Homing in on the Patient Pathway to Care for Heart Failure
A U.S. Based Heart Failure Roundtable

The National Forum for Heart Disease & Stroke Prevention virtually convened patients, clinicians, payers, researchers, and public health experts to identify short- and long-term actions that would improve heart failure care in the U.S. The 1.5-hour virtual Heart Failure Roundtable was hosted in partnership with the World Heart Federation (WHF). The Roundtable was moderated by internationally renowned heart failure expert, Dr. Ileana Piña—professor of medicine at Wayne State University, clinical professor of medicine at Central Michigan University, and senior staff fellow and medical officer at the Food and Drug Administration center for Devices and Radiological Health.

Roundtable Purpose

The purpose of the virtual convening was to engage cross sector stakeholders to share their perspectives on barriers and solutions to heart failure management. The Roundtable used the WHF’s Heart Failure Roadmap to navigate the Roundtable’s discourse on an integrated approach to address roadblocks to diagnosis, treatment, and monitoring.

Speakers & Participants

The virtual meeting brought together 8 speakers (1 moderator, 7 panelists) from the patient, nursing, clinician, federal government (specialty areas: therapeutics, payment, and policy), and industry (pharmacological sciences) sectors. The moderator facilitated a 5-minute Q&A with each panelist that culminated in a rapid-fire portion where each panelist shared their perspective on short- and long-term goals for improving patient outcomes, see Table 2 for list of goals.

The Roundtable was open to the public but required prior registration. Sixty-eight participants joined live and had the ability to ask questions using the virtual platform’s Q & A function but remained muted throughout—see Table 1 for participant statistics.

Panelist Perspectives

Patient Perspective

“Listen to us patients.”

The patient-centered portion of the Roundtable focused on the experiences and emotions patients feel from the day they receive their diagnosis into the years of management that follow. Heart failure has no cure, there is only management; and the journey patients go through is strenuous. A patient turned advocate, Aimee Rodriguez-Zepeda, encouraged the need for clinicians and healthcare providers to truly listen to patients; patients are the ones living with heart failure and are the experts on their bodies.
Nursing Perspective

“...when her mother [a heart failure patient] was discharged, she went to her home and she said to her mother, what did they tell you at discharge? And her mother said I don’t remember they [doctors and nurses] were all coming at me with all this stuff. I don’t remember anything.”

The nursing-centered portion of the Roundtable focused on health information and literacy barriers patients, including their families and caregivers, face when dealing with the plethora of heart failure management messages and materials given to them. Research has shown that the quality of information and the repetition of information can improve patient outcomes.

Clinician Perspective

“One of the things that I really liked about the Roadmap was how we really broke it down into what we could do at the level of the patient, what we could do at the level of healthcare workers and what we could do at the level of the [healthcare] system, because there are changes that need to be implemented at every single level.”

The clinician-centered portion of the Roundtable focused on the complex care that patients require, which is predicated on a systems approach to treating patients and understanding their needs and barriers. A need for standardized instruction was proposed to make sure patients and their caregivers receive consistent, accurate instructions, whether that be from a primary care clinic, to an advanced heart failure clinic – or even a general cardiology clinic. With the explosion of new heart failure medications, a major barrier clinicians also see is access to those medications. Affordability needs to be a high priority. Medications need to be attainable by the most vulnerable patients.

Therapeutics Perspective

“...[adherence] is the highest leverage factor in how well we could do [with patients].”

The therapeutics-centered portion of the Roundtable focused on the need to more prominently address patient adherence to drug therapies and whether there could be a big data-driven approach to setting a system-wide agenda for pathways to patient care.

Payment Perspective

“Heart failure as a field has been in many ways a poster child for the successful development of interventions... academia and industry have teamed up and produced interventions that actually work.”

The payment-centered portion of the Roundtable discussed rebuilding the quality care program for bundled payments. By listening to experts and healthcare practitioners on the frontlines, a new claims approach that is clinically aligned and actionable can be implemented.

Research Perspective

“There is a decline in overall U.S. hypertension control rates, and we know this has a big impact on heart failure incidence.”

The policy-centered portion of the Roundtable focused on the barriers to hypertension control. Overarching barriers include a lack of clear messaging to patients on how important it is to prioritize blood pressure care, lack of insurance, under insurance, lack of access to care, and the social determinants of health. Barriers to implementing team-based and community-based management of blood pressure are also important barriers that could be addressed in the immediate future.
Industry Perspective

"Industry is recognizing the importance of diversity in clinical trials and what that means for excelling in medication development."

The industry-centered portion of the Roundtable focused on the need to ensure clinical trials are representative of communities of color and other target groups. Before industry can even get to the development of a drug, it should ensure that it’s reaching out to underrepresented communities of color because they are often disproportionately impacted by cardiovascular disease, heart disease, diabetes, and hypertension.

Furthermore, advancements in industry have made it easier to identify patients with rare diseases such as those with amyloidosis. In the past, clinicians were not searching for amyloid, because even if they made the diagnosis, there wasn’t much they could do. But now, the fact that clinicians can identify those patients earlier, is really due to industry working on the necessary drug therapies.

Closing: Short- and Long-term Goals for Improving Patient Outcomes

Table 2

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<th>Short-term:</th>
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<td>• Address access and cost barriers for patients—such as implementing a value-based insurance design and increasing access to the right drug therapies, medical care, and screening.</td>
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<td>• Implement toolkits aimed at the patient and the provider for engagement so that patients understand what medicines they’re supposed to be on so that they can ask their clinician, “Is this what I’m supposed to be on? If I’m not on it, why not?” And the same thing for the providers.</td>
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<td>• Write a perspective piece on the importance of hypertension control through a public-private partnership. It could be a piece that shows up in Vogue, The Atlantic, etc. Next is to create a national program similar to what has been done with smoking cessation. This can be accomplished through three parts: 1) a social equity component, 2) the use of incentives for patients and payers that are aligned, and 3) implementation of public service announcements as part of the public-private partnership.</td>
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<td>• Leverage tech to get people to subscribe to a service that reminds them to take their daily meds to improve medication adherence.</td>
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<td>• Help primary care doctors, internal medicine doctors, and family practice doctors understand the complexity of heart failure so that they are better equipped to treat their patients.</td>
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<td>• Address the lack of an immediate support group so that new heart failure patients can understand what is going on with them and what their diagnosis truly means.</td>
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<td>• Teach providers how to identify rare disease patients, such as those with amyloidosis.</td>
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<th>Long-term:</th>
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<td>• Develop a better telemedicine approach for patients that need objective assessment at home.</td>
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<td>• Arm primary care physicians better so that they can provide appropriate care and treatment to heart failure patients, including equipping them to provide preventive care to patients that show heart failure risk factors.</td>
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<td>• Ensure industry is developing the right types of medicines for rare and hard to treat diseases.</td>
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Both:

• Short- and long-term: hypertension control. This is a three-pronged approach: 1) increase patient engagement, 2) implement and expand community health programs, and 3) use technology to make telehealth easier and make treatment and management easier for patients and healthcare providers.
Speaker List

Moderator
- Ileana Piña, MD, MPH, FAHA, FACC
  Professor of Medicine, Wayne State University
  Clinical Professor of Medicine, Central Michigan University
  Senior Staff Fellow and Medical Officer, Food and Drug Administration, Center for Devices and Radiological Health

Patient Perspective
- Aimee Rodriguez-Zepeda
  Heart Failure Patient Ambassador
  American Heart Association

Physician Perspective
- Alanna Morris, MD, MSc, FHFSA, FACC, FAHA
  Assistant Professor of Medicine, Division of Cardiology
  Director of Heart Failure Research
  Emory University Clinical Cardiovascular Research Institute

Nursing Perspective
- Nancy Albert PhD, CCNS, CHFN, CCRN, NE-BC, FAHA, FCCM, FHFS, FAAN
  Associate Chief Nursing Officer - Research and Innovation
  Cleveland Clinic Health System & CNS - Kaufman Center for Heart Failure - Heart, Vascular & Thoracic Institute Cleveland Clinic
  President, Heart Failure Society of America

Governmental Perspective, Therapeutics (FDA)
- Norman Stockbridge, MD, PhD
  Director
  Food and Drug Administration
  Center for Drug Evaluation and Research
  Division of Cardiology & Nephrology

Governmental Perspective, Research (NHLBI)
- Vandana Sachdev, MD
  Senior Research Clinician & Director
  Echocardiography Laboratory
  Scientific Lead, HeartShare Program
  Division of Cardiovascular Sciences
  Heart Failure & Arrhythmias Branch
  National Heart, Lung, and Blood Institute

Governmental Perspective, Payment
- Joseph Dolph Hutter, MD, MA
  CDR, US Public Health Service
  Division of Policy and Evidence Review
  Coverage and Analysis Group
  Center for Clinical Standards and Quality
  Centers for Medicare & Medicaid Services

Industry Perspective
- Carolyn Ha, PharmD
  Director
  Policy & Research Department
  PhRMA