

## Statement on Need for Patient Input Regarding Resumption of Cardiovascular Procedures

Heart Valve Voice US is deeply concerned that the patient perspective was omitted from the recent guidance on resuming cardiovascular procedures released in the Journal of American College of Cardiology and endorsed by more than one dozen medical societies.

On April 20, 2020, Heart Valve Voice US <u>cataloged the myriad of confusing and sometimes</u> <u>contradictory recommendations</u> regarding elective procedures and called for greater consistency and transparency for patients. On April 24, 2020, <u>we issued guidance for patients regarding elective procedures</u>. In this regard, we applaud the American College of Cardiology (ACC) and other CV Societies for issuing consensus guidance May 4, 2020, on how to safely resume cardiovascular procedures, including TAVR and TMVR, and diagnostic tests during the COVID-19 pandemic.

However, we are deeply concerned by the apparent complete lack of patient input or consultation into these recommendations. The ACC lists a "Patient-Centered" approach as its first core value and a guiding principle in all that they do. Omitting patient input from this guidance falls short of meeting their own standard. We also find it perplexing that this guidance would be published behind a paywall and not widely distributed and available to the patients who are trying to make informed decisions about their own care. We stand prepared to engage with the societies to provide meaningful communications for patients so we may appropriately set expectations for diagnosis, care and treatment.

## **About**

Heart Valve Voice US, a nonprofit patient advocacy organization, provides a united voice for people living with heart valve disease. We advocate for early detection, meaningful support, and timely access to appropriate treatment for all people affected by heart valve disease. www.heartvalvevoice-us.org