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Country: **Europe**

Titel of the project: **Global Atrial Fibrillation Registry**

Project details

Atrial Fibrillation Association (AFA)

Award amount: €100,000

Establishing a database of real patient experiences through long-term monitoring of AF patients worldwide and producing a report, which reflects disease management, highlights associated risk factors, determines benefits of optimal treatment strategies and ultimately helps lead to improved healthcare in AF and increased prevention of stroke.

An AF registry would be a useful resource for the AF community since there is currently little data available on the prevalence and incidence of AF and to date there has not been an AF registry independently run by a non-profit organisation, such as the AFA. A registry is an organised system which collects information on a group of patients defined by a particular condition or disease. A registry can provide valuable information in addition to clinical trials because:

- Patients are followed over a longer time period
- A larger number of patients are included
- A broader range of data is collected e.g. patient reported outcomes
- They reflect a real world setting

Registries can be used by patient associations to support campaigns and lobbying activities, can help change policy by targeting health commissioners, policy makers and government officials and can support physicians by improving knowledge regarding the management of a specific condition or disease in day-to-day clinical practice. The AFA would like to set up a registry that collects uniform data from AF patients and evaluates:

- Prevalence and incidence of AF
- Risk factors and co-morbidities associated with AF e.g. increased risk of stroke
- Clinical outcomes including efficacy and safety of treatments
- Patient reported outcomes and quality of life
- Optimal treatment strategies and benefits of intervention (treated AF patients vs. non treated)

The registry will follow approximately 25,000 patients worldwide for 3 years and will involve 5 countries. Data would be collected in real time from a wide range of patients whose information would be entered into a central website by themselves or their physicians using a set questionnaire. Implementation of the registry would require the following:

- A top tier advisory board with physicians, patient association representatives and healthcare commissioners to gain a better understanding of what information should be collated and ensure the relevant data is captured
- A website where patients can input information
- A system which complements the website and allows for storage, retrieval and automatic analysis of the collated data
- Interim and final report
- A strategy for encouraging patients/physicians to enter information and widening reach of the registry e.g. by including a link on other AF websites

Ethics would also need to be taken into account, e.g. when patients sign up they would need to be clear that they have to sign away rights to confidentiality before entering information. The registry would be a valuable tool which would ultimately highlight the risk of stroke in AF patients, the severity of AF-related strokes and the need for improved prevention methods and treatment strategies.

Audience

Type

- AF Patients
- Healthcare professionals
- General public
- patient associations
- healthcare commissioners
- policy makers and government officials

Location

Europe