

Patients in a digital world

Three questions on digital engagement and solutions during the COVID-19 pandemic

EPIS 2020 mini-interview series booklet



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Introduction

Patients in a digital world: the experience of patient groups across europe during COVID-19

There is no doubt that COVID-19 has changed our lives and created challenges that we could never have anticipated. Thankfully, digital technologies have come to the rescue and helped us navigate the diverse challenges faced to stay connected and secure the information and support we need to live as well as possible through this terrible pandemic. Many countries worldwide experienced a strict lock-down and patient organisations had to quickly adapt to a new reality and find ways to connect with patients, many of whom had to self isolate because of their risk of getting the virus.

Patients' experience of digital engagement during COVID-19 is the focus of the 2020 edition of the European Patient Innovation Summit (EPIS). In preparation for the event patient leaders from across Europe were interviewed to learn more about patients' experiences of digital engagement and to understand what can be done to support digital engagement in the future. This booklet contains feedback on the experience of digital engagement from leaders of 14 patient organisations. Some common themes emerged in the interviews which are summarised below.

COVID-19 has acted as a catalyst to accelerate the shift towards digitalisation of healthcare and forced us to accept virtual communications as a normal part of our

daily lives. Many patient organisations already had experience of using existing social media channels, messaging apps and web conferencing, however, COVID-19 created an urgent situation where there was a need to dramatically increase the use of different technologies. This enabled patient groups to stay connected with members, address their concerns about COVID-19 and provide them with the crucial information they needed on how to stay safe.

The learning curve was very steep and challenging for patient organisations, but despite this, patient groups were able to rapidly produce information resources in different formats, often created in collaboration with health professionals, on how patients could navigate the challenges created by the pandemic. Patient groups also signposted patients to webinars hosted by professional societies and governmental organisations such as the World Health Organisation. A few organisations also created mobile phone apps and used these to make a range of resources available to patients. There was general agreement that apps have huge potential to bring benefits to patients and therefore something to be explored further. Another important consequence of COVID-19 for patients has been the increased use of remote consultation which has allowed patients easy access to clinicians and reduced the need to travel to

clinics – an important benefit for patients who are more vulnerable to infection with the virus.

Although the increase in digital engagement during this difficult period has had many benefits for patients, a number of challenges have also been faced. Many patients, especially elderly people, have struggled to use digital technologies which means they have not been able to get the best out of digital solutions. Access to the internet and to digital solutions have also posed big challenges for patients. This has led some patient organisations to call on governments to initiate digital literacy initiatives. Another challenge faced in the era of COVID-19 has been that patients really miss human interaction not only with their peers but also with health professionals. Despite the many benefits of remote consultations, some patients have really struggled to communicate with health professionals using digital technologies. Much work is needed to address this problem.

It would seem that COVID-19 is not going away any time soon and therefore patient organisations need to continue to adapt to the new realities faced so that patients can get the best out of digital engagement opportunities.

Europa Donna Albania

Donjeta Zeqa



ALBANIA

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top three digital solutions used by patients are websites, Facebook Live and podcasts. Patients also tend to use Zoom and WhatsApp.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of these digital tools has been that they help patients get the right information from specialists without creating confusion (which can happen with fake news and unreliable sources found on the internet). Patients are able to share reliable information with peers. Furthermore, these digital tools have provided patients with the ability to communicate with each other and specialists during this difficult time. It is welcomed that patients can ask questions directly via online platforms such as WhatsApp, Facebook, Facebook Live, private groups on Facebook, Instagram Live and podcasts and get answers in real time.

The challenge has been that not all patients are able to use these tools, as they may not have access to the latest technology. Sadly, not all patients are digitally savvy and know how to use Zoom or other digital solutions outlined above.

3. What resources or tools would you recommend to support increased digital patient engagement?

It would be great if all our patients had access to an app. We know the challenges of providing support and educational programs for patients, but they are very necessary and the pandemic has highlighted this further.

There are many resources and tools that we recommend to support increased digital patient engagement. These include resources provided by [ESMO](#), [WHO](#), [Cancer Research UK](#), [Patient Power](#), websites dedicated to breast cancer and the wider patient advocacy community. We also recommend that patients attend webinars and virtual meetings such as ESMO Breast Cancer 2020 (virtual), ABC Global Alliance webinar on COVID-19, Advancing Requirements for Quality Breast Cancer Care (virtual), CEETRIS PTS Meetup (virtual) and the ESSO Webinar: BRESO Breast Surgeon Certification Programme.

Cyprus League Against Rheumatism (Cyplar)

Andri Phoka



CYPRUS

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top digital solutions that Cyplar used during the COVID-19 pandemic are Facebook, YouTube, Zoom and Instagram.

The reason for this is they are easy to use and very popular with the general public. Live videos have been made possible via YouTube with healthcare professionals, and other experts.

Facebook has become more popular with our members and helps them stay close to our organisation. It helps keep patients informed and provides a way to communicate with us.

Zoom interviews and webinars with doctors and health professionals are also easy to use and popular with patients.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of using these digital tools has been that they make it possible for our members to be connected and updated at any time during quarantine. They also allow us to get closer to our members and the wider population in Cyprus.

The challenge that Cyplar faced is the difficulty in reaching older members using digital tools. We had to think of other ways to keep them informed. Another challenge is the lack of knowledge and skills of some of our members to be able to maximise the reach of digital tools.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are various resources and tools that could be recommended to support increased digital patient engagement. We would recommend Facebook, YouTube and Zoom. The reason we prefer these platforms is that they are flexible, easy to use and widely used. It was very useful to use Zoom for webinars on themes like diet and physical activities during the pandemic. In addition, Zoom provides the ability for the participants to interact during the discussion. YouTube is a very good tool for videos and we used it to create some filmed interviews with a rheumatologist who answered patients' questions regarding their medication, their health in conjunction with COVID-19, and many other questions that patients had during the pandemic. These videos were also uploaded to our Facebook page and members and their families can now watch them whenever they want.

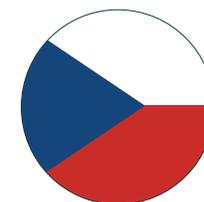
Videos can be found here:

<https://www.youtube.com/watch?v=HH0MINiTE5I>
https://www.youtube.com/watch?v=_v_8vM4G-E
<https://www.youtube.com/watch?v=uKaPlwQmyA>
https://www.youtube.com/watch?v=W7ZD_IHC9uU



The voice of cancer patients (HOP)

Ivana Plechatá



CZECH REPUBLIC

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

I do not believe that the vast majority of Czech patients used digital solution tools other than telephone and e-mail during the COVID-19 pandemic. However, drug prescribing is in the form of e-prescriptions.

E-communication is not widespread among Czech public health service providers and tends to be used more with private providers.

On the other hand, patient organisations have learnt to use Zoom, Microsoft Teams and other tools for their communication.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of digital tools has been that, thanks to e-communication, members of patient organisations were in more frequent contact and were able to continue with projects remotely.

We assume that the use of digital technology by health providers will accelerate e-health provision and further digitalisation of the Czech Republic healthcare system. Patient pressure for this change will be through patient organisations.

3. What resources or tools would you recommend to support increased digital patient engagement?

We have no specific recommendations for digital tools other than those already mentioned (Zoom, Teams, Google Meet).

German Rheuma League (DRL)

Dieter Wiek



GERMANY

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

A large number of patients visited the DRL website as a digital solution to manage their health during the COVID-19 pandemic. The general and medical information provided by the German League is highly appreciated as it is regarded as evidence-based and independent information. Different forums with experts have been a great support and enable an exchange of experiences.

In particular, people with inflammatory rheumatic diseases have lots of questions, for example, whether they are at a higher risk due to their illness or medication.

We also saw that patients used online exercise videos, and relaxation podcasts available on YouTube or via the DRL app, to help with their lack of physical group activity.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

A positive aspect has been that people now use these digital tools – websites, forums, apps, videos, podcasts – and are becoming more acquainted with them. The challenge associated with the use of these tools has been how we manage to reach elderly individuals and so-called vulnerable groups, who do not use these digital tools.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are various resources and tools that could be recommended to support increased digital patient engagement. For the German speaking community we recommend the app Rheuma-Auszeit and also further information can be found on the [DRL website](#).

For English speaking individuals, patient information on rheumatic musculoskeletal diseases (RMDs) and COVID-19 can be found [here](#).

A repository for clinicians can be found [here](#).

Greek Patients Association (GPA)

George Tsiakalakis



GREECE

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

Information gathered from the GPA helpline shows that Greek patients do not widely use platforms such as Skype or Zoom to communicate with their doctor or other healthcare professionals. In a sample of 4,300 chronic patients who called the helpline, only 4% preferred internet communication compared to face-to-face contact. In contrast, 75% of the sample had used the e-prescription system at least once during the pandemic period. This is a measure recently put in place by the Greek government to facilitate patients' access to medicines and medical consultations without the need for a physical visit to the doctor.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

E-government has been used very little in general in the public sector in Greece and especially in the field of health. During the pandemic, the Greek government took important steps such as electronic prescribing. This reform has facilitated the daily lives of chronic patients and improved their access to the healthcare system. However, increasing the electronic literacy of chronically ill patients, especially the elderly, remains a challenge that impacts the implementation and utilisation of e-health.

3. What resources or tools would you recommend to support increased digital patient engagement?

Both the state and patient representatives in Greece should invest in the development of patients' skills in using the internet and digital communication tools. The GPA has launched a series of videos to spread information and tips regarding the use of applications such as Viber, WhatsApp, Skype and Zoom. However, we recognise that this initiative has had limited impact. In cooperation with the state, we should design and implement an overall strategy to increase e-literacy in the medium term in the general population and especially in vulnerable groups, such as the elderly and chronic patients.

Hungarian Transplant Federation

Judit Berente



HUNGARY

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top three digital solution tools that are most in use by patients are Facebook Messenger, Microsoft Teams and Skype.

We provided important information every day, prepared informative videos which were posted both on social media and our website.

Small team meetings were held mostly via Messenger, because it can be easily used by 3-6 people from either mobile, laptop or tablet. Participants can see each other during the meeting and can communicate very quickly using short text messages.

Microsoft Teams was also used when various documents were prepared. Skype mostly was used for talking with patients regarding personal matters.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of these digital tools is that they are very easy to use, allowing different working groups to be created so we could react very quickly to any problems or situations. New information was shared very quickly with patients.

The challenge associated with the use of these digital tools has been that, after a while, patients got tired of digital work and communication as everyone missed personal contact.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are so many resources and tools that could be recommended to support increased digital patient engagement, it always depends on the task you need to do. It is important to raise awareness among patients to be open and use these tools. Social media and website campaigns on interesting topics may help to involve more patients.

Migraine Association of Ireland (MAI)

Sadhbh Armstrong



IRELAND

1.
We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

In our experience, the digital solutions that we have used are Zoom and Facebook live. Zoom and Facebook Live have been used by the Migraine Association of Ireland to host information events and seminars during the Covid-19 pandemic. Migraine Association of Ireland, has also developed their self-management course for people living with chronic migraine and new daily persistent headache, as an online course that has been delivered through zoom. Some Healthcare professionals have also used this platform in their work.

I do feel the majority of healthcare professionals use phone consultations as the main tool for communicating with patients for their appointments during this time with virtual consultation as second choice.

2.
What has been the positive impact of the use of these tools, and what have been the challenges?

The positive implications have been the ease at which patients can access a specialist or information. Patients living with migraine find travelling difficult and being in hospital environments can cause a lot of disease triggers. Using technology has helped with this.

The biggest challenge has been the over-reliance on online platforms which is causing fatigue. The lack of human interaction has also been difficult for some people living alone.

3.
What resources or tools would you recommend to support increased digital patient engagement?

I feel this is an area we need to improve on if we are to continue using online platforms to continue our work. For example, we would need to investigate online platforms that offer a filter to ensure they are friendly for people living with migraine or primary headache disorders.

Italian Association against Leukaemia-Lymphomas and Myeloma (AIL) / Italian Association against Leukaemia Patients Group

Felice Bombaci, Giuseppe Giofrè, Mario Tarricone



ITALY

1.
We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top three digital tools most in use by patients are WhatsApp, e-mail and Zoom. This is because they are more widespread and easy to use. In particular, e-mail and WhatsApp allow one to one doctor-patient communication. We find that Zoom is generally used for family reunions and informative webinars.

2.
What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of these digital tools has been that they have allowed effective, unfiltered communication between doctors and their patients.

Digital tools were also useful for caregivers to interact with the doctor and in some cases to be able to participate (virtually) in the medical consultation, something that is normally only possible for the patient. These tools also allowed patients to keep communicating with their family members (as in the case of bone marrow transplant (BMT)).

The challenge has been the lack of physical contact with the doctor, which normally adds value to a consultation.

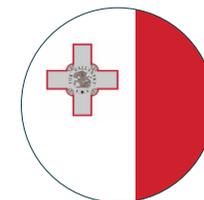
3.
What resources or tools would you recommend to support increased digital patient engagement?

During the pandemic, the AIL patients team increased its services to support patients and their families:

- With interactive online patient medical seminars, providing expert information to patients and family members: <https://pazienti.ail.it/archivio-seminari/>
- A toll-free number was set-up dedicated to consultations with haematologists, psychologists, and experts regarding social welfare issues: <https://www.ail.it/area-pazienti/covid-19-e-pazienti-ematologici>
- To analyse the impact/burden that the pandemic has had on patients and their families, we created and published an [online questionnaire](#) with the aim of investigating the management aspects of the care path, level of healthcare services available during lockdown and the challenges faced by patients.

Arthritis and Rheumatism Association Malta (ARAM)

Mary Vella



MALTA

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top three digital tools that are most in use by patients are Zoom, Microsoft Teams and Google Meet. These digital tools have been widely used on a national level because they are renowned for their reliability. Furthermore, the online camera functionality makes it easier to interact with participants and share documents online. Sharing documents has facilitated the productivity of meetings/workshops/projects and discussions.

As well as the tools outlined above, HCPs are providing appointments via telephone, Microsoft Outlook and Gmail. The best way to reach our members at ARAM has been via WhatsApp, Facebook, Twitter and Instagram.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact has been that, both as a patient and patient group representative, I have been able to remain in contact and participate in online meetings, seminars and information sessions, despite face to face meetings coming to a halt. Given the diversity of online sessions, I have learnt more about best practices shared by others; had access to new content, studies and research; learnt how patients are adapting to new lifestyle challenges; and experienced the importance of sharing knowledge. I have learnt about how others are reacting to developing outcomes of the pandemic.

The challenge has been keeping up with the increased number of online meetings. I discovered that I needed to be more selective and choose the most relevant to me as a patient group representative and patient.

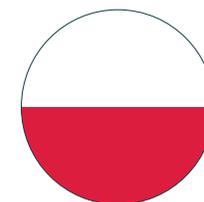
3. What resources or tools would you recommend to support increased digital patient engagement?

M-health apps are increasing in popularity and I believe they have become a necessity to both patients and clinicians. By embracing m-health, patients can keep track of their own health data in real time and inform healthcare providers of any abnormalities at the push of a button. In Malta, citizens are encouraged to make more use of <https://myhealth-ng.gov.mt/>, which provides access to laboratory results, outpatient appointments, procedure appointments and records of your pharmacy of choice.

In my opinion, at a local level, patients seem to prefer telemedicine. Somehow patients seem more reassured by verbal communication, rather than e-health and/or m-health. I feel our country desperately needs a national educational campaign about the benefits of e-health/digital solutions in patient engagement. This needs to be backed up by training on digital literacy and on the use of digital devices.

Further information can be found [here](#).

Smart watches such as Fitbit, Google, Apple watch are also very useful tools.



1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top connection tools that are most in use by patients are meeting and webinar platforms such as Google Meet, Zoom, Microsoft Teams and ClickMeeting. The use of mobile phones has also increased for medical consultations. In terms of social media platforms, Twitter and Facebook are the most in use. They allow patients to get information and links from experts, scientific societies, and government institutions. Furthermore, patients have also been visiting trusted websites with health-related content.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of these digital tools has been that they facilitate home-based telemedicine and communication. They allow patients to participate in events without travelling and to receive information in real time.

The challenge has been that it is often hard to work from home due to the presence of children, small working spaces, and internet connection quality, etc. There is also a lack of personal contact, connections, and human relations.

3. What resources or tools would you recommend to support increased digital patient engagement?

I would recommend the use of all the digital tools outlined above. Further resources that we recommend can be found here:

- [Alivia Foundation webinar](#), dedicated to cancer patients in the time of the pandemic, which was advertised on Facebook and watched by over 40,000 users so far.
- At the Alivia Foundation, we also created a portal with information dedicated to oncology and cancer treatment during the pandemic. This included current information about the availability of oncology centres, scientific oncology association protocols, recommendations on how to act during this time and governmental news related to oncology. The [portal](#) has been visited by over 50,000 users, all spending more than three minutes on the website at a time. We raised awareness for this portal by using social media to reach our patients.

PSOPortugal - Portuguese Psoriasis Association

Jaime Melancia



PORTUGAL

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

Many of our patients interacted with the PSOPortugal social media channels, in particular our Facebook page. Patients posted comments and questions through Facebook about the potential risk of COVID-19 within the psoriatic patient population and whether they should stop treatment.

Patients also used direct e-mail or our website contact form to ask these questions. The telephone was also used to call their dermatologists, mostly in the private sector as it is difficult to reach doctors working in the public sector.

Webinars, hosted mainly via Zoom, were highly attended by patients, in particular those that included dermatologists.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

A positive impact has been that people had easy access to reliable information, not only through live virtual events, but also through recorded ones. It is great that a lot of people are already familiar with using smartphones to access internet, so they were able to connect with us during the pandemic.

The Portuguese Psoriasis Association Facebook page and website provided reliable and comprehensive sources of good information in Portuguese.

The challenge associated with the use of these tools is the issue of reaching elderly patients, who are not familiar with, or have no access to, the internet or other digital solutions. For this patient population, television is still the main source of information.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are various resources and tools that could be recommended to deliver education and information to empower patients, using "patient language".

There are tools that help general practitioners (GPs) to better diagnose psoriasis and recommend treatment for mild to moderate psoriasis. GPs may want to use artificial intelligence (AI) from pictures of skin lesions to make a diagnosis.

There are also apps to help patients manage the disease together with the doctor.

Teleconsulting with the dermatologist is an easy way for patients living far away from the nearest dermatology clinic to book a consultation and reduce their travel cost, and time spent traveling to an appointment.

Federation of Cancer Patients Associations (FABC)

Gabriela Saulea



ROMANIA

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top three digital solution tools that are most in use by patients are the Uber mobility app, on which we offered vouchers for free transportation for patients, website instant messenger and a customised online platform for patient navigation.

Digital solutions that patients have used to manage their health due to the COVID-19 pandemic include real time information from websites, Facebook, Zoom meetings / presentations and YouTube video streaming.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of these tools has been an improvement and increase in communication with our patients. As a non-profit organisation, our activity has been more valuable, and we reached areas we have never touched before the pandemic. A great impact was created by the Uber mobility app (providing patients with vouchers for free transportation) and a customised online platform for the ease of patient navigation.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are various resources and tools that could be recommended to support increased digital patient engagement, for example, interconnected enterprise resource planning (ERP) and social media. Finally, custom customer relationship management (CRM) could be used to guide and provide services for patients.

Slovak League Against Rheumatism (SLAR)

Jana Dobšovičová Černáková



SLOVAKIA

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

The top digital solution tools that are most in use by patients are email, Facebook, newsletters and a variety of communication tools such as Zoom, Microsoft Teams and Skype.

Due to the COVID crisis, a lot of our members and other people with RMDs had questions and used these tools because there was no personal contact, no face to face meetings or events.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

The positive impact of the use of these digital tools has been that we manage to reach more people, not necessarily only our members. An advantage is also the choice to watch live sessions of webinars, as well as download recordings at a later date. We can provide complex information and people do not need to travel anywhere – they can watch the sessions from their homes.

The challenges associated with the use of these digital tools have been that some patients may find it hard to learn how to use these communication tools, that people needed support at the beginning, and sometimes had difficulties accessing online activities.

3. What resources or tools would you recommend to support increased digital patient engagement?

There are various resources and tools that could be recommended to support increased digital patient engagement, for example, a webinar on psychological support during the pandemic found [here](#).

We are also in the process of creating yoga videos specifically for patients with RMDs.

We were very happy with using Facebook live sessions and Zoom virtual meetings and webinars.

Slovenian Lymphoma and Leukemia Patient Association, L&L

Kristina Modic



SLOVENIA

1. We have seen an increase in the use of digital solutions by patients to manage their health due to the COVID-19 pandemic. What digital tools do they use most and why?

During the COVID pandemic, we informed patients and their relatives on a weekly basis, sending them a variety of high-quality support content, making it possible for them to manage their disease, treatment and to deal with their time in quarantine.

Patients were informed and supported via newsletters sent by e-mail, web pages managed by the Association, Facebook, YouTube and Zoom. The content was prepared by professionals in the fields of haematology, oncology, clinical nutrition, physiotherapy, kinesiology and psychological support. Members of the Association and other professionals were at the disposal of patients and their relatives to help and inform them via e-mail and telephone 24 hours a day, every day of the week.

2. What has been the positive impact of the use of these tools, and what have been the challenges?

Patients received individual/group support and high-quality information despite quarantine and cancelled consultations. We held e-workshops and a live information day. Patients adapted well to these new communications tools which gave access to the Association's programmes to patients across Slovenia. When COVID-19 measures were introduced, patients became motivated to look at online content and communicate via Zoom. We were successful in implementing the rehabilitation programme for patients with blood cancers online, which involved pre-recorded exercise videos and online consultations with a clinical dietitian and psychologist. The healthcare professionals who worked with us also adapted to these new forms of communication well.

The challenges have been bringing the use of video-conferencing systems, e-mail and social networks to older patients, and the additional costs associated with increased communications with patients and online programmes.

3. What resources or tools would you recommend to support increased digital patient engagement?

Our Association used various approaches to support patients with digital engagement. I recommend the following approaches that have a wide reach:

- Providing information via electronic mail on a weekly basis (newsletters)
- Regular recording of videos with professionals to provide supportive content for patient. Videos were regularly sent via electronic mail as well as posted on our YouTube channel, website and Facebook page
- Quick redirection of the rehabilitation programme from being performed live to being performed online: <https://www.nazajziviljenje.si/>
- Providing information via Facebook (on the Association's page and in the closed group for patients with blood cancers)
- Use of Zoom for consultations and workshops

EPIS is co-created with the EPIS Steering Committee



Birgit Bauer
European Multiple Sclerosis Platform



Mathieu Boudes
European Patients' Forum



Denis Costello
CML Advocates Network



Christina Fasser
Retina International



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Neil Johnson
Croí, Cardiac and Stroke Foundation Global Heart Hub, Ireland



Patrick Little
European Migraine and Headache Alliance



Susanna Palkonen
European Federation of Allergy and Airways Diseases Patients' Associations



Gilliosa Spurrier-Bernard
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