



All-Party Parliamentary Group Report

Summary of Recommendations



The views and recommendations expressed in this document 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 document 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 recommendations expressed in this document have come from 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.

The APPGHVD is supported by Heart Valve Voice from grants provided by Edwards Lifesciences, Medtronic and Boston Scientific. These funding sources support the APPG's Secretariat, Four Communications, who provide administrative assistance in the preparation and publication of this document.



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 Heart Valve Disease (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

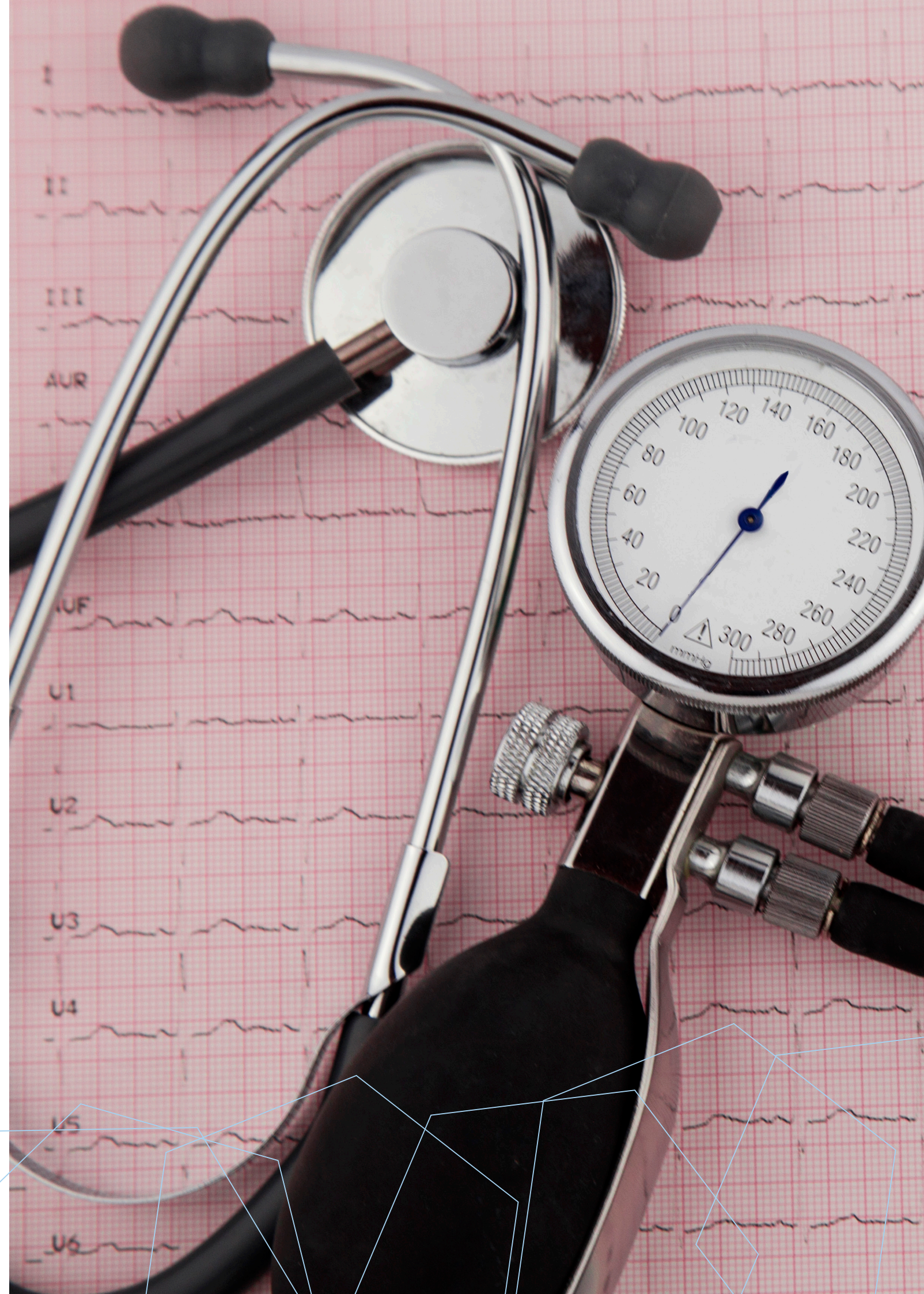
- To fully assess inequalities in access to a community based optimal pathway and variable rates of treatment, an independent report should be commissioned into health inequalities, using Hospital Episode Statistics and National Institute for Cardiovascular Outcomes Research data.
- The National Institute 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, 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 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.



