

Heart Valve Voice draft NICE Guideline Response

Heart Valve Voice carried out an independent and impartial patient consultation on the NICE Draft guideline on heart valve disease presenting in adults. The process was patient-led and inclusive, with both treated and non-treated patients invited to attend. We recognised that not all patients want to share their experiences openly, so we developed an online survey, alongside an interactive webinar, to allow more patients to participate.

Invites for participation were sent on all Heart Valve Voice social media channels (over 4,000 members) and independent valve disease patient Facebook groups (a community of several thousand patients). Interested patients were invited to an Heart Valve Voice Facebook group, and we maintained close contact with the independent patient-led Facebook groups throughout the consultation period.

On February 2nd 2021, Heart Valve Voice held a patient training session for four patients chosen as Ambassadors. Alongside Heart Valve Voice staff, the patients agreed on a strategy for responding to the guideline and methods to encourage patient participation.

Six interactive webinars were carried out between the 22nd - 28th April and were attended by 59 treated and untreated patients, with ages ranging from 36-87. The group represented a broad range of ethnicities and demographics. The online survey was open from April 21st to April 29th and completed by 100 patients.

Earlier detection with more opportunities to detect in Primary Care

Throughout the consultation, we found issues in detection centred mainly on awareness of the signs and symptoms of heart valve disease - both in public and in primary care professionals.

52% of patients asked told us they struggled to explain their symptoms to their GP, with 13% saying they spoke to a different healthcare professional (pharmacist, 111) before presenting with symptoms. Although the large majority of patients reported to the GP with symptoms, a third of them said their GP still did not listen to their hearts. When a murmur

was detected, 69% said they were given no information regarding what the murmur meant.

We found that the draft guideline needed to be clearer around red flag symptoms of heart valve disease and encourage Primary Care providers to listen to more hearts with a broader range of opportunities to detect. When investigated further, the majority of patients were comfortable with any trained healthcare practitioner listening to a heart as long as there was good accuracy, such as using a digital stethoscope, leading us to recommend more explicit guidance on opportunities to detect heart valve disease accurately.

With patients indicating a lack of awareness of symptoms at a Primary Care level and lots of examples of missed opportunities for earlier detection, we recommended that the guidelines refer all patients where a murmur is detected for echocardiography (the gold standard of diagnosis) to assess the severity of the murmur.

Waiting times for echocardiography were mixed, with 39% of patients waiting longer than seven weeks after a murmur was detected. We recommended that symptomatic patients with a murmur receive an echo within two weeks and asymptomatic patients within six weeks, as per our Gold Standard of Care guidance.

Better information and more patient choice

During our review of the draft NICE guideline, we found that patients felt reassured and confident during their surveillance. With the draft guideline suggesting that patients feel anxious about echos, we actually found that although ten patients said they felt anxious waiting for an echo, three times as many said they were reassured and pleased to be under a cardiologist.

Furthermore, echo surveillance made patients feel reassured, calm and confident. It was our view that the final guideline should make clear that surveillance for heart valve disease patients should be decided by collaborative decision making, with patient choice at the heart of it.

Worryingly, although 63% of patients were given good information about their surveillance, 34% received no information or poor information (which hinted at regional variations). We recommended that the need for up to date, clear, patient-led information be offered to all patients be made explicitly clear in the guideline. Health Literacy is a key issue for our community.

More Access To Treatment

The ethos of Heart Valve Voice is about patient empowerment and patient choice. We were pleased to see that the draft guidelines make reference to shared decision making and putting patients at the centre of treatment decisions. However, we felt several parts of the draft guideline put limitations on patient choice. We, therefore, recommended more robust language that gave patients better access to all clinically appropriate treatment options and gave greater opportunities to treat more patients and earlier.

Our consultation found that almost all patients felt that it was essential to be central to treatment decisions. Yet, sadly 30% felt they were not an active part of their treatment decisions. A further 38% felt they were not given all treatment options that were clinically suitable for them, with many saying they had to research options themselves. We recommended the guidelines be more robust in outlining all treatment options available to each patient, with more explicit guidance on where those treatment options were available (if not available locally).

When asked, patients wanted treatment decisions to fully consider the patient choice and that Multidisciplinary Heart Teams (MDT's) (or their Heart Team) use the most up to date evidence. We felt the draft guideline came up short in giving a specific steer on how MDT's and Care Plans should be designed. We felt this would lead to regional variation and poorer outcomes for patients.

Patients also stressed the importance of when to treat, telling us that these decisions should be driven by worsening symptoms, impact on mental health and the optimal time to ensure better outcomes - all linked to earlier treatment. With earlier treatment leading to better outcomes, we recommended the guidelines make a clearer case for earlier treatment when it is in the patient's best interest.

It was clear to us that patients demand collaborative decision making, better access to treatment options and earlier treatment. We made clear in our response that decisions on treatment options and timing of treatment should be a collaborative decision between the patient and their heart team. Patients clearly respect their clinicians and heart team but want to be heard on how to be treated, which aligns with existing NICE guidelines on Shared Decision Making, and we hope to see this recognised in the valve disease final guideline.

Working towards a better future for valve disease care

Throughout our consultation, it was evident that patients are more informed than ever and are passionate about playing an active role in their pathway. There was a clear appetite in

patients to contribute to changes in the way valve disease care was managed. The 159 patients who were a part of our contribution had incredible insight into the pathway and empowered us to create a truly patient-led response. We were disappointed that the draft guideline did not have the same level of patient input. We, therefore, recommended to NICE that Patient Organisations with a strong patient voice, like Heart Valve Voice, be a part of structures that determine guidelines and put patients at the table on decisions on the future of valve disease care.

While we made many recommendations on how the guidelines could be improved, we also recognised that these draft guidelines were a good platform on which to work. With meaningful patient input like ours, we hope the final guideline will offer a better future for valve disease care, with the lived experience of patients at the heart of it.

With bolder, patient-led guidelines, we will have a platform to work towards a better future for valve disease care. We thank every patient who contributed their time to our response and will continue working with patients, clinicians and policymakers to improve the diagnosis, detection and treatment of heart valve disease.

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