IP Survey IP1957

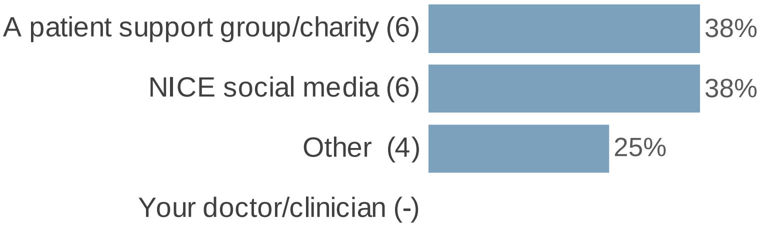
This report was generated on 03/12/24. Overall 16 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'. A total of 16 cases fall into this category.

The following charts are restricted to the top 12 codes. Lists are restricted to the most recent 100 rows.

I have read the information above which explains the purpose of the project and how any information I provide will be used

I consent (agree) to NICE using the information I have given in the ways described above

How did you hear about this survey?



If other, please specify

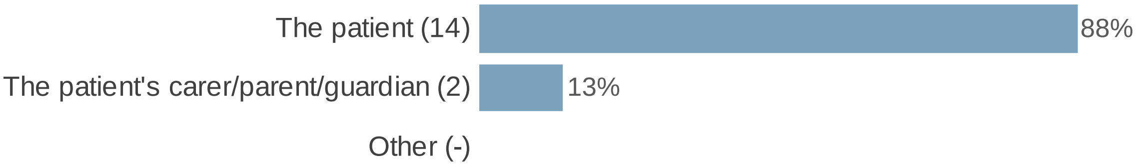
shared by AF Association

Email

Arrhythmia Alliance

Health web site

Are you (the person completing the questionniare)



Your age

77
78
66
80
75
66
62
71
55
57
55
44
84
60

In years

2
1
2
5
0
14
11

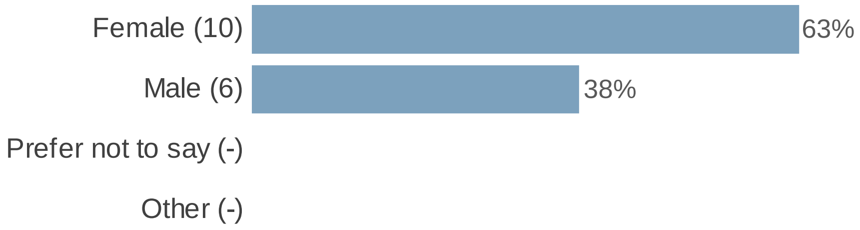
In months

4 months
7
8
14
0
3
1

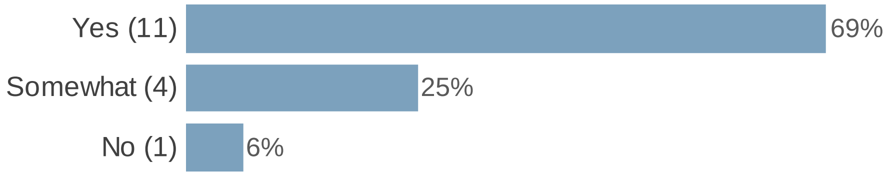
in weeks

3
2
9
12

To which gender identity do you most identify?



Did the procedure work?



If **somewhat or no**, please provide further details along with information about whether symptoms later reoccurred.

I was diagnosed with AF in August 2015. After three successful, but short lived, DC cardioversions I had my first PVI ablation procedure performed in December 2017. I remained in sinus rhythm until January 2023 when AF returned. In May 2023 I had a DC cardioversion which put me back into sinus rhythm but this only lasted until August 2023 when I went back into AF. In March 2024 (still in AF) I went in for a PF ablation procedure expecting a redo of my previous pulmonary vein isolation. After the operation I was told that investigation revealed that my PVI was still intact and no cause for my AF could be found. No actual ablation had been performed and I had just been given another DC cardioversion. I was started on Flecanide and to date (November 2024) I am still in sinus rhythm with fingers very firmly crossed!

I had further symptoms in August however when I went for my check up in September they were not sure whether it had been AF or not so I have remained on patient referral for 1 more year.

Not at first as had an issue   Cardiac tampenard

Only one month ago. Had afib since but still in blanking period so too early to tell

Did you have any side-effects following your procedure?

If **yes**, please provide further details along with information about whether symptoms later reoccurred.

On 9 August a procedure was acutely successful but Atrial Fibrillation returned intermittantly at first and then continuously from 23 August. On 6 September the heart center made unsuccessful attempts including cardio version to stop Atrial Flutter. I was rapidly loaded with Amiodarone 400mg x 3 a day and collapsed 3 days later. The dose was reduced to 200mg x2 a day for 2 weeks and then to 200 mg a day. On 4 October Sinus Rhythm returned. My next appointment is at the end of January 2025.

Painful catheter ablation procedure under sedation. Exhaustion for one week, then on day 10 early morning palpitations, vomiting, chest pain etc. A+E admission and was discharged following day. Next day early morning same thing happened and back to A+E and discharged same afternoon. No symptoms since. Had given up all alcohol and caffeine (not that I ever consumed much before).

Urinary retention which necessitated a trip to A&E and catheterisation. This in turn led to me contracting a bladder infection with all the worst symptoms of a UTI.

As before

Pneumonia and plural effusion

Major bruising in groin

How long did it take you to recover from the procedure?

couple of days

I became very anxious after collapsing . After the unsuccessful attempts to stop Atrial Flutter It took 26 days for the Amiodarone to work and I was again very anxious. This included not being able to sleep. Added together this makes over 3 months of anxiety and sleep deprivation.

See above

I have not recovered from the procedure. I have been referred to urology and await my first appointment which is not until November 2025!

About 6 weeks

A couple of days.

1 week approx - really just needed to get over the general anaesthetic

Aproximately 5 days, only side effects were fatigue and sore throat from intubation tube

10 weeks

10 days

Still in recovery

Only one month ago so still recovering

About a week

How did the procedure positively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

gave me confidence to live normally again as took away symptoms and doctor told me i was no longer in AF - fantastic

fantastic

improved it

I continue to be anxious as I understand there are serious side effects form taking Amiodarone. All 5 things on the list have improved.

Positive effect on all aspects listed, though I am still somewhat nervous about how to exercise (what I should or should not do). Also I am somewhat apprehensive about travelling abroad in case AF comes back.

How did the procedure positively affect your condition and/or your quality of life? Please consider things such as:

- Your physical symptoms
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- Your quality of life, lifestyle and/or social life
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The DC cardioversion putting me back into sinus rhythm allowed my heart to start repairing the heart failure that had worsened while waiting for the PFA. I have been around the loop enough times now to know that it takes roughly the same time I have been in AF to get back to something approaching normal after a DC cardioversion or an ablation procedure. A wait of a year in AF for treatment means a wait of two years before feeling fully well again. The longer I wait the more my heart remodels itself and the worse my heart failure symptoms get. I have been lucky thus far in that my heart has largely reverse remodelled itself after each intervention. Quality of life is pretty poor at the moment with all the usual symptoms of a UTI. Pain on urination, urge incontinence, inability to completely empty bladder, waking multiple times during the night to pee, etc, etc. Ability to perform daily activities is restricted by the need to remain close to a toilet at all times! I went in for my PF ablation anticipating a repair of my previous PVI and a good possibility of another five years without AF. I came out to find that there was no known reason for me having gone back into AF and I had not had a PF ablation but rather another DC cardioversion; which past experience has shown not to last. I was absolutely crushed. The urinary retention and consequent bladder infection were the icing on the cake and the thought of having to live as I am for at least another 12 months is depressing in the extreme.

I was given back my life, more energy and a life to look forward to.

I was no longer worried about AF, I had a lot more energy and was able to do a lot more things like walking up steep hills without feeling shattered.

Very early days for me - I am not aware of any paroxysmal AF since my procedure but as I often go 1 month between episodes it’s too early for me to know if it’s worked. I am feeling much more positive than I was. I had a pacemaker implanted for SSS and I wasn’t looking forward to further surgery . Recovery this time has been so much easier and I hope to be able to stop dronedarone

It’s very early days, but I have had steady heart rate with no ectopics palpitations or AF episodes. I have more energy and more confident about returning to my pre AF active lifestyle

Once 2nd op was done I had more energy and could carry out my work without fear

Maintaining a normal heart rate makes such a difference. Having had persistent AF for at least 3 years, I can now exercise which is something I couldn't have done before. I am starting to feel like I can lead a reasonably normal life although my heart rate is still very low 44bpm I am also starting to feel like I can actually plan things, without thinking, will I be well enough when the time comes. I stopped taking Amiodarone 4 weeks ago and so am a little bit anxious that unsupported the AF may return but am taking one day at a time and trying to adopt a positive approach

All improved

No more afib, however still recovering from pneumonia and plural effusion.

Too early to say. Ask in a year!!!! :-)

It sorted my AF

How did the procedure negatively affect your condition and/or your quality of life?

Please consider things such as:

- Your physical symptoms
- Your ability to perform daily activities
- Your quality of life, lifestyle and/or social life
- Your state of mind, emotional health and/or wellbeing
- The effect on family, friends and others

it didnt

it didnt

it didnt

No negative effects on quality of life, though the experience of the procedure and aftermath were unpleasant.

See previous answer to positive affects question.

I could walk, shop and do chores, I had a happy outlook on life and looked forward to every day. I was happy and got back my zest for living. Life was fun again.

It did not have any negative impact on me or my quality of life.

Pulsed field ablation has been totally positive for me. Minimal groin bruising, no sore throat post op and no episodes of AF in blanking period as yet. I still get sweaty on minimal exertion and after some drink or hair drying. This really adversely affects my Q of L but no-one has confirmed if it’s due to my heart condition.

No

It didn’t for a while

I don't feel any negative impact. My resting heart rate is still very low, but it is unclear what is causing that. 44bpm. This means I struggle with exertion particularly on the stairs (shortness of breath, palpations, need to sit down) I am very happy to be back in normal rhythm

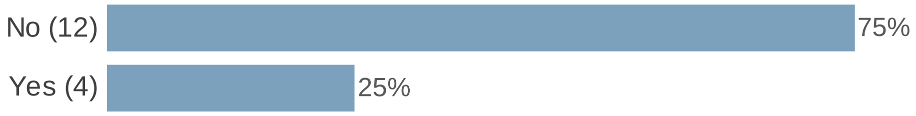
None

Very ill.

Too early to know

Not applicable

Did you require anymore treatment, including procedures or surgery after this procedure?



If **yes**, please provide further details.

On going monitoring by the Heart Center .

Post operative urinary retention necessitated a trip to A&E to be catheterised. Consequent bladder infection has seen DRI, ultrasound scans of the bladder, flow tests, continuous antibiotic treatment for seven months thus far and likely at least a further twelve months, plus whatever further treatments/procedures are recommended when I eventually get to see a urologist.

Hospitalized w pneumonia, chest xrays, ecgs, cscan, thoracentesis.

Emergency DCCV

Would you recommend this procedure to another patient with your condition?

If **yes**, what might you tell them?

Go for it - it restored me to my 'normal' self

go for it - it gives youback your life

To get an ablation before their condition deteriorates, as it appears that the procedure is less effective/successful if the patient waits too long (if the medicines seem to be effective)

Think very carefully about the benefits versus the risks. In my case I gained nothing from the PFA as no actual ablation was performed and I have lost a decent quality of life for at least two years. Having said that I would still go for a PFA again because of the (hopefully soon to be proven) reduced risk of collateral damage to the heart and surrounding tissue. It would be of great benefit if a way could be found of determining the status of a previous PVI ablation without the need for effectively performing another, all bar the tissue destruction.

Go get your life back, you don't have to live with AF

Yes I would, I did not suffer any pain, the team were brilliant and the only downside was the amount of time you have to remain lying flat after the procedure but that soon goes.

No bruising, pain or increased AF in blanking period. I consider myself lucky to have had a pulsed field ablation. I am optimistic that it may work which I wasn’t pre- procedure

It prevents you require medication

Although it's early days, the procedure has worked. It was a pain free experience (although I had a General Anesthetic). Recovery time was relatively short and remembering not to overdo it in the first few weeks. The palpations may still continue after the procedure but are short lived and less severe. It's better than being in AF

Cheap

Risks are rare but not impossible. That’s true with any procedure.

Procedure is easy to go through

Go for it!

If the procedure had an impact on any other areas of your life that are not covered by the questions above please tell us about them here.

i lead a 'normal' life now and i am active and positive attitude

-/-

I have never felt so frustrated or depressed. I have been waiting for treatment, recovering after treatment or hiding from Covid-19 continuously since 2015 and I just want to have a life again. Knowing that there is no prospect of this for at least another year (and maybe not even then) is just adding to the strain.

Creativity, art, theatre, going out with friends. I couldn't do any of that with the AF because it made me bad company and so I become a recluse, and lived in fear of AF, but not anymore.

None

Back on my feet

Not applicable