

# Patient Consultation Response

**Fifty-nine patients**

participated in an interactive webinar and

**One hundred patients**

participated in an online survey, these were the findings



# Methodology

## What we did

Heart Valve Voice carried out an independent and impartial, patient-led, consultation for both treated and untreated heart valve disease patients.

## How we did it

With the support of a patient engagement expert and four Patient Ambassadors, we developed a series of webinars and interviews to learn from patients about their experiences of heart valve disease treatment.

To maximise access, we carried out an online survey for patients who were not comfortable discussing their experiences in an open forum.

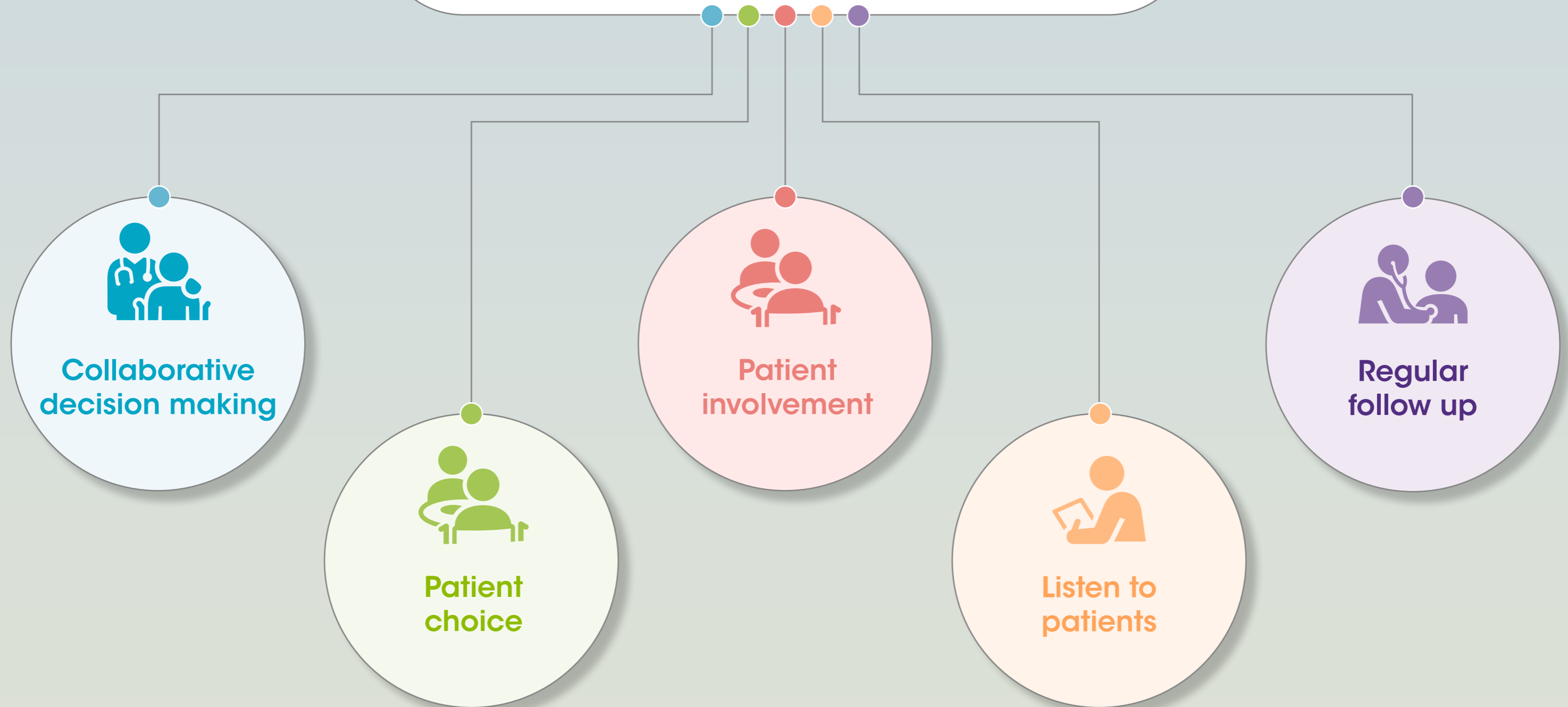
## Patient Engagement

Requests for participation were sent out on all Heart Valve Voice social media channels (over 4,000 members) and many independent valve disease patient Facebook groups (a community of several thousand patients). Patients from a range of backgrounds and ethnicities contributed, with ages ranging from 36-87.



The more we listen, the more lives we save

The **top five** most important patient issues the NICE guideline panel should consider



57-year-old Aortic Stenosis Patient, Derrick, said:

"After my experience, I realised the importance of detection and increased awareness of heart valve related issues. An opportunity to contribute to this came after being introduced to Heart Valve Voice and collaborate with them on their response to the NICE guidelines for the care of heart valve patients.

My involvement allowed me to share my experience and it gives me great satisfaction to know that my contribution may help shape diagnosis and treatment of future patients thanks to Heart Valve Voice and NICE."

# Heart Valve Disease Detection



## Symptoms

52% of patients did not recognise their own symptoms and struggled to explain symptoms to their GP.



## Stethoscope check

A third of patients said their GP did not listen to their heart when they presented with symptoms.



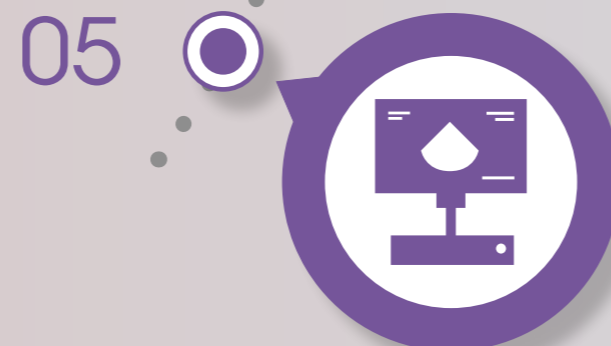
## Murmur information

69% of patients were given no information regarding what their murmur meant.



## Healthcare practitioner

When asked, the majority of patients said they were comfortable with their heart being listened to by any healthcare practitioner trained to listen to with accuracy - such as using digital stethoscope. Only 25% of patients thought it should be a GP.



## Echo referrals

42% of patients received an echo within 6 weeks after a murmur was detected, 32% of patients said they waited more than 7 weeks. However, 25% patients felt there were missed opportunities to detect their condition.

# Heart Valve Disease Diagnosis



10 patients in the webinar said they felt anxious waiting for echo, while 30 said they were reassured and pleased to be under the care of a cardiologist.

63% of patients were given good information about their valve surveillance. However, 34% were given unclear information or no information at all about their surveillance.

When given the choice to choose words which best describe how they felt leading up to their repeat echo, 39% said anxious, 32% said reassured, 36% said calm, 26% said confident, 26% said not bothered and 11% said scared.

# Heart Valve Disease Treatment



70% of patients in an online webinar felt an active part of treatment decision. While 30% felt they were not.

69% of patients surveyed felt an active part of treatment decisions, 28% felt they are not and 3% didn't know.



When asked, which factors should treatment be based on? They said:

- Treatment should be determined by a Heart Team (30%)
- Treatment should be based on the most up to date evidence (27%)
- When clinically appropriate, treatment should be based on the patient choice (26%)
- Treatment decision should be based on the treating clinician (17%)



During an interactive webinar, patient said the top three most important factors on deciding when to treat were.

- Symptom driven
- Early treatment to ensure better outcomes
- Mental Health considerations



95% of patients were frustrated by treatment options being limited due to limited availability or local restrictions.



38% of patients felt they were not given all treatment options that were clinically suitable.

47-year-old Bicuspid aortic valve patient, Angie, said:  
"I was pleased to be invited to contribute to Heart Valve Voice's response to the draft guideline as it was an opportunity for me to use my experience to help others. The sessions were really good, and it was interesting to hear about so many peoples heart valve disease experiences. I hope my contributions help, and thank you to Heart Valve Voice for inviting me to attend and for the work they do for valve disease patients."

# Patients Word Clouds

When asked what they wanted to see prioritised in the NICE guidelines, patients said:



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# Patients Word Clouds

When asked why it was important for them to be involved in decision making, patients said:



they knew much more about it than i did!  
sense of ownership and responsibility  
reducing need for further surgery    unwilling to undergo further surgery  
acceptance in future treatment involved  
**long term considerations**  
follow up; understanding, preparedness    trust reassurance  
to feel you are joining a team    **empowering**    we have to live with the decision  
to get better    **lifestyle choice**    confidence    could not obtain treatment on nhs  
not too reliant on drugs    **being in control**    took their advice for best outcome  
acceptance of medical condition    not wishing to take warfarin  
took their advice for best outcome be



# What patients need from the final NICE guidelines

**1** Earlier detection with more opportunities to detect in primary care.

**2** Faster referrals, with patient choice at the heart of decisions on surveillance

**3** Better access to all clinically appropriate treatment options.