



INSIGHTS AND ANALYSIS—HIGHLIGHTS
Atrial Fibrillation Survey Report
JANUARY 2015

Conducted for



SURVEY INFORMATION AND METHODOLOGY

Client	Alliance for Aging Research
Date Conducted	August 7–19, 2014
Sample Size	N = 507
Sample Universe	Adults 65+ who have been diagnosed with atrial fibrillation
Methodology	Online interviewing
Analysis	Ronald A. Faucheux, Ph.D., President and Chief Analyst Andrew Rugg, Director and Analyst



SURVEY INSIGHTS AND ANALYSIS

- **First reactions:** Afib patients have had varied experiences in terms of when they first learned of their conditions. Most said it was when they had symptoms that were bad enough to go to an emergency room (33%). However, large segments also said it was during a regular check-up (25%), or when they went to a health care professional for something else (20%), or when they felt symptoms and scheduled an appointment to discuss them (17%).
 - Whites were more inclined than racial minorities to say they had symptoms that were bad enough to go to an emergency room; minorities were more inclined to say it was a regular check-up or they felt symptoms and scheduled an appointment to discuss them.
 - Those 65-70 years old more often say they went to a health care professional for something else, while those 71 or older more often say it was during a regular check-up.
 - In the 2012 survey, 35% said they had symptoms that were bad enough to go to an emergency room (compared to 33% in the latest survey). Also in that survey, large segments said it was a regular check-up (19%), they went to a health care professional for something else (11%), or they felt symptoms and scheduled an appointment to discuss them (22%).
- **Perception of the problem:** After diagnosis, more Afib patients thought Afib was a major problem (48%) than those who thought it was a minor problem (31%); 18% had no idea. Only 3% thought Afib was not a problem at all.
 - Respondents 65-70 were more likely to say it was a major problem than were those 71 and older (56% vs. 43%).
 - Minorities, much more so than whites (80% vs. 45%), thought it was a major problem.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Symptoms:** 28% of respondents said they had Afib symptoms less than a week before they were diagnosed; another 27% said it was between a week and a year; and an additional 14% said it was more than a year. Also, 8% said they had no symptoms.
- **Diagnosis:** Most respondents were diagnosed by a cardiologist (55%). Considerable numbers were also diagnosed by general practitioners (23%) and emergency room doctors (17%).
 - After diagnosis, 88% of respondents saw cardiologists and 20% saw electrophysiologists.
 - Visits to electrophysiologists were highest among those with incomes above \$100,000.
 - Visits to electrophysiologists were higher among those with Afib less than two years (25%) than those with the condition for more than 10 years (13%).
 - The percentage of respondents who said they were initially diagnosed by a cardiologist is down 7 points since the 2012 survey, going from 62% to 55%. The percentage of respondents who said general practitioner in the 2012 study is about the same (22% vs. 23%) as it is now. The percentage of respondents who said emergency room doctors is now a little higher than in 2012, 17% vs. 12%.
- **Diagnosis satisfaction:** Most respondents (76%) were very satisfied with the way their Afib diagnosis was handled by medical professionals. Additionally, 16% were somewhat satisfied. Only 3% were dissatisfied at some level.
 - In the 2012 survey, 85% were either very or somewhat satisfied, compared to 92% now; 3% were dissatisfied in both surveys.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Second opinions:** After initial diagnosis, only 20% of respondents sought a second opinion.
 - Seeking second opinions was highest among minorities (33%), those with incomes over \$100,000 (26%), those with Afib for less than 2 years (26%), and 71-75 year olds (24%).
 - Of those who sought a second opinion, most (71%) went to a cardiologist.
 - Getting a cardiologist's second opinions was highest among minorities (100%), women (77%), those 76 and older, those with incomes under \$50,000, Westerners (86%), and those with Afib less than 2 years (89%).
 - For second opinions, 22% went to a family physician and 19% went to an electrophysiologist.
- **Patient research:** 62% of respondents did research on their own after diagnosis or during treatment. That percentage was highest among women (69%), those with incomes over \$100,000 (76%), minorities (74%), and those with Afib less than 2 years (67%). In the 2012 survey, 66% said they did research on their own (compared to 62% in the latest survey).
 - According to the latest survey, most Afib patients who did their own research sought information on treatment choices (85%), symptoms (75%), potential complications (72%), and stroke risk (67%).
 - These findings fairly closely track the 2012 survey, when Afib patients who did their own research sought information on treatment choices (80%), symptoms (71%), potential complications (71%), and stroke risk (62%).
 - Based on the latest survey, most of those who did their own research went to online search engines (79%) or medical websites such as WebMD (70%). Also, 48% went to a medical professional, 36% to a medical institution, 15% to government sources, 11% to family and friends, 10% to patient organizations, 8% to drug company sites, and 4% to traditional news media sources.

SURVEY INSIGHTS AND ANALYSIS (continued)

- In the 2012 survey, most of those who did their own research went to online search engines (74%) or medical websites such as WebMD (60%). Also, 31% went to a medical professional, 29% to a medical institution, 14% to government sources, 18% to family and friends, 18% to nonprofit patient organizations, 10% to drug company sites, and 10% to traditional news media sources.
- Looking at web vs. traditional media channels, note that while online search engines increased by 5 points over the past two years, medical websites went up 10 points, and traditional media went down 6 points.
- **Ongoing care:** 82% of respondents see a cardiologist at least a few times a year for treatment of Afib. Additionally, 45% see a family physician, 20% see an electrophysiologist, 10% see a health care professional at an anticoagulation/INR clinic, and 6% see a nurse or physician's assistant.
- **Doctor-patient communications:** 99% of doctor-patient communication is conducted through in-person visits. Also, 10% is through phone calls, 5% through emails, and 2% from postal mail.
 - Most emails and postal mailers are less than once a month.
 - Most phone calls are at least once a month.
- **Treatment satisfaction:** 74% of all respondents surveyed have been very satisfied with the treatment they receive for Afib and an additional 21% have been somewhat satisfied. Less than 2% have been dissatisfied.
 - Satisfaction levels have improved a little since the 2012 survey, when 68% were very satisfied and 22% somewhat satisfied.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Treatment decision teams:** 92% of respondents said a cardiologist was involved in their treatment decisions, while 50% said a family physician, 25% an electrophysiologist, 8% a family member or friend, and 5% a nurse or physician's assistant.
 - Those with incomes over \$100,000 were much more likely to say an electrophysiologist than those with incomes below \$50,000 (38% vs. 15%).
 - More respondents 65-70 said an electrophysiologist than those 71 or older (31% vs. 22%).
 - More with Afib less than 2 years said an electrophysiologist than those with it more than 10 years (30% vs. 21%).
 - In the 2012 survey, 88% of respondents said a cardiologist was involved in their treatment decisions compared to 92% now. In 2012, 43% answered a family physician (vs. 50% now) and 18% answered an electrophysiologist (vs. 25% now).
- **Medication awareness:** 99% of respondents said they have heard of Warfarin (or Coumadin or Jantoven); 80% have heard of Dabigatran (or Pradaxa); 54% have heard of Rivaroxaban (or Xarelto); and 72% have heard of Apixaban (or Eliquis).
- **Anticoagulant medication use:** 79% of respondents said they have used anticoagulant medications; 60% said they are taking them now.
- **Why anticoagulant medications are not being used:** The primary reason is concern over complications or side effects (43%); that's followed by: Afib is not severe enough to need medication (40%), could cause internal bleeding (38%), feel fine don't need it (36%), too many lifestyle changes (16%), tried it and didn't like it (15%), too expensive (12%), don't take prescription medicines when OTC available (12%), tried more than one and didn't like them (5%), instructions too difficult (4%), didn't feel like it was working (3%).

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Brand of anticoagulant medication used:**
 - 65% of respondents said they have used Warfarin (or Coumadin or Jantoven)—that's down from 70% in 2012;
 - 17% said they have used Dabigatran (or Pradaxa)— that's up slightly from 16% in 2012;
 - 10% said they have used Rivaroxaban (or Xarelto)—that's up significantly from 3% in 2012;
 - 5% said they have used Apixaban (or Eliquis)—this medication was not included in the 2012 survey.
- **Medication recommendations:** When health care professionals *first* recommended anticoagulant medication, 81% of respondents said the recommendation was for *one* medication, 7% of respondents said the recommendation provided *multiple* options, and 6% said their health care professional did not make any recommendation.
 - Of Warfarin (or Coumadin or Jantoven) users: 88% said the recommendation was for *one* medication, 7% of respondents said the recommendation provided *multiple* options, and 4% said their health care professional did not make any recommendation.
 - Of Dabigatran (or Pradaxa) users: 84% said the recommendation was for *one* medication, 14% of respondents said the recommendation provided *multiple* options, and none said their health care professional did not make any recommendation.
 - Of Rivaroxaban (or Xarelto) users: 81% said the recommendation was for *one* medication, 13% of respondents said the recommendation provided *multiple* options, and 2% said their health care professional did not make any recommendation.

SURVEY INSIGHTS AND ANALYSIS (continued)

- Of Apixaban users (or Eliquis): 97% said the recommendation was for *one* medication, 3% of respondents said the recommendation provided *multiple* options, and none said their health care professional did not make any recommendation.
- In the 2012 survey, 67% of respondents said the recommendation was for *one* medication. That number has increased 14% since then, a significant rise to 81%. The percentage saying multiple options has dropped from 17% in 2012 to 7% now.
- **Medication decision:** 75% of respondents said their doctor or other health care professional made the decision and 21% said they made it themselves.
 - A large majority also answered cardiologist to a similar question in the 2012 survey; the same percentage (21) answered that the decision was made on their own in both surveys.
- **Years of medication use:**
 - 47% of Warfarin (Coumadin or Jantoven) users have taken for more than 5 years and 29% for 1-5 years.
 - 7% of Pradaxa (Dabigatran) users have taken for more than 5 years and 56% for 1-5 years and 42% for 1-5 years.
 - 0% of Xarelto (Rivaroxaban) users have taken for more than 5 years and 42% for 1-5 years.
 - 0% of Eliquis (Apixaban) users have taken for more than 5 years and 7% for 1-5 years.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Switchers:** 24% of anticoagulant medication users said they have switched from one to another at some point. The percentage of switchers was lowest among those who have had strokes (16%) and minorities (11%).
 - By far, the main reason why patients switch medications is their doctors or other health care professionals recommended a new one (69%). That is followed by side effects (18%), went off medication to have a procedure (11%), too difficult to use (10%), and cost too much out of pocket (9%).
 - 30% of Warfarin (Coumadin or Jantoven) users have switched from one anticoagulant medication to another at some point. 68% of them switched based on a doctor's recommendation; 16% switched because of side effects; 11% switched because of difficulty taking the medication.
 - 67% of Pradaxa (Dabigatran) users have switched from one anticoagulant medication to another at some point. 66% of them switched based on a doctor's recommendation; 17% switched because of side effects; 10% switched because of difficulty taking the medication.
 - 66% of Xarelto (Rivaroxaban) users have switched from one anticoagulant medication to another at some point. 74% of them switched based on a doctor's recommendation; 22% switched because of side effects; 12% switched because of difficulty taking the medication.
 - 63% of Eliquis (Apixaban) users have switched from one anticoagulant medication to another at some point. 60% of them switched based on a doctor's recommendation; 17% switched because of side effects; 11% switched because of difficulty taking the medication.
- **Aspirin:** 70% of respondents said they have taken aspirin to reduce stroke risk and 56% said they now take aspirin to reduce stroke risk.

SURVEY INSIGHTS AND ANALYSIS (continued)

- Men more than women say they now take aspirin (60% vs. 40%). More respondents with Afib less than 10 years than over 10 years have taken aspirin (59% vs. 46%).
- 88% said the aspirin they have taken since they were diagnosed with Afib was recommended by a doctor or other health care professional.
- 47% of Warfarin (Coumadin or Jantoven) users now take aspirin; 43% of Pradaxa (Dabigatran) users now take aspirin; 40% of Xarelto (Rivaroxaban) users now take aspirin; and 33% of Eliquis (Apixaban) users now take aspirin.
- In the 2012 survey, 63% said they were taking aspirin to help manage Afib. Since then, it has declined to 56%.
- **Combination therapy:** 32% say they have been on a combination therapy and 65% say they have not. (In the 2012 survey, 31% say they have been on combination therapy, compared to 32% now.)
 - Groups most likely to say they have been on a combination therapy are: those who have had strokes (51%), men (37%), and Southerners (44%).
 - 35% of Warfarin (Coumadin or Jantoven) users have been on a combination therapy; 41% of Pradaxa (Dabigatran) users have been on a combination therapy; 43% of Xarelto (Rivaroxaban) users have been on a combination therapy; 29% of Eliquis (Apixaban) users have been on a combination therapy.
- **Rate and rhythm of heartbeat:** To restore the rate and rhythm of heartbeat, 65% of respondents use medication to control the rate (including beta blockers, calcium channel blockers, and digoxin); 31% use medication to control rhythm (anti-arrhythmic drugs); 29% use electrical cardioversion; 8% use chemical cardioversion; 15% use pacemakers, defib implants or stents; 13% use catheter ablation; 3% use maze or mini-maze surgery; and 2% do it with exercise; 5% said they do nothing.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Feeling Afib.** 50% of respondents say they can feel their AFIB and 43% say they can't. Another 8% aren't sure.
 - Patients 65-70 are more likely to feel their Afib than those who are older (59% vs. 43%).
 - Women are more likely to feel it than are men (55% vs. 46%).
- **Missing medication schedules:** 88% of respondents claim they always take their medication. Another 9% miss taking medication either once a month or once every couple of weeks. Only 2% miss taking medication at least once a week.
 - The percentage saying they almost always take their medication when they're supposed to increased 4 points since the 2012 survey, from 84% to 88%.
- **Stroke worry.** 13% of respondents said they are very or extremely worried about having a stroke. (In the 2012 survey, 11% said they were very or extremely worried.)
 - Patients 65-70 are twice as likely to be very or extremely worried than those who are older (18% vs. 9%).
 - 30% of respondents who have had a stroke are very or extremely worried.
 - Whites much more than minorities are very or extremely worried (14% vs. 4%).
 - Only 6% of those with Afib more than 10 years are very or extremely worried. That compares to 18% for those who have had Afib less than 2 years.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **How long does Afib last?**
 - 71% are paroxysmal or intermittent (episodes come and go but don't last more than 7 days)
 - 5% are persistent (episodes last longer than 7 days)
 - 21% are longstanding persistent (Continuous Afib that lasts longer than a year)
 - 4% are permanent (decision made not to stop it)
- **Stroke risk timeline:** 90% of respondents say their health care professionals did not tell them their stroke risk over either a one or five-year period; 5% said five years and 3% said one year.
 - In the 2012 survey, only 6% of survey respondents received a 1- or 5-year risk number; it's a little higher now, at 8%.
- **Knowledge of stroke risk:** 76% of respondents believe they know enough about how Afib can lead to stroke; 12% said they need more information and 12% said they don't know.
- **Stroke experience:** Since Afib diagnosis, 9% of respondents said they've had a stroke (most of which were minor); 64% of the stroke victims reported having only one stroke and 50% reported having ischemic strokes.
 - Additionally, 12% reported having had blood clots since their Afib diagnosis.
 - In the 2012 survey, 8% of respondents said they have had a stroke, compared to 9% in the latest survey.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Stroke risk factors:** Between 3% and 20% of respondents said they are very concerned about the stroke risks they were asked about.
 - The top risk factors that gained the most numbers of respondents saying they are very concerned are: overweight, high cholesterol, diabetes, low levels of physical activity, age, previous heart condition, family health history and high blood pressure.
- **Bleeding risk and anticoagulant medications:** 14% of respondents are very or extremely worried about the risk of internal bleeding from medications; 29% are somewhat worried and 56% are either not too worried or not at all worried.
 - In the 2012 survey, 13% said they were extremely or very worried compared to 14% now. In 2012, 52% said they were either not too worried or not worried at all, compared to 56% now.
- **Anticoagulant trade-off:** Respondents are more concerned with the risk of stroke if they don't take anticoagulant medications (42%) than they are with the risk of bleeding if they do (9%); 30% are worried about both equally and 17% are worried about neither.
 - In the 2012 survey, respondents were also more concerned with the risk of stroke if they didn't take anticoagulant medications (34%) than they were with the risk of bleeding if they did (11%). Also, in 2012, 30% were worried about both equally and 17% were worried about neither.
- **Discussions:** 75% report that the health care professional treating their Afib have discussed with them the possibility of bleeding complications from anticoagulant medications; 19% said they haven't.
 - There has been a marked change during the last two years in this area: In the 2012 survey, 63% said their health care professional discussed with them the possibility of bleeding complications from anticoagulant medications (vs. 75% in the latest survey).

SURVEY INSIGHTS AND ANALYSIS (continued)

- In the latest survey, 81% of respondents said their health care professional explained to them the risk of increased bruising and bleeding from minor cuts from taking anticoagulant medications; 25% said their health care professional explained to them the risk of increased serious bleeding that could be fatal; 15% said their health care professional explained to them the risk of brain bleeding in case of a fall.
 - 37% said their health care professional explained to them the risk of falling and the possibility of bleeding complications from a fall; 54% said they did not.
 - 87% said their health care professional described the risk of bleeding just as something they should be aware of; less than 3% said the risk is a reason to avoid medications.
 - 82% said the risk of falls was not a factor in their treatment.
 - Less than 2% said the risk of falls kept them off of anticoagulant medication.
- **Bleeding risk factors:** Between 1% and 13% of respondents said they are very concerned about the bleeding risk factors they were asked about.
 - The top risk factors that gained the most numbers of respondents saying they are very concerned about are: age, high blood pressure, and small vessel heart disease.
- **Bleeding experience:** 40% of respondents reported having had a minor bleed while on anticoagulant medication and 5% reported having a life threatening bleed.
 - Minor bleeds were more often experienced by men (45%), those 71-75 (45%), those with incomes above \$100,000 (46%), Southerners (47%) and stroke victims (57%).

SURVEY INSIGHTS AND ANALYSIS (continued)

- Life-threatening bleeds were most often experienced by those 76 years old or older (8%) and Midwesterners (8%).
- In the 2012 survey, 31% said they have had minor bleeds (compared to 40% who said so in the latest survey) and 5% said they have had a life threatening bleed (the same as the latest survey).
- **Rating Afib care:** 24% of respondents rate the level of Afib care in the country as excellent and 46% rate it as very good—for a total positive rating of 71%.
 - Also, 24% rate the level of care as pretty good, 5% as only fair and less than 1% as poor.
- **Self-rating of overall health:** Of all Afib patients surveyed, 5% rate their health as excellent, 34% very good, 41% good, 18% fair, and 3% poor.
 - This means that 39% rate their overall health very positively (excellent or very good). The self-rating is highest among those with incomes over \$100,000 (51%), college graduates (45%), and those with Afib for more than 10 years (44%).
- **Medical advice and treatment support:** 89% of respondents feel that their health care professionals provide them with enough information and treatment support. Only 6% said they do not.
- **Emotional and psychological support:** 82% of respondents feel that their health care professionals provide them with enough emotional and psychological support. Only 7% said they do not.

SURVEY INSIGHTS AND ANALYSIS (continued)

- **Afib information sources:** 94% of respondents say they get useful information on Afib from their health care professional. Also, 43% said they get useful information from website articles and postings; 16% said newspaper and magazine articles; 14% said from other Afib patients; 14% said from their local pharmacist; 8% said from a family member or friend; 4% said from a local clinic, and 2% said online forums and social network discussions.
 - The groups that get the most information from websites and web postings are those with incomes over \$100,000, Northeasterners, college graduates, and stroke victims.
 - The groups that get the most information from newspaper and magazine articles are: women, those 71-75, Northeasterners, and those with Afib 10 years or more.
 - Of the most useful print and online information, 4% of Afib patients report that they were referred to *all of it* by their health care professional; 10% report that they were referred to *most of it* by their health care professional; 32% report that they were referred to *some of it* by their health care professional; 49% report that they were referred to *none of it* by their health care professional.