



EHRA
European Heart
Rhythm Association

EUROPEAN HEART RHYTHM ASSOCIATION

A Branch of the ESC

EHRA Patient Survey “Living with atrial fibrillation”

Coordinating centre:

Scientific Initiatives Committee (SIC) of the European Heart Rhythm Association
(EHRA),
European Society of Cardiology (ESC) 2035 Route des Colles - Les Templiers,
BP 179 06903 Sophia Antipolis – France

Objectives:

The European Heart Rhythm Association (EHRA) Scientific Initiatives Committee (SIC) will conduct a patient survey entitled “Living with atrial fibrillation”. The main objectives of the survey will be to assess knowledge the patients with atrial fibrillation (AF) have about their arrhythmia, the sources which were useful for them to learn about AF, and their preferences regarding these sources. The survey will also evaluate aware involvement of AF patients in the process of diagnostic and therapeutic decision-making, and the burden the disease itself and the treatment poses to them. By recognizing patients attitudes, and expectations regarding information about their arrhythmia, but also their knowledge about AF, and their involvement in diagnosis / treatment of arrhythmia, this survey is expected to identify the gaps existing between contemporary patient involvement, education, and self-management in European countries and current recommendation of cardiac societies. Knowledge on the burden that AF and its management poses to patients, will identify areas, where integrated patient care requires further patient-tailored optimization. Consequently, the results obtained will allow to identify main areas of uncertainties and suggest the directions of further research.

Design and methods:

The electronic patient survey will be a prospective, multicentre survey of consecutive patients presenting with AF at centres which are located in countries-members of the ESC . A letter will be sent to the participating countries’ Arrhythmia working groups to



ask for participation. The questionnaire¹ was created as multiple-choice questions (attached), and will be filled out by AF patients at admission to the hospital, by patients already hospitalised or on outpatient visits. Atrial fibrillation will not have to be the main reason for hospitalisation, or the outpatient visit. No follow-up is planned.

Inclusion criteria:

All patients with any form of atrial fibrillation.

Exclusion criteria

Patients unwilling or unable to participate.

Duration of the study

The total study inclusion period is planned to last 8 weeks. In case of insufficient patient inclusion rate (i.e., less than 10 PM patients per centre), the EHRA-SIC may decide to prolong the inclusion period for a duration which will not exceed 15 working days.

There will be no follow-up of enrolled patients.

Ethical considerations:

Data (excluding personal data) will be entered by the patient on the internet using an online platform. The data can also be collected and entered on the online platform by a healthcare worker following a telephone interview with the patient or through a completer paper questionnaire. Data will therefore be collected anonymously by the ESC, through the online platform. Then, only the assigned SIC members will have access to the anonymised results. There will be no storage of clinical data outside the data collection instrument, which will be a secure, web-based form at The European Heart House. The main database will be secured according to current standards to

¹ This questionnaire includes the Jessa Atrial Fibrillation Knowledge Questionnaire (JAFKQ) – CONFIDENTIAL ©2016 Universiteit Hasselt and Jessa Ziekenhuis (BE) – all rights reserved – Licensed to the European Society of Cardiology



ensure both ethical and integrity requirements of the data. If required by a local policy, the approval of local Bioethic Committees will be obtained by the investigators.

Publication:

Publications of results are planned for the EP Europace Journal.

Reference

This questionnaire includes the Jessa Atrial Fibrillation Knowledge Questionnaire (JAKQ) – CONFIDENTIAL ©2016 Universiteit Hasselt and Jessa Ziekenhuis (BE) – all rights reserved – Licensed to European Society of Cardiology

Data Protection Policy

The ESC complies with the General Data Protection Regulation (GDPR) 2016/679 and the data protection laws in France. The ESC therefore takes all reasonable care and action to prevent any unauthorised access to the centres' and patients' personal data. Please refer to the dedicated GDPR webpage if needed.