

Paving the way: a roadmap to the successful implementation of shared decision-making in heart valve disease





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Foreword

Heart valve disease (HVD) is a common, serious but treatable condition which is particularly associated with ageing. It is the name given to any malfunction or abnormality of one or more of the heart's four valves, affecting the flow of blood through the heart.

People who are diagnosed with HVD are often presented with different treatment options, and decision-making can be complex. In 2021, the European Society of Cardiology (ESC) and the European Association for Cardio-Thoracic Surgery (EACTS) released *Guidelines for the management of valvular heart disease*, which included clinical practice guidance on shared decision-making. Following this, Global Heart Hub released a patient guide in 2022, *Shared decision-making for people with heart valve disease*, to support people with HVD in participating in decision-making about their care. The guide empowers patients to express their goals and treatment preferences to their care team. However, too often this does not take place, and more work is needed to help drive effective implementation of shared decision-making.

In August 2023, Global Heart Hub convened an in-person roundtable to find solutions for successful implementation of shared decision-making in HVD. The event brought together 19 experts from around the world representing all heart team stakeholders, including people with HVD and patient organisations, surgeons, cardiologists, researchers and nurses. It was co-chaired by leading patient advocate Sandra McGonigle and leading cardiovascular nurse Dr Sandra Lauck.

The roundtable formed the basis for this consensus-driven roadmap, and we are grateful to these experts for their invaluable contributions throughout this project. By aiding the facilitation of shared decision-making, these contributions will make a real difference to people's quality of life.

Following the roundtable, Global Heart Hub, in partnership with The Health Policy Partnership, developed this global roadmap to support patient organisations and other advocates, including healthcare professionals and researchers, in driving shared decision-making best practices for people with HVD in their countries. This roadmap will help improve patient access to shared decision-making by addressing the perceived barriers. The roadmap highlights the need for a gold standard for shared decision-making in HVD as there is currently no standardised model available at the national or international level.

We know that shared decision-making in HVD has huge benefits for people with the condition. It aims to ensure that the person feels fully supported to make treatment decisions that are right for them, and it has been shown to improve their satisfaction, quality of life and other meaningful outcomes. We hope this roadmap will provide patient organisations and other advocates with the power and guidance to make shared decision-making a reality for all people living with HVD in their countries and settings.

Ellen Ross

Managing Director, Heart Valve Voice Canada, and Chair, Heart Valve Disease Patient Council, Global Heart Hub

About this roadmap

Despite recommendations in several valvular heart disease clinical guidelines across the globe,^{1,2} too often, people living with heart valve disease (HVD) are still not being optimally involved in conversations about their treatment options and preferences.^{3,4}

This global roadmap is the result of consensus recommendations made by an international group of people with lived experience of HVD, multidisciplinary clinicians, researchers and policymakers. It aims to support patient organisations and advocates to work with other key stakeholders and partners, such as Global Heart Hub, to drive effective implementation of the roadmap in their different countries and settings.

Noting the need for action at both the international and local levels, the roadmap outlines five key areas for united international action and six local calls to action within four themes.

They target several areas that were found to be critical for improving access to high-quality shared decision-making in HVD:

Global areas of focus

- A common understanding of the components required to constitute quality shared decision-making
- Data and research on the effectiveness of shared decision-making and interventions to facilitate it
- A heart team/multidisciplinary care approach within all cardiac disciplines, including HVD
- Incorporation of shared decision-making into health policies
- Partnerships with key stakeholders

Accelerating change at the local level: calls to action

Preparing patients

- **Local call to action 1:** Develop comprehensive and accessible local-level patient information materials on shared decision-making in HVD

Developing and implementing patient decision aids

- **Local call to action 2:** Identify and develop patient decision aids for use by people living with HVD and their healthcare providers

Training healthcare teams

- **Local call to action 3:** Improve training and competencies in shared decision-making for healthcare professionals

Creating a supportive system

- **Local call to action 4:** Seek to include a distinct step(s) within local HVD patient care pathways where the individual's preferences, values and priorities can be understood and captured
- **Local call to action 5:** Encourage investment in research to identify and scale-up best practices for shared decision-making in HVD
- **Local call to action 6:** Push for the adoption of novel funding or reimbursement models in healthcare to help shift the culture of care from procedure-driven to person-centred

Each local call to action is presented in context and offers recommendations on key partnerships, key objectives and potential outcome measures.

The content is designed to be applicable across different countries and health systems; however, practical applications may vary depending on context.

The roadmap is designed to support patient organisations and advocates who wish to implement shared decision-making for people facing HVD treatment options. It does not provide decision support for people with HVD contemplating their treatment options. Please refer to *Shared decision-making for people with heart valve disease: a patient guide* for more information on this.⁵

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The vital role of shared decision-making in heart valve disease

What is shared decision-making and what are its benefits?

Shared decision-making is a two-way process between a person receiving care and healthcare professional(s) which aims to ensure that the person feels fully supported to make treatment decisions that are right for them. It involves an exchange between the healthcare professional(s) – who share information about the condition, treatment options, and the associated risks and benefits of each – and the affected person, who shares their preferences, values and goals.^{3,6} It goes beyond informing and educating a person on their condition; it involves working together to reach consensus on the most suitable treatment for them.⁶ A quality decision is one that is informed and based on what is most important to the person.

Shared decision-making has been shown to have several benefits, especially in terms of improving patient outcomes and experiences, such as increased knowledge, reduced uncertainty around choosing treatment options and greater satisfaction with care.⁷

Decision-making in heart valve disease (HVD) is often complex. People diagnosed with HVD may be eligible for different treatment options, depending on their risk profiles, the severity of their condition and other potential chronic conditions they may be living with.^{3,8} Most treatment options involve a device, to either repair or replace the diseased heart valve(s), alongside medication and routine follow-up. This makes the decision around treatment options more significant, as valve repair or replacement cannot be reversed in the same way as starting new medications. Each option is associated with risks and benefits. For example, recovery periods and durability can vary by treatment option, impacting a person's return to physical function, quality of life and ability to regain independence.⁸ Moreover, HVD requires lifetime management and the consideration of future treatment options.

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It goes beyond informing and educating a person on their condition; it involves working together to reach consensus on the most suitable treatment for them.



As the number and complexity of HVD treatments continue to increase, shared decision-making can be used to help people facing a new treatment decision navigate the various options that may be appropriate for them. With shared decision-making, the individual is empowered to make an informed decision on their treatment, based on their own preferences, personal circumstances and recommendations from their healthcare provider. For example, older adults who may have additional chronic conditions and various degrees of frailty might have different goals from those of younger adults who are working, have family or other social responsibilities, and are potentially facing subsequent treatments; different people may therefore have different objectives of care and benefit from different discussions and treatment choices.⁸ Shared decision-making can relieve the individual of the burden of wondering whether they have made the right decision.

Shared decision-making is increasingly recognised and recommended within clinical practice guidelines. In the most recent European Society of Cardiology (ESC) and European Association for Cardio-Thoracic Surgery (EACTS) *Guidelines for the management of valvular heart disease*, published in 2021, the importance of shared decision-making and patient engagement is highlighted throughout.¹ Similarly, the 2020 American College of Cardiology (ACC) and American Heart Association (AHA) *Guideline for the Management of Patients With Valvular Heart Disease* outlines that the individual's values and preferences, as well as the risks and benefits of each treatment option, need to be discussed when considering suitable interventions or surgery.²

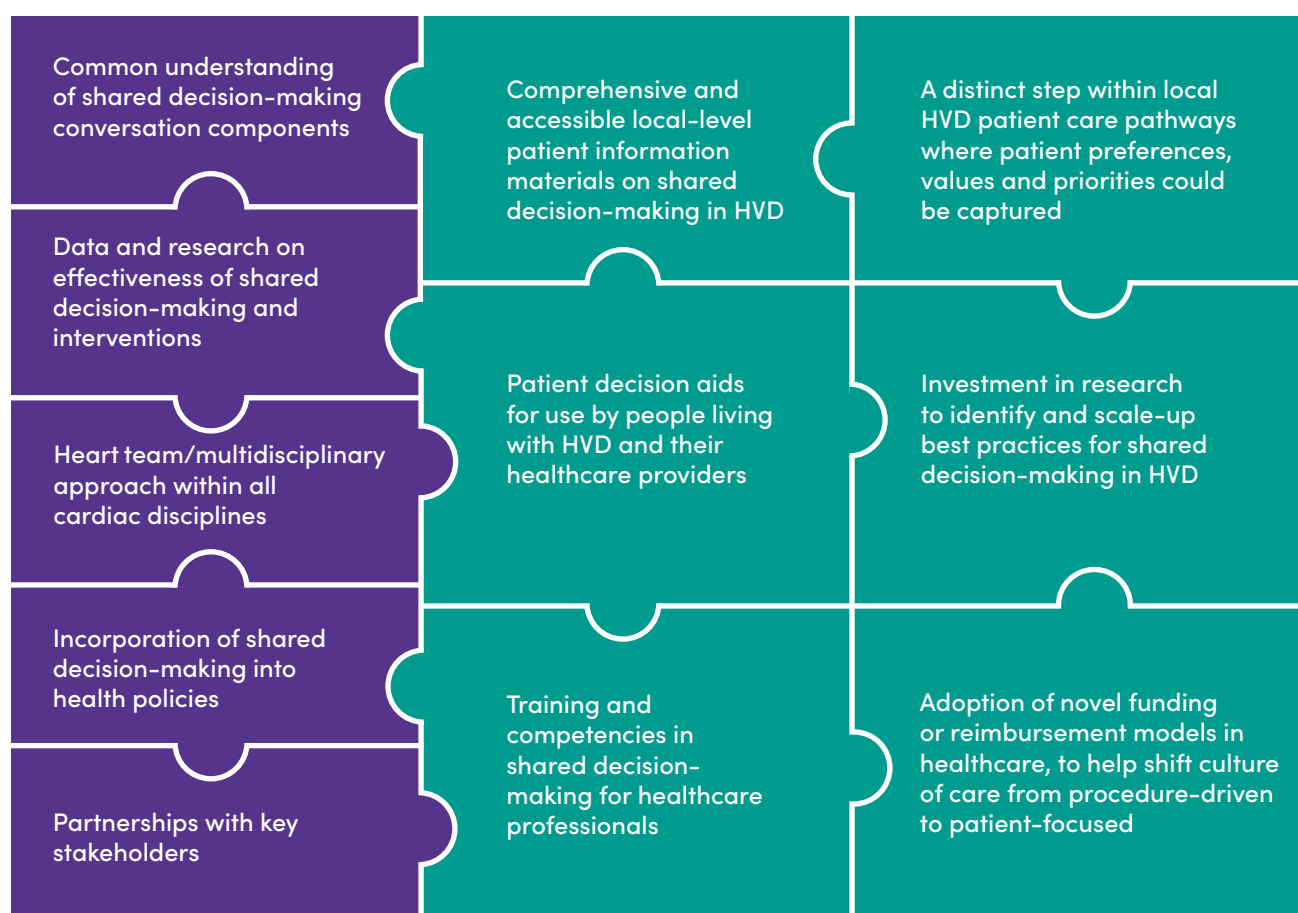
However, uptake of shared decision-making in routine practice has been slow, and too often does not take place at all. This is despite evidence of improved patient outcomes for people living with HVD.³ A recent survey of people with HVD in Austria and Germany found that only around half had been involved in discussions about the different treatment options available to them.⁹

Building a picture: what is needed to successfully implement shared decision-making in heart valve disease?

Shared decision-making represents a cultural shift in healthcare. To move the needle in the right direction, actions and steps taken now at both the international and local levels will pave the way towards global implementation of shared decision-making in HVD.

Given this context, and in close consultation with the 19 experts, we identified five key areas for united international action and six local calls to action (Figure 1).

Figure 1. Global and local actions needed to drive implementation of shared decision-making in HVD



● Global actions ● Local actions

Global areas of focus

The five global areas of focus require united advocacy and movement at local, national and international levels. They seek to address issues that continue to be faced by many countries when working towards improving people's access to shared decision-making. Progress made within these areas will help ensure advancement towards the implementation of shared decision-making in HVD.

A common understanding of the components required to constitute quality shared decision-making

One of the biggest challenges in implementing shared decision-making is the lack of a common understanding or definition of what it should involve. Shared decision-making is an invitation for people receiving care to be actively engaged in an informed conversation and a collaborative process with their healthcare professional(s) to reach a joint decision about care.

It goes beyond patient education and acknowledges important forms of expertise such as the healthcare professional's knowledge of the condition, prognosis, treatment options and possible outcomes; and the person's expertise, informed by the impact of their health condition on their daily life, their values, and their preferences for outcomes.

For example, the Stiggelbout framework outlines four steps to a shared decision-making conversation:¹⁰

1. The healthcare professional informing the person that a decision needs to be made and that their opinion is important and valued
2. The healthcare professional explaining available treatment options and their pros and cons
3. A discussion between the healthcare professional and the person receiving care regarding the person's preferences
4. A discussion between the healthcare professional and the person about whether or not the person wants to make the decision, after which they either make or defer the decision

Shared decision-making supports a person's ability to provide informed consent, which is an ethical and legal 'contract' that seeks to obtain a person's permission to proceed with treatment. Thus, significant efforts are required to expand the understanding of shared decision-making beyond simple 'information giving' and the signing of consent.¹¹



Data and research on the effectiveness of shared decision-making and interventions to facilitate it

At present, there is no single established or standardised model for the integration of shared decision-making in HVD available for hospitals or other care settings to adopt. To take the necessary steps towards implementation, it will be important to generate rigorous data to:

- **identify effective implementation strategies**, in terms of how to make shared decision-making work in routine clinical practice and ensure that it can be tailored to diverse settings and disciplines
- **evaluate the effectiveness of shared decision-making interventions** and demonstrate their impact. For example, the Institute for Healthcare Improvement's 'quintuple aim' principle speaks to the importance of showcasing improvements in patient experience, patient-reported outcomes (e.g. quality of life) and patient decision-making outcomes, clinician experience, health system outcomes (such as costs and resources), and health equity.¹² These are all useful to consider when thinking about how to measure and evaluate effectiveness.

Any research into the above needs to be underpinned by measurable quality indicators that are agreed at an international level. These will be beneficial for benchmarking performance, for understanding incentivisation and when making the case to decision-makers for investment in or funding for shared decision-making models and interventions.

A heart team/multidisciplinary care approach within all cardiac disciplines, including HVD

Adoption of the heart team approach for the treatment of HVD is uneven across regions. It is important to continue advocating for this best-practice approach as an integral part of the HVD care pathway, as it has been shown to improve prognosis.¹³ The ideal structure and composition of a heart team have been widely discussed in literature and may include, but are not limited to, cardiac surgeons, cardiologists, interventional cardiologists, imaging cardiologists, specialist nurses and heart team coordinators.¹⁴

Incorporation of shared decision-making into health policies

Shared decision-making should be viewed as a fundamental right of people receiving care; it is a critical aspect of all healthcare interactions and, as such, it needs to be incorporated within national and international health policies. This challenging and long-term goal will require patient advocates to come together to engage with policymakers and decision-makers and explore ways in which this can be done – legislatively, within funding models, and/or in existing or upcoming health policies and strategies.

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At present, there is no single established or standardised model for the integration of shared decision-making in HVD available for hospitals or other care settings.

Partnerships with key stakeholders

The kind of change required to make a difference for people living with HVD is dependent on a collective effort and strong collaboration between multidisciplinary experts. International and national partnerships with like-minded individuals who are passionate and motivated to push for the implementation of high-quality shared decision-making across all cardiac disciplines, including HVD, will be instrumental, as there is significant and varied expertise to draw on, and learnings and best practices can be shared. Stakeholders might include:

- patient representatives, including people living with HVD
- heart patient organisations
- clinicians e.g. HVD heart team representatives, professional cardiac societies
- researchers with expertise in implementation science and shared decision-making
- health system leaders and decision-makers
- hospital administrators.

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Accelerating change at the local level: calls-to-action

Movement at the local level is critical – whether that is national, regional or provincial. The six local calls to action highlight the key steps that need to be taken towards the implementation of shared decision-making in HVD. Heart patient organisations should seek to work in collaboration with several stakeholder groups and bodies to push these strategic priorities forward.

Preparing patients

Access to high-quality information about HVD is crucial to strengthen the integration of shared decision-making. A person who is equipped with knowledge about their disease and their treatment options is more likely to feel empowered when there is an opportunity to engage in shared decision-making with their healthcare providers. This is important for ensuring people living with HVD feel prepared and are fully aware of the next steps in their care.

The development of such materials should be a collaborative effort between people receiving care and clinicians. This is essential to prioritise the appropriate level and tone of content desired by people living with HVD while also ensuring any clinical information is communicated properly and accurately reflects the national HVD care pathway.



Local call to action 1

Develop comprehensive and accessible local-level patient information materials on shared decision-making in HVD

Patient organisations are recommended to work collaboratively with:

HVD clinicians and researchers (desirable: national multidisciplinary cardiac societies); communication specialists

Key steps:

- 1) Develop dedicated patient information materials for people living with HVD to help them engage in shared decision-making in line with local context and cultures.
- 2) Ensure the HVD patient information materials are of high quality, with language accessible to patients and reflecting cultural appropriateness. They should be available in both print and digital format, with audio-visual elements and text translated into all local languages and made available in English if sharing for wider publication.
- 3) Disseminate the HVD patient information materials to community cardiologists and other primary care providers, hospitals and other clinical settings where HVD care is provided and encourage them to share the materials with people living with HVD.
 - a. These materials should be made available to people with HVD at a minimum of two key stages of the care pathway: following diagnosis of HVD and while awaiting treatment (prior to an appointment where treatment options would be discussed with their healthcare provider).
- 4) Guarantee that all HVD patient information materials are periodically updated as new evidence and treatment options emerge over time.

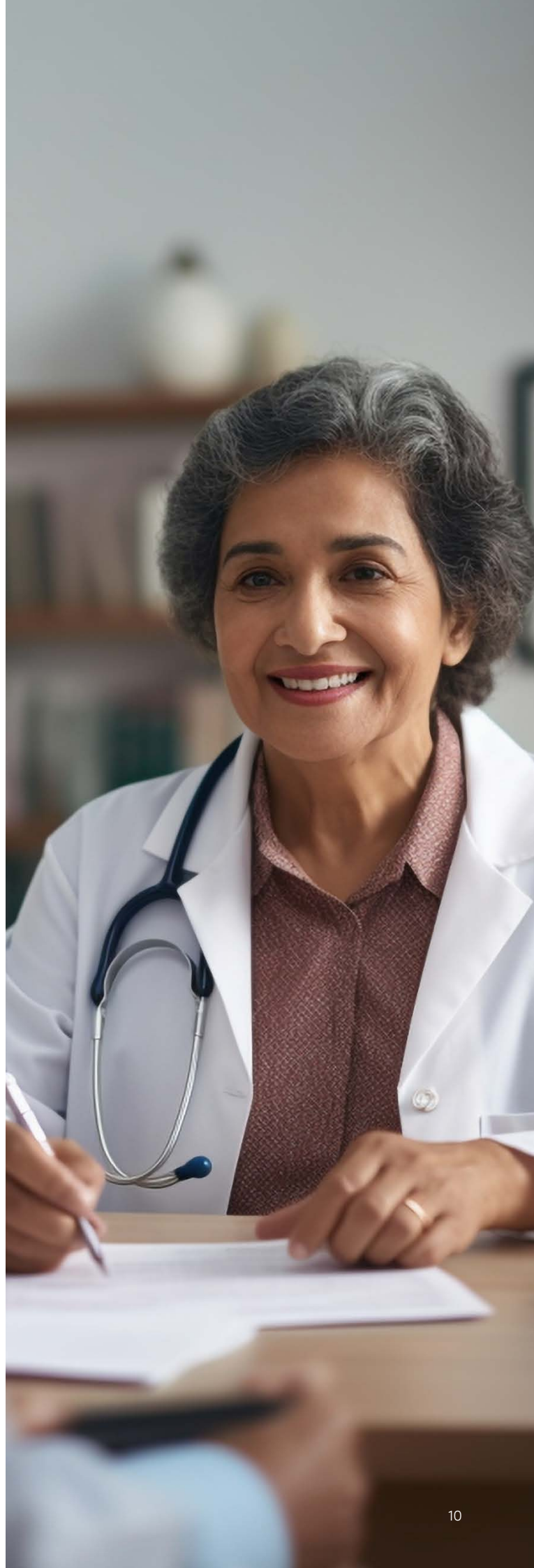
Ways to measure impact:

- Track digital and paper use of the patient information materials.
- Distribute surveys:
 - among people with HVD to measure patient-reported outcomes and find out: whether they are receiving the information materials at the key stages, whether they find them useful and have felt improvements to their care experience, and if there is any additional information they would find useful.
 - among HVD healthcare professionals to ascertain whether they feel the patient information materials have been helpful in enabling more informed conversations during consultations.

Key considerations

The patient information materials should be tailored to the national or local health system and structures, and should aim to include information on:

- the condition and disease progression
- the typical HVD care pathway
- treatment options, including short- and longer-term risks and benefits, as well as guidance on whether certain treatments are not available e.g. due to the type of HVD, individual risk profile, reimbursement or coverage of health insurance
- what support might be required before or after treatment e.g. from local healthcare providers or the person's loved ones
- recovery and rehabilitation
- what life might look like after treatment and lifetime management
- questions or issues to consider during discussions with the person's designated healthcare professional
- local support groups or moderated forums for people with HVD.





Developing and implementing patient decision aids

Patient decision aids, or decision-support tools, help people to make decisions about their healthcare options. They are designed to inform conversations and enhance shared decision-making between a person receiving care and a healthcare professional. They usually outline evidence-based information on treatment options and potential outcomes, benefits and risks, with the aim of supporting a person to think about what matters to them most when deciding on their preferred treatment, including whether to have treatment at all.^{15 16}

These tools can be particularly helpful for people living with HVD, who may have varied goals of care and benefit from different treatment choices. Decision aids acknowledge the importance of key elements in decision-making such as support, realistic expectations and value-based choices. Research has also shown that the use of patient decision aids can lower decisional conflict and improve communication between the person receiving care and healthcare professionals.^{17 18}

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Patient decision aids, or decision-support tools, help people to make decisions about their healthcare options.



Local call to action 2

Identify and develop patient decision aids for use by people living with HVD and their healthcare providers

Patient organisations are recommended to work collaboratively with:

HVD clinicians (desirable: national multidisciplinary cardiac societies); HVD researchers with expertise in implementation science and shared decision-making; communication specialists; hospital/organisation administrators

Key steps:

- 1) Develop high-quality patient decision aids that reflect the best contemporary evidence and can be readily used by diverse populations e.g. ensuring they are reflective of the local context and cultures, and available in appropriate formats with translations into all local languages.
- 2) Explore how patient decision aids could be incorporated and used across the HVD care pathway, by patient organisations and within clinical processes.
- 3) Engage with hospitals and all care settings where HVD care is provided to encourage use of the decision-support tools as a core tenet.

Ways to measure impact:

- Track usage of the patient decision aids.
- Distribute surveys:
 - among people with HVD to measure patient-reported outcomes and find out: whether they are using the patient decision aids, whether they find them useful and have felt improvements to their care experience, and if there is anything else they would find helpful to reach a decision about treatment.
 - among HVD healthcare professionals to ascertain whether they feel the patient decision aids have been helpful in engaging with shared decision-making.

Key considerations

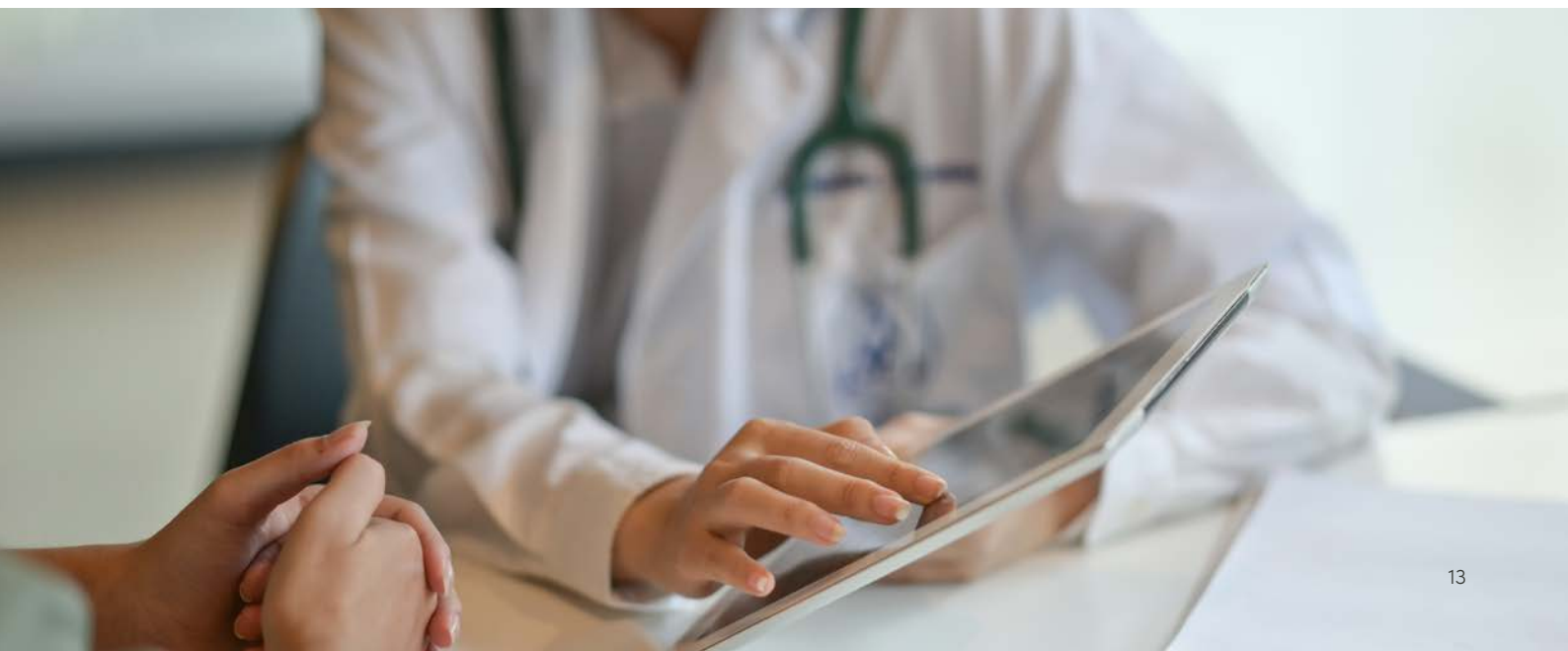
- People living with HVD may find decision aids useful to use before, during or between consultations, depending on how their HVD care pathway is structured.
- Potential qualifying criteria for patient decision aids could include that they:
 - identify the target audience
 - describe HVD as a health condition
 - recap the treatment options and include active surveillance and medical management within that
 - explicitly state the decisions that might be under consideration for the person receiving care
 - help people with HVD clarify what matters to them most in terms of outcomes of the various treatment options.

Training healthcare teams

Healthcare professionals may benefit from more training and guidance on how to engage people with HVD in a shared decision-making conversation.

Healthcare professionals interviewed for this roadmap reported that they believed shared decision-making was an important goal but felt limited by uneven knowledge and competencies to engage effectively in such conversations. The importance of shared decision-making was not an area they had frequently encountered in learning, and this topic was rarely featured

as a key component of the curricula for undergraduate or postgraduate programmes, in on-the-job training or as part of materials developed by professional cardiac societies. Healthcare professionals highlighted the need for tools, direction or advice on how to effectively invite people with HVD into a shared decision-making process, ascertain their preferences and convey complicated information to them in an easily understandable format to ultimately reach a high-quality recommendation/decision.





Local call to action 3

Improve training and competencies in shared decision-making for healthcare professionals

Patient organisations are recommended to work collaboratively with:

HVD clinicians (desirable: national and regional multidisciplinary cardiac societies); local educational bodies and clinical bodies responsible for education standards; universities

Key steps:

- 1) Explore how shared decision-making could be incorporated into the undergraduate and postgraduate training curricula as an essential standard in which healthcare professionals must demonstrate competence. Use any relevant case studies to showcase how this could work.
- 2) Investigate the opportunities to incorporate shared decision-making into continuing professional development competencies or scientific meetings, demonstrating that shared decision-making skills and competencies are an essential part of the framework for good clinical practice. Use any relevant case studies to showcase how this could work.
- 3) Identify what guidance could be developed for healthcare professionals that is closely aligned with the HVD clinical practice guidelines in your country/locality that would support healthcare professionals to offer shared decision-making and push for its development.

Ways to measure impact:

- Track the number and type of meetings/conversations with local educational and clinical bodies regarding the incorporation of shared decision-making into undergraduate/postgraduate curricula/competency standards. For example, are the conversations becoming more fruitful? Are you having more conversations year on year? Are any commitments being made?
- Monitor updates on whether shared decision-making has been incorporated into undergraduate/postgraduate curricula, continuing professional development competencies and scientific/professional meetings.

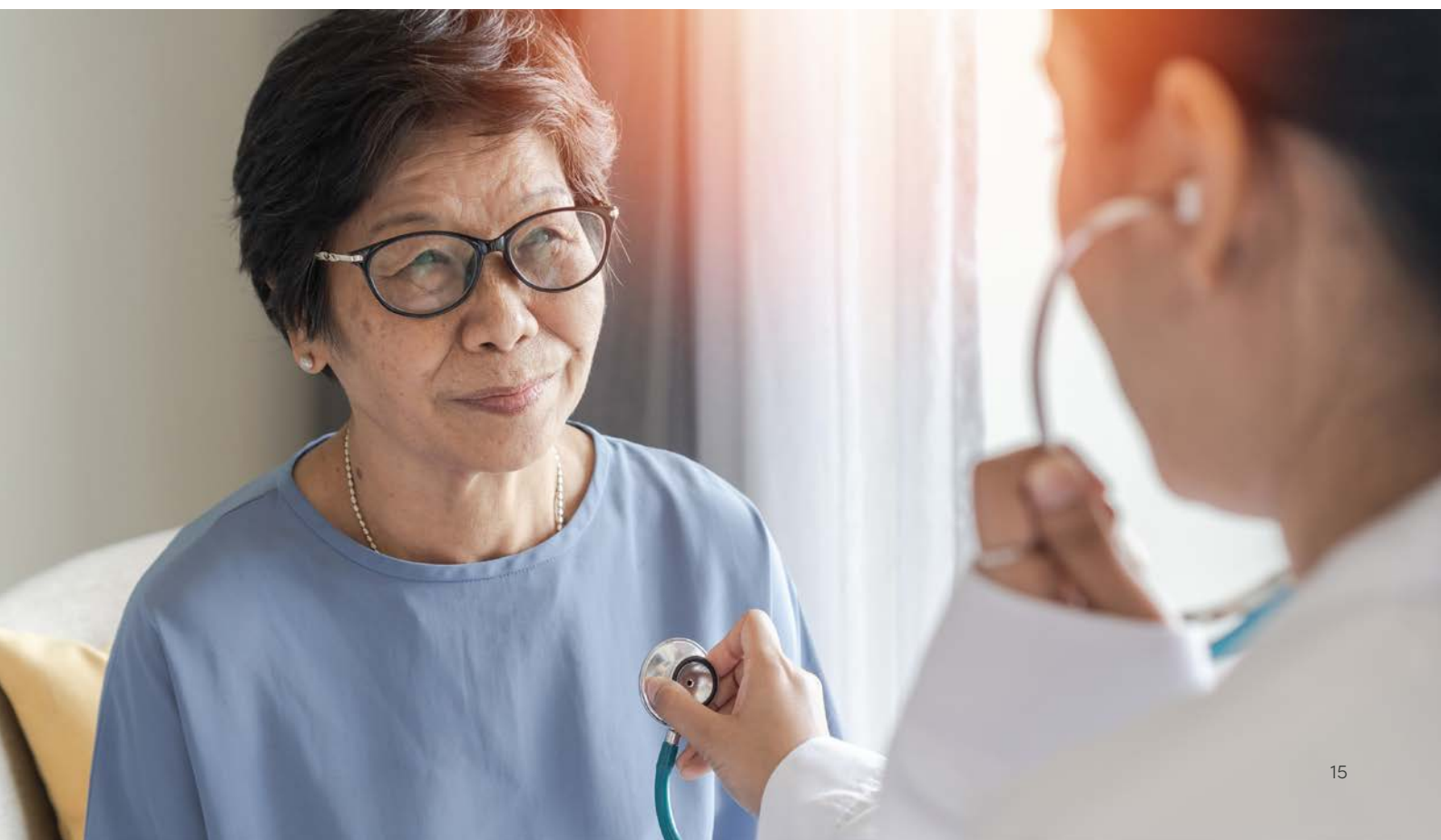
Key considerations

- It is important that any supporting guidance for healthcare professionals is developed within or adapted for the country of use, to understand nuances around health literacy, language and culture. Such guidance should be co-developed by end-users including people living with HVD, healthcare professionals and other stakeholders to ensure all relevant perspectives are integrated.
- To be effective in their shared decision-making practice, clinicians must learn more about and understand gender and cultural differences that may play a role in people's attitudes towards shared decision-making.¹⁹
- Given that HVD is more prevalent among the older population, resources on how to have meaningful conversations about surgery with older people living with frailty and coexisting conditions may also be useful.²⁰

Creating a supportive system

It is essential to have system enablers that allow for the successful implementation of shared decision-making in HVD. This includes care delivery models, the health workforce, better data and research, and funding models to ensure that shared decision-making is reimbursed and/or incentivised by the health system.

It is not realistic to aim to fix the entire system. However, in order to work towards the end goal where everyone living with HVD has access to shared decision-making, we need to start somewhere and there are several areas to focus on.





Local call to action 4

Seek to include a distinct step(s) within local HVD care pathways where the individual's preferences, values and priorities are understood and captured

Patient organisations are recommended to work collaboratively with:

HVD clinicians (desirable: national multidisciplinary cardiac societies); researchers with expertise in implementation science and shared decision-making; local health bodies responsible for care pathways/provision of care

Key steps:

- 1) Aim for general agreement that the individual's preferences, values and priorities will be elicited ahead of decision-making about HVD treatment and integrated into the final decision.
- 2) Identify how this could work and be implemented across the entire HVD care pathway e.g. through additional consultations with healthcare professionals such as those within nursing, cardiology, cardiac surgery and primary care.
 - a. It will be necessary to think about what is needed for effective implementation e.g. whether guidelines/care pathways need to be updated to reflect any agreed changes; what training might be needed to ensure shared decision-making is performed effectively; how the information could be made accessible to the multidisciplinary heart team and/or the individual's local cardiologist.

Ways to measure impact:

- Track the number and type of meetings/conversations with local bodies regarding the incorporation of shared decision-making into HVD care pathways. For example, are the conversations becoming more fruitful? Are you having more conversations year on year? Are any commitments being made?
- Distribute surveys:
 - among people with HVD to find out whether they have been a part of more shared decision-making conversations, how these have been conducted, and whether they have improved the person's experience and satisfaction with their care.
 - among HVD healthcare professionals to find out whether they have been eliciting more shared decision-making conversations, how these have been conducted, and whether they have been helpful.
- Monitor any announcements of updates to local/national HVD care pathways regarding the incorporation of shared decision-making within them.



Key considerations

- Discussions around potential treatment options can be overwhelming for people living with HVD, so it is useful for them to be offered additional time with a healthcare professional to ask any questions they may have felt unable to ask during previous consultations e.g. when receiving their diagnosis.
- Additional consultations should be introduced at a minimum of two key stages of the care pathway: following diagnosis with HVD and when making a choice about treatment. If capacity is constrained, it may be useful to consider whether the additional consultations need to be conducted in person or could be done virtually/via teleconference.



Local call to action 5

Encourage investment in research to identify and scale-up best practices for shared decision-making in HVD

Patient organisations are recommended to work collaboratively with:

HVD clinicians and researchers with expertise in implementation science and shared decision-making; relevant local data institutions or registries/audits; academic/university hospitals

Key steps:

- 1) Identify existing models and initiatives that are embedding shared decision-making in HVD patient care pathways, or in other disease areas in your country, or in other countries with a similar health system.
- 2) Explore ways in which these existing initiatives could be developed into transferable models and written up into accessible case studies.
- 3) Review and synthesise existing evidence to encourage relevant local bodies in your country and/or governments to fund research on shared decision-making in HVD, with a view to scale-up standardised best-practice processes at the national level.

Ways to measure impact:

- Track the number and type of meetings/conversations with local bodies or the government regarding more research into shared decision-making. For example, are the conversations becoming more fruitful? Are you having more conversations year on year? Are any commitments being made?
- Monitor levels of public funding allocated and research grants being made available towards investigating how to implement shared decision-making in HVD.

Key considerations

- The AIMD framework could be useful to refer to when thinking about how to translate research into healthcare policy and practice.²² The framework outlines four key stages:
 - Aims: what you want your intervention to achieve and for whom
 - Ingredients: what comprises the intervention
 - Mechanisms: how the proposed intervention may work
 - Delivery: how the intervention would be delivered



Local call to action 6

Push for the adoption of novel funding or reimbursement models in healthcare to help shift the culture of care from procedure-driven to person-centred

Patient organisations are recommended to work collaboratively with:

HVD clinicians (desirable: national multidisciplinary cardiac societies); researchers with expertise in implementation science and shared decision-making; relevant local bodies responsible for commissioning or funding healthcare services

Key steps:

- 1) Explore how novel funding or reimbursement models could work in your locality/country.
 - a. Look to existing models that already centre funding around a person in HVD or other disease areas, either in your country or in other countries with a similar health system. Use any relevant case studies to showcase how this could work.
 - b. Think about how healthcare professionals and hospitals, or similar organisations providing HVD care, could be incentivised to centre care around a person, and what the criteria or indicators for measuring or quantifying quality HVD care and successful reimbursement should be.
- 2) Work with the researchers and implementation science experts to encourage relevant local bodies and/or the government in your country to adopt novel funding or reimbursement models built around the person with HVD.

Ways to measure impact:

Track the number and type of conversations with local bodies or the government on the adoption of novel funding or reimbursement models being centred around the person with HVD. For example, are the conversations becoming more fruitful? Are you having more conversations year on year? Are any commitments being made?

Key considerations

- Funding and reimbursement models can shape how care is delivered, as well as how healthcare professionals and care settings are incentivised to prioritise recommending certain treatments or interventions over others. However, care outcomes and patient satisfaction should form a key component of the criteria for reimbursement.

Where next?

Shared decision-making represents a cultural shift in healthcare, and it is important to note that change like this will take time. To move the needle in the right direction, actions and steps taken now at both the international and local levels will pave the way towards global implementation of shared decision-making in HVD.

This roadmap is designed to be applicable across different countries and health systems, but its practical applications may vary depending on local context. As such, it will be beneficial to take any specific cultural nuances or challenges into consideration when seeking to implement the recommended actions. It would also be useful to identify which actions could be prioritised in the short vs. long term.

Throughout this journey to drive implementation of shared decision-making in HVD, Global Heart Hub remains a key stakeholder and partner to all advocates, with resources available for use and adaptation at the local level. These include:

- *Shared decision-making for people with heart valve disease: a patient guide*⁵
- *Heart valve disease: working together to create a better patient journey*²⁴



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References

1. Vahanian A, Beyersdorf F, Praz F, *et al.* 2021. 2021 ESC/EACTS Guidelines for the management of valvular heart disease: Developed by the Task Force for the management of valvular heart disease of the European Society of Cardiology (ESC) and the European Association for Cardio-Thoracic Surgery (EACTS). *Eur Heart Journal*: 10.1093/eurheartj/ehab395
2. Otto CM, Nishimura RA, Bonow RO, *et al.* 2021. 2020 ACC/AHA Guideline for the Management of Patients With Valvular Heart Disease: A Report of the American College of Cardiology/American Heart Association Joint Committee on Clinical Practice Guidelines. *Circulation* 143(5): e72–e227
3. Lindeboom J, Coylewright M, Etnel J, *et al.* 2020. Shared Decision Making in the Heart Team: Current Team Attitudes and Review. *Struct Heart*: 10.1080/24748706.2020.1859660
4. Initiative Herzklappe e.V. 2022. *Herzklappen-Erkrankungen: Eine Umfrage unter Patienten und Ärzten zur Erfassung des Ist-Zustands in Deutschland und Österreich*. Berlin: Initiative Herzklappe e.V.
5. Harding E, Budig K. 2022. *Shared decision-making for people with heart valve disease: a patient guide*. London: The Health Policy Partnership and the Global Heart Hub
6. Faiman B, Tariman JD. 2019. Shared Decision Making: Improving Patient Outcomes by Understanding the Benefits of and Barriers to Effective Communication. *Clin J Oncol Nurs* 23(5): 540–42
7. Coylewright M, Forrest JK, McCabe JM, *et al.* 2020. TAVR in Low-Risk Patients: FDA Approval, the New NCD, and Shared Decision-Making. *J Am Coll Cardiol* 75(10): 1208–11
8. Saeed S, Skaar E, Romarheim A, *et al.* 2022. Shared Decision-Making and Patient-Reported Outcome Measures in Valvular Heart Disease. *Front Cardiovasc Med* 9: 863040
9. Näumann J, Teichert K. 2021. Patient JourneyHerzklappen-erkrankungen. Erfassung des Ist-Zustands in Deutschland und Österreich. Available from: https://www.meineherzklappe.at/wp-content/uploads/2021/11/Patient-Journey-HerzklappenpatientInnen_Endversion.pptx [Accessed 03/11/23]
10. Stiggelbout AM, Pieterse AH, De Haes JCJM. 2015. Shared decision making: Concepts, evidence, and practice. *Patient Educ Couns* 98(10): 1172–79
11. Dennison Himmelfarb CR, Beckie TM, Allen LA, *et al.* 2023. Shared Decision-Making and Cardiovascular Health: A Scientific Statement From the American Heart Association. *Circulation* 148(11): 912–31
12. Itchhaporia D. 2021. The Evolution of the Quintuple Aim. *J Am Coll Cardiol* 78(22): 2262–64
13. Sardari Nia P, Olsthoorn JR, Heuts S, *et al.* 2021. Effect of a dedicated mitral heart team compared to a general heart team on survival: a retrospective, comparative, non-randomized interventional cohort study based on prospectively registered data. *Eur J Cardiothorac Surg* 60(2): 263–73
14. Imran Hamid U, Modine T, Maessen J, *et al.* 2023. Structure of multidisciplinary heart teams, a survey-based heart team study. *Interdiscip Cardiovasc Thorac Surg*: 10.1093/icvts/ivad134
15. National Institute for Health and Care Excellence. Making decisions about your care. Available from: <https://www.nice.org.uk/about/nice-communities/nice-and-the-public/making-decisions-about-your-care/patient-decision-aids> [Accessed 06/10/23]
16. NHS England. Decision support tools. Available from: <https://www.england.nhs.uk/personalisedcare/shared-decision-making/decision-support-tools/> [Accessed 06/10/23]
17. Stacey D, Légaré F, Lewis K, *et al.* 2017. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*: 10.1002/14651858.CD001431.pub5
18. Col NF, Otero D, Lindman BR, *et al.* 2022. What matters most to patients with severe aortic stenosis when choosing treatment? Framing the conversation for shared decision making. *PLoS One* 17(8): e0270209
19. Hawley ST, Morris AM. 2017. Cultural challenges to engaging patients in shared decision making. *Patient Educ Couns* 100(1): 18–24
20. New South Wales Government. Shared decision-making resources for older people living with frailty considering surgery. [Updated 04/2023]. Available from: <https://aci.health.nsw.gov.au/networks/frailty-taskforce/resources/shared-decision-making> [Accessed 06/10/23]
21. Takkenberg H. 2023. Personal communication via email: 24/09/23
22. Bragge P, Grimshaw JM, Lokker C, *et al.* 2017. AIMD – a validated, simplified framework of interventions to promote and integrate evidence into health practices, systems, and policies. *BMC Med Res Methodol* 17(1): 38
23. Stolz-Klingenberg C, Bünzen C, Coors M, *et al.* 2022. Sustainability of large-scale implementation of shared decision making with the SHARE TO CARE program. *Front Neurol* 13: 1037447
24. Wait S, Krishnaswamy P, Borregaard B, *et al.* 2020. *Heart valve disease: working together to create a better patient journey*. London: The Health Policy Partnership

