

## Global Spotlights

# The essential role of patients in advocacy and policy

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Patient advocacy is an important aspect of healthcare policymaking; patients are the primary stakeholders in healthcare, and their voices and perspectives must be considered when developing healthcare policies. From a political perspective, patients are the voters, and therefore their needs are a priority. Advocacy can take many forms, including public awareness campaigns, lobbying efforts, and grassroots organizing. To be effective, patient advocacy in policy must be grounded in the experiences and perspectives of patients themselves. This means healthcare providers must engage with patients to understand their needs and concerns, and use this information to inform policymaking. It also means working in partnership with other stakeholders, including policymakers, healthcare regulators, and industry representatives, to develop policies that meet the needs of patients while also addressing broader healthcare challenges.

The European Society of Cardiology (ESC) recognised the important role of patients in shaping practice with the establishment of the Patient Forum in 2018. Members come from across Europe with a variety of backgrounds, cardiovascular (CV) conditions and experience, weaving a golden thread of patient experience through the activities of the ESC. Patient contributions are many and include membership of task forces and committees, co-authorship, and reviewers of publications. Furthermore, they serve as speakers, chairs, and discussants at the ESC Congress and at all subspecialty Congresses.

In addition, the ESC Patient Forum has been involved in developing the new ESC Strategic Plan 2023–2028 ESC. Three members of the Patient Forum attended workshops held in 2022. We pay tribute to our colleague, Noemi de Stoutz (1958–2022), who overcame her health challenges to be part of this plan and to ensure that the patient voice remains at the core of the ESC. This is reflected in the strategic aim of patient-centred care; one of only six priorities of the ESC strategic plan 2023–2033.

The ESC Patient Forum functions as an internally facing group, but they also have a desire to be consulted on and influence EU healthcare policy. Many members already lobby at a local/regional level in their own countries. Patient Forum members wish for greater involvement in a range of advocacy work and, as appropriate, also to involve carers and family. They also desire to advocate alongside other ESC

members—joining forces to lobby for change. Future Patient Forum and ESC Advocacy initiatives will provide the structure and support to allow more external advocacy in the future. The tenet of *nothing about us without us* needs to be observed within the realms of healthcare policy making too.

In 2020, the ESC and European Heart Network published ‘Fighting cardiovascular disease—a blueprint for EU action’.<sup>1</sup> ESC Patient Forum members underlined the need for immediate and urgent action from the EU, by asking a range of important questions such as:

- What can the EU do to support research that will improve diagnosis of those who are potentially at high risk of developing CV disease (CVD)?
- What can the EU do to help advance the knowledge around CVD in women?
- How can the new Horizon Europe programme support research, education, and policy changes to help improve CVD understanding and management?

Since its inception, the Patient Forum has provided testimonials to change the perception that policymakers and public have and advocate for public health awareness and better research funding. These testimonials were used for the launch of Lancet Report on CVD in Women (May 2021), World Heart Day (September 2021), and launch of the European Alliance for Cardiovascular Health (October 2021). Most recently, the Women’s Health Subgroup of the Patient Forum took to Social Media to create powerful messages for International Women’s Day. These messages, shared via the ESC Advocacy Twitter account, gained around 12 000 impressions.

The potential for the Patient Forum to influence external policy is vast. An individual patient story can be more meaningful than dry statistics and facts. Storytelling helps remind policymakers that each statistic represents a real person. One clear example is that of the National Service Framework for coronary heart disease, published in the UK in March 2000. It was immediately noted that there was no chapter on arrhythmias. The patient advocacy group, the Arrhythmia Alliance, lobbied hard to ensure the change was made. In 2005, a chapter on

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arrhythmia and sudden cardiac death was launched. This action was noted in a letter from the then Prime Minister, Tony Blair, and in a comment from the National Clinical Director for Heart Disease, Professor Sir Roger Boyle:

*'The Arrhythmia Alliance was fundamental in drawing up the CHD NSF chapter on arrhythmia and sudden cardiac death, launched in March 2005, and the organisation continues to play a key role in the chapter's delivery—not just in its awareness-raising activities with patients and professionals, and supporting patients and families, but also in the ongoing development of policy in this area.'*<sup>2</sup>

One key challenge for healthcare professionals (HCPs) working with patients to address advocacy agendas is that contemporary medical programmes focus only on advocacy in partnership with community organisations and community-based advocacy projects. To date, no educational programmes prepare HCPs to have the knowledge and skills around legislative advocacy. Nor is there an emphasis on persuasive communication, an essential component of persuading policy-makers of the importance of the focus on specific issues related to CVD.<sup>3</sup> While courses and degree programs in public policy, law, and social work that cover topics related to advocacy do exist, they are not designed specifically for the HCP or the patients. These programs can provide individuals with a strong foundation in the legal and policy frameworks that underpin advocacy work, as well as practical skills such as public speaking, research, and campaign management. Potentially, the ESC could provide education to support ESC members and patients to become advocates at a national and international level.

The ESC Patient Forum is keen to support developments in advocacy across the ESC and beyond. Ultimately, the most effective advocates are those who are able to combine their knowledge and skills with a deep commitment to their cause. People on the ESC Patient Forum, who have lived experience, are experts in their condition and give up their time to lend their voice, are ideally positioned to become our leading advocates. Strong patient advocates working in partnership with an

ESC community that recognizes the importance of advocacy and are willing and trained to engage, can make the ESC a driver for policy changes in healthcare.

## Pre-registered clinical trial number

None supplied.

## Ethical approval

Ethical Approval was not required.

## Data availability

No data were generated or analysed for this manuscript.

## Conflict of interest

The authors report that there are no conflicts of interest in relation to this work.

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