

The ‘myrhythmdevice.org’ educational website for patients with implanted cardiac devices from the European Heart Rhythm Association

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The implantation rate of cardiovascular implantable electronic devices (CIED) is steadily increasing.¹ The ageing population, the increasing life expectancy, and the technological developments of the last decades have turned the CIED to everyday clinical praxis. Cardiovascular implantable electronic devices are more accessible than ever, and the variety of types and models is large. The choice of the right device is crucial, as it may have significant impact in patients' private and professional life, but the decision process is not always clear. Hence, active participation of patients on decisions regarding their CIED is important.

The approach of patient-centred care is steadily gaining ground in modern health care systems and has been proven to improve the health care outcomes and experiences.^{2,3} The role of the physician is not anymore limited to making diagnosis and providing treatment. Health care professionals have the duty to educate the patients providing validated, unbiased, and up-to-date information. The patients have an active role in their care, by expressing their will and preferences and by participating in decision-making. The 2021 ESC Guidelines on cardiac pacing and cardiac resynchronization therapy particularly emphasize the need of such an approach.⁴

Recognizing the importance of patient education in shared decision-making, the European Heart Rhythm Association (EHRA) created a website which would provide validated and unbiased information to patients with CIED and their caregivers, the ‘myrhythmdevice.org’ website. A similar website, ‘afibmatters.org’, directed to patients with atrial fibrillation, has been launched by EHRA since many years and has been highly appreciated.⁵ As the patients with a CIED is a growing population, the introduction of a website dedicated to this patient group was imperative.

Design of the website—a unique collaboration between patients and physicians

The novelty of the ‘myrhythmdevice.org’ website (*Figure 1*) is the fact that it was designed and created by a task group involving physicians and patients from the beginning. The initial content and structure of the website was proposed by a group of physicians and reviewed by patient representatives of the ESC Patient Forum. The structure was evolved, changed, and expanded taking into consideration the suggestions from members of both groups. Most parts of the website, particularly those included on the ‘Living with a cardiac device’ section, were carefully redacted in order to meet the needs of the patients for more practical information regarding daily life.

The text was written by physicians and revised by the patients to ensure that the information was presented in an easily comprehensible way, without demanding previous knowledge on the subject. The information provided is essential, evidence-based, and consistent with the 2021 ESC guidelines on cardiac pacing and cardiac resynchronization therapy. The main purpose of the whole project was to meet the patients' need for theoretical and practical information about important issues and challenges that they face in daily life and to put their perspective in centre.

To better understand the specific needs and expectations of patients living with CIED a research study was carried out based on qualitative interviews with patients from five European countries (France, Germany, Italy, Spain, UK). The patients were recruited via physicians or from existing panels. All participants were either pacemaker or

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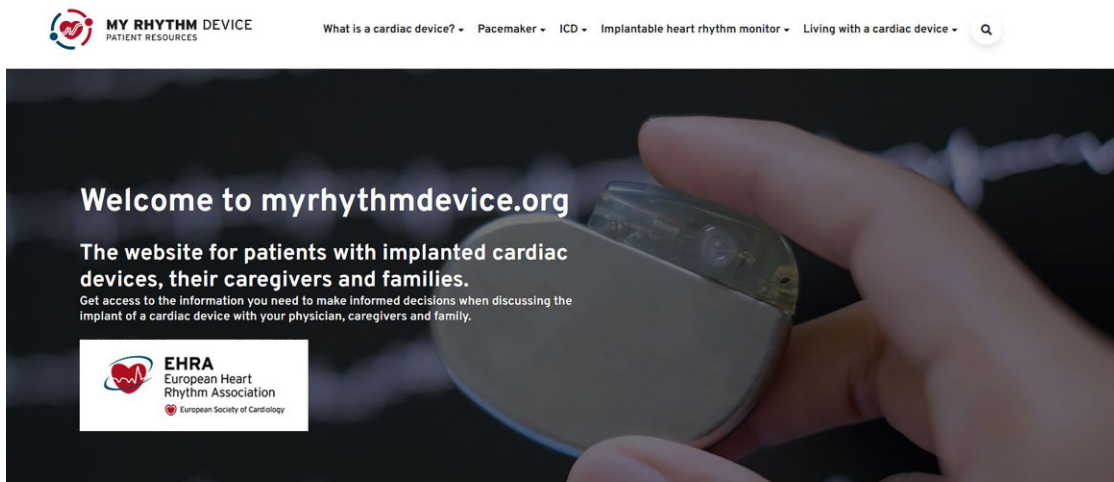


Figure 1 The myrhythmdevice.org website.

implantable cardioverter-defibrillator (ICD) owners for at least 3 months and were a representative sample regarding age, gender, geographic location, and level of education. The spouse/caretaker was invited to participate if desired. The survey was a 60 min in-depth telephone interview in native language.

The interview was structured in seven separate sections, with a specific focus on the first section:

- Living with a cardiac device,
- Understanding the medical condition and cardiac devices,
- Implanting a pacemaker/ICD,
- Cardiac device follow-up and maintenance,
- Sports, driving, working, travel, medical interventions, etc.,
- Mental well-being, friends, and family,
- Interest for patient website.

The results of the survey have been used to adapt the website in order to better meet patients' needs and expectations.

Content of the website

The website is divided in five main sections: 'What is a cardiac device?', 'Pacemaker', 'ICD', 'Implantable heart rhythm monitor', and 'Living with a cardiac device' (Figure 2).

In the first section 'What is a cardiac device?' the patients get familiarized with the normal heart anatomy and heart rhythm, as well as with the main heart rhythm disorders that can require the implantation of a CIED. General information about the three main types of CIED (pacemaker, ICD, and heart rhythm monitor) is also provided in this section.

In the 'Pacemaker' and 'ICD' sections, the patients are provided information about the main indications for a pacemaker or ICD implantation, how the devices work, and the different types of pacemakers and ICD. In addition, information regarding the procedure of pacemaker or ICD implantation can be found: the preparation required before the implantation, the procedure itself, and what to expect after the procedure is performed. The common routines before discharge, the routine follow-up, and the potential complications and warning symptoms are discussed. In the 'ICD' section, patients can additionally find information about ICD shocks and electrical storm.

The 'Implantable heart rhythm monitor' section presents the conditions when such a device is indicated, explains how the device works and how the implantation is performed, and describes what happens if the device makes a recording.

The last section 'Living with a cardiac device' is dedicated to practical aspects of the everyday life. The patients can find important information regarding driving, travelling, physical activity, mental health, and sexual life. Potential interferences of the CIED with daily life technologies, medical procedures, and professional life are also discussed here. Finally, end of life considerations and information useful to family, friends, and colleagues are presented.

Future perspectives

The website is currently available in English, but the translation in more languages is already planned. This is of high importance since the availability of the information in patients' native language is crucial for a better understanding. Moreover, further translations can help reach a broader audience.

The website will gradually be enriched with patient testimonials, an important resource created from the patients, for the patients. Providing information from the patient's perspective is an essential element for the proper decision-making. The content will be regularly renewed.

Conclusion

The 'myrhythmdevice.org' website is a novel educational website aiming to provide validated and EHRA-endorsed information to patients with CIED and their caregivers. The website was created in a collaboration between patients and physicians to cover the need for education of the patients with CIED, which is a necessary first step when engaging patients in decision-making.

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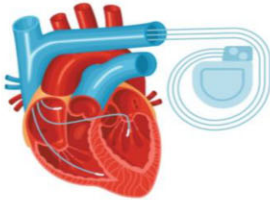
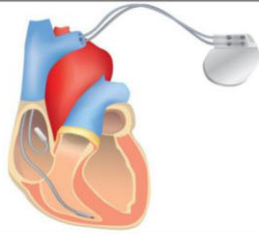
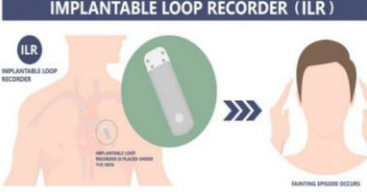

		
What is a cardiac device	<p>The normal heart rhythm and anatomy</p> <p>When do I need a cardiac device?</p> <p>What is a pacemaker?</p> <p>What is a defibrillator?</p> <p>What is an implantable heart rhythm monitor?</p>	
Pacemaker		<p>When do I need a pacemaker?</p> <p>How does a pacemaker work?</p> <p>The different types of pacemakers</p> <p>Implanting a pacemaker</p>
ICD	<p>When do I need an ICD?</p> <p>How does an ICD work?</p> <p>The different types of ICDs</p> <p>Implanting an ICD</p> <p>What happens if I get a shock from ICD?</p> <p>What is an electrical storm?</p>	
Implantable Heart Rhythm Monitor	<p>IMPLANTABLE LOOP RECORDER (ILR)</p> 	<p>When do I need a heart rhythm monitor (ILR)?</p> <p>How does an implantable heart rhythm monitor work (ILR)?</p> <p>Implanting a heart rhythm monitor</p> <p>What happens when I make a recording?</p> <p>What happens if the device records an arrhythmia?</p>
Living with a cardiac device	<p>Driving</p> <p>End of life</p> <p>Information you may give to family, caregivers, friends, colleagues</p> <p>Mental well-being</p> <p>On the job</p> <p>Physical activity and sports</p> <p>Potential interferences in daily life and medical environment</p> <p>Sexual life</p> <p>Traveling</p>	

Figure 2 The main sections of the myrhythmdevice.org website.

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