

Breakout discussion summary

ELF PATIENT ORGANISATION NETWORKING DAY 2020

A summary of the discussions held about the COVID-19 pandemic and how it has changed what you do, both as individuals and as patient organisations. The discussions focused mainly on what has worked well during this time.



Individual changes due to COVID-19

Negatives

I was very isolated and it was tough

Missed face-to-face meetings

No travels and hardly seeing my family and friends

I feel like life has passed me by

Positives

I enjoyed the time in quarantine as I got to spend time doing the things I enjoy and with my husband

Had to become computer literate

I've got to know people in my organisation better – those who are in different countries

Working from home has led to healthy habits and eating as more time to prepare

People have been taking holidays at home and seeing the beauty of their own country

Coping strategies

Coping strategies

I am trying to learn a lot and focus on the future, otherwise anxiety would take over. I have been using distraction techniques and games to keep my mind active

I have more 'me' time and have learned to chill out

I can't visit my sister who is ill so we have adapted by having a daily phone call

Patient organisation changes: adapting quickly to information needs

Understanding early the need to produce COVID information

Some conditions had less accessible information during the pandemic so more research was needed

We increased frequency of our newsletter

Challenging because of different government advice between and within countries

Government guidance was so simplified/ generic and not tailored to the needs of different patient groups

Using organisation's website as a means of communication and providing information

This crisis has taught us to look for better information from official channels and to distribute online via webinars, group leaders meeting, online engagement, social media, etc

We experienced more enquiries from around the globe and so significantly increased activity connecting people with clinicians to try to give as much support as possible

Less travel - but busier!

Organisations were busier than usual having to search for information and share it with members. And had to work out how best to disseminate

My patient group has been meeting more often as it's easier to do so online

COVID made us busier in comparison with the time we spent working for our associations when we could travel to attend meetings; the time invested with the community is now actually longer

Working from home is not less time consuming because you are more engaged online but it's an improvement for patient engagement with the organisation. Even though it's a difficult change

Membership of our organisation increased by 30% thanks to better awareness in the media

New activities

Everything went digital and moved online

We set up a dedicated helpline and offered a range of tools e.g. a phonenumber as well as digital information was important

We developed webinars and online group meetings

I am amazed how well everything worked with different systems like Zoom, Go to meetings etc

We invested in helping to improve the mental wellbeing of staff including how to set boundaries between work and home

So grateful that we had the internet and many digital meetings even if it was scary in the beginning

More online relationships with patients e.g. our national meeting went online and we have more meetings

We set up web support groups and had chatrooms and it was very important to keep in touch

Greater coordination and collaboration between different organisations

Replaced member meetings with online versions

Promoted physical activities and had programmes online for members

More online working

ADVANTAGES

- Easier for some people if unwell as there is less travelling
- Busy people (clinicians and politicians) are more accessible online
- Efficient in terms of time and getting business done

DISADVANTAGES

- Lose human factor and personal interaction
- Excludes people without access to the internet or with language/hearing difficulties
- Downside is all the connectivity issues with Zoom meetings

Relationships with health care services

As doctors were too busy, the role of patient organisations increased and strengthened

Our organisation created a superline to talk with team of respiratory physicians who answered by Zoom/Facebook

Nurse helplines became overwhelmed in some cases

Too much 'fake' news during first weeks. Nobody knew anything including healthcare professionals so patient organisations had to step in to support and provide information

Issues which had been ignored by clinicians for years e.g. fatigue, breathlessness, were gaining recognition and research interest

Australia has moved to telehealth sessions, which have been positive due to flexibility

Greater flexibility = increased attendance rate to appointments

Ireland have been able to expand services to a WhatsApp service to connect patients with clinicians directly via text

Relationships between associations and medical societies/ doctors improved. We looked for an expert, built relationship and raised our profile

Has made clinicians more inventive and innovative

Within UK the different nations have taken different approaches, may potentially be a role for charities in analysing this

Financial difficulties

**INCOME STREAMS HAVE
DRIED UP**

**STAFF LAID OFF OR MADE
REDUNDANT**

Raising awareness

Lung health is now on the table

Helping people with Alpha-1 to get transfusions and treatment with hospital closures was a challenge, but became an opportunity to create awareness about home therapy and a better use of the online tool

Our patient organisation has opened up good links and communication channels with policy makers. We hope these new connections will create productive discussions and advocacy in the future

People have spent less time travelling and this is also better for the climate

The general public have had a small taste/ understanding of what it must be like to be a patient with a lung condition and have to stay at home, fearing infection if you leave home or being too ill to leave home

Created a sense of solidarity and collaborations to help vulnerable people, and towards “the greater good”

Reduced stigma of masks wearing

Has been very challenging for patient organisations to stay above political commentary when you feel the government is not doing enough. Have set up a private Facebook group where members can air their frustrations more openly

What will you continue to do?

Continue links with more organisations, big and small, to share best practice

More ideas pooling/sharing, especially cross-state, regions and countries

Build on the new collaborations and maintain better coordination of activities

At least one day working from home and more digital meetings and less travels

Having webinars was very appreciated

Move to more online meetings and conferences as they are less costly to run and allow more people to join from wider geographical area

In Italy we are going to host all the meetings online now and have understood how important being able to connect in this way is for so many people and as an association we want to be more active online