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This report was generated on 16/08/21. Overall 13 respondents completed this questionnaire. The report has been filtered to show the responses for 'All Respondents'.

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

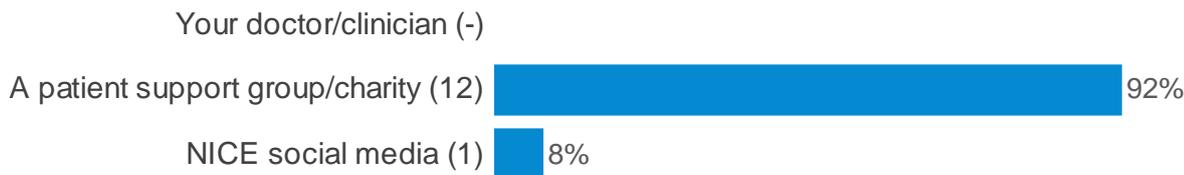
I have read the information above which explains the purpose of the project and how any information I provide will be used



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



How did you hear about this survey?



Other (please sepcify)

- Marfan forum
- The Most Exclusive Club in the Planet

Are you (the person completing the questionnaire):



Your age (in years)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
13	539	41.46	12.49	21	63	42

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How long ago did you have the procedure?

16.5 years	2019
This year January 2020	2009
2	2010
4 years ago	1 year and 8 months

In years

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
5	20	4	4.18	0	11	11

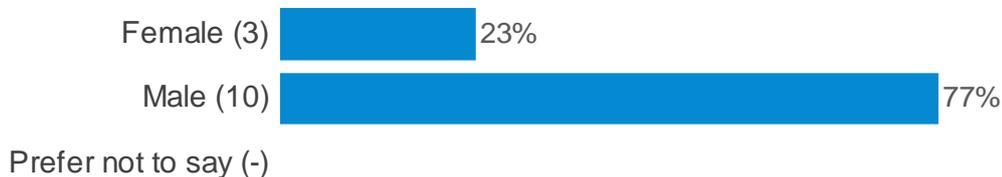
In months (OR In months)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
7	92	13.14	7.99	1	22	21

In months (OR In weeks)

Count	Sum	Mean	Sample Standard Deviation	Minimum	Maximum	Range
0	-	-	-	-	-	-

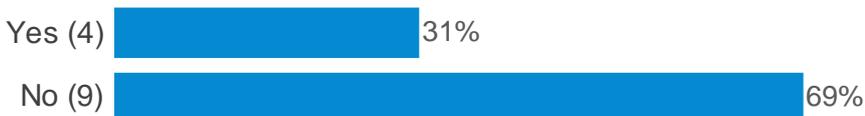
To which gender identity do you most identify?



Did the procedure work?



Did you have any side-effects following your procedure?



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

Atrial fibrillation, initially a few days after the operation. It went away a couple of days later recurred a week or so after but has been fine since.

While in hospital I developed Atrial fibrillation but it resolved. This reoccurred 2.5 years later so may not be connected. I now have paroxysmal afib. I also developed a plural effusion which. Resulted in going back to hospital 6 weeks after discharge. This has not reoccurred.

I had AF(atrial fibrillation). Something which is possible after opening of the chest wall cavity, in any heart procedures, & not actually caused by the PEARS itself. I've had 3 re- occurrences of AF since then.

I wouldn't know as my surgeon has not followed up with my since surgery. Quite a lot of discomfort when trying to sleep. Feels tight around incision. Palpitations. Quite horrible symptoms of tightness after contracting the flu, leading me to have lung infection and terrible pain around chest. Low levels of energy, low levels of libido, and overall chest discomfort.

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

I was back to work part time in 4 weeks and fulltime in 3 months having had the procedure at age 47 years. Stamina was low immediately post op but rose to 95%+ after 10-12 weeks. Thereafter back to pre op levels

3 months back to basic level,(post discharge re hab paused due to Covid)so 6 months to fitness

Reasonably fit after 4-5 weeks fully recovered after a few months

Out of the hospital in 5 days. Walking an hour a day starting the day after I was discharged. Obviously there are pains and aches just like any other open heart surgery. One month out and I feel really well.

6 weeks

I spent 4 nights in hospital and then had to be careful for 6-8 weeks in order that my sternum could properly heal.

I was home in 5 days, theatre and other activity in three weeks. Flew home to the states in five weeks.

3.5 months

3 months

Full recovery is a very individual thing. I had been fit before& know that helped. I was out of hospital in 5 days. Going for small walks immediately& feeling ok to do a lot of daily things in 2 months say.

3-6 months Operation was for Ross PEARS pulmonary autograft

Complete recovery about 4-6 months. Partial recovery sooner than that. In two months I was running. In three I was back at the gym. After six months I was doing pretty much everything I did before.

I am still recovering. By September I was able to get on with life, but challenges have been there.

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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

I was asymptomatic before the procedure and remained so. My physical ability post-op recovered to the pre op level. The only noticeable change was the relief from the mental stress of worrying about a dissection. This cannot be quantified but has a profound impact on one's quality of life. I believe my family were relieved and are now entirely comfortable: annual CMRIs of my aorta show it is dimensionally stable and fully functional, ie the PEARS procedure has achieved its aim.

Physical symptoms are gone. I have a normal heart beat and feel really well. My quality of life is that of a normal person. I feel extremely grateful and happy. My children, my wife, my parents and friends are all very happy that I have my life back.

Physical symptoms, I feel normal and able to perform all the activities I did prior with peace of mind. Emotionally/mentally I am happy that I do not have to take lifetime anti coag.

Knowing that my dilated aorta is repaired and that I get to keep my own aorta is fantastic. The PEARS procedure is the surgery of the future. It is so nice to know that no other patients have needed reoperation. I believe recommending the other operations, if PEARS is viable, is just reckless. The surgeons are setting the patients up for a tougher life ahead due to re-operation and/or a life of blood thinners. Overall, I'm very happy. I traveled from the USA to London to have my surgery. I'd do it all over again in a heartbeat.

Yes my quality was greatly improved, family very relieved great success, reduced dilation of aorta, can still participate in playing basketball which helps my mental and physical health

Left me secure in the knowledge that my aorta is now stable, supported and no longer at risk of rupturing or dissecting. It also enables pregnancy to be a safer option for me (currently 32+3 weeks pregnant).

Quicker recovery No bypass fog All vascularly external Confidence in full activity

Greater peace of mind has been the biggest affect. Living with an a dilated aorta feels like a ticking time bomb in your chest and knowing something done to stop it rupturing has been such a relief. I was an early patient so my peace of mind has increased as the procedure has been more widely used and successfully. I do not need blood Anticoagulation which has been a great benefit for me.

Greater peace of mind. Otherwise did not have any symptoms

It was obviously great when it was successfully done. All family members were relieved& happy. It is better to have help at home, that will speed up your recovery. Its pretty major having your chest opened up& everyone has different reactions. My chest bones creaked a lot while reuniting together, that always caught me out.But, I was also determined& positive&?had 2 teenage children, so there was no time to dwell. I felt overwhelmingly positive& my family did too. As my sons both have Marfan's, I needed it to be a positive thing, & it was.

Removal symptoms Better mental Heath generally No meds Long term results hopefully

PEARS brought back my life style. I didn't need to give up anything I did before - different if I had done the traditional procedure. Since I was not a symptomatic patient when I decided to have it, the main impact was on my state of mind and emotional health.

Family is relieved I had this procedure plus the obvious reinforcement on my dilated aorta. Aorta has a lower risk of getting dilated. body feels warmer.

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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

The negative affects were so trivial (after recovery from the sternotomy) that an inability to eat spicy food in the evening without regurgitating later on (caused by the TOE probe upsetting my cardiac sphincter during the procedure?) seems almost too trivial to comment on.

No negative effects at all. I only wonder why this is not the standard way to treat Dilated aorta's.

Short term recovery from the operation but that would have been the case for whatever operation type. Long term none and removed my worry of dissection.

No negative affects besides the general pains of open heart surgery.

N/A nothing negative

Not applicable

As stated above PEARs has increased my peace of mind greatly living with a tailgated aorta it's like living with a Ticking time bomb. It is also meant that I have avoided the need for anticoagulation for another 11 years and hopefully more.

The alternative was having a larger surgery with greater risk. So it did not negatively impact my well being overall.

I can honestly say I had more negative feelings before the procedure, as is totally normal, I would think. I was advised to be sensible, & put affairs in order, which I did, but as I had two teenage boys, this was very hard. So, for me, that fear was the greatest, the 'what may occur', with regards my sons. But any major medical procedure would have had same affect. I had some small negative reactions to some of the AF medication when home (very believable nightmares), but the medication was altered & that stopped.

In none aspect at all

My ability to perform daily activities have gone down just a few months after the surgery. Things are very slowly going back to normal but pain and discomfort is there and self-esteem is below my normal range. There was a botch stitch up situation. When they stitched me up they stitched one side higher than the other side, leaving my nipples misaligned (VISUALLY EVIDENT). I was very upset a day or two after the actual surgery, raised my concern and upset with hospital and surgeon. There was never a follow up. My libido has gone down the drain. I feel sad and anxious every time I look myself at the mirror. My partner is supportive but I do not feel like myself. I feel like a monster with this horrible finishing job. I had a ravitch procedure done before this surgery and it took me months of physiotherapy and psychotherapy to be happy with my body after reconstructive surgery ... now I feel like I am back at square one. My pectus carinatum is worse than before PEARs surgery. My cardiac team at St. Georges are aware of the lack of communication from St. Thomas and Dr. Austin regarding a follow up after surgery. North Middle Sex Hospital is trying to deal with my low libido through their erectile dysfunction clinic. I recently had a cardiac appointment with my cardiologist at St. Georges and it was very evident they saw my upset both in person and via telephone. I am filing a pals form today to complain formally. What is the point of having this procedure if I am left feeling like Frankenstein's monster? Dignity really means that I deserve the best treatment I can receive.

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



If yes, please provide further details.

I had a Cardioversion for post op A fib but have been stable ever since.
 probably not related but Treatment for atrial fib (medication) shocks and aborted ablation
 Cosmetic surgery, possibly psychotherapy.

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



If yes, what might you tell them?

Retaining all your own aortic anatomy, having a short procedure, probably off-pump, recovering quickly and not having to take anti coag drugs (TRR) nor worry about re-operation (VSRR) makes this option a no-brainer when compared to the alternative Root Replacement surgeries. And it saves our NHS money.....

Absolutely I would recommend this. If you look at the death rate during surgery and the recovery after the standard root replacement surgery the PEARS procedure looks considerably safer. No need for blood thinners afterwards and no re operations so far. Looks like the way forward to me.

That it should be the defacto standard for aortic dilation correction and is the operation type I would recommend for a relative

It's a great surgery done off pump. You get to keep your own aorta. No blood thinners needed. Chance of re-operation is slim. Quick recovery time. There is no down side to this procedure!

Very non-evasive surgery very fast recovery, no need for anticoagulants drugs 🖱

Amazing procedure, very smooth recovery.

Do it. It should be the standard of care.

The procedure does involve opening your rib cage so is not minor surgery but recovery was much easier than other surgeries I have had for my spine. It gives you great peace of mind and weighing up the options it felt like a much better option than the ones currently available.

That I have had it save it appears to have been successful.

My youngest son had the procedure in 2017. He had no hesitation when we were told he required it. He'd seen what I'd gone through, good & bad, met others who'd had it & although he listened to the alternative offered, was determined to go ahead. He was 22. I volunteered to talk to a few patients having the procedure, afterwards. I was honest, with pros & cons, but the bottom line is the PEARS procedure speaks for itself, in that it is less time in surgery, less time in hospital, better & faster recovery rates. Less cost to the NHS. Why choose the other options, if you are given the option of another way to go, or PEARS, you would choose PEARS.

Best chance for freedom from long term re-operation

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If yes, what might you tell them?

This is a safe procedure; it delivers what it promises - which is keeping your aorta on a safe sizeN/A

My brother and I had different procedures done and it is evident that I had a faster recovery and I am not on warfarin for the rest of my life.

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.

Only positive impacts for me.

none

N/A

Minimally invasive considering the alternatives.

It did not.

I seem to be of interest to many medical staff, when they find out what I have& what I had done about it. But that's fine, I enjoy educating them,& indeed volunteer to do this now on some medical exam courses.

N/A