

Supplemental Materials

Table S1. Bleeding events in survey aligned with definitions from the International Society on Thrombosis and Haemostasis (ISTH)/Scientific and Standardization Committee (SSC)

Bleeding Event	Survey Description	ISTH Nomenclature	ISTH Definition
Bruising and minor Bleeding	Nosebleeds, bruising. No change in AC or special MD visits	Minor Bleeding	Any other bleeding not meeting criteria for major bleeding OR CR-NMB
Bleeding Requiring Medical Care and/or Change in AFib Medication	Gastrointestinal bleed, had to stop AC and had colonoscopy at an outpatient clinic. No transfusion	CR-NMB	Does NOT meet criteria for major bleeding and requires medical intervention for bleeding_OR hosp or increased level of care for bleeding OR change in AC ⁸
Bleeding Requiring Emergency Care and Blood Transfusion	Gastrointestinal bleed, went to ED, required emergency surgery, blood transfusions, could have died, several days in hospital, stopped AC	Major Bleeding	Fatal bleeding AND/OR bleeding in a critical area or organ (e.g. brain, spine, eye, EP, intra-articular, pericardial , intramuscular with compartment syndrome) AND/OR transfusion of 2+ units of blood or hemoglobin drop of 20 g/L

AC, anticoagulant; CR-NMB, clinically relevant non-major bleeding; ED, emergency department

Table S2. BWS weights scaled relative to death and 95% CIs

Event	BWS Weights	95% CI
Death	1	
Stroke (mRS 5)	0.834	0.814 - 0.855
MI with HF	0.500	0.477 - 0.523
Major bleed	0.525	0.495 - 0.556
Stroke (mRS 3)	0.277	0.263 - 0.292
Systemic embolism	0.127	0.115 - 0.140
CR-NMB	0.096	0.086 - 0.107
MI no HF	0.055	0.050 - 0.060
Stroke (mRS 0,1)	0.041	0.037 - 0.045

Table S3. Rank order of event importance from BWS, token-allocation exercise and ranking exercise

Event	BWS	Tokens	Rankings
Death	1	1	1
Stroke (mRS 5)	2	2	2
MI with HF	3/4*	3	3
Major bleed	3/4*	4	4
Stroke (mRS 3)	5	5	5
Systemic embolism	6	6	6
CR-NMB	7	7	7
MI no HF	8	8	8
Stroke (mRS 0,1)	9	9	9

* BWS weights were not significantly different between MI with HF and major bleed ($p=0.104$)

PEARL-AF Survey Instrument

INTRODUCTION

Thank you for participating in our study.

It is important for doctors and health officials to understand your concerns about living with atrial fibrillation (AFib for short).

The medical problems we describe in this survey could be different from your own experience or knowledge. It is important that everyone who takes this survey use the same information when answering questions.

YOUR HEALTH HISTORY

1. When were you first diagnosed with AFib?

- Within the past year
- 1-3 years ago
- 4-10 years ago
- More than 10 years ago
- Not sure

2. What type(s) of health care provider(s) manages your AFib? (check all that apply)

- Primary care physician
- Cardiologist
- Electrophysiologist
- Other medical provider
- Not sure

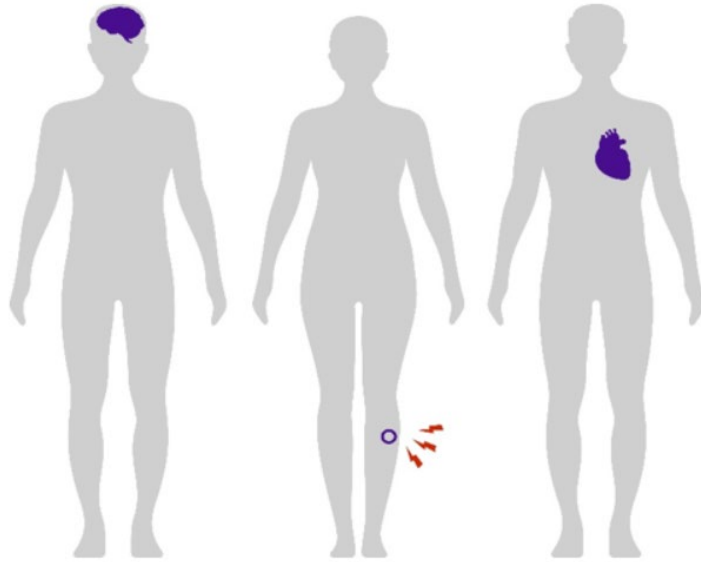
3. On average, over the past month, how many days per week have you exercised at least 30 minutes? _____

4. Which of the following treatments have you received for AFib? (check all that apply)

- Anticoagulant medicine**, common medicines include apixaban (Eliquis); dabigatran (Pradaxa); edoxaban (Savaysa); rivaroxaban (Xarelto); and warfarin (Coumadin)
- Heart rhythm medicine**, common medicines include amiodarone (Cordarone), dofetilide (Tikosyn); flecainide acetate (Tambocor); propafenone (Rythmol); sotalol (Betapace); and dronedarone (Multaq)
- Heart rate medicine**, including **beta-blockers** (metoprolol, atenolol, bisoprolol, acebutolol, propranolol, carvedilol), or medications like verapamil (Verelan), diltiazem (Cardizem), and digoxin (Lanoxin)
- Cardiac/catheter ablation to try to prevent recurrent Afib** (Afib ablation, AV node ablation, or pulmonary vein isolation ablation procedure)
- Electrical cardioversion (brief electric shock to reset your heart's rhythm)
- Pacemaker
- Maze procedure
- WATCHMAN device, Amplatzer Amulet, left atrial clip, or other left atrial appendage closure
- None of these
- Not sure

MEDICAL EVENTS

Patients with AFib can have a blood clot that forms in the heart and goes to other parts of the body, including the brain, the legs, or the heart.



AFib medicines reduce the chance of blood clots, thereby reducing the chance of stroke, heart attack, and other problems in the body.

However, these medicines can increase the chance of bleeding.

In this survey, we will ask you to think about different medical problems that people living with AFib have had. We will ask you to assume that these people:

- are the same gender as you
- are about the same age as you
- have had AFib about as long as you.

You will need this information to answer questions later in the survey.

STROKE



A blood clot in the brain can cause a stroke.

Early symptoms of stroke include numbness and weakness in the face, arms, or legs. Symptoms can also include difficulty speaking or understanding language, memory difficulty, and partial vision loss.

Strokes can occur at any time. When stroke symptoms begin, immediate medical attention is required. People with stroke symptoms are usually admitted to the hospital to receive treatments to allow blood to flow again to all parts of the brain.

On the next page, we will describe **three people who had different types of stroke.**

Stroke with no problems afterward

The first person had a stroke that caused minimal brain damage. However, after the stroke, they had **no problems**.

- They continue to work full time and do their usual activities.



Stroke with some problems afterward

The second person had a stroke that caused some permanent brain damage.

After the stroke, they continue to have **some problems**.

- They have weakness in their legs and **require a cane to walk**.
- They still can do some daily activities like brief trips to the grocery store, cooking simple meals, and doing light housework.
- But, they **need someone to help them at least once each week**.



Stroke with serious problems afterward




The third person had a stroke that caused serious permanent brain damage.

Because of the stroke, they have **serious problems** that will last **the rest of their life**.

- They cannot walk and **require constant care**.
- They need a family member or nurse to help them with all **basic activities** such as dressing, eating, bathing, and using the toilet.



Here are the types of stroke the 3 people had.

Person 1	Stroke with <u>no</u> problems afterward		No problems
Person 2	Stroke with <u>some</u> problems afterward		Can walk, but dependent on others at least once a week
Person 3	Stroke with <u>serious</u> problems afterward		Require constant care

5. Based on what you just read, can the person who had a **stroke with serious problems** afterward continue to use the restroom by themselves?

Yes [\[Show ANSWER KEY A1\]](#)

No [\[Show ANSWER KEY A2\]](#)

[ANSWER KEY A1]

Your answer was incorrect.

People who have a stroke with significant problems afterward **cannot use the restroom by themselves.**

They must have someone, like a family member or nurse, help them every day with dressing, eating, bathing and using the toilet.

[ANSWER KEY A2]

That's correct!

People who have a stroke with significant problems afterward **cannot use the restroom by themselves.**

6. Based on what you just read, can the person who had a **stroke with some problems** afterward continue to do housework?

- Yes [\[Show ANSWER KEY B1\]](#)
- Yes, but only light housework [\[CORRECT, show ANSWER KEY B2\]](#)
- No [\[Show ANSWER KEY B1\]](#)

[ANSWER KEY B1]

Your answer was incorrect.

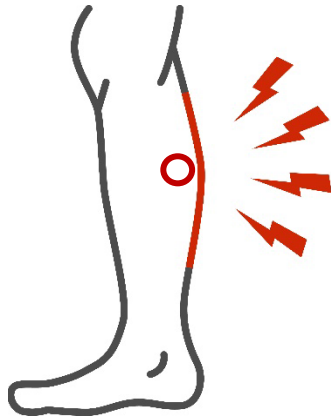
People who have a stroke with some problems afterward can still do activities like shopping at the grocery store and cooking meals. **They can do housework, but only light housework.**

[ANSWER KEY B2]

That's correct!

People who have a stroke with slight problems afterward **can still do housework, but only light housework.**

CLOT in the LEG



Another person had a blood clot in an artery in their leg that blocked blood and oxygen from reaching the lower part of their leg.

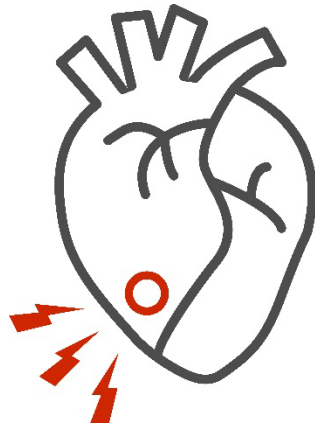
Their symptoms included severe swelling, pain and loss of feeling in the lower leg and foot.

After calling their doctor to report these symptoms, they had to go immediately to the hospital where they received an emergency procedure to remove the clot.

They continue to have some problems with blood flow in their leg. They cannot run. They also have to walk more slowly to avoid pain in their lower leg.

**Note: this person did not have a deep vein thrombosis (DVT). This person's leg clot was more serious than a DVT.*

HEART ATTACK



A blood clot in the heart can cause a heart attack.

In this survey, we will ask you to think about two people who had a heart attack, but did not die from it.

Both of them went to an emergency room to receive a treatment or procedure to allow blood to flow again to all parts of the heart. They stayed in the hospital for 3 nights.

After the heart attack, they both had to take 6 new medicines.

Heart attack with no problems afterward

The first person's heart attack caused minor damage to their heart.

However, about 4 weeks after the heart attack, they had **no problems**.

- They continue to work full time and do their usual activities.



Heart attack with weakened heart afterward

The second person's heart was damaged by the heart attack and was **permanently weakened**. While this sometimes is called "heart failure", the heart doesn't actually fail. It just doesn't pump blood as well.

For the **rest of their life** after the heart attack,

- They continue to **get out of breath** doing things that were previously easy for them like walking a block or going up stairs.



DEATH

We also want you to consider a person with AFib who died.

We don't know if the person died as a result of AFib or some other cause.

7. Based on what you read earlier, how often did the person who had a **stroke with some problems afterward** need help from someone else?

- Never [\[Show ANSWER KEY C1\]](#)
- About once a month [\[Show ANSWER KEY C1\]](#)
- At least once a week [**CORRECT**, [show ANSWER KEY C2](#)]
- Once a day [\[Show ANSWER KEY C1\]](#)

[ANSWER KEY C1]

Your answer was incorrect.

The person who had a stroke with some problems afterward **needs help at least once a week.**

[ANSWER KEY C2]

That's correct!

The person who had a stroke with some problems afterward **needs help at least once a week.**

8. Based on what you read, did the person who developed a clot in their leg continue to have long-term problems with walking and leg pain even after the clot was removed?

Yes [CORRECT, show ANSWER KEY D1]

No [Show ANSWER KEY D2]

[ANSWER KEY D1]

That's correct!

The person with a leg clot continued to have long-term problems with walking and leg pain after the clot was removed.

[ANSWER KEY D2]

Your answer was incorrect.

The person with a leg clot **did continue** to have **long-term problems with walking and leg pain after** the clot was removed.

BLEEDING

AFib treatments have resulted in bleeding for some people. We will ask you to think about three people who had different types of bleeding problems.

The severity of a bleeding problem depends on:

- where in the body the bleeding occurs and the amount of blood loss
- medical care required
- need for a blood transfusion

Bruising and minor bleeding

Bruises are bleeds that occur under the skin.

The first person has frequent bruises from bleeding under the skin, tends to bleed more from small cuts, and has a nosebleed about every 2 months.

While bruising, small-cut bleeding, and nosebleeds are a nuisance, they do **not** require medical treatment or a change in their AFib medicine that works by thinning the blood.

Bleeding requiring medical care and change in Afib medication

The second person had a bleed in their stomach. Their doctor found the bleed after the patient reported seeing blood in their stool.

Their doctor changed the person's AFib medicine that thins the blood.

To make sure the bleeding had stopped, the person had to have a colonoscopy at an outpatient clinic.

Because the person had lost blood over time, they felt weak for about a month, but felt back to normal afterward.

Bleeding requiring emergency care and blood transfusion

The third person had a much more serious bleed in their stomach. The person went to the emergency room when they began to cough up blood.

The person had emergency surgery and several blood transfusions. If they had not gone to the emergency room, they could have died.

After the bleeding was stopped, they stayed in the hospital for several days. They felt weak for about three months, but felt back to normal afterward.

Their doctor had to stop using AFib medicine that thins the blood.

9. Based on what you just read, did the doctor change Afib medicines for the person with bruising and minor bleeding??

- Yes [[Show ANSWER KEY E1](#)]
- No [[CORRECT, Show ANSWER KEY E2](#)]

[ANSWER KEY E1]

Your answer was incorrect. The correct answer was "no".

Ongoing bruising and bleeding **did not** require the doctor to make a change to the person's AFib medicine.

[ANSWER KEY E2]

That's correct!

Ongoing bruising and bleeding **did not** require the doctor to make a change to the person's AFib medicine.


On the following pages, we will show you sets of four people who are your age and gender, and have had AFib for about as long as you.

For each question please select which of the four people has the **MOST serious** medical problem and which of the four people has the **LEAST serious** medical problem.

Here is an example

In this column, the person who had a heart attack with weakened heart afterward was selected as having the **MOST serious problem**.

In this column, the person who had a stroke with no problems afterward was selected as having the **LEAST serious problem**.



Most Serious	People with the medical problems below	Least Serious
<input type="radio"/>	Clot in leg	<input type="radio"/>
<input type="radio"/>	Stroke with no problems afterward	<input checked="" type="radio"/>
<input type="radio"/>	Bleed requiring hospitalization and transfusion	<input type="radio"/>
<input checked="" type="radio"/>	Heart attack with weakened heart afterward	<input type="radio"/>

How we plan to use your answers

Although there are no right or wrong answers to these questions, please think carefully about your responses.

Your answers could affect how clinical trials for Afib treatments are interpreted.

Your responses will be used to assign “weights” to medical events that occur in clinical trials that reflect their relative importance to patients. More important events get higher weights, and less important events get lower weights.

Current practice is to count all medical events using equal weights.

Let’s begin.

(#1 example of 10 BWS questions)

Please select which person you think has the **most serious** medical problem and which person has the **least serious** problem.

MOST SERIOUS	People with medical problems below	LEAST SERIOUS
<input type="checkbox"/>	Death	<input type="checkbox"/>
<input type="checkbox"/>	Clot in leg	<input type="checkbox"/>
<input type="checkbox"/>	Heart attack with heart damage	<input type="checkbox"/>
<input type="checkbox"/>	Stroke with some problems afterward	<input type="checkbox"/>

If needed, click on the events in the table to review their descriptions.
The same person cannot be selected twice. Please select different people as having the Most Serious and Least Serious medical problem.

[NOTE: Bruising and minor bleeding was not included in the BWS exercise, but it is included in the ranking and token allocation exercises]

In this section, please rank order the people with medical events listed below from: (1) the person with the most serious event to (10) the person with the least serious event.

Drag and drop the gray boxes. [event order was randomized for each respondent]

Ranking_5
[Stroke with some problems afterward](#)

Ranking_8
[Heart attack with weakened heart afterward](#)

Ranking_2
[Bleeding requiring medical care and change in AFib medication](#)

Ranking_4
[Stroke with no problems afterward](#)

Ranking_7
[Heart attack with no problems afterward](#)

Ranking_9
[Clot in leg](#)

Ranking_1
[Bruising and minor bleeding](#)

Ranking_10
[Death](#)

Ranking_6
[Stroke with serious problems afterward](#)

Ranking_3
[Bleeding requiring emergency care and blood transfusion](#)

Most Serious

Least Serious

Assume you have 100 tokens. In the 10 boxes below, assign tokens based on the seriousness of each medical event.

Assign a higher number of tokens to events that are more serious. Assign a smaller number to events that are less serious. If an event is not a concern at all, it is okay to give it 0 tokens.

Please use all 100 tokens. To help you, the total is shown at the bottom.

[event order is randomized for each respondent]

<input type="text"/>	Bleeding requiring emergency care and blood transfusion
<input type="text"/>	Heart attack with weakened heart afterward
<input type="text"/>	Stroke with some problems afterwards
<input type="text"/>	Heart attack with no problems afterward
<input type="text"/>	Stroke with no problems afterwards
<input type="text"/>	Bruising and minor bleeding
<input type="text"/>	Clog in leg
<input type="text"/>	Bleeding requiring medical care and change in AFib medication
<input type="text"/>	Stroke with serious problems afterward
<input type="text"/>	Death
[SUM]	Total

Assume you have 100 tokens. In the 4 boxes below, assign tokens based on the seriousness of each medical event.

Assign a higher number of tokens to events of greater concern. Assign a smaller number to events of lesser concern. If an event is not a concern at all, it is okay to give it 0 tokens.

Please use all 100 tokens. To help you, the total is shown at the bottom.

[event order was randomized for each respondent]

Clot in leg

Bleeding requiring medical care and change in AFib medication

Stroke with serious problems afterward

Death

0

Total

THANK YOU for your responses. We have several more questions for you before the survey is complete.

The remainder of the survey should take less than 5 minutes.

T1. How often do you have problems learning about your medical condition because of difficulty understanding written information?

- Never
- Occasionally
- Sometimes
- Often
- Always
- Prefer not to say

T2. How confident are you filling out medical forms by yourself?

- Extremely
- Quite a bit
- Somewhat
- A little bit
- Not at all
- Prefer not to say

T3. How often do you have someone help you read hospital materials?

- Never
- Occasionally
- Sometimes
- Often
- Always
- Prefer not to say

[Life Orientation Test; Scheier et al. J Pers Soc Psychol, 1994; 67:1063-1078]

Instructions: Please respond as accurately and honestly as you can. There are no right or wrong answers. Please select your answer below.

L1. In uncertain times, I usually expect the best.

Strongly disagree Disagree Neutral Agree Strongly agree

L2. It's easy for me to relax.

Strongly disagree Disagree Neutral Agree Strongly agree

L3. If something can go wrong for me, it will.

Strongly disagree Disagree Neutral Agree Strongly agree

L4. I'm always optimistic about my future.

Strongly disagree Disagree Neutral Agree Strongly agree

L5. I enjoy my friends a lot.

Strongly disagree Disagree Neutral Agree Strongly agree

L6. It's important for me to keep busy.

Strongly disagree Disagree Neutral Agree Strongly agree

L7. I hardly ever expect things to go my way.

Strongly disagree Disagree Neutral Agree Strongly agree

L8. I don't get upset too easily.

Strongly disagree Disagree Neutral Agree Strongly agree

L9. I rarely count on good things happening to me.

Strongly disagree Disagree Neutral Agree Strongly agree

L10. Overall, I expect more good things to happen to me than bad.

Strongly disagree Disagree Neutral Agree Strongly agree

ABOUT YOU

As the final part of this survey, we'd like to ask you a few questions about yourself.

B1. Which of the following describes your ethnicity?

(Check only one answer.)

- Hispanic, Latino or Spanish origin
- Not Hispanic, Latino or Spanish origin

B2. Which of the following racial groups best describes you?

(Check all that apply.)

- American Indian or Alaskan Native
- Asian
- Black or African American
- Native Hawaiian or Other Pacific Islander
- White
- Other

B3. What is the highest level of education you have completed?

(Check only one answer.)

- Less than high school
- Some high school
- High school or equivalent (such as GED)
- Some college but no degree
- Technical school
- Associate's degree or 2-year college degree
- 4-year college degree (such as BA, BS)
- Some graduate school but no degree
- Graduate or professional degree (such as MBA, MS, MA, MD, PhD)

B4. What is your marital status?

- Single / never married
- Married / living as married
- Divorced or separated
- Widowed / surviving partner
- Other
- Prefer not to answer

B5. What sex were you assigned at birth on your original birth certificate?

- Male
- Female

B6. How do you currently describe your gender?

- Male
- Female
- Transgender- male
- Transgender- female
- Non-binary
- Other

B7. Which of the following best describes your employment status?

- Employed part time (less than 30 hours per week)
- Employed full time (30 hours or more per week)
- Homemaker
- Retired
- Student
- Unemployed
- Disabled/not able to work
- Other

B8. How do you get your health insurance?

(Check all that apply.)

- Through a state or federal insurance exchange
- Through my (or another person's) employer or union
- Medicare alone
- Medicare and supplemental insurance
- Medicaid
- Veterans Affairs
- Other
- Prefer not to answer
- I do not have health insurance

We have one final question for you.

Please think for a moment about the survey, and indicate whether you agree or disagree with the statement in the table below.

	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
My survey responses should be used to help doctors and health care regulators interpret results from clinical trials.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for participating in this study.