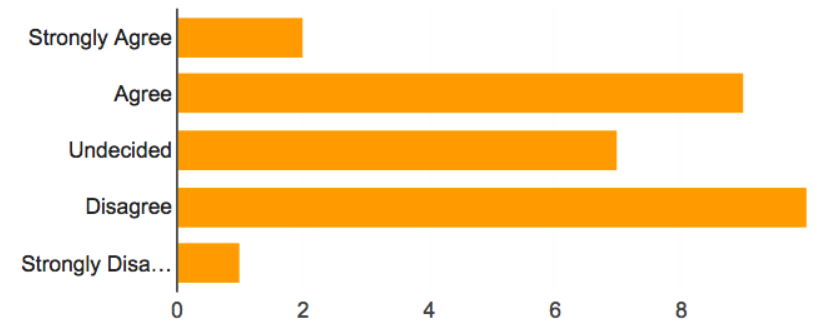


# Challenges from social media in general

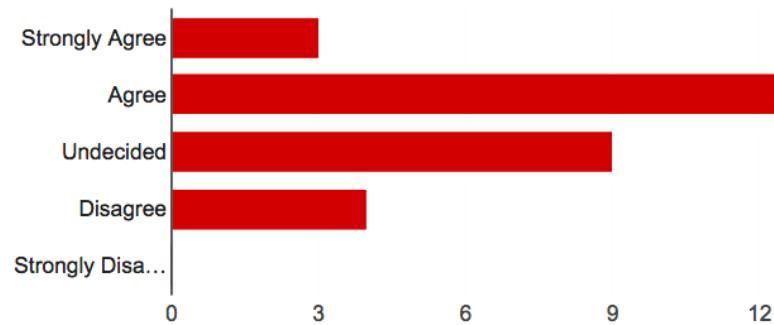
**Abuse [7a. What are the threats/challenges when using soci**



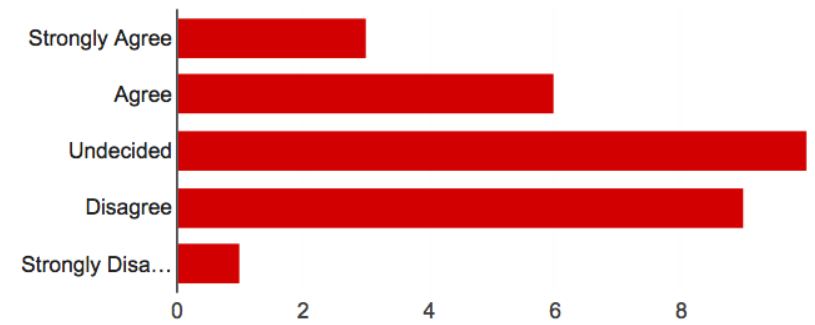
**Abuse [8a. What are the threats/challenges for social media**



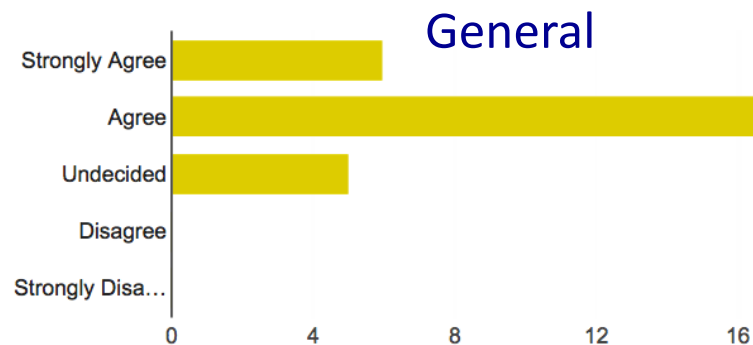
**Identity theft [7a. What are the threats/challenges when usin**



**Identity theft [8a. What are the threats/challenges for social**

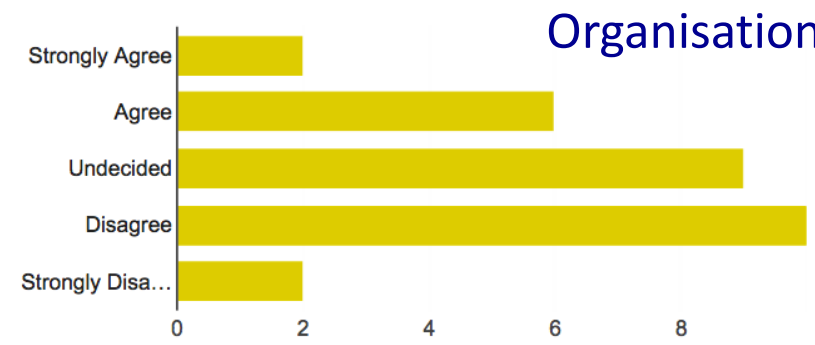


**Interference with privacy [7a. What are the threats/challenge**



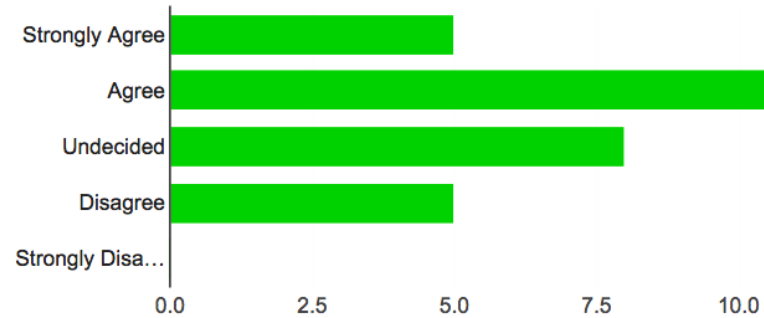
General

**Interference with privacy [8a. What are the threats/challeng**

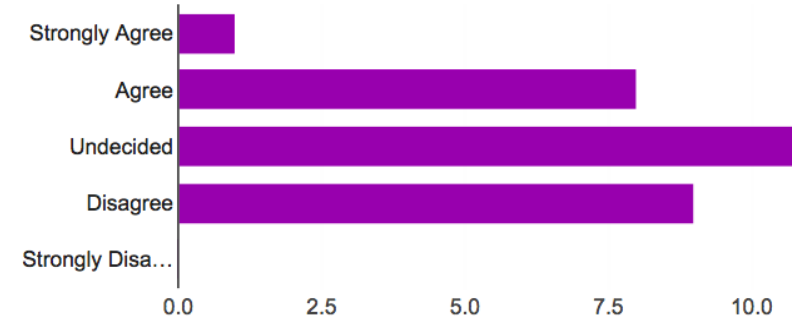


Organisation

**Loss of control of messages [7a. What are the threats/chall**



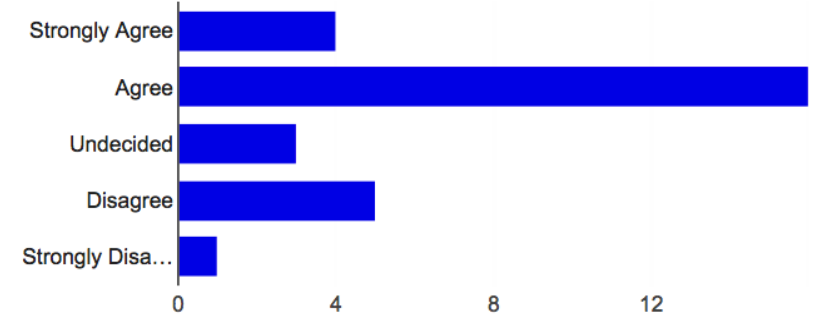
**Loss of control of messages [8a. What are the threats/cha**



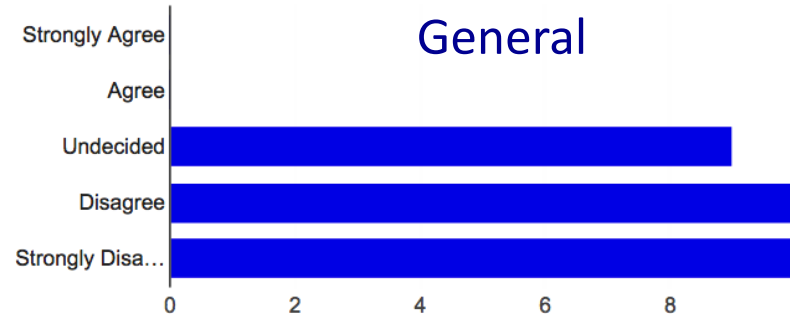
**Misinterpretation of messages [7a. What are the threats/ch**



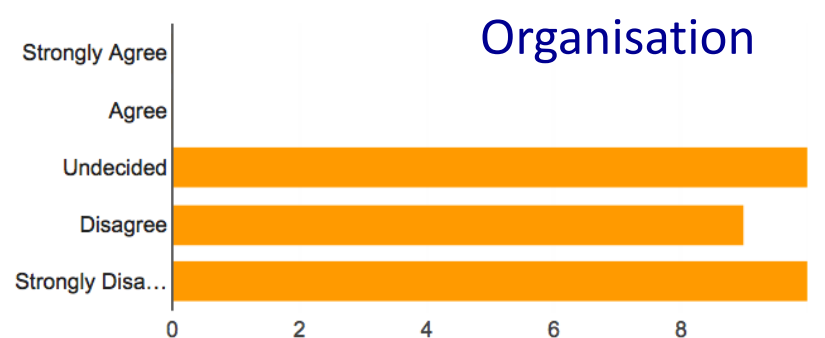
**Misinterpretation of messages [8a. What are the threats/cf**



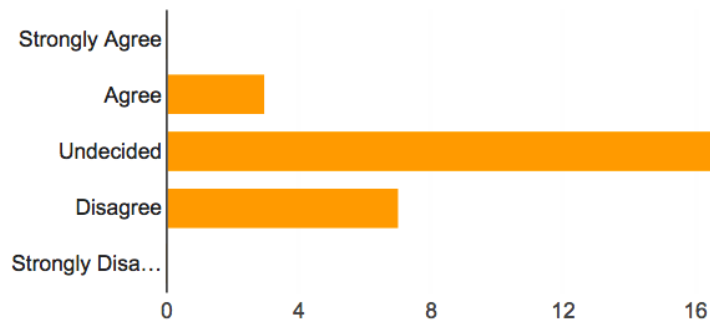
**None [7a. What are the threats/challenges when using soci**



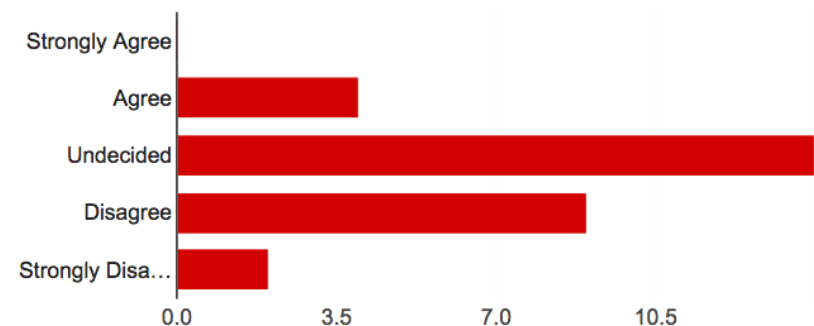
**None [8a. What are the threats/challenges for social media as**



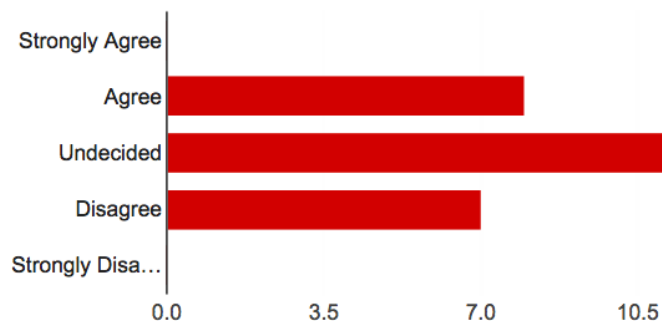
**Personal loss of insurance status [7a. What are the threat:**



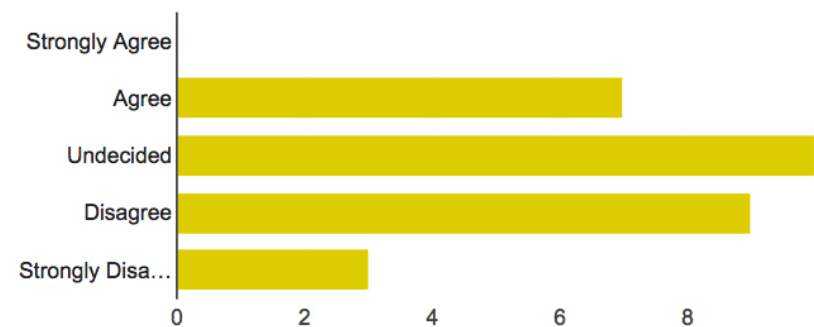
**Personal loss of insurance status [8a. What are the threats/**



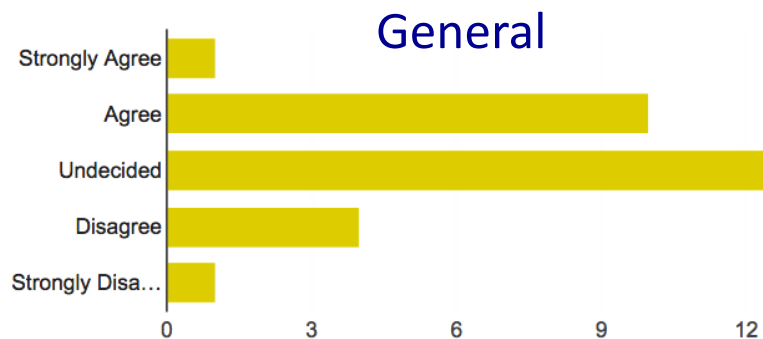
**Personal risk to employment [7a. What are the threats/cha**



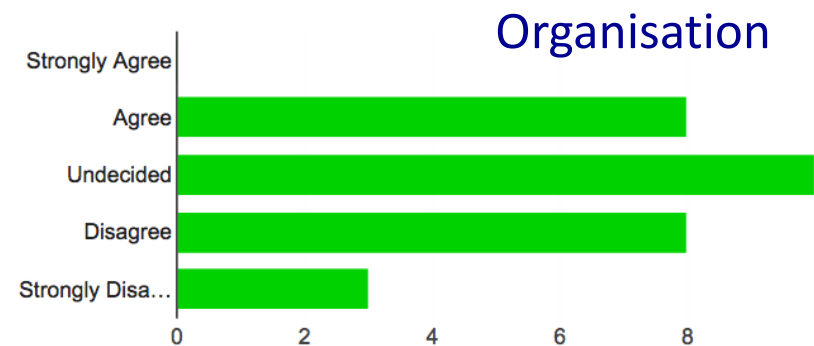
**Personal risk to employment [8a. What are the threats/chall**



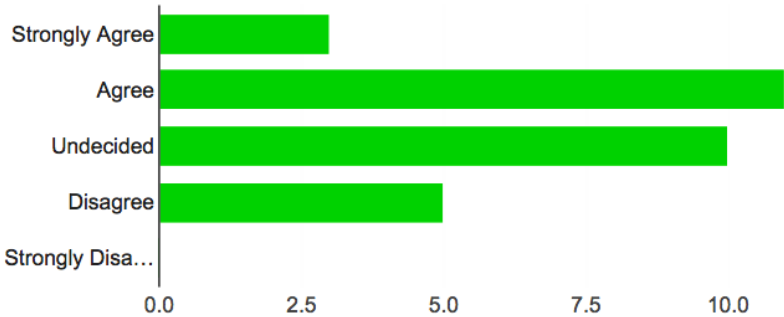
**Risk to personal security [7a. What are the threats/challen**



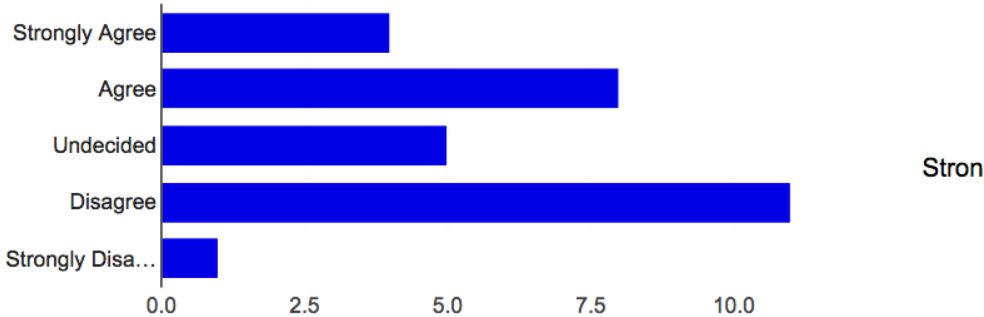
**Risk to personal security [8a. What are the threats/challeng**



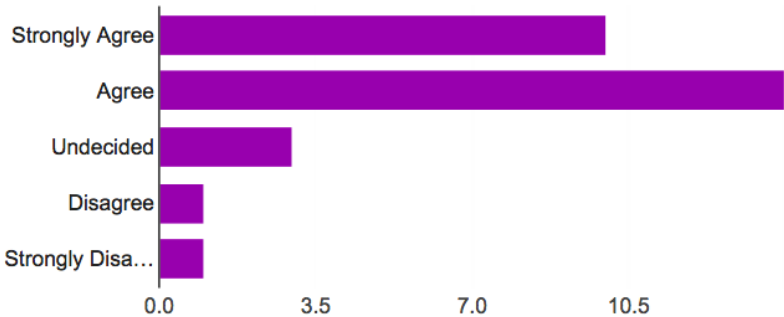
Time-wasting on social media activity with no beneficial outc



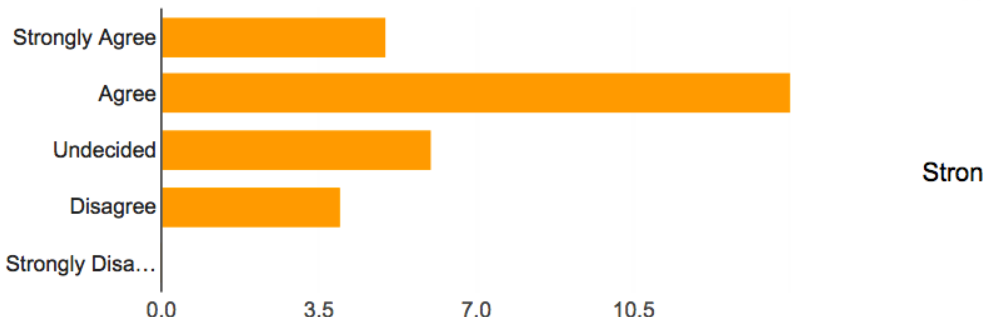
Time-wasting on social media activity with no beneficial outcomes [8



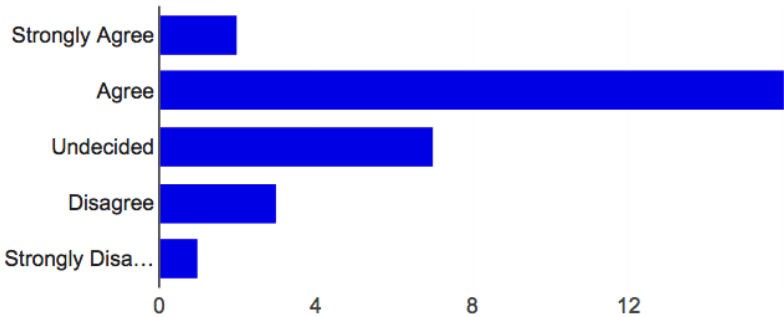
Unverified information [7a. What are the threats/challenges w



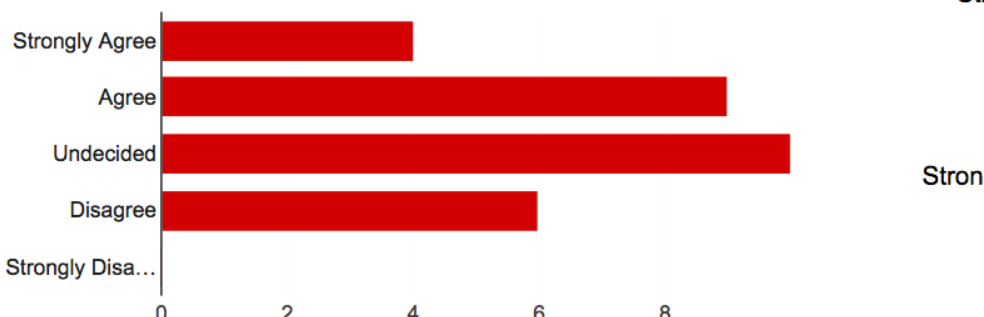
Unverified information [8a. What are the threats/challenges for social



With constant new platforms becoming out-of-date in social i

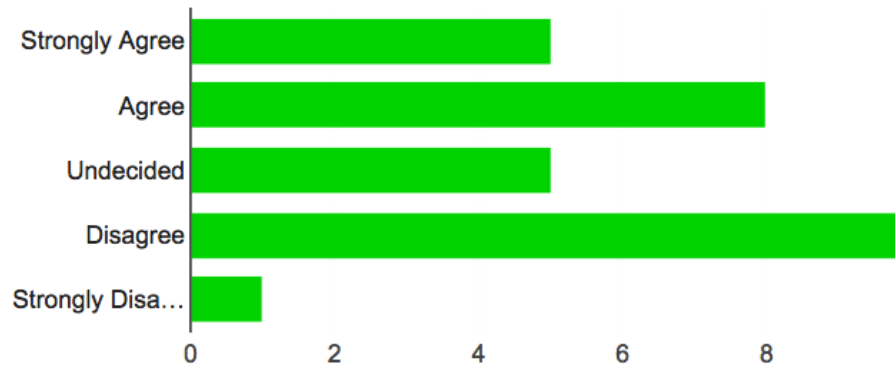


With constant new platforms becoming out-of-date in social media us



# Threats – uncertainty re costs for the organisation

## IT hardware/software costs



## Staff costs

