

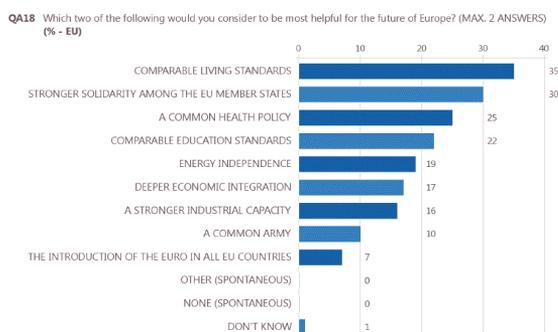
# HEALTH AT THE HEART OF THE CONFERENCE ON THE FUTURE OF EUROPE

Mariano Votta, responsible for EU Affairs at Cittadinanzattiva and Director of Active Citizenship Network, puts forward the vision for a debate towards a healthier European Union

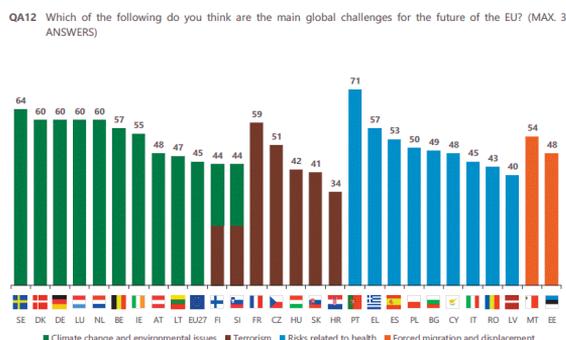
Europe's institutions have finally approved the founding declaration for the Conference on the Future of Europe (COFOE). The work ahead can now officially begin for the conference with the European Parliament playing a leading role in building of a Citizens' Union.

On the day that the Joint Declaration on the COFOE was signed, DG COMM's Public Opinion Monitoring Unit released the first results of the special Eurobarometer survey on the future of Europe. The findings support the launch of a period of deep reflection on the future of Europe: three quarters of Europeans consider that the Conference on the Future of Europe will have a positive impact on democracy within the EU.

**«Comparable living standards» and «stronger solidarity among EU Member States» are seen as the two most helpful things for the future of Europe.**



**«Climate change» is the most given answer in 11 Member States; «terrorism» is the most mentioned answer in another 7 Member States (both items equally first in Finland and Slovenia), while «risks related to health» comes first in 9.**



In the framework of the XV European Patients' Rights Day, this Special Feature on the Conference on the Future of Europe has been created by Cittadinanzattiva/Active Citizenship Network and realised in partnership with *Health Europa Quarterly*.

Among many other things, respondents were asked to choose what developments they want to see in Europe's future. Having comparable living standards (35%) and stronger solidarity among Member States (30%) are the two developments most cited. Europeans also prioritise the development of a common health policy (25%) and comparable education standards (22%).

Perhaps, not surprisingly, given the marked differences on a regional basis, Italy is the only European country where this desire for 'a common health policy' emerges in first place, to be pursued at the national as well as the European level.

## Health risks are a priority

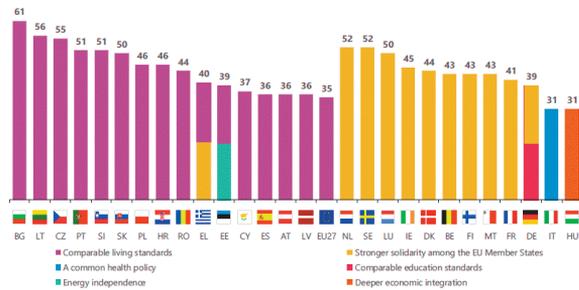
For European citizens, health risks are among the three main concerns, immediately after climate change and terrorism. Indeed, for the citizens of nine countries, including Italy, health risks are the main concern. This is perhaps the inevitable consequence of a still very hard and uncertain present as a result of the COVID-19 pandemic, as well as of a recent past in which citizens and non-COVID patients have been grappling with practical problems almost everywhere, such as the sudden cancellation of visits and examinations, which has seen many people feel cloaked in a sense of abandonment and uncertainty, with health services totally and 'heroically' focused on stemming the epidemic, but which at the same time revealed the limits that predate the crisis.

## COVID-19

The COVID-19 pandemic has had a major impact on citizens' lives in several respects. One of the most important has been the limited access to

«Comparable living standards» is the most given answer in 15 Member States; «Stronger solidarity between EU Member States» in 11. Both items are equally most mentioned in Greece.

QA18 Which two of the following would you consider to be most helpful for the future of Europe? (MAX. 2 ANSWERS)



**15<sup>th</sup> European Patients' Rights Day**

**The role of civic society and Patients Advocacy Groups for more resilient Health Care Systems. Lessons learned toward a European Health Union**

Digital Conference  
5th & 6th May 2021, 10:00-12:00 CEST

For further information, please contact: [brussels@activecitizenship.net](mailto:brussels@activecitizenship.net)

different health services. For the Active Citizenship Network, the European branch of Cittadinanzattiva – a civic organisation which, since 1978 in Italy and 2001 at the EU level, promotes citizens' activism for the protection of everyone's rights, maintaining the common good, and offering support to people in vulnerable conditions – it is simply not acceptable to respond to the immediate needs of citizens facing the COVID-19 pandemic simply by closing services. Instead, alternative organisational solutions are needed to guarantee continuity and quality.

In this regard, it is also necessary to make the most of the contribution of patient advocacy groups (PAGs), civic and rights protection associations which, right from the start, acted with a sense of responsibility, creativity, and energy, often revealing themselves to be the only point of reference and the only service available to citizens. In fact, from their testimonies emerges the great reforming force of civic organisations, capable of responding promptly to new needs by managing services, building alliances, quickly signalling necessary regulatory or procedural changes, mobilising resources (both human and economic), innovating their operating mode, and introducing and promoting practices from which it will not be necessary to go back once the health emergency is over.

For this reason, we have decided to begin with several concrete experiences in reaction to the pandemic in order to celebrate the 15th European Patients' Rights Day, which is planned for 5 and 6 May in the presence of representatives from the

«Climate change and environmental issues» is seen as the biggest challenge for the future of the EU, followed by «terrorism», «risks related to health» and «forced migration and displacement».

QA22 Which of the following six you think are the main global challenges for the future of the EU? (MAX. 3 ANSWERS)



European Commission and the European Parliament, leaders of patient advocacy groups, experts, and relevant stakeholders (to register click [here](#)). This is a celebration that will take place three days before the start of the Conference on the Future of Europe.

Such an initiative could pave the way for the reform of the European system together with the need to respond to citizens' demand to participate in change by laying the foundations for a renewed consensus on the European project.

## A debate towards a healthier European Union

"I want citizens to have their say at a Conference on the Future of Europe," said the Commission President; and in January 2020, in its resolution on the Conference on the Future of Europe, the European Parliament proposed that several thematic Citizens' assemblies reflecting the policy priorities should be held throughout the Conference process.

We would like to consider the 'MEPs' Interest Group on patients' rights and cross-border healthcare', which has been promoted by the Active Citizenship Network since 2015, as the assembly focused on patients' unmet needs, as well as the health priorities from a citizen's perspective. For this reason, we are working to organise, as a follow-up to the European Patients' Rights Day, a cycle of EU meetings and webinars hosted by the above-mentioned MEPs' Interest Group; in order to concretely contribute – with a multi-stakeholder vision and greater civic and patient participation – a debate towards a healthier European Union.

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# TOWARDS A HEALTHY EUROPEAN UNION

MEP Tomislav Sokol about the role of EU institutions in achieving more equal and accessible healthcare across the bloc

**M**EP Tomislav Sokol (EPP) is a member of the Group of the European People's Party (EPP Group), the largest and oldest group in the European Parliament. He is also a member of the Committee on the Internal Market and Consumer Protection, and a substitute in the Special Committee on Beating Cancer. In the context of the 15th European Patients' Rights Day (which takes the theme of civic society's and Patient Advocacy Groups' role in achieving more resilient healthcare systems) and the Conference on the Future of Europe, *Health Europa Quarterly* and the Active Citizenship Network (ACN) have collaborated on a series of interviews for this Special Feature.

In this interview, International Editor Clifford Holt spoke to Sokol about the commitment on the part of the European institutions in terms of providing impetus to the Conference, the importance of issues in the context of the Conference, and what areas need to be prioritised in terms of European healthcare.

**In its resolution of 18 June 2020 on the position on the Conference on the Future of Europe, the European Parliament proposed that several thematic Citizens' agoras reflecting the policy priorities should be held throughout the Conference process. How would you evaluate the European institutions' commitment regarding providing impetus to the Conference and what do you think should be focused on in the immediate, medium, and long terms?**

The Conference on the Future of Europe is a very important project in terms of bringing citizens closer to the European institutions to obtain feedback from them on what they consider to be priorities. The EU's institutions can use this opportunity to emphasise their renewed commitment to Europe's future success, and we know that it is important to have this level of co-operation to achieve that.

The Executive Board, which consists of representatives from the European Parliament,



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Council, and Commission is extremely important as they will act as the main driving force behind the whole process.

While this level of commitment is, of course, fundamental, it is also important to acknowledge that there are different visions of, and opinions on, what the Conference on the Future of Europe should achieve. First, there is the question of leadership. But perhaps a more fundamental question is how far should we go? And the main dividing line here is deciding what to do with the treaties. Should they be changed, or not?

The European Union is not without its problems, of course, and particularly as a result of the COVID-19 pandemic, and so an obvious solution to some of these problems should be to change the treaties, particular those pertaining to healthcare. One of the main reasons behind many of the problems we have experienced in terms of dealing with the pandemic, is the fact that healthcare is a primary national competence. As such, there is the argument to change the treaty. However, I personally believe there is no real will on the part of the Member States to do this, and a consensus is needed before any action can be taken.

The European Parliament is typically more ambitious than either the Commission or Council; it always wants to go further when it comes to strengthening the integration. But in terms of discussing the possibility of changing the treaty, it remains unlikely that this is something we will see for some time.

A third dividing line is perhaps related to the follow-up: what should be done once the exercise is completed and we have obtained information



The European Union is not without its problems, of course, and particularly as a result of the COVID-19 pandemic, and so an obvious solution to some of these problems could be to change the treaties, particularly those pertaining to healthcare

from European citizens? Again, we will undoubtedly see the European Parliament being much more ambitious and willing to go further, but we cannot do this without willingness on the parts of Member States.

The commitment is thus there to develop a vision for Europe's future, but there are different visions, and while the Parliament is likely to be the institution that wants to go the farthest, the Council will probably be the one to hold back, and the Commission will, as usual, carefully try to find a balance.

**The Conference is invited to reach conclusions that will provide guidance for Europe's future direction. In light of the pandemic and the concerns of citizens as expressed by Eurobarometer data, our focus today rests solely on health-related issues. In your opinion, how central will these issues be in the context of the Conference?**

The main problem with EU health policy in the past was that one didn't exist, and if you look at the most important pieces of legislation in this area it is clear that they are typically *ad hoc* answers to problems that had emerged; there was no systematic policy. Now, things are changing. The

COVID-19 pandemic has resulted in us thinking about having a systematic, coherent set of quality of health policies for the first time, which is extremely important.

I believe that healthcare will definitely have a much stronger role in comparison to a few years ago, and, of course, the Joint Declaration has provided a non-exhaustive list of possible themes which, in addition to healthcare, also include things like climate change, the digital transformation, the EU's role in the world, and so on. But at the beginning of the European Parliament's mandate, the focus was on institutional setup, such as the role of the Committee in electing the President of the Commission, the role of the European Parliament, and so on, all of which are things that are not essentially related to people's everyday lives, even though they may be of interest to those of us in Brussels.

Now, the emphasis has shifted, because healthcare is the main topic and other topics now being discussed are related to healthcare in one way or another, such as the economy. Indeed, when we discuss the challenges facing the economy, we need to think about how we can recover from the consequences of the pandemic. And while, of course, the pandemic has had a devastating affect

across the board, perhaps one positive to come out of it is that it has helped to place a much stronger emphasis on what people actually care about, which is how to increase and improve healthcare protection, how the EU can become better prepared for future crises, mobility between different Member States, how to ensure equal access to healthcare treatments and health and medical equipment, and so on. These practical issues will now be much more in focus than they were before COVID-19.

**What priority themes do you believe the Conference should focus on in order to feed a reflection that could lead to a 'European Health Union', as advocated by the European Commission President Ursula von der Leyen?**

The first topic is to help increase preparedness for health emergencies at the national level. We are aware that we didn't respond very well, especially at the beginning of the crisis, after which time things became a little better. Now, however, we are experiencing challenges in terms of vaccine procurement, which demonstrates the need for a much better-developed system of preparedness to provide solutions and responses to public health emergencies. This could be achieved by strengthening the role of the current EU agencies and, moreover, potentially creating additional EU agencies with stronger powers. Developing the institutional framework on how to better respond to future public health risks is definitely one of the main priorities for us.

A second important point that should be a focus is ensuring equality in terms of access to healthcare. Healthcare standards across the EU differ significantly, and that reason alone means that it is impossible to speak of a 'European Health Union'. For instance, citizens are at a 30-40% larger risk of dying from cancer in some Eastern parts of Europe than they are in Western countries and, in these same Western countries there is also a lot of work to do in terms of ensuring that all citizens are treated equally. That is, in some parts of the EU, healthcare provision, the health quality of the healthcare system, and health protection are much higher in some parts of the EU than in others, essentially resulting in first and second class citizens when it comes to health. Providing equal access to top quality healthcare is a problem that needs to be addressed, and that can be achieved by building infrastructure, for instance, as well as by helping to educate more healthcare professionals to prevent them from leaving their home countries to live and work in the Western



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countries where the quality and accessibility of healthcare is much higher.

Addressing these inequalities will be one of the biggest challenges for the European Union as a whole, and the EU can play a crucial role here because this is a problem that Member States cannot resolve by themselves.

**What do you predict/hope will come out of this process? Are there reasons to be optimistic (or indeed pessimistic) when it comes to achieving concrete repercussions from the Conference when it comes to the EU's future?**

It is easier to be optimistic if you do not have high expectations, and I do not believe that we will see profound changes to the EU's overarching constitutional framework. This is because I do not believe that the common will is there on the part of the Member States to achieve that, particularly in terms of, for instance, changing the division of competencies between the EU and the Member States. Indeed, some Member States want part of the competencies to return to the national level, while others want stronger powers in some areas, and others still want certain competencies to return to the EU level. Thus, there is no common vision regarding the direction that the European Union should take, and that is perhaps the biggest problem.

Nevertheless, in a more positive light, I do believe that some things will come to be discussed more thoroughly now, especially in terms of relations with the media and of citizen engagement. Indeed, I believe that it is very important to engage citizens as much as possible because, currently, many people in many Member States are unaware of what the EU is doing – and the fact that many of these same people are critical of the EU's efforts to provide enough COVID-19 vaccines for the population means that the EU's image is not very positive. This needs to be changed, and to achieve that we need to engage people and get them to become more involved in the discussions that take place at the European level around a wealth of different topics, especially healthcare. We also need to enhance the transparency and visibility of our work, so that more citizens across the EU are aware of its importance.

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# SUPPORTING NURSES ON THE FRONTLINE

International Editor Clifford Holt spoke to the EFN's Secretary General Paul de Raeve about how the COVID-19 pandemic has affected Europe's nurses and what needs to be done to better support the profession

**T**he mission of the European Federation of Nurses Associations (EFN) is to promote and protect nurses and the nursing profession with particular reference to the EU by lobbying the European institutions. It provides a broad platform for developing health and social EU policy by supporting the European Union decision-making process on all areas which affect the nursing profession.

In the context of the 15th European Patients' Rights Day (which takes the theme of civic society's and Patient Advocacy Groups' role in achieving more resilient health care systems) and the Conference on the Future of Europe, *Health Europa Quarterly* and the Active Citizenship Network (ACN) have collaborated on a series of interviews for this Special Feature.

In this interview, International Editor Clifford Holt spoke to the EFN's Secretary General, Paul de Raeve, about how the COVID-19 pandemic has affected Europe's nurses and what needs to be done moving forwards, including via the Conference, to better support the profession.



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## What do you feel are the current largest issues faced by nurses in Europe? What needs to be done to solve them and, at the end, improve patient outcomes?

The COVID-19 pandemic has disrupted society in its entirety, of course. But out of all the different sectors, one profession remained working day and night: nurses. Of course, physicians, physiotherapists, and the many other professions which staff a hospital were also at work. But it should be emphasised that it has been, and continues to be, the nurses who work incredibly long shifts, without a break or the possibility of a holiday, and that this has now been going on for over a year. Similarly, doctors are no longer visiting

a patient's bedside unless it is absolutely necessary; they are protected behind glass, from where they instruct the nurses; they do not enter rooms they do not have to. In the intensive care environment, it is the nurses who are cleaning, washing, and feeding the patients; it is the nurses who are recording the observations. It is the nurses who are most at risk.

In the beginning of the pandemic, we were without the proper protection and personal protective equipment (PPE), which has sadly resulted in the deaths of several of my own colleagues and many other nurses around the world. And yet we continued to go to work. We were like soldiers going into battle without weapons or armour – something that would never be expected of a soldier!

In addition to those who have died, many more have experienced burnout: as nurses, we are used to patients dying; but when you are confronted with so many deaths every day, it takes its toll.

It should also be emphasised that most nurses in Europe (93%) are women, and, given the fact that it is women too who take care of much of the work at home – from childcare to cleaning, cooking, laundry and so on – their working day is certainly not over when their shift comes to an end; they have more to look forward to when they arrive home, and achieving any semblance of a decent work/life balance is almost impossible.

In a recent meeting with the EFN members, we discussed what they felt was the biggest problem they were currently encountering at work, and the decisive answer was violence. This is wholly unacceptable; they are giving everything they have to patient care, and they receive violence in return!

The evolution of such violence tends to accompany a societal nervousness, and that is certainly something we are experiencing as a result of the pandemic. However, that is absolutely no excuse, and nurses should not feel that either they or their property is at risk from members of the public who, for instance, have a misguided idea that nurses are somehow responsible for spreading the disease.

A further point is that nurses too can get sick – whether from COVID-19 or anything else – and many have also needed to take time away from work due to the side effects of the COVID vaccine. This has meant that an already strained and understaffed workforce has come under even more pressure. But those nurses who were able have continued to work and to fight the pandemic.

In light of these challenges, and many more besides, I would call for the governments throughout Europe to treat the nursing profession with more respect and to give us what we need to continue to do our jobs. We should not be offered a

1% pay increase or expected to be grateful for a weekly round of applause.

It should also be recognised that, even before the COVID-19 pandemic, there was not enough nurses in Europe. And given the fact that it takes four years to train to be a nurse, there is no way to immediately staff an under-resourced workforce, which is a significant problem because this is the key to resilience.

If we do not get the tools and the staff we need, then I have no doubt that we will start to see systems collapse. This is something I raised as early as 2008 in a resolution at the European Parliament on the shortage of nurses in the EU. And while some people from some quarters made the right noises at the time, nothing was done, even though I explained that there is absolutely no evidence to concretely demonstrate how EU initiatives have led to the creation of more nurses, and that we therefore need either solid data or initiatives that actually work.

It is highly unlikely that anything from the resilience budget that is now being allocated to Member States as a result of the pandemic – which stands at around €9bn to €12bn in grants and loans – will be spent on developing the nursing profession. I therefore urge the European Commission to act now, before it is too late.

### **The Conference on the Future of Europe is invited to reach conclusions that will provide guidance for Europe's future direction. How central do you feel health-related issues will be in the context of the Conference?**

I do not believe that the Conference will be about health; it will be about political power between the European Parliament, Council, and Commission. The Conference on the Future of Europe was not designed to be about health, of course; it is all about who has the power in Europe and will perhaps tackle subjects such as whether to move to a federalisation system, how the next European Commission President can be chosen, and so on.

The recent 'sofagate' incident, in which the President of the European Council Charles Michel seated himself in a chair beside Turkish President Recep Tayyip Erdoğan during a visit to Turkey, while Commission President Ursula von der Leyen was offered to take a seat on a sofa in the same room across from the Turkish Foreign Minister Mevlüt Çavuşoğlu, is demonstrative of the power struggle that takes place across the EU's institutions. And while it is apparently being acknowledged that the views of citizens are important – and the Conference is designed to bring a louder voice to the concerns of citizens – it should be highlighted

that EU mechanisms for this are already in place. For instance, if a million citizens' signatures are gathered, then the item needs to be placed on the EU agenda for discussion. Similarly, the European Ombudsman, Emily O'Reilly, has the duty of investigating complaints against EU institutions, bodies, offices and agencies by citizens. And yet, it would seem, the voice of citizens continues to go unheard. As such, I seriously doubt that nurses will become a priority for the European institutions; just as we are not a priority at the national level, as has been made clear by the stances of leaders such as France's Emmanuel Macron and Germany's Angela Merkel, amongst others.

And, of course, Guy Verhofstadt is chairing the Conference on the Future of Europe. He was the Parliament's initial choice to lead the entire conference, but, assumedly due to his views on federalisation, has been effectively demoted, and will now work alongside an Executive Board composed of representatives of the Commission, Council, and Parliament, and so, again, we see this power struggle.

This is wrong. The Conference's governance body should not be about politicians, but about citizens. When we look at this in the context of the increasing shift towards far-right politics across Europe – for instance, in Italy, Germany, and Belgium – it is clear that citizens are not becoming more empowered – the opposite, in fact. And we have to worry about what will happen when Merkel, as an example, finishes her term in office. The Conference, via the voice of citizens, should therefore be a platform to discuss how to save democracy in the European Union; how we can maintain Europe's core values and principles. We also need to discuss how we can ensure the EU doesn't continue to lag behind the developments taking place elsewhere, such as in China and the USA.

### **European Commission President Ursula von der Leyen has discussed her hopes for a 'European Health Union'. What are your thoughts on this?**

Citizens' voices are crucial, and organisations such as the EFN, which is the voice of three million nurses, are therefore important, as are journalists. Together, we can continue to advocate for the rights of civil society. To do so successfully, we need to listen to the needs of the people. And if these are ignored by politicians, then I believe that their days in politics are numbered, while those in the nursing profession will continue to do their important work, just as we have always done; we will not give up; we will keep on working with the same enthusiasm until the politicians are replaced with those who deliver on the voice of the citizens.





In addition to those nurses who have died as a result of the pandemic, many more have experienced burn-out; as nurses, we are used to patients dying. But when you are confronted with so many deaths every day, it takes its toll

I believe in democracy, but we need to ensure that citizens are inextricably linked to our democratic values and principles. And if Europe cannot hold to these principles, then it is they who face an uncertain future.

### **What barriers are in the way of any proposals actually being taken forward, and how can they be overcome?**

As I have said, the Conference should have been led by civil society rather than politicians, but the problem is that civil society is not well organised, could be considered weak and is often financially supported by the pharmaceutical industry.

To return to another of my previous points: journalists also have a key role: this is demonstrated by the fact that it is journalists who are often murdered in countries experiencing political turmoil – most recently Myanmar, for instance – because it is they who seek out and publicise the truth. As such, they too need to make sure their voice is heard at the European level.

For my own part, I never communicate my own views; only the views of the three million nurses I represent, and we need to have such diverse stakeholders around the table to act on behalf of their group.

It is civil society's job to ensure that it has a defining role in deciding Europe's future, and I strongly believe that the Conference should be developed within this context. It is not for civil servants from the Commission, Parliament, or Council to tell organisations such as the EFN, or anyone else, what to say and when to say it.

I would like to see active citizenship properly realised in Europe; meetings should be held that include civil society, industry, the media, and others, and these meetings need to be large enough and sufficiently representative in order to affect change.

Perhaps one answer would be to hold our own Conference on the Future of Europe, inviting the Commission, those who defend the rights of European citizens, the Parliament, the Council, the European Ombudsman, and others, and have it led by citizens rather than politicians. Then, perhaps, our voices might be heard.

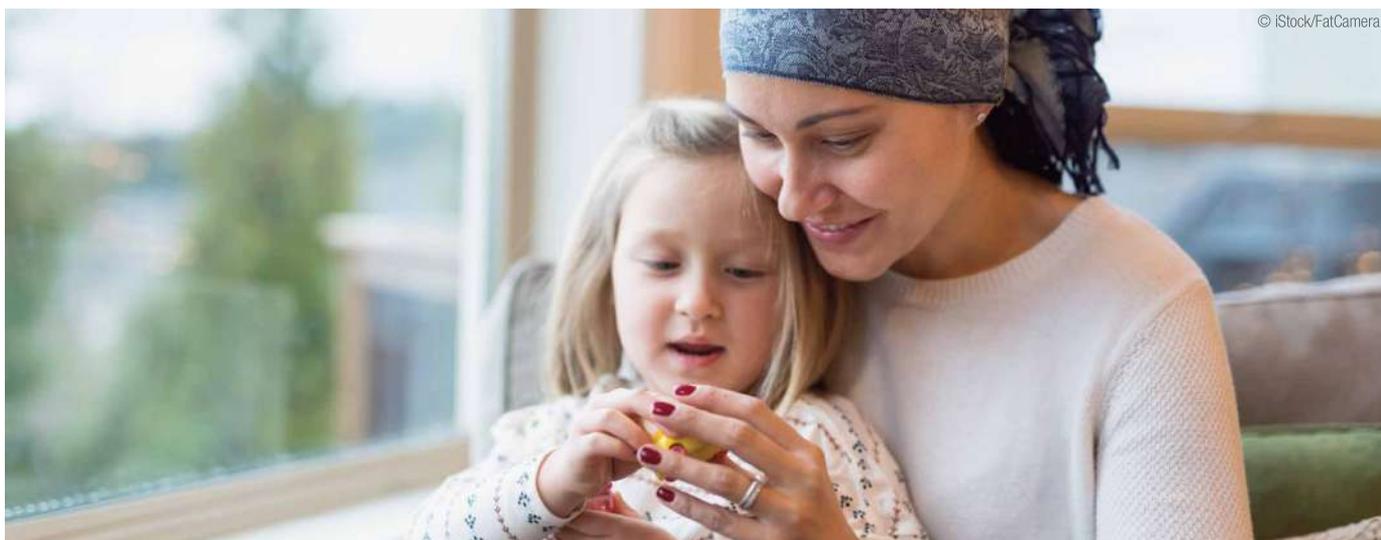
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# TACKLING CANCER CARE INEFFICIENCIES IN EUROPE'S FUTURE

All.Can International's Chief Executive Officer, Eduardo Pisani, discusses inefficiencies in cancer care and what might come out of the Conference on the Future of Europe



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Inefficiency in cancer care is not just about money; it is also about time, quality of life, and missed opportunities for patients and their families

**A**ll.Can International aims to identify inefficiencies in cancer care, which it defines as anything that does not focus on what matters to patients. Through research and collaboration, it highlights best practices and develop policy recommendations to improve cancer care for all.

In the context of the 15th European Patients' Rights Day and the Conference on the Future of Europe, *Health Europa Quarterly* and the Active Citizenship Network (ACN) have collaborated on a series of interviews for this Special Feature. International Editor Clifford Holt spoke to All.Can International's Chief Executive Officer, Eduardo Pisani, about inefficiencies in cancer care and what might come out of the Conference.

## What do you feel that the current largest inefficiencies in cancer care in Europe? And what do you feel now needs to be done to improve patient outcomes?

There is widespread recognition that 20% of healthcare expenditure is wasted. This is based on reports published by the OECD, the WHO, and several other national institutions. Thus, to deliver high quality cancer care and, indeed, to secure



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access to innovation, it is clear that we must make better use of existing resources.

Against this background, the notions of efficiency and value become increasingly important, and it is here that All.Can places its emphasis in order to protect the sustainability of cancer care by placing a greater global focus and drive towards efficient and sustainable care.

In addition, I would also like to underscore the fact that inefficiency in cancer care is not just about money; it is also about time, quality of life, and missed opportunities for patients and their families. Improving the efficiency of cancer care must therefore start with a better understanding of what patient outcomes we are trying to achieve, and this means both eliminating what brings little or no value

and benefit to patients and prioritising interventions that offer, on the contrary, the greatest benefit to patients and greatest value to the system overall.

To achieve this, we need to measure health outcomes, rather than outputs, because the former not only matter to patients, but can also mean lower costs for the healthcare system and thus for society.

All.Can is thus working to illustrate the fact that efficient healthcare systems that deliver the best possible outcomes for patients are, or have to be, evidence-based. They also need to be systems that learn and which systematically incorporate meaningful input from healthcare users in order to make continuous assessments of products and processes and report the results of healthcare interventions in a transparent manner.

I believe that a collaborative multi stakeholder approach will advance better health outcomes, and perhaps the momentum we are seeing in Europe around speeding up the Beating Cancer Plan is truly an invitation for such multidisciplinary collaboration and teamwork.

### **Can you tell me a little about All.Can's recent patient survey and what cancer patients feel matters most to them?**

This survey was conducted towards the end of 2019, with the results being delivered in 2020. It was conducted in 10 countries and collated the responses of 4,000 participants, which is quite a significant size for a survey of this kind. Our aim was to identify the main opportunities to improve efficiency from the patient's perspective, and four areas were identified in the survey and which therefore define where opportunities to improve exist. The first of these is related to ensuring a swift, accurate, and appropriately delivered diagnosis, which is fundamental. When asked to select the one area of cancer care where patients experience the most inefficiency, 26% of respondents identified diagnosis as a fundamental area.

The second relates to improving information sharing, support, and shared decision-making. This perhaps implies that too much information is being given at once and can therefore sometimes be overwhelming for patients. As such, they would prefer to receive relevant information at appropriate points along the entire care pathway. At the same time, almost half of the respondents did not feel sufficiently involved in deciding which treatment option was best for them. Hence, this area is a combination of information sharing and shared decision making.

The third area relates to making integrated multidisciplinary care a reality for all patients. For example, specialist cancer nurses were found to

have played a critical role both during and after treatment, with 24% of respondents having felt that support from allied health care professionals – whether physiotherapists or dieticians, etc. – was not always available, despite it being extremely valuable in terms of improving their quality of life.

Finally, the fourth area concerns addressing the financial implications of cancer. This does not exclusively refer to paying for the treatment or care; it also concerns financial loss as a result of losing one's employment, as well as the need to invest in travelling to a cancer care centre, and so on. Many cancer patients may also experience difficulties post-treatment, for example in obtaining a mortgage, loan, or health insurance policy, which is wholly unacceptable.

### **The Conference on the Future of Europe is invited to reach conclusions that will provide guidance for Europe's future direction. How central do you feel health-related issues will be in the context of the Conference?**

Health-related issues are extremely central, and the COVID-19 pandemic has perhaps accelerated something that had been already discussed and promoted by several advocacy groups and also several policymakers. That is, until recently we used to talk about how 'health equals wealth'; in other words, the socioeconomic impact of health is absolutely fundamental for all European citizens. COVID-19 has, unfortunately, rather demonstrated the need for additional co-operation, preparedness, and system resilience.

### **What priority themes do you believe the Conference should focus on in order to feed a reflection that could lead to a 'European Health Union', as advocated by the European Commission President Ursula von der Leyen?**

To choose just a few priorities, perhaps first and foremost it is necessary to tackle inequalities in health. In the context of 'leaving no one behind' – a slogan that has also been used by the WHO – this is something that is perfectly applicable to the European Union as well. Inequalities must be a parameter of reference when implementing a number of policies. One additional element here concerns strengthening collaboration across Member States in areas such as health promotion, disease prevention, and cross-border healthcare which translates, at least for the time being, to helping with the mobility of patients that suffer from rare diseases, as well as to strengthening the European Reference Networks. These items have been on the EU's agenda for a number of years,



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and I believe that they can be strengthened and scaled up without having a negative impact on the sovereignty of Member States.

A further dimension concerns implementing a research and innovation policy strategy, the importance of which has been underlined by the COVID-19 pandemic in terms of vaccine development and procurement. Research and innovation must be developed and, indeed, must be looked at hand-in-hand with an industrial policy that strengthens the European assets that we need.

Finally, there is also a need to define a framework for digital health. The digital transformation has certainly been highlighted as a priority, and in the case of health, digitalisation is fundamental to improving efficiency and therefore ensuring that the resilience and sustainability of healthcare systems can be guaranteed over time.

**Given that it is perhaps easier to identify priorities than it is to envisage how those priorities will be realised, what barriers are in the way of any proposals actually being taken forward, and how can they be overcome?**

To return to the larger picture: I believe, as a committed European, that sovereignism of any nature is the wrong concept. Only by joining forces can we address common challenges and achieve ambitious goals in the field of public health.

Discussions have been going on for decades around the so-called 'subsidiarity principle' which particularly pertains to public health policy, which has so far been considered a national prerogative. Certainly from a budgetary perspective, it does remain a national prerogative. However, when it comes to issues such as preparedness, healthcare system resilience, collaborative research, and so

on, I believe that it is important to ensure that Europe has both the tools and the appropriate legal framework that allows us to work together to address these challenges.

A second area, which I have already alluded to, concerns budgetary resources for health, which have to increase. A perfect example is the fact that we have recently seen over €5bn being allocated to the EU for Health plan, which is the right way to go. This level of funding should remain consistent or even increase; cost containment in health is a major threat to everything we have discussed and is thus a significant barrier to future progress.

Cost containment measures in health are indiscriminate and if you look at the EU Member States which have suffered cost containment measures and cuts to their healthcare budgets in recent decades, it is clear that they also lack the ability to rapidly respond to a major pandemic such as COVID-19.

A third barrier concerns the lack of digital infrastructure. Data is a driver for efficiency, and it is therefore extremely important that the European Commission has launched the European Health Data Space initiative. Data and digitalisation underpin a smart healthcare system and act as a catalyst for a continuous cycle of improvement and drive towards the better use of resources in order to achieve better outcomes for patients.

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