



# Patient engagement

## A strategic objective of the ESC to improve cardiovascular care

The core purpose of the ESC is identified in its mission, ‘to reduce the burden of cardiovascular disease’. This aligns firmly with the National Cardiac Societies which are primarily composed of Doctors, Nurses, and Allied Health Professionals specializing in the care of people with cardiac conditions. Not surprisingly, the ESC focus has traditionally been on improving clinical practice in Cardiology through connecting and educating health care professionals. However, of late there has been an increased awareness that patients and patient groups’ experiences, knowledge and skills, may offer insight that can help provide both more effective care and improved communication. Already within the ESC family, groups such as the Heart Failure Association have been very active in developing patient-oriented materials. The purpose of this article is to consider how such initiatives might enable movement beyond traditional terrain by engaging with patients and their families as a strategic goal in order to more effectively fulfil the ESC mission.

Patient engagement is a concept that has been open to different definitions and interpretations. For the purposes of this article, it is defined as a set of behaviours by which patients take more responsibility for their own health care, and health care professionals take more account of patients’ health needs. It implies an ethos of shifting from medical dominance within the health care environment to one of equality, that facilitates patient involvement in their health care. As a central feature it ‘combines a patient’s knowledge, skills, ability and willingness to manage his/her own health care with interventions designed to increase activation and promote positive patient behaviour’ (Health Affairs Website<sup>1</sup>).

As such, patient engagement potentially represents a powerful mechanism by which the ESC can combine its collective professional expertise with the unique insight provided by patients leading to a more effective achievement of the mission of reducing the burden of cardiovascular disease. The key concept in engagement is one of partnership, where health care professionals listen and learn from patients to work with them to more effectively meet their needs. As such, patient engagement is not such a libertine approach, rather what good doctors and nurses have been doing for centuries to provide safe and effective care. Engaged patients are more likely to understand their condition and the risk factors associated with it, and will want to influence decisions about diagnostics or treatments they receive. It follows that adherence to therapy can be expected to be enhanced as a result of such partnership.

A recent example of the strong positioning of patient engagement within the ESC is reflected in the 2016 ESC Guidelines on Atrial

Fibrillation (AF).<sup>2</sup> In this document, it is recommended to facilitate tailored patient education in all phases of AF management to support patients’ understanding. Further, the Guidelines state that patient involvement in the care process should be considered to encourage self-management and responsibility for lifestyle changes (Class IIa recommendation), and shared decision making should be considered to ensure that care is based on the best available evidence and fits the needs, values and preferences of the patient (Class IIa recommendation). This is just one example, overall, there are many robust approaches already established within the ESC to emphasize, integrate and support patient engagement in clinical decision making. We are now at a stage when we wish to connect and develop these initiatives more formally in order to maximize their impact.

Over the last decade patient engagement or involvement has had increasing prominence in health care literature, and in some health care systems it is regarded as a gold standard for achieving key performance indicators. In other cultures, it represents a radical departure from medical paternalism and may be regarded as threatening or jeopardizing the unique role of clinicians. There are explanations for both perspectives—one is that the rise in information technology enables easy access to state-of-the-art knowledge on health and disease, enhancing patients’ potential as well-informed partners. For instance, the Heart Failure Association of the ESC HeartFailureMatters website has 250 000 users per month and is one of the most popular on the ESC site.<sup>3</sup> The therapeutic achievements of such a resource and its potential to positively impact on patient outcomes appears logical, but needs further formal scientific testing.

There are also challenges to effective patient engagement that merit careful consideration. The concept is clearly challenging to some clinicians trained in the traditional, ‘doctor knows best’ model. It may be difficult to find patients or indeed people, who can articulate a balanced group perspective of a specific condition without their individual experience dominating. Language and the varied health care infrastructure across the different European countries may also present additional hurdles. It is also evident that some patient groups are supported by funding from industry which may raise questions about the independence of their input and conflict of interest concerns. We recognize as health care professionals, that members of the ESC may have expertise in the best treatments, but may not necessarily be expert in knowing what lay people and patients actually wish for, or need, in terms of being able to understand treatment options outlined in ESC Guidelines, or in participating in health care decisions.



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The Patient Engagement Unit within the ESC has been developed by the authors of this paper under the leadership of the ESC Board. A Workshop with over 40 delegates has been convened in the Brussels Office with representation from patient organizations and the Minister of Health within the European Parliament. Active debate and discussion of this issue has resulted in development of a roadmap and deliverables are being agreed. Internal and external patient engagement activities are being catalogued within the ESC and potential partners are being examined for independence from vested interests before further partnerships are developed.

An early part of this endeavour is to develop Patient Engagement as a strategic objective of the ESC and continue to build and expand collaboration between patients and professionals. The ESC has committed to raising the profile of patient engagement within its activities because it regards this approach as central to the future development of high quality care. The ethos of Patient Engagement is directly aligned with our mission and also facilitates the Society to retain and strengthen its leadership role in reducing the burden of cardiovascular disease internationally. It is with great pleasure that we confirm that Patient Engagement has been agreed as strategic objective of the ESC and going forward all our activities will reflect this principle. Exciting times! We invite you to consider how facilitating Patient Engagement can augment your professional development and encourage you to look out for further developments!

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#### References

References are available as supplementary material at *European Heart Journal* online.

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### Pioneers in cardiology

## Antonio Colombo MD

### Mark Nicholls speaks to Professor Antonio Colombo about his pioneering work with dual anti-platelet therapy (DAPT) and Intravascular Ultrasound impacting on cardiac stenting outcomes

It was a bold step; critics at the time thought it odd and barely rational to combine dual anti-platelet therapies (DAPT) for coronary stent patients.

Yet with a growing number of patients undergoing stent procedures in the early 1990s suffering bleeding and myocardial infarction,