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SPECIAL REPORT

Priorities for Patient-Centered Research in Valvular Heart Disease: A Report From the National Heart, Lung, and Blood Institute Working Group

Brian R. Lindman, MD, MSc; Suzanne V. Arnold, MD, MHA; Rodrigo Bagur, MD, PhD; Lindsay Clarke, JD; Megan Coylewright, MD, MPH; Frank Evans, PhD; Judy Hung, MD; Sandra B. Lauck, PhD, RN; Susan Peschin, MHS; Vandana Sachdev, MD; Lisa M. Tate, CAE; Jason H. Wasfy, MD, MPhil; Catherine M. Otto, MD

ABSTRACT: Over the past decade, the field of valvular heart disease (VHD) has rapidly transformed, largely as a result of the development and improvement of less invasive transcatheter approaches to valve repair or replacement. This transformation has been supported by numerous well-designed randomized trials, but they have centered almost entirely on devices and procedures. Outside this scope of focus, however, myriad aspects of therapy and management for patients with VHD have either no guidelines or recommendations based only on expert opinion and observational studies. Further, research in VHD has often failed to engage patients to inform study design and identify research questions of greatest importance and relevance from a patient perspective. Accordingly, the National Heart, Lung, and Blood Institute convened a Working Group on Patient-Centered Research in Valvular Heart Disease, composed of clinician and research experts and patient advocacy experts to identify gaps and barriers to research in VHD and identify research priorities. While recognizing that important research remains to be done to test the safety and efficacy of devices and procedures to treat VHD, we intentionally focused less attention on these areas of research as they are more commonly pursued and supported by industry. Herein, we present the patient-centered research gaps, barriers, and priorities in VHD and organized our report according to the "patient journey," including access to care, screening and diagnosis, preprocedure therapy and management, decision making when a procedure is contemplated (clinician and patient perspectives), and postprocedure therapy and management. It is hoped that this report will foster collaboration among diverse stakeholders and highlight for funding bodies the pressing patient-centered research gaps, opportunities, and priorities in VHD in order to produce impactful patient-centered research that will inform and improve patient-centered policy and care.

Key Words: aortic valve ■ heart valve ■ heart valve surgery ■ mitral valve ■ patient-centered care ■ shared decision making ■ transcatheter valve implantation

There has been an explosion in valvular heart disease (VHD) research over the past few decades with a shift in the evidence base from expert opinion alone, with virtually no randomized clinical trials (RCTs), to numerous RCTs addressing the safety and efficacy of devices to relieve stenosis or reduce regurgitation.[1–3] However, many guideline recommendations for VHD are still only supported by expert opinion and observational studies. Further, as is true of many areas of cardiovascular research, studies of patients with

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Correspondence to: Brian R. Lindman, MD, MSc, Structural Heart and Valve Center, Vanderbilt University Medical Center, 2525 West End Avenue, Suite 300-A, Nashville, TN 37203. Email: brian.r.lindman@vumc.org

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Nonstandard Abbreviations and Acronyms

AS	aortic stenosis
BP	blood pressure
HF	heart failure
RCT	randomized clinical trial
SDM	shared decision making
TAVR	transcatheter aortic valve replacement
VHD	valvular heart disease

VHD are driven primarily by clinicians and often fail to answer the questions of most importance to patients.

Patient-centered research is characterized both by its orientation and the process by which that research is formulated and executed. While acknowledging that basic science research involving cells and animals is relevant to patients, as the long-term goal of those avenues of investigation is often to prevent or slow VHD progression, patient-centered research involves and studies patients either prospectively or retrospectively. Every bit as important, though, patient-centered research ought to involve patients at each stage of the research process, from identifying research questions to prioritizing outcome measures to implementation into clinical practice. Although researchers and patients will agree on many questions and outcomes, patients often identify other issues that may not have been considered.

RATIONALE AND WORKING GROUP GOALS

The National Heart, Lung, and Blood Institute convened a Working Group on Patient-Centered Research in Valvular Heart Disease in July 2019 to identify gaps in patient-centered VHD research, develop a list of important patient-centered research questions, and consider any barriers that discourage investigators from pursuing these questions. Predictably, there are areas of overlap and distinctiveness with respect to these issues for patients with VHD versus other forms of cardiovascular disease. Because considerable attention has recently focused on devices and procedures, we concentrated less on important questions surrounding device performance and procedural optimization (acknowledging that these are patient-centered lines of investigation) and more on knowledge gaps regarding preprocedural and postprocedural management, decision making, and the opportunity to consider other end points for device trials. We also recognize that there is overlap between patient-centered care, patient-centered research, and patient-centered policy—the focus of this Working Group is the “research” piece, recognizing that an ultimate goal of this research is to inform healthcare delivery and policy.To meet the objectives for this Working Group, we included representatives from VHD-related patient organizations, clinicians with expertise in VHD, and researchers with active studies on VHD, while recognizing that many other areas of expertise are included in a Heart Valve Team and in caring for patients with VHD. We chose to frame our discussion in terms of the “patient journey” from diagnosis to long-term management (Figure 1). The specific aims of this Working Group were to: (1) identify knowledge gaps and generate a list of patient-centered VHD research questions spanning the patient journey from the initial diagnosis to long-term outcomes; (2) identify gaps in patient-oriented information about VHD and effective decision aids and implementation strategies for shared decision making; (3) identify barriers to patient-centered VHD research; and (4) disseminate an open access summary to researchers, clinicians, policymakers, the general public, and patient interest groups.

ACCESS TO CARE

Access to care for patients with VHD is not equitable with, for example, documented racial disparities in diagnosis and treatment of black patients with severe aortic stenosis (AS) (Table 1).[4–7] Black patients with severe AS are more likely to decline AVR when recommended, raising questions about trust, historical discrimination, and delivery of care.[6,8] Understanding the role that access to care has in the mechanisms of these outcome differences is difficult, since black patients also have a higher prevalence of risk factors for VHD than white patients, including hypertension, diabetes mellitus, and chronic renal insufficiency. Importantly, black patients are not the only racial minorities affected, with emerging data of undertreatment of valve disease among Latino populations and Native Americans.

Sex disparities in care are also seen in patients with VHD. Women have higher mortality than men after mitral surgery and present with higher case complexity, possibly because of less guideline-directed surveillance.[9,10] For patients with AS, the relative mortality benefit of transcatheter aortic valve replacement (TAVR) versus surgical aortic valve replacement appears to be greater for women compared with men.[11]

Innovation in care delivery is being studied, although there are few links to reduction in disparities. Electronic consults have been shown to be amenable to clinical questions about valve disease with cardiologists reviewing electronic data and images (eg, echocardiogram) in a shared electronic medical record and then providing detailed clinical recommendations in the electronic medical record to the referring clinician

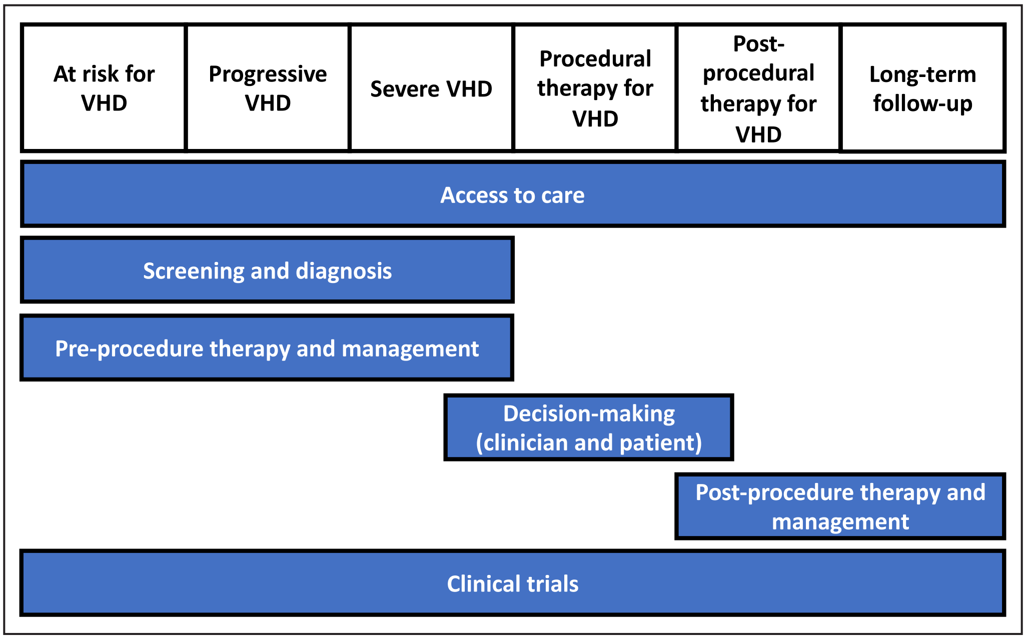

Figure 1. Context for patient-centered research in valvular heart disease (VHD)—the patient journey.
This figure outlines the patient journey and puts the sections of our report in context of this journey.

without an office visit.[12,13] Cardiology electronic consults are cost-saving relative to traditional care[14] and associated with fewer emergency department visits in a cluster-randomized trial.[14] Overall, evidence suggests that cardiology electronic consults improve access to outpatient cardiology care.[15] As such, electronic consults and other alternatives to office-based visits may improve access to care for patients with VHD. However, differences in valve-specific end points in electronic consults are unknown.

Table 1. Access to Care—Patient-Centered Research Questions in VHD

Disparities in care delivery • What factors underlie disparities in care delivery (eg, echocardiographic surveillance according to guidelines and performance of valve repair/replacement at the appropriate time) for women, minorities, low-income, and rural patients? How can those factors best be addressed and corrected? • How do referral rates differ among various subgroups and why? • Why is there a higher refusal rate for valve intervention among blacks? • What alert systems (eg, echo parameter alert) would promote equitable, timely identification, and appropriate monitoring and treatment of VHD? • How are Medicare coverage and reimbursement policies impacting access to available valve interventions, in general and among subgroups? • Do current health insurance systems limit access?
Telemedicine • How might telemedicine be employed to address challenges in the diagnosis and delivery of care for patients with significant VHD?
Heart valve centers • What are the pros and cons, benefits, and costs of having valve care delivered via heart valve centers (concentrated expertise and procedures) vs a more disseminated model? • Do heart valve centers have better clinical outcomes after adjustment for risk? • How do patients weigh differences in outcomes between centers and the burden of travel to centers further from home? How aware are patients of the options available to them regarding where to receive care?

VHD indicates valvular heart disease.

Specialized comprehensive valve centers are recommended in guidelines for patients with asymptomatic severe VHD, patients who may benefit from repair versus replacement, and patients with multimorbid disease.[1,16] This recommendation is based on a known surgical volumes-outcomes relationship as well as high rates of mitral repair for mitral valve prolapse at some centers.[17,18] In addition, more recent data suggest that mortality following transfemoral TAVR is higher and more variable at lower-volume centers.[19] Lower-volume centers treat greater proportions of rural patients, black patients, and Hispanic patients.[19]

The implications of concentrating VHD care at high-volume comprehensive valve centers are unclear. For coronary artery disease, centers of excellence do not appear to have better outcomes.[20] Adding nuance, the focus of high-volume comprehensive valve centers is on the procedural aspect of care for patients with VHD. However, there may be value to patients with VHD being followed in more specialized heart valve clinics during the progressive stage of disease and after a valve procedure.[21–23] How this specialized longitudinal care would be integrated into a system of care that might concentrate expertise and procedures in certain centers (that may be less practical to access for patients longitudinally) is unclear. Optimizing and integrating care for patients with VHD along the continuum of disease before and potentially after an intervention is fraught with challenges and uncertainties, particularly in a healthcare environment of increasingly restricted lines of referral mandated by insurance providers or other forces.[16] The cost implications of various models are also uncertain but inevitably intersect with considerations of quality and access to care. These issues are clearly not unique to patients with VHD, but there are some particular ways in which these system-of-care issues may specifically affect them. Diverse stakeholders need to engage Centers for Medicare & Medicaid Services (CMS) and other policy makers to ensure that policies are developed that are evidence based and in the best interests of our patients.

SCREENING AND DIAGNOSIS

A comprehensive understanding of risk factors for VHD will allow for a more targeted approach to screening and diagnosis as well as prevention (Table 2). Current screening of VHD primarily relies on patient symptoms and physical examination, despite wide variation in clinical practice and lack of accuracy for diagnosis of VHD, leading to variations in treatment.[24] In a study comparing auscultation by primary care clinicians and cardiologists against echocardiography, both groups had poor sensitivity for detecting mild or significant VHD (22–32%) with suboptimal specificity ranging from 67% to 83%.[25] Accordingly, tools other than auscultation are needed to effectively screen for VHD. Notably, undiagnosed VHD appears to be more common in lower socioeconomic groups, but the reasons for this are not fully understood.

Screening for VHD using echocardiography and advanced imaging approaches has not been well studied. Among individuals 65 years and older without a prior diagnosis of VHD, systematic echocardiography identified 51% with mild or more left-sided VHD or moderate or severe right-sided VHD, including 6.4% with significant (moderate or more) VHD.[26] The increasing availability of handheld ultrasound machines and application of artificial intelligence algorithms is likely to lower costs. Research is needed to determine optimal screening algorithms, including the scope of these efforts, cost-effectiveness, tools utilized, how to leverage new technologies, and how these efforts may need to be adapted based on geography, clinical setting, and available resources. Important areas for study are determining which patient populations will benefit from screening (eg, relatives of those with VHD and age-based or risk-based [based on genetics, biomarkers, or comorbidities] subgroups) and how detection of VHD early in the pathophysiological process (eg, mild in severity) impacts costs and patient outcomes and how this may differ depending on the type of VHD. Whether screening should be focused on identifying only more significant (eg, moderate to severe) VHD versus mild disease needs to be considered and will likely depend on the specific VHD and whether interventions are available to prevent or slow progression of earlier-stage disease. Finally, there is wide variation among practitioners with respect to monitoring for progression of diagnosed VHD.[27] Patients who are women, black, or on Medicaid are less likely to be screened for progression of VHD at appropriate intervals.[10] Further studies are needed to clarify optimal monitoring timeframes and the factors underlying variations in surveillance for progression of VHD. The role of multimodality imaging in the diagnosis and assessment of severity of VHD requires additional research.[28–31]

Table 2. Screening and Diagnosis—Patient-Centered Research Questions in VHD

Risk factors for VHD • What risk factors are associated with the development of each type of valve disease and how could knowledge of these factors inform screening and prevention efforts?
Tools to screen for VHD • What is the effectiveness of potential tools to screen for VHD? Examples include patient questionnaires, cardiac auscultation, serum biomarkers, point-of-care cardiac ultrasound, machine learning image analysis, and standard echocardiography • How often should testing be repeated for patients with and without a prior diagnosis of VHD?
Scope of screening for VHD • What are the pros and cons, benefits, and costs of screening efforts focused on specific patient groups or broadly applied to entire populations? • If screening efforts are focused, which prescreening or enrichment criteria for patients “at risk” are best?
Integrated screening for VHD • Which combination of screening tools and approaches will identify the most patients with significant valve disease for the least costs/resources? • Which approaches will ensure appropriate and consistent screening of all patients without bias related to age, sex, ethnicity, finances, and insurance?
Consequences of screening for VHD • What are the consequences of improved screening for VHD in terms of costs, patient anxiety/well-being/satisfaction, procedural volumes, survival, and quality of life?
Accurate diagnosis of significant VHD • How can adjunctive imaging tools (eg, cardiac magnetic resonance or computed tomography), circulating biomarkers, or other tools be employed to improve the accuracy of diagnosis of significant/severe VHD?

VHD indicates valvular heart disease.

PREPROCEDURE THERAPY AND MANAGEMENT

Valve lesions, such as AS and mitral regurgitation, are commonly viewed as mechanical problems requiring a mechanical solution with a transcatheter or surgical

Table 3. Preprocedure Therapy and Management—Patient-Centered Research Questions in VHD

Prevent/slow/reverse VHD with medical therapy • What factors are associated with the development and progression of VHD? • What medical therapies (currently available or targeting new pathways) are effective at slowing or reversing established VHD?
Prevent/slow/reverse maladaptive ventricular remodeling and dysfunction with medical therapy • What factors/pathways are associated with the development and progression of maladaptive ventricular remodeling and dysfunction in the setting of pressure or volume overload? • Despite potentially progressive valve disease, are there medical therapies that could prevent, slow, or reverse adverse consequences to the ventricle resulting from pressure or volume overload? If so, what is the optimal timing for those therapies to be utilized? • What differences exist between the right and left ventricles with respect to pathophysiology and targets for and timing and efficacy of intervention with medical therapy?
"Prehabilitation" in frail patients • In patients with impaired physical function needing a valve procedure, does a rehabilitation strategy before intervention improve periprocedural and short-term outcomes? • What types of prehabilitation are feasible and which components (eg, resistance exercise, aerobic exercise, reducing sedentary behavior, and nutrition) are most important? • What patient-centered delivery strategies are best suited to optimize the impact of prehabilitation programs?
Blood pressure targets in patients with VHD • What are the optimal blood pressure targets in patients with VHD? Should they differ from the general population? • How do age, type of valve disease, severity of valve disease, and comorbidities influence optimal targets for blood pressure?
Activity recommendations and restrictions in patients with VHD before a procedure • What activities and exercises promote the progression or increased risk of adverse events for specific types of VHD? • What activity recommendations should be made to patients with VHD? How can this evidence be best conveyed?

VHD indicates valvular heart disease.

procedure (Table 3). This is attributable to the fact that there have been no medical therapies proven to prevent, slow, or reverse primary VHD to date.[1,32] There was enthusiasm that statins might play such a role for patients with aortic sclerosis or AS based on preclinical studies, but several clinical trials demonstrated a lack of clinical benefit.[33,34] Progress is being made in elucidating underlying mechanisms of valve disease, but these discoveries have yet to be translated into effective therapies.[32,35,36] In some cases, promising targets and therapies exist, but they have not been tested in patients with VHD. For example, elevated Lipoprotein(a) is associated with incident and progressive AS and emerging data indicate a potential role for PCSK9 in valve calcification. Therapies targeting these molecules are available, but they have not been tested as potential medical therapies to prevent or slow progression of AS.[37,38]

The morbidity and mortality of valve disease often stems from how pressure or volume overload affects the ventricle. The sequelae of VHD overlap significantly with heart failure (HF) with preserved ejection fraction and HF with reduced ejection fraction both in terms of ventricular remodeling and dysfunction as well as clinical manifestations and symptoms. Most patients with VHD develop manifestations and symptoms of HF before an intervention on their valve and many have residual HF after a valve procedure. Even if the primary valve abnormality progresses, perhaps medical therapy targeting the maladaptive ways in which the ventricle responds to pressure or volume overload could delay the onset of HF symptoms or leave the heart in a healthier structural and functional place after a valve procedure is performed to mitigate HF after a procedure. For example, in patients with AS, excessive hypertrophy and the presence and extent of myocardial fibrosis are associated with increased HF, worse left ventricular function, and increased mortality.[39,40] Accordingly, medical therapy targeting maladaptive hypertrophy or fibrosis may promote ventricular health and improve survival even if the AS progresses and valve replacement is still needed. Although the mechanism for the potential benefit is unclear, there are retrospective studies suggesting that renin-angiotensin system blockade may be associated with improved survival and a lower risk of cardiovascular events.[41]

Several tools will be needed to elucidate pathobiology in the valve and the ventricle and to test medical therapies directed at promising targets. Phenotyping should include circulating biomarkers (including -omic approaches), multimodality and molecular imaging, tissue analyses (eg, myocardium, valve), studies done under resting and stress (eg, exercise) conditions, and invasive hemodynamics.

Beyond medical therapy targeting the valve and ventricle, there are other knowledge gaps pertinent to the stage of progressive valve disease related to the blood pressure (BP) and physical activity goals and guidelines. With respect to BP goals, the VHD guidelines defer to BP guidelines for the general population and offer no specific targets for patients with VHD.[1] However, for AS, while hypertension is a risk factor for incident AS and faster progression, a post hoc analysis of SEAS (Simvastatin Ezetimibe in Aortic Stenosis Study) showed that event rates were higher for those with a systolic BP <120 mm Hg or diastolic BP <70 mm Hg.[42–44]

Guidelines on physical activity and restrictions for patients with progressive VHD are generally based on expert consensus, but further research could refine and improve those recommendations.[45] At the other end of the spectrum, given the increased procedural risk and postoperative events associated with impaired physical function and frailty, it is unclear whether "prehabilitation" (rehabilitation before an intervention) before a valve procedure may reduce risk and improve outcomes.

DECISION MAKING WHEN A PROCEDURE IS CONTEMPLATED (CLINICIAN PERSPECTIVE)

There are a number of factors a clinician must consider in order to determine whether to recommend a valve procedure or surgery to a patient: appropriateness, timing, feasibility, and approach, and whether the recommendation is reflective of the patient's goals and preferences. Each of these areas has potential for important research questions (Table 4). Particularly among younger patients, considering the longitudinal patient journey and the potential need for multiple interventions over the patient's life, consideration needs to be given to and research directed at clarifying the optimal treatment path when multiple procedures over a lifetime can be predicted.

A critical step in the decision-making process for clinicians is to determine whether the procedure is *appropriate*. Determining the appropriateness of a procedure centers on assessing whether the anticipated benefits of the procedure are likely to outweigh the risks, which is inextricably linked to understanding the patient's goals and preferences and determining whether the procedure has a reasonable likelihood of achieving these goals. Notably, the research suggests that clinicians often make a "preference misdiagnosis," and thus tools and skill sets to clarify patient values are needed.[46] There are generally 2 broad categories of inappropriate (or ineffective) procedures: (1) futility of a valve procedure because of comorbidities and frailty—even if the procedure is technically successful, the patient will die soon or experience an ongoing decline in health status; or (2) nonresponder to a valve procedure—even if the procedure is technically successful, it does not improve health status, survival, or other goals of the patient. The first scenario is easier to conceptualize; an example of the second from another cardiovascular specialty would be the lack of clinical response to cardiac resynchronization therapy among patients with a nonleft bundle block QRS morphology.[47] While we are gaining more insight into patients for whom TAVR may be futile, much work remains to be done to clarify which patients will not benefit from mitral or tricuspid procedures.

Timing of the procedure is also an important step in decision making: Does the patient meet criteria for treatment of the valve? Our current indications for treatment with transcatheter therapies reflect practice patterns when surgery is the only option. With less invasive treatments and increasing options for repeat procedures, the optimal timing of intervention should be questioned. With the introduction of TAVR and the opportunity for valve-in-valve TAVR in the treatment of AS, strategy trials are important to better understand whether TAVR may be beneficial earlier in the disease, ie, before symptoms (eg, EARLY TAVR [Evaluation of Transcatheter Aortic Valve Replacement Compared to Surveillance for Patients With Asymptomatic Severe Aortic Stenosis] NCT 03042104], or in symptomatic moderate disease (eg, TAVR UNLOAD [Transcatheter Aortic Valve Replacement to Unload the Left Ventricle in Patients With Advanced Heart Failure: A Randomized Trial] NCT 02661451). Similar questions about timing exist for the treatment of mitral and tricuspid valve disease. The technology, however, is at an earlier stage in defining the efficacy of approaches and devices.

An additional step in the decision process is to determine the best *approach* to treating the valve. The best approach might depend on technical feasibility (eg, is the left ventricular outflow tract too large or small, are the mitral [or tricuspid] leaflets amenable to clipping, how much mitral annular calcification is too much) but also consider other issues. The choice of a transcatheter versus surgical versus hybrid approach, optimal choice of valve, simultaneous versus sequential procedures for multiple valve disorders, and whether concurrent cardiac conditions (eg, coronary disease) need to be addressed depend on the patients' medical condition, procedural risk, age, and cardiac function, as well as patient preferences and values.

To improve decision making from the clinician perspective, the emphasis should be on identifying factors and developing and validating risk models that will inform, influence, and guide clinical decisions and actions regarding: (1) timing of a procedure (perform it now versus later); (2) whether to recommend a procedure when futility is anticipated (either because of frailty and impaired physical function or a predicted lack of clinical response to the intervention); or (3) whether a specific adjunctive intervention should be employed in a subgroup of patients alongside a procedure to optimize outcomes. For example, a risk prediction tool for poor outcome after TAVR identified 8.4% of patients with a ≥70% predicted risk of a poor 1-year outcome; of those very high-risk patients, 60.3% were dead and an additional 16.9% had poor quality of life or quality of life decline by 1 year after TAVR.[48] Given that average 1-year mortality in patients with symptomatic severe AS not getting TAVR is ≈50%, knowing that a patient is in this very high-risk subgroup may inform shared decision-making conversations regarding whether to perform TAVR.[49] Similarly, a risk score for outcomes after TAVR that includes a frailty component is useful not so much because it improves discrimination of mortality (eg, improved c-statistic), but because it identifies patients at very high risk for death or disability at 1 year for whom TAVR may be futile and also identifies patients for whom an aggressive rehabilitation plan is particularly important as an adjunct to TAVR for outcomes to be optimized.[50]

Table 4. Decision Making (Clinician and Patient Perspectives) When a Procedure is Contemplated—Patient-Centered Research Questions in VHD

Clinician Perspective
Optimal timing of a valve procedure • What is the optimal timing of a valve procedure for patients with asymptomatic severe valve disease or symptomatic moderate valve disease? Do cut points for "severe" valve disease need to be re-evaluated and refined? Do recommendations for valve intervention need to more explicitly integrate the severity of the valvular lesion with the ventricular response to it? Examples include clarifying the optimal timing of valve replacement for patients with severe asymptomatic AS, moderate AS with left ventricular dysfunction or symptoms of HF, and severe asymptomatic aortic regurgitation with evidence of left ventricular dilation or subclinical dysfunction. • For these patient groups, if all patients do not benefit from earlier intervention, which subgroups (as identified by imaging, biomarkers, or other factors) may benefit from earlier intervention?
Nonresponders to a valve procedure • What are the reasons that some patients do not experience an improvement in survival, quality of life, or functional status after a valve procedure? • What are the reasons for a lack of reverse ventricular remodeling or improvement in ventricular function in some patients after a valve procedure? • How can we predict who will be a nonresponder to a valve procedure and how can that inform our recommendations and SDM with the patient? Areas of particular interest include patients with significant secondary mitral regurgitation or tricuspid regurgitation. • Which patients with secondary mitral regurgitation (eg, based on age, left ventricular size or function, severity of mitral regurgitation, biomarkers, and comorbidities) will benefit from a mitral procedure (eg, transcatheter valve repair or replacement or surgery) vs left ventricular assist device /transplant vs guideline-directed medical therapy alone? • Which patients with secondary tricuspid regurgitation (eg, based on right ventricular size/function, associated pulmonary vascular disease, biomarkers, and severity of tricuspid regurgitation) will benefit from a tricuspid procedure? • How best can we understand patient goals and preferences and determine whether the selected therapy is likely to meet patient goals?
Futility of a valve procedure caused by comorbidities and frailty • Can we accurately predict when, caused by comorbidities and/or frailty, a valve procedure will not substantively improve the health status of patient even if the procedure is successful? • Can current or future risk scores be efficiently and effectively utilized in practice to improve patient counseling and SDM? • What role might palliative care consultation play in these scenarios in particular?
Clarifying the relationship between valve disease and symptoms and anticipated benefit of a procedure • When is valve disease significant enough such that treating it with a valve intervention is likely to benefit the patient? • How do we determine whether symptoms are caused by valve disease or other cardiac or noncardiac comorbidities?
Health status assessment • Are currently HF-specific health status measures appropriate for monitoring patients with valve disease and their response to therapy? • What role might alternative or adjunctive assessments tailored to patients with valve disease have in evaluating and monitoring the well-being of patients with valve disease longitudinally, including before and after a procedure?
Approach to valve procedures • Based on patient and anatomical factors, when are surgical vs transcatheter vs hybrid approaches preferred? • What are the pros and cons, benefits, and risks of valve choices in various clinical settings (eg, mechanical vs bioprosthetic at a younger age and surgical vs transcatheter valve or type of transcatheter valve when a bicuspid valve is present)? • What type and severity of coronary disease ought to be fixed before transcatheter valve repair or replacement and what can be deferred? • For multivalve disease, when is a concomitant procedure preferred and when is a staged approach preferred?
Patient Perspective
Patient goals and preferences and integration into VHD trials • What do patients with VHD understand about their disease process? What early educational interventions are most effective so patients are prepared to participate in SDM? How does this differ among a diverse patient population (ie, age, frailty, comorbidities, race, sex, language, health literacy)? • What outcomes are most important to patients with VHD? How do they vary across diverse patients, including geography (ie rural vs urban locations)? How may this inform the operationalization of advanced heart valve centers? • Can a patient-reported outcome measure based on patients' goals for therapy perform with reliability and validity to evaluate new treatment options within clinical trials? • How would such a goal-attainment patient-reported outcome measure correlate with other outcomes, including health status measures, rehospitalization, and mortality? • How can a goal-attainment patient-reported outcome measure be implemented successfully into clinical practice? What are the measures of success?
Selection of outcomes for SDM trials in VHD • Which outcomes most accurately reflect the patient experience as defined by patient stakeholder groups (eg, trust, knowledge, and anxiety)? • How do patients prioritize outcomes in the treatment of VHD? • Which additional outcomes might also be evaluated to assess the value of SDM (eg, choice of therapy and costs)? • How is SDM most accurately measured in cardiovascular care settings? How does the quality of decision making change? How is this different from other clinical scenarios when a heart team is involved in decision making?
Strategies to support an SDM process • How is SDM most effectively delivered? • Where and when in the care process are SDM interventions most effective (eg, at home, before and/or after clinic)? Who is the most effective at delivering SDM interventions? What is the effect of limited diversity among VHD clinicians on measured outcomes of SDM? Can the interventions be divided up among team members effectively? • How might technology be leveraged to aid in SDM (ie, telehealth, electronic health record, smart phones)? • What is the comparative effectiveness of an electronic health record–embedded vs paper decision aids for patients with VHD? • How does the method of delivery of SDM interventions influence clinician SDM skill sets and attitudes and sustained use?

(*Continued*)

Table 4. Continued

Patient Perspective
Impact of policy on delivery of care to patients with VHD • Following Medicare mandates for SDM, how does care delivery change? • Are changes associated with improved outcomes? • What are the unintended consequences of policy mandates for decision aid use or documentation of SDM?

AS indicates aortic stenosis; HF, heart failure; SDM, shared decision making; and VHD, valvular heart disease.

DECISION MAKING WHEN A PROCEDURE IS CONTEMPLATED (PATIENT PERSPECTIVE)

The expansion of treatment options for VHD and the increase in the number of older adults with multiple competing comorbid conditions make shared decision making (SDM) increasingly relevant (Table 4).[51] SDM is a process in which clinicians and patients deliberate reasonable treatment alternatives and collaborate on a final treatment plan, with the final choice informed by patients' goals and preferences.[52] An SDM process is most applicable for preference-sensitive decisions, defined as those in which more than one reasonable option exists; there remains uncertainty in the evidence; or patient preferences vary between patients or compared with clinicians. In these types of medical decisions, patients' values and preferences play a significant role in identifying which treatment may be best for them.[53]

SDM is distinct from patient education, which is a 1-way stream of information from clinician to patient. SDM involves listening to the values and preferences of informed patients incorporating this into decision making.[54] There is consistent evidence that clinicians do not elicit patient values and preferences, nor adjust care to preferences.[55,56]

SDM research, pioneered and rigorously evaluated in fields including oncology and orthopedics over the past 3 decades, includes the study of strategies to improve patient-clinician communication when making medical decisions.[57–60] Numerous randomized trials on the effectiveness of decision aids to promote an SDM process have demonstrated improvement in patient-centered outcomes including knowledge, satisfaction, and decisions consistent with patients' values.[57] Decision aids, which may include paper handouts, videos, websites, or tools embedded in the electronic health record, raise awareness there is a choice to be made, provide information on risks and benefits, and may also assist in values clarification.[61,62] However, large-scale implementation projects identify that while decision aids are helpful, clinician skill sets in SDM—combined with positive clinician and leadership attitudes towards meaningful change in healthcare delivery—are critical for effective SDM.[54] An SDM approach is consistently advocated across multiple disease conditions in cardiology by professional society guidelines, yet there remains a lack of recommendations regarding best practices or most effective tools for implementation.[16]

It is essential that validated frameworks and measures are used in study conceptualization, design, deployment, evaluation, and implementation of SDM interventions, such as patient decision aids.[61–64] Study designs often include cluster randomized trials, quasi-experimental designs with pre-post testing, or repeated observations over time.[65] While a review of all measures of the quality of decision making is outside the scope of this review, examples include independent, third-party review of audiotaped clinical encounters, patient surveys, or simply noting that a decision aid was used in the visit.[66]

Because some of the research in SDM is striving to describe natural phenomena, including clinician and patient attitudes, beliefs, and behaviors, qualitative research is also utilized. These studies may employ nominal group technique, semistructured interviews leading to framework-guided qualitative analysis, or more traditional focus groups.[56,67,68] The National Quality Forum provides additional best practices to help guide implementation efforts of evidence-based tools, such as decision aids.[53] SDM is the "science of allocating time for care," and time will remain a significant barrier until SDM is no longer seen as "a 'nice-to-have' extra for which new time needs to be found."[69] This requires an investment in research into healthcare delivery innovations that embed the process of SDM into our existing structures, valuing the outcomes that reflect high-quality decisions so that patient engagement returns to its rightful place as intrinsic to our actions as clinicians.

POSTPROCEDURE THERAPY AND MANAGEMENT

Continuity of care and seamless management of the complexity of VHD after an intervention are central to ensuring patients derive their expected benefits of treatment (Table 5). For example, the 3M TAVR (Multimodality, Multidisciplinary, But Minimalist TAVR) study recently demonstrated the safety and reproducibility of a clinical pathway inclusive of minimalist periprocedure approach, a standardized

Table 5. Postprocedure Therapy and Management—Patient-Centered Research Questions in VHD

Supporting a Safe Recovery
Getting home safely—improving transitions of care • Which postprocedure care pathway(s) yield the best patient outcomes? • Do different patient groups have different early recovery requirements? • What clinician and patient factors are associated with early readmissions and what are the most effective interventions to reduce readmissions in risk-stratified groups? • How do we improve self-care among patients discharged after a valve procedure? How should patients be monitored upon discharge after a valve procedure (including components and delivery of monitoring)? • How can mobile health and technology be leveraged to optimize these processes?
Getting better after a heart valve procedure—rehabilitation and improving physical functioning • What factors are associated with improvement in physical function? • How can frailty be treated after a heart valve procedure? • What interventions (eg, aerobic exercise, resistance exercise, nutrition, medications, mindfulness, and coaching) are most effective to optimize physical function? • What are the most effective, translatable, and generalizable ways to implement these interventions? • How can interventions in the home and those that leverage technology and mobile health facilitate these objectives?
Managing complications and the long-term sequelae of valve procedures • How should conduction disturbances and potential need for a pacemaker be monitored after transcatheter aortic valve replacement? • What is the long-term impact of conduction disturbances and pacemakers after valve procedures? • How do patients report their experience of needing a new pacemaker after a valve procedure? • What are the implications of leaving the inter-atrial septum open or closing it after a left-sided valve procedure? • What are the implications for cognitive function of small particle emboli to the brain?
Managing Heart Disease Related to VHD
Treating HF and abnormal ventricular structure and function after a valve procedure • What is the relationship between changes in ventricular structure and function after a valve procedure and subsequent clinical outcomes? • What factors/pathways underlie these changes and could they be targeted with existing or novel medical therapies? For example, greater regression of left ventricular mass after aortic valve replacement has been associated with improved clinical outcomes. What medical therapies may augment left ventricular mass regression after valve replacement and would such a strategy improve clinical outcomes? • Residual pulmonary hypertension and increased systemic vascular load are associated with worse outcomes after valve procedures. What medical therapies might target this pathophysiology and improve clinical outcomes?
Blood pressure targets in patients with VHD • What are the optimal blood pressure targets in patients with VHD after a valve procedure? Should they differ from the general population? • How do age, type of valve disease, type of intervention, and comorbidities influence optimal targets for blood pressure?
Anticoagulation and antiplatelet therapy after valve procedures • After specific types of valve procedures, what anticoagulation and/or antiplatelet regimens are best, including which agent(s) and timing of initiation and length of administration? • What are the benefits and risks of various treatment options? How do certain comorbidities (eg, afibrillation or coronary disease postpercutaneous coronary intervention) affect these decisions? • To reduce stroke risk in patients with VHD and a concomitant atrial arrhythmia, which patients may benefit from left atrial appendage closure devices vs anticoagulation?
Device Surveillance and Durability
Valve durability and surveillance • What is the average lifespan of normal function for various surgical and transcatheter valves? • What factors are associated with degeneration and which of those may be modified? • What is the optimal cardiac imaging (eg, echocardiography and cardiac computed tomography) monitoring regimen after a valve procedure and how might the type of valve disease and valve procedure performed influence that? • How should the interval development of a high transvalvular gradient during follow-up be managed?

HF indicates heart failure; and VHD, valvular heart disease.

postprocedure protocol of rapid mobilization and reconditioning, and criteria-driven discharge to achieve safe next-day discharge.[70] These findings reflect the experience of single-center observational studies that prioritize a bundle of care that promotes the mitigation of postprocedure risks in the mostly elderly patient population with VHD.[71] The development and evaluation of health service delivery interventions is complex because of the multiple interacting components, the number and difficulty of behaviors required by those delivering or receiving the interventions, the number of organizational levels targeted by the intervention, and the measurement of outcomes that must be reflective of and responsive to the intervention.[72]

The CMS, Joint Commission, and the Institute of Medicine have consistently highlighted that the failure of ensuring appropriate transition of care—the movement of patients between healthcare practitioners, settings, and home as their condition and care needs change—can have devastating effects on patients.[73,74] We currently lack evidence to guide and risk-stratify the use of postprocedure pathways, determine the optimal length of stay, and support patient-centered discharge planning in an increasingly heterogenous VHD population. There is a pressing need to focus research on strategies to address patients' vulnerabilities in the early recovery period and optimize care transitions in healthcare systems to improve outcomes. Given the high prevalence of frailty in patients with VHD and its association with poor outcomes after valve procedures, effective strategies to improve postprocedural physical function are sorely needed. However, enrollment in center-based cardiac rehabilitation programs is low and there are numerous barriers to participation.[75] Novel approaches that leverage technology and can be implemented entirely or partially at home may be more effective.[76] More research is also needed regarding the consequences of and how to monitor for complications of valve procedures.

Many patients continue to have a poor quality of life and adverse outcomes after intervention for VHD. Maladaptive left ventricular remodeling and dysfunction in response to pressure or volume overload does not always reverse toward normal after the valve is fixed, which is associated with worse outcomes.[39,40,77,78] Research to elucidate mechanisms of persistent maladaptive ventricular remodeling and dysfunction after a valve procedure may identify novel targets for medical therapy to improve outcomes as an adjunct to a procedure.[49,79–81] Optimal BP targets after a valve procedure may differ than those for the general population, but further work is needed to clarify these relationships and appropriate goals.[82,83]

It is also critical to identify best practices for antiplatelet and anticoagulant medications after different

Table 6. Barriers to Effective Patient-Centered Research on VHD

Barrier	Impact
Lack of recognition of VHD as a specific area of expertise	• No specific training pathway and lack of training opportunities for VHD experts. • Inadequate numbers of noninterventional VHD physician and advance practice provider experts. • Inadequate focus on VHD research at scientific meetings as specified pathway.
Limited funding and lack of recognition of need for VHD research	• Industry funding is focused on device-related questions, which limits innovative research on many nondevice-related VHD research questions. • Pharmaceutical companies often exclude patients with VHD from clinical trials on medical therapy and are reluctant to perform medical therapy studies that target VHD populations. • VHD grant applications to the National Institutes of Health assigned to reviewers with limited expertise in VHD.
Lack of patient involvement in VHD research priorities, study design, and implementation	• Research fails to consider important patient-based questions. • Challenge to change the culture of research and implementation science. • Reduces patient engagement in shared decision making if tool development does not include the patient perspective.
Lack of diversity in VHD researchers	• Lack of diversity among researchers reduces the range of research questions. • Lack of diversity in VHD researchers reduces recruitment of diverse patient groups in clinical trials.
Lack of inclusion of patients with VHD in clinical trials of HF, hypertension, arrhythmias, and other cardiac conditions	• Medical therapies that may benefit patients with VHD have not been studied. • Clinical trials of hypertension treatment in patients with VHD are not available. • Effect of medical therapy on HF with preserved ejection fraction in patients with VHD has not been studied.
Lack of validated VHD-specific patient-reported outcome measures	• Patient-reported outcome measures developed for other cardiac conditions may not capture all aspects of VHD or the diversity of patient perspectives.
Few measures of effectiveness of approaches to improving outcomes in patients with VHD	• Standardized measures of effectiveness would allow more rigorous research on approaches to shared decision making, heart team approaches, and heart valve centers.
Traditional views on diagnosis and treatment of VHD	• Reluctance to consider that screening with a stethoscope by primary providers might not be the optimal approach to screening for VHD. • Reluctance to treat patients with VHD with medications known to be effective for hypertension and HF.
Healthcare system inertia in the approach to provision of care to patients with VHD	• Lack of implementation science studies of pathways of care to improve outcomes in patients with VHD.
Silos based on type of physician and type of medical center	• Particularly in settings without integration of transcatheter therapy options, care for patients with VHD is often siloed between cardiologists (pretreatment and posttreatment care) and surgeons (procedural care). • Communication and care handoffs between smaller community or rural facilities and large medical centers are often poor, leading to suboptimal care for patients with VHD. • Procedure-focused programs vs comprehensive VHD centers that provide continuity of care, access to multiple modalities of treatment, and seamless communication with primary care providers.
Lack of diversity in the clinical VHD workforce	• Poor recognition of barriers to care in specific populations, including poor communication, geography, and access to care. • Lack of trust and engagement by patients with backgrounds different from clinicians.
Difficulty in publishing patient-centered research in cardiology journals	• Educating editors about patient-centered research, patient-centered outcomes, and standards for qualitative research would increase acceptance by major medical journals.

HF indicates heart failure; and VHD, valvular heart disease.

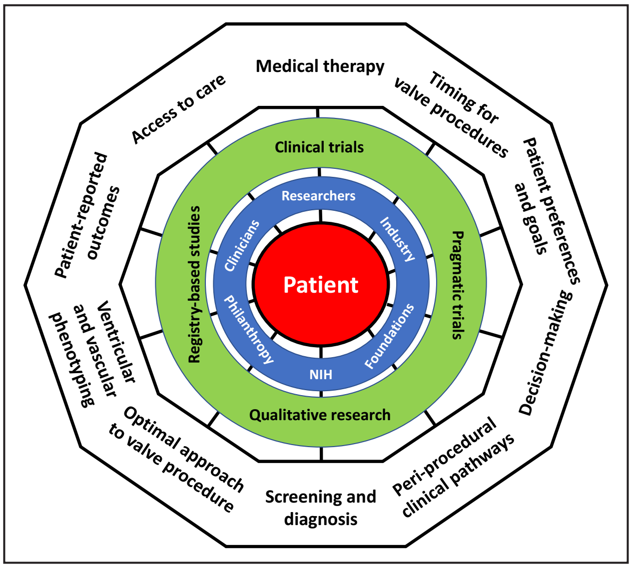

Figure 2. Patient-centered research in valvular heart disease (VHD).
This figure shows the multifaceted aspects of what we define and characterize as patient-centered research in VHD. The patient (red) is a participant in and focus of the research. The outer ring represents some of the many research questions and knowledge gaps in the field. The most common research tools and methodologies to address those knowledge gaps are shown in the next inner circle (green). Those doing and funding the research are shown in the final inner circle (blue).

valve procedures. While valve thrombosis does occur after TAVR and may influence valve durability, indiscriminate treatment with anticoagulation is associated with harm.[84] The rapid increase in the number and types of devices to treat VHD also emphasizes the need for research to rigorously assess device durability, identify best practices for surveillance of device performance, and determine the clinical significance and appropriate treatment of abnormalities identified.

CLINICAL TRIALS IN VHD—CHALLENGES AND OPPORTUNITIES

With the introduction of transcatheter options to treat VHD as an alternative to surgery, a rapid succession of numerous well-designed RCTs have been completed, providing a robust evidence base particularly for the role of TAVR in the treatment of AS (Table S1). Most trials in VHD over the past decade are device-focused. While there is an ongoing need for more device and procedure-related trials, there is also an urgent need for RCTs to address many nondevice research questions in VHD along the full spectrum of the patient's journey from screening to long-term post-procedure management. Indeed, many of the questions included herein could be optimally addressed by RCTs. Yet, there are several challenges to performing clinical trials, particularly those addressing questions not related to a device. Leveraging existing registries (eg, TVT [Transcatheter Valve Therapy] and STS [Society of Thoracic Surgeons]) to perform pragmatic trials could be a good starting point. These registries capture an extensive number of data but they are designed for tracking quality and outcomes and less as a vehicle for prospective research. Incorporating use of their data into prospective studies is currently onerous and expensive.

BARRIERS TO PATIENT-CENTERED RESEARCH IN VHD

There are many barriers to patient-centered research in VHD as summarized in Table 6. Until recently, VHD was not recognized as a common and important clinical condition and there are no defined training pathways for clinical expertise in VHD. Research on VHD tends to be spread across different specialty scientific meetings and medical journals, which are organized by the type of research rather than the patient with VHD (eg, the disease not the method). Similarly, the concept that patients should be involved in clinical research is relatively new and has yet to gain wide acceptance, although some medical journals now require a statement about patient involvement.[64] Some patient-centered research questions and outcomes seem "soft" compared with the traditional "hard" end points of clinical trials; researchers and reviewers are often unfamiliar and uncomfortable with standards for performing and reporting qualitative data.[63] Investigator-initiated funding for VHD research is difficult to obtain given this lack of expertise and priority by funding agencies. Many of these barriers can be reduced or eliminated by promotion of training and research in VHD; education of researchers, reviewers, and journal editors about patient-centered research; increased funding opportunities for VHD research; and closer collaboration between researchers, clinicians, and patients with VHD.

CONCLUSIONS

Over the past decade, an explosion of research in VHD has centered on new opportunities to perform valve procedures less invasively utilizing transcatheter approaches. There is little doubt that, on the whole, this is good for patients. Numerous opportunities exist to build on these advances and improve outcomes for patients with VHD. Herein, we have outlined knowledge gaps and research priorities for patient-centered research in VHD, recognizing that the patient ought to be the center of our attention and not simply a valve or device (Figure 2). There are a number of barriers that impede progress, but also numerous opportunities for collaboration and progress among diverse stakeholders who can be united with a common purpose (Table S2). Ultimately, patient-centered research needs to intersect with, promote, and provide evidence for patient-centered care and policy to yield the greatest benefits for those who have the most at stake: our patients.

ARTICLE INFORMATION

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Affiliations

From the Cardiovascular Medicine Division, Structural Heart and Valve Center, Vanderbilt University Medical Center, Nashville, TN (B.R.L.); Saint Luke's Mid America Heart Institute/UMKC, Kansas City, MO (S.V.A.); Division of Cardiology, University Hospital, London Health Sciences Centre, London, Ontario, Canada (R.B.); Alliance for Aging Research, Washington, DC (L.C., S.P.); Heart and Vascular Center, Dartmouth-Hitchcock Medical Center, Lebanon, NH (M.C.); National Heart, Lung, and Blood Institute of the National Institutes of Health, Bethesda, MD (F.E., V.S.); Cardiology Division, Massachusetts General Hospital, Harvard Medical School, Boston, MA (J.H., J.H.W.); Centre for Heart Valve Innovation, St. Paul's Hospital, University of British Columbia, Vancouver, British Columbia, Canada (S.B.L.); Heart Valve Voice US, Washington, DC (L.M.T.); Cardiovascular Division, University of Washington, Seattle, WA (C.M.O.).

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Supplementary Materials

Tables S1–S2

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Supplemental Material

Table S1. Clinical Trials in VHD – Challenges and Opportunities.

• How should the “patient voice” be incorporated into trial design and endpoints selected and prioritized in way that aligns with FDA and other policies? What are the best ways to analyze these endpoints?
• Most trials in the valve space are device-based trials sponsored by industry and there is a lack of medical therapy trials. Heart failure trials tend to exclude patients with significant valve disease or those who have recently had a procedure. Pharmaceutical companies seem to view patients with valve disease as a small/niche population despite the epidemiology studies which clearly show the large size of this population of patients. Accordingly, there is a lack of data on the effects of medications for heart failure on patients with valve disease and it is often challenging to convince the relevant stakeholders of the importance of these studies.
• What is the most effective way to study imaging-based studies with imaging efficacy endpoints in the context of their expense?
• How can people of color, women, rural, and less resourced patients be appropriately represented in clinical trials?
• What is the appropriate “control arm” for device studies (e.g. GDMT, surgery, or another transcatheter therapy)? How do they affect trial enrollment?
• How do the heterogeneity of patients with secondary MR and TR (e.g. spectrum of valve and ventricular anatomy and function, differences in patient characteristics, sensitivity to loading conditions, etc.) impact identification and enrollment of appropriate patient groups? What are strategies to overcome resulting challenges?
• How can registries (e.g. TVT, STS, etc.) be leveraged effectively to answer patient-centered research questions and run pragmatic clinical trials?

FDA, Food and Drug Administration; GDMT, guideline directed medical therapy; MR, mitral regurgitation; STS, Society of Thoracic Surgeons; TR, tricuspid regurgitation; TVT, Transcatheter Valve Therapies.

Table S2. Resources for Patient-Centered Research in Valvular Heart Disease.

Heart Valve Voice US https://www.heartvalvevoice-us.org	Heart Valve Voice US is the only patient advocacy organization in the U.S. solely focused on heart valve disease (HVD). The organization works to increase public awareness and understanding of HVD, provides patient and care giver education, and advocates for increased HVD research and access to all valve disease treatments.
Heart Valve Voice UK https://heartvalvevoice.com	The six objectives that drive all of the work we do: (1) raise awareness of the symptoms and severity of heart valve disease in the UK in order to save lives and improve the quality of life; (2) increase the awareness of symptoms of heart valve disease; (3) work towards ensuring there is a clear and effective treatment pathway among care providers to ensure more effective management of the disease; (4) effectively campaign for early diagnosis and treatment of heart valve disease across the UK; (5) provide credible, independent and practical advice and information about heart valve disease; and (6) represent the UK’s heart valve disease patients to help ensure that they receive the best treatment at the right time, improving quality of life and overall outcome for each individual.
Heart Valve Society https://heartvalvesociety.org	The mission of the Heart Valve Society is to promote awareness, advance knowledge, and innovate to reduce the burden of heart valve disease with a global and multidisciplinary approach.
Alliance for Aging Research https://www.agingresearch.org/	The Alliance for Aging Research (AAR) is the leading nonprofit organization dedicated to accelerating the pace of scientific discoveries and their application to vastly improve the universal human experience of aging and health. AAR provides education on heart valve disease and leads activities every February for National Heart Valve Disease Awareness Day.
Mended Hearts https://mendedhearts.org/	Mended Hearts (MH) is the largest patient-to-patient heart disease support network in the world. MH provides education, support and hope to patients with all types of heart disease and activates its extensive network of patient volunteers to visit patients in more than 460 hospitals nationwide.
National Heart Valve Disease Awareness Day www.valvediseaseday.org	The goal of National Heart Valve Disease Awareness Day on February 22 is to increase recognition of the specific risks and symptoms of heart valve disease, improve detection and treatment, and ultimately save lives. While heart valve disease can be disabling and deadly, available treatments can save lives,

	making education and awareness particularly important. On this day and throughout the year, the campaign partners—60+ non-profits, advocacy organizations, professional societies, and hospitals and heart centers—are helping to spread the word about valve disease.
Association of Black Cardiologists www.abcardio.org/	Mission: To promote the prevention and treatment of cardiovascular disease, including stroke, in Blacks and other minorities and to achieve health equity for all through the elimination of disparities.
NHLBI site on VHD https://www.nhlbi.nih.gov/health-topics/heart-valve-disease	
European Society of Cardiology Council on Valvular Heart Disease https://www.escardio.org/Councils/Council-on-Valvular-Heart-Disease/About	The ESC Council on Valvular Heart Disease aims to be a multidisciplinary forum for the Heart Valve Team, to encourage research, knowledge exchange, teaching and other educational activities in valvular heart disease.
HeartValveSurgery heartvalvesurgery.com	Robust online patient community
Living with Valve Disease livingwithvalvedisease.org	
WomenHeart womenheart.org	The National Coalition for Women with Heart Disease was founded in 1999 by three women who had heart attacks while in their 40s and faced many obstacles, including misdiagnosis, inadequate treatment, and social isolation.
Patient-Centered Outcomes Research Institute (PCORI) www.pcori.org	PCORI funds studies that can help patients and those who care for them make better-informed healthcare choices. PCORI funded a project on aortic stenosis: valveadvice.org
Society for Cardiovascular Angiography and Interventions (SCAI) http://www.scai.org SCAI Patient Site http://secondscount.org http://www.secondscount.org/treatments/treatments-detail-2/transcatheter-aortic-valve-replacement-tavr-2#.XW6ONflKi2w	
The Society of Thoracic Surgeons https://www.sts.org/	
American College of Cardiology https://www.acc.org ACC Patient Site **Cardio Smart** https://www.cardiosmart.org/TAVRDecisionAids	
American Heart Association https://www.heart.org/	
MAGIC Project https://app.magicapp.org/app#/guideline/1308	TAVI versus SAVR for patients with severe symptomatic aortic stenosis at low to intermediate perioperative risk

Sharedcardiology: A resource for clinical cardiologists and their patients sharedcardiology.org	A website updated by a practicing cardiologist, collating decision aids for cardiology clinicians; includes links to relevant policy documents (e.g. National Coverage Determinations).