EXPERT PANEL REPORT FROM A WEBINAR HELD ON 21 APRIL 2020

Short & long term implications of Covid-19 on patient engagement & advocacy

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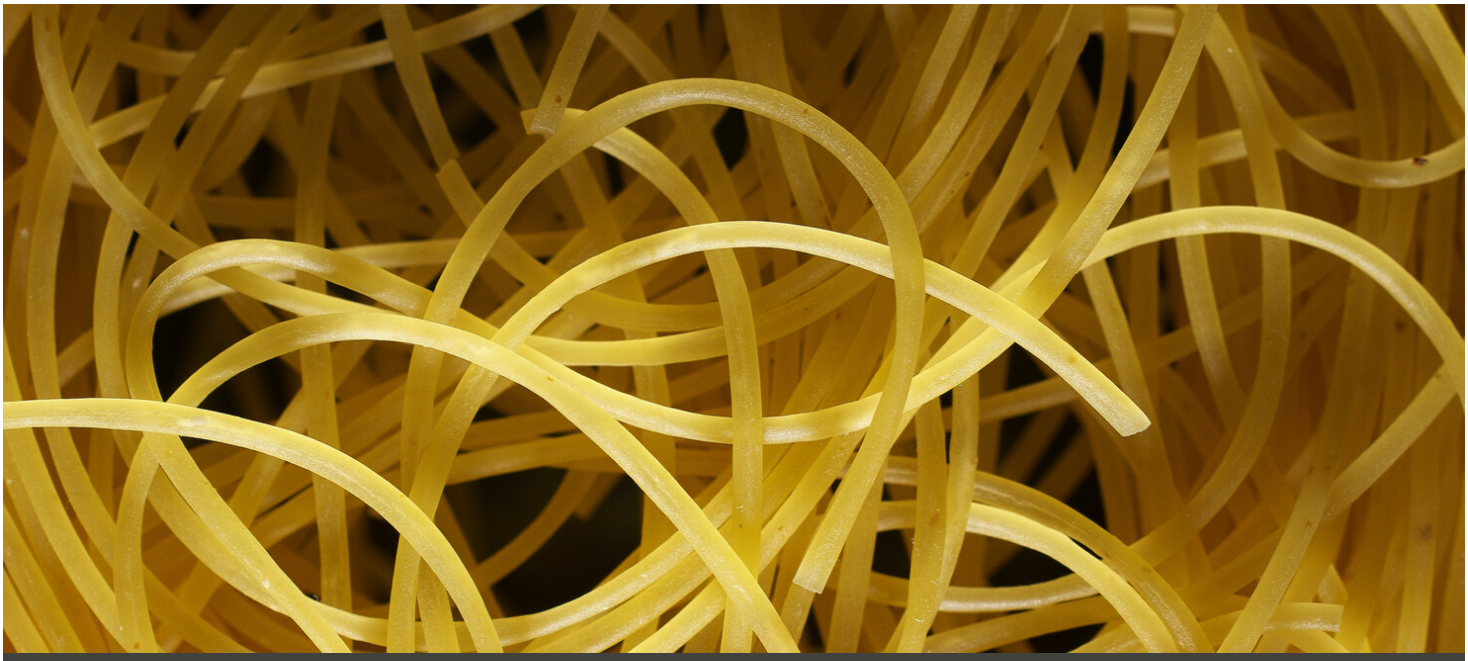

What are the implications for patient advocacy & engagement?

Despite the catastrophic & unpredictable effect on society, one of the themes coming out of the webinar was COVID-19 being seen as a force for positive change at many level of healthcare; Global, European and National with a greater patient focus, more informed collaboration between all stakeholders. Co-creation of future initiatives being a recurring theme.

The healthcare agenda for the foreseeable future will be very heavily, perhaps exclusively focused on COVID-19. Already resource-limited patient groups, will have to break through this new reality to ensure their own specific disease agenda is heard. To do this in the future, patient engagement and advocacy initiatives with the patient groups and communities must tie in the specific disease with COVID-19 and make it relevant to the new health policy landscape.

How this will be achieved will mean looking at new ways of working, rethinking existing procedures and redesigning ways of working amongst others. Taking a quote from another webinar on the same topic, it may be a little like throwing spaghetti on the wall in the early stages while the necessary deep thinking is being done.

Digital communications, allowing more virtual working, will mean redefining the advocacy relationship. There will be a need to adapt the learnings gleaned from patient engagement over the years to this new digital driven advocacy world and this means a greater focus on improving patient health literacy. The social isolation of disease will be viewed far more sympathetically. COVID-19 is breaking down traditional boundaries. Many of tomorrow's new treatments and services were developed in a pre COVID -19 time but will be launching in a post COVID environment. Future patient engagement and advocacy will have to ensure that even more, there is the triple win, The Patient, The Industry and the Health System .

Webinar expert panel

Nick Hicks, is the Director of Commutateur Advocacy Communications. He supports advocacy leaders within life science companies to build & implement their patient engagement strategy.
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Dr Albert Farrugia is a well-recognized bio-therapeutics consultant, patients rights advocate and is a member of the bleeding disorder community.
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Pedro Carrascal is the President of the European Multiple Sclerosis Platform and CEO of the Spanish MS society.
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Gareth Powell is Business Development Officer with the UK's National Institute for Health Research and supports the life sciences to engage patients' clinical design.
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Webinar expert panel

Each speaker was asked to provide a three minute review of the short and long term implications of COVID-19 on patient engagement and advocacy before being asked to summarise the three main points from their perspective. The audience of Industry, Patient Groups, Patient Advocates and Academia were then invited to ask the panel questions.A slightly edited transcript of the meeting is attached. Wherever possible the text is a faithful reproduction of what the speakers said during the webinar.

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SUMMARY: NICK HICKS

Covid-19 is going to create a more informed understanding of the importance of the emotional burden of disease, particularly social isolation and mental health, a subject which is very often neglected by regulators and HTA.

The patient groups with whom we work will be at different places in the transition to the new norm and we shouldn't assume we know where each of the groups are. There'll all be in very different places. In industry, we're going to need to use appropriate supportive and engagement strategies in helping the patient groups make a successful transition.

Digital communication is going to become a far more new way of working, especially in clinical trials and patient engagement. We must make sure that the learnings we've already had over the past years in patient engagement are not lost, but they're used in moving forward.

"In industry, we're going to need appropriate supportive & engagement strategies, in helping the patient groups make a successful transition."

SUMMARY : ALBERT FARRUGIA

Well, as I initially said, we are living still in a historical event. This is really going to change everything. I think that is rapidly sinking in. I think moving forward patients need to in some ways seize the day. There are a number of opportunities. The authorities, which we all engage you on, whether they are regulators, whether they are policy makers, finance reimbursement type agencies, they are needing all the help that they can get. I think that it falls on us to make very rapid and voluble representations in the way that we can do this.

I think we've discussed some of these in this webinar. I'll go over a couple of points which I myself have intimated as being my main areas of interest. In the area of publication peer review, there are ideas around how we can make those easier. I myself have some findings on these which hopefully I will publish myself.

In the area of clinical trials, well we have spent, encouragingly quite a lot on that and I think the involvement of patient organisations, this is done very much by haemophilia societies in Europe, European Consortion and in particular the haemophilia society of Ireland who make very direct representations to insert themselves into the process, knowing full well that especially with these disorders, many patients know more most normal physicians with all due respect.

" So I think my summary is Carpe Diem"

SUMMARY : PEDRO CARRASCAL

The last point here, connecting the current situation with the future. Of course I am aware of some limitations of the patient organization sometimes, but things have been moving in the last years. As an example, I was talking previously about the patient organization umbrella in Spain. Plataforma de Pacientes was created in 2014. We have been doing a lot of things.

There are a lot of things still pending to be done. I've seen also some of the comments in the Q&A panel. But of course these new moments need new models.

We need some flexibility and those patient organisations ready to face them and there are more and more, more than five years before. They are ready to be a greater stakeholder for this new situation because sometimes the public part, the private part, the health system, and the companies and others are just facing those sorts of flexibility in different moments, so I want to put the stress and underline the value of those more developed and more ready to manage the new situations, the value they could put on the table of these new models and the flexibility needs for the future and for facing these new needs.

"They (patient groups) are ready to be a greater stakeholder for this new situation."

SUMMARY : GARETH POWELL

As difficult as this time is, we have to see it as a catalyst for change and for positive change as well. We've mentioned about the collaboration we're seeing between both the life science industry, patient organizations and patients as a whole, and this new kind of uptake in awareness in clinical trials. This is really, especially from the industry as a whole, is an opportunity to re-brand effectively, to put clinical trials into the limelight, to showcase how important they are. But equally we need to ensure that that collaborative approach continues right through moving forward. It's also good, from a political standpoint, it's a good opportunity to showcase the benefits of healthcare R and D spending.

We're seeing an increased, globally, increased funding into the healthcare environment and hopefully that will continue to be the case and we'll continue to streamline and improve our processes both to manage global pandemics, but equally just for our ways of living. Social care for example is getting a new limelight shined onto it, a much needed limelight as well. I hope we will start seeing improvements in these areas as well. But, it is an opportunity to move forward. What we don't want to see is regression at the end of this. We need to carry on moving forward together.

" We need to ensure that that collaborative approach continues right through moving forward ."

SUMMARY : TAMSIN ROSE

We are living through a transformation event. I think this is a catalyst that is accelerating some of the things that were already happening in healthcare. I think the transformation of the health systems is going to move much faster. We've been forced to do as much as we can virtually and in an online environment. So it has been a big push towards telemedicine, remote consultations because there's been no alternative and they were blocked for a number of reasons before. So the digital transformation and the use of new tools to deliver care in more useful localized ways is going to continue. I think it's also opened up areas of collaboration within hospitals and within healthcare because people were very siloed in their own speciality, in their own discipline and what they did.

And now everyone's had to move out and learn something deep and see how other teams come together. What do they do, how do they manage safety? So I think this is a really useful horizontal thing that's had to happen across health and got people out of their silos. Much needed. We've been talking about it for years, never been able to make it happen. Covid 19 might've been the catalyst for change. There's also, within the overall focus of the health system environment, governments have woken up sharply to how critically important their life sciences industry is to them. And to their national security. So I expect to see a lot more government interest and not just from the health department or even the education department, from the defense department, from the treasury, from the ministry of finance on how do they custom, build and strengthen life sciences.

And that goes beyond just medicines. It's also going to involve devices but it's also going to involve new forms of innovation. So I think there'll be suddenly health systems and their manufacturing is going to be a key thing that governments are going to want to invest in and see happen on their territory, not just part of global supply chains. And the final element I want to leave you all with, which is a bit of an open question for me. For years we've had problems with vaccination. In Europe, we're exporting measles problems back to the rest of the world. We have historically high levels of mistrust in the vaccination process. The only way to get out of the lockdowns we're in now in the future is going to be a vaccine. That's our big hope. But you know, there's been a survey in France saying a quarter of the population wouldn't take it because they distrust vaccines. If your ability to leave your home and go to work is affected by whether your neighbour is prepared to get a vaccine, this is a very different conversation about the relationship between individual choice and public good.

" I think this is a catalyst that is accelerating some of the things that were already happening in healthcare."

Q&A

Nick: Pedro, I have a question for you from a European patient group perspective and from a national patient group perspective. Where do you think patient groups are at the moment regarding their management of the situation? Are they still in the early shock stage or are they in a transition stage?

Pedro: Okay, thank you Nick. Well I see here three scenarios, not only one because we are facing different situations. We are facing the situation of the advocacy and we were talking previously about the information consensus, the data registry or access to treatments for example. But we are also facing some issues about the service provided to the people with MS or to patients in general on the quality of life. And of course we are facing the economic and financial impact of the crisis. So in every different scenario, we are in a different state. We are still working on the advocacy issue. I have seen in the Q&A that there also has been a comment about the advocacy role of the patient organization. So I would like to say that, I am not talking about the decision-making process. Of course, probably their ministry of health and their new teams and probably a new decision process has been created but in any case the role of the patient organisation has been to provide information, to put on the table the needs of the people with MS, to put pressure on how this needs to be resolved. And of course we have been working and gathering information with the various patient organisations. For example in Spain through Plataforma de Pacientes (POP) organisation. And we have been sending letters to the ministry about the crisis cabinet and we have been talking about what were the needs, we have been making surveys, we have been calling the hospitals, the doctors, the pharma companies.

So the role is clear. Probably we are not, we have not been involved in the decision processing those moments. But we have been replying weeks after and updated by the government, okay, we were reading your letters, we have been taking notes of what you were saying. So I think that has been in the process and representing the needs of the people or the patients. In any case there are different states and the mix of states will be the economic and the financial issues of course. How we can adapt and be more flexible with the providing of services for the patients.

Q&A

Nick: Albert, a question which just follows on from what Pedro was saying. And perhaps it's best share between you and Tamsin. What is the role of patient groups to ensure that clinical trials are being conducted, have a solid scientific basis and are ethical?

Albert: I think, you know, my main involvement is with the bleeding disorders community where I am very much aware that as a result of the adversity efforts of the past, you know, quite a few years now, many, patient representatives are actually embedded in those areas of regulatory affairs where you actually have an opportunity to have a say. I know that regulatory authorities such as the USA, several of the UK authorities, the Australian authority all have committees in which patient representatives, so called consumer representatives and also put in. So I think that there was already a very good grounding of infrastructure. As a result of what we're going through at the moment. I think that this is going to accelerate by leaps and bounds. I think that there's going to be a very rapid appreciation of the fact that in order to facilitate and accelerate a clinical development wherever it is possible, it's going to have to require a very and marked patient input because otherwise there is not going to be a sharing, an appropriate sharing of the responsibility. We have to appreciate that what we're looking at now with clinical trials is actually a substantial paradigm shift and in terms of the sharing of the responsibility, additional regulation has involved the sharing between the regulatory authority and the industry. I think that would be an inoculation into the system if you like, of more rapid and different pathways towards rapid approval. That responsibility is also going to have to be shared with the patients. And if that is not equally shared with the patient, it's not possible.

Tamsin: I think the first thing to say is traditional clinical trials or randomized, controlled trials are complex things. They're not like going to a kitchen and saying, "Oh, I'll add in a few more ingredients into my recipe". They take a long time. There are ethics committees that need to be dealt with. There are criteria for patients for eligibility, etc. So to be able to participate, for patient advocates to be part of that in a meaningful way, they've got to already have quite high level of understanding of health terms, how the health system works. They need to understand confidentiality issues, trust issues, ethical boundaries. So it isn't, I think, an easy case to say Covid is going global. It's affecting people all around the world. We've got critical trials happening everywhere, we can suddenly bring lots of patients into those types of trials. Because the trials that we, I think we've got going on for Covid 19 are emergency trials where doctors are just trying anything that they can, they're learning as they go along.

Q&A

Tamsin: Information is being shared very rapidly. It's very different from a kind of gold standard, carefully developed clinical trial where you would be comparing a new drug against existing treatment. We don't have treatments. Covid is a brand new disease. So I think it's a different perspective. I think the existing patient advocates who have experience of clinical trials would be extremely useful to be bought into the process because they can bring their knowledge, their historical understanding, their ability to provide input. I don't think anyone can be considered an expert patient on Covid 19 because even those who've been through it, what we understand is everyone's experience is very different. Our knowledge of the disease is growing very quickly. Now we understand it effects more organs of the body. It's no longer just a respiratory infection. It affects the brain, we're seeing kidney failures. So, it's an area where traditionally a clinical trial would be around a specific disease for a specific drug. Covid 19 has opened all of that up and we're not just trialling treatments. We're trialling how hospitals are organized. We're trialling triage, we're trialling public drive in testing. So we're in a completely new area for clinical trials with this disease.

Gareth: Part of the challenge of this which it has been alluded to as well as obviously some of these trials have been conducted on people who are in intensive critical care units, effectively on ventilators and one of the issues we have is consent for this. If they're being moved to separate units, for example, have we traced them through the system? We've got very difficult situations and likewise you have families who are in very difficult positions as well because their last moment with that relative or family member, whoever it might be, will soon be rushed out of the door effectively into an ambulance. They're not able to go and visit them in hospital. It's very disconnected. So we need to be very, very conscious of this when we're actually approaching individuals to provide consent on behalf of that individual. So we're looking at exploring new ways of how we can do this, but as I mentioned, it's very different from bringing a patient voice in regards to identifying what are the quality of life outcome measures compared to standard clinical measurements. For example, how do you integrate those two together. So having that different tiers of expertise, we're still very early on that process, it's still very rapid. This is the catalyst for innovation and new ways of working, but it's how do we embed that voice to make that easier when as we say everyone is effectively a patient advocate in this. How do we tie the two together? We're still in unknown territory largely.

Q&A

Nick: I'll open this question up to the panel. Is Covid 19, does it provide a greater opportunity to promote registries on a global scale and even extended international collaboration amongst authorities, patient associations, medical bodies and governments? Quick one Albert. What do you think? Quick, yes or no on that one.

Albert: So the answer to that is that I don't want to make Covid 19 the owner and responsible for all of the things which should be happening irrespective. Registries are here to stay. There are a zillion reasons for why they are doing this. I think we have to be wary of giving the impression that we are pushing everything on this epidemic. Having said that, I think that for the reasons already discussed during the epidemic they can be accelerated as well.

Pedro: I agree this is an opportunity to accelerate the process and I have seen during these months things that I didn't see before in years. In Spain, but also worldwide things are moving and the Covid registry could be used as an example of how we can accelerate the process for sure in the future. So I agree with that comment. I think that will be changed.

Tamsin: I think the importance of registries and the importance of sharing information is immediately obvious to everyone. I think the key question here is trust. Because you know, we already have certain amount of competition between countries about whether their death rates are higher or lower. Countries are being compared to each other as a way of seeing has the government done their job? And then other people say, yeah, but we're not comparing the s same things because the death rates are being measured in different ways. It's whether they're confirmed or tested. So this what you have in the area of something as simple as tracking mortality, all of these other criteria and political issues coming in. Now at European level it's been a work of 10 to 15 years to get some registries in place and it's still complex. Going global, and the importance of that's been shown to us from Covid, is going to be complicated by some of these political factors.

So what Covid19 has seen is what I would call political health diplomacy. So some countries are sharing information, they're sharing medics, they're sending equipment, they're branding side of their playing, from this country to that country. So it isn't as easy as saying this knowledge should all be shared so that we can have a global good, because there are lots of other political reasons behind it. And I think although Covid has shown us we need to do it at global level, the challenges of doing that, I think have just got a lot more difficult as a result of the political context of this pandemic.

Q&A

Nick: I'll also open this question up to the panel. How can patient groups be best supported at this time by the industry? And I'm talking CROs, pharma, medical devices. Okay. Does anybody want to give some insight into that?

Albert: These are the bread and butter issues. And I rejoice to see companies which I have an awareness of moving rapidly into the landscape. A bread and butter issue such as the supply of the medicine of products which chronic disease patients require. Given that we have this lockdown situation, given that access to hospitals is less easy, given that in fact life goes on for patients with chronic disorders and they do get mobility issues and they do get their health challenges, I see bread and butter issues such as the actual delivery of the product to be something quite important. Not very glamorous, but I'm glad to see that are companies who seek to be observers without necessarily seeing much glamour.

Pedro: I think the point there is to consider us as a stakeholder. So we are not a provider of information for example. We are not only a provider of services. We are all. So if we are not bypassing the patient organisation, we are using them strategically, because if we are supporting in information issues or we are supporting in, I don't know in advocacy, we are all the parts. We are strengthening the organisation and we are making a great favour for their future. So it's not only supporting economically. Of course it’s more than welcome from the governments or pharma companies and society in general, from individuals because the situation is incredibly difficult for us, but not only supporting economically, but also supporting strategically. I would want to underline again, not bypassing and trying to use as a whole. Not just using for this concrete proposal, those other proposals as a whole because a lot of things are impacting an outcome of the quality of life of patients, are provided by the patient organisation.

Q&A

Nick: A follow up question is how do you think, Covid 19 is obviously a devastating disease, but how are patient groups in other disease areas going to ensure that their health care agenda is represented at both a European and national level in the coming months when everybody's talking about Covid. I'll kick off with Tamsin perhaps on that one because it may be a more policy related question.

Tamsin: Yeah, I think to be quite honest that's going to be very hard because, governments are focused right now. They're still in emergency management mode. They're still trying to sort out getting PPE equipment to the frontline workers and you know, managing the critical care situation. So I think the chances of being able to engage in a meaningful conversation about anything else is, in the next three months, possibly six months, is very limited. There will be a moment where that sort of emergency time set moves on and there'll be a chance to reflect and there'll be a lot of focus on lessons learned. What did we do right? What did we do wrong? And how are we moving things forward? And there is an opportunity to say, well, you know, for patient organizations and patients who were recognized in this pandemic as being particularly vulnerable, what was the level of support? What was the role of patient organizations in helping to maintain these groups in security, make sure their needs were met, etc. And if we now understand that this pandemic is not going to go away, it's possibly going to come back. We're going to have more waves of it. It may become seasonal like flu, the importance of patient groups to help strengthen the resilience of people who are particularly affected for it, I think they will have an important place at the table to discuss this because at a certain moment we're going to move away from how do we manage this first wave to how do we live with this?

How do we deal with the fact that this is going to be coming back and back and certain sets of people will not just be vulnerable now they will be vulnerable again in the future and new people will be moving into the vulnerability category because there's some new research showing that if you live in a polluted city, your chances of getting a serious version of Covid 19 were higher than if you lived in the less polluted era. Wow. That creates a whole new set of vulnerable people. And patient organizations with all of their skills and knowledge have things to offer in that conversation.

Q&A

Nick: Gareth, Firstly, what is the NIHR doing to facilitate patient engagement? And how can a patient advocate get more involved to add value in the UK?

Gareth: I'm going to tie that into the previous question as well if I can. So at the moment, for example, the UK are focusing very much on the delivery of Covid 19 urgent public health research. Other trials are being suspended effectively, life science companies are putting these on pause because there isn't necessarily the resource, interest or the capacity to deliver those clinical trials. So in the long term as we start, hopefully being able to open these trusts to start delivering those, I won't say standard clinical trials, but non Covid clinical trials for example, in long-term conditions, I think the life sciences industry is going to have to find a way of both raising awareness and also the accessibility or these individuals, especially these at risk groups to be able to participate in these trials and that's where the conversation for these patient organizations, these patient groups are going to be necessary to come forward to support that.

And that's really where we're going to see patient advocates, being able to support and acting as ambassadors effectively for individuals living with life conditions, we have to do that. In the short term, at the moment, what we're trying to do is find opportunities and new ways of working for our own patient research ambassadors, our patient advocates to be involved where we can, and obviously it's a very challenging time at the moment. We are all very much focused on research delivery but then our challenge to remain fully committed to patient engagement and patient involvement where we can. In the short term, we're finding out what are the opportunities for that outside of intelligence dissemination for example, we're aware there is a lot of information going out which we touched on earlier. And it's ensuring that the right information is reaching the right audiences. So it really depends effectively on local situations. I think to be involved with this, it's sign up, in the UK especially, is be part of research, the online platform for advocating for opportunities for that as well and also continuing to express your interest in being a patient research ambassador. Our patient involvement teams will be able to reach out to you directly and showcase the opportunities for involvement which are beginning to come through more and more, especially as we seeing online tools and platforms to enable the patient voice to come together effectively to be involved, not just in Covid research but in research in general. So we're talking about social research and social care in other areas as well. So it's very much a movable feast at the moment which I appreciate isn't the best answer, but I think it's something we're trying to rapidly mature and develop as we go on.

Q&A

Nick: Albert, how can scientific publications be rapidly peer reviewed? Is there a process for making this happen in the future because as you say, so many papers are coming out there which are not being reviewed correctly.

Albert: Without wanting to take up too much time but the area of peer reviewing for journals is a massive problem. I myself am in involved in this very, very directly. I get a lot of papers to review. I am finding it increasingly difficult to do so because what happens is that the main publishing houses basically use people like me as a source of gratuitous unpaid labour and we get more and more material because with the appearance of Covid there is already a massive scientific medical literature. In my opinion there are too many journals, just as there are too many conferences and too many of these kinds of activity. And therefore to accelerate the process is not easy. Already in the time that I've been involved, I've seen review periods or, major journals giving reviews to, giving papers to reviewers to review. Curtailing the time. They've already curtailed the time from about four weeks to about one. So really in the mainstream system outside Covid, this is already a problem. Now for many journals in the Covid era, this problem has basically been obviated by removing the system. In some journals the editor himself or herself together with a very small panel are making very rapid decisions. In others nothing is being done, which I find to be deplorable. I don't have an immediate solution to offer because I think that the amount of dross which has come out is in a minority. Much valuable information has been very quickly made accessible and above all freely. Because what you have to understand is that unless you are a subscriber or you are such as myself in a university environment, you cannot actually get papers unless you pay for them, which is another problem. It's a massive industry. So I think that making things more rapid, things are already very rapid. In fact, things are already too rapid and in some ways there are too many things. So all of this now is going to have to be very rapidly, like I used the word reviewed, once this crisis is over.

Q&A

Nick: I've got a very specific question. It's regarding the need to share more information with patients. For clinical trial patients, what type of information is crucial and missing today? Perhaps Gareth and Pedro may be the best two people to answer that.

Gareth: I think the difficulty of saying what information is missing isn't something we can really answer without first giving patients an opportunity to see what information is out there. So patient information sheets a lot of the time we don't explain. Obviously, there's a lot of regulation around. We can’s say this is going to provide a cure or this is going to improve your quality of life. That's obviously the ultimate goal of these trials. What we can't do is promise, because obviously at this stage it's sort of trial. It's still an unknown factor effectively. But a lot of the time we're saying, well when we're having these discussions, when people are being invited to provide their feedback on these documentation, to ensure there is enough information for people to make an informed decision on whether or not they want to participate in that trial is ultimately what is the purpose of that trial? What are they hoping to achieve? Not necessarily will it achieve, what are they hoping to achieve? And sometimes that's missing. The language itself. We've went on to about health literacy for example, without it being patronizing to individuals, we want to ensure it's easy to understand. Equally to ensure that it’s designed for people who have language difficulties or just a lower reading age than we may expect from a kind of an academic or clinical background, that they also have the opportunity to be able to digest that information. And we’re moving towards apps for example, or electronic consent. That bite size bits of information we're seeing where it's quite easy to digest, you can make that decision. And equally the carers, partners, people who are very close to those individuals who are making that decision with them as a unit effectively, they equally have an opportunity to participate in that decision and be fully informed with that. So the best thing I can really say is rather than us saying this is what’s missing. Put together the information. Give patients the opportunity to say, does this fulfil your needs, fulfil your requirements? Does that answer your questions effectively? And certainly at the moment, just to jump back from the earlier question about what can I do at the moment. There’s still a lot of feasibility. There’s still a lot of these companies wanting to answer these questions because now we have that opportunity to ask that, the timeline has been extended, so they can conduct that patient input effectively. So look for those opportunities to help with those conversations too.

Q&A

Nick: Pedro, do you want to give any insight into patients in clinical trials?

Pedro: I agree with those needs. The gap on the culture also of the collaboration with clinical trials is more wider than concrete needs and of course I agree with those. But in countries like Spain there are so many things that we need to work on and one of them is the accessibility. Making more attractive to the people. There are a lot of things that are a problem to participate in clinical trials. And one is the culture of participating in clinical trials. So yes.

Webinar transcript

Nick: Good afternoon everybody and welcome to the webinar on short and long term implications of COVID 19 on patient engagement and advocacy. Now situations like COVID 19 can be split into three phases. There is the first initial, the shock phase, where people are wondering, well, how is it going to affect me, the fear stage, Then moving on to the acceptance stage. It is what it is. Before then going into the final stages, which is the transitioning into the new norm and whether people realize that, that the new world is not the same. So where is patient advocacy and engagement? Well to help us answer this question, an expert panel from clinical research, patient groups, patient advocates and European health policy has been developed for today to attempt to answer these questions. I'm Nick Hicks, the Director of Commutateur Advocacy Communications and I'll be facilitating today's workshop.

Now, just a quick introduction to the panel. Dr. Albert Farrugia is a respected Biotherapeutics consultant who was also a patient rights activist and also as a sufferer from a rare primary immunodeficiency and is currently locked down in Italy. Pedro Carrascal is the president of the European multiple sclerosis platform and the CEO of the Spanish group, a Spanish ms group and is currently locked down in Bilbao. Gareth Powell is with the National Institute of Health Research in the UK and as he's the business development officer and he supports life sciences to engage patients with clinical design. He's locked down in the UK. And Tamsin Rose, who's a European health policy consultant currently locked down in Brussels. And there's also Paul Copcutt who's behind the scenes to ensure everything runs smoothly. Now there's no slides. The format's going to be very simple. I'll be asking each of the four experts to give a three minute overview of their understanding of the short and long-term implications of Covid on patient engagement and advocacy. There will be questions as well from the floor. I've also got questions from people who unfortunately couldn't attend. So I'll be asking the panel those questions. The meeting is being recorded. A report will be coming out and we would love to hear your feedback on the event. So when you do exit the webinar, there's just two simple questions and wouldn't it be great if you could answer them? So without any further ado, I'd like to pass you on to Albert Farrugia. Thank you Albert.

Webinar transcript

Albert Farrugia: Good morning. Good afternoon. Good. Whatever time it is. Wherever you are. I have to tell you, this is my first webinar so excuse my nervousness. I'll clarify first of all a slight detail about myself and that is that I'm not a member of the primary immune deficiency community although I support it as strongly and as much as I can. I am a member of the bleeding disorders community of people. In my professional work as well as in my academic activity, I'm observing this phenomenon, this historical period in which we are all immersed. , and obviously reflecting on the way in which it affects myself and my work and I want to kick off by making briefly two points for patients to consider the scenarios which I think are immediately relevant to them. All patients with rare disorders are the immensely interested of course in the scientific literature which reports on medical advances and scientific developments in relation to the areas which affect our lives. And in the current era of the Covid 19 epidemic, we have a vast literature which has very altruisticly been made available free by the main medical publication houses.

This literature is being made available very fast without rigorous peer review as we are used to it, those of us who publish, which takes months and months. Those who like me have an active publication activity are frequently frustrated by this. It is the case that we are getting a lot of scientific information very, very quickly and very, very cheaply. But I would just like to warn people about the need to be very much aware that what is being provided has not been peer reviewed and there have been some instances already where discussion has shown that some of the information imparted has not exactly been accurate. This I think is important. Equally important and somewhat linked is the area of clinical trials and this is going to be imparted to you in more detail by another speaker later on, but I would just like to make the point that as in everything else, things in the area of clinical development are moving very, very fast, which is something which we rejoice at. We are seeing enormous flexibility from the regulatory authorities.

We're also seeing a remarkable level of cooperation, at least in the space which I occupy in the industry itself with companies cooperating in developing treatments. These are extremely good developments and we welcome the adaption of the current clinical trial framework to provide treatments more quickly. A word of warning here as well.

Webinar transcript

Albert: The development of this clinical trial framework for many, many years has not been out of caprice, it has been out of the needs to ensure efficacy and safety of drugs, and we must remember that in abbreviated pathways towards access, which is what we're dealing with now, these have been somewhat curtailed. I think this is something which should interest patients. It should not unduly concern them because the regulatory authorities are still very much in control. But I think that linked again to the issue of what is published, this is something of relevance and of potential concern. I think at this stage, Nick, I've used up by three minutes, so I'll pass over to you.

Nick: Thank you very much Albert. Pedro, over to you: short and long-term implications.

Pedro Carrascal: Okay. Thank you Nick. Thank you everybody attending the webinar and for the opportunity to underline the patient organisations in this webinar. For sure this crisis of the Covid 19 has been a great opportunity to show the value of the patient organisation. Probably today more than ever, because of their advocacy, the added value of the patient organisation. Everything has changed, everything has been blocked. This is an extraordinary opportunity to advocate for the new circumstances. Need of new information, about sharing data, about new consensus. Lots of new things should be done, has been done this last month and the patient organization has been playing a role playing new cards on the table. And the goal has been, both in Europe and Worldwide, that our members are not left out and they are informed and involved.

We have been putting the needs of the people with MS, the patients in the centre again. So advocacy is one of the highest value tasks in a crisis and of course I said information or the lack of information is serious. New registries should have been put in place. We can talk later about that as we have a great opportunity during this crisis of sharing data and of putting the patient reporting data on the table.

Webinar transcript

Pedro: Other stakeholders actions have been more broad. For example, between the health system and patients, between the role of the doctor with the patient. Also dealing with their pharma companies and trying to work with them in all of this.

Of course there are sometimes implications, advocacy, information, consensus and so on. But in the future I see the opportunity also of improving all those things connected with the data sharing for example and the participation of the patients engagement in Europe. We have been talking a lot about this but the patients would be better coordinated inside the health system. Not only during a visit to the hospital or whatever, but also in daily basis. So I think that's more long-term.

Nick: Thank you Pedro. We'll obviously have a lot more time to go into some of those individual points. I'd like to pass on to Gareth now please.

Gareth Powell: So I think one of the key things we're going to be seeing is a big change in culture. We've obviously picked up about the collaboration, which we're seeing with the life science industry working very closely with one another, but also about the culture change of patients themselves we're going to see a much higher uptake in interest, and potentially even , understanding of clinical trials effectively. We're all effectively patient advocates looking for that vaccine coming through or a potential treatment which will end the various lockdowns we are seeing at the moment. Likewise, the media's appreciation of clinical trials and of the life science industry is a big change at the moment. We even got Donald Trump for example who was originally vilifying the life science as villains is now changed completely to saying that they are heroes and geniuses effectively. So that's going to have a trickle-down effect.

Webinar transcript

Gareth: Likewise, we seeing individuals who are using online platforms like Zoom and Skype and what have you. I've, for example, I've been speaking, my parents were using their tablet using my tablet. As we move towards the uptake of virtual clinical trials, we can do see a much more readily embedded, technological understanding way of working both with their own healthcare providers but also with regards to enrolling into clinical trials. I think the rapidity of what we're seeing, this isn't normal at all. It's we use the term when you're normal. but it's not normal. This is an exceptional situation, effectively. But that change is going to have a quite a major effect. And as the rapidity of the set-up of trials we're seeing well, can we keep doing this? Potentially. I think the risk is the good steps we've made with patient involvement and patient engagement. We can't lose that as we move towards or you potentially move towards that new model. We want to ensure that carries on and we continue collaborating not just with an industry but also with patients or patient advocacy groups as well.

Nick: Thanks Gareth. Anything else? You've got plenty of time left. You're okay. I've got my little timer.

Gareth: Great stuff. Pedro mentioned this as well. There's going to be a lot of input required by patient advocacy groups. As we get more kind of interesting uptake of clinical trials accessing the right information is going to be very, very important. Likewise, at the moment we realize the funding streams available to these patient advocacy groups is at risk unfortunately, which has an impact on research being coordinated by these groups. But likewise, the focus of research at the moment is very much on Covid 19 and public health trials. So we're moving away from potentially under-served groups. Hopefully in the long term as we move towards a safe, virtual clinical trials again, we going to increase the accessibility, the ability for people to be involved both in clinical trial design, clinical trial output, but also about the objectives, the life sciences treatment. Hopefully get back to the patient voice, much more embedded in trial design aside. There is that risk I think that we could lose that if we're not careful.

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Nick: Okay. Thank you, Gareth. And Tamsin over to you.

Tamsin: Hi, thank you very much. In building on what some of my colleagues have said, I think this issue of health literacy is critical. For a long time it's been a niche part of health policy and suddenly everyone has had to get up to speed on issues like flattening the curve, understanding the basics of epidemiology, the question of transmission rates, I mean everyone's talking about them. So I think in order to get the population to follow the lockdown measures, there needed to be a greater understanding both of what a disease is, how can it be transmitted, what your risks are, the difference between a virus and a bacteria. All these kinds of information has had to be put out into the public domain and get people to understand it in order to change their behaviour. So I would expect to see quite a big focus on this area, which is a key area for patient engagement.

Working with patient groups, helping them to understand their disease, helping them to understand what conditions they can live under, how they can live more healthily, how they can follow their treatments, how they can talk to their doctors. So I can see there's a, a good connection there between this broad approach on health literacy and the work of patient groups. I think one other area that will be easier for patient groups in the short term is that for a long time they've been trying to make the case of what is the socioeconomic impact on the and their families of living with a condition. And guess what, everyone's in lockdown, everyone has just really got the message of how difficult and frustrating it is if you can't get out, you can't move around, if you're not able to do your normal social activities, if you can't work.

So I think the case of the impact economically and socially on an individual, their family, what it's like living with a condition, that message will resound much more clearly with audiences because they've just been through a process where they have found themselves unable to do things that they would normally do and realize what this means to their connections with their family and with their friends, their ability to engage in everyday life. So that's I think, that's one area of interest. Another one is that we go out and we clap for the carers and the care is in the way that it's talked about today is you know, frontline medical staff. But there's also been a broader understanding when we talk about people who are vulnerable populations isolating at home that this, there's an enormous army of hidden, unpaid and unseen carers who are families taking care of patients with different diseases.

Webinar transcript

Tamsin: So I think there's a new focus that patient groups can build on, on the role of carers, how critical they are to the well being of people. And this leads me to the final point I wanted to make, which is that there is going to be again, a new interest in the issue of mental health. That it isn't just about physical health, it's about the impact of what happens if people are unable to go out and do things and work and contribute and be part of society and the long-term impact. I've seen people talking about concepts like social scarring. That this, the fear of the pandemic, the impact of being locked down, the loss of jobs, the fear for the future is going to leave social scars on people and we would expect to see people with long-term trauma concerns about this. So I think there's a number of different areas that the Covid lockdown, some avenues that are quite positive for patient engagement to pick up on.

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