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All-Party Parliamentary Group On Heart Valve Disease

Reviewing current detection and care for those with heart valve disease in the UK, and identifying solutions to ensure optimal outcomes in the future.

The views expressed in this report are those of the All-Party Parliamentary Group on Heart Valve Disease (APPGHVD), which is an informal group of Members of both Houses of Parliament with a common interest in heart valve disease.

This report is not an official publication of the House of Commons or the House of Lords and has not been approved as such by either House or its formal committees.

The information contained in this report was gathered through two oral evidence sessions with patient representatives, health care professionals, charities, patient organisations and industry experts, and a written call for evidence issued on behalf of the members of the APPGHVD.

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Introduction

Across the UK, heart valve disease (HVD) affects approximately 1.5 million people.¹ Patients with the condition can experience a shortness of breath, light-headedness or dizziness,² and if left untreated HVD can be life threatening.³ However, with timely treatment, it is possible for patients to go back to a good, and even better, quality of life.⁴

Like many other conditions, the COVID-19 pandemic has sadly had a significant impact on the investigation and care of those with HVD, with a recent British Heart Foundation study finding that between March and October 2020, there were over 5,000 excess deaths from heart problems in the UK.⁵

In light of the impact of COVID-19 and the anticipated publication of NICE's draft Clinical Guideline on the [investigation and management of HVD presenting in adults](#),⁶ the APPG felt now was a good time to consider how patients are currently being treated and what needs to be done to deliver optimal care both now and in the future. We therefore sought oral and written evidence from a number of experts in the field, asking them to share their views on four key themes covering the whole patient pathway. These themes included:

- i) detection, assessment and diagnosis;
- ii) treatment, and how it can be improved;
- iii) patient surveillance; and
- iv) the information and support that patients receive.

We are extremely grateful to all those who have submitted written evidence to the APPG, as well as our members and the representatives from the HVD community who presented their thoughts at our two oral evidence sessions. This report sets out our findings and makes recommendations as to how the NHS can deliver the best possible care to HVD patients once it begins its recovery from the pandemic.

Thank you once again to all involved in this important inquiry and to my colleagues on the APPGHVD for their ongoing support and commitment to improving outcomes for patients with this condition.

Steve McCabe

MP for Birmingham, Selly Oak and
Chair of the APPG on Heart Valve Disease





Overview

Evidence Sessions

On Wednesday 24th March, members of the APPGHVD came together to hear oral evidence as part of its review into the current standards of management and care for HVD patients in the UK. The session was split into two sections, with evidence initially taken from members of the Heart Valve Voice Clinical Advisory Panel, chaired by Professor Huon Gray (previously National Clinical Director for Heart Disease, NHS England), followed by patient representatives.

The second oral evidence session was held on Wednesday 14th April. This session was again split into two sections, this time the evidence was initially taken from patient advocacy group representatives, followed by representatives from the MedTech sector.

Open Consultation

The APPGHVD also accepted evidence from a broad range of interested parties following a call for written evidence.

The full list of contributors to the oral and written evidence session can be found below:

- Alison Banayot, heart valve disease patient
- Angie Martin, heart valve disease patient
- Philip Reed, untreated valve disease patient
- Olivia Osborne, untreated valve disease patient
- Daniel Colgan, heart valve disease patient
- David Eaton, heart valve disease patient
- Simon Ray, President of the British Cardiovascular Society
- Benoy Shah, President of British Heart Valve Society
- Claire Colebourn, President of the British Society of Echocardiography
- Jim Moore, President of the Primary Care Cardiovascular Society
- Jane Nixon, Medtronic and Vice Chair of the ABHI Heart Valve Disease Group
- Abbott
- Somerville Foundation
- Ameer Alley, Edwards Lifesciences and Chair of the ABHI Heart Valve Disease Group
- Barbara Harpham, Chair of the Medical Technology Group
- Wil Woan, Chief Executive at Heart Valve Voice
- Martin Lock, Silver Surfers
- Neil Betteridge, Independent health consultant
- 3M
- British Society of Cardiovascular Imaging
- Edwards Lifesciences
- British Society of Echocardiography
- Aortic Dissection Awareness UK & Ireland
- Dr Chris Arden
- Society for Cardiothoracic Surgery
- University of Leicester and University Hospitals of Leicester NHS Trust
- Valve for Life
- British Heart Foundation
- British Heart Valve Society
- British Cardiovascular Society



Summary of Recommendations

Detection, assessment and diagnosis

Detection and diagnosis

- National health services, such as NHS England, should establish a national detection programme comprising of annual stethoscope checks for all those aged 65 or over.
- National health services, such as NHS England, should develop a national breathlessness awareness campaign to ensure that the population is aware of the link between this key symptom and heart disease, including HVD, and recognise the need to visit their GP should they experience it.
- In line with the NHS Long Term Plan and the Mike Richards Report, the expansion of community diagnostic hubs should continue in the post-pandemic era, so that patients can receive timely diagnosis, diagnosis backlogs caused by the pandemic can be reduced, and much needed hospital capacity is freed-up.
- The Accelerated Access Collaborative should undertake studies into the use of innovative technology, such as digital stethoscopes, to assess their impact on aiding detection of HVD in primary care.
- The Royal College of General Practitioners (RCGP) should increase educational support provided to GPs to enable them to operate community echocardiography services in line with British Society of Echocardiography certifications.

The impact of the COVID-19 pandemic on heart valve disease

- National health services, such as NHS England, should encourage the longer-term adoption of novel ways of working implemented during the pandemic, such as telemedicine, as the NHS seeks to recover. However, it is important to continue face-to-face appointments for diagnosis and treatment where appropriate.

Treatment, and how it can be improved

Unequal impact of HVD

- To fully assess inequalities in access to a community based optimal pathway and variable rates of treatment, an independent report should be commissioned into health inequalities, using Hospital Episode Statistics and National Institute for Cardiovascular Outcomes Research data.
- The National Institute for Health Research should undertake research to establish the actual prevalence of HVD in the UK, as estimates suggest that cases will rise to around 3m by 2046 and rise further to 3.3m in 2056.

- Equity of access to treatments must be considered as part of a move to encourage shared decision making, to ensure that patients receive the right treatment for them as well as the necessary information so that informed decisions can be made.
- A fast-track transcatheter aortic valve implantation (TAVI) or surgical aortic valve replacement (SAVR) pathway for severe aortic stenosis should be implemented, covering the entire patient journey from initial diagnosis to final treatment and recovery.
- NHS Digital should facilitate the linkage of registry data to national routinely collected data e.g. primary care data, Health Episode Statistics (HES) data or Death Registry data. This would enable us to understand the impact of interventions over a lifetime for the patient and the entire health service, allowing for an in-depth assessment of clinical and cost effectiveness.

Patient support during treatment

- A nationwide regulated HVD patient ambassador network should be established with formal training and backing supplied by a health organisation, such as NHS England.

Technology appraisals

- NICE should review the current system of appraisals for medical devices, allowing for additional data, such as real-life demonstrations of products to be taken into consideration by regulators.

Patient surveillance

Ensuring delivery of ongoing surveillance and monitoring regime

- The APPG supports the 'Echocardiography Training Programme', established by the National School of Healthcare Science (NSHCS), in collaboration with the British Society of Echocardiography (BSE) to tackle the ongoing echocardiography capacity challenges and encourage recruitment and specialisation in this field.
- In order to maximise health service capacity, trained staff, such as clinical nurse specialists and physiologists, should be used to take on additional responsibilities, ensuring that pressure can be taken off surgeons and echocardiography consultants.

Patient support

- More detailed information should be provided to patients regarding their surveillance regime post intervention, as well as a list of reliable sources that patients could access to seek answers to specific questions.
- In the final clinical guideline [GID-NG10122], NICE should recognise the value of multidisciplinary teams (MDTs) in relation to supporting shared decision making between patients but also between other clinicians. In addition, virtual MDTs should be continued where appropriate, as this more agile approach will allow for faster decision making while services are returning to normal.

Further research

- Further research should be conducted into the value of establishing valve surveillance clinics across the UK to secure stronger links between the patient's GP and valve surgeon to enable a joined-up monitoring process.

- The APPGHVD agrees with NICE's key recommendation for research to be undertaken into 'monitoring where there is no current need for intervention' and 'monitoring after an intervention', as part of the draft NICE guideline [GID-NG10122].

The information and support patients receive

National awareness

- It would be beneficial to establish a national awareness campaign to ensure that the general public are aware of HVD 'red flags', such as breathlessness, dizziness or light-headedness when carrying out everyday tasks, as well as the general prevalence of the condition.

Patient information

- Tailored, up to date information should be made available to all patients and their families in a range of easily accessible formats, such as written, verbal and digital. These should also be provided in a range of languages, where appropriate.
- To ensure patients know which sites to trust, organisations which provide support materials should look at adopting the 'kite marking' of sources of information, as is currently being explored by the Patient Information Forum.
- Information on all parts of the HVD pathway is inconsistent. As such, a collaboratively approved resource centre for HVD patients should be established through collaboration from the health service, charities and healthcare professionals.

Mental health support

- Patients with HVD and their families should be able to access psychological support when necessary. However, additional Government funding is required to ensure that these services can be provided by the NHS.



Detection, Assessment and Diagnosis

Detection and Diagnosis

Once a patient presents to primary care with a red-flag symptom for HVD, such as breathlessness or a new on-set chest pain, auscultation should then be undertaken to determine whether any heart murmur exists. Should a murmur be detected, patients should immediately be referred for an echocardiography to confirm whether this is an innocent or pathological murmur that needs to be investigated further. Referral to echocardiography should occur as quickly as possible (ideally within 4-6 weeks), but we are aware that this is not always the case. Likewise, many patients are unaware of the symptoms of HVD and as a result the true number of patients with HVD is still largely unknown.

Questions posed to respondents on this topic included:

- Early identification of HVD and onward referral where appropriate, are essential to enable timely assessment and advice on appropriate treatment. What steps do you think should be introduced to ensure that people with HVD are detected and diagnosed?
- How can we ensure that all people presenting with a heart murmur are referred for echocardiography?
- When should patients with HVD be seen in a specialist heart valve clinic? Should a national detection programme for HVD in primary care settings be introduced, to ensure that more patients are diagnosed earlier?

Throughout the evidence that the APPG has collated, it is clear that more can be done to ensure that those with HVD are detected in a timely manner. In particular, respondents made the point that the level of auscultations undertaken within primary care is low, in part most likely to be due to short consultation appointment times. A patient survey by the charity Heart Valve Voice showed that almost three-quarters (72%) of over 60s claim that their doctor rarely or never checks their heart with a stethoscope.⁷ It was noted within the evidence received that these checks are vital to early diagnosis and that in order to address this, a national detection programme comprising of annual stethoscope checks should be implemented for all those aged 65 or over.

While stakeholders noted that any detection programme should first be rolled out on a pilot basis to prove that it leads to increased diagnoses, there was a general consensus that such a scheme would be beneficial in the long run. However, some respondents noted that a general population 'screening programme' would have a low yield and detect people with minor valve thickening and risk unnecessary health anxiety. It was therefore suggested that echocardiography be targeted at high risk individuals with murmur, atrial fibrillation, or a family history of bicuspid aortic valve. Elsewhere, there were calls for a national breathlessness awareness campaign to ensure that the population is aware of the link between this key symptom of heart disease, including HVD, and recognise the need to visit their GP should they

experience it regularly. GPs should also receive educational support regarding the symptoms of HVD so that the condition is actively considered when patients present with breathlessness.

The APPG notes that rolling out this programme could prove challenging due to the capacity challenges the NHS is currently facing, so we would recommend the increased use of innovative technology, such as digital stethoscopes, to aid detection in primary care. This would enable other healthcare professionals, such as pharmacists, to participate in the national detection programme and perhaps enable checks to occur in tandem with the annual flu vaccination programme given the similar target demographic.

A successful detection programme is likely to lead to more echocardiography referrals, which is why it is crucial to ensure that the NHS has the capacity to meet existing and future demand. We heard anecdotally during the pandemic how waiting times for echocardiography have increased to 18 weeks in some cases. This is consistent with the findings of a recent report from the think tank Institute for Public Policy Research (IPPR), which found that the total number of echocardiograms undertaken in 2020 has decreased by 44% compared to 2019.⁸ This is at odds with the recommendations contained within Heart Valve Voice's Gold Standard of Care report, which highlights the need for symptomatic patients to have an echocardiography within six weeks of referral.⁹

The APPG understands the significant pressures that COVID-19 has placed on the health service, and we would therefore encourage greater investment in echocardiography training to ensure that the workforce is expanded and that patients are able to access this service quickly. This is also crucial in light of a 2016 report by the APPG on Heart Disease, which noted that there is an acute shortage of echocardiographers in the United Kingdom – with only 44 individuals trained in 2016, and severe delays for many patients waiting for an echocardiogram.¹⁰ To help address this problem in the short term, triaging could be utilised to ensure that those with the greatest need are able to access echocardiography in a timely fashion. However, in the longer term, a training pathway for new echocardiographers needs to be established. As such, the APPG positively notes the work of the NSHCS, in collaboration with the BSE to set up the 'Echocardiography Training Programme' pilot, which aims to respond to the urgent workforce needs for Accredited Echocardiographers.¹¹

Furthermore, reducing the variation in access to echocardiography is also crucial to increasing detection rates, and this can be aided by the establishment of more wide scale access to diagnostics within community care settings. This should be accompanied by education programmes for healthcare professionals, to enable GPs to operate community echocardiography services in line with BSE certifications.

"I was always tired, really drained and kept getting breathless. I was treated at the height of COVID, which provided its own challenges, but I realise how lucky I was to be treated then. I just remember thinking, here I am having my second open-heart surgery before I am even 50!"

Angie Martin
Patient with HVD

Improving the patient pathway

Questions posed to respondents on this topic included:

- How can we ensure that the care pathway for HVD patients is optimally set out so that once detected, patients are rapidly referred for investigations and treatment, e.g. rapid diagnostic assessment centres?
- How can innovative diagnostic technologies improve HVD pathways? What are the main barriers for adopting these technologies?
- What can we do to improve and accelerate the treatment pathway?

As part of the NHS Long Term Plan, NHS England has sought to introduce community diagnostic hubs to act as "one stop shops".¹² The APPG believes that these hubs could provide an ideal location to undertake transthoracic echocardiograms so that once a patient with a heart murmur is detected, the necessary steps can be taken to identify HVD as quickly as possible. Throughout the COVID-19 pandemic, the APPG notes how the portability of echocardiography machines has meant that patients have been able to attend a community centre for a full echo study, just as they would have in hospital departments. It is therefore our hope and recommendation that the expansion of these community diagnostic hubs continues in the post-pandemic era, so that patients can receive timely diagnosis, backlogs caused by the pandemic can be reduced, and much needed hospital capacity is freed-up.

In order to support the roll-out of community diagnostic hubs and an expansion in diagnostic testing, the APPG encourages the use of innovative technology to aid with this. Throughout the oral and written evidence presented to the group, it was highlighted that handheld echocardiography devices, and digital stethoscopes in particular, can help to improve the accuracy of diagnoses in those with heart murmurs. In addition, due to their ease of use, such devices can be used by a greater number of healthcare professionals (such as pharmacists or nurses), to ease the burden on GPs and aid detection in non-traditional settings. Wearable technology, such as Fitbits and Apple Watches, were also discussed as they can detect patients with reducing exercise tolerance, an early symptom of valve disease, and can also detect atrial fibrillation. The APPG acknowledges that barriers to the adoption of new innovative technologies do exist and are mostly cost related. However, it is our belief that the benefits that such technology delivers will mitigate the potential cost impact.

While the expansion of community diagnostic hubs and increasing access to innovative technologies are good first steps, it is our view that a national detection and treatment pathway should be established to reduce variation across the UK and to ensure that clear benchmarks are established for optimal diagnosis and care.

The impact of the COVID-19 pandemic on HVD

Questions posed to respondents on this topic included:

- What steps have been taken as a result of the COVID-19 pandemic to ensure continued access to diagnostic tests, and what more needs to be done?
- Are there novel ways of working that have been developed during the pandemic that should be continued (such as telemedicine, COVID-free surgical pathways, rapid access to diagnostics etc.)?

The COVID-19 pandemic has seen the NHS face its greatest challenges since its creation in 1948, and despite the best efforts of NHS staff, many HVD patients have not been able to access the care they need. Throughout the evidence received by the APPG, we have heard how waiting times for echocardiography and treatment have routinely exceeded recommended guidelines as the NHS seeks to deal with the backlog in care caused by the pandemic.

While improving treatment times is important, it is also vital that patients feel able to come forward if they experience symptoms of HVD. The APPG has received evidence that during the early part of the COVID-19 pandemic, there was a significant reduction in the number of patients presenting in primary care, due to fears of contracting the virus. We therefore support campaigns, such as the #JustGo championed by Heart Valve Voice, to encourage patients to reach out and receive care in a timely fashion. 13 As we head out of the pandemic, we are hopeful that patients will feel more comfortable seeking care, but are conscious of the impact that this may have on NHS capacity and resources if patients require emergency treatment due to a delayed diagnosis.

Furthermore, while the COVID-19 pandemic has been a challenging time for the NHS, it has fostered the use of novel ways of working, many of which should be maintained moving forward. Specifically, telemedicine has been highlighted as an innovation that had been of real benefit to the patient community by allowing consultations to occur without the risk of visiting a healthcare setting. However, respondents also expressed the view that telemedicine should not be exclusively used across the patient pathway as certain milestones, such as a new or a change in diagnosis, should occur via an in-person appointment where possible.

"COVID has had a big impact on my surgery as rather than having to wait 3 months, it will most likely be 8 to 9 months before my heart valve can be repaired. This means that I am having to manage the symptoms each day which can sometimes be frustrating and challenging. My symptoms are mostly breathlessness and fatigue. Working full time also provides it challenges but I am looking forward to getting some energy back and getting back on my bike, which I have really missed."

Phil Read
Patient with HVD

Treatment

Heart valves can be repaired or replaced during surgery. The type of treatment needed is dependent on the condition of the valve, its effect on the heart and whether the patient has other comorbidities.

There are two main types of replacement valve.

- **Artificial mechanical valves**
Usually used in younger people because they last for a long time. To keep them working well and prevent blood clots, you need to take an anti-clotting medicine (such as warfarin) for life.
- **Animal tissue valves**
Tend not to last as long as mechanical valves, but patients do not need to take warfarin (unless there are other medical reasons indicating a patient should).

Valves can be repaired or replaced using different types of procedures. Below is an overview of some of these procedure types:

- **Open heart surgery**
This involves a large cut in a patient's chest, through which a surgeon does the operation.
- **TAVI**
A thin wire is used to guide a replacement valve into a blood vessel and up into a patient's heart. This may be offered if a patient has aortic stenosis but cannot have open heart surgery due to high surgical risk.
- **Balloon valvuloplasty**
A procedure used to widen a narrowed valve, for example, if a patient has mitral or aortic stenosis. A surgeon makes a small cut in the vein in the groin and passes a thin catheter (tube) along it until it reaches the heart valve. The tip of the catheter has a balloon a doctor inflates when it reaches the narrowed part of the valve, to stretch it. The benefits of balloon dilatation of the aortic valve in adults are generally short lived, so the technique is often used as a precursor to more definitive treatment.

It is crucial that patients are involved in each step of their care journey, and this is equally true when it comes to the decision making process around their own treatment. Patients should be empowered to discuss their options and ask questions of their respective healthcare professional. It is also important to ensure that all patients can access the right treatment at the right time, however, there are a number of barriers that some patients have to overcome in order to receive treatment. As such the APPG asked a series of questions regarding the patient's treatment pathway.



How can low HVD treatment numbers, and geographical inequalities best be addressed?

In the UK, there are many geographical inequalities in the provision of healthcare at different points in the journey of a patient who presents with HVD – from diagnosis to investigations and treatment. The NHS has introduced a number of novel ways to deliver care to isolated communities, such as an NHS charity, which is hoping to build a Cardiac Diagnostic Vehicle, which will be fitted with technology allowing clinicians to journey to vulnerable patients so that diagnoses and assessments can be performed remotely.¹⁴



However, sometimes patients have to travel considerable distances to access the necessary treatment. This has been exacerbated by the pandemic, which has highlighted inequalities in access to treatment throughout the country, caused by a mixture of capacity and commissioning issues across the patient pathway. One example given to the APPG that touched on both treatment numbers and geographical inequity was access to TAVI in the UK. It was highlighted using data from the National Institute for Cardiovascular Outcomes Research (NICOR) that there was an 11-fold variation in TAVI numbers per million population (pmp).¹⁵ However, in regards to supporting rates of treatment for HVD patients, it was highlighted that TAVI has some advantages in the post-COVID era, as it can be performed under local anaesthesia rather than general anaesthesia, it requires no ICU stay and has a shorter overall hospital lengths of stay (3 days average vs 8 days for SAVR).¹⁶ Following the COVID-19 pandemic, addressing inequity of access to treatment should be considered a priority by the NHS to ensure that patients can receive the right care and that they can return to a good quality of life. As such, the APPG believes that equity of access to treatments, when appropriate, must be considered as part of this move to encourage shared decision making to ensure that patients receive the right treatment for them as well as the necessary information so that informed decisions can be made.

One final point that was made by a number of witnesses, was that the current system of appraisals for medical devices needs to be reformed to allow for real-life demonstrations of products to be taken into consideration by regulators to increase the speed at which innovative technology can be approved. For HVD, it was explained that a reformed system could allow for further technologies to be introduced to help treat the mitral and tricuspid valves. Other witnesses noted that clinicians need to be supported and trained when using innovative technologies as well as how and when is appropriate to recommend these technologies to patients. In particular, greater utilisation of the Accelerated Access Collaborative (AAC) was suggested as a way to expand access to these technologies in order to drive up rates of treatment.



In your view, could more support be offered to patients on a waiting list? If so, what might this support look like?

The APPG heard from a range of patient representatives who outlined the importance of social media groups as a way to interact with others in similar positions. In particular, the way that social media groups allow for the exchange of information and advice, as well as general support, was praised. These groups were often set up by charities, or by specific interest organisations, such as the [Silver Surfers](#).

Overall however, there was broad agreement from a number of respondents that a network of expert patients could be established to provide support to the newly diagnosed as they make their way through the patient pathway. This nationwide regulated HVD patient ambassador network, would be comprised of those who have already gone through a procedure, allowing them to share their experiences with those people about to undergo treatment. These experts could then help to train the next generation and help to ensure that patients are able to pose questions to someone with the same lived

“Since finding out that I had heart valve disease, it has had a big impact on both myself and my family. I have tried to stay positive and open minded about the symptoms I am dealing with now, as well as the heart surgery that is pending.”

Phil Read
Patient with HVD

experience, as well as having access to information online or at their GP surgery. Although witnesses were not certain on the exact process for rolling this out, it was agreed that patient experts would require full training and the scheme should be backed by a national institution, such as NHS England.



What needs to be in place to facilitate shared decision making and helping patients make informed decisions about their treatment that takes into account their personal preferences or individual circumstances?

During the APPG's evidence sessions, a specific point was raised around the work needed to be done to ensure that the various treatment options are fully explained to patients (especially younger patients), and that their wishes are taken on board by secondary care professionals. Patient representatives stressed that they had to undertake a significant amount of independent research, with the British Heart Foundation and Heart Valve Voice websites being identified as specific sources of information. Unfortunately, several patients indicated that their treatment options were effectively decided for them without proper input, and in one case the patient felt that treatment was delayed until they were 60, so that they would be eligible for a tissue valve replacement. In another case, a patient felt they were not offered minimally invasive surgery, despite this being their preferred treatment option. Furthermore, other patients noted that not all treatment and therapy options were discussed with them, including minimally invasive surgery and transcatheter therapies. The use of patient information sources, such as those listed above, helped to combat confusion that patients had regarding certain treatment options offered to them, which sometimes differed from existing UK and European clinical guidance. Experiences did vary however, with other patients indicating that they were actively consulted by clinicians and felt empowered to ask questions and shape their treatment programme. Overall, there was a consensus amongst the group that patient choice was extremely important to them, and that more needs to be done to ensure the views of patients are actively considered and that support is easily accessible.

The importance of MDTs in helping to advise patients regarding treatment decisions, specialist advice and general support was also discussed. MDTs are not mentioned within the draft NICE guideline for HVD presenting in adults: investigation and management, however it was widely accepted that these teams would provide an ideal specialist point of contact for patients between appointments, as they could provide specific knowledge, explaining the different treatment options (surgical, transcatheter, minimally invasive etc.) to patients as well as providing general support. MDTs are crucial for the "sharing" of information and opinions between clinical experts, ensuring a holistic view of the patient pathway and for treatment options to be fully explored, along with their risks and benefits. During the pandemic, virtual MDTs were set up and these should be continued where appropriate, as this more agile approach will allow for faster decision making while services return to normal.



Do current intervention rates (surgical and transcatheter) match the prevalence of the disease? How does the UK compare to other countries, and what inequalities exist?

Respondents to this question pointed out that unfortunately the levels of intervention in the UK do not match the prevalence of the condition, which was mostly due to a lack of, or delayed, detection. It was stated that the level of severe HVD is not fully known, although it is likely to be higher than many suspect. This was demonstrated by the OXVALVE study, which found that "clinically significant (moderate or severe) valvular heart disease (VHD) was newly diagnosed in 6.4% of participants [over the age of 65].

In addition, of the further 4.9% of subjects with pre-existing VHD from the overall study cohort (assuming that moderate or severe VHD would result in a clinical diagnosis), this created a derived total population prevalence of moderate or severe VHD of 11.3%.¹⁷ Extrapolated across the over 65 age group of the UK population and this study indicates a prevalence rate in the hundreds of thousands. However, further research is needed to establish the true prevalence of HVD in the UK.

During the APPG's oral evidence sessions, the group heard from patients who explained that the condition has limited their employment opportunities, their freedom (such as the ability to drive) and has led to debilitating side effects, such as breathlessness and fatigue, that prevent them from leading a full and active family life. All of this is made worse by delays to diagnosis and treatment, and we therefore call on the Government to do more to ensure that patients are able to receive the diagnosis and care they need in a timely fashion. As a way of tackling this, the APPG noted with interest the proposal from the 'Valve for Life' initiative for the establishment of a fast-track pathway. This pathway would be based around the template used for the investigation and treatment of suspected cancer, which would then be applied to the management of severe AS, whether by TAVI or SAVR. The 'Valve for Life' proposal is that centres offer a single common pathway for AS, incorporating surgical or TAVI clinic appointments within two weeks. Following outpatient assessment, patients would be discussed at the heart valve multidisciplinary team (MDT) meeting and undergo valve intervention, where indicated, within a target of 8 weeks in total from referral to treatment.¹⁸ The APPG would support the implementation of such a pathway to ensure optimal outcomes for patients waiting for intervention, be that transcatheter or surgical.

On the issue of geographical variation, witnesses explained that just because an area has low levels of intervention, this does not necessarily mean that access to this intervention is restricted. Instead, it could be that low levels of referral have led to low intervention rates, which therefore demonstrates why a more holistic overview of the patient pathway should be sought when trying to determine the cause of variation. Many respondents gave the example of unequal SAVR, mitral valve procedures and transcatheter rates, which was evidenced in a 2016 study looking at patient access for heart valve disease in the UK. Here it was found that there was significant variation in the number of HVD procedures across England, in 2014 for example it varied by between 6x and 16x from the best to the worst served region. For AVR there were rates between 1.8 and 30.4 per 100,000 (7,043 procedures), including TAVI this was 9940 aortic valve procedures performed in comparison with 44,727 new admissions for diagnosis of aortic valve disease. Similar geographical variation was seen for mitral valve procedures (between 1.3 and 11.8 procedures per 100,000 population, a total of 3851 surgeries) and a similar increase in the number of new admissions for mitral valve disease.¹⁹



Surveillance

The established processes for ensuring safe outpatient surveillance of patients with known HVD not currently requiring intervention, is echocardiography. An echocardiogram, cardiac echo or simply an echo, are terms used to describe an ultrasound imaging investigation of the heart.²⁰ An echo may be requested by a heart specialist (cardiologist) or designated healthcare professional, with the test usually being carried out at a hospital or clinic by a cardiologist or a trained specialist (cardiac physiologist).

HVD and specifically aortic sclerosis, is present in up to 25% of adults over the age of 65 years with progression to severe AS within seven years in about 16%.²¹ It is therefore important to ensure ongoing surveillance so that potential progression is identified early.

Recent guidelines suggest that patients with mild AS can be reviewed infrequently (up to every five years). Those with a higher degree of AS should be kept under more frequent review. However, there is currently a lack of agreement between national and international guidelines on the best surveillance frequency for HVD. This is because the evidence base does not exist for this and there is also a lack of cost-effectiveness analysis in this field. Given this challenge and lack of agreement, the APPG asked the following questions to participants at the oral evidence sessions and to those supplying written evidence:



Where intervention (surgical or transcatheter) is not currently indicated, what is the most clinically and cost-effective surveillance, with respect to:

a Frequency of echocardiography or clinical review?

In response to this first question, healthcare professionals explained that each heart valve requires surveillance at a different frequency rate, and that as a result, detailed information should be provided to cardiac departments to ensure that each patient is being assessed at optimal intervals. Anecdotal evidence was provided that patients who have been diagnosed with moderate HVD are often not provided with adequate monitoring information. They also agreed that the two most important areas where more detailed information should be provided to patients was regarding their surveillance regime post-intervention, as well as a list of reliable sources that patients could use to seek answers to specific questions they may have.

Surveillance gives confidence to patients and allows for early detection of any deterioration which will then indicate more frequent surveillance or earlier intervention. Further research is needed in this area and as such, the APPG welcomes NICE's key recommendation for research into 'monitoring where there is no current need for intervention', as part of its draft guideline on HVD presenting in adults: investigation and management.²²

Once a firm evidence base is established however, it will be important to update guidelines around the frequency of undertaking echocardiographic surveillance of asymptomatic AS, as currently they are often ambiguous and conflict with one another, meaning that it is difficult for healthcare professionals to follow.²³ In fact, 'When should heart valve intervention occur in asymptomatic patients?' is the fifth national priority in UK cardiac surgery research set by the recent 'James Lind Alliance Adult Cardiac Surgery Priority Setting Partnership' led by The University of Leicester.²⁴ Unambiguous guidance is needed to minimise variation in the quality of care received, while providing a clear framework to maximise the impact of investigations.²⁵

b Where intervention (surgical or transcatheter) has already been undertaken, what is the most clinically and cost-effective means of future surveillance?

As with the question above, current practice is variable and depends on patient factors, such as co-morbidities, other cardiac disease or previous heart surgery, as well as the type of procedure performed (repair or replacement). Follow up also depends on the type of valve used for a replacement, with a biological valve anticipated to show some structural degeneration after ten years.²⁶

In response to this question, some respondents to the APPG's call for evidence suggested that over the next decade it would be prudent to facilitate the linkage of registry data, which currently record valve intervention procedures and short-term outcomes, to national routinely collected data e.g. primary care data, Health Episode Statistics (HES) data or Death Registry data. This would enable us to understand the impact of interventions over a lifetime for the patient and the entire health service, allowing for an in-depth assessment of clinical and cost effectiveness.

Elsewhere, studies have been undertaken into the establishment of AS surveillance clinics in the UK and the impact they may have in a district general hospital setting in terms of capacity and patient outcomes. Here it was found that it resulted in a modest reduction in patients attending the cardiology out-patient department. The new system was also found to be more clinically efficient, which will likely lead to cost-efficiencies, as it negates the need for a formal cardiology clinic review, saves consultant time, standardises care and potentially reduces the number of echocardiograms requested.²⁷

The issue of regional variation was subsequently brought up again, this time regarding the number of GPs with a special interest in cardiology. It was noted that even where patients do not need to be referred for interventions, ensuring that specialist GPs are responsible for the management of the condition is an excellent way to ensure that patients are referred at the optimal time. Once referral has occurred, heart valve clinics were offered as a key example of how clinical nurse specialists and physiologists can take on additional responsibilities, by running these clinics and ensuring that pressure can be taken off surgeons and other consultant specialists. It was suggested that in future these valve clinics should establish stronger links between the patient's GP and valve surgeon, to ensure a joined-up monitoring process. It should be noted though that according to a 2015 British Heart Valve Society survey, dedicated heart valve clinics were only present in 11% of district hospitals and 60% of cardiac centres,²⁸ highlighting once again the impact of geographical variation.

Overall, the APPG welcomes NICE's key recommendation for research into 'monitoring after an intervention', in its draft guideline on HVD presenting in adults: investigation and management.²⁹



"All in all, I'm just incredibly thankful to my Cardiologist and everyone in our incredible NHS for everything they did for me. Both in terms of my surgery and their comfort and support. They were simply amazing. I could not fault a single thing about my experience in the hospital. I don't even have the words to say to describe the work they do for us"

Angie Martin
Patient with HVD

Information and Support

A key pillar of the NHS Long Term Plan is person-centred care, with the NHS 'recognising – as National Voices has championed – the importance of 'what matters to someone' is not just 'what's the matter with someone'.³⁰ As part of this, communication between patients and healthcare professionals is paramount. Patients require a clear understanding of their disease and the reasons that treatment or no treatment has been prescribed. This includes: the timing of surveillance; guidance on medication, dental care, and general cardiovascular fitness; individual advice on the feasibility of exercise – based on their specific condition and their favoured activities; as well as knowledge of potential triggers to treatment and red flag symptoms. Here the APPG asked the following question to participants at the oral evidence sessions and to those supplying written evidence:



What information, advice and educational materials could (a) the NHS; (b) charities and patient groups; and; (c) pharmaceutical and MedTech industries; provide that would be useful to adults with HVD, their family and carers?

NHS

From our evidence sessions, the APPG found that there was variation in the quantity and quality of information materials received by patients from the NHS. Patients explained that information about their disease mostly consisted of a few informative leaflets and verbal advice. They noted that it would be useful to receive more written information, so that this can be shared with friends and family. It was also found that the information they received needed to be updated on a regular basis. One patient representative found that information available to younger patients was significantly lacking and that more thought should be given to ensuring that all age groups are adequately considered by the NHS and charitable organisations when drafting patient guidance. In addition, for ease of access, this information should ideally be contained within one place on a specialist HVD website, as many patients found that they spent considerable time searching for the right information for them.

The APPG also heard from healthcare professionals who outlined that modern technology, such as specialist apps should be considered as an effective way to relay patient information, and it was proposed that this could include a series of "red flag" symptoms that patients and their families would need to alert their GP to in the future.

It was also stressed that the first point of contact for HVD patients is often their GP surgery, and so it was emphasised that more high quality information needs to be provided in primary care settings. Others noted that it is important that patients get the option to meet a cardiac surgeon to discuss options, as frequently patients are anxious about surgery and are influenced by TV, social media, friends and other clinicians. There is also confusion around the multiple options for treatment, so the opportunity to meet a surgeon, prior to making a decision, is often very useful.

Charities and patient groups

The need for a well-informed, confident patient population was also stressed as a contribution towards the delivery of optimal care. Two types of patient information were noted as being crucial to achieving this: information from healthcare professionals, and information developed by fellow patients on their lived experience with the condition. Heart Valve Voice was praised as being a useful source for both types of information, which helps to ensure that patients receive well rounded guidance, not only on their

treatment options, but also on how HVD can impact their everyday life. Ensuring that the information received by patients can be easily understood was also noted as being vital, as well as making sure that the right information can be accessed at the right time within the patient pathway. It was also acknowledged that health is the number one concern for people over 50 but their willingness to use the internet to access information on conditions, such as HVD, is often underestimated. The CEO of Silver Surfers gave examples of Facebook live sessions hosted with doctors that received a great deal of interest from the over 50s demographic.

Overall, a consensus emerged that patients have a thirst for knowledge and it is the role of the NHS and charities to ensure that this multidisciplinary information is brought together for patients, their families and carers to utilise as they see fit.

MedTech industries

Respondents, both from the written and oral evidence sessions, agreed that it was the responsibility of MedTech industry partners to collaborate with the NHS and charities in order to enable them to continue to do what they do best in supporting patients. In particular, the work of the British Heart Foundation and Heart Valve Voice were praised, and it was noted that industry continues to have a good supportive relationship with these charities and others.

Mental health

Patient representatives confirmed that the process and the pandemic had had a significant impact on their mental health, with one patient noting that they had "really struggled" due to delays in treatment. This feeling was exacerbated by the condition meaning that they were unable to be prescribed antidepressants by their GP. Patients also reported that they often had to fight "tooth and nail" to access rehabilitation services, a factor that also had a debilitating impact on their mental health. This impact however was often not realised until after support had been received, and patients noted that the fact this experience was shared by so many, indicated that more needed to be done to address this lack of access.

The APPG notes that the draft NICE guideline on HVD presenting in adults: investigation and management, calls for psychological support to be offered to people with heart valve disease, whether or not they have symptoms. Many of the patient representatives the APPG heard from during the oral evidence session stated that the treatment and diagnosis had a significant impact on their mental health. Given that this experience was shared by many patient representatives the APPG heard from, this suggests that more needs to be done to address the ease of access to these services.

The pandemic has shown how virtual networks including social media and video conferencing can be an effective means of communicating, sharing experiences and building community. Whilst this has significant benefits, there remains a challenge to ensure that the information shared on these platforms is evidence based, accurate, and not unduly influenced by industry or other third parties who may have conflicting interests. As such, to ensure that patients know which sites to trust, it could be worth exploring the 'kite marking' of sources of information, which is being explored by the Patient Information Forum.³¹

Overall, the APPG found a real willingness from patient representatives and those involved in patient support to be more involved in their own care. To help support this, information should be provided via a range of sources, including face-to-face communication, telephone consultation, as well as written and online materials. Furthermore, where appropriate, these materials should be provided in a range of languages to ensure that hard to reach groups can also access necessary information related to their condition. There should also be greater alignment between the NHS, charity and industry in supporting patients.

"I am determined to live my life after heart valve disease treatment to the full, and celebrate the power of positive ageing. In the 2 years since I was treated, I've gone back to work, I've abseiled down the hospital I was treated in for charity, gone to testing events to educate others on the symptoms, and I've spoken to hundreds, if not thousands, of people about the condition. I'm proud to give back to the people who gave me this new lease of life."

Alison Banayotti
Patient with HVD



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