



Global
Heart Hub



Summary Report

Heart Valve Disease in Europe: Creating a Better Patient Journey

*27th April 2022
Brussels, Belgium*



A joint seminar, hosted by Global Heart Hub and
MEP Brando Benifei, Co-Chair of the MEP Heart Group

In a joint seminar to raise awareness of the challenges faced by those living with heart valve disease and to improve patient care, leading thinkers and decision-makers met in Brussels to discuss the Global Heart Hub report: 'Heart Valve Disease in Europe: Creating a Better Patient Journey'.

The meeting, which took place on 27 April in Brussels, hosted by the Global Heart Hub (the international alliance of patient organisations) invited MEPs, patient advocacy groups from across Europe and beyond, as well as leading experts to discuss the recommendations in the report.

In his keynote speech, Brando Benifei MEP, Co-Chair of the MEP Heart Group, said that Europe needs a plan that builds on the 'Better Patient Journey' report. "For us at the EU level in the institutions it means providing a framework for cross-border co-operation and it also means setting standards so that no one is left behind wherever they live, whether you are in Bulgaria, France, Portugal or Denmark. The Parliament's heart group which I co-chair has pushed for the European Commission to be active together with the member states."

Benifei said that Europe is not going back to where it was pre-COVID and that citizens now want a well-functioning European Health Union. He highlighted the progress that has been made on non-communicable diseases, in the Beating Cancer Plan, but that we need to apply further pressure at both member state and EU level to address heart diseases.

Global Heart Hub Executive Director Neil Johnson welcomed all participants and said that the presence of non-European affiliates, from places like Brazil, Mexico, USA, Australia and Canada underlined the global nature and the urgency of the topic and the imperative for co-ordinated global action.

"I'm delighted that we have over 70 international patient organisations from more than 27 countries. Our vision is to create a united, informed and empowered community of patient organisations. A global cardiovascular patient community that at both at a national and international level supports patients and their caregivers as they navigate their journey and their interactions with healthcare systems and healthcare providers. The aim is to provide the best possible life and to achieve the best possible health outcomes."

Silent epidemic

Johnson emphasised that with a growing ageing population particular attention was needed to ensure those over 65 can enjoy a healthy and active life. While heart valve disease can occur at any time in life, everyone is subject to some "wear and tear" as they age. The number of people affected by heart valve disease is growing rapidly and expected to double by 2040 and triple by 2060.

"We have a good news story, because valve disease is treatable. The treatment options have become minimally invasive, requiring shorter hospital stays, and delivering transformational outcomes in terms of symptom relief, and improved quality of life.

"Policymakers and others tend to view this as a cost when they should be investing to ensure that we can intervene and deliver a longer life that's healthier and less of a burden to society in terms of economic cost."

Towards a better patient journey

“Patients don't choose to go on a journey, it's more that they are forced to go on a journey or a pathway because of their diagnosis,” said Suzanne Wait of the Health Policy Partnership. “If we want to achieve optimal outcomes, we need to empower them to really help themselves and self manage and recognize what they can do working with our clinical teams to improve their outcomes. It also means that everyone involved in that journey needs to work together for improved outcomes.”

Wait and others pointed out that there is a danger of siloed thinking and that it was necessary to look at a patient from a multi-disciplinary care team perspective to ensure that clinicians do not miss opportunities for effective intervention. In particular, Wait emphasised that primary care providers needed to be more aware of early signs of deterioration, to ensure that there is effective early intervention.

Leave no one behind

Jens Näumann, who was diagnosed with aortic valve stenosis at the age of 42, spoke about his experience and called for improvements across the EU. Näumann said high-quality data was required and spoke about a study being carried out in Germany and Austria that took into account the patients and the clinicians' experience. The project resulted in patients and specialists developing tools to ensure no one is left behind, to raise awareness, and to reach people in rural communities. One such example was the use of videos with patients speaking about their experience.

Marta Sitges, a leading European cardiologist, spoke about the need to have more networking among professionals and with patients to ensure that care is patient focused. She emphasised the need for cross-disciplinary links, as well as between primary care and more specialised fields: “What I would like is that our governments help us to increase the awareness of this disease, which is largely unknown; and, to push to establish network systems and pathways to facilitate the early diagnosis of this treatable disease. In particular, we can improve the quality and quantity of life. If we do not treat these patients they will die.”

Pushing the European agenda forward

Vytenis Andriukaitis, former European commissioner for health and food safety, was a cardiovascular surgeon before entering politics in Lithuania. Andriukaitis spoke about how Europe's health ambitions had been transformed by the COVID pandemic and the stark situation in relation to cardiovascular disease: “Every year we are losing more than a half a million people because of premature deaths due to cardiovascular disease. We need to send a very clear message to EU member states that they need to do more.”

Andriukaitis said that with the debate taking place during the Conference on the Future of Europe, citizens are calling for Europe to take more action. He said that much could be learned from the EU Beating Cancer Action Plan and that the Global Heart Hub should press the European Parliament to agree on a non-binding resolution requesting that the European Commission take a similar approach to cardiovascular disease as it has taken towards

cancer. He added that the European Centre for Disease Control should broaden its mandate to cover non-communicable diseases, which would improve the quality and availability of data across Europe.

“The first thing that we have to do is to increase awareness of heart valve disease. I will try within the European Parliament,” said Spanish MEP Nicolás Gonzalez Casares, who is also a member of the MEP Heart Group.

He pointed to the forthcoming proposal on European Health Data Space, hoping that this could raise awareness of heart disease and lead to new models for early detection and treatment. It was also a question of addressing lifestyle questions and making use of new innovation, for example, through Artificial Intelligence.

Group discussion round-up

Each table present worked together to address two questions.

Can you think of two ideas to make the most of the Patient Journey Report as an effective tool for advocacy at EU level? And, what are the key priority actions of effectively influence policy and why?

The event facilitator Nicola Bedlington, summed up the responses:

“The patient journey report is robust and relevant to drive forward the EU’s response to heart valve disease, it really is something that people can work with. We’ve heard from the politicians, we’ve heard from many of you today. There are really some exciting opportunities because health, non-communicable diseases and cardiovascular health have never been higher on the agenda than today.”

Participants agreed that an action plan for cardiovascular health action plan, similar to the ‘Beating Cancer Action Plan’ was needed. The Patient Journey Report can feed into this, giving the patient a stronger voice and personal agency, which will be critical in any future plan.

Delegates also thought that digital transformation presented new opportunities to integrate care, empower patients, improve diagnostics and lead to better shared decision making.

While things are moving in the right direction there was a call for progress to be accelerated.

Conclusion

Ellen Ross - Chair of the Heart Valve Disease Patient Council - thanked all participants at the day’s events: “There were tremendous insights on how we’re going to take this evidence-based document forward and inspire action. I think what’s really important is we can learn from everyone’s experience in the EU and beyond. When it comes to heart valve disease, we know what the ideal patient pathway is, and it needs to be effectively resourced and that will take political will.”

About the Heart Valve Disease: Working Together To Create A Better Patient Journey Full Report

This report takes a European perspective on what an optimal care pathway should look like for people with heart valve disease, from awareness to follow-up care, what gaps exist, and how we can best address them. The report was developed under the guidance of a multidisciplinary advisory group, whose members included patient representatives and different healthcare professionals engaged in heart valve disease care from around Europe.

You can read the full report here: <https://globalhearthub.org/heartvalvreport2020/>



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