Five years at the heart of change

Anniversary Report
November 2019

the more we listen, the more lives we save
Foreword

Heart Valve Voice is the UK’s dedicated heart valve disease charity. Working to raise awareness and deliver change on the ground since 2014, the charity is comprised of people with real experiences of heart valve disease, including patients and clinical experts such as cardiologists, cardiac surgeons, general practitioners and nurses.

As Chief Executive, I work with many patients who have been diagnosed with, and effectively treated for the condition. Unfortunately, many people with heart valve disease in the UK continue to go undiagnosed and access to effective treatment is variable across the country. Our mission is to improve the diagnosis, treatment and management of the condition by raising awareness of the need for timely detection and intervention in order to ensure all patients receive the best possible care and support.

Thanks to the generosity of an ever-increasing number of supporters, collaborators and clinicians, we have come a long way in our first five years. We have raised awareness both at home and abroad, bringing our message to all levels of the policy and implementation landscape. Politicians, officials, clinicians, commissioners, and most importantly patients, are all better equipped to tackle the challenges of heart valve disease today than they were five years ago.

As we move forward, we will build on the fantastic work we have done to date and support the development and implementation of the new clinical guideline for heart valve disease. I look forward to continuing to work closely together with all our friends and partners as we do so.

Wil Woan
Chief Executive
Heart Valve Voice
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1- About Heart Valve Voice

Our vision

Since Heart Valve Voice began work in 2014, we have been working to address the under-diagnosis and under-treatment of heart valve disease in the UK. Through raising awareness of the disease and providing evidence-based guidance to patients and healthcare professionals, we have seen real progress made to improve the patient experience and create an integrated, cohesive approach to heart valve disease treatment.

Heart Valve Voice is a coalition of experts in heart valve disease, including cardiologists, cardiac surgeons, GPs, alongside cardiac patient societies, patients and carers. Since 2014, Heart Valve Voice has evolved into a patient-led initiative, with a patient action group and team of ambassadors throughout the UK. It is through this vital work with real people affected by heart valve disease that we can ensure our charity’s goals reflect the genuine concerns and opinions of patients, and fight for the care they need.

Our goals

We have kept the same six core objectives at the centre of all the work we have done over the last five years, they are:

1. Raise awareness of the severity of heart valve disease
2. Increase the awareness of symptoms of heart valve disease
3. Work towards ensuring there is a clear and effective treatment pathway between primary care, secondary care and expert heart teams
4. Effectively campaign for early diagnosis and treatment of heart valve disease
5. Provide credible, independent and practical advice and information about heart valve disease
6. Represent the UK’s heart valve disease patients to help ensure that they receive the best treatment at the right time, improving quality of life and overall outcomes

Our team

Wil Woan
Chief Executive

Elske Simpson
Project Manager

Oliver Sian-Davis
Project and Fundraising Manager

Chris Young
Chair

Keith Jackson
Treasurer

Pat Khan

Dr Jarir Amarin
Amanda Bott

Dr Shelly Rahman Hayley
Alison Banayoti

Dr Chris Arden

Trustees

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Amanda Bott

Dr Shelly Rahman Hayley

Alison Banayoti

Dr Chris Arden
2 - Five years at a glance

The last five years in numbers

- **Thousands** of hearts listened to at our testing events
- **5** policy and guidance reports published
- Over **60** politicians engaged
- Over **50** patient stories shared
- More than **30** pieces of media coverage secured
- **3** regional summits
- **13,475** miles cycled
- **Hundreds** of patients supported
- **100,000** steps taken
- **Millions** of radio listeners reached
- Over **60,000** social media impressions made
- 4 webinars hosted, reaching **500** clinicians and **23,000** potential patients
- **NICE Clinical Guideline due in 2021**

…and countless lives changed!
“Both through their public awareness campaigns and educating healthcare professionals, Heart Valve Voice is doing vital work to raise the awareness of – and support patients living with – heart valve conditions.”

Benoy Shah
President
British Heart Valve Society (BHVS)

3 - Raising awareness

Raising awareness of heart valve disease is one of our most central aims as an organisation. In just five years, Heart Valve Voice has made significant progress in contributing to the overall increase in heart valve disease awareness that can be seen at the political, clinical and public levels. Our work has spanned across many different stakeholder groups and has translated into tangible changes as to how they tackle the challenges of heart valve disease.

In 2018, in collaboration with Global Heart Hub, the Alliance of Heart Patient Organisations, Heart Valve Voice helped organise UK activities for the very first World Heart Day. Following on from the success of this inaugural awareness-raising event, in 2019 we played a central role in expanding this initiative to become the European Heart Valve Disease Awareness Week, which was held in September.

In this chapter, we recap some of the work we are most proud of delivering so far, including some of our favourite elements from World Heart Day and European Heart Valve Disease Awareness Week.
HCP Education

Practical guidance for primary care (2018)

Prior to NICE’s decision to develop a clinical guideline for heart valve disease there had long been a serious need for better resources to support GPs, especially in detecting and referring for heart valve disease. Our response to this need was to create our first guidance document for primary care professionals.

This short 9-page guidance document was launched at the Best Practice Conference 2018 where it was distributed to primary care experts from across the UK. This practical guidance has been sent to thousands of primary care professionals who are now able to use its insights and recommendations to ensure optimal outcomes for patients and their families. We are also planning to create an interactive online version to support effective learning and implementation in the near future.

This report was made possible by authors Dr Jarir Amarin; Dr Chris Arden; Dr Matthew Fay; Dr Yassir Javaid; and Dr Denis Pellerin.

Regional events (since 2017)

Heart Valve Voice recognises that to achieve better outcomes for patients we need to work at both the national and the local levels. To help do our part to understand and address the unjustified variation in care at a regional level, we set about in 2017 to organise regional best practice summits. These summits focused on how systems and professionals at the Sustainability and Transformation Partnership (STP) level could better address common deficiencies in heart valve diagnosis and care.

Supported by an array of local experts, we have been able to:

- Help develop a more detailed picture of challenges facing heart valve disease patients in England;
- Understand the clinical burden of the disease on patients and health services;
- Identify the barriers to effective diagnosis and treatment of heart valve disease; and
- Encourage greater local collaboration (e.g. Academic Health Science Networks and STPs).

We have now successfully held three such summits — south coast of England; north east of England and Hull — and will look to do more in future where there is clear need as the Long Term Plan is delivered and Primary Care Networks evolve.

Heart Valve AR (2018)

In 2018, working with tech start-up Digital Pop-Ups we helped launch Heart Valve AR, an augmented reality tool that allows patients to explore the workings of a catheterisation laboratory on their phone or tablet. The app is now used in hospitals to support and reassure patients ahead of their appointment. A video of the app in action is available on Digital Pop-Ups' YouTube page (https://www.youtube.com/watch?v=Vgb1kVB5ScU&feature=emb_title).

The King’s Fund debate (2018)

In July 2018, our CEO Wil Woan and patient ambassador Geoffrey Pritchard helped provide the patient perspective at a debate event hosted by The King’s Fund on whether the NHS was equipped to adopt innovative technologies in the current economic climate.

This event provided a valuable opportunity to raise the challenges of bringing new innovations to heart valve disease patients and how these challenges can and should be overcome in front of an audience of high-level stakeholders. Think tanks such as The King’s Fund are expected to be a growing part of our policy engagement plans for the future.
HCP specialist webinar (2018 and 2019)

In 2018, we hosted our first two HCP webinars, focused on educating GPs across the UK on heart valve disease; what symptoms to watch out for and how to effectively manage patients once they’ve been diagnosed. During these first two webinars, held in the autumn and winter of 2018, over 270 GPs joined us to learn more about heart valve disease.

Following on from that success in 2019, as part of European Heart Valve Disease Awareness Week, Heart Valve Voice hosted a webinar for primary care professionals. Our trustee Dr Chris Arden, who is a GP with a speciality in cardiovascular disease, delivered the CPD-accredited webinar to over 200 clinicians from across the primary care landscape.

Conferences and meetings

Over the last five years we have been able to attend many events focused around heart health and improving the care people receive, including the British Society of Echocardiography annual meetings, the European Society of Cardiology Congress and the British Cardiovascular Intervention Society Conference. Our presence at these meetings has been focused on sharing the patient perspective with clinicians and researchers, emphasising how their work affects patients’ lives.

We’ve been lucky enough that some of our incredible patient ambassadors have attended these events themselves to share their stories, including David Eaton at the HTAi conference and Marina McGrath at the MTG Valve Disease meeting. Their insights are always invaluable to the discussions taking place and we look forward to attending more events in the future with them.

Pulse LIVE (2019)

In March 2019, we were delighted to attend and host a stand at the Pulse LIVE Conference in London, where over 2,000 GPs gathered to update their knowledge and skills. This provided an ideal opportunity to network and discuss the importance of early detection in primary care as well as referral times, amplifying our calls in our 2020 vision report.

PCCJ Issues and Answers Conference

The Heart Valve Voice team are a regular presence at the Issues and Answers Cardiovascular Disease Conference. This conference brings together healthcare professionals from the primary care sector, to discuss how to improve the daily care of patients with heart conditions.

In 2016, Heart Valve Voice hosted a stand, full of information for primary care professionals, and also hosted a discussion about valve disease in the UK.

Building on this, in 2017, Heart Valve Voice hosted two webcasts at the event, led by CEO Wil Woan and cardiovascular expert Dr Yassir Javaid.

In 2018, trustees Keith Jackson and Pat Khan attended the conference, networking with primary care professionals from across the UK, discussing the importance of stethoscope examinations and the key role primary care plays in the detection and diagnosis of heart valve disease.

PCR London Valves

PCR London Valves is the world’s largest educational meeting dedicated to the field of valvular heart disease and provides a unique forum for education and interaction between a wide range of clinical experts from across the UK.

Heart Valve Voice has worked closely with the PCR team over the last five years as an education patient group partner for the event, and delivered key note speeches at the meeting, focusing on the importance of prioritising heart valve disease in cardiovascular care. The meeting has also been an opportunity to network with experts in the field of valve disease and learn about the many new innovations, techniques and advances in patient care for heart valve disease.

Q: How many people aged over 75 do you believe suffer from heart valve disease?

Possible answers:

a. 5%
b. 8%
c. 13%
d. 20%
**Events**

Since 2014, we have become increasingly creative about how to grab the public’s attention and raise awareness of Heart Valve Voice’s mission through special events. Detailed here are some of the highlights from our adventures.

**Annual London to Paris Heart Valve Voice cycle**

Since 2017, the Heart Valve Voice team has taken on the challenge to cycle from London to Paris every year in order to attend the EuroPCR conference, the leading annual forum on interventional cardiovascular medicine. Each ride has been an eventful experience for the cyclists, a group made up of clinicians and patient representatives, who have completed the trip every year come rain or shine. Upon arrival at EuroPCR, the Heart Valve Voice team has been given the opportunity to present on the main stage of the conference, raising awareness of the work we do to improve heart valve disease care for patients in the UK.

We’d like to say a big thank you to Bicycle Buddy, EuroPCR, Park Plaza Hotels Waterloo, Arragon’s Cycle Centre and Cyclism for their support, as well as all of the hospitals that have cheered us on these trips each year.

“I am hoping that my participation this year will inspire others to get checked for heart valve disease, particularly if they have symptoms such as breathlessness, tiredness and dizziness. Early detection and timely treatment saved my life and look at me now!”

David Eaton
Heart Valve Disease Patient
SCTS Conference football competition

During their annual conference, the Society for Cardiothoracic Surgery (SCTS) hosts a 5-a-side football competition for all the conference attendees. Heart Valve Voice have always been up for a challenge, and have fielded a team for the competition every year. Our teams have mostly been made up of clinicians who support our mission to raise awareness of heart valve disease, along with some familiar faces from the Heart Valve Voice team.

The tournament has been a great opportunity to raise awareness of our work and make new connections inside the clinical community. We’re proud to say that for the last two years, the Heart Valve Voice team have been crowned champions of the SCTS football cup and we look forward to defending our title at next year’s conference!

St Paul’s climb

In February 2018 the Heart Valve Voice team invited patients and volunteers to join them on a climb to the top of St Paul’s Cathedral in London. The group tackled the 528 steps to the top of the dome of St Paul’s Cathedral, enjoying the beautiful view that greeted them at the summit.

By asking our patient ambassadors to participate in these climbs, they have helped us demonstrate that valve disease treatment can be totally life changing for those affected by the disease, allowing them to live full, active and healthy lives.

“I can’t believe that only three years ago both Marina and I were struggling to walk up the stairs or keep up with our friends, and now we’re leading the pack to the top of St Paul’s Cathedral. What a great experience!”

Pat Khan
Patient Ambassador
“Those with heart valve disease should be able to live, not just survive. For me that means, being able to spend time with family and those you love, laughing and sharing experiences, and being able to see the world and explore new places.”

Brenda Walker
Heart Valve Disease Patient

Patient Portraits: A New You – National Photography Competition

For the last two years Heart Valve Voice, in collaboration with The Royal Photographic Society, has held an annual national photography competition to help raise awareness of heart valve disease and show the human side of the condition.

‘Patient Portraits: A New You’ challenges participants to create a series of photographs that tell the story of a patient affected by heart valve disease. The national finalists have had their photographic documentaries exhibited at the Houses of Parliament. The winner and regional finalists had their photographs exhibited at hospital heart clinics across the UK, as part of a road show to celebrate the European Heart Valve Disease Awareness Day.

This competition has given a group of amazingly talented photographers the opportunity to capture the experiences of patients returning to their best quality of life following heart valve disease treatment, and highlight how vital access to timely, high-quality treatment can be to stakeholders all over the country, including politicians and key NHS decision makers.

“Those with heart valve disease should be able to live, not just survive. For me that means, being able to spend time with family and those you love, laughing and sharing experiences, and being able to see the world and explore new places.”

Brenda Walker
Heart Valve Disease Patient
Patient Walk

In 2019, to mark the last day in European Heart Valve Disease Awareness week, we held our first ever patient walk. Heart Valve Voice encouraged patients to walk a mile with their friends, families and supporters, to celebrate their quality of life after treatment and to honour the memory of those not treated in time. It was truly amazing to see patients who had struggled to walk more than a couple of steps before getting treated take part in the walk with their loved ones. This year over 40 patients completed the walk with us, and we look forward to having more people join us next year.

Materials

Children’s book

As a part of European Heart Valve Disease Awareness Week 2019, Heart Valve Voice created a children’s book called “My Grandad’s Heart Valve Disease story”. The book was written by Michael Woan, a 12-year-old boy whose family has been touched by heart valve disease, and illustrated by artist and designer Sally Brown.

The story is based on a true relationship between a young boy, his sister and his grandad. The book takes readers through the stages of grandad’s heart valve disease, from the perspective of a child. The book provides a useful tool for families dealing with heart valve disease, helping them talk to their children and grandchildren about the condition.

Heart Valve Voice sent 600 copies of the book to primary schools across the UK to be read as part of #HeartValveWeek19, along with handouts on heart valve disease to be taken home to their older relatives. Over 100 schools read the book and 10,000 leaflets were distributed across the week. The book has also reached 1,200 people online and a video of the book being read by actor Chris Geere is available on our YouTube page (https://www.youtube.com/watch?v=JRtRkU7XQts).

Street doctors

As part of European Heart Valve Disease Awareness Week 2019, we sent our amazing team of (stilt-walking!) street doctors and patient advocates out in cities across the UK to provide free heart checks and educate the public about heart valve disease. Our teams in London, Belfast and Edinburgh spoke to 2,385 people about the condition and distributed over 2,500 pieces of educational literature about its symptoms and how to get checked.
Silversurfers partnership

Since 2016, we have worked with Silversurfers, a lifestyle website and social network for people over 50, to raise awareness of heart valve disease and educate their readership on its symptoms. Silversurfers has promoted Heart Valve Voice’s webinar event, along with our work during World Heart Day, and published articles on its site focused on heart valve disease.

Given the increasing risk of heart valve disease as people age, being able to reach the Silversurfers community with our message is incredibly important. Silversurfers’ social media platforms reach over 19 million people each month and our work with them has allowed us to educate their followers about heart valve disease, including 23,000 over 60s who took part in our Silversurfers webinar.

Our articles with Silversurfers have outlined a range of topics related to heart valve disease, including:

- **How much do you know about heart valve disease?**
  Explaining the symptoms of heart valve disease and when people should go to their GP to get checked.

- **Heart Valve Voice: speaking up for those with heart valve disease**
  What the mission of Heart Valve Voice is and how to get involved in our work.

- **My role as a cardiac nurse**
  A leading London nurse practitioner describes their role in treating heart valve disease.

- **Heart valve disease is treatable: an overview of its treatment and management**
  Outlining the key facts about heart valve disease, its symptoms, common risk factors and how it can be treated.

- **What happens in a heart valve clinic**
  Answering common questions Silversurfers readers have about heart valve disease and how it gets diagnosed.
Heart Valve Voice magazine

In 2018, we launched our first annual Heart Valve Voice magazine, which detailed all the incredible work done by the Heart Valve Voice team throughout the year. The magazine also highlighted a number of patient stories, explaining how they have been affected by heart valve disease and how their lives have changed after receiving treatment. The magazine was distributed to 30 heart valve clinics across the UK, allowing patients to learn more about the charity’s activities and the sources of support available to them.

Pulse magazine

In 2018, Heart Valve Voice worked with Pulse Magazine to create a campaign, online and in print, educating its readership on heart valve disease, and promoting the work we've done to improve the care patients receive.

Pulse Magazine is the UK’s most widely read medical monthly publication by primary care clinicians, with more than 70% of GPs reading its content. The articles that were published in collaboration with Heart Valve Voice included information on diagnosis and prevalence, along with patient stories and practical guidance on how to best manage the condition.
Press coverage

Over the last five years, we've been working to secure national and local media attention to increase awareness of heart valve disease in the general public.

Each year, the coverage of Heart Valve Voice's work has increased and we have been able to reach an ever-increasing audience with our message, educating the public on the risk and symptoms of heart valve disease.

In 2018 alone, our activities for European Heart Valve Disease Awareness Day were covered in:

- 6 pieces of regional print and online news publications in the UK, with an online reach of 21 million and a print reach of 150,800
- Newspaper inserts in the Guardian, Evening Standard, Mail on Sunday and The Times.
- 41 syndicated articles across European medical and online news outlets, reaching a potential audience of 1,602,000
- 12 national and regional radio station interviews, reaching 150,700 people
- 2 TV station interviews, reaching over 400,000 viewers

And our 2018 National Photography Competition received coverage in:

- 24 pieces of print and online regional publication across 10 regions
- 5 national and regional radio stations with an estimated 258,400 weekly listeners

Across all of our work we have reached over 10,000,000 members of the public with our message.
Social media

We have also been focused on reaching out directly to people interested in heart valve disease via our social media platforms of Facebook, LinkedIn, Instagram, Twitter and YouTube.

Our work during 2019 European Heart Valve Disease Awareness Week led to…

• 50 new Instagram followers
• 112 retweets
• 200 new LinkedIn connections
• 337 likes
• Reaching 4,000 Facebook followers
• 13,000 view on YouTube
• Over 70,000 impressions

…but more importantly, Heart Valve Voice’s social media has been a platform for people affected by heart valve disease to connect, find community and feel supported…

...and for clinicians to show their support!
Patient stories

Alison Banayoti
Alison is from Brighton and was admitted to St Thomas’ Hospital, London under Mr Chris Young, Chair of Heart Valve Voice. Fourteen years after being diagnosed with aortic and bicuspid heart valve disease, she finally received the treatment that she had been waiting for in 2018 and since then has become a Heart Valve Voice Trustee herself.

David Blair
David Blair believed he was at the top of his health when he got diagnosed with heart valve disease. He had simply put his symptoms down to getting older. Whilst training to complete the difficult cycle from Lands End to John O’Groats in ten days, David, from Belfast, attended a routine check up at his GP in the summer of 2018 and was diagnosed with aortic stenosis. After his surgery David was back on the bike with a new energy and ready to completed the challenge of cycling the length of the UK.

Geoffrey Pitchard
In 2013 Geoffrey Pitchard, of North London was admitted to Watford General Hospital after experiencing an episode of atrial fibrillation and was diagnosed with pericarditis. During his treatment clinicians also found another issue lurking, mitral regurgitation. Geoffrey received his treatment at the start 2018 and is back enjoying his garden and spending time with his family.

David Eaton
When David Eaton’s life and career were suddenly placed in jeopardy by a mystery illness and painful headaches, he never thought that his heart might be the cause. Unknown to him, his aortic valve had been under steady attack from bacteria, caused by a condition called endocarditis. An injury sustained thirty years ago to his lower jaw was most probably to blame and as a result of the infection David underwent an aortic valve replacement and cycled London to Paris with Heart Valve Voice.

Mike Thurston
Aged 53, Mike was training for Insanity, an intensive fitness programme, as he had been doing for the past few years. Ordinarily, he has a low resting heart rate which will usually settle in a predictable way following a work out. However, one session near Christmas 2014 he noticed things were not quite right so spoke to his GP and was diagnosed with heart valve disease. Mike received his surgery at Liverpool Heart and Chest Hospital and in 2019 abseiled down St Thomas’ Hospital for Heart Valve Voice.

Gerry Kijak
Gerry Kijak lives in Solihull with his wife. During a holiday in the Caribbean with his family he started to notice he was getting out of breath. At the GP’s office, it became clear things weren’t right. The GP listened to Gerry’s heart with a stethoscope and heard a heart murmur. In February 2016, he underwent double heart bypass surgery and had an aortic valve replacement due to heart valve disease. He now travels the world and often volunteers for Heart Valve Voice.

Steve Langton
Brighton-based Steve Langton had surgery for aortic regurgitation in February 2016. Steve had been getting breathless for a while, but suddenly developed chest pains and a tingling in his arm. Once in hospital, Steve was diagnosed with emphysema, also known as chronic obstructive pulmonary disease (COPD), and a leaky heart valve. Since his treatment Steve is back at work and enjoying his life with his family.

Victor Hyman
Victor, from Manchester was unaware of his heart valve disease which came to light on a holiday. His condition was fairly mild and he was asymptomatic. The cardiologist decided to monitor his condition. Finally, five years later he has his treatment and recovery went well until endocarditis struck. Luckily it was caught early enough although the infection had colonised the repaired valve and subsequently destroyed it. After another successful treatment, it was six months of recovery before Victor went back to full time employment and to full health.

Bill Dean
Bill Dean from Mold, North Wales, spends most of his free time in the mountains of Snowdonia as a Mountain Rescue Volunteer, a job he’s been proud to do for the past 50 years. However, a number of years ago Bill worried he wouldn’t be able to continue with his volunteer work when he started to get breathless walking uphill, until an aortic heart valve replacement in 2015 made sure he was back on the mountains feeling better than ever.

Brenda Walker
In 2010, Brenda Walker, was suffering from all of the red flag symptoms of valve disease, breathlessness, tiredness and swollen ankles. After a visit to her doctor did not result in a stethoscope exam, she took matters into her own hands and sought out a second opinion from a cardiologist. It was a good decision, Brenda was told she had aortic stenosis and that it needed to be treated. She has since finished her PhD and regularly volunteers for Heart Valve Voice.
“As heart valve disease is increasingly treated, the best practice examples and practical guidelines from Heart Valve Voice help ensure those involved are fully prepared to tackle this disease.”

Joe Zacharias
Chairman
British and Irish Society for Minimally Invasive Cardiac Surgery (BISMICS)

4 - Our policy work

Through collaborative research and advocacy projects, since 2014, Heart Valve Voice has established itself as a trusted partner to stakeholders across the patient, clinical and political spheres. Heart valve disease patients now have supportive allies in the policy landscape as demonstrated in 2016 when 40 MPs from seven different parties signed an Early Day Motion welcoming the work of Heart Valve Voice and expressing concern about the significant under-diagnosis of heart valve disease and the local variation in access to effective treatments.

The number of parliamentary questions on heart valve disease has stepped up significantly since we began our political engagement, driving ministerial attention to issues such as early diagnosis, regional disparities, access to treatment and supporting new innovative technologies to support patients.

Our popular Early Day Motion, report launches and wider political engagement demonstrates our ongoing commitment to bringing policy stakeholders with us by consensus as we pursue our shared aims of raising awareness and delivering improved outcomes for patients and their families.

We have come a long way and are extremely proud to have helped alongside other leading stakeholders to secure the development of a NICE clinical guideline for heart valve disease in adults, which is currently in progress and expected to be published in May 2021.

Looking ahead to the next five years, regardless of the political backdrop, Heart Valve Voice will continue to play its role in ensuring heart valve disease is better prioritised at all levels of policy making and implementation.

This chapter will focus on the progress we have made in pushing for better diagnosis treatment through advocating for policy change.
Heart Valve Voice White Paper (2014)

In 2014, we called on policy makers to implement six key recommendations in our inaugural white paper report. This report, led by Professor Ben Bridgewater, then Consultant Cardiac Surgeon at University Hospital of South Manchester and chairman of the Heart Valve Voice faculty, presented the facts and figures that Heart Valve Voice believed politicians, policy makers and the wider NHS need to know in order to take informed decisions about investing in services to tackle heart valve disease.

It also presented evidence of inequalities in patients’ access to treatment, from where they live, to how old they are. This was in line with the wider evidence base that demonstrates that older people attending hospital with heart disease are less likely to be fully investigated and less likely to receive treatment than younger people (Centre for Policy on Ageing 2009).

Heart Valve Voice recognises that the NHS is under financial pressure and understands that difficult choices need to be made about priorities, and which services to invest in. We therefore called on stakeholders to support six cost-effective recommendations:

1. Heart valve disease to be included in current strategies for cardiovascular disease
2. An awareness campaign for healthcare professionals and potential patients on the symptoms of heart valve disease and the importance of early diagnosis and treatment
3. 15-minute GP consultations for the over-75s
4. Appropriate referral and follow-up between primary, secondary and tertiary care with a key role played by a multidisciplinary team (MDT) to inform treatment decisions in partnership with patients
5. The same level of surgical and transcatheter valve replacement as other leading European countries
6. The same access to heart valve replacement treatment wherever a patient lives within the UK

With thanks to the following people who reviewed the White Paper:

- Dr Jarir Amarin, GP Principal, Carlton House Surgery, Enfield and CHD Clinical Lead for Enfield, UK
- Mr Malcolm Dalrymple-Hay, Consultant Cardiothoracic Surgeon, Derriford Hospital, Plymouth, UK
- Mr Keith Jackson, Chairman, British Cardiac Patients Association (BCPA)
- Dr Clinton Lloyd, Consultant Cardiac Surgeon, Derriford Hospital, Plymouth, UK
- Professor Philip MacCarthy, Clinical Director of Cardiovascular Services, King’s College Hospital, London
- Dr Bernard Prendergast, Consultant Cardiologist and Clinical Director of Cardiothoracic Services, John Radcliffe Hospital, Oxford, UK
- Dr Dave Smith, Consultant Cardiologist, Morriston Hospital, Swansea, Wales
- Mr Joseph Zacharias, Consultant Cardiothoracic Surgeon, Blackpool Victoria Hospital, UK
Heart Valve Voice’s five updated recommendations, endorsed by the British Heart Valve Society, were:

1. Awareness of the signs and symptoms of heart valve disease amongst primary care healthcare professionals and the public must be improved through effective and targeted education and awareness raising campaigns.

2. All over 65s should have their hearts routinely checked with a stethoscope by a trained primary care healthcare professional.

3. NICE should develop guidelines on the diagnosis, management and treatment of heart valve disease as a priority.

4. GPs should have improved access to echocardiography (ultrasound of the heart) for all patients with a heart murmur or suspected heart valve disease.

5. Heart valve disease patients must have access to appropriate and effective treatments;
   a. Across the UK; and
   b. When compared to other leading European countries.


Two years after our inaugural white paper report, we published our 2020 vision to bring together a range of new evidence and data on heart valve disease services in the UK. Our intention was to demonstrate the case for change against a policy backdrop in which major strides had been made in cardiovascular disease more broadly, but heart valve disease had found itself without a NICE guideline, and excluded from key NHS policies such as the Department of Health’s 2013 Cardiovascular Disease Outcomes Strategy.

The findings of this report demonstrated that, given the UK’s aging population and the subsequent increasing burden of heart valve disease, resolving the challenges faced in the diagnosis and treatment of heart valve disease was (and remains) critical. It also made clear that not only would addressing the under-diagnosis and under-treatment improve outcomes for patients with this entirely treatable condition, but it would also save costs in the long term for a struggling NHS.

The report was launched in Parliament with over 30 politicians from across the political spectrum and both Houses attending to show their support, alongside patients, clinicians and thought leaders from the wider policy landscape.

Supporting the launch of the White Paper report, we also organised a successful radio day with Professor Ben Bridgewater, Consultant Cardiac Surgeon, as the lead spokesperson. Ben was fantastic in his role, expertly navigating all questions, with informed responses. Ben spoke in an extremely engaging and reassuring manner about the importance of getting checked for heart valve disease, as well as communicating the role that Heart Valve Voice play in supporting patients during their treatment and recovery.

Overall the campaign secured 7 pieces of broadcast coverage across live radio interviews, and another 34 pre-recorded features for other broadcasters, covering a total of 186 local and regional stations. In all, our potential audience outreach was over 43million listeners, which was an incredible achievement for our team in our first year as an organisation.
Gold Standard of Care (2017/2018)

Heart Valve Voice’s early policy work exposed the lack of consensus on best practice care for patients with heart valve disease in the UK. Our subsequent engagement with clinicians and patients highlighted the need for a disease specific national guideline, authored and published by NICE.

In order to make the case to NICE for the development of this guideline, in 2017 we set out to develop a ‘gold standard’ in the diagnosis, treatment and management of heart valve disease. It was proposed that this document would not only be used to engage NICE and key stakeholders, but also support all healthcare professionals involved in the patient pathway to deliver high quality care of the disease.

Throughout 2017, a number of working groups were brought together to support the development of this document. These groups included senior healthcare professionals and key opinion leaders from the fields of cardiology and heart valve disease, in addition to patients. The resulting report – Towards a Heart Healthy Future: A Gold Standard in the Diagnosis, Treatment and Management of Heart Valve Disease in Adults – was published in 2018 and set out best practice for the care of heart valve disease across the patient pathway.

“I commend Heart Valve Voice for their work on this report. They have brought together this Working Group of leading clinicians and patients to describe the challenges faced by professionals and patients in managing valve disease and have suggested ways in which services might be improved. This will help us in our collective ambition to achieve the best possible outcomes for patients, and will support objectives related to heart valve disease set out in the NHS Long Term Plan.

I look forward to working with Heart Valve Voice and others in achieving this.”

Professor Huon Gray CBE
former National Clinical Director for Heart Disease
NHS England

Chris Evans MP shows his support with Heart Valve Voice CEO Wil Woan.
The final report – which included a foreword from Professor Huon Gray, then National Clinical Director for Heart Disease at NHS England – was shared with senior stakeholders across the NHS and elicited endorsement from a number of leading professional groups, including the Society for Cardiothoracic Surgery (SCCTS) and the British Society of Echocardiography (BSE).

As a result of our tireless campaigning and production of the Gold Standard report, in 2018 the development of a NICE guideline into the investigation and management of heart valve disease presenting in adults was announced.

Our Chief Executive, Wil Woan, was involved in the early scoping discussions for the guideline, providing an excellent opportunity to represent the patient voice.

Gold Standard Taskforce (2019)

A key action within the Gold Standard was to convene an implementation group to agree upon the best ways to achieve the recommendations within the report. In 2019 this was realised in the form of the Gold Standard Taskforce, who met to agree key actions and next steps.

At the first Taskforce meeting, a number of specific actions were put forward to achieve the goals outlined within the Gold Standard. These included the implementation of best practice in cardiac image sharing, capitalising on technological advances such as digital stethoscopes, and engaging with new NHS bodies such as Primary Care Networks.

The discussion was written up in the form of an Action Plan, which will inform the Taskforce’s activity for the next few years. As an immediate action, Heart Valve Voice, on behalf of the Taskforce, will be hosting an event alongside Health Innovation Manchester. This aligns with a key pillar of the Action Plan – to highlight technology and innovation and where it can be used to improve the valve disease patient pathway. The roundtable will look at specific technologies and opportunities for implementation at a local level, with the intention that data be collected from these pilot sites to inform and support national implementation.

Taskforce members:
- Dr Chris Arden (Chair), GPwSI in Cardiology
- Christina Bannister, Nursing Case Manager – Cardiac Surgery, University Hospital Southampton NHS Foundation Trust; Patient Lead, Society for Cardiothoracic Surgery in Great Britain and Ireland
- Neil Betteridge, NHS England Patient Advisor
- Giancarlo Laura, Senior Programme Manager and Medical Directorate, NHS England and NHS Improvement
- Sally Hughes, Head of Health Services Engagement, British Heart Foundation
- Keith Pearce, President, British Society of Echocardiography
- Professor Simon Ray, Getting It Right First Time Joint Clinical Lead, Cardiology
- Wil Woan, Chief Executive, Heart Valve Voice

State of the Nation: Wales (2019)

Although not mandatory, it is our hope that the NICE Clinical Guideline in development for heart valve disease will be adopted in Wales upon its publication. This will ensure that patients in Wales receive the same quality of care as their counterparts in England.

As it stands, heart valve disease does not currently receive an adequate level of prioritisation from key stakeholders in Wales. This lack of awareness and prioritisation is likely to be increasingly damaging to the NHS and patients due to Wales’ ageing population.

To address this and to begin building political advocates for the condition, in 2019 Heart Valve Voice produced a State of the Nation report, evaluating the current provision of services and care for Welsh patients.

In drafting the report, we also conducted a freedom of information survey which was sent to Health Boards in Wales and the NHS England Trusts that sit along the border. This revealed the significant variation in times to diagnosis between Wales and England, as well as the number of Welsh patients being transferred to NHS England Trusts for treatment.

Other policy work

As well as shaping care standards and guidelines through policy reports and Taskforce meetings, we have also been an active member of many wider initiatives involving other patient charities and industry groups. Working with these other stakeholders, we are now part of a more powerful coalition of voices to push for meaningful change in the way the UK tackles heart valve disease.

Global Heart Hub

Heart Valve Voice is a founding member of the Global Heart Hub, the first global non-profit organisation established to provide a voice for those affected by cardiovascular disease. The Hub is an alliance of heart patient organisations, aiming to create a unified global voice for those living with or affected by heart disease.

Heart Valve Voice has been instrumental in the work of the group over the last few years and our CEO Wil Woan has been elected as Chair of the Global Heart Valve Disease Patient Council for the next two years. We look forward to working with our international partners in the future to improve care for heart valve disease patients worldwide.
UK TAVI Trial

The UK Transcatheter Aortic Valve Implantation (UK TAVI) Trial is an ongoing clinical trial to assess the benefits of new valve replacement technology, in comparison to the current replacement for high-risk surgery patients.

In 2017, Heart Valve Voice was selected to be part of the steering committee for the research project as an independent member, in order to provide the patient perspective on various aspects of the trial. The trial has been running since 2013, and we look forward to working as part of the steering committee until 2022, when the results of the research have been collected. Being involved in clinical research helps us shape the way new heart valve technologies are developed, ensuring they are focused on providing the greatest benefit possible to the patients we represent.

Medical Technology Group

Heart Valve Voice is also a proud member of the Medical Technology Group (MTG), a coalition of patient groups, research charities and medical device manufacturers aiming to increase patient access to the best technology available.

The MTG provides patient groups like ourselves with a forum to discuss the needs of patients directly with medical technology manufacturers. Through the MTG we’ve had regular engagement with clinicians, commissioners and public bodies, and we’ve worked to help them understand the patient perspective and ensure it is factored into policy decisions.

We are also proud to say that our CEO Wil Woan was elected to the management committee of MTG, and has been working with the other committee members to develop the group’s strategy and plans for the future.
“Given our ageing population it is more important than ever that diagnosing and treating heart valve disease is a priority across the NHS. Over the last five years Heart Valve Voice has worked tirelessly to ensure patients receive the best care possible.”

Richard Page
President
Society of Cardiothoracic Surgery (SCTS)

5 - Surveys

One of the first projects launched by Heart Valve Voice after it was established in 2014 was the commissioning of a "Heart Health Survey", investigating the state of heart valve disease diagnosis and treatment in the European Union.

Every year hundreds of people over 60 complete these surveys, giving us invaluable insights into how heart valve disease is viewed by the people it affects and the public as a whole. We’ve been able to use the UK survey results to educate key policy makers, and strengthen our case for change in the treatment of heart valve disease.

This chapter will focus on the results of these surveys and how they have shaped the work we do.
How do over 60s think about heart valve disease? (2014)

In 2014, we commissioned the first Heart Health Survey to help us understand the following key issues:

- The awareness and understanding of heart valve disease
- The level of concern of heart valve health
- Assess the frequency of heart health check-ups and stethoscope testing in the UK

Over 1,000 people over the age of 60 in the UK answered our questions and the results provided us with some key insights about heart valve disease. It became clear that a lack of awareness was a key barrier to good heart valve disease treatment.

For example:

- Fewer than 3% of people surveyed were worried about heart valve disease
- Over half of respondents said their GP rarely or never listened to their heart with a stethoscope
- One in five said they would want medical advice on heart conditions if they knew about the less invasive treatments that were available

Based on these facts and figures, it became clear that our mission needed to focus on raising awareness of heart valve disease and how it can be checked for.

Who is affected by heart valve disease? (2016)

In 2016, we collected responses from 1,411 people over the age of 60, spread across 14 UK cities. Our survey results highlighted the difference between the awareness of other types of cardiovascular disease and heart valve disease:

- 59% were aware of heart attacks
- 42% were aware of angina
- 42% were aware of coronary heart disease

Whereas:

- Only 7% were aware of heart valve disease

Encouragingly, although knowledge of heart valve disease was low, after receiving additional information about the condition:

- 66% of over 60s were more concerned about aortic stenosis
- 31% said they would seek further information
- 7% of the respondents even recognised symptoms of the disease in themselves

Our survey also revealed a gender gap in the way patients were treated:

- Only 17% of men said they had never been checked for heart valve disease; this number was 30% for women
- Over twice as many men than women had their heart listened to every time they saw a doctor

These results highlighted to us the importance of reaching as many people as possible with information about heart valve disease, not just the people who are traditionally thought of as being at high risk for cardiovascular disease.
The power of positive ageing (2017)

In 2017, more people than ever before answered our survey questions about how they viewed heart valve disease. Our survey delved into a number of issues that limit awareness and diagnosis rates for people at risk of heart valve disease and the results from the survey were later published in Clinical Research in Cardiology:

- Again, we found a significant gender gap in diagnosis; 28% of men regularly get their heart checked but only 20% of women do
- People in rural areas are less likely to receive regular heart checks, compared to people in urban areas by a rate of 8.6% to 5.6%
- The rate of regular heart checks was lowest in Brighton and highest in Belfast
- The UK had the lowest self-reported rate of stethoscope use in Europe at only 7%. The highest rate, France, was 79%
- The rate of stethoscope checks in the UK has only increased by 4% since 2015

This data clearly demonstrates the need for people from across the UK to have equal access to heart checks, and subsequently has shaped the way we engage with the public to raise awareness of heart valve disease.

Worryingly, over 25% of people were concerned about heart valve disease but had no plans to take any action, which may be because only 30% of respondents were aware that treatments for heart valve disease existed.

Given the fact that half of patients will die within two years of developing symptoms if severe aortic stenosis is left untreated, this data shows how important it is that checking for heart valve disease is routine for over 60s.

Survey radio day (2018)

As part of the first ever European Heart Valve Disease Awareness Day, and with the help of clinicians and patients from across the UK, Heart Valve Voice presented the results from the 2017 Heart Valve Disease Survey on local radio stations.

The Heart Valve Voice team and supporting clinicians spoke about the symptoms of heart valve disease, how people could get checked, and how treatment can change a patient’s life.

Special thanks to Pat Khan, our amazing patient ambassador, for taking to the airways to share her story with us. This was part of a wider campaign across Europe, which called for action to improve awareness, early diagnosis and treatment.

In total Heart Valve Voice took part in interviews for 12 different radio stations, including 10 live features. These stations had a combined weekly reach of over 1 million regular listeners, and reaching such a large potential audience with our message was an incredible way to celebrate the first ever European Heart Valve Disease Awareness Day!
6 - Testing events

Over the last five years, we’ve held testing events across the UK, from cricket grounds to parliamentary buildings. At these events, our clinicians have been able to provide stethoscope checks for heart valve disease, as well as raise awareness of the condition in the public. Ensuring that people are aware of symptoms and know how regularly they should be getting checked makes a real difference in tackling heart valve disease.

For people over 50, getting your heart checked should be a regular part of your healthcare, but our research has demonstrated that for many people this is not the case. Holding these events for politicians, as well as the general public, has allowed us to show policy makers how important these checks are.

In this chapter we look back on all the testing events we have held over the last five years and share some of our favourite photos from the thousands of heart checks we’ve done.

“There are powerful tools available to screen for and diagnose heart valve disease but more awareness and training around these technologies is needed. Heart Valve Voice has supported these efforts during our annual meetings, sharing their expertise in the patient experience and gaining support from clinicians from all over the UK.”

Keith Pierce
President
British Society of Echocardiography (BSE)
At sports events

Over the last five years, Heart Valve Voice has hosted a number of check-up events at major sporting events including international cricket tests, and local football grounds across England. These testing events have been an amazing opportunity for the Heart Valve Voice team to discuss symptoms with members of the public, and provide check-ups to people at risk of heart valve disease. Over the years we’ve listened to thousands of hearts across the UK.

Special thanks to Everton FC’s Goodison Park, Brentford FC’s Griffin Park, Southampton FC’s St Mary’s Stadium, Emirates Old Trafford Cricket Ground, Crewe Alexandra FC, and Lancashire County Cricket Club for their support in making these events such a success.

“Ever since I became involved with Heart Valve Voice, I have always made a point to have my heart checked regularly. It is such a treatable disease and it genuinely surprises me how many people are still unaware of its prevalence, or that it even exists. This is why I support the work of Heart Valve Voice in raising awareness and also support their check-up events”

David Gower OBE
former England cricketer
In Parliament

In July 2016, we held a check-up event in the Houses of Parliament, offering MPs the chance to receive a stethoscope check from expert cardiologists and cardiac nurses. Over 40 MPs visited our drop-in event, giving them the opportunity to learn more about the symptoms of heart valve disease, who it affects, and what can be done to improve the care patients receive. Raising political awareness has always been key to pushing for improvements in the way heart valve disease is treated. We have met many MPs at testing events who have since worked with us to change policy and ensure patients receive the best possible care.

In the Welsh Assembly

As part of launching our State of the Nation: Wales 2019 report, we held a testing event in the Welsh Assembly; more than one third of all Assembly Members attended, and the subsequent assembly questions posed to the Cabinet Secretary for Health and Social Services have forced the Welsh Government to clarify their approach to the condition. Additional engagement with the Heart Conditions Implementation Group in Wales has ensured the report is viewed by those ultimately responsible for heart valve disease strategy in Wales. We look forward to continuing our work with patients, clinicians, policy makers and politicians to improve heart valve disease care in Wales.
Looking back over everything we’ve achieved in the last five years, it deserves to be highlighted that as patient advocates in the heart valve disease sector, our relationship with the medtech industry is as important as our partnership with the medical profession and the healthcare system. We base this relationship upon the ethos of innovation, information and independence.

Innovation through collaboration between industry and physicians is key to patient outcomes and quality of life, as seen through advances in treating heart valve disease with groundbreaking transcatheter procedures that have completely transformed the landscape for patients. The first step to treatment is disease detection where promising developments are moving forward every day. New types of digital stethoscope are not only making detection much more reliable, but they offer the promise of allowing detection in the community with practice nurses and pharmacists.

The support of industry is important for us and our patients, and we’ve worked to ensure these partnerships are based on our shared aim that the right patients get the right treatment at the right time. We’ve demonstrated this day-in, day-out by being transparent in our dealings and by ensuring that our independence at patient groups is respected and maintained at all times. This is beneficial for all, as we want to protect the path for innovations, which have and will continue to transform the lives of people suffering from heart valve disease.

Heart Valve Voice would like to thank the organisations opposite for their ongoing support of our work.

**Special thanks**

Heart Valve Voice would also like to thank our photographer Michelle Richards, videographer Steve Pycroft and designer Emma Cooke for all their hard work and support over the last five years.
"Having a strong coalition of patients, researchers and healthcare professionals is key in ensuring progress continues to be made in treating heart valve disease. Heart Valve Voice has been the voice of that coalition, over the last five years and in the future."

Professor Simon Ray
President
British Cardiovascular Society (BCS)

8 - Looking ahead

Looking ahead to the next five years, regardless of the political backdrop, Heart Valve Voice will continue to play its part in forwarding the interests of all those facing the impact of heart valve disease. We already have a number of plans for the coming year, building upon the strong foundation of awareness and support we have achieved so far.

We will drive forward our Gold Standard Taskforce’s Action Plan and help ensure the patient voice is listened to as NICE develops its clinical guideline. In future, we will also seek to deepen our relationship with Royal Colleges to see how further progress can be made by working more closely with workforce stakeholders to increase early detection and the use of the most effective innovations. Ensuring that GPs and other healthcare professionals make use of the flu jab season to screen more patients for heart valve disease will also remain a priority.

Heart Valve Voice extends a huge thank you to all those that have worked with us to date and invites anyone with an interest in tackling heart valve disease to join us and share their views.

If you are interested in being involved with our future work, please contact us at admin@heartvalvevoice.com

For more information about Heart Valve Voice and the work we carry out, please visit www.heartvalvevoice.com

You can also show your support and receive regular updates by following us on our social media platforms:

- Facebook: /HeartValveVoice
- Twitter: @HeartValveVoice
- Instagram: HeartValveVoice
- YouTube: Heart Valve Voice

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