

Patient Perspective: We have embraced digital technologies to support arrhythmia patients during the COVID-19 pandemic



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National Health Service (NHS) England views shared decision-making as a vital part of providing good care, describing it as “a process in which clinicians and individuals work together to select tests, treatments, management, or support packages, based on evidence and the individual’s informed preferences.”¹ It also states the need for “evidence-based decision support tools that are tailored to support people (especially those with low levels of health literacy) to understand their options and what is known of the benefits, harms, consequences, and burdens of those options.”

Arrhythmia Alliance has always believed that a core part of its role is providing “evidence-based decision tools”—in the form of information, education, and support—to empower patients with arrhythmias to play an active role in shared decision-making. In an article for *Europace*, Professor A. John Camm (President of Arrhythmia Alliance) and I note that patient associations, such as Arrhythmia Alliance, “play a crucial role in educating the public about specific conditions” and are “often the first port-of-call for people when either a patient, or a family member, has been diagnosed with a disease.”²

Prior to the pandemic, we delivered information through a mixture of physical events, printed booklets, and online resources. However, since the pandemic began, we have had to switch to delivering everything online, with the greatest shift being converting our annual Patients Day into a virtual event. Each year, we host a Patients Day at the International Convention Centre in Birmingham, United Kingdom, as an opportunity for patients to learn from, and discuss with, leading medical professionals. However, because of the pandemic, we were not able to host a physical event last year. Therefore, as we did not want to cancel, we had to find a way to provide a “Virtual Patients Day.”

Consequently, we created a bespoke virtual platform that allowed patients to watch on-demand presentations from experts in the field. The key benefit of the virtual platform

was that patients who could not “attend” the Patients Day on the launch day (September 27, 2020) were able to log in and watch at a time and date that suited them, and those who were able to attend on the launch day appreciated being able to revisit the presentations. One patient told us: “It is wonderful that we can go back to re-watch the array of really useful presentations.... There are so many other presentations that I cannot wait to see.”

In fact, the Virtual Patients Day has been so successful that we are continually adding content to the platform and have made it into a “Virtual Patient Education Platform.” Furthermore, we regularly produce how-to videos in support of our core campaigns “Know Your Pulse” and “Defibs Save Lives.” We have always been keen to provide education in the form of videos, as the medical literature clearly shows how beneficial they can be for patients. Oudkerk Pool et al³ report that, after being shown a video, 40% of patients were able to explain the benefits of a procedure compared with 16% before being shown a video.

During the pandemic, we also helped many of our affiliated patient support groups shift from physical to online meetings. We did this by e-mailing invites to relevant patients (providing details of the online meeting), promoting the meetings on our social media platforms, and advertising them in our patient e-newsletters. Although some patients initially were unsure of these online meetings, the vast majority have found the accessibility and support of these meetings to be beneficial, with some even expressing a desire for online meetings to continue even after COVID-19 restrictions have been lifted. The value of patient support groups is again backed by the medical literature. Hildingh and Fridlund⁴ found that people who, following a cardiac event, participated in a “peer-support group” “exercised more regularly, smoked less, had a denser social network and more social support from members of their clubs” than those who did not participate. Therefore, whether in-person or online, peer-support groups should always be encouraged.

Another way we have supported patients in terms of digital technology over the last year is by working with health care professionals and industry to make remote monitoring technologies more accessible to patients, which is particularly important given that nonurgent in-person hospital consultations had to move online or be canceled because of

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the pandemic and the need to “stay at home.” Arrhythmia Alliance, therefore, initiated a scheme in which health care professionals asked companies that provided remote monitoring technologies to directly send these technologies to patients. With this scheme, the health care professionals provided medical advice, the companies provided technical support, and we provided support and information. (For details, see <https://heartrhythmalliance.org/aa/uk/covid-19-partnerships>). For many patients, remote monitoring technologies were a revelation. They did not need to worry, as they had been, about every symptom because they knew the remote monitoring system would immediately alert their health care team if something was wrong. Some patients have expressed astonishment that, given the benefits of remote monitoring, they have not been offered the technology before. In fact, we believe that the increased use of remote monitoring and other digital health care technologies during the pandemic has been a positive trend and one we hope will continue after the pandemic abates.

According to the feedback we have received from patients, the virtual platform and all our efforts to support the patients during this past year have been greatly appreciated. However, shared decision-making is about focusing on the individual wants and needs of the patient. Therefore, with the advent of new technologies and the new ways of delivering information, we must recognize that not all patients will want to embrace these methods. In its *AF White Paper—Put People First* (published March 2021), Atrial Fibrillation (AF) Association observes that some people are not digitally literate, do not have the economic means to access digital technologies (ie, they cannot afford the technologies and/or a good Internet connection), or simply are uncomfortable with sharing personal (including health) information online.⁵ Thus, Arrhythmia Alliance recognizes that there will be a need to continue to provide physical (COVID-19 restrictions permitting) as well as virtual resources to educate, inform, and support patients. Additionally, we recognize that some patients may want to “go digital” but will need

help in doing so. Even before the pandemic saw a pivot to a greater use of digital technologies, we provided resources on understanding and using these technologies. For example, our Know Your Pulse page (www.KnowYourPulse.org) has posters and videos on using mobile technologies to *detect AF*.

Ultimately, as the AF White Paper notes, the care of people who cannot or do not want to use digital technologies must not suffer if greater use of these technologies is to be adopted. As we look to the future and emerge from the pandemic, Arrhythmia Alliance aims to support patients using whatever ways, be they physical or virtual (including supporting patients to go online), meet their individual needs. Whether we offer a resource as physical or virtual, more likely both, will depend on what our patients tell us that they need.

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Authorship

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