IP Survey IP1192_2

This report was generated on 14/04/25. Overall 1 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'. A total of 1 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

100%

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

100%

How did you hear about this survey?

Other (1)

Your doctor/clinician (-)

A patient support group/charity (-)

NICE social media (-)

If other, please specify

NICE email

Are you (the person completing the questionniare)

The patient's carer/parent/guardian (1)

The patient (-)

Other (-)

Your age

87

In years

8

In months

0

in weeks

0

To which gender identity do you most identify?



What other treatment options did you consider, and why did you choose this one?

Weren't given any

Did the procedure work?



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

It did work but there was no information about heart failure and what this arrythmia would look like for a person with Dementia. They aren't always able to articulate if there is something not quite right and in the end we had to do a lot of guessing and asking the heart failure nurse in the community. One visit a year to a Physiologist isn't enough. It was only in the last year of life that the patient was given a wireless monitoring system - this would have helped as soon as the device was fitted. Wireless was an option 8 years ago - but not everyone got one. I have a fear it might have been younger heart patients. I hope this wasn't the case. The word discrimation isn't a good one.

Did you have any side-effects following your procedure?



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

8 months

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

Breathlessness but also not understanding what heart failure was after the procedure. Too little information out there. Once a patient is discharged from hospital, it is in the hands of the GP. If they are crap - and some are, let's face it - they won't follow up or even bother. When the patient needs help, they shove them over to A&E when in fact they could be under a cardiologist in an MDT to help monitor.

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

Just a fragility of life really.

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



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



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

Because it allows people to live without that fear of another cardiac arrest. Be sure to understand that not all patients get a pacemaker with a defibrillator. There is a difference and patients who have both say they feel they can do all sorts of things again because they know their heart will be maintained and shocked back into progress. Hmmm. I wonder what that does to people psychologically. It's like a neighbour who was given a heart bypass - he still goes out and eats chicken and chips because they've unclogged everything. What are these clinicians telling people and how do they educate them?

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.

Psychologically, being told you have a device that regulates your heart rhythm but won't save you if you have real heart failures, well that is devastating. Then in the same clinic seeing other people having all singing, all dancing devices and told they can have a normal life again.... it felt as though someone had said, here's your death sentence and to the others, here you go - roam free as a bird.