



# Living with Warfarin



The *reality* of life on  
Anticoagulation therapy

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A report by the Atrial Fibrillation  
Association and AntiCoagulation Europe

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# Foreword

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**We wish to thank you for reading this important new research, the first comprehensive attempt to understand what it is like for patients to live with atrial fibrillation and receive an anticoagulant drug - warfarin.**

The report highlights areas where change will greatly improve patient care. We, the Atrial Fibrillation Association (AFA) and AntiCoagulation Europe (ACE) are united in calling for change in key areas of policy and healthcare professional practice to improve the experience and lives of people with atrial fibrillation.

We hope this report helps with the understanding of the issues faced by people with atrial fibrillation on warfarin and can act as a stepping stone for real change.



**Mrs Trudie Lobban MBE**  
Chief Executive Officer  
Atrial Fibrillation Association



**Mrs Eve Knight**  
Co-founder and Chief Executive  
AntiCoagulation Europe

# Executive summary

**Atrial fibrillation (AF) is the most common heart rhythm abnormality, affecting well over a million people per year in the UK. The condition is a life-threatening illness in its own right, and a leading cause of stroke.<sup>1</sup> Over the last 50 years warfarin has been widely used to reduce the risk of stroke in people with AF and is well understood by the healthcare profession. Although warfarin is very effective clinically when well controlled, it can present challenges for patients as they require regular monitoring and may need to alter their lifestyle to prevent complications.**

*Living with Warfarin* shows for the first time the day-to-day reality for people with atrial fibrillation (AF) taking warfarin. Key findings are:

- For the majority of patients questioned, warfarin affected their lives more than AF itself
- Lack of knowledge about AF, the risk of stroke or the importance of treatment with warfarin was widespread
- The time and potential inconvenience of monitoring of patients was significant
- Less than half of patients (44%) were warned about AF during a routine health check, reinforcing the need for opportunistic health screening

The report provides a clear series of calls for action, to inspire change amongst clinical practice and give people living with AF hope. The key requests are:

- Clinicians must ensure every AF patient understands the need for therapy, and to work to minimise the impact therapy has on everyday life
- Patients need to ensure they speak up if any aspect of care is too intrusive on their life
- Patients and healthcare professionals can work through the different management options available to ensure the best care for patients

“Improvements in monitoring and the introduction of new therapeutic options means treatment to prevent AF-related stroke in people with AF is now highly effective and without many of the restrictions associated with warfarin.” – *Trudie Lobban MBE AFA*

# Introduction

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**Atrial fibrillation (AF) is the most common heart rhythm abnormality, affecting well over a million people a year in the UK. The condition is not just a heart murmur or fast pulse. It is a life-threatening illness in its own right and a leading cause of stroke.<sup>1</sup>**

**Warfarin effectively prevents strokes in those people with AF who are eligible and able to tolerate it, and it is widely available in the NHS, but the treatment is not without its challenges. Patients require regular monitoring and may need to alter their lifestyle to prevent complications. Until now the extent of this on patients was unknown. Whilst many people with AF are not provided with warfarin management, *Living with Warfarin* is the culmination of a groundbreaking research project to show for the first time the day-to-day reality for people with atrial fibrillation (AF) taking warfarin, and the ways in which it impacts on their lives.**

**Understanding AF and warfarin is also critical, to ensure patients can see the value of warfarin as a reduction on the risk of stroke because of the underlying risks of their condition. The research therefore investigates levels of knowledge and awareness about AF and its management.**

# Call to action

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**As two of the leading groups dedicated to improving the care of people with AF and eliminating stroke, the AFA and ACE make the following recommendations for change:**

## **To all people living with AF**

This report aims to give people living with AF hope, so that their voices will be listened to and so that not only warfarin but also new and less-invasive options may become realistic options for stroke prevention increasingly become the norm for stroke prevention:

- Speak up if any aspect of your care is too intrusive on your life. There may be options available that alleviate the burden
- Work with your doctor/HCP to understand your therapy, to ensure you are making the right decisions for you
- Do not be worried about asking questions of your clinician: you can both work in partnership to give you a life free from the fear of stroke

## **To healthcare professionals**

AF and stroke prevention health professionals are hugely dedicated, delivering quality care to hundreds of thousands of patients across the NHS. To these individuals this report wants to say:

- You can do more to ensure every AF patient understands the link between AF and stroke and the need for therapy
- Healthcare professionals (HCPs) need to demonstrate the impact of poor control to aid compliance with therapy
- All primary care professionals should set aside dedicated time for professional education to remain up-to-date
- Provide patients with options to make sure patients don't have their lives ruled by warfarin

# The research

The research results are broken into four key areas, getting to the heart of the problem for people with AF. These are:

## **The patient journey**

Charts the course patients take when receiving a diagnosis and being placed on warfarin treatment.

## **Knowledge and understanding**

Creates the clearest picture yet of how patients perceive their chronic condition, its treatment and the information they receive from healthcare professionals.

## **Impact of warfarin-related monitoring**

Provides a greater understanding of the effects on everyday life of the regular blood tests (known as International Normalised Ratio or INR monitoring) required for people taking warfarin.

## **Life with AF and warfarin**

Looks in-depth at the ways in which the condition and its management may be preventing or hindering people with AF from reaching their full potential.

# Methodology

This research was conducted by Branding Science in 2011.

## **The core aims of research were:**

- Provide insight into the patients' views and experience of atrial fibrillation
- Provide an understanding of what it is like to live with warfarin
- Provide an understanding of the impact of AF and warfarin therapy on patient lifestyles

## **The research methodology consisted of:**

- A quantitative telephone survey of 104 people in the UK (70 men, 34 women), between the ages of 30 and 80+ who have AF and were taking warfarin.
- 11 qualitative interviews and patient (and partner) video diaries

Research was conducted according to geographic quotas to ensure relevance across UK.

# The patient journey

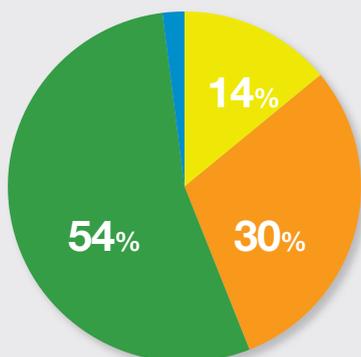
## The research identifies three critical phases in the journey of any patient being diagnosed with AF and then receiving treatment with warfarin.

The first step, dubbed pre-diagnosis, is the point at which initial concerns about AF were raised.

Crucially in this phase, less than half of patients (44%) were warned about AF during a routine health check or while being investigated for another health complaint.

### How diagnosed with AF?

- During routine health check
- During investigation of another health complaint
- Due to experiencing symptoms of AF
- Can't remember



Base: All (n=104)

“This reinforces the need for greater education of at-risk patients to attend regular health screening. Family doctors and nurses also have a role in understanding how opportunistic screening can uncover hugely important conditions like AF.” – *Trudie Lobban MBE, AFA*

In the second phase, diagnosis, hospital specialists become the most important liaison with patients. 62% of respondents received an official diagnosis of AF from a hospital-based specialist.

The third phase is **management** with warfarin. Here the research draws attention to the time taken for patients to receive warfarin therapy.

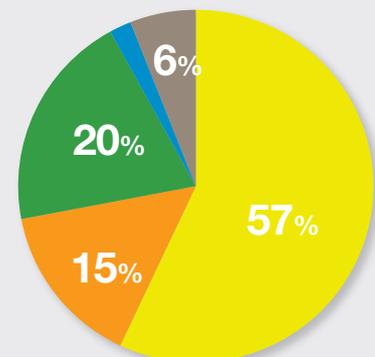
**Almost three-quarters (72%)** will be on warfarin to prevent stroke within four weeks, but **one in five patients (20%)** report waiting between a month and a year before receiving warfarin.

The research also indicates that patients treated by a GP are more likely to receive warfarin later than those under the care of a hospital specialist.

Although it is important to stress that there may be many factors influencing this, it is clear that patients need to be empowered with information about management options and, where appropriate, challenge clinical opinion.

### When were you prescribed Warfarin

- At diagnosis
- Within 4 weeks
- 1 to 12 months
- Over 1 year
- Can't remember



Base: All (n=104)

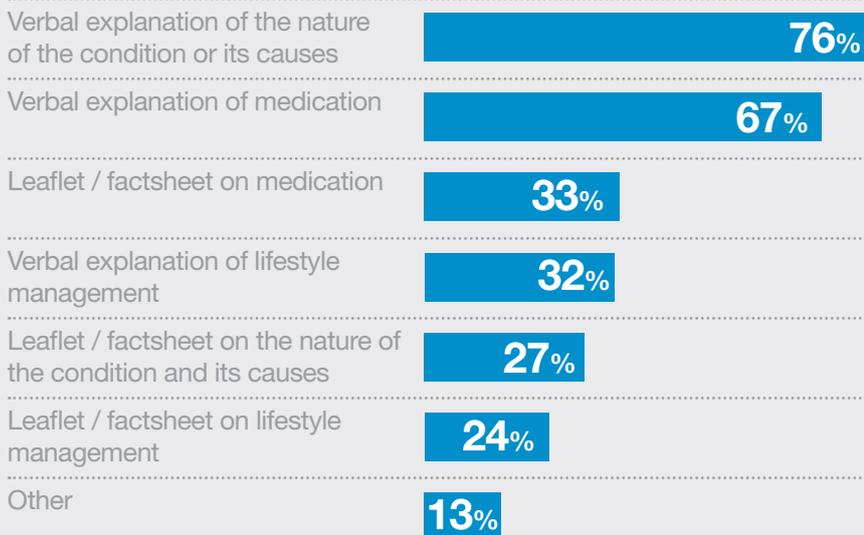
“Time is often of the essence when starting patients on anticoagulation therapy such as warfarin, which is why GPs have such an important role to play. We advise all primary care professionals to take part in regular evidence-based education to ensure their practice remains up-to-date.” - *Professor David Fitzmaurice, Academic GP, University of Birmingham*

# Knowledge and understanding

## What is AF?

A vital question for anyone newly diagnosed, and one that the NHS broadly answers with three-quarters (75%) of respondents receiving some information of the condition, most commonly a verbal explanation.

### Information received at diagnosis



Base: All receiving information (n=78)

However, **25% could not recall** or did not receive any information on the condition from their healthcare professional.

Despite the information provided, **ignorance was widespread with only two thirds** (66%) of patients accurately described AF correctly and **one in ten** could not describe it at all. This problem was especially acute amongst older patients (those 70+).

“It isn’t just about giving patients information, we all need to do more to make sure they understand. AF is a long-term, potentially life-threatening condition. Patients need to know about their disease so they can make informed decisions.” – *Trudie Lobban MBE, AFA*

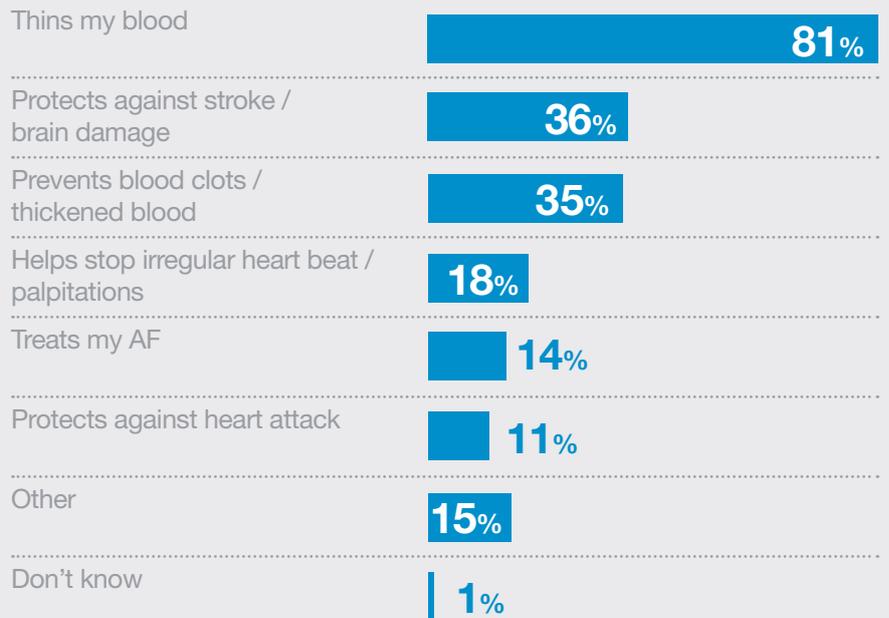
**Link between AF and stroke**

AF is a major risk factor for stroke, with **22,500** strokes a year thought to be directly attributable to AF.<sup>2</sup> The outlook is also bleaker for those with AF who have a stroke with more likelihood of death and disability<sup>2</sup>. Shockingly then, **38%** of patients questioned had no idea of any of the risks of AF, and **56%** were not aware that AF increases the risk of stroke.

**Stroke prevention treatment with warfarin**

Patients questioned were asked about their understanding of what warfarin did for them:

**What is your understanding of what warfarin does for you?**



**Base:** All receiving information (n=104)

Despite the widespread assumed understanding of the simplistic action of warfarin in thinning the blood, just a **third** of patients (36%) knew that this could prevent a stroke.

Low levels of understanding were mirrored by a lack of interest in information, with patients generally not proactive in seeking additional information on warfarin. **Less than a third** (29%) said they actively searched for information on warfarin.

“In general, the more information patients have access to enables them to get better care. People with AF and those on whose lives anticoagulation has a large impact, should take advantage of the wide range of clear patient literature available to ensure they make the right decisions for them.” - *Eve Knight, ACE*

**Nine out of ten (89%)** remember receiving information on warfarin, whilst only 75% remember receiving information on AF itself.

# Impact of warfarin-related monitoring

Management with warfarin isn't just a simple matter of taking medication as prescribed, and getting on with life. Living with warfarin shows the reality of life on warfarin, and the extent to which the therapy is helping patients.

## INR monitoring

Warfarin therapy requires active monitoring, as the right dose varies from patient to patient. Patients have a regular blood test at a hospital clinic or their GP surgery to check their International Normalised Ratio (INR). The INR compares how fast the patient's blood clots compared to an international standard: normal blood clots at an INR of 1. To prevent the risk of stroke in someone with AF, their blood needs to clot 2 to 3 times more slowly- therefore the INR generally needs to be between 2-3. By measuring the INR – the patient's therapeutic range -, clinics can ensure that the patient stays within their therapeutic range by taking the right dose of warfarin.<sup>3</sup>

## Time spent being monitored

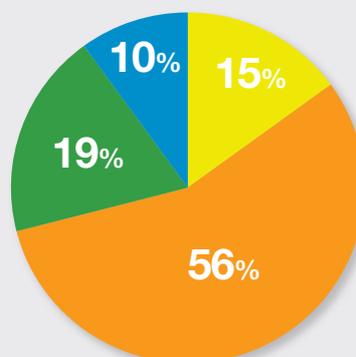
**Over two-thirds** (69%) of patients questioned needed their INR monitored at least every 4 weeks.

**Four in ten** (42%) are having their INR monitored every two weeks. This rises to almost **two-thirds** (61%) amongst patients diagnosed in the past 12 months.

For the majority of those interviewed, monitoring takes place in the GP's surgery, with trips to hospital or other clinics usually the norm. Only older patients (70+) were likely to have their INR monitored at home.

## Where do you go to have your INR monitored?

- Hospital
- GP
- Clinic
- Home



Getting to the clinic on a regular basis adds to the time and inconvenience.

**Almost half** (49%) of patients said they drove to monitoring appointments, but **one in six** (16%) relied on someone else driving them.

For most patients having their INR monitored takes up to one hour, including travel to and from the appointment.

Despite the time required for INR monitoring diminishing as more intensive monitoring gives way to monthly check-ups, the research demonstrates a significant time impact for patients.

“Warfarin can be inconvenient - especially initially. For many it becomes part of the daily routine, accepted as something they have to do to stay healthy, but we should still try and minimise the impact on people’s lives.” – *Trudie Lobban MBE, AFA*

## 30 minutes

- **42%** of patients take less than half an hour these patients are likely to:
  - be monitored by their GP
  - walk or drive to their appointment
  - be monitored at home

## up to 1 hour

- **39%** take between 30 minutes and an hour and are likely to:
  - be monitored by their GP or a specialist clinic
  - drive to their appointment

## over 1 hour

- **19%** take over an hour and are likely to:
  - be monitored by the hospital or a specialist clinic
  - use public transport or drive to their appointment

### All that effort and no gain

Considering how much time patients spend on monitoring, and the inconvenience and lifestyle restrictions encountered in order to get their warfarin treatment right, a significant number often don't even meet their INR targets.

- **Half** (50%) of patients said they meet the target always or most of the time
- **One third** said they only meet their target some of the time

Over **one in ten** (13%) of respondents said they did not know their INR target.

Based on these findings, the time required from a patient for INR monitoring could range from six hours or less in a year, **up to a huge 52 hours a year.**

“Just half (47%) of patients who only met their targets some of the time felt concerned about the situation. Clinicians need to be able demonstrate the impact of poor control to patients in order to make them a full partner in the management of their anticoagulant therapy.” – *Eve Knight, ACE*

# Life with AF and warfarin

## Warfarin a bigger burden than AF itself

Patients reported that warfarin had **more** of an impact on life than AF itself. According to the survey, **57% of patients** felt that AF had a fairly low impact or no impact at all on their overall quality of life. By contrast **half of patients** (54%) felt that warfarin had a very high or fairly high impact on their overall quality of life.

	High impact of warfarin	High impact of AF
Overall quality of life	54%	43%
Employment	54%	29%
Diet	33%	22%
Friends / social life	28%	24%
Living situation	20%	25%
Ability to do things around the house	19%	28%
Family	17%	24%

### Food for thought

Patients should be mindful of a number of food and drug interactions that can affect warfarin levels, which can in turn reduce treatment effectiveness and increase the risk of side effects.<sup>3</sup> Patients should inform their doctor if they want to change their diet, for example if they think they will drink more alcohol while on holiday. Patients also need to talk to their doctor before taking any other medicines.

### Patients call for more options

Warfarin is currently one of the few options available to AF patients for stroke prevention and it is effective. The overall picture is of general acceptance, but an underlying dissatisfaction with limited options and the difficulties of living with warfarin exists.

**Almost a third** (30%) strongly agreed with the statement that **'warfarin is like a guardian angel'**.

- 15% strongly agreed with the statement 'I get a real sense of achievement when I meet my therapeutic target'.

By contrast **over two thirds** (37%) fairly strongly /strongly agree with the statement **"I hate having to take warfarin."**

- 31% fairly strongly/strongly agreed that "I feel my whole life is controlled by warfarin"
- 18% agreed with "I find it difficult to keep to the right diet on warfarin"

Ultimately, the research indicates that patients are making the changes required to live with warfarin. However, most patients would be open to an alternative that eliminates the 'difficulties' that come with warfarin.

# About atrial fibrillation

Atrial fibrillation is the most common heart rhythm abnormality and a leading cause of stroke.<sup>1</sup> It is estimated that **1.2 million** people are diagnosed with AF in the UK.<sup>4</sup>

People living with AF are **five times** more likely to have a stroke<sup>5</sup> but many are unaware of the risk. In addition, strokes related to AF tend to be associated with poorer prognosis; in one large study, almost **50%** of people who had a stroke related to AF **died within one year**.<sup>6</sup>

AF can manifest in symptoms such as fatigue, breathlessness and chest pain, or it can have no symptoms at all - but the risks to health are very real.

In addition to the risks and severe discomforts of the condition, people living with AF also face limited preventative treatment choices that, while effective, can impact further on their lives.

AF is a condition that has serious implications for the individual, their families and carers, and the health system. For this reason, it is invaluable to understand some of the additional pressures that might surround current preventative treatment in the area, and how these might impact on quality of life and quality of outcomes.

## References

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# Atrial Fibrillation Association (AFA) *and* AntiCoagulation Europe (ACE)



## Atrial Fibrillation Association

The Atrial Fibrillation Association (AFA) is a UK registered charity which focuses on raising awareness of Atrial Fibrillation (AF) by providing information and support materials for patients and medical professionals involved in detecting, diagnosing and managing Atrial Fibrillation. AFA works closely with medical professionals, Department of Health, government, NHS Trusts, PCTs, patients, carers, patient support group members and allied groups.

### The AFA aims to:

1. To provide support and information on Atrial Fibrillation to those affected by this condition
2. To advance the education of the medical profession and the general public on the subject of Atrial Fibrillation
3. To promote research into the management of Atrial Fibrillation

[www.atrialfibrillation.org.uk](http://www.atrialfibrillation.org.uk)

## AntiCoagulation Europe

AntiCoagulation Europe (ACE) is a UK registered charity founded in the year 2000. We work with patients, healthcare professionals, NHS trusts, Industry, Governments, other charities and patient groups and a wide range of other organisations.

**Our Aims are:** The prevention of thrombosis; the provision of information, education and support; the promotion of independence - supporting people to take an active part in their own healthcare.

[www.anticoagulationeurope.org](http://www.anticoagulationeurope.org)