Background: Survey undertaken to assess the level of patients and carer understanding of CIED device infection. Cardiac implantable electronic devices (CIEDs) continuously monitor heart rhythm. The device can slow or increase the heart rhythm and can shock it back into normal rhythm when a potentially fatal arrhythmia is detected. CIEDs are life-saving medical devices. By 2030 it is predicted that 2.3 billion devices will have been implanted globally. There are relatively few risks associated with the implant of the device, the most common are infection, bleeding and bruising. Infection is the most serious risk, yet the majority of survey respondents were unaware of the signs and symptoms of CIED infection and the potentially fatal consequences.

Purpose: Arrhythmia Alliance1 (A-A) in collaboration with Mended Hearts,2 conducted a survey to gather insights from patients on their knowledge of awareness, signs, symptoms, treatment and implications of device infection through their own experience or somebody they care for. The results will be used to support the findings of research undertaken by Duke University Medical School into CIED infection and adherence by healthcare professionals (HCPs) to international CIED infection guidelines.

Method: An online questionnaire was designed and distributed across the A-A, AF Assoc, Mended Hearts and STARS (Syncope Trust) databases, social media and online forums.

Results: 265 patients responded to the online questionnaire, 94% of respondents had a CIED or were a caregiver to someone with a CIED. Findings from the questionnaire are summarised in the diagrams.

Conclusions: This survey highlights a lack of patient knowledge about risk of CIED infection. There were limited discussions with doctors, and patients were unaware of infection signs or symptoms and unaware of potential relapse. It is therefore evident that HCPs need to engage with patients and caregivers regarding the risk of infection and the signs and symptoms of infection. Patients need to better understand signs and symptoms of infection and when to seek medical attention. HCPs, patients and caregivers need to know where to find further information and support from professional patient organizations such as Arrhythmia Alliance.

Arrhythmia Alliance Devices for an Arrhythmia Patient Booklet, 2021

**Figure 2**

**Figure 3**

**Figure 4**

**Figure 5**
Back-up notes: Results. A total of 265 people responded to the online questionnaire; 94% of respondents had a CIED or were a caregiver to someone with a CIED; 39% of patients experienced a CIED infection when they were over 65 years old, with all other age categories each making up a minority of the results; 59% of respondents were unaware what a CIED infection was, with only 41% knowing.

The majority (64% of respondents) also highlighted that their doctor did not discuss the risks of CIED infection with them. Those that did discuss the risks were told verbally by their doctor/physician (84%), and 12% reported that they were informed through their discharge paperwork. Furthermore, 61% noted that they would not be able to identify signs or symptoms of CIED infection, with 82% indicating that they had never experienced an infection.

For those that did have symptoms, 70% experienced swelling or redness of the area where the device was implanted, 48% said they had a fever, nausea, or chills, 54% had pain around the device area and 23% selected other. When diagnosed, 64% were identified as a pocket infection, 13% as a systemic infection, and 23% selected other or that they did not know.

When patients were asked how they responded to these symptoms, 43% contacted their cardiologist, 32% contacted an electrophysiologist and 13% made contact with a primary care physician; only 3% ignored them.

In terms of treatment options, 94% said they were treated for the infection, with 55% treated with both antibiotics and lead extraction, and 31% treated with antibiotics alone.

Half of patients (50%) said they searched for information prior to when they received their device; 85% used the internet, 45% spoke with their cardiologist and 42% spoke with their electrophysiologist.

Overall, 71% of patients were not aware of the high relapse rate of 50–100% when CIED infections are treated with only antibiotics; however, it is feared that this is higher, as 234 skipped this question.